

Improving patient-centered cancer care through human-centered design

Co-creating a health literacy-sensitive tool for shared decision-making in esophagogastric cancer

Master Thesis by Sophie Kuipers

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Design for Interaction
Faculty of Industrial Design Engineering
Delft University of Technology

Author

Sophie Kuipers

Graduation committee

Dr.ir. M. Melles
S.C.M. Brand-de Groot

Company mentor

M. van Eick

Preface

This project marks the final step in my master's degree in Design for Interaction at the Technical University of Delft. It began in February 2025 and unfolded over the course of six months.

During this project, I immersed myself in the field of esophagogastric cancer care, exploring the central question: How can communication between patients and healthcare professionals be improved? Within this scope, the focus was specifically on individuals with limited health literacy.

Although I had no prior experience or knowledge on healthcare projects, the topic immediately resonated with me on a personal level, as both of my parents have dealt with cancer.

During a ten-week internship at Amsterdam UMC, I developed a patient journey map, identifying bottlenecks and opportunities in the treatment decision-making process for esophagogastric cancer patients at the Gastro Intestinal Oncology Centre Amsterdam (GIOCA). This internship laid the foundation for the graduation project, allowing me to continue the work and conduct a co-creation study with the target group. I am especially grateful to Merel for our inspiring collaboration, for trusting my abilities, and for supporting me in transforming an endless chaos of ideas and insights into a structured and meaningful project.

The project aimed to apply a human-centered design approach that integrates the perspectives of both patients and healthcare professionals. Equally important was exploring how to tackle such a complex problem within a multi-stakeholder environment.

Numerous individuals have made this project possible. I am deeply grateful to all participants who generously shared their time and experiences, providing insight into their lives and challenges, even when discussing sensitive topics and sometimes experiencing a language barrier.

I also thank the experts who shared their knowledge, and provided invaluable feedback that helped refine the project's findings.

I extend my gratitude to my supervisory team for their knowledge, guidance, and encouragement. Marijke, thank you for your inspiring insights and thought-provoking questions that enriched the results. Susie, I am grateful for your openness, collaborative spirit, and encouraging words. Your guidance and feedback gave me confidence throughout the project.

I also wish to thank Amsterdam UMC for giving me the freedom to explore this domain, and the colleagues of the RISC research group for sharing their expertise and enthusiasm for inclusive healthcare decision-making.

Finally, I am thankful to my friends and family for their unwavering support, advice, and encouragement. Arthur, thank you for listening endlessly to my yapping, experiences, and frustrations, and for your advice and pep talks. To my family, thank you for giving me space to focus while being there when I needed support. And to my friends, thank you for participating in brainstorming sessions, showing interest, and providing a safe space to share doubts and struggles.

Dear reader, I hope this project inspires you to explore ways of making cancer treatment decision-making more patient-centered.

Sophie

* unless a reference is provided, all figures are my own

* Chat GPT was used for the following: make the text input I gave more; fluent, structured, concise, logical, easy-to-read, avoid repetition, and generate subheaders.

Abstract

Healthcare is undergoing a paradigm shift from a paternalistic model, where healthcare professionals (HCPs) made decisions on behalf of patients, to a patient-centered approach that recognizes patients as active partners in care.

Shared Decision-Making (SDM) has emerged as a cornerstone of this transition, aiming to align treatment decisions with patients' values, preferences, and lived experiences. For patients with esophagogastric cancer, SDM is particularly beneficial: treatment and care options are limited, invasive, and burdensome, yet differ substantially in side effects and impact on quality of life. Decisions in oncology care are preference-sensitive, emotionally charged, and made under conditions of uncertainty and stress. These factors make it essential to include the patient's perspective in decision-making to ensure decisions are aligned with what the patient values most.

However, individuals with Limited Health Literacy (LHL) face significant barriers to meaningful participation in SDM. These barriers stem from challenges in processing medical information, expressing personal values, and navigating increasingly digitalized healthcare systems. Without tailored support, these patients risk exclusion from the decision-making process, which increases the chances of decisional regret and reinforces health disparities.

This thesis explores how esophagogastric cancer patients with LHL can be better supported in healthcare decision-making. Conducted in collaboration with Amsterdam UMC, the project employed systemic, service, and human-centered design methodologies. A multi-layered research process combined literature review, patient journey mapping, a case study of an outpatient clinic, an extensive co-creation study involving individuals with LHL, and expert consultations. These steps revealed systemic barriers to SDM, including fragmented communication practices. Co-creation identified several needs of the target group, including a desire for more balanced

communication in which HCPs allow time for pauses and actively encourage patients to ask questions.

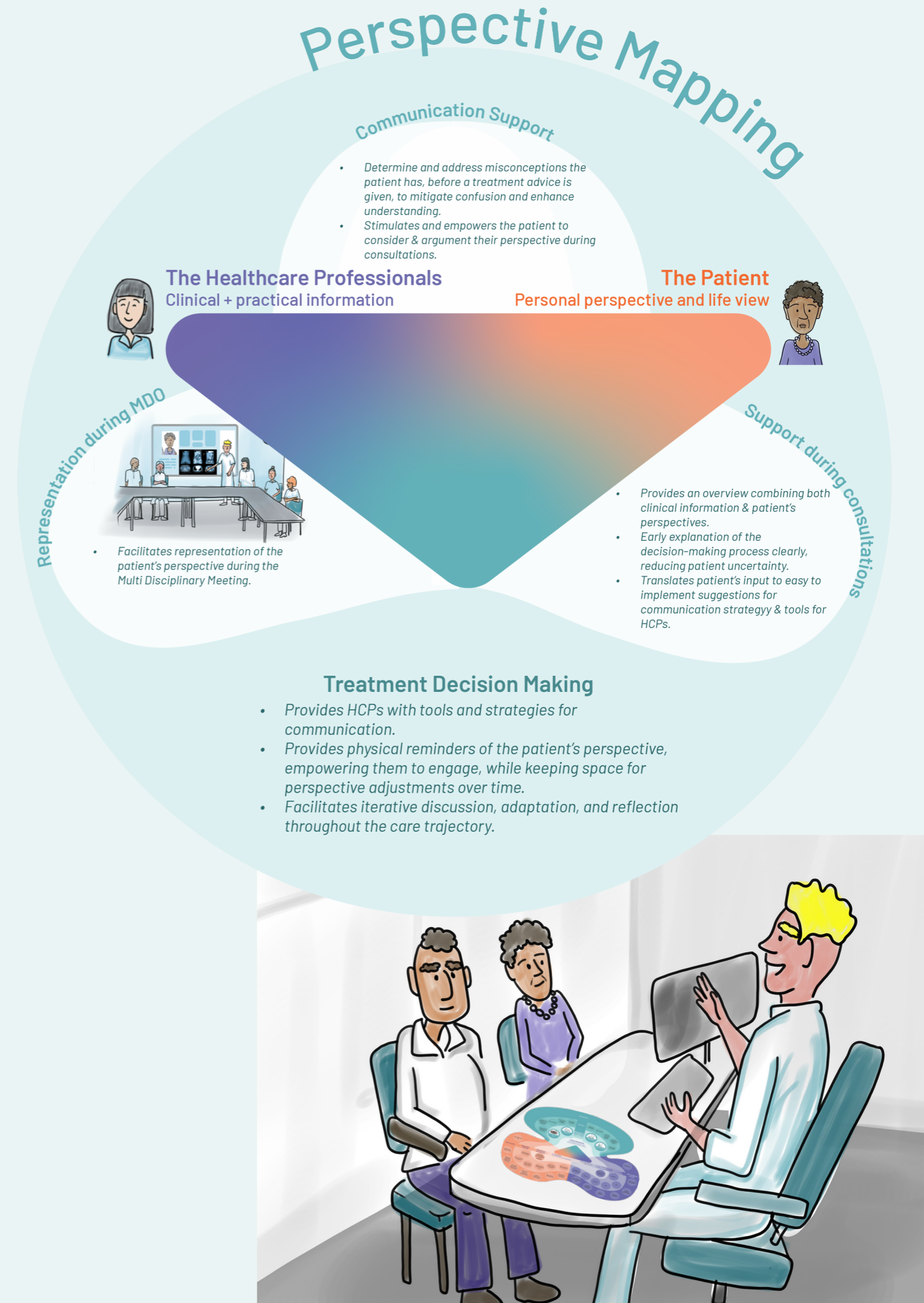
Building on these insights; iterative idea development; prototyping; and co-creation with individuals with LHL; alongside evaluation with HCPs and experts; led to the development of a modular communication tool aligned with the project's design goal:

"To support patients with LHL in articulating their values and information needs, while enabling healthcare professionals to actively elicit these insights and tailor their way of informing and supporting accordingly"

Perspective Mapping, the developed tool, facilitates relational, stepwise consultations. It helps HCPs elicit and incorporate patient values, clarify treatment trade-offs, and co-construct summaries that feed into multidisciplinary meetings. Its modular structure allows flexibility, supports reflection, and enables patients to build communication skills transferable across their care trajectory.

Evaluations highlighted the toolkit's potential to reduce uncertainty for patients, strengthen trust, and align treatment decisions more closely the patient's perspective. However, for sustainable adoption of the tool, and for any implementation of a communication intervention in that matter, the importance of seamless integration into clinical workflows is underscored.

This thesis offers both a practical design intervention and a conceptual reframing of the challenges limiting communication between HCPs and esophagogastric cancer patients with LHL. It emphasizes SDM as an integrated, continuous process rather than an isolated event. By addressing the communication needs of patients alongside the workflow requirements of HCPs, the project advances the development of more equitable and patient-centered oncology care decisions.



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CHAPTER 1

INTRODUCTION: THE PROJECT

This chapter introduces the project. It outlines the increasing strain on the Dutch healthcare system and the growing inequities it faces (1.1). Section 1.2 delineates the project's scope and clarifies the assignment. Finally, the methodological approach adopted for this project is presented (1.3).

Chapter overview

- 1.1 Increasing inequity and healthcare decision-making
- 1.2 Project scope and relevance
- 1.3 Approach

1.1 Healthcare decision-making and increasing inequity

Historically, healthcare professionals (HCPs) made decisions for patients, guided by the belief that they knew what was best for them (Hoving et al., 2010). In the past decades, a new perspective has emerged: patients are also experts; of their bodies, symptoms, and personal context. Patient input has increasingly been acknowledged as essential to effective treatment. As a result, patients are increasingly perceived as partners in care, with both rights and responsibilities. Policymakers support this shift, aiming to enhance self-management and reduce pressure on healthcare systems. (Grover et al., 2021; Hickmann et al., 2022; Chehade et al., 2024).

Simultaneously, healthcare systems are facing mounting challenges: aging populations, rising rates of multimorbidity and chronic conditions, and widening disparities in access to care (CBS, 2025; Centraal Bureau voor de Statistiek, 2025 & n.d.; Land, 2023). These pressures demand care to be delivered more efficiently. Enabling patients to act as co-managers of their care is increasingly viewed as a critical strategy for building a high-performing and cost-effective healthcare system (Hickmann et al., 2022).

Patient-Centered Care

Patient-Centered Care is a foundational concept in this shift, defined as “care that is respectful of and responsive to individual patient preferences, needs, and values, ensuring that these values guide all clinical decisions” (Hickmann, 2022).

Shared Decision-Making (SDM)

To effectively implement Patient-Centered Care, Shared Decision-Making has emerged as a key strategy. SDM is a collaborative process in which patients and HCPs jointly make decisions about treatment or care, particularly when multiple medically appropriate options exist, see figure 2. The goal is to ensure that healthcare decisions align with what matters most to the patient. Evidence shows that SDM leads to improved patient’s knowledge, satisfaction, and reduces decisional regret. (Stiggelbout et al., 2015).

This strategy comes with additional challenges, which are discussed in the following section.



Figure 1: Balance between medical knowledge and personal knowledge (Federatie Medisch Specialisten et al., 2019)

The SDM process

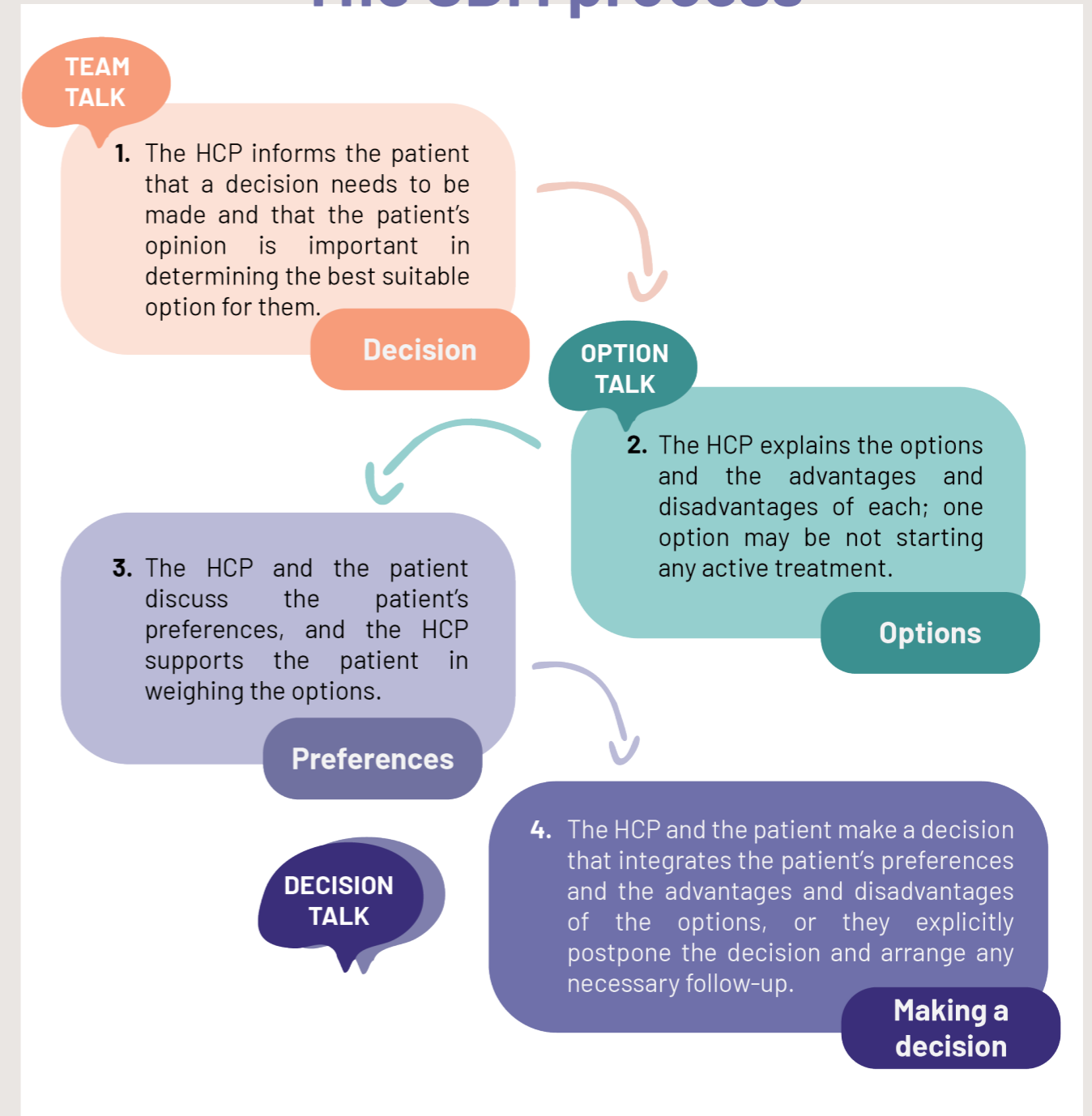


Figure 2: Four-step Shared Decision Making model by Stiggelbout (2015) – based on Elwyn’s 3-talk model (2012). adapted from (Wat ls Samen Beslissen? | Federatie Medisch Specialisten, n.d.)

1.1.1 Health Literacy and decisional regret

Decisional Regret

Health-related decisions are inherently complex, often involving multiple treatment options, time constraints, uncertainty, and competing personal or clinical goals. A crucial outcome influenced by the quality of SDM is decisional regret: the distress or remorse patients may experience when reflecting on past healthcare decisions. This regret tends to be higher when patients feel they did not fully understand their options, lacked involvement in the process, or were not supported in aligning choices with their personal values. (Chehade et al., 2024). In contrast, when patients are actively engaged and informed, they report lower levels of decisional regret, even when faced with unfavorable outcomes (Stiggelbout et al., 2015). However, effective participation in SDM is not equally accessible to all.

Limited Health Literacy

Patients with LHL often encounter greater challenges in participating in SDM compared to patients with higher health literacy (Oosterveld, 2019; Van Eick et al., 2025). LHL refers to the reduced ability to access, understand, evaluate, and apply health information to make appropriate health-related decisions (Oosterveld et al., 2019). While anyone can experience LHL depending on the context, it is more common among individuals with lower education levels, men and older adults (65+). LHL affect nearly 48% of the European population, with rates ranging from 36% in the Netherlands to 62% in Bulgaria (Noordman, 2019).

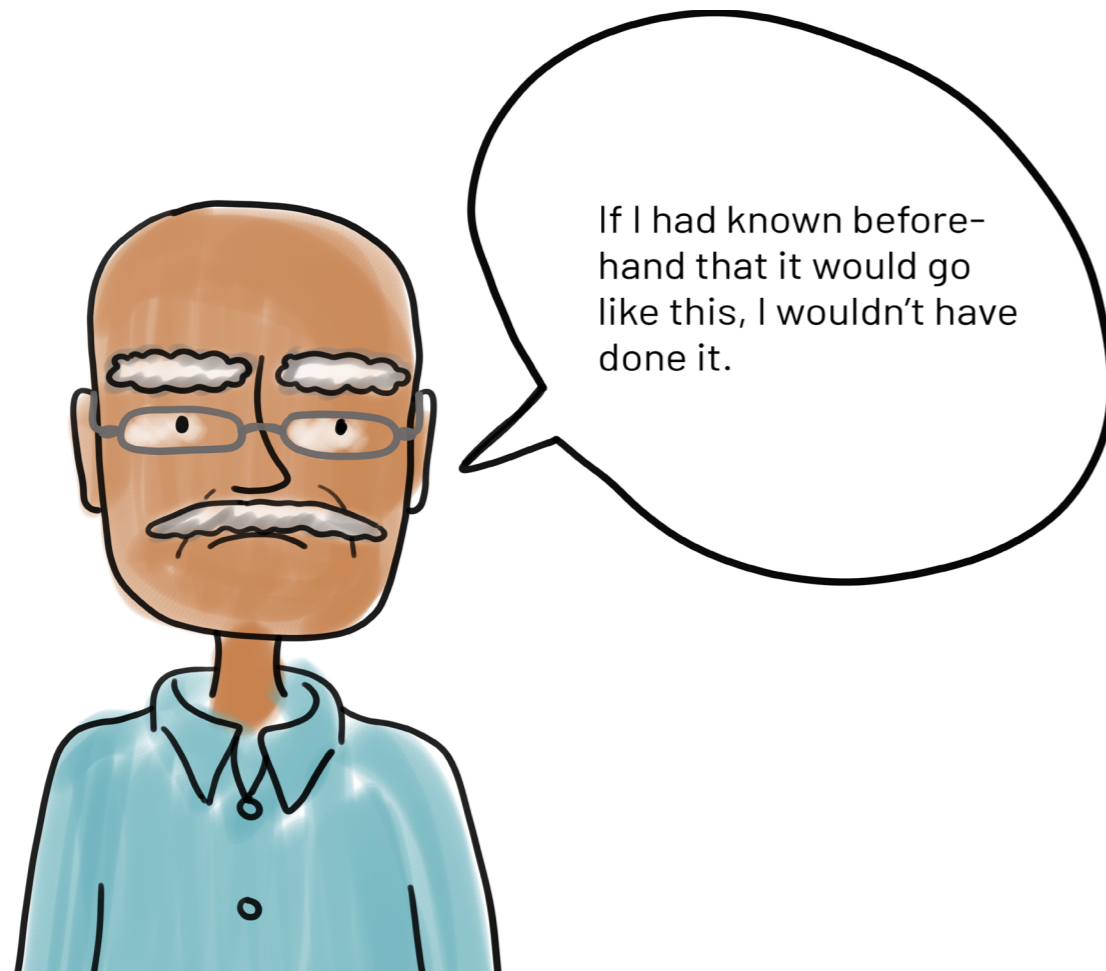


Figure 3: A former esophageal cancer patient who experiences decision regret

1.1.2 A call for systemic change

Digital health tools

In support of the shift towards Patient-Centered Healthcare, numerous tools and services have been developed to facilitate patient engagement and shared responsibility in care decisions. While analogue tools still exist, the majority of recent developments focus on digital and online platforms (Hasannejadasl, 2022).

Digital health tools can enhance autonomy for many, but they do not benefit all patients equally. As individuals with LHL, especially those with limited digital skills or access, often rely more on in-person support to make healthcare decisions (Oosterveld, 2019).

When healthcare increasingly adopts digital-first strategies, there could be a risk of unintentionally widening existing health disparities. To promote equitable care, it is essential to complement digital innovations with accessible, face-to-face alternatives tailored to the needs of underserved populations.

Systemic Barriers

Addressing barriers to SDM is essential to ensure the process is both inclusive and effective, particularly for patients with LHL (Durand et al., 2014; Shay & Lafata, 2015; Muscat, 2020; Josfeld et al., 2021). A key barrier to the widespread adoption of SDM is its treatment as a set of isolated events rather than as an ongoing process. As Sañudo et al. (2024) argue in their systematic review, this fragmented view limits the integration of SDM into routine care. Reconceptualizing SDM as a continuous, embedded practice is therefore essential for achieving meaningful patient involvement across the care pathway (To et al., 2024).

According to Sañudo, service design methodologies offer a promising route to support this shift. By emphasizing the alignment of processes, roles, and touchpoints, service design enables SDM to be woven into clinical workflows rather than added as an extra task. This approach reinforces the idea that SDM is not a single conversation but a sustained practice that reflects the broader principles of patient-centered care (Sañudo et al., 2024).

The barriers to SDM extend beyond individual health literacy levels. Systemic factors such as: ineffective communication by HCPs, a lack of health literacy-sensitive decision aids, and time-pressured consultations, significantly hinder patient participation (Hasannejadasl et al., 2022). These challenges are further intensified by mounting pressures on healthcare systems, including rising care complexity, efficiency demands, and workforce shortages.

1.2 Project scope and relevance

This chapter outlines the scope, relevance, and organizational framework of the graduation project. It explains the specific oncology context considered, describes the institutional setting in which the project is embedded, and clarifies how the project aligns with ongoing research goals and methodologies.

Communication barriers between patients with LHL and HCPs become particularly significant in situations that require preference-sensitive decisions. This is especially true in oncology, where decision-making often involves complex trade-offs and emotionally charged conversations (Noordman et al., 2019; Oosterveld et al., 2019).

Complexity of esophagogastric cancer care

Esophagogastric cancer refers to malignancies that occur in the esophagus, the stomach, or the junction where these two organs meet. These cancers are often diagnosed at an advanced stage and typically require complex treatment decisions involving surgery, chemotherapy, and/or radiation therapy.

These treatments are often invasive, burdensome, and difficult to compare in terms of benefits and trade-offs. The complexity of these decisions, combined with the emotional impact of a cancer diagnosis, can overwhelm patients. More information on esophagogastric cancer and treatment can be found in chapter 2.

1.2.1 Target groups

Esofphagogastric cancer patients with LHL

This thesis focuses specifically on developing support for esophagogastric cancer patients with LHL, a group particularly vulnerable to the challenges described in 1.1.1.

Moreover, many esophagogastric cancer patients are older adults, have lower educational attainment, or come from socioeconomically disadvantaged backgrounds (Kanker in Nederland: Sociaaleconomische Verschillen, n.d.) These are all factors associated with higher rates of LHL (Noordman, 2019).

Esophagogastric cancer patients with LHL are not only more likely to experience difficulties in processing medical information, but they may also be less confident in voicing concerns, asking questions, or expressing preferences.

Healthcare professionals

In addition to patients, HCPs are considered crucial stakeholders due to their central role in facilitating communication, coordinating treatment plans, and supporting informed choices. Understanding their workflows and needs contributes to the effective development of decision-making and communication support interventions. This is further explored in chapter 5. *Context case study.*

1.2.2 Case study: GIOCA outpatient clinic

To explore the research objective within a concrete and relevant context, the GIOCA (Gastrointestinal Oncology Centre Amsterdam) outpatient clinic was selected as the case study. Part of Amsterdam UMC, GIOCA specializes in the diagnosis and treatment of esophagogastric cancer (Amsterdam UMC, n.d. -a). This setting brings together both key target group patients, who are involved in complex, preference-sensitive decision-making processes.

Relevance and accessibility

The clinic's engagement in academic research ensures both practical relevance and institutional access, providing a basis for in-depth study.

Contextual focus and transferability

Although some findings may be transferable to other contexts, this project is intentionally rooted in GIOCA's specific workflows and stakeholder relationships (see Chapter 5), offering nuanced insights into the systemic and interpersonal factors that influence SDM in this setting.



Figure 4: Impression of initial consultation between patient, their next-of-kin, and a HCP.

1.2.3 Project focus

The project's focus, including the approach taken in the co-creation study (chapter 5), is informed by a consultation with an expert oncologist, they were later included in the evaluation of the final concept (P2, chapter 10.3).

Initial Consultation

The design and research efforts primarily target the initial consultation at GIOCA, with a strong focus on how HCPs can effectively explore and respond to patients' values, preferences, and personal context. In agreement with the experts view, this first meeting serves as a critical foundation for personalized, patient-centered care and represents a meaningful intervention point for improving SDM, particularly for patients with LHL.

Follow-up consultations

Follow-up consultations are considered a secondary focus, intended for patients who experience lingering doubt or uncertainty after the initial conversation. While important, according to the expert these sessions are highly individualized and context-dependent, making them more challenging to standardize and design for. In addition, designing for follow-up means addressing symptoms rather than tackling the root of the problem during the first interactions.

Targeted approach to follow-up support

It is recommended by the expert that support tools or interventions for follow-up consultations be selectively applied, based on the patient's condition, care trajectory, and personal preferences. The design scope should therefore include a component for identifying which patients benefit most from structured follow-up support and under what circumstances such interventions are appropriate.

Overall goal:

Explore how esophagogastric cancer patients with LHL can be better supported in healthcare decision-making.

Assignment:

Create a tool to support oncology patients with limited health literacy in articulating their needs, values and preferences with healthcare professionals to navigate the decision-making process in a confident and effective way.

1.2.4 Initiation of the project

Institutional Framework

This master's thesis is part of a broader PhD research initiative at the Department of Public and Occupational Health (POH), Amsterdam UMC, in collaboration with Delft University of Technology and funded by KWF Kankerbestrijding (Dutch Cancer Society). The research aims to improve communication and decision-making in healthcare, with a particular focus on esophagogastric patients with LHL.

The RISC Research Group

Within the POH department, the RISC (Risk Information, Strategy and Communication) research group investigates how individuals, professionals, and policymakers understand and respond to risks in health, safety, and care. Their work focuses on supporting informed decision-making through effective communication strategies. The group includes 10–15 researchers and collaborates with organizations such as RIVM, Maastrou, and Radboud University (Public & Occupational Health, n.d.; Onderzoek – RISC Amsterdam, n.d.).

Throughout the project, the author participated in RISC group meetings and discussions, gaining insights into current approaches to risk communication, co-creation, and the challenges of reaching underserved populations. These experiences informed both the project's scope and design process.

“Amsterdam UMC is a leading medical center that combines complex high-quality patient care, innovative scientific research, and education of the next generation of healthcare professionals. We believe that healthcare practice, research, and education belong together, with each shaping and informing the other.”
(Amsterdam UMC, n.d.)

1.3 Approach

This project employs an iterative, design-driven approach, combining Systemic Design, Service Design and Human-Centered Design to tackle the complex communication and decision-making challenges experienced by esophagogastric cancer patients with LHL and their HCPs. Rather than following a strict chronological order, the documentation is organized logically to enhance clarity. The document follows the Systemic Design Framework (page 24), resulting in the structure shown in figure 5. The iterative design process, where iterations took place throughout the project, is presented on the next page and discussed in detail in more detail in chapters 6 and 7.

Foundations and Contextual Grounding

Two early activities shaped the methodology of this project:

1. Patient Journey Mapping

Mapping the experiences and decision points of esophagogastric cancer patients and HCPs at GIOCA, included in chapter 4.2.1.

2. Literature Review

Exploring patient-centered care, systemic design, SDM, LHL, and co-creation methods, included in chapter 1 - 3 and 5.

These were supplemented by expert consultations with oncologists and design professionals, grounding the project in both clinical realities and design theory.

Human- and Service-Centered Orientation

Drawing from human-centered design and service design, the project engaged the target group of LHL individuals as active collaborators in co-creation sessions. This participatory approach ensured the proposed concept is contextually grounded, and responsive to individual needs and preferences. Service design can strengthen implementation by examining the full SDM process, while co-creative approaches help develop patient-centered solutions that align seamlessly with HCPs' workflows (To et al., 2024). Service design tools such as journey mapping helped identify critical decision points in the esophagogastric care trajectory.

Contextmapping

Contextmapping, developed by Stappers and Sanders (2012), is a research approach to uncover people's experiences, values, and tacit needs in their everyday context. Through generative techniques such as diaries, collages, or storytelling, it helps participants express what is difficult to verbalize. In human-centered design, it supports analysis by revealing patterns and insights, while also generating evocative materials that enrich co-creation.

Frame Innovation: reframing

Frame Innovation, as discussed by Dorst (2015) offers a design-based method for addressing complex problems by reframing how they are understood. Rather than working within existing frames, it creates new perspectives by exploring tensions, drawing on other domains, and involving stakeholders in developing and testing alternatives. In human-centered design, it functions both as an analytical tool to question assumptions and as a creative strategy to co-develop solution spaces aligned with lived realities.

Outcome Orientation

Rather than viewing SDM as a single event, the taken approach frames it as an ongoing process supported by systems, tools, and relationships. The resulting intervention aims to reduce decisional regret, enhance patient confidence, and strengthen participation in SDM.

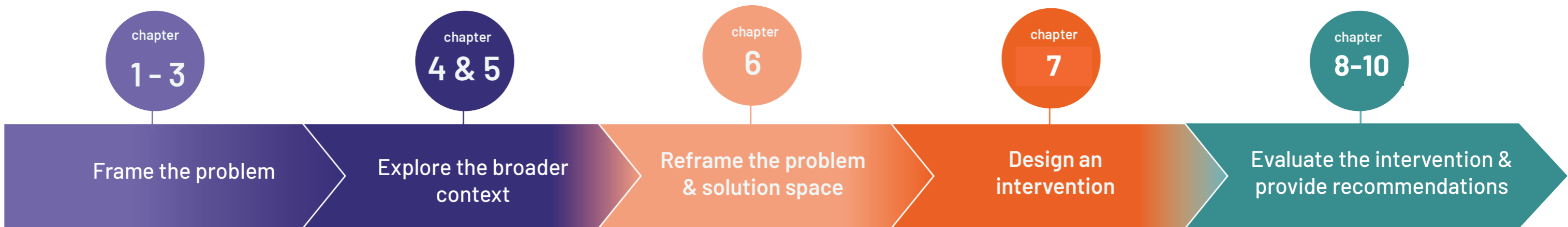


Figure 5: A linear depiction of the phases in this project, with corresponding chapters. Based on the Systemic Design framework (Design Council, n.d.)

Creative Process

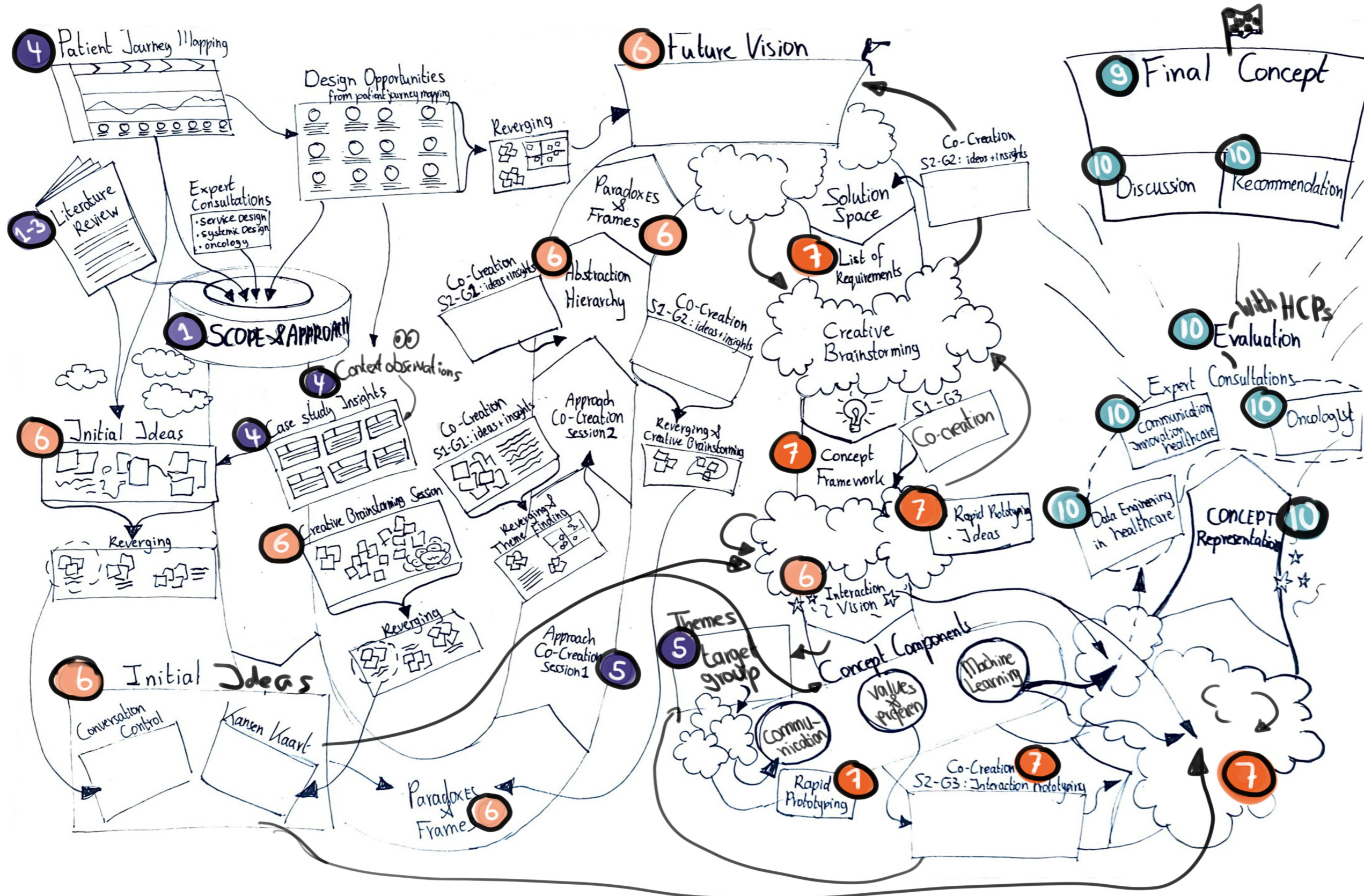


Figure 7: Visual representation of the creative process, showing how it is non-linear, displaying key research and design activities and in which chapter to find them. Clouds represent the development of ideas.

Design Framework

Systemic Design Principles

The Systemic Design Framework (Design Council, n.d.), figure 5, was chosen for its ability to combine design thinking with systems thinking in complex, multi-stakeholder environments. The structure of this thesis is based on this framework, from explore to catalyse. However, multiple small-scale iterations following the framework were conducted throughout the project. In contrast to other design models, it supports:

- **Explore:** Seeing the bigger picture

Seek to understand the wider system, mapping stakeholders, contexts, and interdependencies.

Mapping the patient journey, patient-centered design and SDM processes and the healthcare system to understand interdependencies.

- **Reframe:** Identifying root causes

Shifts focus from surface-level problems to underlying causes, redefining the challenge in ways that open new possibilities for change.

Applying generative research, frame innovation and abstraction hierarchy to move beyond visible symptoms.

- **Create:** Engaging diverse stakeholders

Solutions are co-designed, prototyped, and tested iteratively to ensure they are practical, human-centred, and system-aware.

Involving patients, HCPs, and experts throughout the design process, and conduct co-creation with the target group.

- **Catalyse:** Navigating uncertainty

Embeds and scales these solutions, building partnerships and structures that support long-term adoption and systemic impact.

Using parallel idea development and iterative feedback to adapt over time, and provide a detailed concept, intervention and research recommendations.



CHAPTER 2

ESOPHAGOGASTRIC CANCER

This chapter begins by providing background information on esophagogastric cancer (2.1). It then elaborates on how treatment decision-making for esophagogastric cancer is structured and implemented in The Netherlands (2.2). Finally, it briefly outlines the essential conditions and considerations for treatment decision-making (2.3).

Chapter overview

- 2.1 What is esophagogastric cancer?
- 2.2 Treatment decision-making in The Netherlands
- 2.3 Treatment possibilities
- 2.4 Treatment overview
- 2.5 Conclusion

2.1 What is esophagogastric cancer?

Esophageal and gastric cancer are two different forms of cancer, but they are often diagnosed and treated by the same team of HCPs. Gastric carcinoma and esophageal carcinoma are the terms often used to describe these forms of cancer. Carcinoma is the medical term for the malignant multiplication of cells in the upper layer of skin or mucous membranes, see figure 8. (SPKS, 2018).

Adenocarcinoma is the most common type of esophagogastric cancer. It originates from glandular cells in the lining of the lower esophagus, the gastroesophageal junction, or the stomach, and is often linked to conditions such as Barrett's

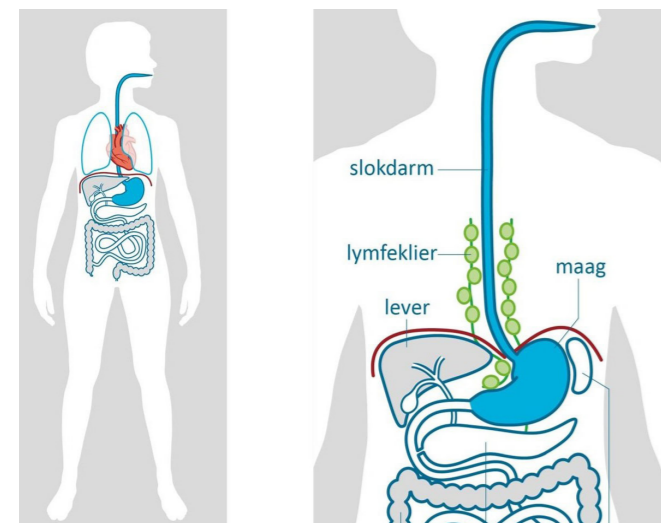


Figure 7: Anatomy of human organs: esophagus, stomach, liver and lymph nodes (Wat Is Slokdarmkanker?, n.d.)

Prevalence

In 2021, 2,648 individuals in the Netherlands were diagnosed with esophageal cancer. Esophageal cancer typically causes no symptoms in its early stages. Symptoms usually appear only once the tumor has grown significantly, which often leads to the disease being diagnosed at a more advanced stage, which lowers survival chances (Slokdarmkanker: Symptomen Tot Vooruitzichten, 2025). Physical fitness of the patient and treatment effectiveness further impact survival chances.

esophagus or chronic acid reflux (Kanker.nl, n.d.).

Risk factors

The specific cause for both esophageal and gastric cancer is unknown. What is known is that there are some important risk factors existent like smoking, alcohol consumption and obesity. (SPKS, 2018; Stichting kanker.nl, n.d. -a, b).

Impact of esophagogastric cancer

Both esophageal and gastric cancers often lead to nutritional issues. Esophageal cancer often causes swallowing difficulties, starting with solid foods and eventually affecting liquids as the tumor narrows the esophagus. Patients commonly experience the sensation of food "getting stuck" (passageklachten), which leads to decreased appetite, unintended weight loss, fatigue, and dizziness due to anemia. (Stichting kanker.nl, n.d.-a,-b; Nederlandse vereniging van Diëtisten 2021).

Gastric cancer symptoms are broader but commonly include unexplained weight loss, decreased appetite, early satiety, pain in the upper abdomen or behind the breastbone, reflux, nausea, vomiting, and occasionally bleeding (Stichting kanker.nl, n.d. -a; SPKS, 2018). In early stages, symptoms may be minimal or absent; however, as the tumor grows, nutritional decline becomes more pronounced, often necessitating interventions such as dietary modifications or supplemental feeding (SPKS, 2018).

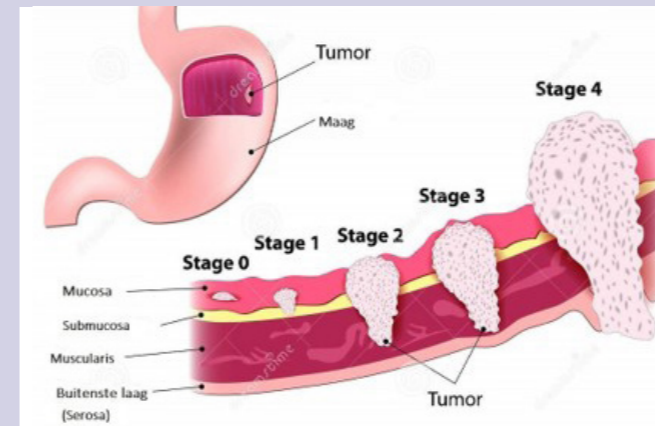
Rapid weight loss and malnutrition can significantly weaken patients, making early diagnosis and timely treatment essential to improving survival rates and maintaining quality of life. (SPKS, 2018; Stichting kanker.nl, n.d. -a,-b).

Metastases

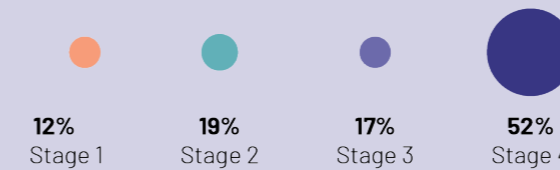
Metastases are cancerous growths that have spread from the original (primary) tumor to other parts of the body: a process called metastasis (stage 4). This occurs when cancer cells break away from the primary tumor and travel through the blood or lymphatic system to form new tumors in other tissues or organs. (Wat Zijn Metastasen?, n.d.)

Both esophageal and gastric cancers frequently metastasize to critical organs such as the liver and lungs, and, less commonly, to the bones or peritoneum (Erasmus MC, n.d. -a, -b).

Gastric



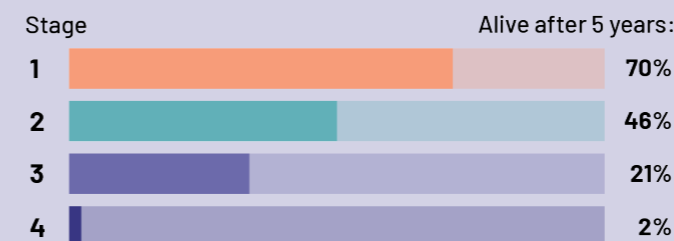
At what stage is **gastric cancer** at the first diagnosis?



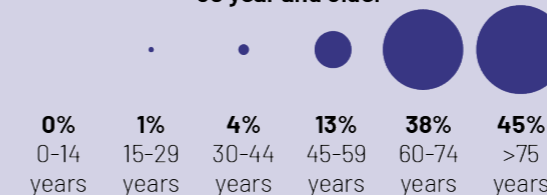
Gastric cancer is more prevalent among **men**



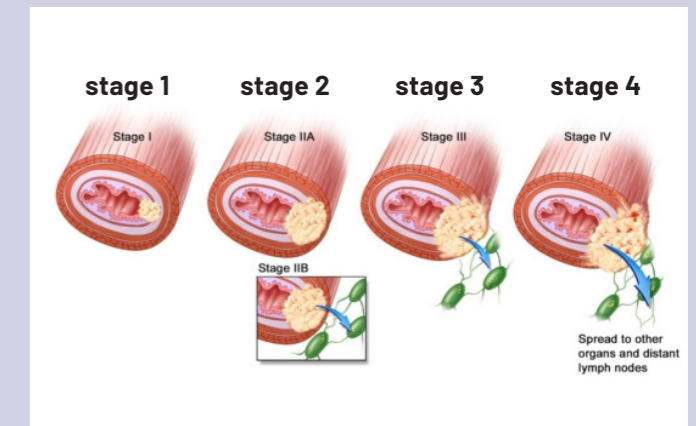
The survival of gastric cancer per stage



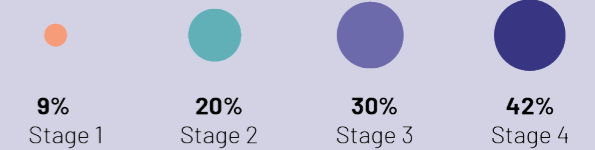
Gastric cancer is more prevalent among people aged **60 year and older**



Esophageal



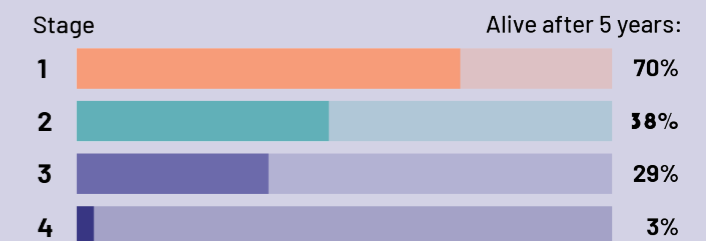
At what stage is **esophageal cancer** at the first diagnosis?



Esophageal cancer is more prevalent among **men**



The survival of esophageal cancer per stage



Esophageal cancer is more prevalent among people aged **60 year and older**

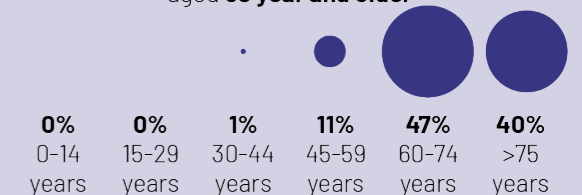


Figure 8: Esophageal and gastric cancer fact sheet for The Netherlands, based on information from SPKS (2018), including visuals representing the four stages of esophageal and gastric cancer retrieved from (ForYou Media, 2023-a,-b)

2.2 Treatment Decision Making in The Netherlands

In the Netherlands, the treatment of esophageal and gastric cancer follows a nationally standardized yet regionally coordinated approach. The process aims at being patient-centered, multidisciplinary, and guided by Dutch oncology guidelines (Integraal Kankercentrum Nederland, 2023 -a, -b), see figure 9 for an impression of the process. Figure 10 on the right provides information on the differences between hospitals.



Figure 9: The process of diagnosis and treatment decision-making in The Netherlands

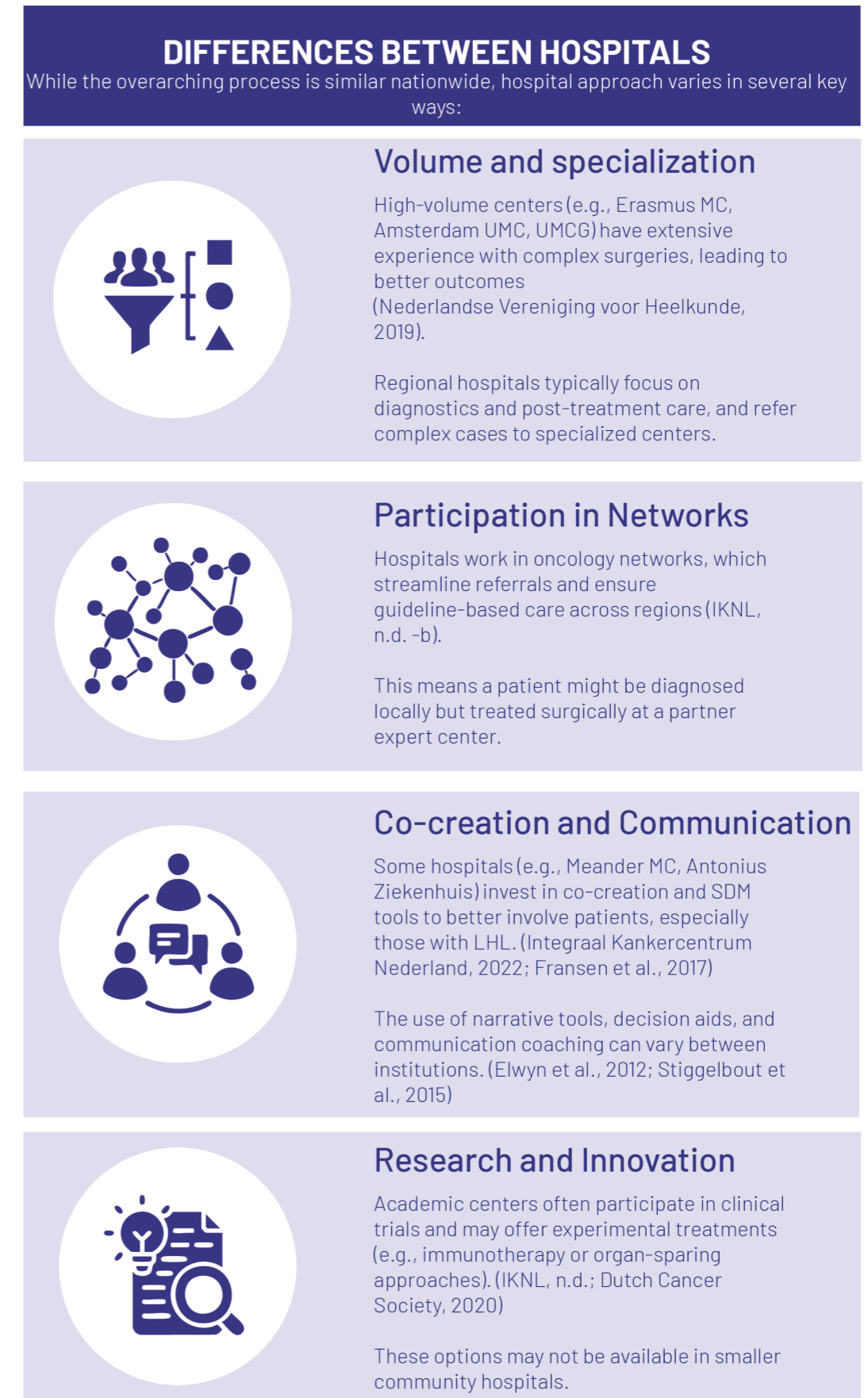


Figure 11: The four main differences that can occur between hospitals that treat esophagogastric cancer.

2.3 Treatment possibilities

Treatment options for esophagogastric cancer depend primarily on three factors: the stage of the disease, the presence of metastases, and the patient's overall physical condition. Tumor-specific characteristics, such as location and aggressiveness, alongside patient preferences, also shape the treatment strategy (Integraal Kankercentrum Nederland, 2023 -a, -b).

Tailored treatment in esophagogastric cancer

Within each treatment pathway, there is room for further customization. For instance, the intensity of radiotherapy or the dosage of chemotherapy can be adjusted based on the patient's tolerance, response, and health status. This individualized approach ensures that treatment is both medically sound and personally appropriate.

Complexity of Metastatic Disease

When metastases are present, treatment planning becomes significantly more complex. When tumors have spread beyond the original site, treatment strategies must address not only the primary tumor, but also the condition and function of affected organs, such as the liver or lungs, which are common sites of metastasis in esophageal and gastric cancer (Kanker.nl, n.d.; Erasmus MC, n.d. -a, b). Clinical decision-making becomes more nuanced, as physicians must weigh the potential benefits of systemic treatments—such as chemotherapy, immunotherapy, or targeted therapies—against their side effects and the patient's overall prognosis and quality of life (IKNL, 2016).

Ongoing decision-making across the care pathway

Patients frequently face a series of medical decisions throughout the care trajectory, not just at the moment of diagnosis. These decisions often require weighing intricate clinical information against personal values and preferences; a process that demands clear, supportive communication from HCPs.

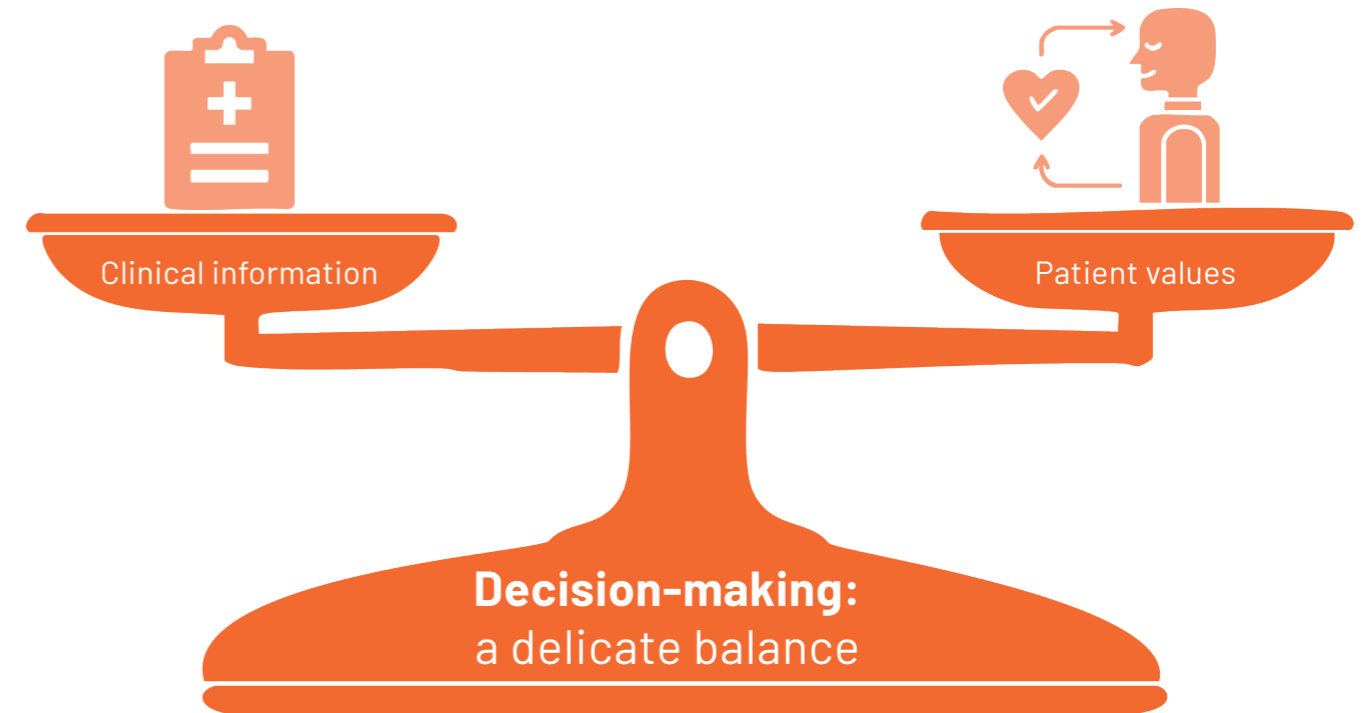
Treatment goals can shift from curative intent to a palliative focus, prioritizing symptom relief, nutritional support, and preservation of quality of life (Integraal Kankercentrum Nederland, 2022;

Kanker.nl, n.d.). In such cases, care typically involves multidisciplinary teams, including oncologists, dietitians, nurses, and palliative care providers. This is particularly important in esophageal and gastric cancers, where eating and digestion are frequently compromised, making nutritional management a critical part of care (Kanker.nl, n.d. -c). Ultimately, the care pathway becomes more personalized, requiring clear communication and SDM to align treatment with the patient's values and preferences (Integraal Kankercentrum Nederland, 2022; Kanker.nl, n.d.).

Burden of Illness and Its Role in Decision-Making

The Dutch National Cancer Institute (IKNL) emphasizes that understanding the total burden of cancer, including disease, symptoms, and treatment, is essential for high-quality decision-making and patient-centered care (Integraal Kankercentrum Nederland, 2022).

These burdens not only shape clinical recommendations but can also influence what patients value in their care. For example, a physically frail patient with a high disease and symptom burden may prioritize comfort over aggressive treatment, choosing a plan focused on maintaining quality of life.



Clinical information: The type and stage of cancer, diagnostic test results, and the risks and benefits of potential treatments. Other health conditions that may influence treatment are also considered.

Patient values: Personal factors such as quality of life, tolerance for side effects, daily functioning, and personal, family, religious or cultural values must also be taken into account.

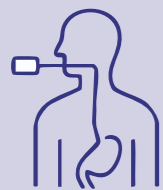
Figure 12: The delicate balance for optimal decision-making in care: including both clinical information and patient values.

2.4 Treatment overview

STAGE	TYPICAL TREATMENT OPTIONS
Early	Endoscopic resection
Localized (resectable)	Neoadjuvant chemo (radio) therapy followed by surgery (esophagectomy or gastrectomy)
Locally advanced or border line resectable	Possibly definitive chemoradiation
Metastatic	Palliative chemo, immunotherapy, best supportive care

Figure 13: Overview of most typical treatment options per disease stage (Integraal Kankercentrum Nederland, 2023 -a, -b).

Endoscopic Treatments (early stage)



Endoscopic mucosal resection (EMR) and endoscopic submucosal dissection (ESD) are minimally invasive procedures used to remove early-stage cancerous lesions from the mucosal lining of the esophagus or stomach using an endoscope, without external incisions. (MCL, n.d.)
EMR is often used for lesions smaller than 2 cm (Amsterdam UMC, n.d. -b) while ESD allows en bloc resection of larger or slightly deeper lesions (Catharina Ziekenhuis, n.d.).

Surgery



Esophageal cancer

Standard curative treatment typically involves esophagectomy with reconstruction (often creating a gastric conduit), preceded by neoadjuvant chemoradiotherapy according to the CROSS protocol to shrink the tumor and improve outcomes (Slok darm- en maagkanker.nl, n.d.; IKNL, 2016).

Gastric cancer

Treatment commonly includes partial or total gastrectomy combined with D2 lymphadenectomy. Perioperative chemotherapy regimens—such as FLOT—are often administered before and/or after surgery to improve survival (IKNL, 2016).

Chemotherapy



Chemotherapy uses cytotoxic drugs to destroy cancer cells throughout the body and can be used in different settings:

- Neoadjuvant (before surgery) to shrink tumors,
- Adjuvant (after surgery) to eliminate residual cells,
- or palliative (in advanced disease) to slow progression and relieve symptoms (IKNL, 2016; IKNL, 2020).

Radiotherapy



Radiotherapy delivers high-energy radiation to destroy or stop the growth of cancer cells. In esophageal cancer, it's routinely combined with chemotherapy (as in the CROSS protocol). Radiotherapy is used less frequently in gastric cancer, usually in palliative situations to relieve symptoms such as pain or bleeding (IKNL, 2016; IKNL, 2020).

Immunotherapy



These treatments are reserved for advanced or metastatic cases, with immunotherapy enhancing the immune response to cancer cells and targeted therapies disrupting specific molecular pathways (Richtlijndatabase, n.d.; IKNL, n.d.).

Palliative Care (Best Supportive Care)



Focuses on symptom management and quality of life:

- Stent placement to relieve dysphagia (having trouble swallowing)
- Palliative chemotherapy or radiotherapy
- Nutritional support, psychosocial care, and hospice services (IKNL, 2020)

Active Surveillance (SANO-trial, not generally available yet)



Active surveillance, such as in the SANO trial, is a structured monitoring protocol used after a complete response to neoadjuvant therapy. Instead of proceeding immediately to surgery, patients are closely followed with imaging and endoscopy to avoid unnecessary surgery unless recurrence occurs (Integraal Kankercentrum Nederland, n.d. -a).

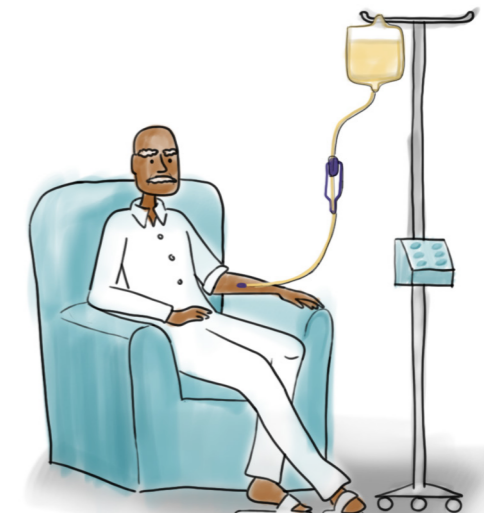
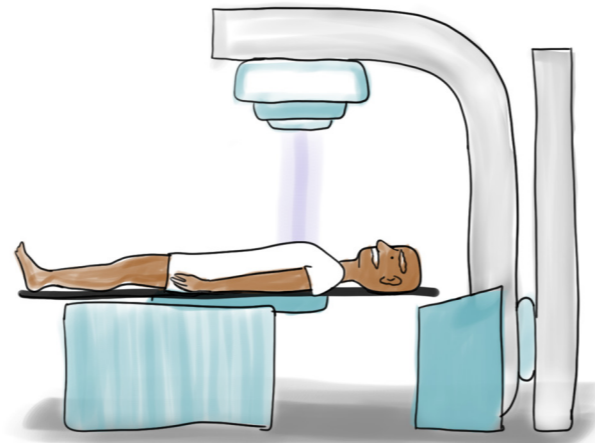
Figure 14: General overview of overall treatment possibilities that are taken into account for esophagogastric cancer, combinations are possible and dependent on disease stage, the patient's fitness, and patient values..

Conclusion

Esophageal and gastric cancers are complex diseases that often present at an advanced stage, leading to significant challenges in diagnosis, treatment, and patient well-being. Both cancers are associated with a high disease, symptom, and treatment burden, which strongly influences patient outcomes and quality of life.

Effective decision-making in this context requires a balance between clinical evidence and patient values, emphasizing the importance of patient-centered communication and SDM.

Considering that LHL is more prevalent among older adults and men, the primary patient group for esophagogastric cancers, special attention to clear communication and tailored decision support is essential.



CHAPTER 3

PATIENT CENTERED CARE

This chapter elaborates on patient-centered care by discussing its prerequisites (3.1). It then discusses what kind of barriers need to be overcome when trying to apply SDM. It concludes with an adapted health literacy sensitive SDM model that specifies how SDM can facilitate understanding, communication, and reflection (3.3)

Chapter overview

- 3.1 Understanding the system
- 3.2 Barriers towards Shared-Decision Making
- 3.3 A health literacy sensitive SDM approach

3.1 Understanding the system

Understanding processes and relations is a key part of service design. This paragraph explores the process of patient-centered care and elaborates on two key components.

Patient-centered care provides the conceptual foundation for SDM: it positions the patient as an active, equal partner and emphasizes the continuity of engagement throughout the care journey.

Hickmann et al. (2022) propose a concept map (Figure 15) that illustrates the interrelated components of patient-centered care. Service-oriented frameworks help translate this vision into practice.

Patient Empowerment

At the heart of patient-centered care is patient empowerment—a process and outcome that shifts the balance of power in healthcare interactions. Hickmann et al. (2022) define empowerment as enhancing the patient’s ability to think critically, make informed decisions, and self-manage their care.

Empowerment entails:

1. Enhancing the patient’s capacity for autonomous decision-making
2. Creating a state in which the patient feels confident in managing their care.

Empowered patients benefit from:

- Personalized interventions;
 - Access to appropriate resources;
 - Ongoing commitment to health management;
 - A trust-based relationship with their HCP.
- Empowerment and engagement are mutually reinforcing. Engagement requires empowerment, and vice versa. Together, they support shared ownership of care outcomes, requiring collaboration between patients and healthcare professionals. A design intervention that aims to overcome the barriers discussed in 3.1 thus should aim to make the patient feel more confident during consultations and to enhance a trust-based relationship with HCPs.

Health Literacy as a personal asset

Within this framework, health literacy is understood as a personal asset that underpins patient enablement and, in turn, contributes to patient empowerment. Conceptually, it comprises a set of transferable cognitive and practical skills, including the ability to comprehend health-related information and navigate complex healthcare systems. Transferability denotes the applicability of these skills across multiple contexts and stages of the patient’s care trajectory, allowing individuals to engage meaningfully in diverse health-related decisions.

From a theoretical perspective, embedding health literacy within decision-making processes can extend beyond immediate choices to foster sustained autonomy. When patients possess and can apply these skills across the continuum of care, they are better positioned to exercise agency, interpret information critically, and participate actively in SDM.

However, given the temporal constraints under which newly diagnosed patients must often make urgent decisions, the deliberate cultivation of health literacy lies outside the immediate scope of this project. Nonetheless, the framework prioritizes the preservation and transferability of acquired skills, ensuring that patients can leverage them to navigate subsequent decisions and interactions within the healthcare system.

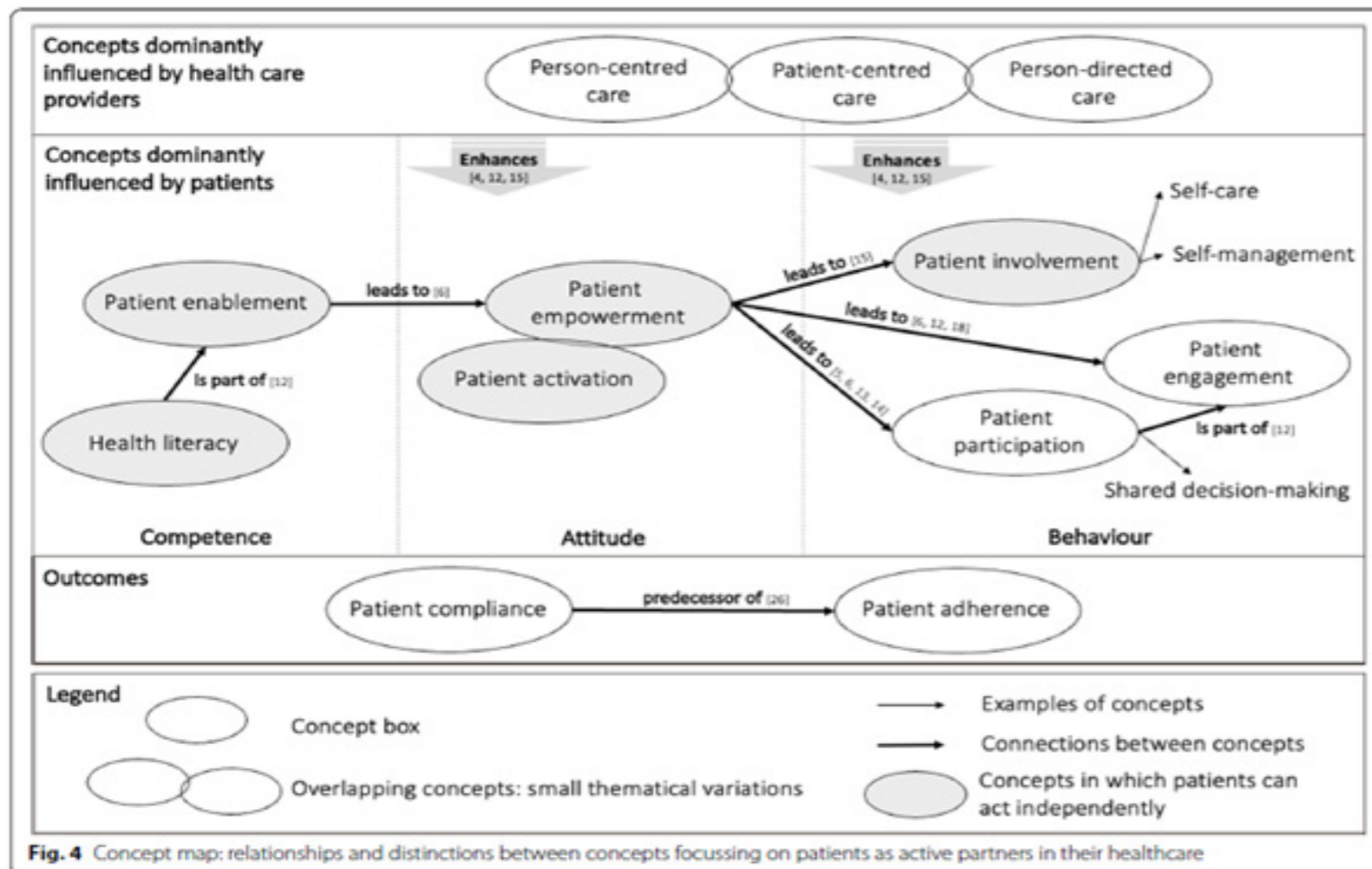


Fig. 4 Concept map: relationships and distinctions between concepts focussing on patients as active partners in their healthcare

Figure 15: Patient-centered care concept map by Hickmann et al. (2022): relationships and distinctions between concepts focusing on patients as active partners in their care

3.1 Barriers towards Shared Decision-Making

As outlined in chapter 1.1, addressing barriers to SDM is essential to ensure the SDM process is both inclusive and effective, making patient-centered care possible. (Durand et al., 2014; Shay & Lafata, 2015; Muscat, 2020; Josfeld et al., 2021). Despite clear benefits, SDM remains underutilized in clinical practice, especially for patients with LHL (van Eick et al., 2025). This underuse is often due to practical, perceptual, and systemic barriers which will be detailed in this paragraph.

1.2.1 Why overcoming barriers is needed

Gaps between SDM theory and practice

In practice, SDM is rarely implemented in full, especially in complex care trajectories. Studies in Dutch esophageal and esophagogastric cancer care reveal that medical consultations often fall short of applying SDM. The four steps of SDM are often not completed within a single consultation, and treatment discussions frequently prioritize medical arguments over patient preferences. This highlights a structural disconnect between SDM theory and how decisions are actually made in clinical contexts (Hermus, 2024; Hermus et al., 2023).

Misconceptions among clinicians

Implementation is hindered by myths among HCPs. For example, patients prefer not to participate, SDM is too time-consuming, or it adds little clinical value. Such misconceptions reinforce the perception of SDM as optional rather than essential (Oosterveld et al., 2019). Attitudes remain divided, with some clinicians advocating strongly for SDM while others question its feasibility in high-pressure settings such as oncology (Roodbeen et al., 2020).

HCPs reluctance of using tools

Clinicians are often hesitant to integrate PROMs into their regular practice, as they worry these tools might increase their workload instead of improving efficiency and effectiveness. In addition, many clinicians who already spend significant time engaging with patients feel they have a sufficient understanding of their patients' concerns and do not require extra information. Patients, on the other hand, are generally supportive of the consistent use of PROMs. Still, they emphasize that these systems need to be implemented thoughtfully—ensuring they enhance, rather than distract from, the clinical conversation, avoid placing unnecessary burdens on patients, and capture aspects that matter to patients themselves, not just to clinicians.

Participation enhances the care experience

Even when SDM does not lead to a different treatment choice, patients still benefit significantly from the process. In oesophageal cancer care, patients who were actively involved in the decision-making process, report greater satisfaction, reassurance, and a stronger sense of control, even when their initial preference remains unchanged. (Hermus et al., 2023)

This emotional and psychological impact is especially valuable in life-limiting conditions, where patients need to make complex decisions that reflect their values and long-term quality of life. A lack of participation can contribute to uncertainty and dissatisfaction with care, particularly among patients with LHL (Oosterveld et al., 2019; Edwards et al., 2023).

1.2.2 Three main barriers

Barriers for patients with LHL

Patients with LHL are less likely to ask clarifying questions, more inclined to follow clinician recommendations, and less confident in expressing their values (Murugesu et al., 2018). Co-creation studies confirm that, for these patients, being heard and having preferences acknowledged is the most influential factor for effective SDM (Murugesu et al., 2024). Yet HCPs often use fewer adapted communication strategies with this group, further limiting their ability to participate (Van Eick et al., 2025; Noordman et al., 2019). Patients with LHL are also more vulnerable to cognitive overload and tend to rely more on their clinician's guidance and advice (Noordman et al., 2019). While trust in professionals is not inherently problematic, it becomes an issue when the advice given does not align with the patient's values and preferences. In such cases, patients may lack the confidence to question recommendations or articulate what matters most to them (Muscat et al., 2019; Rademakers & Heijmans, 2024).

Steering behaviour of HCPs

Even when information is intended to be neutral, patients' interpretations are shaped by their experiences, emotions, and cultural beliefs. This underscores the importance of using communication tools that help patients reflect on and articulate their values in relation to available treatment options (Hermus et al., 2023).

To mitigate the risk of (un)intentional steering behaviour from HCPs, especially with LHL populations, SDM tools must go beyond simply presenting medical facts. Decision aids should incorporate value clarification exercises and be designed with sensitivity to health literacy levels. This approach increases the likelihood that patients will make informed decisions that genuinely reflect their preferences. (Hermus, 2024; Richter et al., 2023; Reyes et al., 2024).

Mitigating steering behaviour from HCPs is most crucial in the early phase of dialogue on treatment options. Once patients form initial preferences, they rarely shift, even in light of new information. This highlights the need for balanced communication at the outset (Hermus et al., 2023) and supports findings on "diagnostic closure," where early framing strongly shapes decision trajectories (Timmermans, 2013).

SDM requires system-level support

Successful implementation of SDM is not only about individual clinician attitudes. Implementation also depends on whether clinicians are equipped with the necessary skills, tools, and supportive organizational structures. Effective SDM requires strong communication skills, a clear overview of all treatment options, and the ability to adapt discussions for patients with LHL (Oosterveld et al., 2019).

Yet many clinicians lack skills and training in health literacy-sensitive communication. Studies show that up to 50% of HCPs do not specifically adjust their language or approach when working with LHL patients, citing time constraints and a lack of resources as key barriers (Murugesu et al., 2018). Even when Patient Decision Aids are available, they are often underused due to limited awareness or accessibility. Without sufficient integration into workflows and clear guidance on how to use them, these tools cannot support SDM effectively (Josfeld et al., 2021).

3.3 A Health literacy-sensitive SDM approach

Effective participation in SDM depends on patients' cognitive and social skills—such as asking questions, evaluating risks, and articulating preferences—which are often limited in individuals with LHL. Muscat et al. (2020) provide a conceptual framework that explicitly links health literacy to SDM, identifying three key pathways through which it shapes patient participation: understanding, communication, and reflection.

- **Understanding:** Improvements in understanding equip patients to more accurately interpret medical information, comprehend risks and benefits, and recognize the implications of different treatment options.
- **Communication:** Enhanced communication skills enable patients to ask informed questions, articulate their preferences clearly, and engage in meaningful dialogue with HCPs.
- **Reflection:** Fostering reflection allows patients to consider how medical decisions align with their personal values and circumstances, promoting more deliberate and confident decisions.

Recognizing Values and Lived Experiences

For patients with LHL, the most influential factor in effective SDM is having their preferences heard and acknowledged (Murugesu et al., 2024). According to Murugesu and colleagues, a cornerstone of health literacy-sensitive SDM is therefore the recognition of each patient's unique background, values, and lived experiences. Decision-making is not purely rational or clinical—it is deeply personal, shaped by priorities and life context.

To support this, HCPs must actively create space for patients' questions, tailor communication to their level of understanding, and integrate preferences into decision-making from the outset rather than only after presenting options (Murugesu et al., 2024). By framing options through the lens of patient values, HCPs can reduce the negative effect of (un)intended steering and foster more authentic engagement (Hermus, 2024).

Expanding the SDM model

The existing four-step model can be enhanced by adding two explicit steps specifically designed to improve patient comprehension and reflection (Noordman et al., 2022), figure 16.

Step Zero ensures that patients fully understand their diagnosis or health problem before any decision-making begins, allowing HCPs to identify and address misunderstandings and misconceptions early.

Step Five introduces a reflective review phase after a decision has been made, giving patients the opportunity to revisit outcomes, express concerns, and evaluate how well the chosen path aligns with their values and circumstances.

These additions suggested by Noordman make the SDM process more adaptive and supportive for patients with LHL. Emphasizing both pre-decision **understanding** and post-decision **reflection** fosters deeper engagement and long-term skill development. Meaning that patients with LHL can be enabled to learn transferable skills that can be applied throughout their care trajectory. Reflection, in particular, has been highlighted as an ongoing, iterative process essential for learning and growth, with feedback loops and evaluative discussions shown to enhance patient autonomy and preparedness, even in emotionally complex decisions (Edwards et al., 2023).

This model emphasizes enhancing **communication** by integrating patients' values and lived experiences throughout all steps of the decision-making process. In particular, it focuses on supporting patients in preparing for decision-making by helping them understand their diagnosis (step 0), the process itself, and the role they can play. This preparation empowers patients to engage in meaningful conversations and facilitates more effective communication.

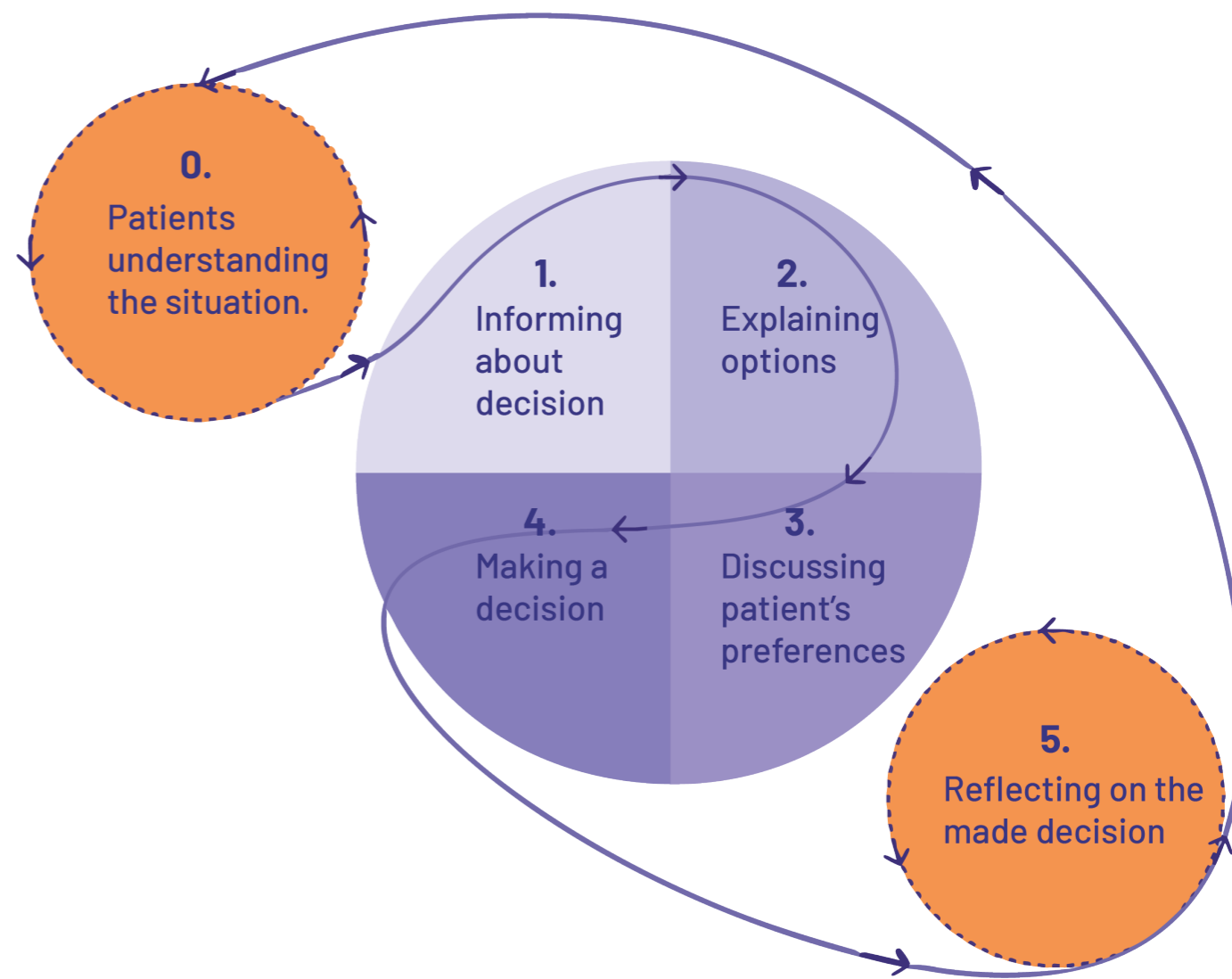


Figure 16: Health literacy sensitive SDM model: adaptation of the four-step SDM model by Stiggelbout (2015) – based on Elwyn's 3-talk model (2012). Adaptions are based on suggestions from Noordman et al. (2022)

Towards a Value-Centered SDM Model

This shift toward a dynamic and value-centered model is illustrated by Van der Pol et al. (2016), who propose discussing patients' values and preferences before presenting treatment options. In line with this approach, Van Lent et al. (2024) developed an online value clarification tool that helps oncologists integrate patient values and care goals throughout all steps of SDM. In real-world clinical settings, this tool has been shown to enhance patient involvement and strengthen alignment between treatment decisions and personal priorities.

Conclusion

Bridging the gap between SDM theory and practice requires a patient-centered approach that explicitly addresses the needs of individuals with LHL. Empowerment, engagement, and health literacy are deeply intertwined, forming the foundation for meaningful participation in decision-making.

Research shows that early clinical encounters strongly influence treatment decisions, with later information often used to justify decisions already made. In practice, medical arguments tend to dominate over patient preferences, and HCPs' misconceptions about the feasibility or value of SDM further limit its use. For patients with LHL, these issues are intensified by communication gaps, a lack of communication adaptation by HCPs, and greater vulnerability to (un)intentional steering. Tools like patient decision aids with value clarification exercises can help, but they are often underused because of improper integration into clinical workflows.

By acknowledging patients' values and lived experiences, and by introducing preparatory and reflective steps into the SDM model, the process becomes more inclusive, adaptive, and sustainable. Such an approach can not only improve immediate decision quality but can also build transferable skills that strengthen patients' long-term agency and autonomy in navigating their care.

Ultimately, enhancing communication and fostering trust-based relationships between patients and HCPs are essential to making SDM both effective and equitable.

CHAPTER 4

CONTEXT CASE STUDY: GIOCA POLICLINIC

This chapter explores the GIOCA outpatient clinic as a case study to examine the complexities of treatment decision-making, particularly for individuals with limited health literacy. It aims to uncover structural and interpersonal factors that shape these decisions.

The chapter outlines the study's objectives and research questions (4.1). Then it introduces the context (4.2), describes the specific approach used (4.3) for mapping the context and generating valuable insights who are presented in chapter (4.4).

Chapter overview

- 4.1 Goal
- 4.2 Introduction: working method of GIOCA
- 4.3 Approach
- 4.4 Main insights

4.1 Goal

The primary objective of this case study is to map the existing interactions and workflows involved in treatment decision-making for patients with esophagogastric cancer.

As outlined in Chapter 1.2.2, the intervention will focus on the consultation setting. More specifically on the moment when patients and healthcare professionals first discuss treatment options. To ensure that the intervention that is to be developed integrates seamlessly into clinical practice and aligns with patients' decision-making processes, the broader context is considered, utilizing a Context Mapping approach (1.3). As described in 3.2, one of the causes for limited adoption of SDM in clinical settings is that the materials and methods available do not fit the workflows of HCPs. The insights gained from this study will be utilized to try to overcome this barrier.

GIOCA

In particular, this study concentrates on the Gastrointestinal Oncology Centre Amsterdam (GIOCA), where the outpatient clinic's unique workflows serve as the central focus.

The specificity of the GIOCA outpatient clinic provides a valuable lens through which to understand the complexity of treatment decision-making, especially for individuals with LHL.

By examining this setting and its key stakeholders in depth, the case study aims to develop a nuanced understanding of the structural and interpersonal dynamics that shape treatment decisions.

The transferability of this project's insights will be discussed in chapter 11: Discussion.

Objective

To achieve the goal, three activities were conducted with each activity addressing a sub-goal.

- **Patient Journey Mapping (4.3.1)**
Understand the care pathway and existing interactions.
- **Observations: Multidisciplinary Meeting (4.3.2)**
Understand how treatment decisions are made in a multidisciplinary setting.
- **Observations: GIOCA outpatient day (4.3.3)**
Understand how communication occurs during consultations and how patients are guided



Figure 17: VUmc polyclinic building (Parkeerlocaties | Parkeerbedrijf VU-VUMC, n.d.)

4.2 Introduction: working method of GIOCA

GIOCA stands for Gastro-Intestinal Oncology Center Amsterdam, a clinic for rapid diagnostics of digestive tract diseases, which may be malignant. It is a specialized clinic within Amsterdam UMC that offers fast-track diagnostics and treatment planning for cancers of the digestive tract, including the esophagus, stomach, liver, bile ducts, and intestines. Its goal of rapid diagnostics is to reduce waiting times and uncertainty through rapid, expert evaluation and care. All information on this page is retrieved from Amsterdam UMC, (n.d. -a,-b).

Who is it for?

- Patients with suspected or confirmed gastrointestinal issues (e.g., esophagus, stomach, intestines).
- People referred for a second opinion.
- Patients needing diagnosis or treatment not available at their original hospital.

GIOCA outpatient day

On this day, patients undergo all necessary tests, such as blood work, imaging (CT/MRI), endoscopy, and consultations with specialists, in one coordinated visit, see the image on the right for an impression of this day.

At noon, the medical team reviews the results and aims to provide a diagnosis and preliminary treatment plan advice during a MDO. In the afternoon patients are informed on the treatment plan and a decision is made. This approach is taken to significantly reduce waiting times and patient uncertainty.

Team and case management

GIOCA operates with a team of specialists and nurses who hold MDOs to determine the best treatment. Patients are assigned a case manager (nurse specialist or consultant) as their point of contact.

Nursing Consultant:

- Explore patient's values, concerns, and preferences
- Provide psychosocial support
- Help the patient understand the structure of the day and what to expect
- Act as liaison between patient and MDO

Medical Specialist

(e.g., oncologist, radiotherapist, surgeon):

- Assess diagnosis and staging
- Determine treatment options and decide on treatment advice
- Begin to align treatment plan with clinical guidelines
- Explain medical implications to the patient

Dietitian / Supportive Care Specialists (if applicable):

- Assess and advise on nutritional or supportive care needs
- Provide preventive guidance to prepare for treatment side effects

Radiologist / Gastroenterologist / Other diagnosticians:

- Conduct and explain diagnostic tests
- Ensure all data is available for decision-making
- Inform patients of immediate next steps, if applicable

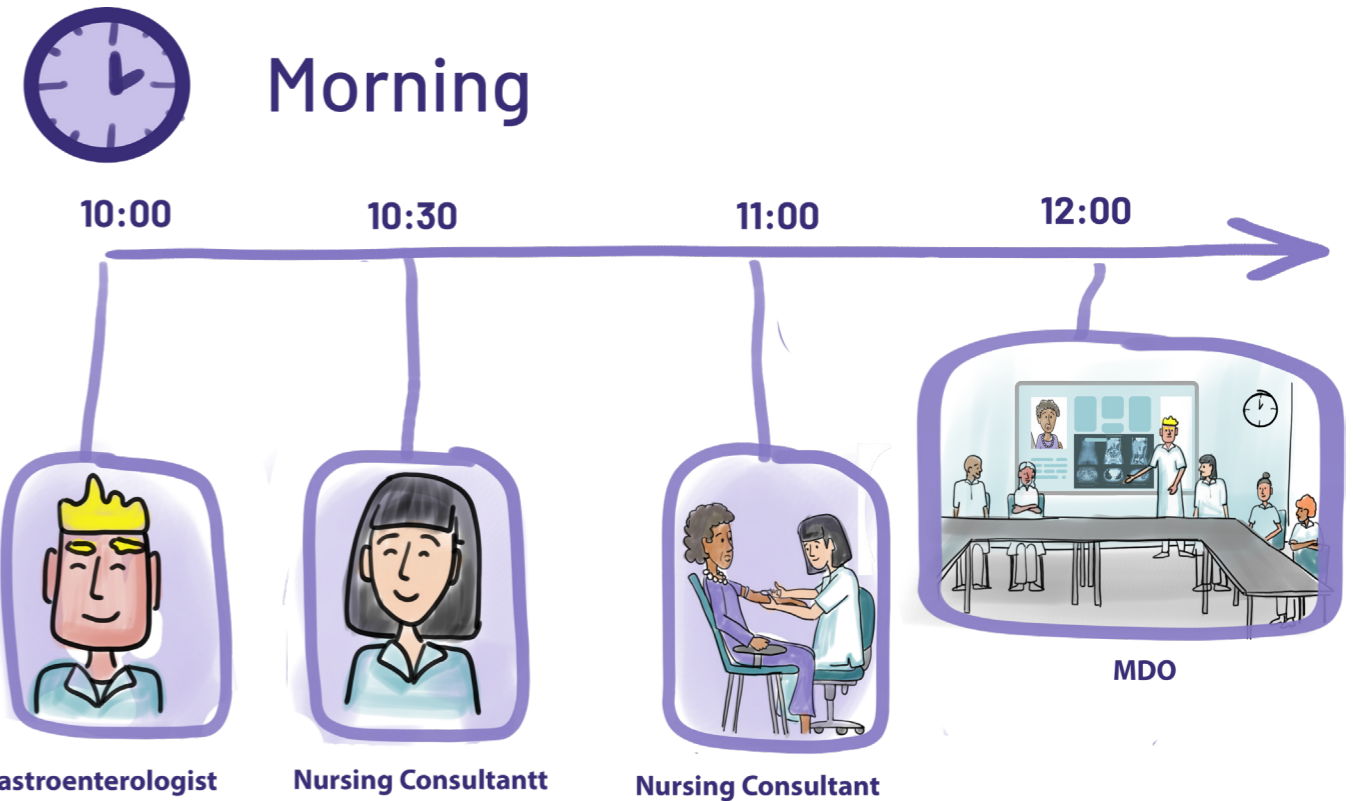


Figure 18: Simplified sequence of meetings a patient has during GIOCA outpatient day: the morning. The patient does not attend the MDO.

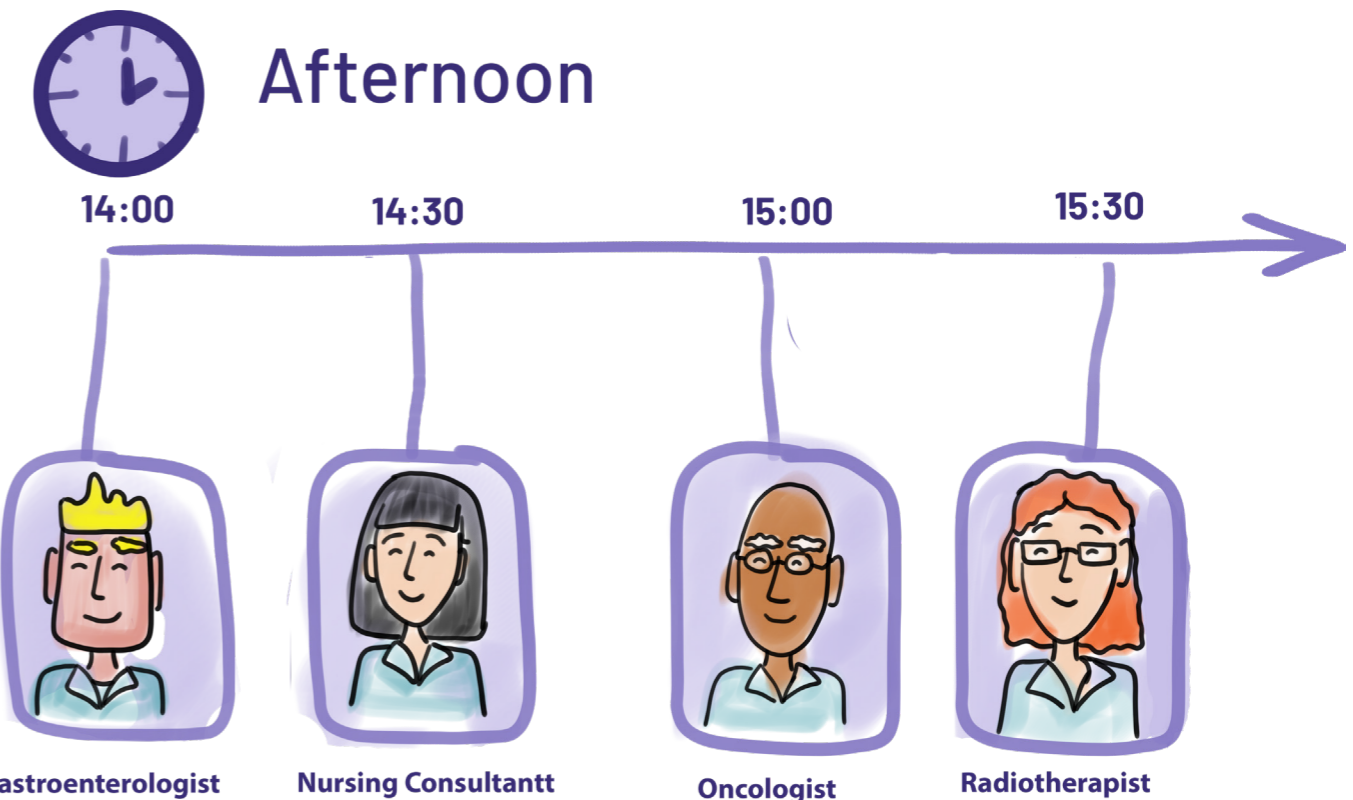


Figure 19: Simplified sequence of meetings a patient has during GIOCA outpatient day: the afternoon.

4.3 Approach

This field research involves three core activities, which will be explained in the corresponding paragraphs:

- Patient Journey Mapping (4.3.1)
- Observations of Multidisciplinary Team Meetings (MDO) (4.3.2)
- Observations of Consultations during the GIOCA Outpatient Day (4.3.3)

4.3.1 Patient Journey Mapping

The Patient Journey Map described in this paragraph served as a tool at the beginning of the innovation process, offering a systematic overview that deepens the understanding of the healthcare experience, particularly in relation to decision-making.

Development as a first step in the project

This Journey Map was developed as the first step in this project. Its primary purpose is to visualize the care journey from both the patient and healthcare professional perspectives, helping to identify pain points, unmet needs, and opportunities for improvement.

Dual perspectives: patients and healthcare professionals

Within the context of the GIOCA, the map provides insight into current clinical practices. It captures key moments across the care pathway, integrates firsthand experiences from both patients and HCPs, and highlights communication challenges that may affect shared decision-making and patient satisfaction.

Insights into current clinical practices

This dual-perspective approach supports the identification of bottlenecks and serves as a foundation for designing targeted interventions. The overarching goal of this mapping exercise was to reveal actionable opportunities to enhance care delivery for esophagogastric cancer patients with LHL.

Use of real stakeholder data

It is important to note that the map draws on data from actual GIOCA stakeholders, including real patients and practicing healthcare providers.

Integration of diverse data sources

The Patient Journey Map integrates a variety of data into a single visual overview. This integration enables a clear, accessible representation of the care process and its challenges.

Further details and full report access

The map was developed as a preparatory activity during an internship. The approach for finding participants, gathering data, and analyzing the results will be briefly addressed; for more details on the design process of the journey map, the full report can be requested.

Recruitment of participants

HCPs were primarily recruited via email and through referrals from the first interviewee. In total, five HCPs participated in the study. The first interviewee provided a list of potential interview candidates. All individuals on this list received a standardized email invitation, explaining the purpose of the study and requesting their participation in a 30-minute interview. Prior to each interview, participants were asked for their consent to record the conversation using an audio recording device.

For my company supervisor's PhD research **patients with LHL** diagnosed or treated at GIOCA were interviewed by my supervisor. The study included 11 patients with LHL interviewed at multiple points in their care trajectory, allowing for rich reflections on their understanding of the process and their lived experiences. These transcripts were reviewed and analysed as the first step in designing the patient journey.

Probe materials

Insights retrieved from patient interviews informed the development of the first semi-structured interview with a healthcare professional (P01). In preparation for this interview, a visual overview of key action points within the care pathway was created. This visual, based on care trajectory documents shared by P01, served as a discussion probe to facilitate reflection and dialogue.

As the HCP interviews progressed, the Patient Journey Map was gradually constructed. Initially, the plan was to bring the most recent version of the journey to each interview so it could function as a dynamic discussion tool. This probe material was intended to help participants articulate their routines, emotions, and values, following the principles of the 'path of expression' (Sanders & Stappers, 2013).

However, after the first interview, the strategy was adjusted. The journey visual tended to steer the conversation toward specific action points, rather than eliciting broader reflections on experiences, needs, and goals. For the remaining four interviews, a new probe was introduced: a vertical timeline of consults during the GIOCA outpatient day. This alternative visual provided space to discuss goals, strategies, tools used, and both positive and negative experiences. It enabled participants to reflect on their own practices. In addition it enabled me to compare the interview results which helped the analysis process.

Semi-Structured Interviews

The semi-structured interviews with HCPs were set up around the main themes and topics displayed in the Patient Journey Map. The goal of these interviews was to gain insight in HCPs' experiences around treatment decision making, specifically their experiences with patients with LHL. These interviews centered on informing patients and eliciting patients' wishes during consultations with patients on outpatient days. To ensure consistency during the interviews an introduction was written out. In this introduction the HCPs were introduced to the topic of LHL and the goal of the interview was briefly addressed.

Preparation for these interviews consisted of the following elements:

1. Analyzing the insights from Interview 1.
2. Formulating general questions to be answered by every interviewee.
3. Formulating questions addressing specific topics per interviewee where tension and confusion occur as seen by patient interviews.
4. Sending the Consent Form to the interviewee in advance.

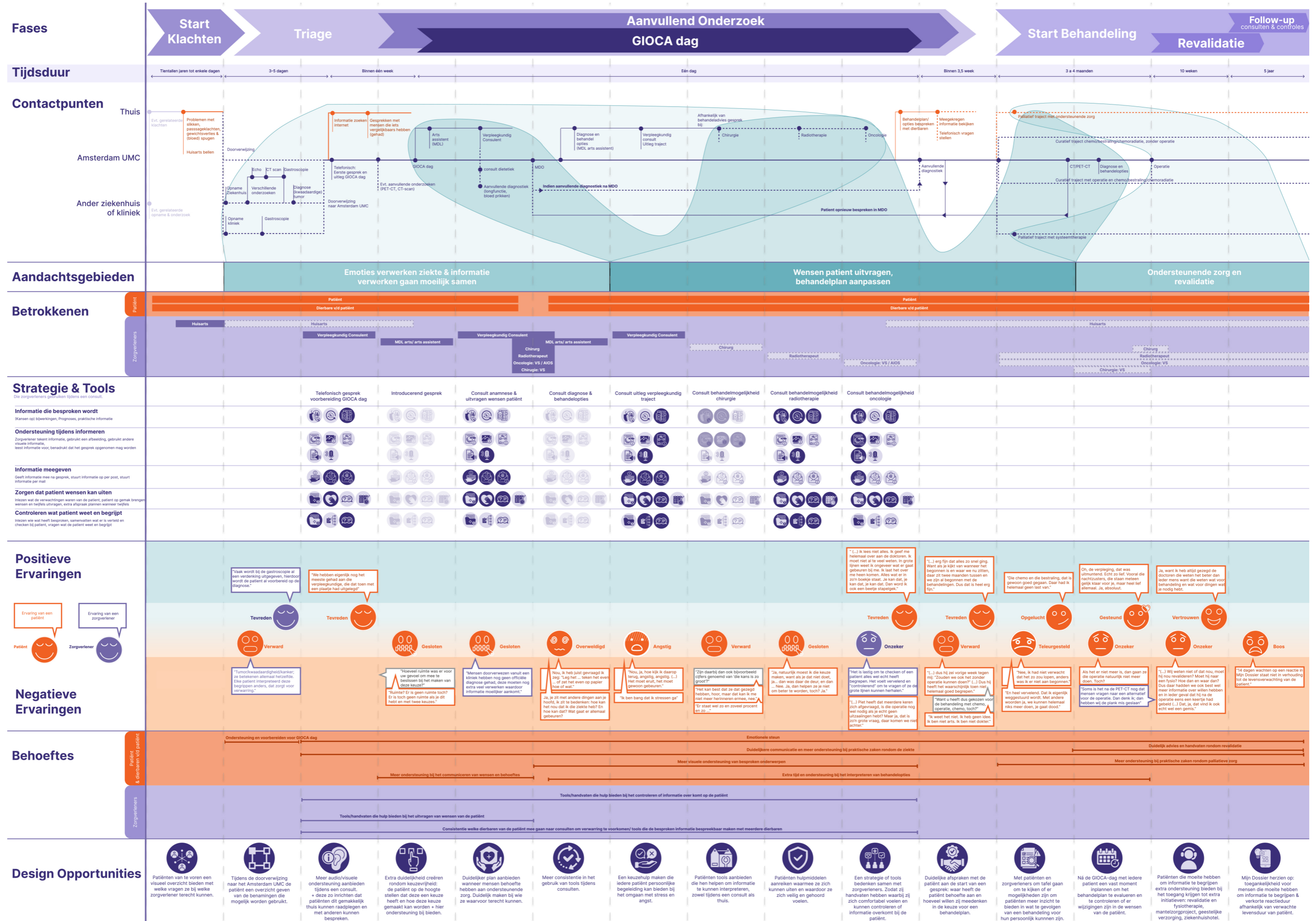


Figure 20: Impression of the created Patient Journey Map. A higher, readable, quality version can be requested. The journey includes Phases, Timespan, Contactpoints, Focus areas, Stakeholders, Strategies & tools, Positive and negative experiences of both HCPs (purple) and patients (orange), Needs and Design Opportunities.

4.3.2 Observations: Multidisciplinary meeting (MDO)

Purpose

The observations of the MDO were conducted to gain deeper understanding on the major decision-making moment for the treatment advice. The goal was to gain insight how patient values and perspectives, as discussed in the morning, are represented during the MDO. Next to that, insight was gained in how the trade-offs for every patient are discussed and how a treatment advice is generated by this. It also provided insight in the workflows of HCPs in terms of division of roles and tasks.

Approach

Over the duration of half a year four MDO's were attended. Due to the highly specific and clinical nature of discussions the first meetings that were attended were difficult to follow. While the project evolved and more knowledge on esophagogastric cancer and treatment was gained, the conversations became more comprehensible. It was decided to attend multiple meetings to gain a broader understanding of the workflows and interactions. Notes of observations were made during the meeting and were after the meeting combined to write out a detailed recollection, following the Context Mapping method as described in 4.3.4.

4.3.3 Observations: Walkthrough consults during GIOCA day

Purpose

The walkthrough day was set up to be able to gain deeper insight in the dynamics and interactions between HCPs and patients during and in-between consultations during the GIOCA day. In addition, the observations during this day provided insight in the workflows of HCPs as well as the navigation of patients through the polyclinic.

Scope of the field research

This field research involved observations of five consultations and one MDO. At the beginning of the GIOCA day, nursing consultants were contacted to help identify which patients would be attending and what kinds of consultations could be expected. As case managers, they are closely involved in coordinating the patient journey and are well-positioned to guide patients through the various appointments scheduled for the day.

Consent and introduction of research

To facilitate a smooth process and minimize potential confusion or disruption for patients, consent was first sought from the healthcare professionals (HCPs) prior to approaching any patients. The nursing consultant provided a brief introduction to their colleagues, after which I introduced myself, outlined the purpose of my research project, and requested their consent to observe the upcoming patient consultation.

The nursing consultant then identified a suitable patient and, in order to reduce any perceived pressure, sought their consent in my absence. Once patient consent had been obtained, I introduced myself and briefly explained the aim of the research. Thereafter, I remained as unobtrusive as possible, positioning myself in the background during the consultation.

Morning observations: first patient journey

In the morning, consultations involving a single patient were observed. This began with a session with a nursing consultant, followed by a consultation with a gastroenterologist. Later that same day, the related MDO in which treatment options for this patient were discussed was also observed. This provided a comprehensive view of the decision-making process from both the patient's and clinical team's perspectives.

Afternoon observations: switching to a second patient

In the afternoon, a deliberate decision was made to observe consultations involving a different patient. The first patient had entered a non-curative care trajectory and required further diagnostics; consequently, their remaining interactions for the day would be limited. In agreement with the nursing consultant, the focus shifted to another patient.

The following consultations were scheduled and attended, including:

- A discussion with a gastroenterologist regarding diagnosis and treatment advice
- A meeting with a nursing consultant about logistics and nursing care possibilities
- A consultation with an oncologist about chemotherapy
- A session with a radiotherapist regarding radiotherapy options

This provided a more comprehensive view of the patient journey and the collaborative clinical process.

Data collection

Between consultations, patients and their next-of-kin returned to the waiting area. A respectful distance was maintained to ensure their privacy. During these intervals, notes were taken on previous observations to capture the insights in real time without intruding on the patients' personal space.

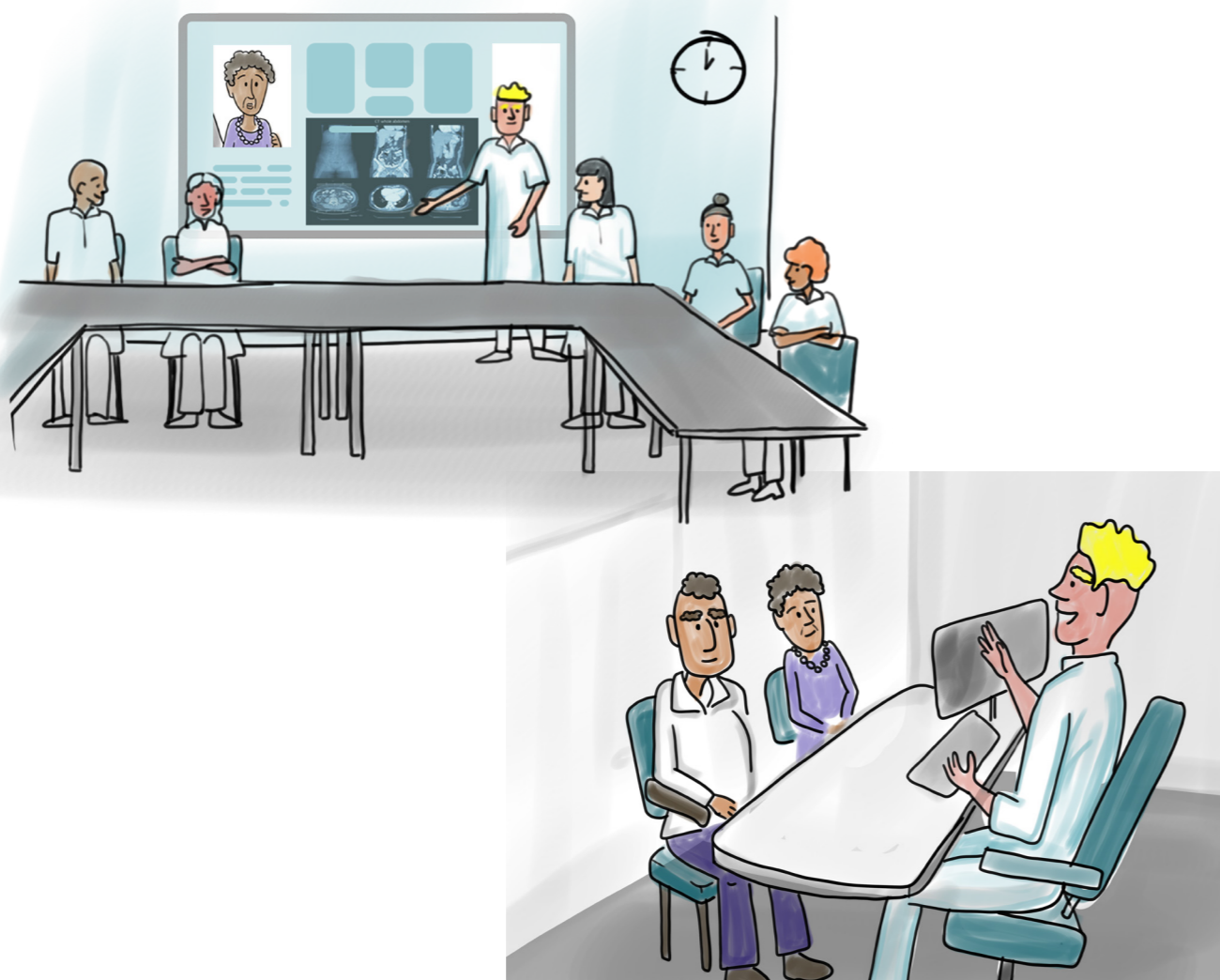


Figure 21: Impression of multidisciplinary meeting (top), and conversation in the consultation room (bottom).

4.4 Main Insights

4.3.2 The healthcare professionals' perspective

Insights from interviews conducted during the development of the Patient Journey Map (4.3.1) revealed that most HCPs develop their communication skills primarily through clinical experience. Although their training includes theoretical education on patient communication, this is typically only applied and refined in practice much later. As such, learning to communicate effectively with patients, particularly those with LHL, often lacks structure and support in the early stages of a medical career. In addition, it causes a wide heterogeneity across approaches of HCPs, they have all developed their individual approaches and use of tools and strategies.

"Sometimes even after the PET-CT, people still ask about an alternative to surgery. Then I think: we must have missed the mark." -HCP

"It's difficult to check whether a patient has really understood everything. It feels unpleasant and 'controlling' to ask them to repeat the main points." -HCP

"There's a lot of variation in whether and how treatment outcomes are shared." -HCP



4.3.3 The patient's perspective

"Yes, of course I had to make that choice, because if you don't, well... then there's the door, and then... No. Yes, then they won't help you get better, right? Yes." -patient

"Well, I actually asked, I said: 'Explain it... draw it quickly... or just put it down on paper, how and what.' -patient

"(...) so last week he said to me: 'Could we also do it without surgery?' (...) So he probably didn't fully understand it at the time." -next of kin



Lack of fixed resources in the consultation room
All consultation rooms are modular, used by various departments throughout the week. This limits opportunities to store or display consistent tools like leaflets, diagrams, or models. Patients move from room-to-room during the GIOCA day, and, according to HCPs, patients staying in the same room and HCPs moving from room-to-room is not an option.

Response to patient disagreement
When patients express differing views from the medical advice provided, an extra consultation is often scheduled. However, the focus tends to be on convincing the patient of the clinical recommendation, rather than on SDM.

Limited continuity consultations and MDO
There is minimal structure for integrating patient input from earlier consultations into MDOs. This is mostly conducted verbally during the meeting.

Recognizing and addressing patient's needs
Many HCPs struggle to recognize LHL, and struggle to check a patient's understanding, and accommodate their additional needs.

Constant language switching
HCPs must switch frequently between clinical jargon when communicating with colleagues and plain, accessible language when speaking to patients and families. This constant switching adds to their cognitive load.

Reflection on decisions post-GIOCA day
Despite weekly contact during treatment (e.g., in radiotherapy and oncology), patients' doubts often remain unspoken or are expressed only at a late stage (when changing the treatment plan is no longer possible). Opportunities to address and support these concerns are difficult to seize, as HCPs are reluctant to repeatedly revisit the patient's decision, fearing to cause the patient to feel insecure or anxious.

Perceiving a choice
Many patients do not perceive treatment discussions as involving real choices, due to the often limited options presented. HCPs echo this, and say that they work with a treatment advice, and do not present options.

Misunderstanding despite higher health literacy
Even patients with relatively strong health literacy sometimes misunderstand key parts of their treatment plan, leading to visible distress. Although this is often clarified in follow-up conversations, it highlights the importance of explicitly checking how patients interpret and contextualize information.

Expressing insecurities and doubts
Some patients struggle to articulate their doubts or insecurities, leading to delayed communication, increased stress, and uncertainty. Negatively impacting the overall care and decision-making experience.

Fear of not receiving care
Some patients fear that expressing concerns, specifically when they consider a palliative care pathway without treatment, might negatively affect their care, leading them to remain silent. HCPs do not consistently discuss the possibility of no treatment with patients, leaving them to feel insecure to discuss it. This causes a missed opportunity for deeper, and more effective communication.

Overwhelm after conversation on treatment advice
According to some HCPs, patients who struggle with processing information are most negatively affected after the initial consultation in which the treatment advice is explained. This often diminishes the effectiveness of subsequent conversations, as patients are less receptive to further communication.

Challenges in involving next-of-kin
Patients are often accompanied and supported by different next-of-kin throughout their care journey. Ensuring consistent communication across this group can be challenging for both patients and HCPs. As patients involve a diverse set of supporters, HCPs are often required to repeat information multiple times, which can lead to frustration. Additionally, conflicting interpretations among next-of-kin may cause confusion and stress for the patient.

Figure 23: Case study research insights. Right: insights that relate the most to HCPs, left: Case study research insights that relate the most to esophagogastric cancer patients with LHL.

Conclusion

This chapter explored a specific context for esophagogastric cancer treatment decision-making: GIOCA polyclinic. The case study provides an understanding of the care process and implications for decision-making for both HCPs and patients.

The HCPs perspective:

Understanding a patient's values is complex, and turning them into actionable input for MDO discussions is even harder. Just as patients need guidance with choices, HCPs need strong support to lead these conversations. This support must go beyond communication training. Practical, evidence-based tools should be built into workflows, helping HCPs capture and convey patient perspectives clearly. Time and flexibility are also essential to tailor discussions to individual needs. Efficiency matters: integrating patient perspectives early reduces miscommunication, builds trust, and cuts down on follow-up consultations—freeing resources for others.

In short, equipping HCPs with the right tools, processes, and systemic support is key to patient-centred care, efficiency, and ensuring decisions align with patients' values from the start.

We should support HCPs to:

- Identify the patient's communication and information needs and gain confidence in adjusting their communication.
- Use structured communication tools that guide the dialogue without relying on abstract probabilities.
- Focus on relational communication: building trust, checking understanding in non-patronizing ways, and validating emotional responses.
- Shift from 'informing' to 'framing together': collaboratively making sense of the decision in a way that fits the patient's life and values.
- Providing support in argumenting the patient's perspective during the MDO

The patient's perspective:

Patients with limited health literacy often struggle to relate complex medical information to their own situation. Difficulties interpreting risks, probabilities and practicalities of the care trajectory can lead to information overload, confusion, and fear. As a result, some avoid information altogether, fearing emotional overwhelm, bad news, or feeling disrespected by misaligned communication.

We should support patients by:

- Providing support in navigating the entire decision-making and treatment process
- Helping them feeling more confident and in control of their own process and stimulating them to express their values, preferences, insecurities and doubts.
- Creating clarity, cohesion, and consistency in all information they receive
- Making the information and assistance they need accessible (no hard-to-find online tools, but directly applied in the consultation room)

CHAPTER 5

CO-CREATION STUDY

This chapter focuses on gathering insights on the first main target group: individuals with LHL. Chapter 6.1 outlines the study objectives, research questions, and session design. The methods for participant inclusion, facilitation, data collection, and analysis is detailed in chapter 6.2. The main insights are presented in Chapter 6.3.

Chapter overview

- 5.1 Goal
- 5.2 Approach
- 5.3 Main Insights

5.1 Goal

This chapter explores how barriers experienced by individuals with LHL can be addressed to improve communication with HCPs and support more inclusive healthcare decision-making.

By engaging directly with the LHL target group, the study seeks to understand their experiences, expectations, and preferences, ensuring that interventions are grounded in the realities of those they are intended to serve.

Through co-creation, the research adopts a participatory approach in which participants actively contribute to shaping solutions. This involvement can foster interventions that are more relevant, acceptable, and effective. Although participants were not esophagogastric cancer patients, they belonged to the relevant population: individuals with LHL aged 45+.

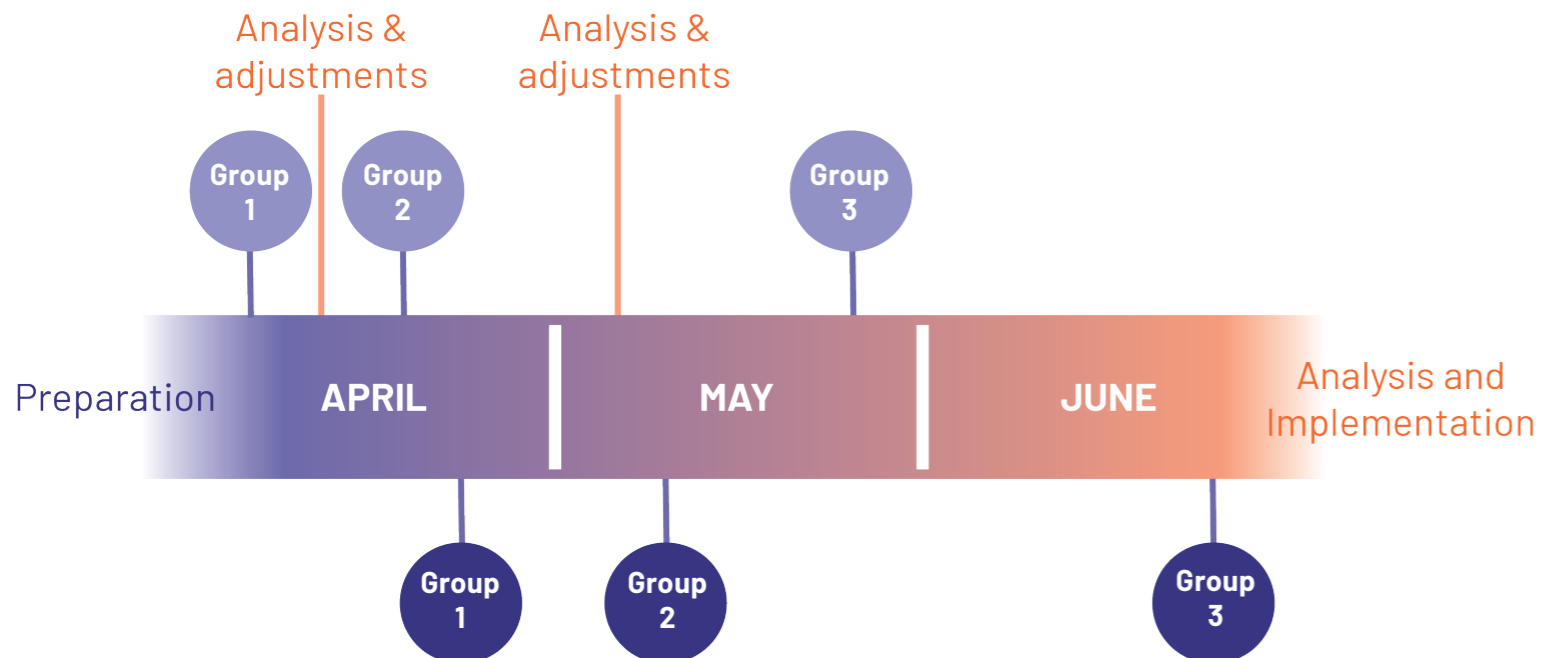
The co-creation study engaged three diverse participant groups across four locations in Amsterdam-West. Each group participated in two co-creation sessions (each lasting two hours), conducted over a three-month period (see timeline in Figure 24). The research goals and session structures were iteratively refined in collaboration with a multidisciplinary research team, including colleagues from the RISC research group.

5.1.1 Main research question and objective

The study's objective builds on previous research activities described in this thesis (literature review and case study) and was further shaped through discussions with an expert professor of oncology. They advised to focus on developing intervention to support communication in the consultation room. While the sessions focused on communication in the consultation room in the context of esophageal cancer, a broader perspective was maintained to ensure the development of holistic interventions. Esophageal cancer was chosen as the narrative example because it allowed for a clearer and more relatable discussion with participants than including gastric cancer, which would have increased complexity.

Main Research Question

How can communication and information-sharing during consultations be improved to better support patients with LHL in understanding their treatment options, expressing their concerns, and participating in emotionally and cognitively demanding decision-making processes?



5.2 Approach

The Integrated Creative Problem Solving (iCPS) method (Heijne & van der Meer, 2019) was employed to develop the session plans and facilitate creative output. In addition, the Convivial Toolbox (Sanders & Stappers, 2013) was consulted for the development of generative materials and forms the basis for the data collection and analysis approach further detailed in (5.2.5 & 5.2.6). Prior to the sessions, the session plan was reviewed in consultation with multiple experts in the fields of LHL, SDM, and risk communication who all had experience with co-creation. This included discussing the research objective (informed by previous insights) and the design of the exercises.

Structured Approach

Given participants' limited experience with creative problem-solving and the presence of cognitive, linguistic, or cultural barriers, a structured format was adopted. Exercises were carefully designed to be straightforward, with clear and concise explanations provided between each activity to ensure accessibility and maintain engagement throughout the session. Further elaboration on the session design can be found in Appendix B.

Respectful environment

Given the personal and sometimes emotional nature of discussing healthcare experiences, special care was taken to create a safe and respectful environment. The sessions took place in locations that were easy to access for participants, in spaces that provided privacy. Food and drinks were either provided by us or by the participants, which made for a cosy and friendly atmosphere, see figure 25. In addition, it was explained during every exercise that there was no right or wrong and all input was helpful and welcome.

Focus of the sessions

Rather than concentrating solely on past experiences, the sessions explored two central themes:

- 1. Communication Barriers:** Challenges in expressing personal values, asking questions, and describing symptoms during consultations with HCPs.
- 2. Responses to Complex Medical Information:** Participant reactions when receiving information for the first time about esophageal cancer.

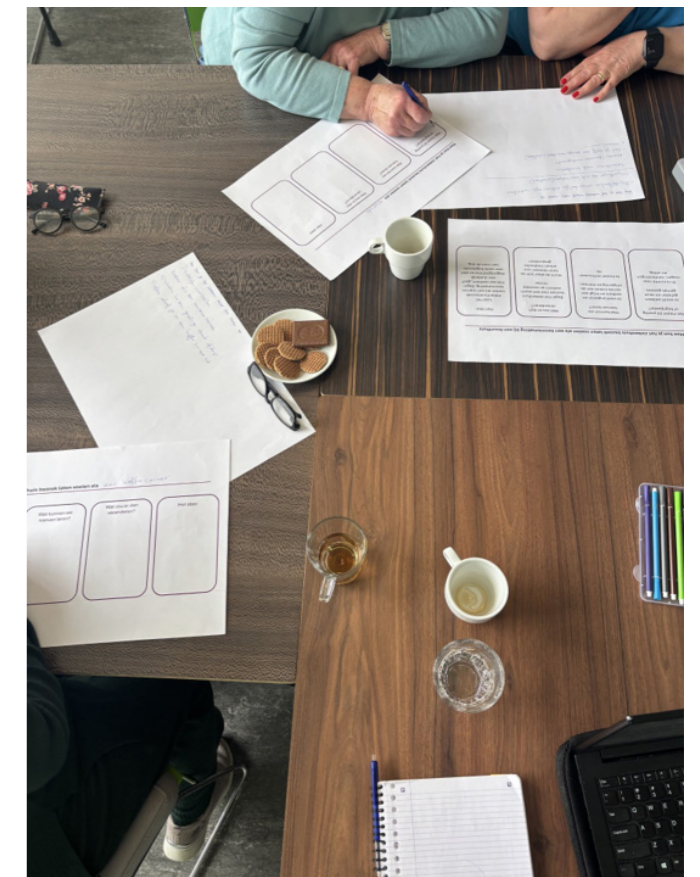


Figure 25: Cozy and friendly environment during the co-creation session.

5.2.1 Participants

In total, 16 participants took part in this study. An overview of group composition and participant characteristics is shown in Figure 26. To ensure a human-centered yet privacy-sensitive approach, acronyms are used throughout.

Participants were selected based on age (45+) and suspected, or earlier identified LHL. While the participants were not (former) esophagogastric cancer patients, this profile does mirrors the communication and decision-making challenges experienced by the target patient population. It was found that 12 of the 16 participants met de criteria for LHL. To assess this, the Newest Vital Sign – Dutch (NVS-D) was applied, which is a validated tool for assessing health literacy (Fransen et al., 2014). The remaining four participants had adequate health literacy levels, yet all reported experiencing difficulty with processing medical information in the past.

Rationale for participant selection

Involving people with lived experience is essential to mitigate unintended consequences of co-design in healthcare (Shé & Harrison, 2021). However, involving (former) esophagogastric cancer patients with LHL proved unfeasible. Despite extended outreach at the GIOCA clinic, patients found participation too physically or emotionally demanding. Furthermore, the ethical justification of involving (former) patients with LHL warrants consideration.

Engaging participants in a process that may impose additional burdens—without the ability to offer a direct and meaningful benefit in return—raises questions about both necessity and fairness. This ethical dimension is examined in greater detail in chapter 10.

Recruitment

Recruitment was facilitated through the lead researcher's previous fieldwork and professional networks, along with support from colleagues in the RISC research group. Groups 2 and 3 were formed via community contacts, who also participated in the sessions and helped communicate practical arrangements to their peers. Participants in Group 1 were contacted individually.

Consent and privacy

At the start of the first session, participants received an explanation of the informed consent form from the research lead, which they signed with support when needed. Several participants assisted peers by translating the content or explaining key points in their native language. Although the consent form was written in plain Dutch, additional verbal guidance was often necessary, also for participants who spoke fluent Dutch.

Participants gave consent for:

- Participation in the study
- The non-identifiable use of photos taken during the sessions
- Collection and anonymous storage of background characteristics
- Use of anonymized session data for research purposes
- Secure data storage for up to three years

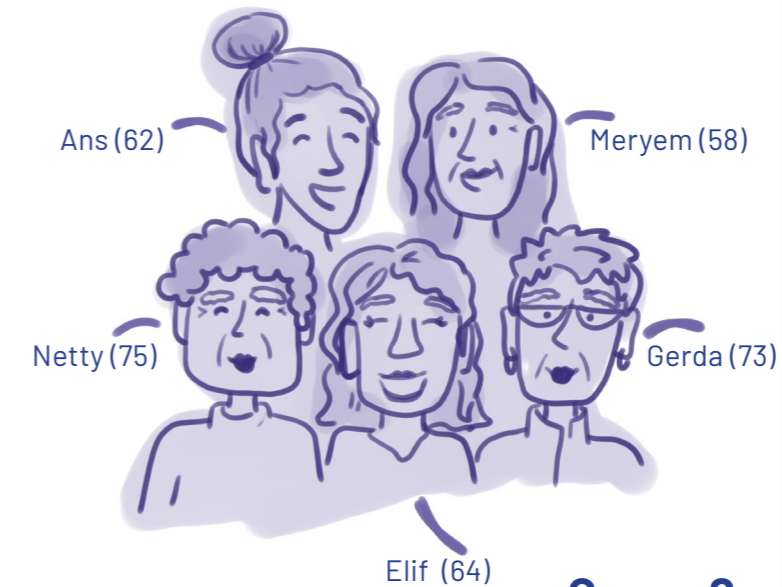
Background characteristics

All participants were asked to complete a short questionnaire about their background, including age, country of birth, gender, and highest level of education. Similar to the consent process, many participants required help understanding and filling in the form.

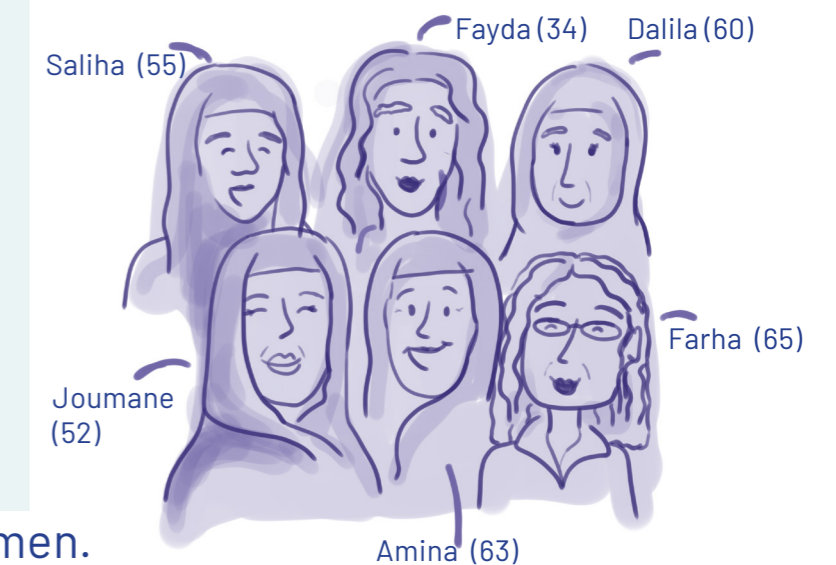
Health Literacy assessment

The NVS-D was administered individually at the end of the first session every participant was present at. When possible this took place at a distance from the rest of the group, to safeguard privacy and ensure a more quiet less distracting environment. Participants who were not sufficiently fluent in Dutch received help from peers, who translated the questions and explained the purpose of the tool.

Group 1: Turkish and Dutch born women.



Group 2: Moroccan and Dutch born women.



Group 3: Turkish and Dutch born men.

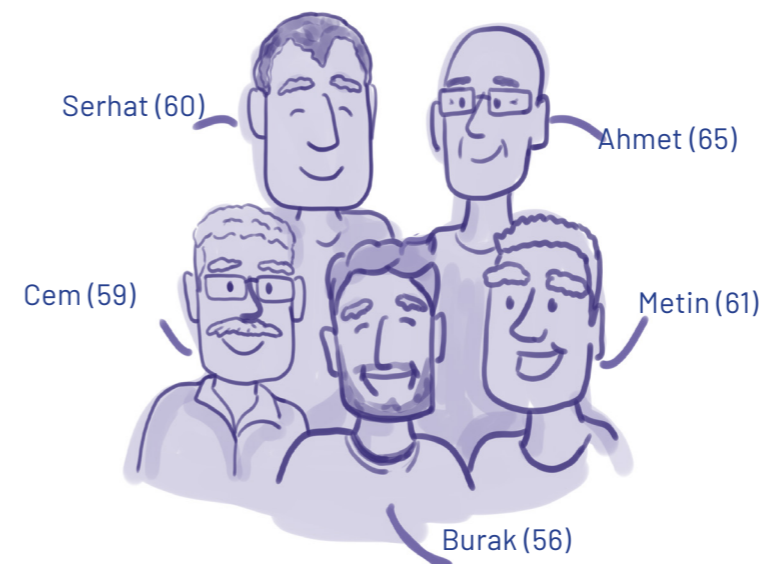


Figure 26: Overview of participant groups. Including country of birth, age, gender. All participants are anonymized and acronyms are used

5.2.2 Research lead and facilitator

All sessions involved two researchers: a research lead and a facilitator, with roles alternating based on availability. In some sessions, two facilitators were present. I facilitated five of the six sessions and acted as research lead once. The research lead opened the session, introduced the icebreaker, monitored time, ensured objectives were met, and took notes. The participants were informed of this to avoid misinterpretation. The facilitator guided activities, supported discussion, and recorded supplementary notes and reflections immediately after each session.

5.2.3 Facilitation approach

The facilitator created a safe and respectful environment, using open-ended questions, active listening, hypothetical scenarios, pauses, and time for reflection. Information provision and information gathering were balanced according to each group's energy, engagement, and comprehension.

Storytelling

Storytelling was incorporated to help participants grasp the emotional and practical complexity of treatment decision-making for oesophageal cancer. This narrative approach aimed not only to foster empathy toward a newly diagnosed patient confronting the moment of making a treatment decision, but also to facilitate participant engagement with emotionally sensitive topics. By allowing participants to reflect through the lens of a fictional persona, storytelling created a degree of emotional distance, enabling them to express concerns, values, and needs that might otherwise be difficult to articulate from their own perspective.



Figure 27: Facilitators utilizing storytelling during the co-creation session to engage participants.

5.2.4 Session structure

The detailed design of session exercises is provided in Appendix B. Below, the overall objectives and approach are summarised.

Session 1 - Exploring expectations and initial responses

This session examined participants' experiences and expectations during a hospital visit. Through the narrative of a newly diagnosed oesophageal cancer patient, participants reflected on the day the patient was to receive their diagnosis and treatment plan. They were introduced to possible treatment options, enabling exploration of how they process medical information, identify communication barriers, and suggest ways to improve understanding and dialogue.

Session 2 - Co-creating solutions for trust and clarity

Building on Session 1, this session focused on co-developing strategies to strengthen patient-HCP communication. Participants enacted a first consultation between patient and HCP, and through a creative exercise—designing an information folder—expressed how they prefer medical information to be presented and what content they considered most important.

Flexibility in exercises

Although session plans, exercises, and templates were prepared in advance, flexibility was central to the approach. As discussions involved sensitive personal experiences, facilitators prioritised patience, respect, and psychological safety. Adapting pace and content to participants' comfort levels encouraged openness and meaningful engagement.

5.2.5 Data collection methods

Data were collected using three complementary methods:

- Session Notes** - Detailed notes were taken during each session, documenting key points from the discussions as well as participants' immediate responses to questions. (taken by the research lead)
- Post-Session Reflections** - Immediately after each session, the facilitator and research lead recorded reflective notes capturing additional observations, clarifications, and impressions. These notes included:
 - The source of the information (who observed, recorded, or reported it)
 - The location, date, and time of collection, along with relevant contextual details
 - Participant identifiers, later anonymised into acronyms for use in this thesis
 - Insights or preliminary interpretations that emerged during data capture.
- Completed Templates** - Templates filled in during the exercises provided direct, and when possible, participant-generated material for analysis.

Across all methods, the documentation captured both the substantive content of discussions and observations of participants' interactions. These interactions include those of participants with one another, with the exercises, and with the facilitators or research lead. These observations also addressed non-verbal engagement, attitudes, and the ways participants navigated the session activities.

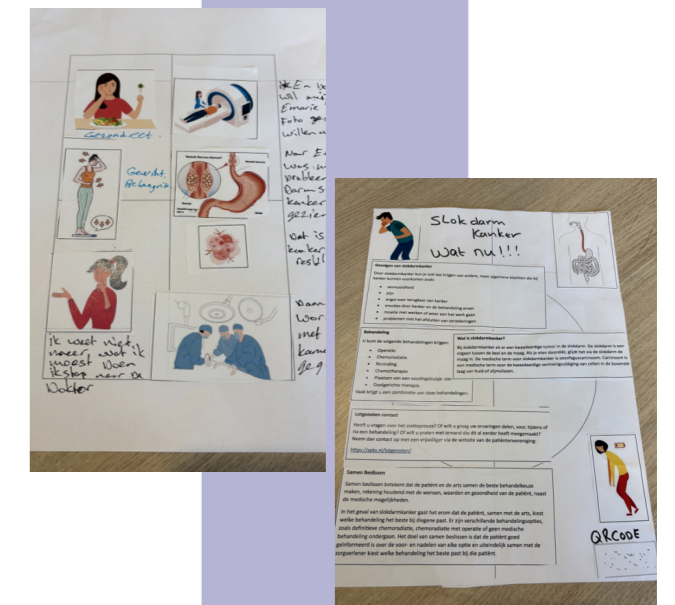
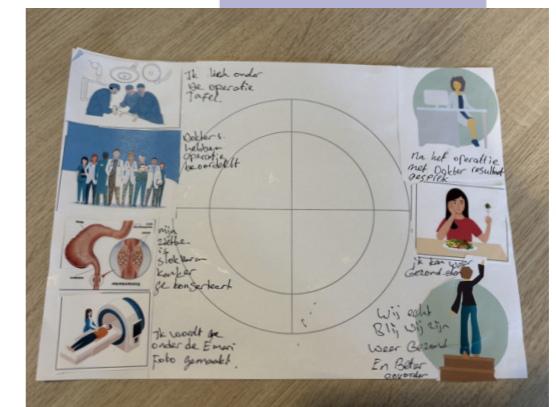
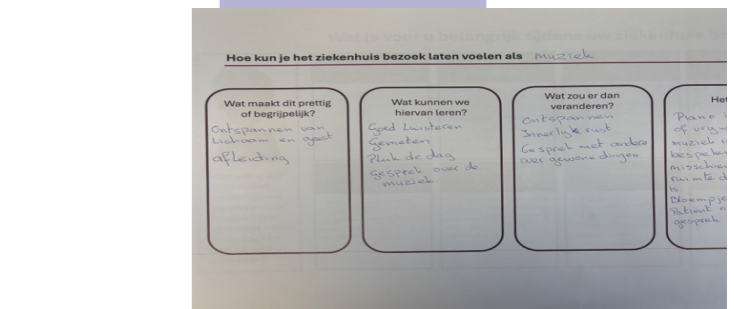
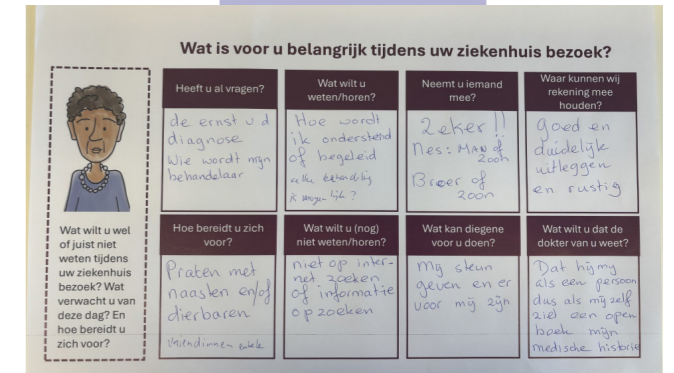


Figure 28: Impression of filled in templates.

5.2.6 Data analysis

The analysis took inspiration from the Contextmapping approach as described by Sanders and Stappers (2013), aiming to uncover deep insights into participants' lived experiences, needs, and preferences. Rather than focusing on quantification, the emphasis was placed on interpretation and meaning-making, translating personal narratives into design-relevant insights.

Guiding principles

Two principles guided the analysis:

- **Immersive analysis:** Engaging deeply with the qualitative material to capture both explicit statements and subtle dynamics. This included working with quotes, drawings, and metaphors, allowing the richness of the participants' lived experiences to be preserved.
- **Clustering and theme discovery:** Identifying recurring patterns, needs, and points of tension across the material. Contextmapping provided the framework for organising and translating these findings into actionable insights for design.

Analytical steps

The process began with the extraction of meaningful quotes, key statements, and emotionally charged expressions from the session data. These were examined for patterns, recurring needs, and thematic relationships. The analysis was carried out in two complementary ways:

1. Design-focused first analysis

Conducted between the co-creation sessions, this phase was deliberately immersive and less structured. Its primary aim was to quickly generate inspiration and gain a rapid understanding of the target group while the design process was still in progress. Insights from this stage could be immediately implemented in the ongoing concept development. This approach is described in more detail in the following chapter (6), as it served to define a solution space rather than to establish a final set of themes.

2. Research-focused second analysis

A more structured phase followed, aimed at producing a comprehensive and systematic description of the emerging themes. For each session, post-session reflections and detailed notes were reviewed. As the material was read, initial topics and themes were noted (1), forming a first iteration of thematic clusters. These topics were coded per session, group, and exercise to maintain a clear link with the original raw data.

Clustering process

See figure 20 on the right for a visual impression of the process. All identified topics were placed on digital post-its (2), colour-coded by session and group for clarity. The topics were then rapidly clustered by grouping related concepts (3). Clustering began with a single word or phrase and expanded as new topics added nuance or variation to the theme. Each resulting cluster was then described in detail (4), drawing directly from the information it contained.

The descriptions from this clustering exercise were combined with the insights generated during the first, design-focused analysis. This integration allowed for a richer, multi-layered understanding of the findings. The final resulting themes are presented in Section 5.3.

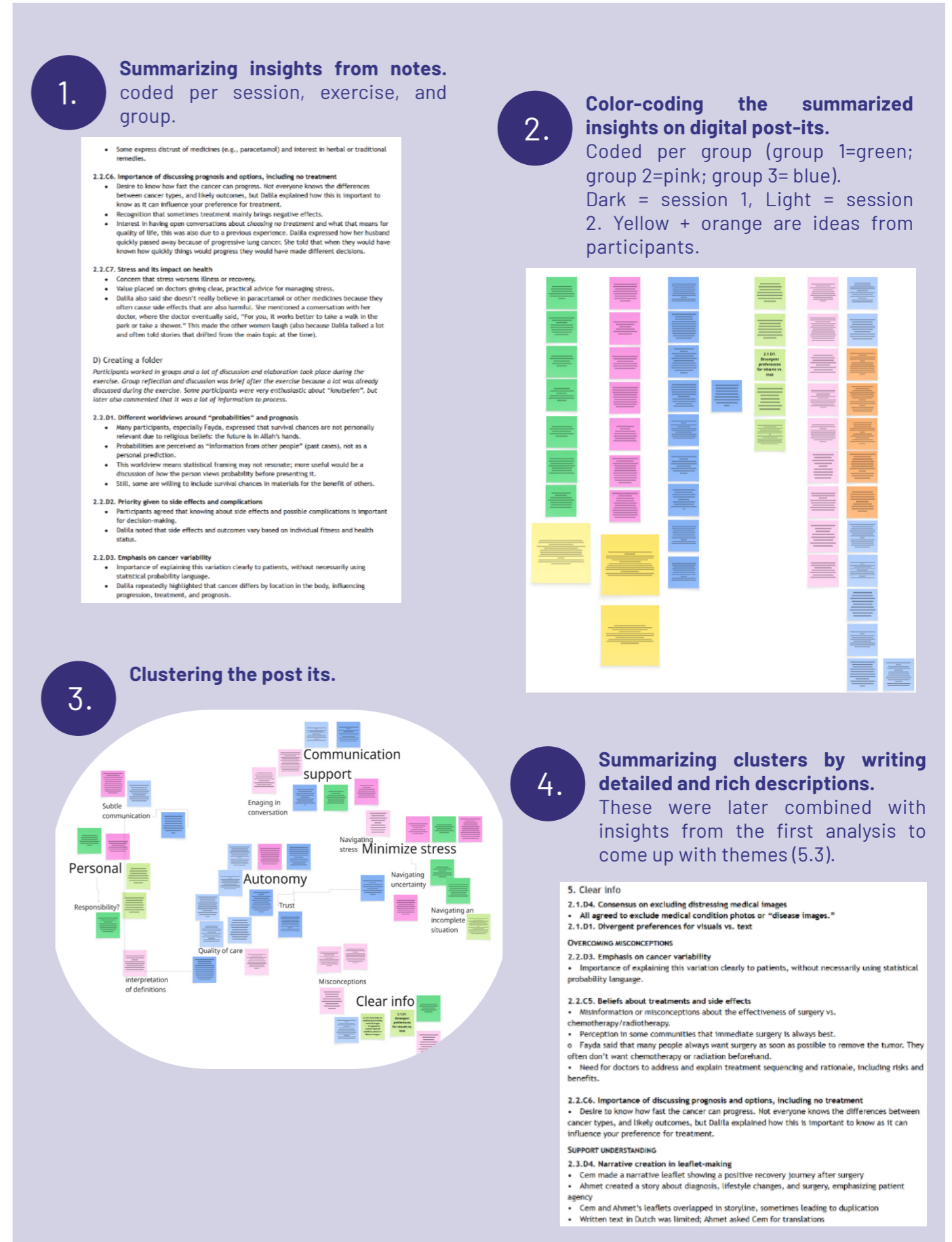


Figure 29: Impression of research-focused analysis of co-creation findings

5.3 Main Insights

Theme 1: Recognized as a whole person

Being recognised is about more than polite manners; it means the patient is understood within the context of their values, culture, worldview, and lived experiences.

Before discussing diagnoses or treatment options, it can help to first explore the patient's worldview and specific information needs. This ensures the conversation aligns with their frames of reference rather than forcing them into purely medical language.

This includes:

- Rephrasing commonly used medical terms in ways that resonate with the patient's worldview.
- Understanding that people who struggle with communication or decision-making are diverse, with needs shaped by many factors (culture, past experiences, trust levels).
- Building personal connection and open dialogue, which fosters psychological safety, lowers stress, and makes patients more active participants.
- Grounding examples:
 - Some participants did not want statistics at all, as their future was "in the hands of a higher power".
 - Starting with a personal introduction from the HCP was seen as a small but powerful trust-building act.

Underlying insight: Recognition is relational and contextual; it's about meeting the patient where they are, not where the system assumes they are.



Theme 2: Balancing control and guidance

The right mix of patient autonomy and HCP leadership shifts depending on timing, trust, culture, and emotional state.

The Everyone Makes Decisions Differently perspective strengthens this cluster:

- Decision-making styles vary; support needs may not become clear until the situation is real and emotionally charged.
- Early exploration of values gives both patient and HCP a shared reference point for later complex choices.
- Pros and cons cannot be presented generically: what is a "pro" for one might be a "con" for another.

The intervention should:

- Identify the benefit most relevant to the patient's values first, then explain how the treatment achieves it.
- Allow flexible framing of pros and cons depending on how the conversation evolves.
- Pace information so the patient has space to process before deciding.
- Grounding examples:

Underlying insight: True SDM is adaptive, not formulaic.

"You can't fully imagine the situation until it's real... by then, the overload makes it hard to think clearly." -Gerda

"I don't see that as an advantage... now I know the tumor often isn't fully removed." -Fayda

Theme 3: Anchors in the conversation

This cluster is about the structures and techniques that help patients follow, process, and reflect on the conversation.

Creating "space" for the patient means:

- Personal introductions to lower stress.
- Purposeful pauses and silence to let patients process information.
- Explicit invitations for questions, both during and after the consultation.
- Summaries to support post-visit reflection and family discussion.

Why it matters:

Patients often only think of key questions after the appointment, when they had the time to process and reflect on conversations and information in a familiar and safe space. Anchors help them reconnect with the conversation later, especially when overwhelmed in the moment.

Grounding examples:

- Participants valued having visual prompts to start a dialogue.
- Summaries can help people re-engage with the decision after speaking to loved ones.

Underlying insight: Comprehension is co-created through rhythm, repetition, and cues.

Theme 4: Navigating the uncertainty space

Uncertainty is a major source of distress. Whether it is before, during, or between appointments.

Support includes:

- **Early, clear explanation of what to expect, both medically and procedurally.**
- **Comfort and reassurance personalised to beliefs and coping styles.**
- **Space to clarify fears about disease and treatment burden without relying solely on statistical terminology.**
- **Proactive end-of-life conversations that prevent decision-making under crisis conditions.**

Underlying insight: Managing uncertainty is not just about facts. It is about pacing, trust, and emotional readiness.

Grounding examples:

"Everyone knows stress is the main cause of all diseases right" -Cem

"When the moment suddenly comes, it overwhelms you... you can't think clearly then." -Gerda



Theme 5: Making sense of the journey

Patients don't just need "information" : they need it to be meaningful and usable within their own interpretive frameworks.

This means:

- Clarifying terms in everyday, culturally resonant language.
- Helping patients visualise treatment and disease burden without heavy reliance on probabilities.
- Ensuring any framing of pros and cons is tailored, contextual, and paced.
- Using visuals strategically: abstract, informative, not overly playful, then they can aid comprehension and spark dialogue.
- Providing plain language explanations, early discussion of side effects, and comparison of disease burdens across treatment types.

Grounding examples:

Participants use of visual storytelling to explain care pathways.

"This image should be in there, it gives me something to talk about". -Elif

Underlying insights: Making sense of care is an act of translation, from medical systems to personal meaning.

Perception of pros and cons: Sometimes, what healthcare professionals present as a benefit is perceived as a disadvantage by patients. For example, when told that surgery has the highest chance of completely removing the tumor, one participant responded:

"I don't see that as an advantage, because now I know that the tumor often isn't fully removed." -Joumane



Conclusion

Individuals with LHL, facing barriers in communication and decision-making with HCPs, form a highly diverse group, shaped by culture, beliefs, prior experiences, and decision-making styles. Despite this diversity, key needs consistently emerged:

- **Personal connection and space to participate**

Beginning with personal introductions, allowing pauses, and inviting questions fosters trust, lowers stress, and supports better information processing.

- **Clarity tailored to the individual**

"Clear" communication depends on the patient's worldview and prior knowledge. Before discussing diagnoses or treatments, HCPs should explore the patient's values, beliefs, and preferred communication style.

- **Meaningful framing of pros and cons**

The same fact can be perceived as an advantage or disadvantage depending on the patient. Effective discussions require pacing, preparation, and framing aligned with the patient's priorities.

- **Understanding treatment trade-offs**

SDM relies on clear explanations of the diagnosis, available treatments, and how each may affect symptoms, daily life, and prognosis. This means simplifying medical language while actively exploring what matters most to the patient.

These findings suggest that the first consultation should be reframed as a generative process: rather than focusing solely on information transfer, it should actively build shared understanding by integrating the patient's worldview, values, and interpretations of medical terms into the conversation.

Implications for developing the communication tool:

- The tool should guide HCPs in structuring the consultation to create space for relational connection and reflection, including prompts for pauses and invitations to ask questions.
- It should include modules for exploring patient worldviews and values early in the conversation, helping to tailor language and framing to the individual.
- The tool should offer flexible ways to present treatment options; moving beyond standard lists of pros and cons to approaches that adapt framing to patient interpretations and values.
- It should provide post-consultation support materials, enabling patients to revisit and reflect on the discussion with their next-of-kin between appointments.
- Visual aids, where used, should be abstract, neutral, and optional, serving as conversation starters without undermining seriousness.

By embedding these functions, the communication tool can better meet the needs of a wide range of patients, but improves the ability of HCPs to address the needs of patients with LHL during consultations. This conceptual reframing will form the basis for the next phase of the project, in which these insights are synthesised with prior findings to inform the design and testing of the intervention.

CHAPTER 6

FROM RESEARCH TOWARDS DESIGN

This chapter describes the transition from research to design by reframing the problem statement to generate innovative concept directions. It begins by examining current perceptions of the problem (1.2), drawing on findings from the exploration phase. A root cause analysis results in an overview of contextual paradoxes, who are explored to reveal opportunities for innovation. The chapter concludes with a visual synthesis of the resulting innovation space, which serves as the foundation for concept development in the following chapter.

Chapter overview

- 6.1 Goal
- 6.2 Approach: create a new frame
- 6.3 The broader context

6.1 Goal

The goal of this phase is to define a solution space that bridges empirical research with practical design opportunities. Through an integrated synthesis of insights, the chapter explains how the process of reframing opens up new directions for meaningful, context-sensitive design interventions.

6.2 Approach: create a new frame

To support the transition from research to design, frame innovation is applied. This approach involves redefining how a problem is understood by shifting the underlying “frame” through which the system is viewed (Dorst, 2015). Instead of addressing challenges within existing boundaries, it encourages questioning assumptions and reframing the context to uncover root causes, overlooked leverage points, and new opportunities. This ensures that emerging design concepts are grounded in the lived experiences of stakeholders and aligned with the systemic complexity of the healthcare environment.

The broader context was first mapped using an Abstraction Hierarchy (6.2.1), enabling diverse insights to be synthesized and underlying paradoxes to be identified. These paradoxes provided a foundation for reframing the problem statement (6.2.3) opening new perspectives on the challenge. Subsequently, potential solution spaces were explored and documented, resulting in a portfolio of ideas that addressed the problem from multiple angles (6.2.4). Insights from this portfolio informed the emergence of a final concept direction, which is positioned within the broader systemic context and integrates findings from earlier reframing steps (6.3).

The example on the right shows how a conventional frame may not provide the solution space to truly tackle the problem, and shows why reframing is needed.

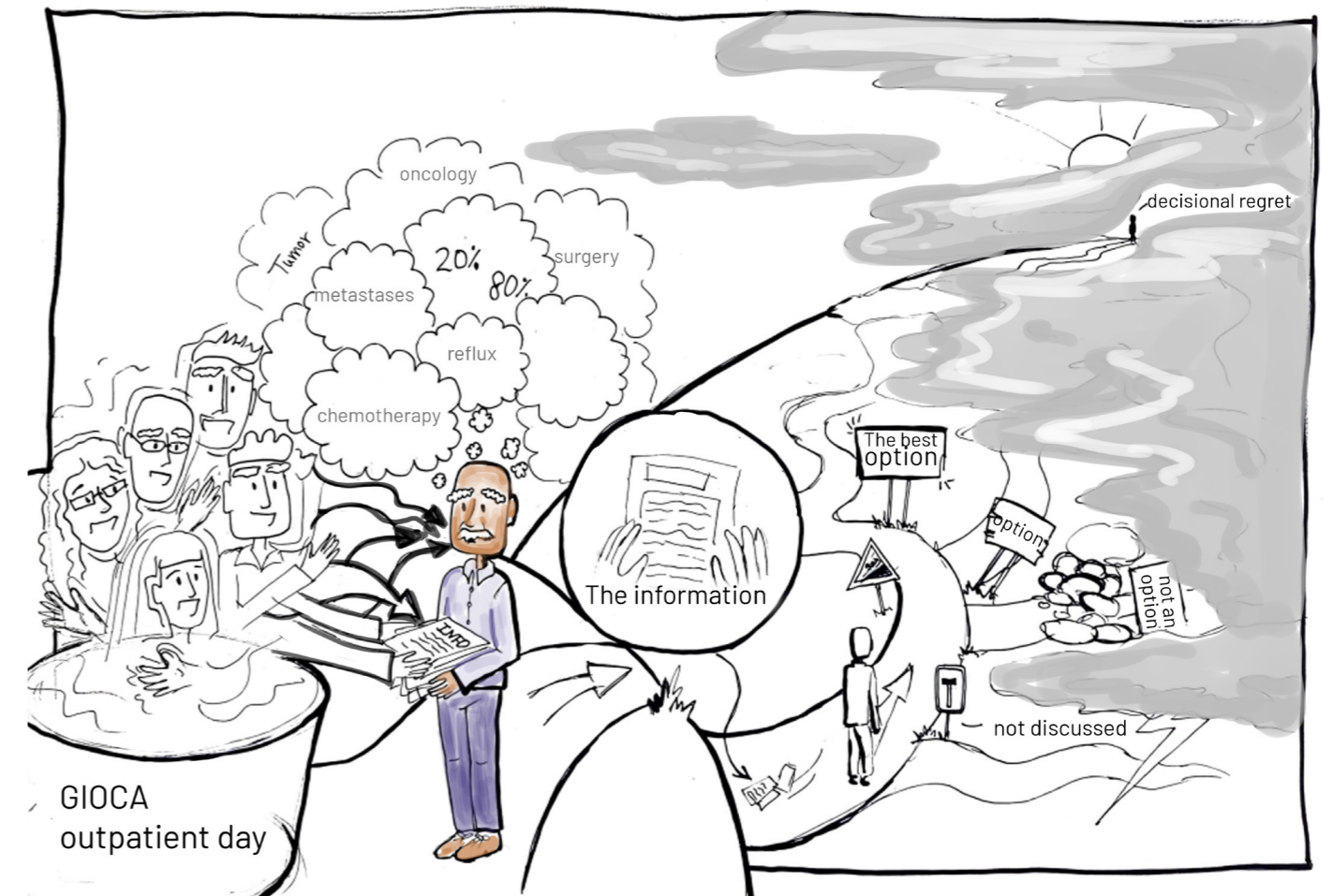


Figure 30: Visual representation of the current interaction: the patient is overwhelmed by the information, and blindly trusts the advice of the HCP, only to later discover the advice did not fit their personal values and perspective, resulting in decisional regret.

Example of a conventional frame

Problem Definition

“To prevent decisional regret, esophageal or gastric cancer patients with LHL need to be better informed on what a treatment entails so they can make a better decision”

Assumptions in this frame

- The problem is mainly a lack of information.
- More or clearer information will automatically improve decisions.
- Decision-making is treated as a single moment in time.

Resulting Solutions

- Leaflets or videos with simplified treatment explanations.
- Longer consultations where more information is given.

These are informational fixes, but they do not address emotional, cognitive, or systemic barriers to effective decision-making. The patient may better understand the possibilities, but is not met in their need for support in decision-making throughout their trajectory for example. Next to that the effect of information overload is not taken into account.

6.2.1 Abstraction Hierarchy

Goal

An abstraction hierarchy was developed to uncover relationships between insights gathered from theoretical research (chapter 1-3), the case study (chapter 4), and co-creation study (chapter 5). This method organizes insights across multiple levels of abstraction and synthesizes diverse findings into a cohesive overview, allowing patterns to emerge and highlighting opportunities for innovation, see the image below.

Abstraction hierarchies have proven valuable in design research, where the focus is on shaping the future rather than analysing the present. Organizing insights in this way supports the transition from research to design by making implicit knowledge explicit and actionable (Sanders & Stappers, 2013).

Approach

The abstraction hierarchy was built by repeatedly asking “why?” questions, starting from the most overall problem statement: Oncology patients with LHL more often experience decisional regret (concerning their treatment) than patients with a higher health literacy. This helped move from surface-level observations to deeper, underlying issues as will be described in the next paragraph.

The abstraction hierarchy not only organizes information but also serves two critical purposes:

1. Relational overview of research insights
It aligns fragmented insights by mapping them onto a shared level of abstraction, making it easier to identify overarching patterns and tensions.
2. Enabling Reframing:
It reveals alternative means to achieve a goal, thus expanding the solution space. The orange areas mark solution spaces.

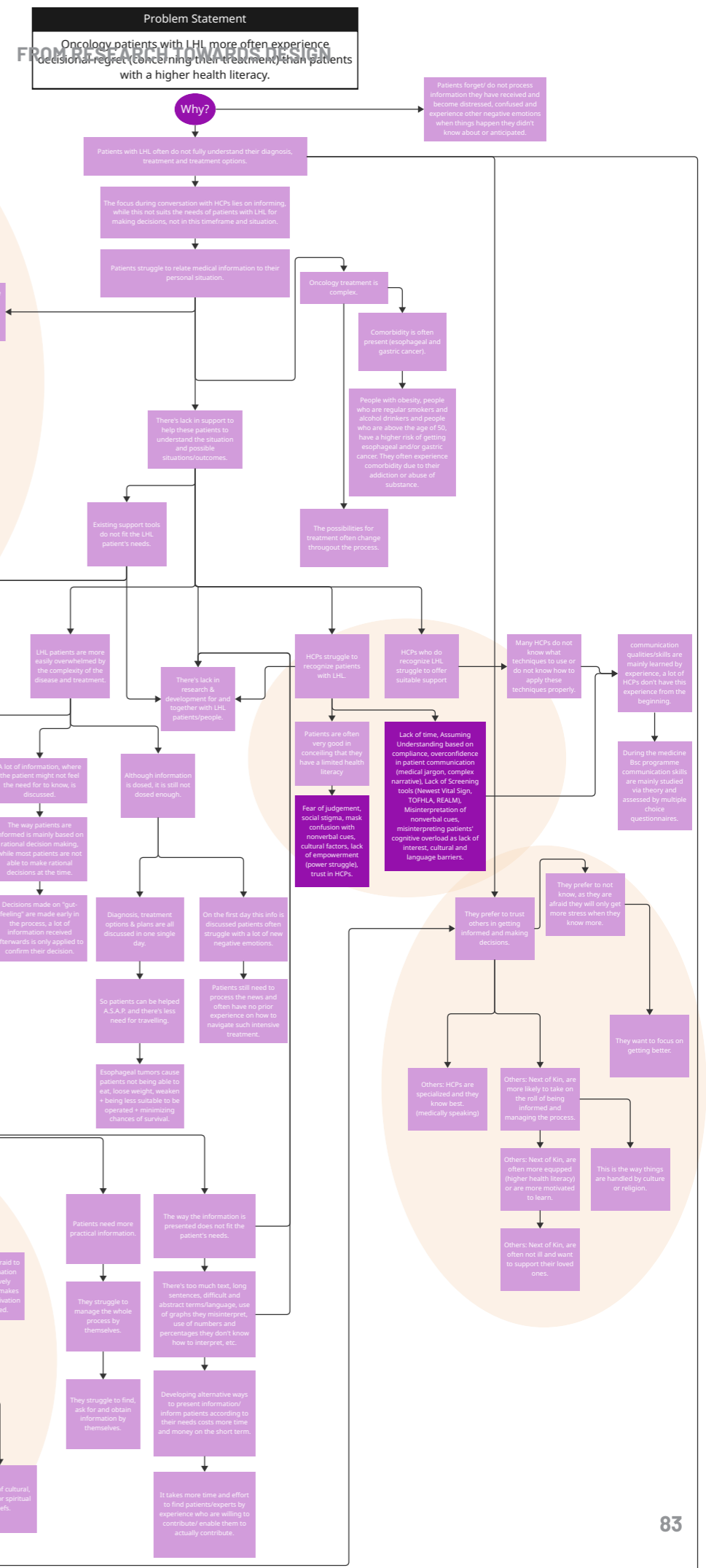


Figure 31: Abstraction Hierarchy that combines insights from all activities from the explore phase (Literature review, chapter 1-3; Context case study, chapter 4; Co-creation study, chapter 5).

6.2.2 From Paradox to frame

Goal

This section presents findings from the Abstraction Hierarchy, which revealed systemic tensions in healthcare communication and decision-making. These tensions appeared as paradoxes: points where needs, values, and constraints intersect. In frame innovation (Dorst, 2015), paradoxes are not problems to remove but prompts for rethinking the problem and expanding potential solutions. The goal is to reframe the problem definition to open innovative solution space.

Approach

The problem definition was not fixed at the outset; it evolved continuously as new insights emerged from both the Abstraction Hierarchy and the reframing activities in H4 and H5. These processes ran in parallel, feeding into each other – analysis informed reframing, and reframing sharpened analysis. Over time, several interpretative frames were explored, refined, and merged into a single, integrated frame.

In frame innovation, this evolution is intentional: the problem definition shifts as paradoxes are examined and reinterpreted. The steps below outline how this convergence unfolded, leading to the final frame and solution space in Section 7.1.1, with alternative frames documented in Appendix C.

By combining these paradoxes with insights from the parallel analysis and clustering processes in H4 and H5, a single, coherent frame was developed. Paradox 6 is the main paradox that informed the solution space and will be discussed in more detail in this paragraph. All paradoxes emerged throughout the project and were identified through research insights documented in the abstraction hierarchy and a reflective workbook. The workbook captured ongoing thought processes, which, together with the abstraction hierarchy, enabled the formulation of six key paradoxes, summarized below. Below each paradox, steps for reframing them are summarized.

1. Identify the paradox

Begin with a provisional problem definition to guide exploration. Identify two conflicting needs or realities in tension, and uncover the beliefs or circumstances that sustain this conflict.

2. Unpack the underlying assumptions

Examine why these elements are seen as opposites. Question the assumptions, mental models, and cultural beliefs that make the conflict seem inevitable. This often reveals that the original problem framing is incomplete or too narrow.

3. Look beyond the current domain

Seek inspiration from other fields (e.g., coaching, game design, hospitality) that handle similar tensions productively. Use creative brainstorming, analogies, and metaphors to generate alternative perspectives.

4. Create a new frame that dissolves the paradox

Integrate both sides of the tension into a new frame where they can coexist or reinforce one another. This crystallizes the evolved problem definition, transforming it into a generative design opportunity.

Paradox 6 is the main paradox that informed the solution space and will be discussed in more detail in this paragraph. All paradoxes emerged throughout the project and were identified through research insights documented in the abstraction hierarchy and a reflective workbook. The workbook captured ongoing thought processes, which, together with the abstraction hierarchy, enabled the formulation of six key paradoxes, summarized in this paragraph. Below each paradox, steps for reframing them are summarized.

1. IDENTIFY THE PARADOX

1. The information paradox

Tension

Patients often express a desire for “all the information” in order to feel prepared and in control. Yet, when presented with exhaustive details (especially outcome probabilities, statistical risks, and clinical terminology) the result can be cognitive overload rather than clarity. For some, this intensifies anxiety instead of reducing it. The paradox lies in the fact that “all the information” is subjective: for one patient it may mean raw data, for another it may mean a distilled narrative. What many truly seek is not volume, but relevance and clarity.

Design Insight

Effective communication design is less about a one-time information dump and more about orchestrating a progressive journey of knowing: one that is adaptive to patient capacity, priorities, and emotional state at each stage.

Design Opportunities

- Shift from “informing now” to orchestrating the flow of knowing.
- Use phased, anticipatory communication structures: “Here’s what we’ll focus on today; here’s what will come next week.”
- Treat information delivery like physical rehabilitation. Gradually built cognitive capacity, with time for reflection, practice, and integration.

2. The communication gap

Tension

Healthcare professionals carry both an ethical and legal obligation to fully inform patients. Yet, the complexity of tailoring that information to individual comprehension levels, cultural contexts, and lived experiences is significant. Many patients leave consultations with partial or misunderstood knowledge, even when professionals believe they have been clear. The misalignment between what is communicated and what is understood, creates a persistent “gap” that undermines informed consent and SDM.

Design Insight

Communication in healthcare should be seen not as the transfer of facts, but as the translation of meaning. This translation must span medical, cognitive, and emotional dimensions, ensuring that what is said resonates with what is heard.

Design Opportunities

- Reframe communication as an interpretive act, where language, context, and emotional state is bridged.
- Facilitate co-construction of understanding, where patient and professional collaboratively shape the narrative of care.

3. The trust-control dilemma

Tension

Patients with LHL often face two simultaneous challenges: mistrust of the healthcare system (rooted in previous negative experiences of being unheard or excluded) and reduced confidence in navigating complex decisions. During high-stress, high-fatigue phases in the care trajectory, the mental effort required to process intricate information can exceed capacity, leading patients to delegate decisions to relatives or clinicians. The paradox: the very people patients delegate to are embedded within the same system they struggle to trust.

Design Insight

Agency in decision-making is not binary, it is a spectrum that fluctuates over time and context. Systems must account for moments when patients choose not to be in control, without eroding their long-term sense of ownership and trust.

Design Opportunities

- Enable patients to define when and how they wish to delegate decisions, rather than forcing constant active participation.
- Create “control contracts” where patients pre-define thresholds for autonomy vs. delegation at different phases in the care trajectory.
- Normalize flexible agency where patients can change between active and delegated roles without guilt or disorientation.

4. The steering trade-off

Tension

Some clinicians, aiming to simplify the decision-making process, subtly or even unintentionally steer patients toward a treatment they believe is best. This can reduce cognitive burden and decisional fatigue, helping patients reach a conclusion faster. However, it also narrows the scope of exploration, potentially sidelining options more aligned with the patient’s life priorities. Efficiency in decision-making can come at the expense of autonomy.

Design Insight

The starting point for decision-making should be patient values, not treatment menus. Aligning medical information to those values (rather than the other way around) can preserve autonomy while still managing complexity.

Design Opportunities

- Reverse the order: elicit values and desired life outcomes first, then map medical options to these anchors.
- Use “Values Maps” to visually connect treatment choices to personal priorities and trade-offs.

5. The SDM responsibility paradox

Tension

SDM can initially feel daunting for patients, who may fear the weight of responsibility or doubt their ability to contribute meaningfully. This hesitation can lead to disengagement. Yet, once patients understand the process and experience how their input shapes care, many become active and committed participants. The paradox: when properly structured, the very thing patients resist at first can become a source of empowerment.

Design Insight

SDM should be designed as a supported practice rather than a one-off request for input. Patients need continuous reinforcement, not just an invitation.

Design Opportunities

- Embed SDM as an ongoing, structured element in care pathways, with touchpoints adapted to patient capability over time.
- Redefine the clinician’s role as a facilitator of participation, not merely a provider of information.

6. The belief barrier

Tension

When patients’ personal, religious, or cultural beliefs conflict with a proposed treatment plan, clinical conversations can quickly stall. What begins as an exchange of information often turns into parallel monologues: both patient and HCP speaking from within their own frames of reference, yet struggling to translate them for the other. In this breakdown, opportunities for creative compromise, alternative pathways, or small but meaningful concessions are lost. What could be a space for negotiation between medical possibilities and personal values instead becomes a dead end, eroding trust and reducing engagement.

Design Insight

Beliefs are not obstacles to care, rather they are essential parameters that should inform treatment or care plans from the start. Recognizing them early reframes the interaction from conflict resolution to co-creation, enabling treatment approaches that are both clinically sound and personally meaningful.

Design Opportunities

- Embed beliefs in care planning from the outset, where they are treated as a core design constraint rather than a late-stage problem to be “worked around.”
- Equip clinicians with values-centered prompts to surface the deeper meanings behind patient choices. For example: “What does healing mean to you?”
- Develop adaptation tools: structured frameworks that help HCPs and patients collaboratively explore treatment modifications without compromising safety or efficacy.

2. UNPACK THE UNDERLYING ASSUMPTIONS

For each of the six documented paradoxes, a corresponding Problem Definition was formulated (Appendix C: full documentation reframing). These Problem Definitions made it possible to identify the underlying assumptions embedded within the prevailing frame of thinking. See the problem definition for frame 6: The Belief Barrier below.

Problem Definition:

"Sometimes patients reject recommended treatments due to personal, religious or cultural beliefs, making communication difficult."

This definition enabled me to look at the situation from a specific lens and write down the underlying assumptions existent within this frame.

Underlying assumptions in this frame:

- Treatment conversations are meant to inform patients of medical options.
- Patients' non-medical or non-factual reasoning is a barrier to compliance.
- The primary goal is to persuade patients to accept clinically best options.
- Cultural or religious values are outside the scope of the medical consultation.

Next, I wrote down the solutions that might emerge, or might have emerged from this way of thinking.

Resulting Solutions:

- More persuasive communication techniques.
- Culturally adapted patient education materials.
- Referral to cultural mediators after resistance arises.

This way I was able to write down why this specific frame is not effective in a summarized statement:

These solutions often come too late and don't address the core problem: that the treatment discussion itself is misaligned with the patient's

3. LOOK BEYOND THE CURRENT DOMAIN

needs the beginning.

After identifying how each paradox constrained the existing frame, the next step was to explore alternatives through creative brainstorming. Sessions varied in format: some engaged stakeholders (A), others introduced perspectives from different domains (B), and some were individual (C), enabling synthesis, clustering, and integration of diverse insights.

A: Brainstorming during co-creation:

Ideas and analogies were taken from the co-creation study's insights and the resulting ideas that were generated by participants, as well as ideas generated by myself. Specifically the ideas participants generated with the co-creation exercise: How-To make the hospital visit feel like ... (a, to the participants, positive experience)? This for example inspired to look in the domain of museums, music experiences and shopping.

B: Creative Brainstorming with a mixed group of people:

In addition, a Creative Brainstorming Session with a mixed group of students and a HCP in the field of neuropsychology generated a diverse range of ideas. These ideas were clustered and enabled to look in domains like: counselling, education, UX design, design thinking, museum experience design and aerospace. A full description of the session and the results can be found in appendix C. The clusters resulted in some of the ideas presented in 6.2.4.



Figure 32: Image of clustering exercise during a Creative Brainstorming session with a mixed group of people.

C: Individual Creative Brainstorming:

Lastly, I conducted solo brainstorming sessions, building on insights from earlier co-creation and group sessions. Immersed in the material, I organized post-its, drawings, and notes to create a visual overview and applied creative methods from the iCPS book (Heijne & Van der Meer, 20), including analogies, metaphors, How-To's, and clustering. The most frequently used techniques combined forced-fitting unrelated ideas with the SCAMPER method:

- **Substitute** - What can be replaced? (e.g., materials, people, process)
- **Combine** - What elements can be merged?
- **Adapt** - What can be adjusted to fit a new user or need?
- **Modify / Magnify / Minimize** - What can be exaggerated or reduced?
- **Put to other use** - Can something be repurposed?
- **Eliminate** - What can be removed or simplified?
- **Rearrange / Reverse** - What happens if the order or perspective is changed?

This process allowed me to integrate diverse insights, challenge existing assumptions, and generate new directions for potential frames, solution spaces and ideas (6.2.3).

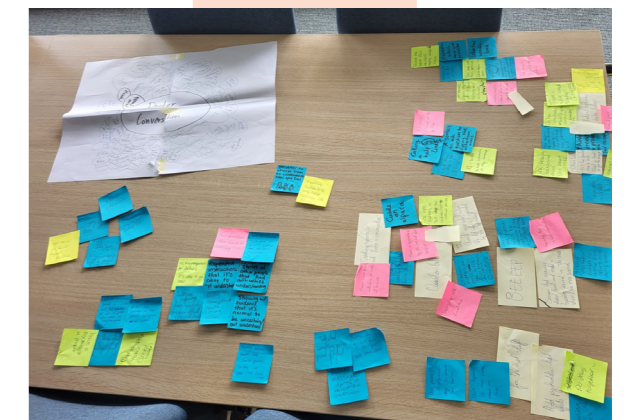
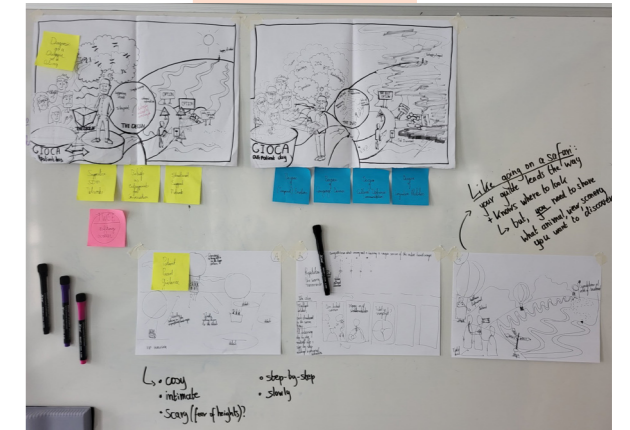
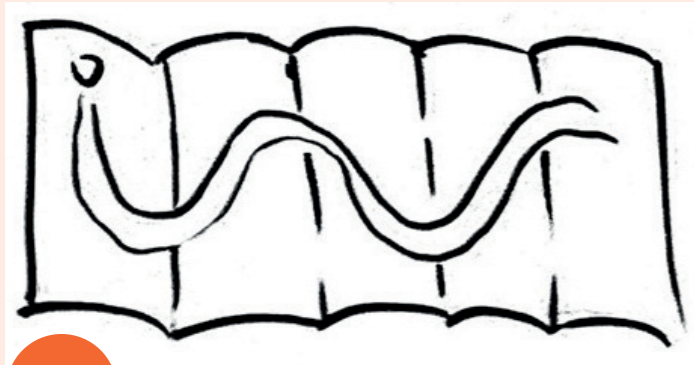


Figure 33: Impression of individual creative brainstorming activities.

6.2.3 Portfolio of ideas

The reframing process generated a range of frames, which in turn sparked the development of multiple solution spaces and ideas. The ten most promising ideas are presented below and on the next page.

Portfolio of ideas (1/2)



1.

Decision-making path

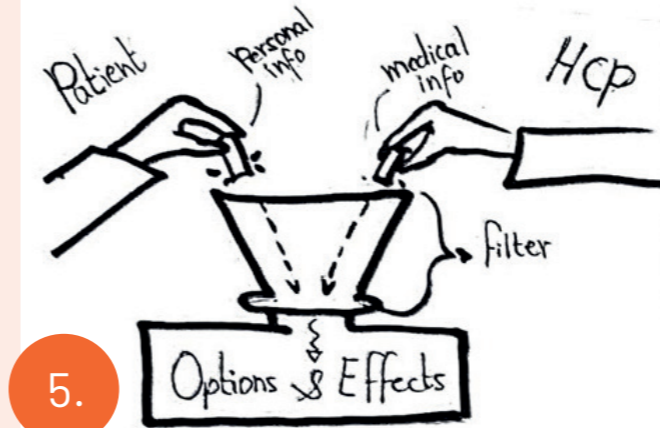
Step-by-step explanation of the treatment decision-making process on a folder. Including info on who provides support, where to find the right info/folder, what role to take, SDM-explanation, when adjustments can be made, and when decisions are definitive.



2.

Treatment Translator

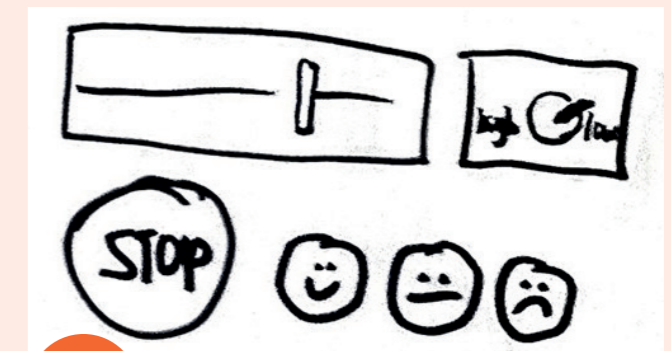
Utilize the patient's input + treatment information input. Combine them via Machine Learning and cluster treatment information in such a way that it is presented in two clusters: This treatment suits me because... This Treatment does not suit me because...



5.

Knowledge mixer

Combine the knowledge of both HCP & patient to filter out a common ground for shared understanding. Fiches are recognized by sensors who give input to a machine learning model that generates output.



7.

Conversation Control

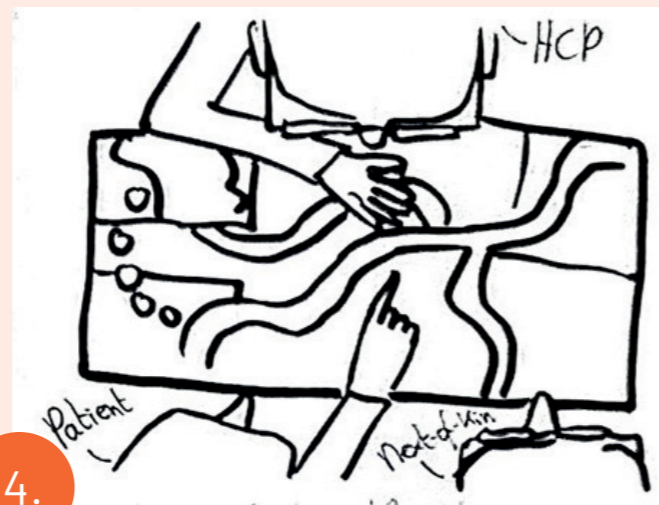
Provide the patient with a set of controls to empower them to interrupt the HCP during communication. Control pace, the number & length of breaks, show emotions/feelings, and the level of understanding.



3.

Concession Clustering

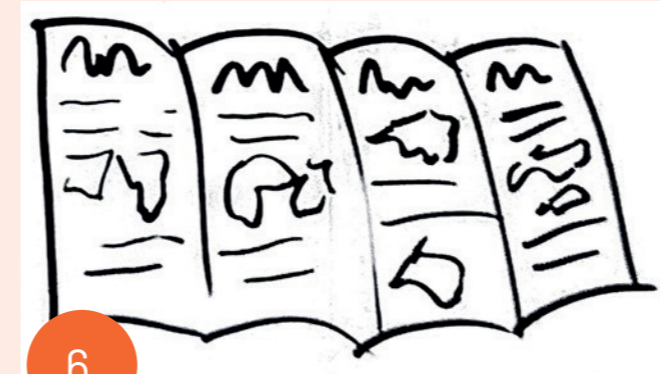
Together the HCP & patient discuss the core components treatment & living with cancer. All components must be clustered into three categories: pros, cons & no-concessions



4.

Possible paths forward

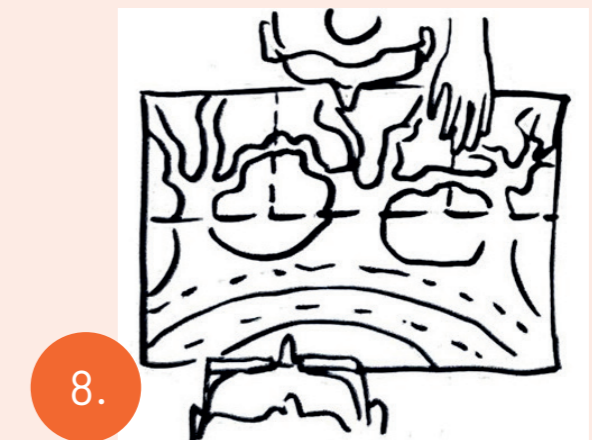
Visually map out the treatment and support process, with action points. Patient and HCP discuss it together, and add marks/ cross out what's not applicable.



6.

Kansen Kaart

Visualize the most common and most severe side-effects and complications for the possible options. Together discuss how the personal perspective of the patient fits in. Relate later to survival chances.



8.

Support & Control

Provide an overview of possible paths forward (treatment pathways) & make visible who can provide the right support (nursing consultant, next-of-kin, oncologist, etc.), + how and when to contact them.

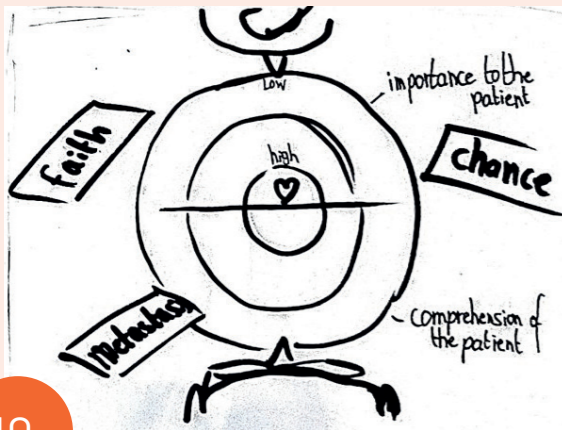
Portfolio of ideas (2/2)



9.

Stickers | Modular folder

Personalize a folder by creating stickers with specific information like the name + function of HCPs. This helps the patient to better understand what is happening and gain feeling of control



10.

Perspective Mapping

Map the patient's understanding, identifying their specific information needs, and capture their preferred way to make decisions. Used iteratively, this map becomes a shared reference point, enabling both patient and HCP to align their interpretations, bridge potential misunderstandings, and relate new medical information directly to the patient's personal context.

4. CREATE A NEW FRAME THAT DISSOLVES THE PARADOX

6.2.4 The final frame

The framing process revealed that a solution should not aim to address a fixed set of user needs. Instead it should be modular and adaptable. Providing space to support both patients and HCPs in navigating their needs as they evolve throughout the care trajectory.

Co-creation insight and central design frame

A pivotal insight from the co-creation sessions shifted the direction of the project:

The way a patient interprets information is just as important as the information itself (from theme 5).

When the patient's interpretive lens differs significantly from the HCP's intended message, miscommunication can arise, creating substantial barriers to dialogue and shared understanding.

Recognizing this led to the central design frame:

What if we see treatment conversations not as a moment to deliver advice, but as an opportunity to co-create a conversation that respects both medical realities and the patient's beliefs? Then the goal is not just to understand rejection, but to build bridges between worldviews and treatments.

Reframing the problem statement inspired the concept of Perspective Mapping: a tool that makes the patient's perspective explicit and tangible (idea 10).

6.3 The broader context

In the introduction (chapter 1) the importance of a holistic approach towards generating interventions is stressed. This section describes how the identified frame for innovation is placed within the broader context to ensure this holistic approach.

6.3.1 Radical new narrative

To break free from conventional thinking, a radical narrative was developed based on the earlier identified paradoxes.

The concept of making informed decisions does not align with the preferred or most commonly practiced decision-making approaches of the target group. The current way of informing is focused on providing all available information in full, rather than delivering information in a targeted and relevant way. Therefore, solutions cannot be effectively developed by focusing solely on providing information.

(Statement generated from insights in literature (2), patient interviews (4), and co-creation study (5))

This insight shifts the focus away from informing patients. Instead, it highlights the importance of supporting them in navigating the complexity of the healthcare and decision-making system. The emphasis should not be on how information is delivered, but rather on how it is perceived and processed. This requires an understanding of each individual's information needs, mental models, and the frameworks they use to make sense of medical information.

6.3.2 Future Vision

The future vision serves as an abstract synthesis of the design opportunity space. It is a visual and conceptual summary that connects research insights with the potential direction for innovation. It helps to keep the broader context in mind and enables a holistic approach.

The vision was created by shifting the current interaction as presented in 6.1.1 in a way that utilizes the radical new narrative and the paradoxes

to make the direction for potential innovation more tangible and easy to communicate. This overview should inspire to generate an effective solution, fitting the established frame and the broader context. This generative element is visualized through a black-box, which symbolizes the concept that will be developed (chapter 7). The interaction vision in the next paragraph provides inspiration for how the concept should make people feel and

interact; it shapes the user experience. Three elements are key in this future vision. The design should..

1. Facilitate more open and honest interaction between HCPs and patients.
2. Support HCPs in guiding the patient through the decision making process.
3. Help patients to find relations between separate pieces of clinical information and keep overview of all information by presenting them an overview tailored to their needs.



Figure 34: Visual representation of the desired interaction: HCPs are supported in providing more clarity and overview in the information they provide, in addition they are supported in explaining the decision-making process to the patient. The patient is empowered to express their values and preferences. This minimizes the negative effect of steering behaviour. The patient feels supported by the idea throughout their care trajectory

6.3. Interaction Vision

An Interaction Vision is a visual and conceptual representation of how interacting with a future concept should feel. By translating design decisions in a relatable metaphor, an Interaction Vision helps ensure that the final concept is not only functional, but emotionally resonant and enables a desired user interaction.

Purpose

The Interaction Vision serves multiple purposes, it is a tool for...:

- **Inspiration:** It sparks creative thinking and helps generate ideas that align with the intended experience.
- **Communication:** It creates a shared understanding among team members, making the abstract more tangible.
- **Facilitation:** It helps align stakeholders around a common design vision and encourages collaborative discussion on how to bring it to life.

Finding the metaphor

An Interaction Vision is created by identifying a strong metaphor that captures the desired experience: **an orchestra playing in harmony under the guidance of a conductor**. From this metaphor, key qualities are distilled. The interaction qualities are: Harmonious, responsive, well-paced, guided and synchronized. Those are the elements that should make the interaction with the design meaningful, intuitive and enjoyable. These qualities are used in the next chapter to generate ideas to develop a concept.

Quilting: a method to generate ideas

The metaphor emerged through a self-devised ideation method called quilting. The name refers to the visual and conceptual outcome of the process, which resembles a quilt: a patchwork of initial ideas, ambiguous images, and new combinations. This method builds on previously found ideas by deliberately forced-fitting them with unrelated elements and a seemingly arbitrary "How-To" question. In this case, the guiding question was: How to make something modular? The initial ideas used were a morphological chart and a foldable bicycle. To encourage more imaginative thinking and steer away from purely practical solutions, an additional element was introduced: an ambiguous image. These images, taken from the game Dixit, were used to stimulate indirect associations and generate more abstract, conceptual outcomes.



Figure 35: Impression of the quilting method

Interaction Vision



Figure 36: Visual representation of the Interaction Vision: an orchestra playing in harmony under the guidance of a conductor.

Just like a conductor in an orchestra doesn't play an instrument but guides the musicians to create a **cohesive** and beautiful symphony, the concept should not take over the process of decision-making or information delivery. Instead, it should facilitate a more **harmonious interaction** between HCP and patient.

The aim is not to create an intervention that dictates the conversation, but one that supports a **responsive, well-paced, guided, and synchronized dialogue**. This allows both parties to stay attuned to each other.

The concept should act as a subtle framework that empowers shared understanding and mutual trust, rather than a rigid structure that leads the interaction. Meaning it can be truly responsive to the individual needs of both healthcare professional and patient. Like a classical orchestra does not play at a fixed pace, but utilizes the instructions of a conductor to keep pace and harmony, the design should enable personalization.

Conclusion

This chapter synthesizes research insights into six key paradoxes, that highlights the tensions and assumptions that constrain current practices in healthcare decision-making and limit meaningful patient engagement. Reframing these paradoxes revealed new perspectives and generated design opportunities that move beyond conventional approaches to patient information and SDM.

Through iterative creative processes—ranging from co-creation with the main target group to cross-domain brainstorming and solo ideation—a future vision and interaction vision were developed. These envision treatment conversations not as moments of information transfer, but as opportunities for co-creation, where medical realities and patient beliefs are harmonized. The chosen metaphor of a conductor guiding an orchestra encapsulates the desired qualities of interaction: harmonious, responsive, well-paced, guided, and synchronized.

Ultimately, this work underscores that improving patient-centered care requires more than tools for delivering information. It demands systemic change that respects patients' values, beliefs, and capacities, while also supporting HCPs in navigating complexity. By offering both conceptual reframings and tangible design directions, this project lays a foundation for further research and innovation. The insights, future vision, and interaction metaphor together provide a holistic framework to inspire interventions that not only inform but also empower, align, and humanize the care process.

CHAPTER 7

CONCEPT DEVELOPMENT

While reframing research insights allowed for a solution space to emerge, this chapter focuses on how this solution space is developed into a practical concept. Utilizing a Concept Framework (7.2) to develop it. Addressing both its modular application (7.3), containing value clarification and interaction prototyping, as its materialization into a product (7.4), informed by experts.

Chapter overview

- 7.1 Goal
- 7.2 Approach: Concept framework
- 7.3 Ideation I: a modular communication tool
- 7.4 Ideation II: materializing the concept

7.1 Goal

The goal of concept development is to go from an abstract idea description to a concept that is thought through and detailed on both practical (informed by the concept framework (7.2.1) and experiential level (informed by the interaction vision (6.3.3)).

The concept direction described in 7.3.4 is taken to write a design goal.

Overall Goal

Design something that enables a more patient-centered and service approach towards treatment decision making.

Design Goal

“To support patients with LHL in articulating their values and information needs, while enabling healthcare professionals to actively elicit these insights and tailor their way of informing and supporting accordingly”.

Idea Description: Perspective Mapping

A tool that makes the patient’s perspective explicit and tangible.

It works by mapping the patient’s understanding, identifying their specific information needs, and capturing their preferred way to make decisions. Used iteratively, this map becomes a shared reference point, enabling both patient and HCP to align their interpretations, bridge potential misunderstandings, and relate new medical information directly to the patient’s personal context.

Iterative Discovery

A dynamic and co-creative communication process in which HCPs and patients explore treatment options together over time. Instead of delivering static recommendations, deciding on a treatment or care plan becomes an evolving dialogue that adapts as mutual understanding deepens. This approach allows for sensitive integration of patients’ cultural, religious, or personal beliefs from the beginning, rather than addressing them after resistance arises.

Targeted Information Delivery

Customized delivery of information based on the patient’s worldview and belief system. Instead of using generalized education materials, HCPs share only what is relevant, understandable, and meaningful to the patient’s context. This enables better alignment between clinical realities and individual value systems, reducing cognitive overload and enhancing trust. Additionally it enables HCPs to ensure consultations become more aligned to the goal of supporting patients in treatment decision making and understanding the situation

7.2 Approach: Concept framework

Concept development started by creating a written summary of the idea and its research foundations (Appendix D), which was reviewed by two experts :a professor in healthcare communication (P1), and an associate professor and expert in cancer treatment and quality of life (P0). Their feedback informed refinements in the concept process around value clarification and the presentation of treatment advice. A concept framework was then created, including a list of requirements and concept flowchart to position the idea within the (GIOCA specific) esophagogastric cancer decision-making process, health literacy-sensitive SDM-model, and patient-centered care.

In the first ideation round, interaction prototyping explored how value clarification could be integrated into a modular, physical tool for consultations. Feedback emphasized avoiding paper-based formats and ensuring outputs were usable in multidisciplinary meetings, leading to updates in the requirements. The second ideation round shifted focus toward reimagining the decision-making service more broadly, prioritizing generative and innovative approaches over strict workflow integration.

7.2.1 List of Requirements

A List of Requirements is a structured set of criteria that defines what the final design must do, offer, or enable. It is captured from the perspectives of users, stakeholders, and the system as a whole.

The list shown in Figure 37 was constructed using the Delft Design Guide (Van Boeijen et al., 2020, p. 103) as a reference framework. Pugh’s checklist was applied to ensure completeness, and the MoSCoW method was used to prioritize items. In this prioritization, P0–P1 denote essential requirements, and P2–P4 denote desirable but non-critical wishes.

Workflow:

1. Generate

Apply Pugh’s checklist to cover all requirement domains.

2. Prioritize

Rank items by criticality using the MoSCoW method.

3. Classify

Distinguish between requirements (P0–P1) and wishes (P2–P4).

4. Validate

Confirm with stakeholders for completeness and

feasibility.

Pugh’s Checklist:

A structured tool ensuring all relevant factors are considered:

- Performance criteria
- Physical characteristics
- Safety and regulatory constraints
- User interaction requirements
- Environmental considerations
- Cost and production factors

Research findings were mapped to these categories to identify gaps and transform preliminary insights into actionable requirement statements.

MoSCoW Method:

Used to assign priority levels:

- **Must-have** – Critical for viability (P0–P1)
- **Should-have** – Important but deferrable (P2)
- **Could-have** – Beneficial but non-essential (P3)
- **Won’t-have** – Out of scope for current iteration (P4)

Priorities were refined following concept evaluation (see Chapter 9), where stakeholder feedback informed the final categorization presented in Figure 37.

Requirements vs. Wishes:

• Requirements

Non-negotiable conditions derived from core user needs, regulatory obligations, and system constraints.

• Wishes

Non-essential enhancements that improve satisfaction or usability.

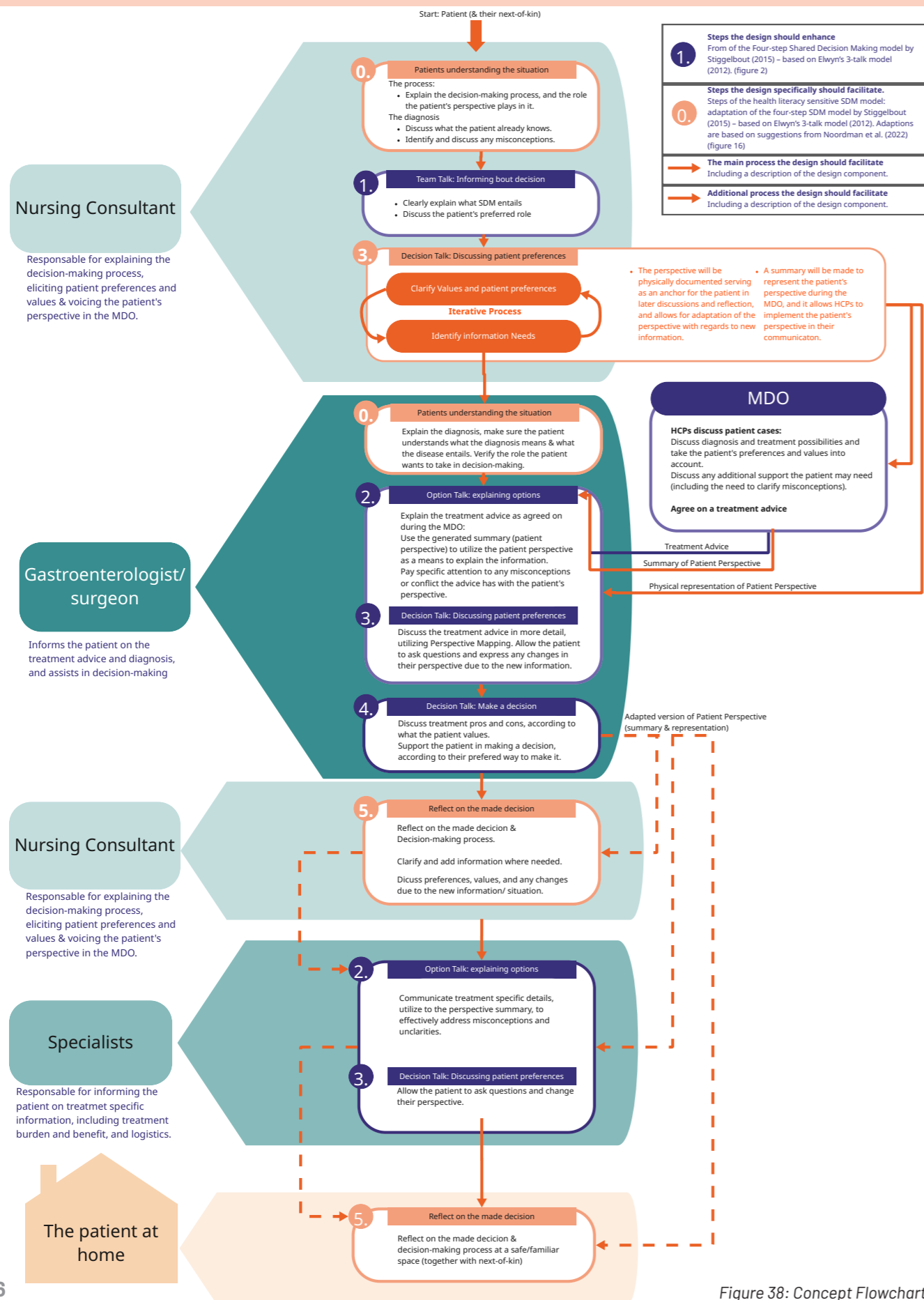
This distinction ensures that requirements are addressed first, while wishes are recorded for potential inclusion in later iterations.

List of Requirements

Functional	P0	The tool must be able to use within the consultation room
Functional	P0	The tool must support the HCP in clarifying the decision-making process to the patient
Functional	P0	The tool must be adaptable to changes within the care trajectory; it should enable an iterative process of value clarification, informing and decision-making
Functional	P0	The tool must enable <u>identification of topics the patient finds overwhelming or unclear</u> . It should help to address misconceptions.
Functional	P0	The tool must be <u>suitable</u> to use with patients with a <u>higher Health Literacy</u> on a basic level
Workflow	P0	The tool must help handover of patient information needs to the care team; The output must be easy to transfer to other HCPs (e.g., via summary or form); by summarizing key patient preferences and comprehension level
Collabor...	P0	The tool <u>must support a two-way dialogue</u> , not a checklist or questionnaire-only format.
Functional	P0	The tool must help <u>identify patient information needs</u>
Functional	P0	The tool must help the <u>patient feel more confident</u> during consultations and while reflecting on consultations
Collabor...	P0	The tool must prompt the nurse to ask about who else the patient wants involved in the decision (e.g., family, GP).
Functional	P0	The tool must help <u>identify patient values before discussing treatment options</u>
Ethical	P0	The tool must be <u>neutral</u> and <u>not steer the patient</u> toward a specific choice
Usability	P0	The tool must be <u>suitable</u> for people with <u>LHL (at B1 level or lower)</u>
Workflow	P0	The nurse consultant must be able to <u>tailor the session length</u> based on patient needs (e.g., 10–30 minutes).
Process	P0	The tool must be <u>usable before formal diagnosis</u> and <u>without complete treatment information</u> .
Ethical	P0	The tool must <u>respect personal differences in communication, values, and decision-making</u> .
Ethical	P0	The service must <u>ensure voluntary participation</u> and informed consent before use.
Emotional	P1	Patients must be <u>explicitly informed</u> that they are <u>not expected</u> to make a <u>decision immediately</u> .
Usability	P1	The tool must not be something made from paper or something that resembles a flyer
Process	P1	The tool must <u>integrate</u> into the patient’s care pathway <u>without delaying diagnostic or treatment planning</u> .
Functional	P1	The tool must provide <u>patients with clarity</u> about their <u>own values</u> and <u>decision-making</u>
Collabor...	P1	The tool must be designed so multiple care team members can <u>easily interpret the outcomes</u> .
Workflow	P1	The nurse consultant must be able to use the tool <u>within 20 minutes</u>
Usability	P1	The language must <u>avoid</u> the use of <u>medical jargon</u> .
Usability	P2	The tool must use <u>visual aids</u> (icons, colors, diagrams) to support understanding.
Emotional	P2	The service must provide <u>emotional safety</u> – questions should acknowledge anxiety and uncertainty.
Usability	P2	The tool must support patients who have <u>difficulty reading</u> or who are not fluent in Dutch.
Usability	P2	<u>Instructions and questions</u> must be <u>clear and actionable</u> (one step per screen or page).
Usability	P2	The tool and its results must be easy to <u>carry around</u> and <u>present on a 60x60 cm surface</u>
Functional	P2	The tool must include a visual reminder to take a pause during consultations and enable patients to process information and ask questions
Functional	P2	The tool must help HCPs to decide what kind of information is suitable to provide to the individual patient, including the use of SOURCE
Functional	P3	The tool must allow patients to reflect on the decision-making process to enable them to learn from it for future decisions
Usability	P3	The tool must be useable by people with <u>cognitive limitations</u> (e.g., memory, attention span).
Functional	P3	The tool must include a <u>mechanism to prioritize values</u> (e.g., ranking, choosing top 3 values, modular system for adaptability).
Scalability	P3	The tool must be <u>easy to update</u> as treatments or guidelines evolve.
Functional	P4	The tool <u>could support clarification of key terms</u> (e.g., prognosis, survival rate, quality of life) in plain language.
Functional	P4	The tool could allow space for patients to <u>note questions or concerns</u> to discuss later in the day.
Technical	P4	The tool must be available in a <u>digital version to enable storage</u>
Technical	P4	The tool must <u>comply with GDPR and data privacy rules</u>
Scalability	P4	The tool must be <u>adaptable to other types of cancer or medical decisions</u> .
Scalability	P4	The <u>paper version</u> (if used) must be <u>printable</u> without losing clarity.
Scalability	P4	The tool must <u>not require complex IT infrastructure</u> if implemented digitally.

Figure 37: List of Requirements

Concept Flowchart



7.2.2 Concept Flowchart

The concept flowchart was developed to visualize the process that the concept aims to facilitate. It situates the idea within the broader decision-making system, illustrating both the types of conversations patients will have and the roles of HCPs within these interactions. The framework was reviewed with multiple stakeholders, including two experts (P0 and P1), whose feedback informed several refinements. The revised flowchart is presented in Figure 38.

Key points raised during feedback included:

In addition, the discussion touched on a consideration:

- Recognizability for HCPs: HCPs must be able to recognize their role in the flowchart and see themselves represented accurately. This also applies to terminology: for instance, the term "options" should be replaced with "treatment advice," since in practice there are rarely multiple equivalent options, and phrasing otherwise may cause irritation.
 - Value clarification: Integration of the patient's perspective into the MDO should be reinforced by introducing it before the medical situation and treatment advice are presented to the patient.
 - How information, communication, and patient perspectives can be consistently integrated and translated across consultations—from the initial discussion of possibilities to the finalization of a treatment plan.
- In addition, the discussion touched on a consideration:
- The potential for word choice in the concept to prime HCPs to communicate at a B1 language level.

7.3 Ideation I: a modular communication tool

7.3.1 Creative brainstorming

As outlined in Chapter 6, several creative brainstorming sessions were conducted throughout the project. This section details the design and concept development process, drawing on the Roadmap for Creative Problem-Solving Techniques (Heijne & Van der Meer, 2020) The methods described in this section were applied iteratively to generate, refine, and evolve ideas.

How-to's

The How-to's method is a creative brainstorming technique that reframes challenges, like complying with concept requirements, as open-ended questions beginning with "How to...?". This framing positions requirements as opportunities, promoting divergent thinking and focusing on possibilities rather than constraints.

For example: "How to build trust?"

At the time, the first five concept requirements were translated into the following How-to questions:

1. How to identify values?
2. How to discuss interpretation of terms?
3. How to identify information needs?
4. How to provide support that functions as an anchor for patients during consultations?

Purge

The Purge technique involves expressing all initial, often obvious, ideas to clear the way for more original and innovative thinking.

For example, the question "How to identify information needs?" generated six initial ideas during the purge phase. These ideas then served as stepping stones toward more novel solutions.

Quilting

Quilting is a self-devised method named for its outcome: a conceptual "patchwork" of purged ideas, ambiguous images, and new combinations. Visual examples are shown in Figure 39.

This method produced ideas for visualizing the concept, but more importantly, it led to two refined How-to questions that better captured the design challenge:

1. How to gain insight into the patient's worldview and information needs?
2. How to make something modular?

How to make something modular?

Exploring this question through repeated cycles of purging and quilting generated initial concepts for modular systems, figure 39 .

To progress effectively, the development of the concept's physical form, including its modular components, was temporarily put on hold. This decision was made to take advantage of the upcoming final co-creation session as an opportunity to test the intended interaction of the concept with the target group. Instead of refining the form at this stage, the focus shifted to developing the contents of the tool, as explained in 7.3.2.

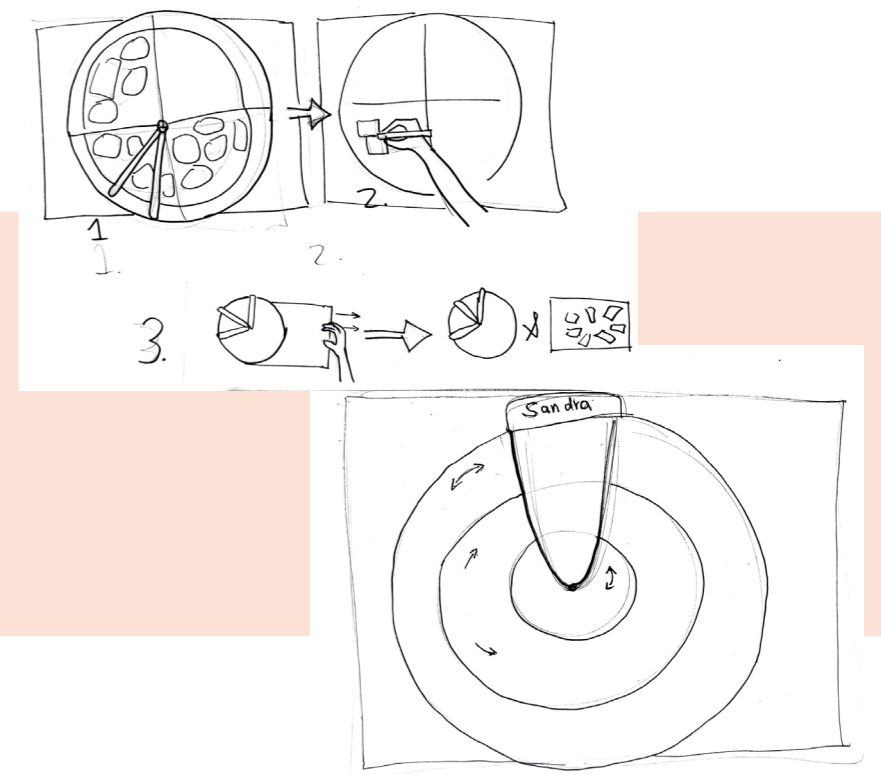
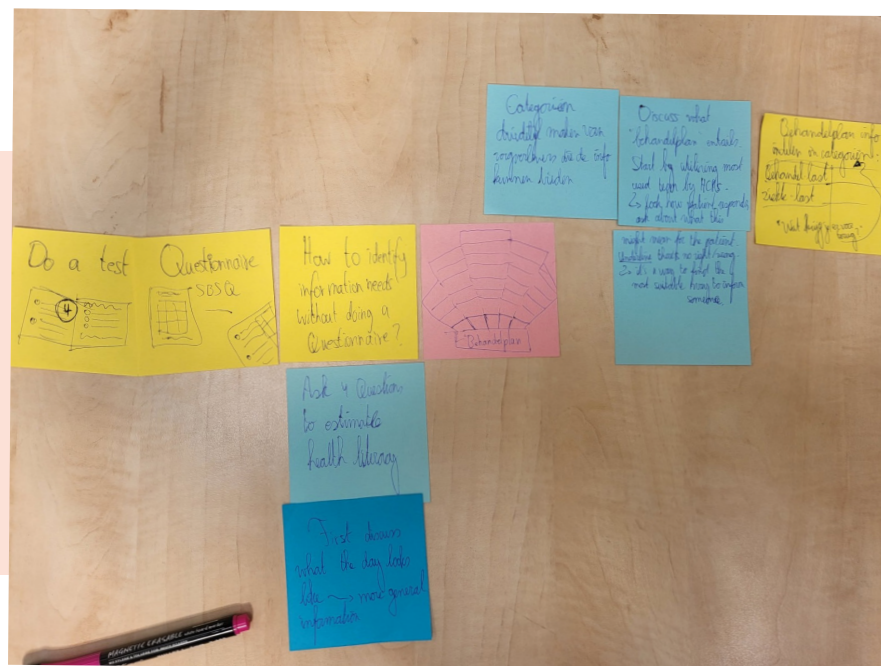


Figure 39: Impression on ideation 1: a modular communication tool, showing the brainstorming methods that were applied, and the ideas that resulted.

7.3.2 Interaction prototyping

Goal

The main objective was to investigate how a conversational tool could be applied during an initial consultation between a patient with LHL and a HCP. In addition, interaction prototyping was applied to validate the intended core interaction resonated with participants before progressing to the physical design. Central to this inquiry was the question: *How can a patient's worldview and information needs be effectively elicited?*

Approach

To address this question, interaction prototyping was applied within a co-creation session (Session 2, group 3). Participants engaged with interaction prototypes presented in the form of templates (see figure 40). Versions of the templates in the Turkish language were provided to overcome language barriers. The session was structured into three main stages:

1. Template completion

Participants were briefly instructed on the purpose of the templates and how to use them. Each person filled in a first template individually, after which they received a second template to complete. Observations were made throughout this process, with notes recorded afterwards.

2. Enactment

Once the templates were completed, participants enacted a simulated first meeting between a patient and an HCP. Each was given a nameplate with role instructions and was explicitly told to incorporate their completed template into the conversation. This enactment followed a similar approach to other co-creation sessions described in Chapter 5, with the key difference being the active use of the templates.

3. Reflection and discussion

Following the enactment, a guided group discussion was held to reflect on both the exercise and the templates themselves. Participants shared impressions, identified strengths and weaknesses, and considered how the tool might function in a real clinical setting.

Material: the template prototypes

The templates were developed using themes primarily drawn from earlier co-creation insights and from patient interviews conducted as part of patient journey mapping.

The value clarification component was strengthened by incorporating inspiration from several sources: themes identified by Van Lent et al. (2024) in the digital value clarification tool they developed (top right, Figure 40); co-creation materials on value clarification shared by colleagues from the RISC research group; and the Value Proposition Canvas (Value Proposition Canvas – Download the Official Template, n.d.).

Results

The use of the conversation tool during the enacted first meeting between patient and HCP showed clear potential to structure discussions around values, information needs, and treatment expectations, but its impact varied greatly between participants.

Early value clarification prompted reflections on personal priorities, such as lifestyle changes, autonomy in decision-making, and trust in medical advice, and occasionally surfaced deeper concerns about stress, uncertainty, and the healthcare system.

However, comprehension and use of the template were uneven. While some participants quickly understood and engaged with the tool, others required repeated clarification or overlooked instructions entirely, suggesting a need for simplified guidance and more active facilitation of such a tool in the consultation room.

The tool sometimes indirectly shaped conversation topics, even when not explicitly referenced during role plays, indicating that its content remained in participants' minds. Nonetheless, without clear integration into the interaction, opportunities to connect the tool to the ongoing dialogue are missed. Language barriers, information overload, and differing communication preferences (visual vs. text, detailed vs. simplified) further influenced engagement. Group dynamics also played a role: humor, dominant personalities, and moments of frustration could both stimulate and derail focus.

Interaction Prototyping

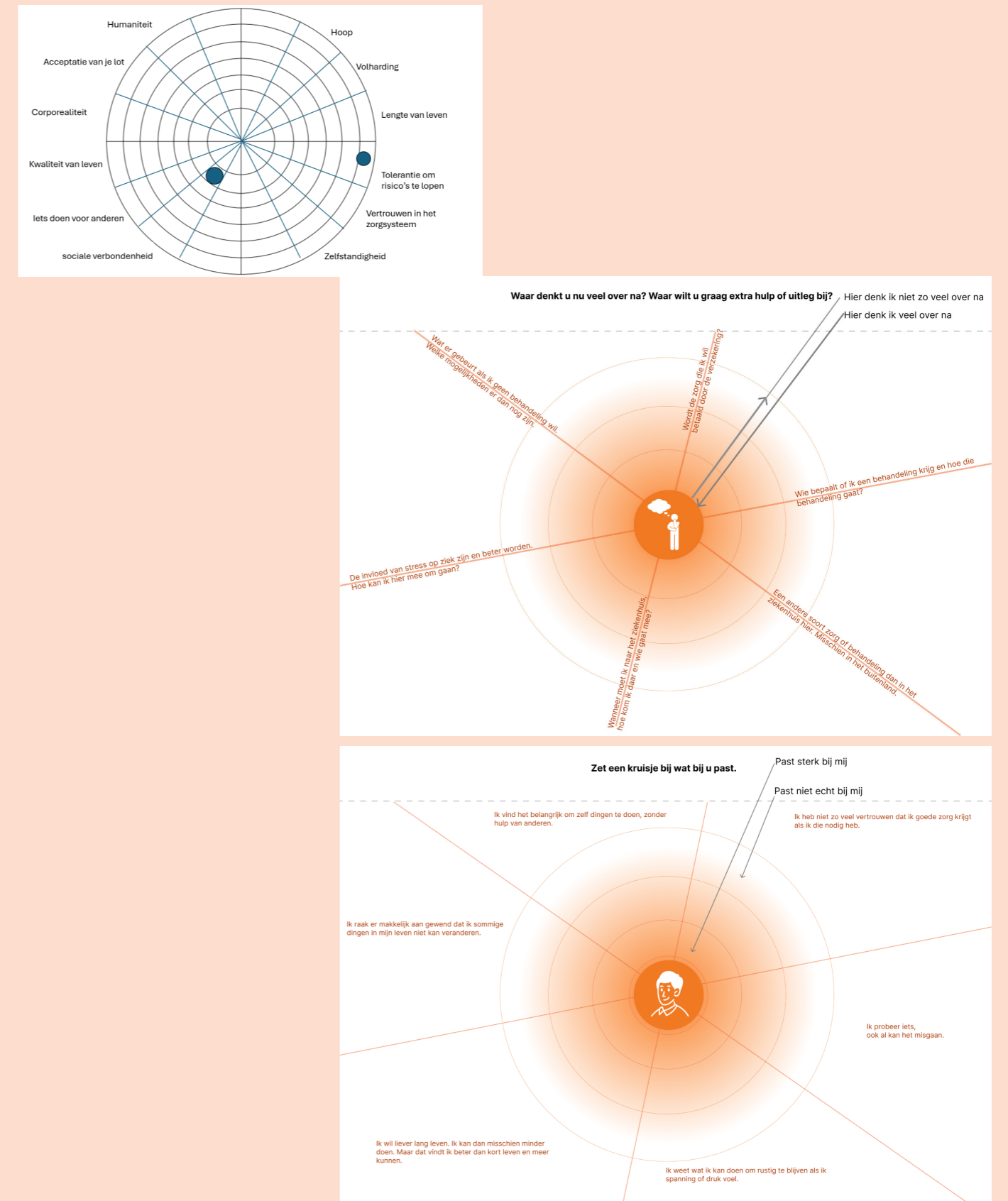


Figure 40: The interaction prototyping templates as used during the co-creation session. The top right template attempts to identify misconceptions and information needs, the bottom attempts to clarify values.

Conclusion Ideation I

This ideation iteration was mainly based on how to incorporate value clarification in a physical, and modular communication tool within the consultation room. Interaction prototyping together with the target group of LHL individuals was conducted to explore how this could take place during a first patient-HCP conversation, participants enacted this conversation and provided input on how this personal approach can be implemented.

Overall, the tool as tested during interaction prototyping facilitated participants to ask clarifying questions, and discuss insecurities, but its success depends on careful introduction, real-time guidance, and adaptation to varied literacy levels, cultural norms, and personal preferences. Integrating it seamlessly into the flow of conversation, rather than as a separate or optional task, appears essential to achieving its intended purpose. This way the tool can be used to enable HCPs to better recognize the information needs of patients and avoid making assumptions on which patients need additional support, potentially overlooking the needs of those who need it most.

7.4 Ideation II: materializing the concept

The client's research team reviewed the project's progress and strongly advised against developing a paper-based design. They also emphasized the importance of ensuring that both value clarification and the clarification of information needs are fully integrated into the MDO. This second iteration incorporates their recommendations and outlines how the service is materialized.

It was decided to prioritize the novelty of the concept over its immediate ease of integration into existing HCP workflows. This approach was intended to encourage more creative materializations of the modular element. Additionally, the concept was designed to inspire stakeholders, both experts and HCPs, to think in new ways about the decision-making service for esophagogastric cancer patients. Resulting in an additional Design Goal.

Second Design Goal:

Create an innovative decision-making service that challenges conventional approaches, stimulates generative thinking, and opens new possibilities for user interaction, without being constrained by current workflow or portability requirements.

7.4.1 Creative brainstorming

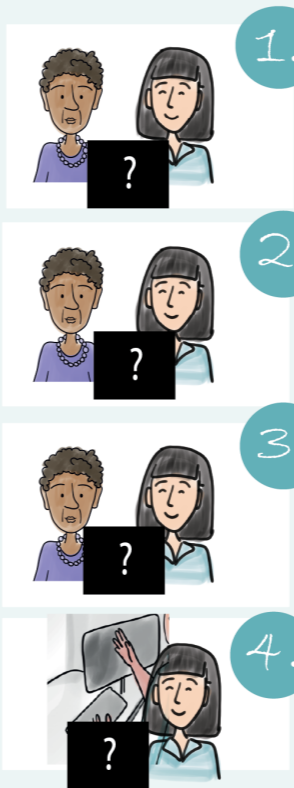
1. Concept description and storyboard

The concept idea, including the newly found focus was again written out in a document (appendix E). In this document the functions of the concept were distilled. This time decisions on materializing the functions were made, with the second design goal in mind.

In parallel, a storyboard was developed to visualize how the idea might take shape and function in practice. The storyboard emphasized the desired interactions (as described in sections 6.3) and explored ways to stimulate these interactions. By using a "black box" approach, the design process created space to map the intended interactions, integrate contextual factors, and ultimately generate a design that fits the intended experience.

CONCEPT DEVELOPMENT


Consultation: Introductory meeting & explanation of the day (patient & nursing consultant)



- General introduction
 - Facilitate: Nursing Consultant explains how the decision-making process at the medical center works, and explains why discussing the patient's perspective is important.
- Provide: Tools for the HCP to facilitate the discussion on the patient's perspective.
 - Provide tools/anchors for the patient to empower them to express themselves.


Result: A two-way dialogue, which stimulates both HCP and patient to communicate on a meaningful
- Provide: Tools for the HCP to explain SDM and enable them to discuss with the patient what kind of role the patient prefers to take in decision-making.
- Enable: Nursing Consultant to generate a summary of the conversation, which provides actionable insights for the MDO and subsequent conversations the patient has with colleagues.

Multidisciplinary Meeting (MDO) (All HCPs)




- Represent: The patient's perspective in an actionable manner during the MDO. Include a description of the patient's information needs, and whether there is need to clarify any misconceptions.
 - Enable: HCPs to include the patient perspective in considerations for a treatment advice.

Consultation: Diagnosis & Treatment Proposal (Patient & surgeon / gastroenterologist)



- Enable: HCP to explain the diagnosis and verify the patient's understanding
 - HCP to explain treatment proposal based summary on perspective map and recommended tools and strategies.
 - Patient to express their perspective and concerns regarding the proposed treatment.
 - HCP & patient to effectively discuss treatment pros and cons in relation to the patient's perspective.
 - The patient to engage in decision-making.

Consultation: Brief reflection & shift in perspective based on new information (Patient and nursing consultant or specialists)

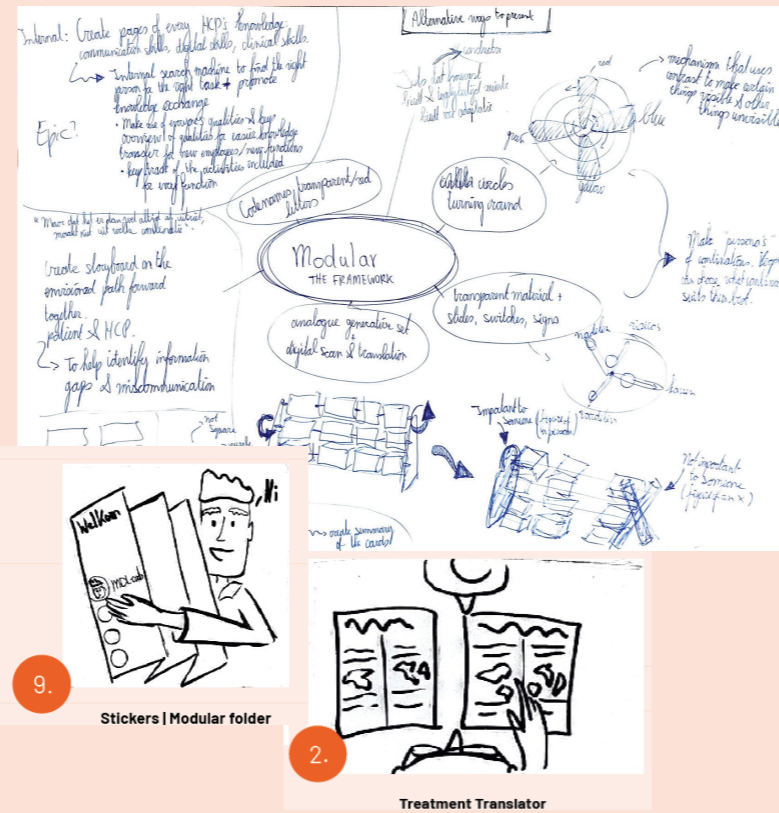


- Briefly reflect on the treatment proposal and how it relates to the perspective that has been identified.
 - Discuss any any adaptations in the patient's perspective based on new information.

Figure 41: Storyboard with description of interaction the concept should facilitate, with the concept represented as a black box.

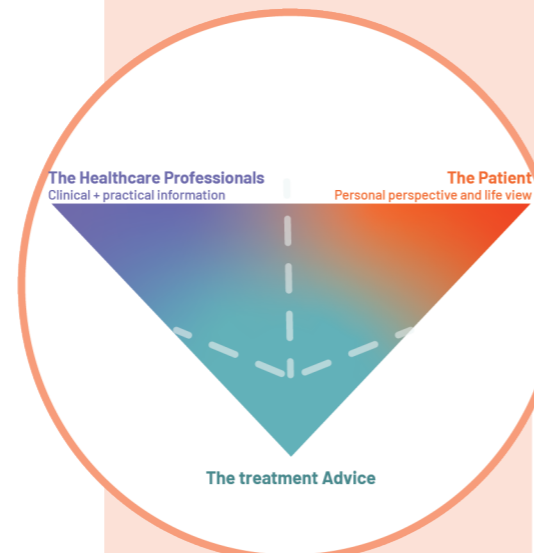
2. Define concept functions: SCAMPER with portfolio of ideas

To create a comprehensive concept, the existing portfolio of ideas (6.2.4) was revisited. Previous ideas, both promising and less promising (not included in the portfolio of ideas), were documented, reviewed, and re-clustered according to the frames identified in the previous chapter. From this process, the most promising ideas and their standout qualities emerged, serving as stepping stones toward the final concept. The SCAMPER method (explained in 6.2.2) was applied to integrate useful and interesting elements from these earlier ideas into the concept description. E.g., "Idea 9: Sticker | modular folder" evolved into using magnetic fiches to map perspectives. It was also decided to utilize Machine Learning as a tool to translate the patients' values and information needs into a brief summary that could be presented during the MDO ("Idea 2: Treatment Translator").

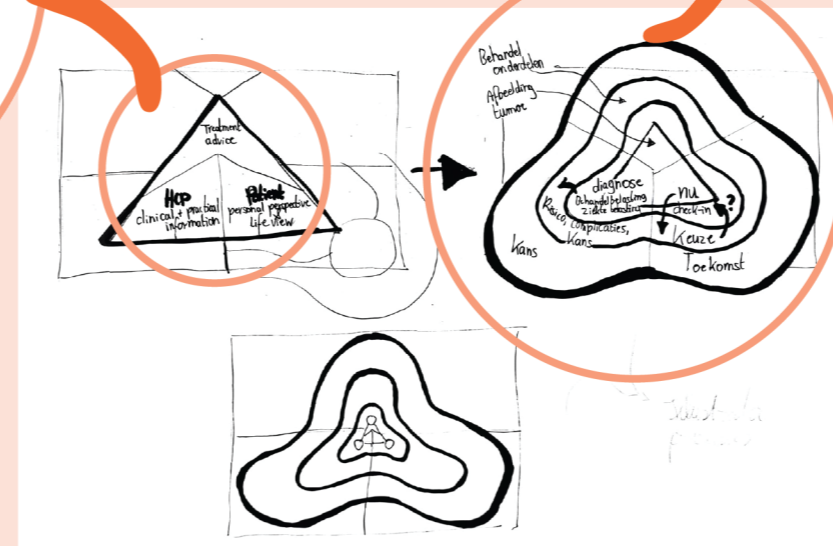


3. Defining the Concept Shape, Look & Feel

A key requirement for the concept is that the tool must help HCPs clarify the decision-making process to patients, by providing overview for example. This facilitates discussions about the roles within SDM, fosters a sense of autonomy for the patient, and ultimately reduces stress by helping patients navigate uncertainty. It does so by explaining how the decision-making process will unfold, providing an overview of what is already known, and outlining the information they can expect to receive. To address this requirement, earlier notes and ideas were revisited. Through mindmapping (a method where spontaneous drawing generates ideas), a visual concept emerged and was refined into its final form: an organic triangle, see Figure 42.

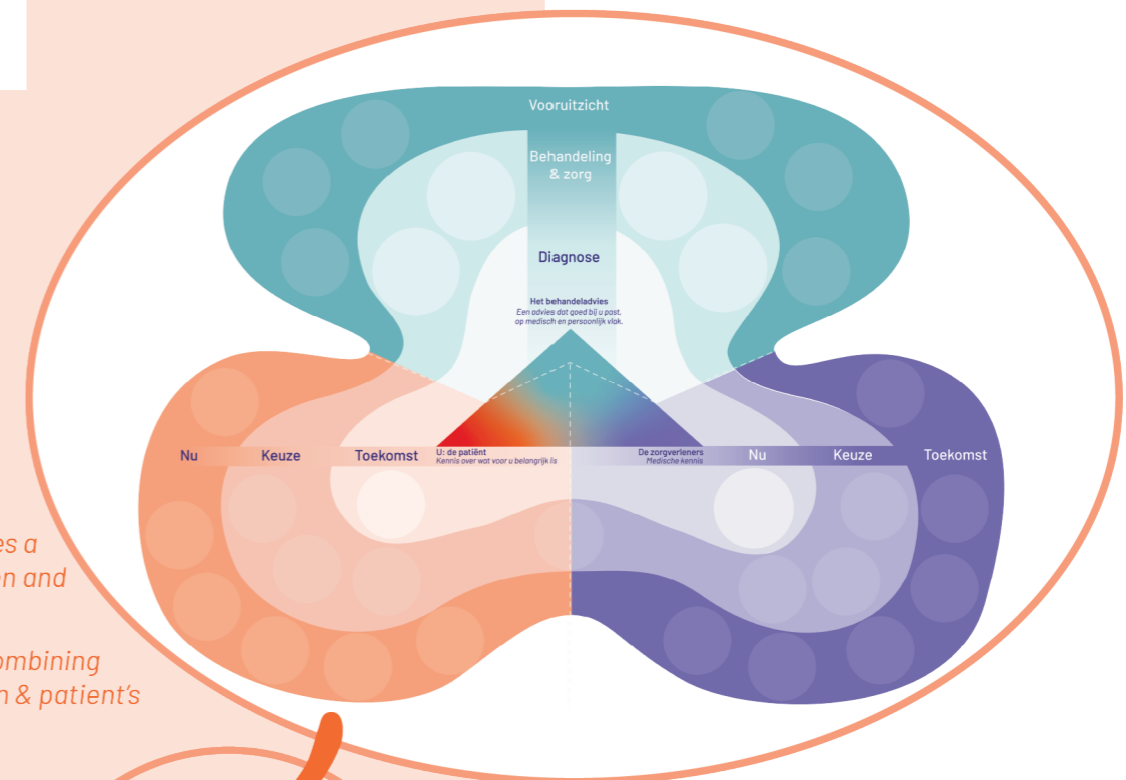


- Facilitates and visualizes a common ground for open and honest communication.
- Provides an overview combining both clinical information & patient's perspectives.



4. Defining the Product Service System

Each element of the concept was given a name, and a table was created detailing its characteristics (Appendix E). When determining which elements of the product-service system to prototype and evaluate, both design goals were kept in mind. The selection prioritized what could be realistically developed and tested within the available time frame and resources. It was decided that the physical tool should be prototyped, as this prototype could facilitate rich discussions with experts and HCPs on the feasibility, viability and desirability of Perspective Mapping.



7.4.2 Paper prototypes

Defining the prototypes contents

Based on the insights gained from interaction prototyping, in combination with co-creation insights and insights from literature (chapter 2) a first idea of the prototypes contents was drawn up. This prototype was adapted after evaluation with experts (9.3). The changes made to create the final concept are summarized on page 119.

Description:

The initial idea was to move from the left outer layer of the prototype, to the inside, and then continue to the right. This way both the personal perspective and the medical perspective of the patient will be discussed in relation to the current situation, and to the future.

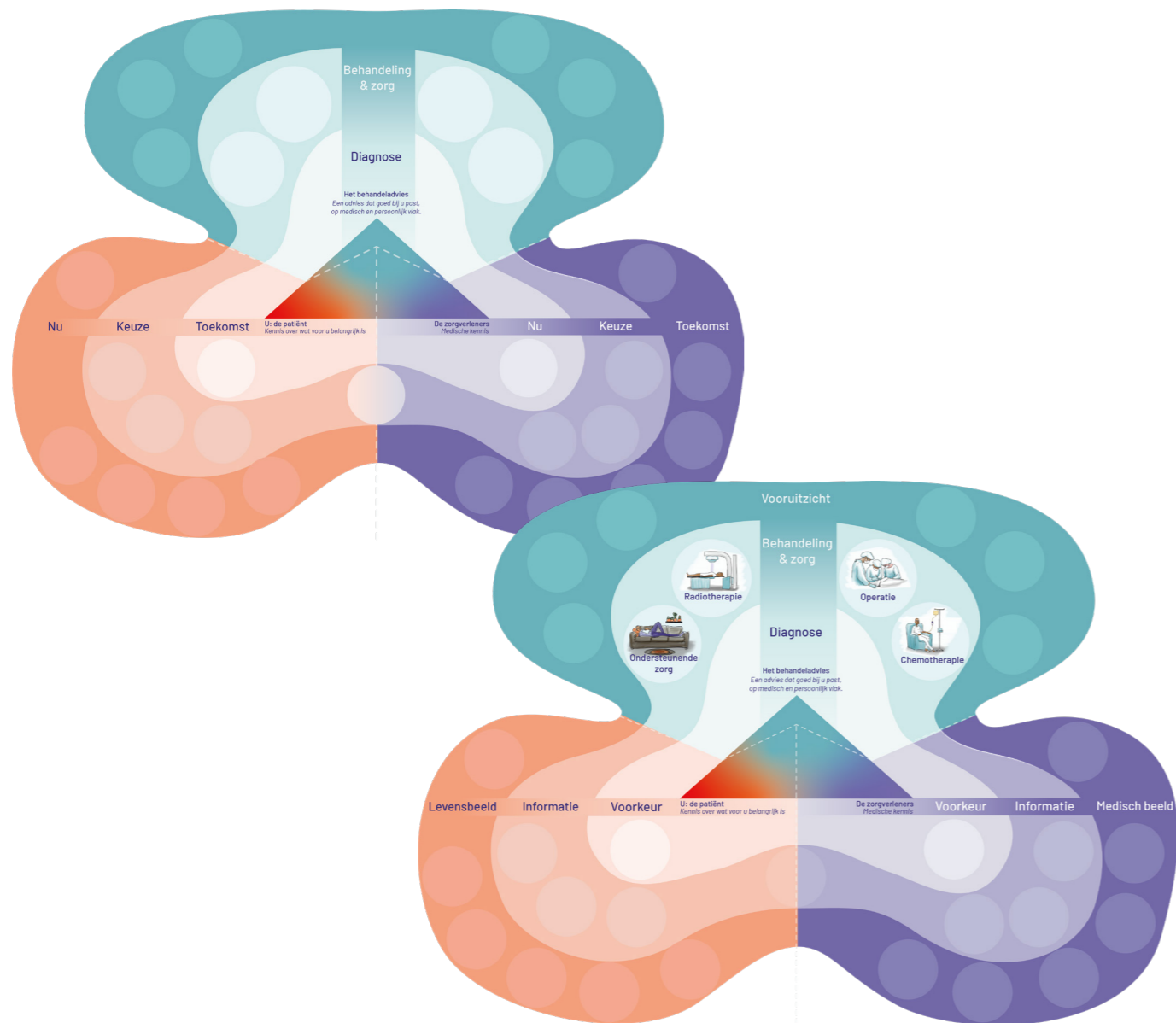


Figure 43: Digital versions of a paper prototypes

Expert Recommendations

Use of Language

Some terms, like "radiation," could be replaced with alternatives that are clearer or more patient-friendly. Language should better reflect the content and meaning of each component.

Wider applicability: diagnosis to the medical situation section (violet)

Consider stretching the violet section to start from the diagnosis phase, allowing the tool to be applicable at any point in the care journey.

Shape of the Triangle

The triangle currently feels too rigid. A softer design would be more inviting. That said, the overall visual style is attractive and organic.

Colour Adjustments

The red used in the triangle is too intense. A softer tone, like the orange used elsewhere in the design, is more appropriate.

Prioritize the Treatment Recommendation

The "treatment recommendation" section should be more prominent than the "diagnosis." The recommendation is the core focus.

Use the Orange Section Primarily for MDO

This part of the tool should be designed with MDO discussions in mind. It is advised to collaborate with HCPs what kind of

topics are useful for this section.

Current Use of the Violet Section

This section is already part of the existing workflow and mainly serves the patient.

a. When appropriate, it could be shown to subsequent HCPs to reflect on what's already been discussed.

b. Collaborate with HCPs to define what kind of information should be included in the blue section and what questions are useful there.

c. Focus especially on working with nurse consultants for implementation.

Bring a 3D Prototype

Consider creating a wooden 3D version of the prototype to bring to VUmc. It can help spark spontaneous conversations with healthcare professionals and allow them to quickly grasp the concept.

Role of the Nurse Consultant

Ideally, the nurse consultant could fill in as much of the perspective map as possible during their consultation, making the tool a supportive reference for the rest of the care process.

Blue Section

Supports the explanation of the treatment plan.

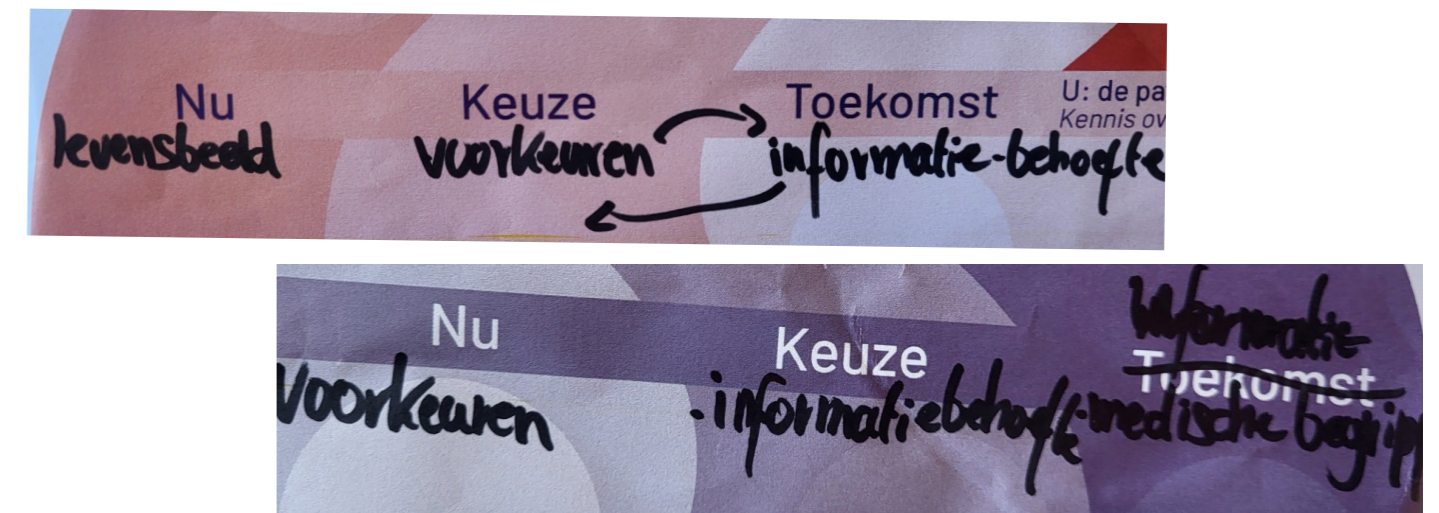


Figure 44: Annotations on paper prototype made during consultation with expert.

CHAPTER 8

FINAL CONCEPT

This chapter presents the final concept and provides information on its usage and implementation. This final concept is developed as described in chapter 7. It starts with a general introduction and elaborates on how the concept is used by the target groups within the context. Subsequently, more elaboration is given regarding the feasibility, viability and desirability of the concept. The most important evaluation points that are gathered during the evaluation phase (Chapter 10) and fitted within the scope of this project are applied in this final concept.

Chapter overview

- 8.1 Perspective Mapping
- 8.2 Argumentation
- 8.3 Concept recommendation
- 8.3 Feasibility, Viability, Desirability

8.1 Perspective Mapping

Perspective Mapping is a product-service designed to improve communication between oncology patients and HCPs inside the consultation room. With the initial goal to improve the treatment decision making process. It is specifically designed to accommodate the needs of esophagogastric cancer patients with LHL, receiving rapid diagnostics at GIOCA. However, Perspective Mapping is modular and can be implemented in other oncology settings too.

It is intended to be applied during all conversations around treatment and care decision making that happen inside the consultation room, for optimal integration of its use. This way SDM and patient-centered care becomes an integral part of the decision making process. Allowing patient preferences to be reflected in treatment decisions.

Perspective Mapping enables to collaboratively explore the patient's needs, preferences, and viewpoint (perspective) while the HCP can provide medical information step-by-step.

The central aim of Perspective Mapping is to create a shared space where medical expertise and patient perspectives are collaboratively explored. By combining product, service, and systemic elements, it empowers patients to articulate their priorities, equips HCPs to tailor their communication, and fosters a patient-centered approach from the very first consultation.

The product: a physical communication tool for inside the consultation room, is envisioned as a stepwise, iterative process integrated into the treatment decision making process. In early consultations, HCPs introduce the map to capture patient values, expectations, and questions. As treatment options are considered, the map is updated to reflect evolving perspectives alongside medical insights. At each stage, the visual overview serves as a reference point, ensuring continuity and shared understanding across patients, HCPs, and the wider clinical team.

The modular, physical toolkit lies at the core of the concept. This toolkit is designed to empower patients to express their preferences, while it helps HCPs explain the decision-making process in a clear and stepwise manner. By making this process transparent and clear for the patient, it aims to reduce patient uncertainty and prepares them for the, often difficult, decision that needs to be made: what kind of treatment or care fits their preference?

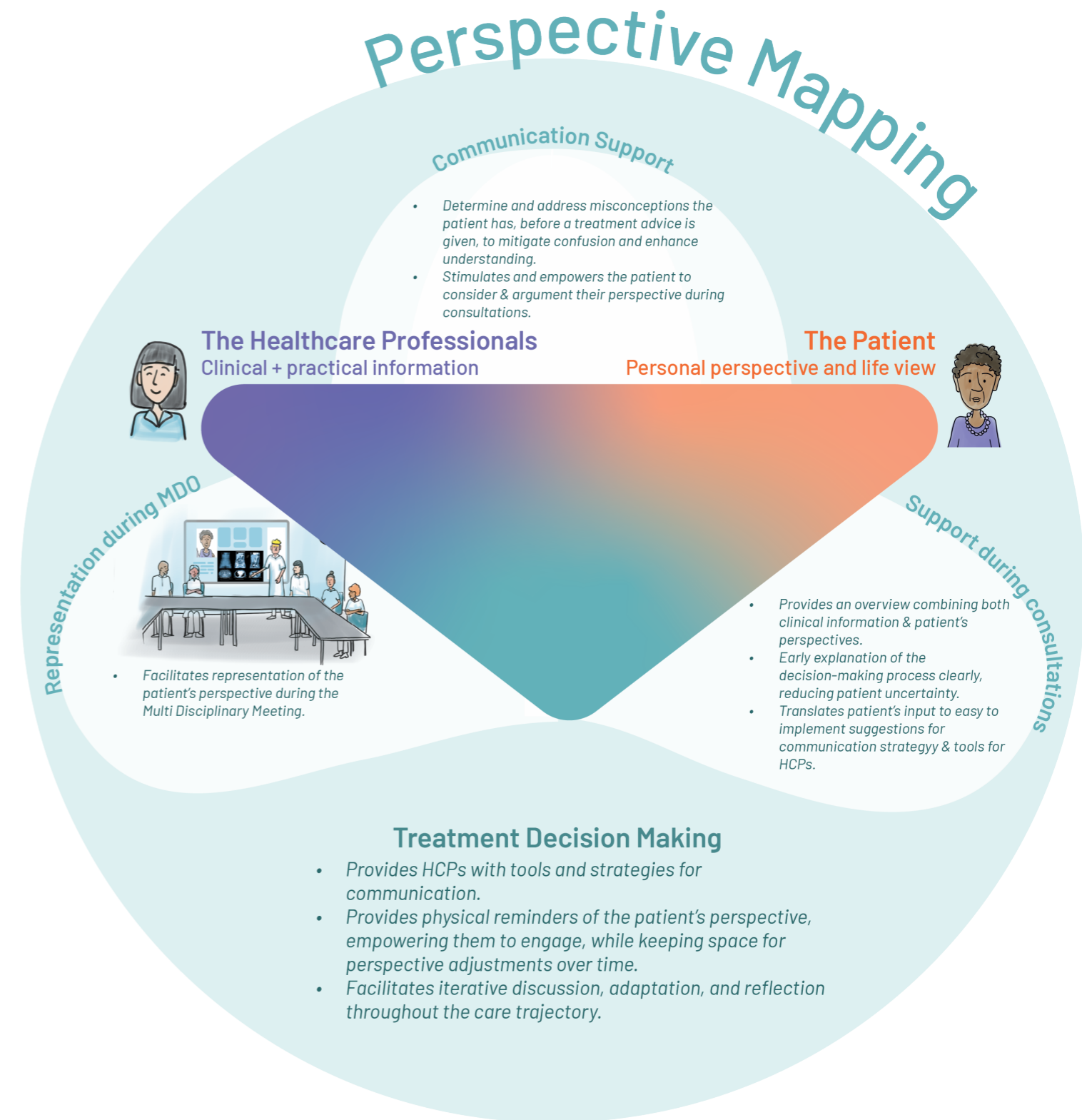


Figure 45: Final concept overview that describes the concept's functions.

8.1.1 The physical toolkit

At the heart of the concept lies a modular physical toolkit, designed for use during consultations, Figure 45. This tool makes abstract and complex issues tangible by visually mapping the patient's individual situation, bringing together both medical and personal perspectives. This mapping happens by placing magnetic fiches on the map. These fiches can be moved and the map can thus be adapted, as the perspective (both the clinical and the patient perspective) changes. It is not a replacement for conversation, but rather a facilitator that strengthens dialogue and ensures both the clinical side and the patient's perspective of the decision-making process are represented.



The toolkit empowers patients by:

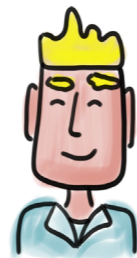
Clarifying the process: Providing a clear overview of upcoming consultations and discussions, helping patients anticipate what will be covered and what remains to come. This reduces uncertainty and fosters a sense of control.

Strengthening personal contact: Focusing on dialogue and human interaction rather than replacing it with technology, ensuring communication remains personal and empathetic.

Representing patient perspectives: Actively documenting patient values and preferences, and integrating them into advice and treatment discussions. This ensures patients feel heard and their perspectives are visibly reflected in the decision-making process.

Encouraging preparation: Prompting patients to reflect on their priorities and questions beforehand, which enables more focused and meaningful conversations when the treatment advice is discussed.

Supporting well-considered choices: Helping patients understand how their preferences may evolve over time and encouraging reflection on the balance between treatment burden and expected benefits. This prepares them for the inherent uncertainty and variability of cancer care.



The toolkit assists HCPs by:

Enabling person-centered care within limited time: Providing structured prompts to elicit values, identify misconceptions early, and ensure effective communication even during short consultations.

Offering flexibility and adaptability: The modular design allows the tool to be tailored to the patient's needs, consultation phase, and available information.

Providing rapid insight into patient priorities: Making preferences, concerns, and needs visible in combination with a brief summary, which helps HCPs address difficult-to-express topics more directly.

Ensuring continuity across disciplines: Documenting patient perspectives in a way that is accessible to all members of the care team, including those meeting the patient for the first time.

Contributing to patient-centered treatment advice: Bringing clinical facts and patient values together in a single overview by generating a brief summary of the discussion's main outcomes, supporting focused, value-based communication and clearer recommendations.

FINAL CONCEPT

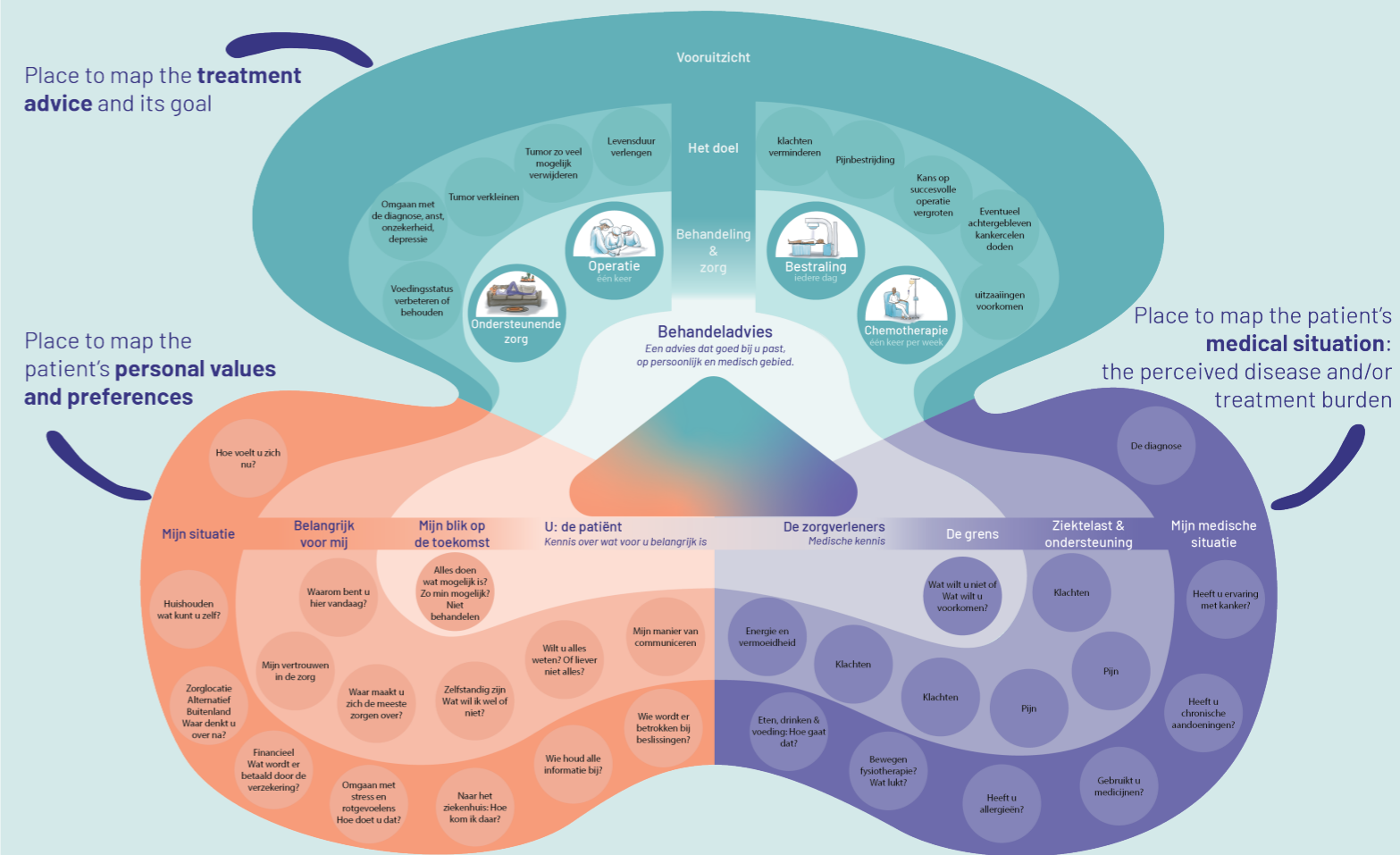


Figure 45: Final prototype of the physical toolkit, and its place in the consultation room during a conversation between patient and their next of kin and a HCP.

6.2.2 Explanation and recommendation of contents

The example on the right shows how the fiches can be used to visualize both a visual depiction of a patient's preference and a description in text. However, to be truly insightful for patients, and not overwhelm them, it should be researched and developed further what kind of questions are essential to elicit information that helps HCPs to inform the MDO discussions and the treatment advice that will be generated by the patient's values and preferences. In addition is should be researched and designed further what kind of visuals, colour, text, language and other cues are helpful for the main target group.

Evaluation with HCPs shows that they see promise in the toolkit facilitating more insightful discussions on the patient's physical state. The physical state of the patient can be mapped in the "clinical perspective" area. The HCPs stress that the connection of the patient's physical state with their personal preferences can be very useful for discussions on treatment. What is most important to research and design further is the following:

- What kind of questions/topics are essential
- What kind of approach with regards to asking questions is most suitable?
- How can the map function as a conversation anchor for both HCP and patient?
- How can visuals be used to make it easier to grasp an overview of the map's contents?
- How can the shape and tiered/ multi layered nature of the map be utilized to increase a natural flow of conversation contents?
- etc.

Probing answers to make it easier to answer and map discussion contents



Answer placed on the perspective map

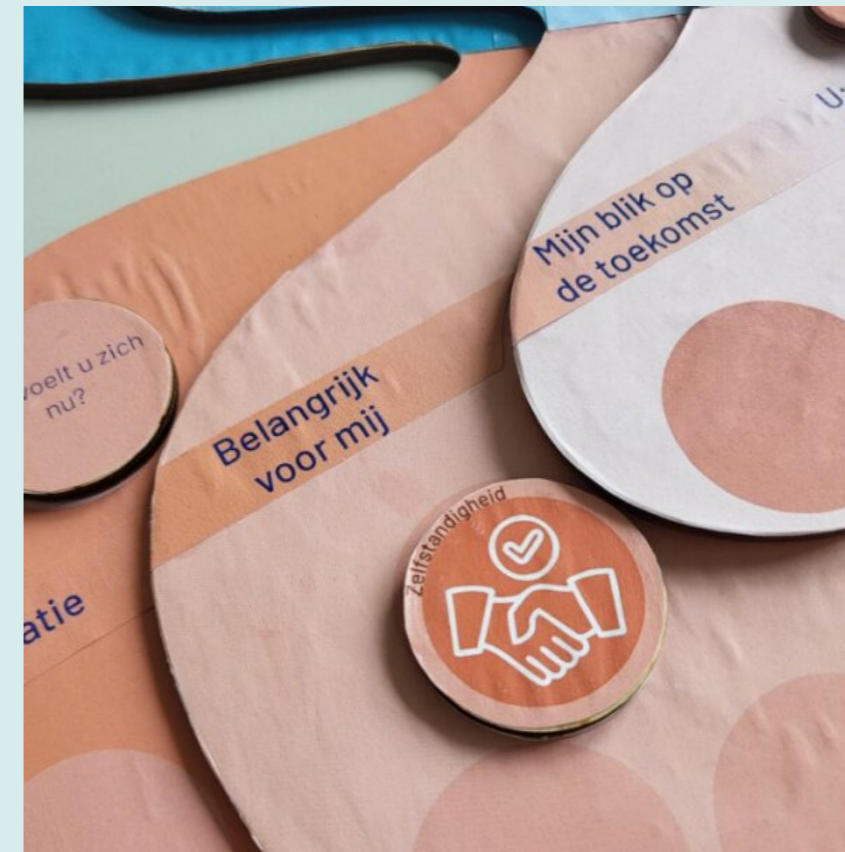


Figure 46: Example questions the toolkit prompts

8.2 Argumentation

Themes found by the co-creation study:

1. Recognising the Patient as a Whole Person

Perspective Mapping creates space to understand the patient as a whole person, by starting with their worldview, values, and information needs before moving into treatment discussions (Theme 1). This shift of focus allows HCPs to tailor language and explanations to resonate with the patient's frame of reference, signaling that their perspective is valued and relevant.

2. Balancing Control and Guidance

Once this foundation is laid, the modular design of the tool supports a dynamic balance between patient autonomy and professional guidance (Theme 2). Rather than forcing premature choices, it enables HCPs to introduce information gradually, aligning medical facts with the priorities that patients themselves have voiced. This ensures that decision-making can evolve flexibly as the patient's circumstances and emotional state shift.

3. Anchors for Continuity in Communication

To keep patients engaged and oriented across multiple consultations, Perspective Mapping provides anchors within the conversation (Theme 3). Visual prompts, summaries, and structured templates make it easier for patients to follow discussions, revisit what has been said, and prepare questions for future meetings. These anchors extend comprehension beyond the consultation room, ensuring that patients can reflect and involve their relatives in the decision-making process.

4. Navigating the Uncertainty Space

Because uncertainty is a constant presence in oncology care, the tool also explicitly addresses the need to manage it (Theme 4). By clarifying what has been discussed and what lies ahead, it reduces stress and creates a sense of orientation. Its iterative nature acknowledges that patients' perspectives and needs may shift, offering a framework that adapts over time. In doing so, it provides reassurance without relying solely on abstract probabilities, while also opening space for sensitive discussions—such as coping with prognosis or end-of-life considerations—before crisis moments force rushed decisions.

5. Making Sense of the Journey

Finally, Perspective Mapping functions as a translation layer that helps patients make sense of the overall care journey (Theme 5). It reframes complex medical information into accessible, culturally resonant terms, supports visual explanation of treatment trajectories, and contextualizes pros and cons according to patient values. This strengthens comprehension and enables patients to consciously weigh trade-offs between treatment burden and expected benefits. Towards More Patient-Centered Decision-Making Taken together, these elements demonstrate how Perspective Mapping transforms the consultation into a shared space where patients feel recognised, supported, and empowered to meaningfully contribute to decision-making. By combining recognition, adaptability, conversational structure, uncertainty management, and translation, the tool directly addresses systemic barriers to patient-centered care and strengthens the practice of SDM in contexts where it is most challenging.

Paradoxes found during reframing of the problem statement:

1. The Information Paradox

The modular toolkit breaks down complex treatment information into manageable, phased steps rather than delivering everything at once. By combining patient values with clinical facts, it emphasizes relevance rather than complete detailed information, helping patients focus on what matters most to them. This gradual, adaptive approach reduces overload and allows time for reflection and clarification between consultations.

2. The Communication Gap

Perspective Mapping shifts communication from information transfer to co-construction. Through guided prompts and structured modules, patients' understanding, perspectives are actively documented and made visible to both parties. This translation process ensures alignment between what is said and what is understood, reducing the persistent gap in comprehension.

3. The Trust-Control Dilemma

The toolkit allows patients to express when they want to take an active role and when they prefer to delegate, without losing ownership of their values. Because patient perspectives are anchored and carried forward (e.g., into MDO summaries), even moments of delegation remain grounded in the patient's worldview, reinforcing long-term trust and agency.

4. The Steering Trade-off

Instead of starting the conversation by presenting a treatment advice, Perspective Mapping begins with value clarification. Patients articulate what matters to them before medical options are introduced, which helps ensure that clinical advice is mapped onto patient values rather than the other way around. This reduces the risk of subtle (un)intentional steering the decision and preserves autonomy while still supporting efficiency.

5. The SDM Responsibility Paradox

By embedding structured yet flexible touchpoints throughout the care trajectory, the concept normalizes patient participation as an ongoing process rather than a one-off decision. Patients are gradually introduced to decision-making, supported in articulating their values, and given space to reflect, making participation less daunting and more empowering over time.

6. The Belief Barrier

Perspective Mapping treats beliefs and personal values as integral design constraints, not late-stage obstacles. By surfacing them early and integrating them into the shared documentation, HCPs and patients can collaboratively explore treatment adaptations or compromises. This reframes potential conflicts as co-creation opportunities, preventing dead ends and strengthening trust.

8.3 Concept recommendation

The research insights within this thesis make clear that one small tool is not able to improve patient-centered care on its own. The successful implementation of any communication intervention in the consultation room is highly dependent on the benefit it holds for making HCPs workflows more efficient and less cognitive demanding. In addition, viewing SDM as isolated moments adds to its limited adoption in clinical practice (chapter 3). Viewing the delivery of a treatment advice as a service, includes optimizing the experience it provides for both patient and HCP. This experience could be enhanced by carefully designing the full process, and ensuring continuity of patient-centered elements throughout. This paragraph provides future oriented, but promising concept recommendations to improve its viability and positive effect in the long term.

The Digital Environment

A digital interface, integrated into the electronic patient dossier (Epic), provides HCPs with step-by-step guidance on using Perspective Mapping in consultations. It should include:

Clear instructions and example questions for exploring values, preferences, and comprehension styles.

A structured space to document and store perspective maps and the generated summaries.

Options to share insights with colleagues, ensuring continuity across the care team.

Functionality to generate patient-specific resources (flyers, videos, websites, or summary templates) that complement general information and can be taken home.

Support for MDOs by making patient perspectives explicit in and actionable for treatment planning, by generating a summary of the discussed contents of conversations on patient values and preferences.

The Machine Learning Model

The ML component enhances the toolkit by:

Translating patient insights into actionable communication strategies for HCPs tailored to comprehension style and emotional state of the patient.

Recommending suitable tools and resources, including visual aids, summary templates, or patient support materials.

Supporting the MDO by summarizing patient priorities as clear talking points for care planning.

Safeguarding communication expertise by documenting the implicit strategies used by experienced HCPs and turning them into practical, transferable guidance for onboarding and training.

Eventually it holds the value of lowering cognitive load for HCPs, which enables them to have more capacity for truly and effectively communicating with patients.

The Library of Tools

The library functions as a curated repository of communication and information resources, including:

Flyers, websites, videos, and tools (e.g., SOURCE).

Visual templates for summarizing or explaining complex procedures.

Interactive aids such as drawings or images to support comprehension of patients during conversations.

Guidance for communicating with patients with limited cognitive or language abilities (e.g., pacing information delivery, checking comprehension). This shared resource supports personalization of care while fostering knowledge exchange across disciplines.

8.4 Feasibility, Viability, Desirability

This chapter focuses primarily on evaluating the feasibility of the product-service Perspective Mapping, while also considering its desirability and viability, based on the evaluation is described in chapter 10. A thorough evaluation of any concept requires assessing these three key factors:

- **Feasibility** considers whether the concept can realistically be implemented, taking into account current technology, available resources, operational capacity, and legal constraints. *Can it be built with what we have? Are the required skills and infrastructure in place? Are there regulatory barriers?*
- **Viability** examines the financial and strategic sustainability of the concept. *Will it be profitable? Does it align with the organization's mission? Is there a long-term market for it?*
- **Desirability** focuses on the user perspective: whether the concept addresses real needs and will be embraced by its target audience. *Does it solve a meaningful problem? Will people want to use it? Is it something they value?*

Together, these dimensions offer a holistic framework for evaluating a concept's potential. It helps to identify potential risks early, before major investments are made. (IDEO's Desirability, Viability, Feasibility Framework: A Practical Guide – Make:Iterate, 2023)

Feasibility

The modular, physical toolkit is considered feasible in principle, as it aligns with existing consultation structures and avoids adding yet another stack of paper information. Its visual, interactive nature is intuitive, and HCPs recognized its potential to guide conversations step by step. However, feasibility is constrained by two recurring concerns:

1. Time limitations:

HCPs emphasized that they often lack the time to apply new tools during consultations. For the toolkit to be feasible, it must be designed for incremental use.

1. Practical integration:

Questions about storage, transport, and stepwise use suggest the need for further prototyping to ensure smooth integration into clinical workflows.

Machine Learning element

Experts stressed that although promising, it is unlikely to be feasible in the short term. Implementation of ML in healthcare is slow, and adoption rates are very low. It should therefore be positioned as a future add-on rather than a core feature in the first rollout.

Overall, feasibility depends on reducing complexity, clarifying roles in usage, and ensuring integration with existing system (e.g., Epic, MDO meetings).

Viability

Strategic fit

The tool aligns with the ongoing push for Shared Decision-Making (SDM), patient-centered care, and reducing disparities for patients with LHL. It also supports existing organizational goals, especially in multidisciplinary cancer care (GIOCA context).

Scalability

Its modular design allows adaptation across oncology contexts, and potentially beyond, which strengthens its long-term relevance.

Economic considerations

While the physical toolkit itself is relatively low-cost, sustained viability depends on demonstrating that it saves time downstream (e.g., fewer follow-up consultations due to less misunderstandings, improved patient satisfaction, more efficient MDO discussions). The ML component could enhance viability later if shown to reduce cognitive and administrative load for HCPs.

Risk of non-adoption

As highlighted by experts, many interventions fail because HCPs do not adopt them. If Perspective Mapping does not convincingly reduce workload or add tangible benefits, its long-term viability is at risk.

Thus, viability is promising but depends on showing measurable efficiency gains and institutional benefits early on.

Desirability

Perceived benefits and limitations for HCPs

The evaluation and case study insights confirm that HCPs struggle to elicit patient values and preferences in ways that are both meaningful for patients and useful for MDO discussions. While HCPs appreciated the potential benefits of the Perspective Mapping concept for patients, they expressed doubts about its added value for themselves during consultations. A recurring concern was the lack of allocated consultation time, which they viewed as a prerequisite for implementing any new tool. At the same time, HCPs emphasized that concise summaries of patients' goals and preferences could help them tailor communication and treatment discussions more effectively.

Integration of the target groups needs

As outlined in Chapter 10.2, the concept draws directly on themes identified in the co-creation study with individuals with LHL. However, it has not yet been validated with the target group itself. To assess its desirability and practical value, further research is needed to explore whether, and to what extent, individuals with LHL consider a communication intervention like Perspective Mapping supportive in their care journey.

CHAPTER 9

EVALUATION

Before implementing a design, it is essential to evaluate and assess the intended interactions and implementation. Early-stage evaluation helps determine whether further development is worthwhile and generates insights to refine and improve the design.

Some features of the final concept presented in Chapter 8 are informed by the evaluations described in this chapter. These include expert consultations (9.2) and healthcare professionals (9.3), both of which provide valuable insights for strengthening the concept itself and for any implementation of a communication tool.

Chapter overview

- 9.1 Goal
- 9.2 Approach
- 9.3 Expert consultations
- 9.4 Evaluation healthcare professionals

10.1 Goal

Two main goals guide this evaluation:

1. Assess the likelihood of intended interactions:

To what extent is the current design effective and appropriate for use in the consultation room?

2. Identify opportunities for improvement:

What key elements of the design need to be adapted to enhance its effectiveness and appropriateness for HCPs in the consultation room?

The evaluation aims to assess both the feasibility of implementation and the likelihood that the intended interactions will occur in real consultation settings. Its usability is also addressed.

Since feasibility is closely tied to desirability in the context of clinical decision-making, both aspects are evaluated in relation to real-world clinical practice. This evaluation thus will focus on how to improve the concept to increase its feasibility.

10.2 Approach

To assess the proposed design, a multi-method evaluation study was conducted. Given the time and budget constraints of this graduation project, a full-scale evaluation of long-term impact was neither feasible nor necessary at this stage. Since the intended impact unfolds gradually throughout the patient's care trajectory, this early evaluation focused on short-term interactions and feasibility of implementing the communication tool within the consultation room.

To define what could be meaningfully assessed, the key elements of the product-service system and their intended interactions were mapped in a table (Appendix E). Based on this analysis, two complementary evaluation methods were chosen:

1. Expert consultations (10.3)

The full concept was presented in separate evaluation sessions with subject-matter experts in oncology, healthcare communication, SDM and machine learning. Each semi-structured session lasted between 30 and 60 minutes.

The experts were asked to provide feedback on the concept's feasibility, viability, and desirability, with a focus on systemic implementation across the product-service system. The goal was to identify opportunities and barriers to adoption from a strategic and organizational perspective.

2. Evaluation with HCPs (10.4)

Targeted sessions were conducted with three HCPs from GIOCA: two nurse consultants (P4, P5) and an oncologist in training (P6). All sessions lasted between 30 and 45 minutes.

The goal of the sessions was evaluating desirability and usability of the concept in the context where consults between HCP and patient are normally held.

Postponing patient involvement

Conducting evaluation sessions and usability testing with LHL patients was intentionally postponed. The early-stage evaluation discussed in this chapter prioritized feedback from experts and HCPs to determine initial acceptability of the design. The rationale was to avoid burdening patients prematurely. Expert consultations revealed that the willingness of HCPs to adopt new interventions is the most critical barrier to implementation. This phased approach allowed for meaningful refinement before moving towards patient-centred testing in future stages.

More information on the approach for expert consultations can be found in 10.3.1, the most important insights are presented in 10.3.2. This chapter includes insights related to the evaluation goals, quick fixes as suggested by the experts are included in Concept Development (7.4.3). More information on the evaluation approach with HCPs can be found in 10.4.1, the most important insights are presented in 10.4.1.

10.3 Expert consultations

To evaluate the feasibility, viability, and desirability of the concept, three experts were consulted. The first expert (P1) is connected to GIOCA and has a lot of context specific knowledge as well as general knowledge for oncology settings. The second expert (P2) has previously conducted research at GIOCA, and knows the workflows existent there. Their knowledge provided input on health communication, more specifically effective communication with vulnerable groups and digital health technologies. The final expert (P3) provided more insight in the technical feasibility of the concept recommendation containing the Machine Learning part.

9.3.1 Approach

Separate meetings were held at three stages of the concept development, all meetings lasting between 30 and 60 minutes. P1 and P2 participated in an in-person meeting, P3 in an online meeting. Depending on the expert's knowledge of the project, and the development of the concept, materials were presented to introduce the research insights and reasoning for the concept. P1 was previously introduced to the project via mail contact. P2 was previously introduced to the project as they provided insight for the project's and co-creation study's scope (1.3). P3 was introduced to the project during the evaluation session. A visual representation of the concept was made, including a storyboard, to enable a quick overview of the concept. This way the broader context and application of the concept could be discussed. In addition the latest version of the physical toolkit prototype was shown, see figure 43 For an impression on the materials.

9.3.2 Participants

P1) A professor of Health Communication and Head of the Department of Communication Science. Whose research focuses on effective health communication, particularly for vulnerable groups such as older adults, migrants, and individuals with LHL, often in the context of digital health technologies.

- Contacted via a personal contact.

P2) A medical oncologist and head of the Department of Medical Oncology. In addition to coordinating multi-center clinical trials and translational research (specialized at esophagogastric cancer), their work also focuses on quality of life, SDM, and spiritual care in oncology.

- Contacted via company supervisor.

P3) Data scientist at a medical centre.

Experience in designing Machine Learning models to improve digital healthcare systems (diagnostics and communication).

- Contacted via a personal contact.

9.3.3 Data collection and analysis

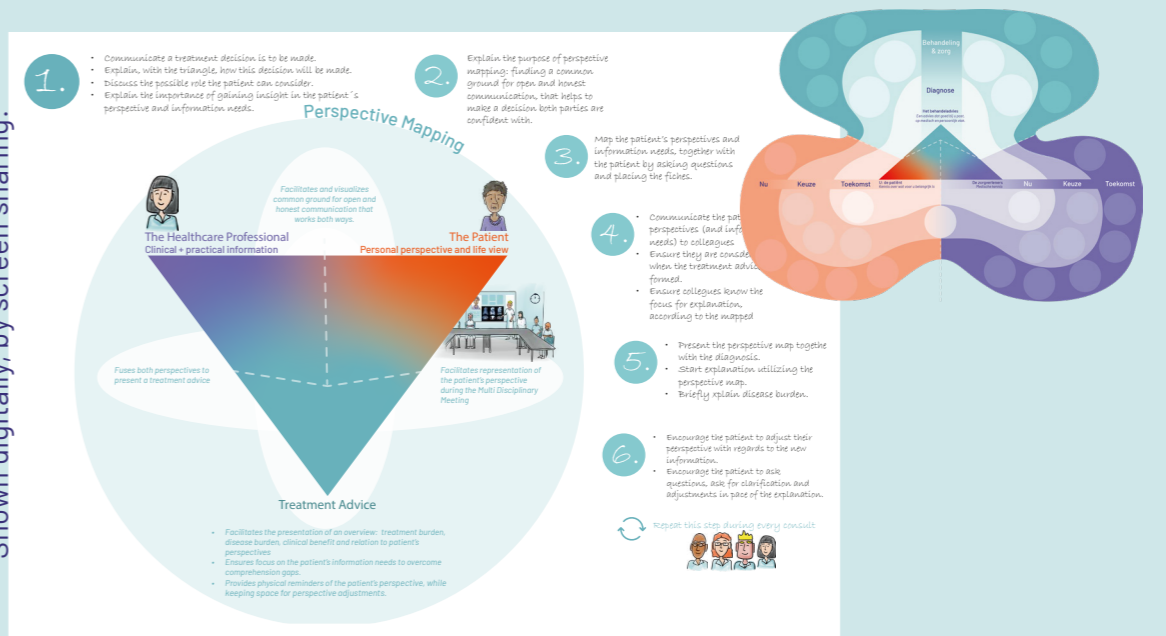
Immediately after each session, a detailed account of the discussions was written out. These notes included direct quotations from participants, as well as a systematic documentation of the conversation flow and communication interactions. Subsequently, the notes were refined by clustering content and organizing it under sub-headers.

The insights were further clustered into three categories: quick fixes (included in chapter 7), concept insights (9.3.4), and suggestions (9.3.5).

EVALUATION

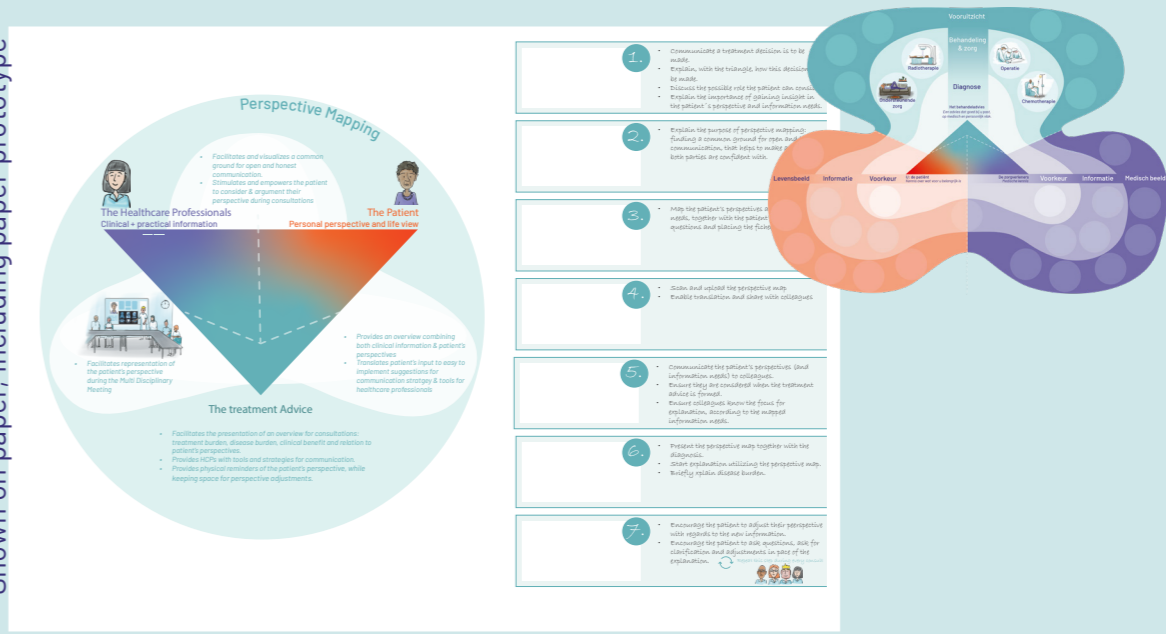
P1

Shown digitally, by screen sharing.



P2

Shown on paper, including paper prototype



P3

Shown on paper, including wooden prototype

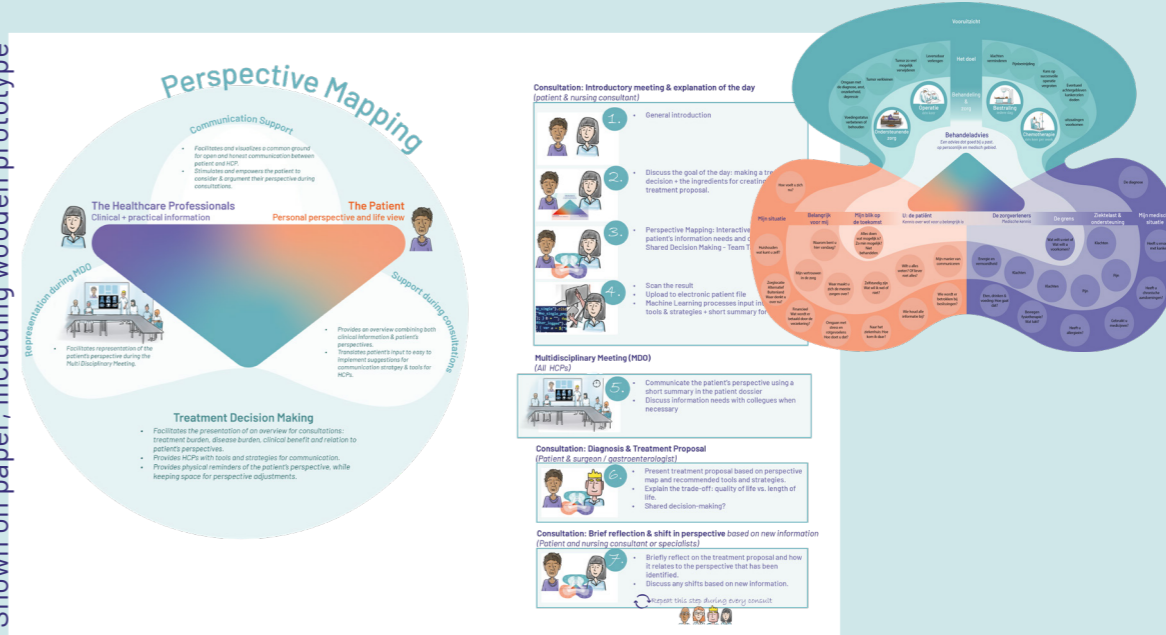


Figure 43: Overview of visual representation of the concept, and physical toolkit prototype that was brought to the consultation session. From top to bottom, P1, P2, P3.

9.3.4 Main insights

Modular tool

P1: They were enthusiastic about the modular element within the concept, as this ensures a more holistic approach by providing continuity within the care path, as the tool can be used during all consultations on treatment, diagnosis and decision-making.

Machine Learning

P1 was enthusiastic about the Machine Learning element within the concept, as this may ensure that HCPs are less strained and balances the extra time perspective mapping may take by streamlining their workflow.

Physical interaction

P1: They were enthusiastic on the physical element of the tool; most of the time paper tools are developed, like flyers etc.. Patients already receive a huge pile of paper information, and HCPs are getting tired of all the loose papers lying around.

Biggest concern: acceptability of HCPs

P2 Their biggest concern was the desirability as perceived by HCPs.

P2 expressed how they perceive that a very limited amount of interventions are actually implemented, and that implementation is almost always limited by the willingness and ability of HCPs to utilize the intervention.

P3 Only a very small percentage of the designed machine learning models are actually implemented in the healthcare setting. Most of the time this implementation is limited by the acceptance of HCPs. It is advised to first develop the concept further to improve acceptability.

Insights per expert

P1) A professor of Health Communication and Head of the Department of Communication Science.

- **Machine Learning – A Strong Asset**

a. It can significantly reduce the workload of healthcare professionals, freeing up time and mental space to actual use the tool and communicate with patients.

b. Applying machine learning in this way is highly innovative and forward-thinking.

- **Key Bottleneck: Healthcare Professionals**

Their interaction with the design is critical. If they are unwilling or unable to use the tool, it simply won't be adopted. It must provide them with clear, tangible benefits to gain their support. She explained how the majority of initiatives she contributed to are not implemented because of this.

- **Multidisciplinary Team Meetings (MDO)**

It would be highly valuable if the tool could be integrated into MDO settings. According to P1, integration of SDM into these meetings at GIOCA has been limited compared to similar contexts where SDM has been more fully integrated into MDO practices.

P2) A medical oncologist and head of the Department of Medical Oncology.

- **Positive Response to the Physical Tool**

They were pleased with the physical version of the tool and immediately suggested it would be valuable to give it to patients to take home.

- **Modular Design Appreciated**

The modular aspect is strong: especially how the tool is built collaboratively by the patient and healthcare professional over time.

- **Machine Learning as a Future Development**

Machine learning holds promise, but it's more of a long-term vision. For now, the tool's immediate usability and applicability are more important.

9.3.5 Suggestions

- **Relevance for Second Opinions**

At GIOCA, many patients come in for second or even third opinions. The tool could be especially useful for these individuals, as it can help uncover the root causes of their dissatisfaction and identify the information they are missing.

- **Supplementary Tools and Strategies**

Additional strategies that could support communication include using tools like MediLanguage (digital application) or arranging for a professional interpreter to assist during consultations, the Machine Learning element could include these tools as suggestions for communication.

- **Use of Animations During Consultations**

It may also be effective to incorporate animations during consultations. They mentioned that visual aids, especially moving images, are particularly impactful for this patient group. Future applications could even utilize holographic animations.

- **Engage Directly with MDO**

It would be beneficial to discuss with care providers how they think this tool could contribute to MDO meetings. You might even visit an MDO session, things are a bit quieter now due to summer holidays.

- **Allow Patients to Contribute**

It might be meaningful if patients could write down and add their own notes to the tool.

- **Bring a 3D Prototype**

Consider creating a wooden 3D version of the prototype to bring to VUmc. It can help spark spontaneous conversations with healthcare professionals and allow them to quickly grasp the concept.

- **Role of the Nurse Consultant**

Ideally, the nurse consultant could fill in as much of the perspective map as possible during their consultation, making the tool a supportive reference for the rest of the care process.

Conclusion

Overall, the concept was received positively, with particular enthusiasm for its modular design, machine learning integration, and physical format. These elements were seen as supporting continuity of care, reducing workload for HCPs, and offering a practical alternative to paper-based materials. However, the key challenge remains the acceptance and willingness of HCPs to adopt and integrate the tool into their practice. Experts emphasized that without clear benefits and usability for HCPs, implementation will be limited, as has often been the case with similar innovations.

To strengthen the concept, it is recommended to focus on improving acceptability, exploring integration into MDOs, and considering supplementary strategies such as patient note-taking, animations, or interpreter support. By addressing these concerns, the tool can move closer to successful adoption and meaningful impact in healthcare settings.

10.4 Evaluation with healthcare professionals

Whereas the expert evaluations concentrated on the concept as a whole, the evaluations with HCPs focused more on the specific interactions the physical toolkit could facilitate in the consultation room. HCPs with experience working at the GIOCA polyclinic and having consultations with patients during the GIOCA day were included. In total, three participants were included in two evaluation sessions, lasting 30 to 45 minutes. At the start of both sessions, participants were asked for informed consent to include their feedback in this thesis.

9.3.1 Approach

Although the overall approach to the sessions was similar, the content of discussions varied. In the session with nursing consultants, most feedback centered on integrating the tool into consultation practice. In contrast, the oncology trainee focused more on its specific application and usability within the consultation setting.

Materials and preparation

Prior to the sessions, materials were prepared, including a concept introduction, questionnaire, and a Keep-Build-Kill worksheet. For the first session, the concept and research foundation were introduced only briefly. However, it became clear that participants had many questions that could be answered with research insights. While the participants learned more about the research foundation, they were more prone to think along and provide deeper insight. For the subsequent session, the explanation was made more elaborate. This helped build trust and encouraged more active contributions from the start.

Adapted approach

A physical prototype of the concept was presented during the sessions (figure). While worksheets and the questionnaire were initially prepared, it became apparent that participants were eager to provide both positive and critical feedback spontaneously. As a result, these materials were set aside in favor of an open discussion approach, using active listening and encouraging participants

to think aloud. This allowed for a rich and detailed conversations about the concept and prototype.

An example of how the fiches could be used was given, figure 33. In addition the overall topics of the physical toolkit were discussed and some topics were discussed in more detail.

9.3.2 Participants

Recruiting participants for the evaluation proved challenging. Initial attempts to approach HCPs directly at the clinic were unsuccessful, as most were too busy for spontaneous conversations. As an alternative, I contacted HCPs who had participated in the Patient Journey Mapping study (4.3.1), aiming to ensure representation from all disciplines involved in the GIOCA-day. Although several expressed interest, many were unavailable due to holidays, while others did not respond, making this strategy largely ineffective.

I then returned to the original plan of visiting the polyclinic in person over several weeks. This eventually led to contact with the nursing consultants, who preferred to give feedback in a shared session. The participating oncologist in training, however, was approached by email following a prior personal meeting, where he had shown interest in the project. This account is not intended as a critique of HCP availability, but rather to provide transparency about the steps taken to include their perspectives in the evaluation while respecting the demands of their roles.

Session one

Two nursing consultants: P4 and P5.

Session two

One oncologist in training: P6.



Figure 43: Impression of the final prototype as brought to the evaluation sessions with HCPs.

9.3.3 Data collection and analysis

Immediately after each session, a detailed account of the discussions was written out. These notes included direct quotations from participants, as well as a systematic documentation of the conversation flow and communication interactions. Subsequently, the notes were refined by clustering content and organizing it under sub-headers.

The notes from both sessions were then synthesized by identifying thematic connections across discussions. For each theme, a brief conclusion was formulated to articulate its relevance for the concept, the evaluation objectives, or the broader aim of implementing a more patient-centered approach. Where appropriate, participant quotations were integrated to substantiate the findings. Please find the results in paragraph 9.3.3 below.

9.3.3 Main insights

Initial Impressions P4 and P5

P4 and P5 appreciated the prototype and understood its rationale but found it hard to imagine how it could realistically be used during consultations. Their main concern was their own lack of time and their doubts that colleagues such as surgeons, oncologists, and radiotherapists would use the tool, which would make it harder to apply the concept consistently.

Positive first impression

They found the tool visually appealing and agreed that in an ideal situation it could be highly valuable, as it can improve communication between them and patients and allow more space for the patient in the conversation.

Limited time

They were very firm in stressing that they simply do not have enough time to apply something like this concept in their daily practice. For this to be feasible, they would need significantly more time per patient. The time they receive per patient differs and is dependent on the length of other conversations the patient has. When previous conversations run out, the nursing consultants receive limited consultation time, because the patient has other subsequent meetings they need to attend at GIOCA.

Initial Impressions P6

P6 found the structure of the tool logical and its design appealing. They quickly understood its purpose and recognized its potential to support patients.

Practical Concerns

At first, they asked practical questions about how the tool would be moved, who would carry it, and where it would be stored. I did not go into detail at that point, and soon other questions followed, such as which sections should be filled in when, and what the purpose of each step was.

Ideas and suggestions

The more the concept was discussed, the more P6 felt comfortable in sharing ideas and suggestions they had for improving support for patients with LHL (9.3.4).

1. Targeted support during the first conversation on treatment advice

P4 reflected on the challenges of informing patients, emphasizing that the amount of information presented in a single day is often overwhelming. They observed that many patients shut down once surgery is mentioned, as they tend to underestimate how invasive it will be. In addition, P4 noted that the GIOCA afternoon can be particularly difficult for "patients who struggle with information". They explained that patients often meet with them after receiving the treatment advice formulated during the MDO. By this point, many are already overwhelmed, which reduces the effectiveness of subsequent conversations.

This finding aligns with the Context case study (Chapter 4) and conflicts with literature insights (Chapter 3), which emphasize that the first conversation about treatment options has the greatest impact on decision-making.

2. Limited implementation by other HCPs

P4 and P5 were skeptical that other HCPs (specialists) would engage with the concept, since many colleagues already make little use of folders and tools.

This was already suspected, but in combination with insight 1 shows a major paradox in making the decision-making process more patient-centered.

This highlights a paradox: while the first conversation on treatment advice/options is the most influential for patients' decision-making, it is also the moment when tools like Perspective Mapping (designed to increase patient engagement and understanding) are least likely to be applied. Together, these perspectives underscore the need to make this initial consultation more patient-centered and effective.

3. Integration of patient's- and clinical perspective

P6 highlighted that while the orange "patient's perspective" section is particularly useful for clinicians, linking it with the violet "clinical perspective" section would add further value.

"Such a linkage could generate a short, patient-authored summary like: "This is what matters to me, and this is what I'd like to discuss." Specialists could then tailor their advice more effectively." -P6

"Fellows, who rotate every few months, often struggle with context during consultations. For them, a patient arriving with a concise, structured overview could be very helpful." -P6

P6 illustrated this with a practical example: if a patient prioritized immediate relief from swallowing difficulties, then a treatment plan limited to chemotherapy and surgery would not suffice, since its benefits appear later. Radiotherapy would be essential. Knowing such a priority upfront would allow clinicians to explain trade-offs more clearly. P6 asked whether the tool was mainly intended for patients. I confirmed this was the starting point, but emphasized my ambition to also make it useful for clinicians, given their limited time. For successful implementation, the tool must fit within existing workflows and needs.

P6 saw strong potential in summarizing patient perspectives into bullet points that specialists could act on directly. It provides a benefit for specialists to engage in perspective mapping: their conversations can become more targeted. In addition, this activity of perspective mapping would prepare patients and help them feel heard, reducing stress and building trust.

4. Added Complexity: The SAN0 Trial

P4 highlighted an additional challenge: the introduction of the SAN0 trial.

"Previously, there were only two options for esophageal cancer curative treatment, but now a third option must be explained, which takes more time and creates more complexity." -P4

They observed that many patients initially want surgery but change their preference after learning about the SAN0 trial (active surveillance with no surgery, chapter 2.3). They thought the tool could play a valuable role here, helping patients compare options more clearly and see which one fits best with their situation.

While it is likely that more clinical treatment options, like active surveillance, emerge it becomes more interesting to utilize conversation tools that support the decision-making process for both HCP and patient.

4. Machine Learning component

I had not explained the Machine Learning component to P4 and P5, as I wanted to focus the conversation on the participants views of utilizing the concept in the consultation room. However, P5 suggested that after the GIOCA day, the tool could help identify more precisely why a patient feels uncertain and what information they still need. This could then guide the provision of tailored resources. They explained that they already sometimes provide patients with specific links to reliable websites on chemotherapy or radiotherapy, since paper-based information is often overwhelming and searching online can expose patients to an excess of information.

This stresses the possible value of the Machine Learning element: by generating personalized recommendations for relevant and trustworthy information sources.

The Machine Learning component was explained to P6. They found this promising, especially for identifying which tools suit which situations. They noted the current lack of tools to explain care logistics clearly, and emphasized that patients should ideally receive supportive tools before consultations throughout their care trajectory, allowing clinicians to better determine their capacity to process information.

This highlights the potential value of a Machine Learning component, and provides a suggestion for another application of the component.

5. Challenges in engaging patients

Both P4 and P5 stressed the difficulty of asking patients—particularly those with LHL—about their own preferences.

“I sometimes ask patients: What do you want yourself? But they become very anxious by this question and fear the worst case scenario because of it. Many patients are highly anxious and can be startled by such questions.” -P4

“I then emphasize that it is important to acknowledge when patients do not want surgery, chemotherapy, or radiotherapy, and to bring this into the discussion so the team can consider it during decision-making.” -P4

P4 explained how they manage this by reassuring patients that HCPs want to understand the patient’s perspective, so it can be included in their advice. They both acknowledged how that the tool could facilitate this conversation.

This underlines the importance of clearly communicating to the patient why and how the patient’s own perspective and values are important to discuss. In order to avoid anxiety for the patient and ensure that all patients are asked for their input and opinion before an advice is presented. Perspective Mapping can facilitate this communication.

Thinking aloud, P6 distinguished two consultation styles:

1. Giving a clear treatment recommendation and later checking how it fits the patient.
2. Offering a less prescriptive plan, leaving more

space for patient input.

They observed that the second approach requires patients to have strong oversight of their situation, which is rarely the case for those with LHL. Thus, they felt the first approach might be more practical for HCPs, provided it includes space for patients to express what matters most and adapt the plan accordingly.

This indicates that HCPs perceive SDM more difficult with patients with LHL, and there is more support for HCPs needed to apply SDM with these patients.

6. Usability for patients with LHL

While all participants recognized the concept’s use for more patient-centered care, they also stressed how such a tool can be overwhelming for patients in the consultation setting, especially for patients with LHL. Showing that all fiches can be addressed is too overwhelming, participants agreed that showing only a few basic questions and expanding with more questions and topics as the conversation evolves could mitigate the overwhelm of patients.

This highlights that for further tool development, usability of the tool should be a priority. It is recommended to focus on a step-by-step unfolding of the tool during consultations.

9.3.4 Ideas for alternative use and other suggestions

Elaborating on treatment logistics

P6 noted that the concept’s “treatment advice” section is not detailed enough for use in specialist consultations. However they noted that expanding it risks reducing clarity of the overview the tool provides.

Instead, they suggested developing a complementary tool—simple, visual, perhaps on paper or as a wall projection—to map treatment sequences and dependencies. They provided an elaborate and insightful example to stress the usefulness:

Example: Patient Struggling with Communication

P6 described a patient under their care who matched the tool’s target group: someone with difficulty keeping track of information, a limited social network, and poor English skills. They explained how communication with this patient often broke down: when treatment plans were explained, the patient nodded in agreement, appearing to understand, but later it became clear they had not.

The treatment plan involved two forms of chemotherapy: a daily pill and a 24-hour infusion administered weekly. The patient attended the infusions but failed to collect their pills, rendering the treatment less effective. P6 highlighted how difficult it was to communicate such plans without a visual overview that showed logistics (which days to be where), what needs to be taken or administered (pills, infusion, etc.), prerequisites (blood tests, consultations, eating/drinking requirements), and the duration of activities. They stressed the importance of a visual timeline with action points—and, crucially, pictorial cues.

Applying the concept post-GIOCA day

P4 contributed several ideas for alternative uses of the tool. They suggested applying it selectively as additional support for patients who remain uncertain after the GIOCA day, rather than trying to use it with everyone. This, they argued, would be more feasible and impactful. They explained that they often call patients the following day to ask how the patient is processing the information, whether they still have questions, and whether everything is clear. In such follow-up situations, the tool could be used as a supportive instrument.

P5 proposed creating a video to send to all patients after the GIOCA day. The tool could feature in the video as a summary of what had happened, along with some reflective questions and the option of scheduling an extra conversation for those who still feel uncertain. The tool could then be applied in that additional session to explore the patient’s situation in more depth.

Although these suggestions are valuable and supportive, they are all centered on providing support post GIOCA day, instead of supporting decision-making (patient’s understanding, communication, and reflection) during the day.

P4 and P5 argued that this is mostly because

patients who struggle are too overwhelmed during the day, and support becomes ineffective. However, I think it might be worthwhile to explore together with other HCPs how this day can become more patient-friendly.

Conclusion

The evaluations with HCPs show that the final concept is appreciated for its visual clarity and its potential to support patient engagement, but it is not yet appropriate for routine use in the consultation room. Its effectiveness is limited primarily by time constraints, doubts about uptake among other specialists, and the complexity of applying it consistently across consultations.

To enhance effectiveness, the design should be adapted to:

- Generate concise, patient-authored summaries that specialists can use as actionable entry points in conversations.
- Link patient and clinical perspectives more explicitly to support shared understanding
- Provide flexible modes of use, such as targeted application for patients who struggle most with information, or as a follow-up aid when uncertainty remains.
- Align better with clinical workflows by ensuring the tool is quick to interpret and easy to integrate alongside existing practices.

With these adaptations, the tool could become more appropriate for HCPs while retaining its patient-centered benefits.

CHAPTER 11

DISCUSSION

This chapter concludes the research and design chapters. It looks at the spillover effects of the concept and discusses the limitations of the project and recommendations for further research and development of the concept.

Chapter overview

- 11.1 Limitations
- 11.3 Recommendations
- 11.4 Conclusion

11.1 Limitations

11.1.1 Research limitations

Qualitative Research

Qualitative research fosters empathy for the target group, provides deep contextual insights, and serves as a valuable source of creative inspiration. However, its findings are inherently subject to interpretation by the researcher. This limitation applies across the case study, co-creation study, and evaluation conducted in this project.

Case Study

Small sample size

Although HCPs from all departments directly responsible for informing and supporting patients during the GIOCA day were included, not all professional roles involved in the day participated. In addition, the small sample size limited the representation of the full diversity of situations that may occur in practice.

Context-specific insights

The GIOCA model of rapid diagnostics and treatment advice is not representative of esophagogastric cancer care more broadly. Insights generated in this context must therefore be applied cautiously to other settings. While the concept was designed based on more generalizable insights, it remains closely tied to the GIOCA sequence of consultations. In other contexts, consultations are typically spread across multiple days, which allows patients more time for reflection but may also increase stress due to waiting, uncertainty, and repeated hospital visits. A major evaluation insight—that the consultation where treatment advice (and diagnosis, when applicable) is first explained negatively affects subsequent conversations—may be specific to GIOCA. However, it can also be argued that the experience of receiving potentially negative news itself, rather than the compressed structure, is the main driver of this effect. Further exploration of this question is needed.

Co-creation study

Selection bias

Including (former) patients proved unfeasible due to the cognitive, emotional, and physical demands of participation. As a result, the study disproportionately attracted participants who were more outspoken and able to engage, potentially excluding those whose perspectives may have been most valuable.

Context dependency

While the chosen methods (e.g., Contextmapping) generated rich insights, the findings are highly context-dependent. What participants expressed was shaped by their interactions with researchers, the way information and materials were presented, and group dynamics during the sessions.

Diversity and language limitations

Although recruitment strategies yielded some cultural diversity, the sample still failed to capture the full range of situations relevant to the target group. In one group, participants were closely acquainted, which may have encouraged conformity and reduced individual expression. Language barriers further constrained participation: while Dutch and English were accommodated, those with other mother tongues relied on peers for translation. This likely altered or diluted their contributions, a significant limitation given that many people with LHL do not speak Dutch or English well enough to participate fully.

Geographic concentration

All participants resided in Amsterdam, which narrows the applicability of insights and limits their transferability to other regions.

Data collection and facilitation challenges

Balancing facilitation and research roles during sessions proved difficult. Leading discussions, practicing active listening, and maintaining an empathic stance left less capacity for simultaneous note-taking or guiding participants in filling out templates. Although notes from multiple researchers were used, the thematic analysis relied heavily on detailed recollections, which may

have been shaped by researchers' perceptions.

Sensitivity of the subject

The sensitive nature of the topic also imposed constraints. Many participants had personal or close experiences with cancer, requiring a careful balance between eliciting valuable insights and avoiding the triggering of strong emotions or memories. Although this sensitivity allowed for deep participation with the storytelling narrative and exercises, this sensitivity made it challenging to maintain both empathic engagement and a sharp focus on the research objectives.

11.1.2 Solution limitations

Feasibility and Desirability

The limited timeframe of the project constrained the depth of validation. With more time, further insights could have been gained into both the feasibility and long-term impact of the intervention. Feasibility and desirability are closely intertwined: this project provided only an initial indication of how HCPs value such a communication tool. Although individuals with LHL were consulted more extensively, the desirability of the concept for esophagogastric cancer patients with LHL remains underexplored. Broader investigation of desirability among both patients and HCPs would strengthen understanding of feasibility in practice.

Collaboration across consultations

The concept is designed to support patients across all consultations during the GIOCA day. Stakeholders argued this is impractical within current workflows, yet consistent support may be essential to meaningfully improve decision-making and communication. Without such continuity, the intervention risks reduced impact and diminished patient trust.

Anchors for reflection

The current design prioritizes modularity within consultations but insufficiently supports patients' need to take materials home for reflection and discussion with relatives. While modularity enables

continuity in clinical conversations, it lacks richness for independent use outside the hospital. Future directions could include leveraging Machine Learning to generate personalized conversation summaries, though this remains speculative. Alternative approaches for enabling reflection in familiar environments should also be explored. Moreover, explicit prompts for questions, pauses, and reflection are not yet integrated, despite being crucial for patient-centered communication.

Machine learning as future potential

Although Machine Learning holds promise for streamlining workflows and supporting patient-centered care, its role in this concept is largely aspirational. The current application is underdeveloped, and other, more effective uses of ML may be possible. Further research is needed to identify feasible applications that genuinely enhance communication.

Broader context and multiple challenges

Patients with LHL often face challenges that extend beyond decision-making, limiting the overall impact of a single communication intervention. HCPs likewise contend with systemic and practical constraints that were not fully explored in this project but will influence the feasibility of implementation.

A small piece in a larger puzzle

The concept addresses problems experienced by both patients with LHL and HCPs but operates within a complex domain shaped by many interrelated factors. Its contribution should therefore be regarded as one piece of a much larger puzzle.

Remaining uncertainties

Uncertainty remains regarding the actual impact of the physical tool on patient-HCP communication. While evaluation sessions yielded preliminary insights, these were limited in scope. Section 11.3 outlines steps needed to build a more robust evidence base.

Limitations of the evaluation with HCPs

Evaluation sessions highlighted persistent concerns among HCPs, particularly the perception that “we have no time for such things.” While reflecting genuine constraints, this restricted opportunities to examine the potential value of the concept in depth. Balancing the presentation of research-based rationale with space for open feedback proved difficult, at times obscuring whether critical responses reflected disagreement with the idea itself or a lack of understanding of its purpose. The evaluation also involved a small number of participants, limiting diversity of perspectives and generalizability. A further limitation was the inability to present the concept within an MDO, due to time constraints. Such a setting could have provided valuable insights into how different disciplines perceive the tool, how it fits into shared workflows, and whether it could enhance cross-specialty communication.

Taken together, these limitations highlight the need for further evaluation with a larger and more diverse group of HCPs, including multidisciplinary contexts, to more fully assess the feasibility and potential impact of the concept.

11.3 Recommendations

Reducing uncertainty and stress

The co-creation study highlighted that individuals with LHL are hindered by uncertainty about the care and decision-making process itself. This uncertainty—about their role, what to expect, and how to act—was described as a major source of stress. Participants emphasized that stress negatively affects their ability to engage, regulate emotions, and even their health. Some reported avoiding information altogether out of fear of stress. To foster meaningful engagement and more positive patient experiences, future interventions must therefore explicitly address patients' need for reassurance and stress reduction before, during, and after healthcare encounters.

Toward a Person-Centered approach

Participants expressed a strong preference for more person-centered consultations. Suggested improvements included:

- Explicitly allocating space for questions.
- Allowing pauses for information processing and reflection.
- Translating medical information into plain language and concrete, practical examples relevant to daily life.

Effective communication was shown to depend heavily on the patient's worldview—including personal, cultural, and religious values, as well as prior experiences. Instead of treating worldview as a barrier, future intervention design should leverage it as a facilitator, helping patients feel seen, heard, and understood. This may increase confidence, lower stress, and ultimately strengthen their capacity to engage in decision-making.

Usability for patients with LHL

Any further tool development must actively involve individuals with LHL. Existing guidelines on communication design provide useful foundations, but success depends not only on understandability. The intervention should also support communication and reflection, and these elements must be co-designed with the target group to ensure usability and relevance. In addition, the effective use of visual cues, images, and comprehension of the tool should be explored.

Usability for HCPs

A recurrent theme in discussions with HCPs is that interventions must integrate into existing workflows. Yet, as this thesis showed, current workflows leave little space for additional tools. Small adjustments to workflow may therefore be necessary to make implementation feasible. Evaluation sessions revealed that presenting ambitious and even unconventional ideas helped spark reflection and suggestions for improvement. This indicates that co-creation with HCPs can both align interventions with practical realities and stimulate rethinking of workflows themselves. Future research should explore where patient-centered interventions can best fit, and where workflows may be streamlined to accommodate them.

Supporting HCPs in Recognizing Patient Needs

The tool should not only support patients but also assist HCPs in recognizing patients' varying information needs. Misunderstandings are common: patients often appear to understand during consultations but reveal confusion afterward. More consistent support is therefore needed to help HCPs identify when additional guidance is required. An intervention could provide tiered support, enabling HCPs to determine when brief assistance is sufficient and when more extensive sessions, such as comprehensive Perspective Mapping, are appropriate. This tiered model warrants further development and evaluation.

Research on integrating preferences

Further study should explore how patients' preferences can be integrated into care planning and MDOs. The International Classification of Functioning, Disability and Health (ICF) model offers a useful framework for linking disease burden, treatment burden, and patient values. Involving HCPs with direct clinical experience in this research will help ensure practical relevance.

The first consultation as a bottleneck

A critical bottleneck arises in the first consultation where treatment advice (and diagnosis, when applicable) is delivered. HCPs reported that many patients become too overwhelmed at this stage to ask questions, process details, or participate in decision-making in subsequent consultations. While follow-up support is often suggested by HCPs, this approach treats the consequences rather than the root problem. Literature underscores the pivotal influence of the first treatment conversation on decision-making. In oncology—an emotionally charged and high-stakes context—the needs of patients who struggle cannot be deferred. Improving the first consultation could enhance patient experience and engagement in later conversations. This does not mean interventions should focus only on that moment; rather, they should streamline communication across the entire decision-making trajectory. For implementation to succeed, the process must be addressed as a whole, rather than as isolated encounters. This critique is directed not at HCPs, who demonstrate commitment and dedication, but at the systemic structures that constrain them. Healthcare should be designed to meet the needs of all patients, not only those already advantaged. A more patient-centered and efficient process could ultimately benefit patients, HCPs, and the wider healthcare system alike.

11.3.1 Recommended next steps

Co-Creation with HCPs

Future development should actively involve HCPs through structured co-creation. Building on evaluation insights, sessions could use methods such as Creative Problem Solving (Heijne & van der Meer, 2016) to:

1. Refine the Perspective Mapping concept itself, or
2. Use it as a springboard for generating new patient-centered solutions.

Engaging HCPs directly may mitigate the "Not Invented Here" syndrome and increase ownership of the intervention. Representation from all relevant disciplines is essential to ensure the solution supports the full decision-making process.

Exploring the Role of Machine Learning

While resource-intensive, Machine Learning could help streamline workflows and personalize patient care by generating summaries or highlighting key needs and values. Such applications could reduce cognitive load for HCPs while enhancing alignment between patient experiences and clinical decision-making. The feasibility and added value of ML should be tested alongside simpler, low-tech solutions.

Final Evaluation: Patient-HCP Interaction

Once refined, the tool should be evaluated in real consultation settings to assess its effect on communication and decision-making. To minimize emotional strain, initial testing could focus on patients further along in their treatment who are more emotionally stable. Evaluation in high-stakes decision moments should follow only after the tool has proven effective and safe in less sensitive contexts.

11.4 Conclusion

The goal of this graduation project was to explore how esophagogastric cancer patients with Limited Health Literacy (LHL) can be better supported in healthcare decision-making.

Research outcomes

A combination of research activities—including a case study using observations and patient journey mapping, interviews with experts and healthcare professionals (HCPs), co-creation sessions with individuals with LHL, and a literature review—provided valuable insights into treatment decision-making, highlighting both the needs for and the barriers to effective Shared Decision Making (SDM)

In-depth exploration of the needs of individuals with LHL around understanding information, communication with HCPs, and reflection on the decision-making process generated a deeper understanding of this target group for Amsterdam UMC.

Using Contextmapping, themes were distilled. Frame Innovation was applied to synthesize research findings into paradoxes that reveal systemic challenges. These paradoxes helped identify potential design solution spaces and highlight areas where interventions could have the greatest impact. The resulting insights provide a foundation for further research and development in this domain.

Design outcome

The project resulted in a concept intervention aimed at improving communication between patients with LHL and HCPs during consultations about treatment and care. The modular physical toolkit enables HCPs to:

- Explain the decision-making process clearly, reducing patient uncertainty.
- Emphasize the equal importance of patient perspectives alongside medical expertise.
- Actively elicit and connect patient values and preferences to clinical facts.
- Determine and address misconceptions the patient has, before a treatment advice is given, to mitigate confusion and enhance understanding.
- Facilitate iterative discussion, adaptation, and reflection throughout the care trajectory.

In addition, a Machine Learning component generates summaries that help integrate patient perspectives into multidisciplinary team meetings, ensuring that treatment recommendations are explicitly informed by patient values. The system can also link to a library of tools, strategies, and resources, providing HCPs with tailored guidance on patient-centered tools, communication approaches, and materials that can be shared to address individual patients' information needs.

The toolkit empowers patients inside the consultation room to articulate their preferences and meaningfully participate in decision-making, while simultaneously supporting HCPs in tailoring their communication. In addition its iterative modular nature that allows for reflection, stimulates the patient to develop skills that are transferable throughout their care trajectory.

This outcome successfully addresses the initial design goal:

“Support patients with LHL in articulating their values, preferences and information needs, while enabling healthcare professionals to actively elicit these insights and tailor their way of informing and supporting accordingly.”

Evaluation and iteration

The concept was positively received by both HCPs and experts, who highlighted its novelty and potential to enhance patient-centered care. Feedback gathered during validation informed refinements and led to broader recommendations for future intervention development.

Contribution and future potential

This project delivers:

1. An in-depth case study of treatment decision-making for esophagogastric cancer, integrating the perspectives of experts, HCPs, patients, and individuals with LHL.
2. An elaborate description of obstacles to overcome and potential ways to overcome them.
3. A practical design concept that addresses key barriers to patient engagement and aims to improve communication during consultations.

In conclusion, the project successfully contributes to its goal of supporting Amsterdam UMC in enhancing patient-centered care in the context of esophagogastric cancer. The research outcomes serve to expand the organization's understanding of both individuals with LHL and the HCPs who support them in treatment and care decision-making. The design outcome offers a practical, actionable concept solution. The feasibility of the concept depends heavily on its seamless integration into existing HCP workflows, an area that warrants further exploration. The recommendations outlined in this project provide valuable directions for future work, aiming to inspire continued improvements in patient-centered care through human-centered design.

Personal reflection

During this project, I immersed myself in the world of patient-centered and esophagogastric cancer care. Here, I reflect on the main challenges I faced and the lessons I learned throughout the process.

Developing a co-creation study plan

At the start, one of the biggest obstacles was developing a co-creation study plan. I had never facilitated creative sessions before and had limited knowledge of the target group of individuals with LHL. Estimating their willingness and ability to engage in creative exercises was challenging. Simultaneously, recruiting participants proved difficult. During multiple visits to the GIOCA outpatient clinic, it became clear that including (former) esophagogastric cancer patients in the study was unfeasible.

Fortunately, a creative facilitation expert offered guidance, which helped reduce my stress and allowed me to continue developing ideas, even before co-creation officially began. With support from my company supervisor and connections within the RISC team, we were eventually able to recruit participants successfully.

Designing and facilitating sessions

Designing and facilitating the sessions was an incredibly valuable learning experience. Balancing empathy and respect with active facilitation, keeping track of study objectives, and simultaneously documenting sessions proved highly challenging. While my good memory helped, I often felt exhausted after the sessions. Over time, I realized that documentation—especially of analysis steps—is a personal bottleneck that I need to address in future projects.

Completing the project

The final, and perhaps biggest, challenge was finishing the project. Accepting that there is always more to do and that improvements are endless was difficult. Reaching a conclusion required acknowledging that perfection is unattainable within the project's timeframe.

Engaging with Stakeholders

This project made me realize that, although exhausting at times, I gain immense energy from working with and for diverse stakeholders in meaningful and complex context. I sometimes missed opportunities to incorporate humor, and keeping the process enjoyable was challenging, particularly during outpatient clinic visits. At times, I felt like a burden when trying to recruit participants. Especially during the more creative phases it felt weird to come in with my project and show it to those who have so much experience in such a serious context. However, witnessing the passion of healthcare professionals and building their trust was immensely rewarding, as they became willing and enthusiastic contributors to the project. I enjoyed sharing my design approach, and was very grateful for their enthusiasm and interest in it.

Trusting the Creative Process

Throughout the project, I occasionally lost confidence in myself. The complexity and seriousness of the challenge sometimes made my contributions feel insignificant. Generating creative ideas was particularly difficult, as I feared my “weird” or “stupid” ideas might appear disrespectful to stakeholders. Over time, I learned that even seemingly trivial ideas can lead to new opportunities and encourage others to share their own unconventional but valuable perspectives.

Building Resilience

Despite moments of self-doubt, I learned to trust the process and my abilities as a designer. Taking intentional breaks, having honest conversations with friends or supervisors, walking in nature, and allowing myself space for reflection were crucial practices. These strategies strengthened my resilience, helping me continue the project with renewed energy and enthusiasm.

Accepting Complexity and Limitations

This project also reinforced that the complexities of patient-centered esophagogastric cancer care cannot be fully resolved within six months. I learned to accept the inherent limitations of the project while still striving to make meaningful contributions.

Empathy and Reflection on Patient Experience

Finally, this project deepened my appreciation for the frustrations people face when they cannot express themselves effectively. It highlighted the importance of designing tools and processes that support patient expression and agency, particularly in high-stakes healthcare contexts.



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APPENDIX



Appendix A: Design Brief



IDE Master Graduation Project

Project team, procedural checks and Personal Project Brief



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

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

STUDENT DATA & MASTER PROGRAMME

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

Family name	Kuipers	IDE master(s) IPD	<input type="checkbox"/>	Dfi	<input checked="" type="checkbox"/>	SPD	<input type="checkbox"/>
Initials	S.J.	2 nd non-IDE master					
Given name	Sophie	Individual programme (date of approval)					
Student number	4682025	Medisign	<input type="checkbox"/>				
		HPM	<input type="checkbox"/>				

SUPERVISORY TEAM

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

Chair	Marijke Melles	dept./section	HCD - Human Factors	<p>! Ensure a heterogeneous team. In case you wish to include team members from the same section, explain why.</p> <p>! Chair should request the IDE Board of Examiners for approval when a non-IDE mentor is proposed. Include CV and motivation letter.</p> <p>! 2nd mentor only applies when a client is involved.</p>
mentor	Susie Brand de Groot	dept./section	HCD - Form and Experience	
2 nd mentor	Merel van Eick			
client:	Amsterdam UMC			
city:	Amsterdam	country:	The Netherlands	
optional comments				

CHECK ON STUDY PROGRESS

To be filled in by SSC E&SA (Shared Service Centre, Education & Student Affairs), after approval of the project brief by the chair. The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total	<input type="text"/>	EC	★	YES	all 1 st year master courses passed
Of which, taking conditional requirements into account, can be part of the exam programme	<input type="text"/>	EC	<input type="checkbox"/>	NO	missing 1 st year courses
Comments:					

Sign for approval (SSC E&SA)

Name	<input type="text"/>	Date	<input type="text"/>	Signature	<input type="text"/>
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APPROVAL OF BOARD OF EXAMINERS IDE on SUPERVISORY TEAM -> to be checked and filled in by IDE's Board of Examiners

Does the composition of the Supervisory Team comply with regulations?

YES	★	Supervisory Team approved
NO	<input type="checkbox"/>	Supervisory Team not approved

Comments:

Based on study progress, students is ...

★	ALLOWED to start the graduation project
<input type="checkbox"/>	NOT allowed to start the graduation project

Comments:

Sign for approval (BoEx)

Name	<input type="text"/>	Date	<input type="text"/>	Signature	<input type="text"/>
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Name student Sophie Kuipers

Student number 4,682,025

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT

Complete all fields, keep information clear, specific and concise

Project title Improving communication between patients with limited health literacy and healthcare professionals to enable informed decision making

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

Introduction

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

People with limited health literacy (LHL) often struggle to discuss treatment options with healthcare professionals (HCPs) and tend to regret their decisions more than patients with a higher health literacy. Combined with the growing pressure on the Dutch healthcare system, this highlights the need for innovative solutions. In collaboration with Amsterdam UMC, this project aims to improve communication between patients and HCPs, specifically within the Gastrointestinal Oncology Centre Amsterdam (GIOCA). Oncology treatment is complex, with multiple options, varying side effects, and often comorbidities. Partnering with patients is crucial for ensuring engagement and satisfaction. Patient engagement involves active participation in healthcare decisions, leading to better outcomes and efficiency. A key approach is Shared Decision Making (SDM), where HCPs and patients collaboratively choose the best treatment based on medical evidence and patient preferences. This project will explore ways to integrate SDM effectively. A holistic approach will be taken, rather than viewing decision moments as isolated events. Successful implementation requires considering HCPs workflows and designing solutions that truly support patients with LHL. Co-creation sessions with patients will increase the chances their needs are addressed and increases the chances of novel solutions. The developed concepts will be prototyped and then tested with HCPs. Complications are that, in spite of their motivation, both HCPs and patients have limited time and mental capacity to contribute to the project. Nevertheless, efforts will be made to effectively integrate their perspectives. Other stakeholders are patients' next of kin and KWF Kankerfonds. Familiarity with the project context was developed through a 10-week internship at Amsterdam UMC, where a Patient Journey Map was created for esophageal and gastric cancer patients at the GIOCA policlinic. Additionally, literature research was conducted as part of the Graduation Launchpad course.

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Problem Definition

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

Research has shown that oncology patients with LHL are not sufficiently supported to make informed decisions. As a result, these patients may experience decisional regret. Addressing this issue requires empowering oncology patients to articulate their values and discuss treatment options effectively, particularly with HCPs. Communication between oncology patients with a limited health literacy and their HCPs contains many challenges, amongst others: Oncology patients with limited health literacy often struggle to express their values, insecurities and doubts, which can lead to stress, uncertainty, and communication barriers; HCPs struggle to recognize LHL and as a result are not able to provide proper support; HCPs sometimes exhibit steering behavior when discussing treatment options which can result in absence of dialogue about patients' preferences and values; Many HCPs do not have a structured approach that aligns with their communication style and where they feel comfortable with to ensure patients fully understand the discussed information. A well-implemented SDM process benefits both patients and HCPs. Improved patient confidence can lead to greater satisfaction, fewer repeat consultations, and, in the long term, better treatment adherence. By fostering open dialogue and providing tailored support, oncology patients with LHL can make treatment decisions that align with their personal values, ultimately enhancing their overall care experience.

Assignment

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

Create a tool to support oncology patients with LHL in expressing their needs, values and preferences with HCPs to navigate the decision-making process in a confident and effective way.

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

This project aims to enhance patient confidence, enabling them to express their preferences and overcome barriers to SDM. Rather than addressing SDM in isolated moments, the goal is to develop a comprehensive approach that integrates SDM throughout the entire decision-making process. Additionally, supporting patients in contributing to conversations with HCPs enables open dialogue and space for SDM. Ensuring the design integrates smoothly into HCP workflows is essential for successful implementation. The project will start with preparations for co-creation sessions with (ex)oncology patients with LHL, aiming to identify effective and novel solutions that truly fit the patient's needs. By developing and testing multiple prototypes with the target group and HCPs, their involvement in the concept's development is ensured. The process is structured into five phases, as can be seen in the Project Planning. For the initial phases, methods from Road Map for Creative Problem-Solving Techniques(ICPS) and Convivial Toolbox will be applied. Additionally, methodologies from Service Design and Systemic Design will guide the process, incorporating principles such as Design for Mental Models and Design for Resilience. Culture Sensitive Design will also be considered.

Project planning and key moments

To make visible how you plan to spend your time, you must make a planning for the full project. You are advised to use a Gantt chart format to show the different phases of your project, deliverables you have in mind, meetings and in-between deadlines. Keep in mind that all activities should fit within the given run time of 100 working days. Your planning should include a **kick-off meeting, mid-term evaluation meeting, green light meeting and graduation ceremony**. Please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any (for instance because of holidays or parallel course activities).

Make sure to attach the full plan to this project brief.
The four key moment dates must be filled in below

Kick off meeting	3 Mar 2025
Mid-term evaluation	17 Apr 2025
Green light meeting	9 Jul 2025
Graduation ceremony	6 Aug 2025

In exceptional cases (part of) the Graduation Project may need to be scheduled part-time. Indicate here if such applies to your project

Part of project scheduled part-time	<input checked="" type="checkbox"/>
For how many project weeks	26
Number of project days per week	4,0

Comments:
I plan to work 4 days a week on my graduation project, the remaining 8 hrs I will spend on a job. The study counsellors are notified.

Motivation and personal ambitions

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

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

Project Planning:
<https://docs.google.com/spreadsheets/d/1CBleaA3VaEm9XXSoJ3RcLaywA0ZRoHsmdeIxB0rwak/edit?usp=sharing>
 Having completed my courses, I feel ready to tackle a final project that serves as the "cherry on top" of my master's degree. My internship further motivated me to make a positive contribution within the described context. I aim to graduate Cum Laude while developing my leadership skills and taking responsibility for my project.
 A key challenge for me is keeping stakeholders informed, and I want to improve in this area which I think can help manage my fear of failure and perfectionism. Additionally, I seek to handle feedback better, focusing on both strengths and areas for improvement to avoid feeling overwhelmed.
 In my project, I will integrate methodologies from Participatory Design, Service Design, and Systemic Design, structuring my process using the Double Diamond framework and Road Map for Creative Problem-Solving techniques (see project planning link). My goals include: Keeping stakeholders informed through visualizations and applying insights from the Advanced Visualization for Communication elective; Creating an agile planning that allows room to fail and try again; Designing, prototyping, and testing a physical product, when possible together with stakeholders (Participatory Design); Ensuring an integrated design that supports a service (Service Design); Taking a holistic approach, incorporating Future Vision, Unintended Consequences, and Radical New Narratives (Systemic Design). This approach will help me refine my skills while contributing meaningfully to my field.

