A thesis report by Olga Bogaerts

# Wat ik zeggen wil

A design to facilitate meaningful communication about end-of-life topics for palliative head and neck cancer patients with their loved ones by mitigating **physical** and **psychosocial** barriers

TU Delft

Erasmus MC

# Master thesis

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*A design to facilitate meaningful communication about end-of-life topics for palliative head and neck cancer patients with their loved ones by mitigating physical and psychosocial barriers*

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# Abstract

This thesis explores how the well-being of palliative head and neck cancer (HNC) patients can be supported within the remote care system at Erasmus MC. The first phase involved in-depth desk and field research through literature reviews, patient interviews, and interviews with experts to identify which fundamental needs, based on the 13 Fundamental Psychological Needs (13 FPN) typology, are currently unfulfilled and considered critical to see fulfilled for this population in this phase of their life. The research identified that Autonomy, Relatedness, and Comfort are the most critical needs to address. Based on these insights and a patient journey map, design opportunities within the Erasmus MC Remote Care system were identified.

Through interviews with VPKC's and showing them an explorative design that was focused on a potential 'practical gap' patients can experience, it became clear there was a much more valuable design opportunity for a specific group of palliative HNC patients: patients who face communication barriers because of severe speech difficulties. A design vision, design goal and interaction vision were developed, along with scenarios illustrating how these speech difficulties negatively impact patient wellbeing.

An explorative concept was discussed with Erasmus MC. The focus group appeared to be very niche and the objective of Erasmus MC was to target more of their patients. Therefore, the target group was expanded to include a wider range of physical barriers characteristic of (palliative) HNC, and the design goal was refined accordingly. The focus shifted from 'restoring a voice' toward managing the social dynamics of conversation, ensuring that patients can remain active participants and maintain agency during interactions.

It became evident that Erasmus MC was primarily interested in the psychosocial dimensions of communication barriers, specifically the challenge of initiating discussions about end-of-life topics with loved ones. Following feedback sessions on three concepts, a concept was chosen that addresses both physical and psychosocial barriers within communication. Strong elements of the other concepts were combined into the final concept. The core elements and a potential user scenario of this refined concept were presented to four different experts for feedback. These results created the base for a new design iteration.

The resulting design, '*Wat ik zeggen wil*', was developed. This design aims to facilitate meaningful communication regarding end-of-life topics between palliative HNC patients and their loved ones by mitigating both physical and psychosocial barriers. It consists of theme cards that serve as conversation starters and various 'agency' components designed to help patients remain active participants in a conversation by maintaining agency in an energy-efficient manner.

The design was evaluated through proxy user tests and feedback sessions with experts from Erasmus MC to start a new design iteration to formulate proposed refinements and recommendations for further development. While the product must still be tested with the actual user group, this thesis provides a foundation for supporting palliative HNC patient wellbeing by supporting better communication.

# Contents

# 1. Introduction of the project

This introduction explains the project context, gives an introduction on HNC and discusses the aim of the project with its research questions and the project approach.

## 1.1 Project Context

Erasmus MC approached the Faculty of Industrial Design at TU Delft to initiate a collaboration aimed at designing interventions that support the wellbeing of their patients with Head and Neck Cancer (HNC) receiving remote palliative care. Although patients are generally satisfied with most aspects of this remote palliative care the hospital offers, they have highlighted a specific need for better psychological and psychosocial support (van den Besselaar et al., 2023). However, how patients would like to receive this emotional support remains unclear. Erasmus MC is particularly interested in the 13 Fundamental Psychological Needs (Desmet & Fokkenga, 2020) to see how this typology could contribute to supporting the wellbeing of their patients. The goal is to provide proactive and compassionate care addressing the psychological and psychosocial needs of palliative HNC patients throughout their palliative phase, enabling them to stay with an optimal wellbeing in their trusted home environment.

It is important to note that **information and insights drawn from sources in this report do not have a direct relation to Erasmus MC unless explicitly stated** (for example, when literature focuses on Erasmus MC or its patients). When knowledge is obtained from Erasmus MC and is specific to its context, this will be explicitly mentioned.

## 1.2 Introduction to HNC

HNC is the fifth most common cancer, with an estimated 500,000 new cases per year (Mayland et al., 2021). HNC includes all cancer kinds in the face, the brain excluded: laryngeal, pharyngeal, nasal, salivary gland, oral, tongue and lip cancer. Most patients will be diagnosed with mouth, throat, or voice box cancer. Predominant risk factors include tobacco use, alcohol abuse, and viruses like HPV. On average, cancer is most common in people over the age of 60, where it is more than twice as common among men as it is among women (Head And Neck Cancers, 2021c).

Treating this cancer is not easy, since it is very unpredictable; much more than many other cancers (Mayland et al., 2021). Although treatments for the disease can be effective, the cancer often recurs and the treatments can have adverse effects, causing numerous negative physical and psychological symptoms. These cause patients to often go through a long, uncertain and difficult journey, impacting their overall wellbeing in a negative way (Goldstein et al., 2008).

When a patient is no longer curable or they decide for themselves that they no longer want to be treated medically, they become palliative and go from curative care to palliative care (Palliative Care Researcher, personal communication, September 25, 2025).

Palliative care focuses on supporting the wellbeing of patients (and next of kin), by ensuring the final stage of life is as comfortable as possible (Van den Besselaar et al., 2025). Palliative care for HNC patients is increasingly recognized as a multidimensional discipline addressing not only physical symptoms but also psychological, psychosocial and psychospiritual needs (Mota et al., 2022). However, unfortunately, the psychological, social and spiritual effects of the illness and treatment are often ignored (Kassianos et al., 2018). This is partly because giving the right palliative care with focus on patients needs can be quite a challenge. Reasons for this include (Mayland et al., 2021):

- There is a lack of knowledge about palliative care among oncologists
- There are limited resources within palliative care
- There are societal misconceptions (such as the idea that palliative care is only for the final stage of life)
- There is a lack of research funding
- Speech problems make it hard for patients to express needs, limiting their ability to communicate well and make decisions.

Approximately 41% of HNC patients will not survive beyond five years and enter the palliative phase (Pattani & Nathan, 2013). As the psychological needs of patients and related social factors often get neglected in this phase and results in a negative effect on the wellbeing of patients, it is important to give greater attention to the psychological and psychosocial needs of patients in palliative care, as these are crucial for enhancing their overall wellbeing (Mota et al., 2022).

## 1.3 Aim and contribution of the project

This project aims to design an intervention that supports subjective wellbeing through the fulfillment of psychological needs of palliative HNC patients at Erasmus MC. To do so, the project first seeks to understand which fundamental needs remain unmet and why, as these unmet needs negatively affect patients' wellbeing. Several frameworks exist to identify psychological needs in healthcare, offering rich and nuanced perspectives. The 13 Fundamental Psychological Needs typology builds on this body of work by providing a clear and actionable structure that is well suited to guiding design decisions. As it has not yet been applied within palliative HNC care, this project uses the 13 FPN typology to systematically identify patients' unmet needs and translate these insights into a design intervention to support their wellbeing.

## 1.4 Project Approach

This project employs the Double Diamond design framework, to give structure to the iterative design process (see Figure 1).

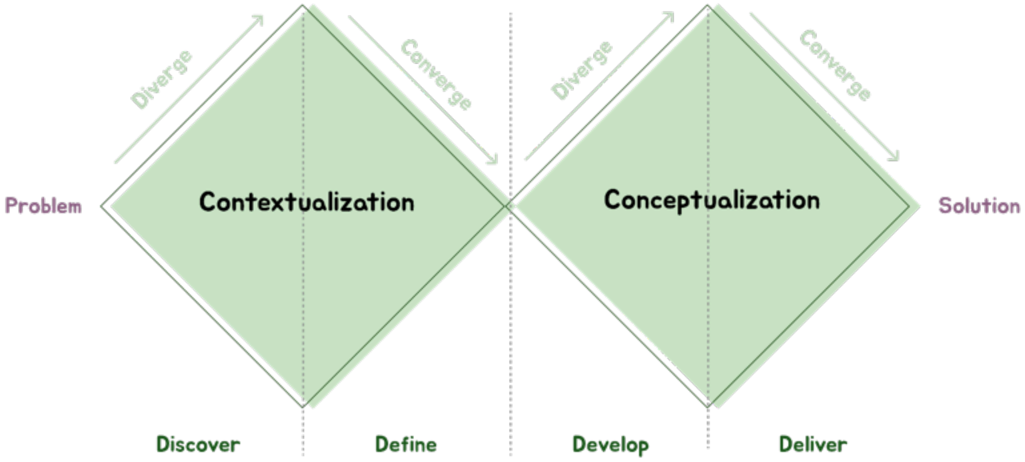

*Figure 1: Double Diamond framework*

**Contextualisation**

This phase consists of *Discover & Define*, where the context is explored based on research questions and the focus and goals of the project are defined, which will serve as the guiding principle for the design process in the second phase. In this first phase, different methods are used:

- **Desk Research**: literature review, reading websites and blogs, watching videos and documentaries.

- **Field Research**: doing interviews with people working at Erasmus MC of the HNC department (Palliative Care Researchers, VPKC's, ENT-resident), palliative patients with HNC, a patient representative and a Practice Nurse.

**Conceptualisation**

This phase consists of *Develop & Deliver*, where the insights from the previous phase are translated into ideas and design concepts.

In this phase, different methods are used:

- **Ideation sessions**: generating ideas based on insights from the contextual phase through brainwriting; braindrawing, conversations, etc.

- **Feedback sessions**: on first concept, with four experts and with three experts working at Erasmus MC on the refined design.
- **Prototyping**: creating a low fidelity prototype to test design directions, creating a high fidelity prototype to test the interaction to gain feedback.
- **Testing**: Testing the interaction of the tool with people to improve the design.

**The main approach** of the project was ‘User-Centred Design’ (Van Boeijen et al., 2013), as I was focusing on the perspective of palliative HNC patients and their needs and desires. During the project, Research through Design was also used as an approach. Some explorative concepts were made during the research phase to gain feedback from experts.

To understand and identify the unfulfilled fundamental psychological needs of palliative HNC patients and later in the project to use as an inspiration source for the final design, the 13 FPN typology is used. By doing all my desk and field research in the first phase of the project by looking at it through a ‘13 FPN lens’, it was possible to identify unfulfilled fundamental needs of palliative HNC patients.

## 1.5 Structure of the report

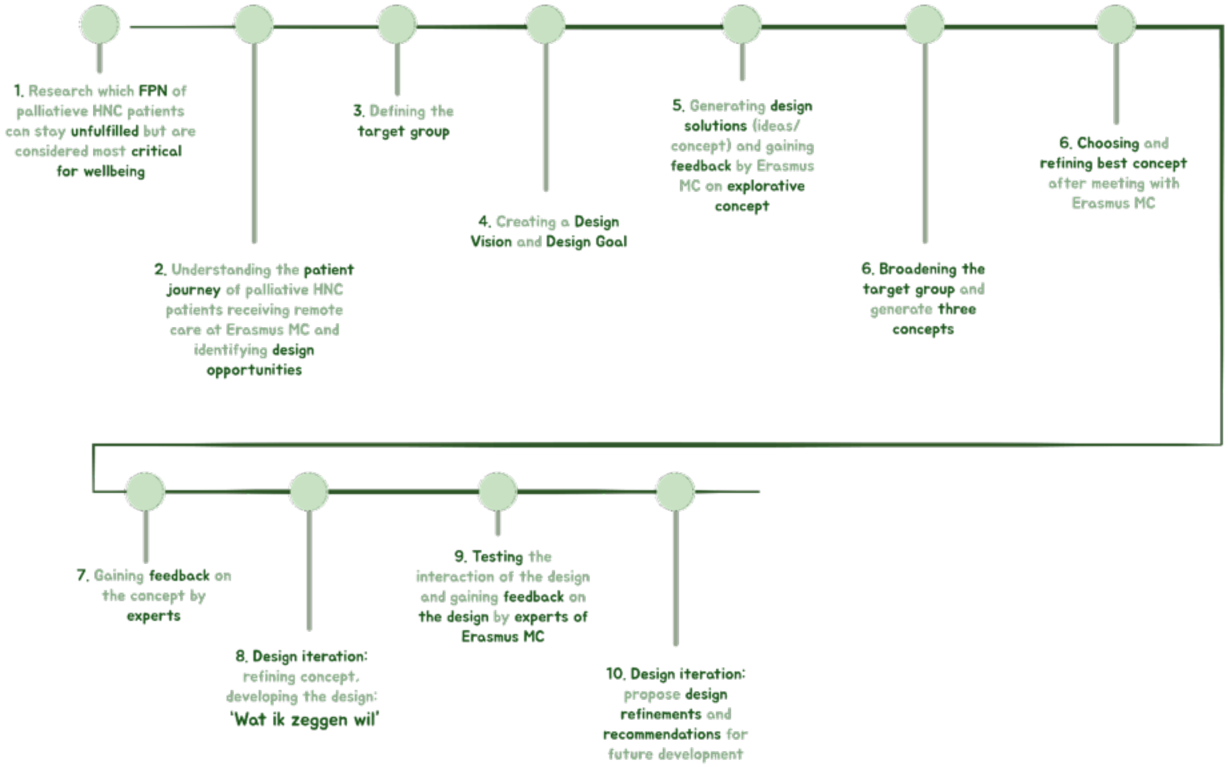

*Figure 2: Structure of the report*

# 2. Understanding the context

To understand the context and answer my research questions, both desk research and field research were conducted. In this chapter, I address my main research questions and the corresponding sub-questions.

**RQ 1**: Which fundamental psychological needs become most critical to be fulfilled for palliative HNC patients in order to support their wellbeing?

- **SQ 1.1**: How can the most common physical and psychological challenges of palliative HNC be linked to unfulfilled needs according to the *13 Fundamental Psychological Needs*?
- **SQ 1.2**: To what extent does a prioritization of fulfillment of fundamental psychological needs occur in the palliative phase, and what factors drive this change?

**RQ 2**: How is the remote palliative care system organized at Erasmus MC, and where are opportunities to better support patients' psychological needs?

- **SQ 2.1**: What does the current remote palliative care infrastructure look like, and which stakeholders are involved in the patient journey?
- **SQ 2.2**: How are patients' psychological needs currently addressed within the remote care context?
- **SQ 2.3**: What are opportunities where design interventions could provide additional support for the psychological wellbeing of patients?

## Desk research

The desk research involved reading literature combined with the analysis of websites of patient communities and audiovisual materials, such as documentaries and videos. These different sources helped to create a good picture of the challenges faced by palliative HNC patients.

## Field research

Several semi-structured interviews were conducted. The following stakeholders participated in the research:

## 1. Healthcare Professionals

- **Erasmus MC Staff**:
    - A Palliative Care Researcher and an ENT-resident from the *Value-Based Health Care* team within the department of *Otorhinolaryngology and Head & Neck Surgery* at Erasmus MC were interviewed. These interviews were based on a semi-structured format.
    - A semi-structured interview combined with a small co-creation session with two nurses (VPKCs).

  ***The goal** of both interviews was to answer both **RQ1** and **RQ2** with their **subquestions**.*

- **Practice Nurse**: A semi-structured interview was conducted with a Practice Nurse specialized in palliative care. A Practice Nurse plays a key role in primary care by monitoring patients at home and providing continuous psychological and physical support.

  ***The goal** of this interview was to answer **RQ1** and its **subquestions**.*

## 2. Patients

Three palliative HNC patients were interviewed to gain insight into their lived experience, primarily to address RQ1 and its sub-questions regarding (unfulfilled) needs.

The data collection for these semi-structured interviews followed two approaches:

- **Collaborative interviews**: Two interviews with palliative HNC patients (of Erasmus MC) were part of an existing research project at Erasmus MC. Because of the significant overlap with my research focus, I was invited to participate. I attended one interview as an observer and conducted the second one myself, following the project's established protocol. While the focus was on their personal lived experience, several responses provided valuable insights into the palliative care services provided by Erasmus MC.

  *Note: During these interviews, patients were asked to select their 3–5 'most important' needs (in general). Within the context of my project, the focus should ideally not be on 'general importance', but on which needs are* ***most critical to see fulfilled (but remain unfulfilled) in the patient's current phase of their life and why****. Therefore, my focus in these interviews was on their qualitative explanations ('why'), to understand the underlying reasons why patients prioritized certain needs in this phase of their life and the consequences when these remained unfulfilled. This approach allowed me to identify the specific tensions in their daily lives, which in turn highlight the most significant opportunities for design.*

- **Independent interview**: The third interview was conducted independently with one palliative HNC patient. While the participant primarily shared her personal lived experience, her role as an active member of a patient association allowed her to also provide a broader perspective on behalf of the wider palliative HNC patient community. This session was specifically designed for my project, allowing for more targeted questions.

## 2.1 Unfulfilled Fundamental Psychological Needs Of Palliative HNC Patients

**The primary goal** of this project is to **support the wellbeing of palliative HNC patients**. Research suggests that for this specific group, the fulfillment of fundamental human needs is critical to maintaining quality of life (Mota et al., 2022). This aligns with the 13 Fundamental Psychological Needs typology, which states that psychological wellbeing is directly dependent on the satisfaction of fundamental needs:

> *“Needs are the basic requirements for our functioning and the nutrients for our well-being and advancement. We can only fully develop and flourish if all our basic needs are satisfied (at least to some degree).”*
> (Desmet & Fokkinga, 2020 P4)

In other words, supporting a patient's wellbeing requires a focus on fulfilling their (unmet) fundamental psychological needs.

The 13 FPN consists of thirteen fundamental psychological needs that are universal to all human beings. Figure 3 outlines these needs and their definitions. For further detail on each fundamental need and its corresponding sub-needs, see Desmet & Fokkenga (2020).

*Figure 3: The 13 Fundamental Psychological Needs*

While all thirteen FPN are inherently essential to every human being's wellbeing, a **prioritization** of the fulfillment of specific needs can emerge once a patient enters the palliative phase. This prioritization occurs either because a need's source of fulfillment is lost, or because the situation increases the significance of a need, even if its source remains available.

Palliative HNC patients face a range of **psychological challenges**, arising from both the physical impairments of the disease and the transition into the palliative phase (Medina & Isaac, 2025). The physical constraints inherent to HNC often lead to the loss of daily activities, routines, and social roles that previously served as primary sources of need fulfillment. When these sources of fulfillment disappear due to the illness and its progression, certain needs become unfulfilled. Simultaneously, entering the palliative phase introduces existential challenges, such as anxiety regarding mortality and disease progression. All these psychological challenges can cause fundamental needs to go unmet.

This chapter identifies the most common psychological challenges of HNC, derived from both desk and field research, and translates them into the 13 FPN. Categorizing these challenges under the 13 FPN typology reveals which prioritized needs are most frequently left unfulfilled and in what specific ways. This provides the necessary foundation to develop targeted design solutions that facilitate need fulfillment and thereby support patients' wellbeing. This chapter addresses the following research question and its sub-questions:

**RQ 1**: Which fundamental psychological needs become most critical to be fulfilled for palliative HNC patients in order to support their wellbeing?

- **SQ 1.1**: How can the most common physical and psychological challenges of palliative HNC be linked to unfulfilled needs according to the *13 Fundamental Psychological Needs*?

- **SQ 1.2**: To what extent does a prioritization of fulfillment of fundamental psychological needs occur in the palliative phase, and what factors drive this change?

### 2.1.1 Translating The Most Common Psychological Challenges of Palliative HNC Patients Into Unfulfilled Fundamental Needs

The most frequently identified psychological challenges from desk and field research were categorized based on the 13 FPN typology. This systematic categorization facilitates a clearer understanding of the unmet needs in the palliative HNC context, which enables the development of effective design solutions that aim to support these needs.

Within the specific context of (palliative) HNC, eight of the 13 FPN were identified as being most frequently affected in a negative way. The persistent unfulfillment of these eight specific FPNs acts as a primary driver for psychological distress, directly leading to decreased patient wellbeing.

The list is a synthesis of multiple sources: literature, expert interviews (with a Palliative Care Researcher, an ENT-resident and a practice Nurse) and patient interviews.

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#### **Autonomy**

Autonomy is one of the most threatened needs in the palliative phase. Physical impairments such as pain, fatigue, and speech difficulties undermine patients' sense of control over their body and choices (Mayland et al., 2021). As HNC is very unpredictable, patients feel like they have no control over their future and their illness, which leads to distress..

As the disease progresses, patients become increasingly dependent on caregivers or medical devices like a tracheostomy (Offerman et al., 2013). For example, patients often need help with basic daily activities like eating and showering. Speech difficulties can make communication hard and in some cases the partner has to act as the voice of the patient (Zeng, 2023). Speech difficulties can not only cause isolation and loneliness, but can also prevent patients from expressing their needs or participating in decision-making in their care (Mayland et al., 2021).

However, the desire for independence remains very strong. Patients want to perform daily tasks themselves, make their own decisions and maintain a general sense of normalcy (Goldstein et al., 2008).

*“I don’t want to be dependent on someone else. I want to be able to do the basic daily tasks myself.”* — Patient, interview

This tension between declining capacity and persistent desire for self-sufficiency is a central source of frustration.

*“Autonomy is very important for patients. They want to be able to do simple daily tasks like eating and drinking by themselves. Because they are ill, they often cannot do that anymore, which can be very frustrating.”* - Palliative Care Researcher at Erasmus MC

## Relatedness

With a life expectancy of less than 5 months (Van den Besselaar et al., 2025), the need for ‘Relatedness’ becomes a top priority to be fulfilled where patients seek to maximize connection with loved ones in the precious time left. However, the impact of HNC can directly create a disconnection from patients' social environment and their loved ones.

Many patients experience a feeling of being a burden to loved ones. As mentioned in ‘Autonomy’, patients become very dependent on them being their caregivers and are very aware of the toll their illness takes on them too, leading to a complex mix of guilt and fear (Mota et al., 2022). This sense of guilt is often compounded by the fear of leaving loved ones behind.

> *“I know this is not easy for my partner either; he goes through all of this mentally as well. The psychological support is missing for my loved one.”* – Patient (Interview)

Challenges in verbal expression common among individuals with HNC, frequently act as a barrier to social engagement. These communication impairments, whether caused by the disease itself or its treatment, can cause a deep sense of isolation and loneliness (Mayland et al., 2021, Sauder et al., 2021). Patients can also experience a form of existential loneliness: while life continues for everyone else, the patient feels alone in their illness (No Pictures, 2024).

Next to this, physical issues such as difficulty with kissing or changes in sexuality can lead to a perceived loss of the romantic bond and intimacy with a partner (Lewis et al., 2024).

Managing numerous practical tasks after a diagnosis often prevents patients from spending quality time with their loved ones. Since their time is so limited and precious, many find focusing on these arrangements to be a significant burden.

> *“I don’t want to think about practical stuff, especially since I might have such a short time left to live. I want to focus on the things that matter, like doing things with my loved ones.”* - Patient (Interview)

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## Comfort

Many patients report feeling anxious and struggle to lead an easy and convenient life. In this context, comfort includes both physical comfort and mental comfort.

### Physical Comfort

Physical comfort is often limited by the symptoms of the disease and the side effects of treatment (Medina & Isaac, 2025). Chronic pain is a common issue that directly impacts daily life and sleep. Basic functions like eating, drinking, and speaking can become difficult or even impossible.

> *“I am always in pain at night, so I sleep poorly. I can never sleep for more than two hours at a time because my throat hurts so much that I have to take more painkillers.”* — Patient (Interview)

> *“I just feel I want to have order in my mouth … so that I can talk and eat”* - Patient (Lang et al., 2013)

Speech difficulties can make normal communication complicated. For many patients, the progression of the tumor or the presence of a tracheostomy makes it physically difficult to express their needs or distress (Gandhi et al.,2014). When a patient is unable to clearly communicate what they want, like thoughts, level of pain or emotional state, it creates a barrier to convenience and true peace of mind: it takes a lot of (physical and mental) effort, social engagement can get difficult and the patient cannot be certain that their symptoms are fully understood by others.

### Mental Comfort

A major challenge for mental comfort is the high risk of the cancer coming back, something HNC is especially known for, which creates a lot of uncertainty and persistent anxiety (Goldstein et al., 2008; Offerman et al., 2013). Accepting the situation can be very difficult and the feeling can create a lot of stress for the patient (No Pictures, 2024).

Patients therefore have a strong need for clear communication with their medical team and emotional support to feel prepared for the future (Mayland et al., 2021). However, many doctors have a 'cure-focused' mindset, where the focus is on treatment rather than emotional support (Miller, 2016). Ongoing emotional guidance is necessary to provide lasting comfort and peace of mind (Song & Happ, 2017).

Becoming palliative and ill in general can cause a feeling of losing structure of life (Black et al., 2018). Patients can feel insecure because their daily activities change completely depending on their physical state.

> *"You really start to feel insecure about the future. The structure in your life changes depending on your physical state... everything becomes different and no one guided me through this process."* — Patient (Interview)

## Fitness

Fitness (defined as having the energy and physical strength to function) is a need that consistently goes unmet in the palliative stage of HNC. A significant majority of patients with palliative HNC, ranging from 77% to 81%, suffer from chronic exhaustion or a notable depletion of energy levels (Mayland et al., 2020). This lack of fitness is driven by a dual burden: the advancing cancer and the side effects of treatments like radiotherapy and chemotherapy. This combination leads to profound physical depletion, leaving patients unable to maintain their baseline energy levels or feel physically fit. The more the disease progresses, the more this need remains unfulfilled.

### Link to Autonomy

Experts all strongly agree that (this lack of) 'Fitness' is directly tied to (a decline in) Autonomy. As patients lose their physical strength, they lose the ability to act independently.

## Competence

In the context of HNC, competence can be defined as the patient's feeling of being capable and informed despite their illness. This need can stay unmet due to both physical and communicative barriers.

### Physical Challenges

Fatigue and severe nutritional difficulties significantly challenge a patient's sense of competence (Mota et al., 2022). When basic daily functions like eating become a struggle, patients often feel less capable, which can lead to a sense of failure or frustration.

### The Role of Information

Complex medical information often acts as a cause to lack the feeling of competence, leaving patients feeling inadequate and helpless (Ferri et al., 2024; Saghafi et al., 2023). Clear, accessible communication is therefore essential to support their sense of competence, empowering them to understand and manage their own care journey.

### Link to Autonomy

Competence can also be linked to ‘Autonomy’. A lack of understanding regarding their condition often leads to a sense of dependency on medical staff. When patients cannot grasp what is happening to them, they lose their sense of Autonomy, as they no longer feel in control of their own care or future.

## Recognition

Recognition is the need for patients to be seen as a person, not just a ‘medical case’. According to Mota et al. (2022), many patients feel they are treated only as 'the patient' instead of a human being with their own qualities. Patients have a strong desire to be valued for who they are, beyond their illness. When doctors only focus on symptoms, the person behind the disease is often forgotten, leaving this important need unfulfilled.

### Link to Relatedness

Experts note that some patients seek recognition not for themselves, but for their loved ones. They want the immense effort of their caregivers to be acknowledged and valued. This could be linked to *Relatedness*: acknowledging the caregiver's efforts could mitigate the patient’s sense of being a burden.

## Purpose

Many patients still strive to achieve personal goals, such as making one last trip or reaching a family event. However, some patients struggle to understand the meaning and purpose of their lives as they face their diagnosis (Mota et al., 2022). When patients lose the ability to see value in their daily existence, it creates a sense of distress, leaving this need unfulfilled.

## Security

Security in the context of HNC involves both physical safety and financial stability. Physically, many patients experience a constant sense of being unsafe .

> “Many patients are scared to choke” - ENT-resident

Beyond physical threats, there can be a sense of financial insecurity. This concern is often not only for their own situation but especially for the loved ones they will leave behind. When patients worry about the financial future of their family, it creates a lack of peace and safety, leaving this essential need unfulfilled.

> *“I am mostly worried about how I will leave my wife behind, financially”* - Patient

**Link to Comfort**
This lack of security is directly tied to Comfort, specifically the need for peace of mind. When a patient is constantly scared of choking or deeply worried about their family's financial future, they cannot reach a state of mental peace. Experts and patients both emphasize that true comfort is impossible as long as these physical and financial fears remain.

### FPN’s not included in this list

*Morality, stimulation, impact, beauty,* and *community* were mentioned significantly less often in the literature and interviews. Experts and patients rarely identified these five needs as primary causes of distress in this specific life stage. Compared to the eight selected needs, their unfulfillment seems to have a less immediate impact on a patient’s daily wellbeing in this specific phase of their life. For this reason, they were not included in this list.

### 2.1.3 Most Critical Needs

While eight needs are significantly impacted by the disease, my analysis of the literature, expert consultations, and patient interviews reveals that *Autonomy, Relatedness,* and *Comfort* are the most critical to be fulfilled. This is due to three main reasons:

- **Frequent Unfulfillment**: Patients often feel these needs are no longer being met because of their illness and becoming palliative. This is evidenced by my research: all interviewed patients provided direct examples of how these needs currently remain unfulfilled. While the literature does not use the specific 13 FPN terminology, it consistently describes themes where these needs can stay unmet due to the illness. Healthcare experts further confirmed that patients frequently experience significant gaps in these three areas for various reasons.

- **Increased Valuation**: According to all my research findings, as patients enter the final stage of life, their internal priorities change significantly. While all fundamental needs remain important, *Autonomy*, *Relatedness*, and *Comfort* are often valued more than before, making the fulfillment of these three specific needs their highest priority. Any lack of fulfillment in these areas has a much deeper impact on their daily wellbeing than in earlier stages of life.

- **Foundational Nature**: Many other identified needs ultimately serve as "feeders" for these three. For example, *Competence* and *Fitness* are not just ends in themselves; they are valued primarily because they enable *Autonomy*. Similarly, feeling safe (*Security*) and feeling valued (*Recognition*) are necessary to reach a state of piece of mind (*Comfort*).

### 2.1.4 Conclusion

To define a clear design focus, a three-level filtering process was applied to the Fundamental Psychological Needs (FPN). This structured approach allowed the research to move from a broad theoretical framework to the specific priorities to see fulfilled of palliative HNC patients:

- **Level 1: All 13 FPN (The Universal Foundation)**
  All thirteen fundamental needs are inherently essential for human wellbeing. They represent the universal psychological requirements for any individual to function and flourish.

- **Level 2: The 8 Impacted Needs (The Patient Context)**
  Within the specific context of (palliative) HNC, eight needs were identified as

possibly being directly challenged by the physical symptoms and psychological distress caused by the disease.

- **Level 3: The 3 Critical Needs (The Design Focus)**
  From the subset of eight possible impacted needs, *Autonomy, Relatedness, and Comfort* emerged as the most critical to address. Because their unfulfillment heavily impacts wellbeing during the palliative phase, these three needs represent the best chance for a meaningful design intervention.

## Project Implications

### Rationale for selection

While the fulfilment of all thirteen FPN's can be vital depending on the individual, this project focuses further on those that appeared most critical to be fulfilled: autonomy, relatedness and comfort. By focusing on those three critical needs, the design aims to reach the largest group of patients effectively and have a high impact on patient wellbeing.

The focus was also chosen because they are the areas where I could make an impact as a designer. In the context of palliative HNC care, me (as a designer) has limited influence over a patient's physical decline or their financial circumstances. Consequently, needs such as 'physical fitness' or 'financial security' were excluded from the primary scope, as these areas require specialized medical or systemic expertise to achieve a meaningful impact.

While the project intentionally prioritizes the three most critical needs, this does not imply the exclusion of others. Should the final design solution happen to support additional FPNs (even unintentionally) it would be considered a valuable secondary benefit.

### System opportunities for improvement and validation

The insights gained regarding these needs provided a structured framework for evaluating the current care system at Erasmus MC. By focusing on these specific FPN's, it was possible to ask more targeted questions to nurses (VPKC's). This approach allowed for:

- Identifying where design could improve support for these critical needs of patients within the Erasmus MC system.

- Determining whether and where there is room for healthcare professionals to better support these needs.

### Considerations and Limitations

It is important to acknowledge certain limitations that shaped this research. First, this project was conducted within the limited timeframe of a graduation project, which required a focused and efficient approach.

Second, direct access to palliative HNC patients was restricted. Because of this, the findings rely heavily on a combination of existing literature, interviews with experts and the few interviews I could do with patients. This means that some conclusions are based on professional assumptions rather than a large number of direct patient experiences.

Finally, while I conducted a thorough review, it is impossible to include every available source or piece of data existing. This research represents a specific selection of sources and interviews. Despite this, the research clearly shows which critical needs often remain unfulfilled. This confirms that there is a valuable opportunity to design for these needs to improve the wellbeing of patients.

## 2.2 Analyzing Remote Palliative Care at Erasmus MC to Identify Opportunities for Supporting Patients' Wellbeing

This chapter addresses RQ2 and its sub-questions. While the previous section identified the unmet psychological needs of patients in general, the focus now shifts specifically to the context of the remote care system at Erasmus MC.

The primary objective was to map the patient journey for palliative HNC patients within the Erasmus MC remote care system. By analyzing the current organization of care, this project aims to evaluate the support for patients' psychological needs in the remote care system and identify opportunities where design could further help support the wellbeing of patients.

**RQ 2**: How is the remote palliative care system organized at Erasmus MC, and where are opportunities to better support patients' psychological needs?

- **SQ 2.1**: What does the current remote palliative care infrastructure look like, and which stakeholders are involved in the patient journey?
- **SQ 2.2**: How are patients' psychological needs currently addressed within the remote care context?
- **SQ 2.3**: What are opportunities where design interventions could provide additional support for the psychological wellbeing of patients?

### 2.2.1 Remote palliative care infrastructure

This overview of the remote care system at Erasmus MC is based on interviews with a Palliative Care Researcher and an ENT-resident working at Erasmus MC, who explained the hospital's internal processes. The goal was to see how psychological and psychosocial support is currently provided and to identify opportunities for improvement within the hospital's internal processes.

The system is visualized through a **stakeholder map** and a **patient journey**. The stakeholder map is created from the patient's perspective and identifies the key people involved in the Palliative Care system and their relationships. This is followed by a patient journey, which maps the specific steps a patient takes within the Erasmus MC system. Together, these tools show how the system works and highlight the key moments where psychological and psychosocial support is given and where there is possible room for improvement.

#### Stakeholders

The Remote Care system for palliative HNC patients involves a network of stakeholders (see Figure 4). While referral-based specialists involved can vary per individual, a core structure of the system remains consistent. The first ring around the core reflects the core care structure, where stakeholders like the VPKC and Next of Kin are always present (if the patient has Next of Kin ofcourse). The second ring shows the specialist(s) a patient can be referred to *through* the VPKC or GP. The last ring shows the stakeholders that are part of the care system, but have no direct contact with the patient.

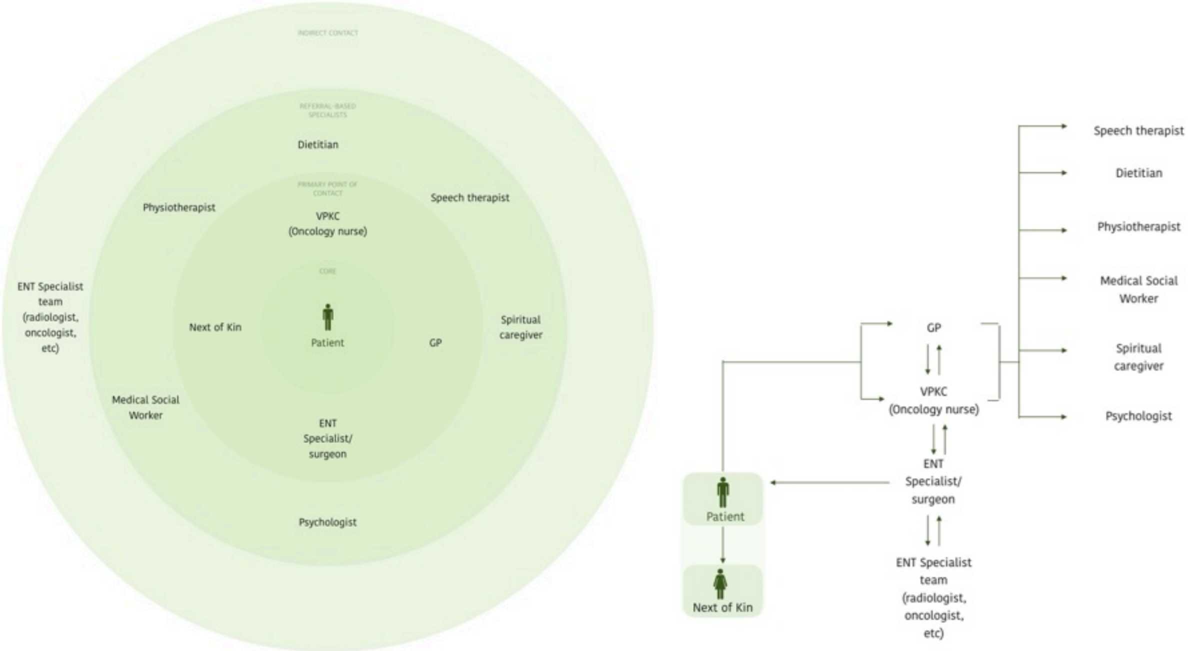


*Figure 4: The Stakeholders in the Remote Care System of Erasmus MC*

**The Core**

At the center of this care system is the palliative HNC patient receiving care at Erasmus MC. This central position shows how all support roles and services are organized around the patient.

**Primary Points of Contact**

These stakeholders have the most frequent and direct interaction with the patient:

- *Next of Kin / Informal Caregivers*: These are the people closest to the patient at home. They often act as the primary caregiver, attending consultations and providing daily emotional and physical support.
- *The Nurse (VPKC)*: Often described as the 'spider in the web', the VPKC manages the care process behind the scenes. They act as the first point of contact and provide mental support.
    - *Routine*: They contact the patient at least every 6–8 weeks based on a mandatory questionnaire (which will be discussed in the patient journey). However, patients can call the VPKC at any time they want or need to.
    - *Role*: The VPKC listens to the patient's needs and either provides direct support or coordinates with third parties. They maintain a close professional relationship with the General Practitioner (GP).
    - *Responsibilities*: They manage their own patient group and are the first to be informed of new palliative intakes.

**Secondary Care & Coordination**

- The GP: The GP is kept informed by the VPKC, and together they determine the next steps in treatment. The intensity of the patient-GP relationship depends on the patient's preference. If a patient lives far from Erasmus MC, the GP often coordinates local third-party care. The VPKC takes the lead if the GP has limited experience with the specific complexities of HNC.
- The ENT Specialist (Surgeon): This specialist focuses on medical possibilities, such as surgery or immunotherapy. They work closely with the VPKC and discuss medical options within the broader ENT surgical team.

**Referral-Based Specialists (Third Parties)**

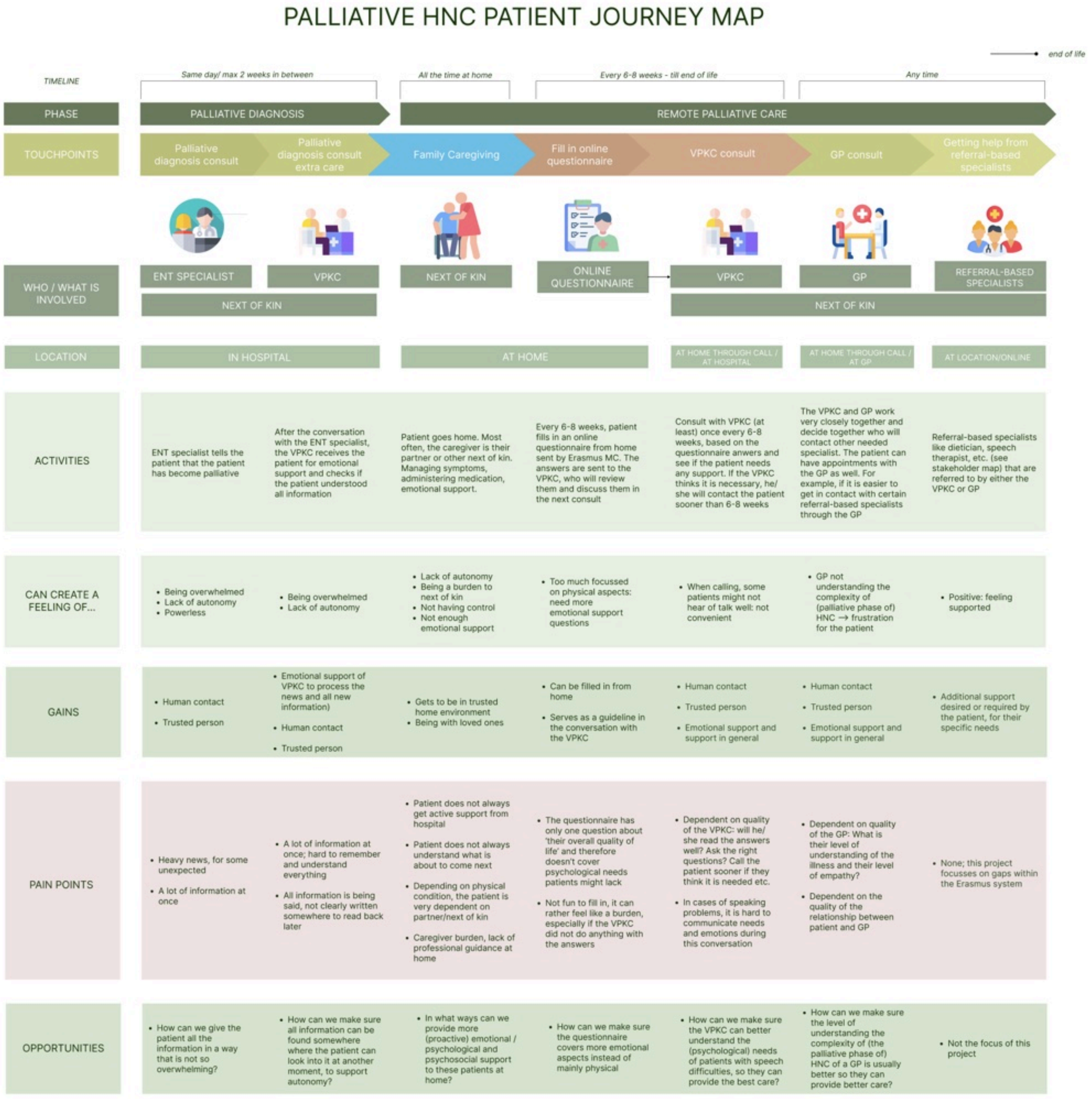
These are specialists to whom the VPKC or GP refers the patient when specialized care is needed. Common examples include psychologists, dieticians, or physical therapists. These parties are brought in when the primary care team cannot fulfill a specific need.

**Indirect Care Team**

Some stakeholders are part of the medical team but do not communicate with the patient directly. This includes the multidisciplinary ENT team (such as radiologists and oncologists) who discuss the patient's medical status behind the scenes to determine the best possible clinical path.

## The Patient Journey

The Palliative HNC Patient Journey Map (see Figure 5) visualizes the care process for palliative HNC patients, starting from the moment of palliative diagnosis. By analyzing this journey, potential opportunities for improvement in the system are identified regarding the delivery of psychological and psychosocial support. This map is based on the official Erasmus MC protocol, established through interviews with a Palliative Care Researcher and an ENT-resident both working at Erasmus MC, patient interviews and further refined with qualitative interviews with two VPKCs.



PALLIATIVE HNC PATIENT JOURNEY MAP

end of life

| TIMELINE | Same day/ max 2 weeks in between | | All the time at home | Every 6-8 weeks - till end of life | | Any time | |
|---|---|---|---|---|---|---|---|
| PHASE | PALLIATIVE DIAGNOSIS | | REMOTE PALLIATIVE CARE | | | | |
| TOUCHPOINTS | Palliative diagnosis consult | Palliative diagnosis consult extra care | Family Caregiving | Fill in online questionnaire | VPKC consult | GP consult | Getting help from referral-based specialists |
| WHO / WHAT IS INVOLVED | ENT SPECIALIST<br>NEXT OF KIN | VPKC | NEXT OF KIN | ONLINE QUESTIONNAIRE | VPKC<br>NEXT OF KIN | GP | REFERRAL-BASED SPECIALISTS |
| LOCATION | IN HOSPITAL | | AT HOME | | AT HOME THROUGH CALL / AT HOSPITAL | AT HOME THROUGH CALL / AT GP | AT LOCATION/ONLINE |
| ACTIVITIES | ENT specialist tells the patient that the patient has become palliative | After the conversation with the ENT specialist, the VPKC receives the patient for emotional support and checks if the patient understood all information | Patient goes home. Most often, the caregiver is their partner or other next of kin. Managing symptoms, administering medication, emotional support. | Every 6-8 weeks, patient fills in an online questionnaire from home sent by Erasmus MC. The answers are sent to the VPKC, who will review them and discuss them in the next consult | Consult with VPKC (at least) once every 6-8 weeks, based on the questionnaire anwers and see if the patient needs any support. If the VPKC thinks it is necessary, he/ she will contact the patient sooner than 6-8 weeks | The VPKC and GP work very closely together and decide together who will contact other needed specialist. The patient can have appointments with the GP as well. For example, if it is easier to get in contact with certain referral-based specialists through the GP | Referral-based specialists like dietician, speech therapist, etc. (see stakeholder map) that are referred to by either the VPKC or GP |
| CAN CREATE A FEELING OF... | • Being overwhelmed<br>• Lack of autonomy<br>• Powerless | • Being overwhelmed<br>• Lack of autonomy | • Lack of autonomy<br>• Being a burden to next of kin<br>• Not having control<br>• Not enough emotional support | • Too much focussed on physical aspects: need more emotional support questions | • When calling, some patients might not hear of talk well: not convenient | • GP not understanding the complexity of (palliative phase of) HNC → frustration for the patient | • Positive: feeling supported |
| GAINS | • Human contact<br>• Trusted person | • Emotional support of VPKC to process the news and all new information)<br>• Human contact<br>• Trusted person | • Gets to be in trusted home environment<br>• Being with loved ones | • Can be filled in from home<br>• Serves as a guideline in the conversation with the VPKC | • Human contact<br>• Trusted person<br>• Emotional support and support in general | • Human contact<br>• Trusted person<br>• Emotional support and support in general | • Additional support desired or required by the patient, for their specific needs |
| PAIN POINTS | • Heavy news, for some unexpected<br>• A lot of information at once | • A lot of information at once; hard to remember and understand everything<br>• All information is being said, not clearly written somewhere to read back later | • Patient does not always get active support from hospital<br>• Patient does not always understand what is about to come next<br>• Depending on physical condition, the patient is very dependent on partner/next of kin<br>• Caregiver burden, lack of professional guidance at home | • The questionnaire has only one question about 'their overall quality of life' and therefore doesn't cover psychological needs patients might lack<br>• Not fun to fill in, it can rather feel like a burden, especially if the VPKC did not do anything with the answers | • Dependent on quality of the VPKC: will he/ she read the answers well? Ask the right questions? Call the patient sooner if they think it is needed etc.<br>• In cases of speaking problems, it is hard to communicate needs and emotions during this conversation | • Dependent on quality of the GP: What is their level of understanding of the illness and their level of empathy?<br>• Dependent on the quality of the relationship between patient and GP | • None; this project focusses on gaps within the Erasmus system |
| OPPORTUNITIES | • How can we give the patient all the information in a way that is not so overwhelming? | • How can we make sure all information can be found somewhere where the patient can look into it at another moment, to support autonomy? | • In what ways can we provide more (proactive) emotional / psychological and psychosocial support to these patients at home? | • How can we make sure the questionnaire covers more emotional aspects instead of mainly physical | • How can we make sure the VPKC can better understand the (psychological) needs of patients with speech difficulties, so they can provide the best care? | • How can we make sure the level of understanding the complexity of (the palliative phase of) HNC of a GP is usually better so they can provide better care? | • Not the focus of this project |

*Figure 5: The Palliative HNC Patient Journey Map*

**Structure of the Journey**
The journey is divided into two primary phases: the Palliative Diagnosis in the hospital and the subsequent Remote Palliative Care at home. As shown in the map, the process involves a multidisciplinary team, including ENT specialists, VPKCs, GPs, and referral-based specialists, centered around the patient and their next of kin. Whereas the initial hospital phase is dominated by the weight of the diagnosis and the intensive intake of information, the home phase shifts toward self-management.

**How patients psychological needs are currently addressed**
The transition to palliative status (the news the surgeon delivers to the patient) is usually very impactful and emotional for the patient and next of kin. To manage the immediate emotional impact, the VPKC provides a follow-up consultation, either immediately or within two weeks, depending on the patient's emotional capacity, to offer mental support and further information to both the patient and their next of kin.

Once patients return home, they fill in a questionnaire (See Appendix A) every 6-8 weeks remotely through the 'Health Monitor' platform. While primarily focused on physical symptoms, it includes a single question regarding overall quality of life, which could be linked to psychological wellbeing. The VPKC conducts a follow-up consultation (usually by phone) to discuss the answers given on the questionnaire. The patient can call the VPKC any time (during work hours) if they want or need to. The VPKC provides psychological support themselves first, but they can refer the patient to a specialist if their needs go beyond what the VPKC can offer and more specialized mental healthcare is needed.

### 2.2.2 Identifying Design Opportunities

The first research phase, involving interviews with three palliative HNC patients, highlighted several design opportunities, visualized in the journey map.

**The 'Practical Gap' Hypothesis**
A perceived design opportunity emerged in active practical support during the home phase. Patients in the interviews expressed challenges in managing logistical tasks, such as navigating financial matters or acquiring medical aids (e.g., wheelchairs or specialized equipment) resulting from physical impairments. Patients viewed this as a significant burden, as they wish to spend their limited time on meaningful activities and with their loved ones rather than on administrative hurdles. This conflict mainly hindered their need *Relatedness*, as the time and energy spent on logistical tasks came at the expense of meaningful interactions and quality time with their loved ones.

At this stage, data suggested that contact with VPKCs occurred primarily every 6-8 weeks, as prescribed by the official protocol, unless the patient actively initiated contact. This created the impression that patients had to navigate the system largely on their own.

Furthermore, patients indicated a desire for *autonomy*, expressing that they "did not want to feel dependent on the VPKC".

Consequently, a **potential 'proactive practical guidance gap'** was identified. However, given the limited access to a larger patient sample at this stage, this finding was treated as an **initial explorative assumption** rather than a definitive conclusion. This initial assumption served as the basis for an explorative concept: *an AI agent designed to guide patients through practical hurdles independently, thereby reducing their perceived dependency on the VPKC* (see Appendix B), which was subsequently presented to the VPKCs to gather their reflections and to see how it aligned with their experiences.

### VPKC's Interview Insights

A subsequent interview, where the explorative concept was shown as well, and co-creation session was held with two VPKCs. During the interview, the VPKC's revealed a discrepancy between the official protocol and the clinical reality. While 6-8 weeks is the guideline, they reported monitoring patients often much more frequently; often speaking with them once a week, depending on the patient's condition.

This led to two insights:

1. **Dynamic Contact Frequency**: The intensity of care is often scaled based on the patient's physical decline, as I understand of the VPKC's. While physically 'fit' patients might follow the 6-8 week protocol, the system proactively increases contact as the disease progresses.
2. **Selection Bias in Initial Data**: A critical reflection suggests that the patients interviewed in the first phase were relatively fit. This could explain their reported low contact frequency and their focus on practicalities. However, the VPKC's emphasized that for the broader, more vulnerable patient population, there is a need for frequent professional contact.

### Identifying a Greater Design Space: The Verbal Communication Barrier

While the need for practical help remained valid, the co-creation session with the VPKC's revealed a much more critical and impactful design space. Although patients can technically contact the VPKC for any questions, a specific group is systematically hindered from effective communication: patients with (severe) speech difficulties.

The VPKC's both mentioned that speech difficulties of patients are a primary barrier to providing high-quality mental and psychosocial support. They mentioned that communication with patients that have speech difficulties, typically shifts to mediated forms, such as e-mail or the partner speaking on the patient's behalf. However, these methods lack the nuance required for deep emotional exploration. Consequently, it becomes very difficult for a nurse to uncover a patient's true needs when the primary medium of communication is filtered through a third party or limited to written text.

This realization fundamentally shifted the project's focus. If a patient struggles to express their deeper needs to a professional VPKC via phone or email, this struggle is undoubtedly also profound in their daily interactions at home; something already identified in the literature review in the previous chapter.

The impact of this communication barrier on *Autonomy*, *Relatedness* and *Comfort* appears more critical to a patient's wellbeing than the burden of practical logistics. This insight presented an opportunity for high-impact design; by focusing on the '*communication gap*', the project can address two interconnected challenges simultaneously:

1. It could tackle the **systemic gap** within Erasmus MC by enabling more effective communication and therefore remote care for patients with speech difficulties.

2. It could support **unfulfilled fundamental psychological needs** (*Autonomy*, *Relatedness* and *Comfort*) of the patient in their home environment.

This **dual benefit** established the final design direction of this thesis.

### 2.2.3 Conclusion

This chapter analyzed the remote palliative care infrastructure at Erasmus MC to identify opportunities where design could support patients (critical) needs. The mapping of stakeholders and the patient journey reveals that while the system is designed for frequent support if needed, it is heavily dependent on verbal communication.

The VPKC plays a vital role as a proactive 'spider in the web,' coordinating care and providing emotional support. However, they mentioned the effectiveness of this support is currently limited for patients with (severe) speech difficulties by the available communication channels. Remote care relies mostly on phone calls and in some cases emails; modalities that are insufficient for patients with speech difficulties when a deeper understanding of patients needs is wanted. When communication becomes 'non-direct' (filtered through a partner or restricted to brief emails), it becomes increasingly difficult for the VPKC to uncover the patient's true needs. As mentioned in literature in the previous chapter (2.1), speech difficulties can have a great negative impact on a patient's wellbeing. This research concludes that this communication problem is a more critical threat to a patient's critical needs (*Autonomy*, *Relatedness* and *Comfort*) than the practical logistical burdens identified earlier.

Addressing this '*communication gap*' offers a dual benefit: optimizing the effectiveness of the Erasmus MC remote care system for patients with speech difficulties (which the VPKCs identified as a significant area for improvement) by improving the communication barrier between the VPKC and patients with speech difficulties and directly support the fulfillment of the patient's (unfulfilled) critical fundamental psychological needs.

## Project Implications

All insights gathered thus far have led to a specific focus of this project. While the '*practical gap*' remains a valid issue that can decrease a patient's wellbeing, this project will now focus on the '*communication gap'*, the communication barrier faced by patients with speech difficulties. This shift is driven by the potential for a much higher overall impact.

My research indicates that communication barriers can significantly impact patient wellbeing across both professional and personal spheres. Beyond the emotional strain at home, these barriers hinder the VPKC's ability to deliver tailored care, which could impact the quality of care and eventually the wellbeing of the patient. Therefore, I am investigating an intervention that could address both: an intervention that supports the patient in home setting while ensuring the VPKC can better understand and meet the patient's specific needs. This approach aims to align with Erasmus MC's preference for a home-based intervention while addressing the identified '*communication gap'* between patients and healthcare professionals.

### Deepening the focus on 'speech difficulties'

This new direction requires a deeper investigation into the specific experiences of patients with speech difficulties. While the initial literature review provided a foundation, further research is needed to map the following areas:

- **Kinds of speech difficulties**: What are different kinds of speech difficulties and do they have a different level of impact on wellbeing?

- **Scenarios**: in what scenarios can speech difficulties have a negative effect on the wellbeing of the patient?

# 3. Define

Building on previous research in Chapter 2, this chapter investigates the focus group further, by getting a deeper understanding of what the different types and nuances of speech difficulties are and in what scenarios this can have a negative effect on the wellbeing of the patient. Its primary objective is to define a specific target group and establish a clear design vision and goal, providing the necessary foundation for the subsequent ideation phase.

*In this project, a distinction is made between **speech difficulties** and a **(verbal) communication barrier.** While speech difficulties refer to the physical impairments of the speech-producing parts of the body and can lead to a communication barrier, 'communication' refers to the broader exchange of meaning (like a conversation) and therefore 'Communication barriers' refers to all reasons that can hinder this communication (for example, next to physical reasons, psychosocial reasons as well).*

**Summary** of the findings of my literature review in the previous chapter, where speech impairments could impact the feeling of fulfillment of the critical needs:

Autonomy

→ *Dependency*: Because patients cannot speak properly for themselves, they become dependent on others, who talk for them and have to interpret their needs, leading to deep frustration and a diminished sense of control over their lives. Therefore, losing the ability to speak often leads to a loss of autonomy; they want to be able to decide what (and how) they want to share themselves.

→ *Loss of Voice in Decisions*: Speech difficulties prevent patients from clearly expressing their preferences and needs, which can make having a say in the decision-making process regarding their own care difficult.

Relatedness

→ *Social Isolation*: The inability to participate in 'normal' social interactions (like a quick joke or a clear conversation) leads to a profound sense of loneliness.

→ *Broken Connections*: Physical barriers to verbal expression make it difficult to maintain meaningful emotional bonds, as the patient can no longer share their inner thoughts or 'self' with loved ones.

→ *Feeling like a burden*: Becoming dependent on others, mainly their loved ones, can create a feeling of being a burden to them

Comfort (Peace of Mind and Convenience)

→ *Inconvenience and Mental Vulnerability*: Not being able to communicate properly, creates an inconvenient life. On top of that, without the ability to share what they want to share, patients cannot achieve true peace of mind. For example, the fear of not being understood by the care team creates constant anxiety for a patient.

## 3.1 (Severe) Speech Difficulties and Their Impact on Verbal Communication

As mentioned in the previous chapter (Chapter 2), treatments for HNC, such as surgery and (chemo)radiation therapy, frequently result in physical impairments that can have long-lasting, negative effects on a patient's ability to verbally communicate, resulting in a decreased wellbeing. Speech difficulties exist on a broad spectrum, ranging from impairments to a complete loss of voice. These were categorized into three main areas, based on previous literature and analysing the medical information lists of PVHH (PVHH, z.d.).

- **Voice**: A reduction in vocal quality or total loss of voice. This is often caused by the presence of a tumor on the vocal cords or the medical treatment used to remove it.

- **Articulation**: Difficulty forming clear words and sounds. This is primarily caused by treatments like surgery, which may change or remove parts of the mouth used for speaking, such as the tongue or the jaw.

- **Pain and discomfort**: The physical distress of speaking (for a long time). This pain or discomfort can be caused by the tumor itself or by side effects of treatment, such as a very dry mouth (Xerostomia; which can also affect articulation) or scar tissue.

*For more details on exact causes, see Appendix C.*

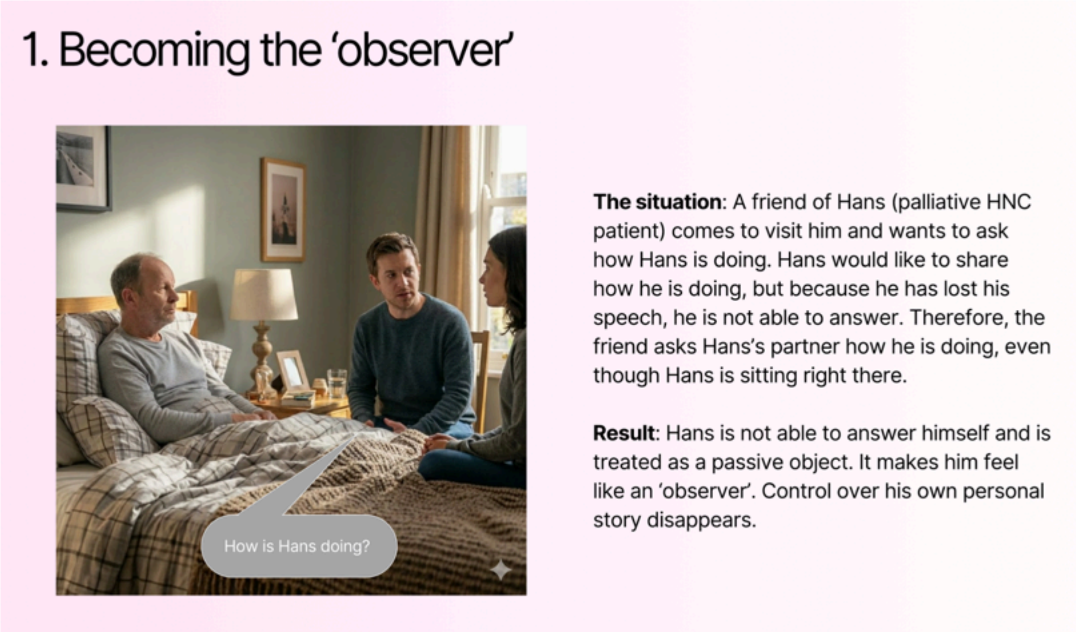
It stands to reason that the severity of a patient's speech difficulty directly determines the scale of the verbal communication barrier. For example, there is a significant difference between a patient whose tumor makes speaking somewhat difficult and a patient who has completely lost their voice after treatment. A more severe physical impairment creates a wider gap between the patient and their environment and therefore a bigger impact on wellbeing.

For example, as explained by Murariu et al. (2025), the psychosocial consequences of conditions like laryngeal cancer are particularly profound. A total laryngectomy results in the complete loss of the natural voice and the necessity of a permanent tracheostomy, which fundamentally alters social interaction. Even in cases involving partial surgery or chemoradiotherapy, patients often suffer from significant impairments in speech clarity and communication. These functional limitations are strongly linked to emotional distress, anxiety, and social withdrawal, affecting the feeling of 'relatedness' and 'comfort' in a negative way. Patients often struggle with an altered self-image and frustration over their loss of independence in social settings, affecting their feeling of 'autonomy' in a negative way.

On top of that, the loss of vocal identity is uniquely distressing, as the voice is central to personal expression. Many patients describe a traumatic sense of ‘losing themselves’, viewing the experience not just as a physical impairment but as a holistic ‘silencing’ of their individual identity (Murariu et al., 2025, Bickford et al., 2018). Whether speech difficulties range from having (severe) difficulty speaking or having no voice at all, it often leads to a feeling of powerlessness; not only because patients can no longer (technically) speak for themselves, but they also lose the ability to express themselves in the way they would want to (Gibson et al., 2022).

Because severe speech difficulties (such as the total loss of voice) profoundly impact patient wellbeing by creating a significant communication barrier and negatively affects the fulfillment of critical needs *Autonomy, Relatedness,* and *Comfort*, they served as the project's initial focus. The following scenarios illustrate how severe speech difficulties like speech loss can create communication barriers that negatively affect the wellbeing of a patient.

## Scenarios where severe speech difficulties negatively impact wellbeing



1. Becoming the ‘observer’

**The situation**: A friend of Hans (palliative HNC patient) comes to visit him and wants to ask how Hans is doing. Hans would like to share how he is doing, but because he has lost his speech, he is not able to answer. Therefore, the friend asks Hans’s partner how he is doing, even though Hans is sitting right there.

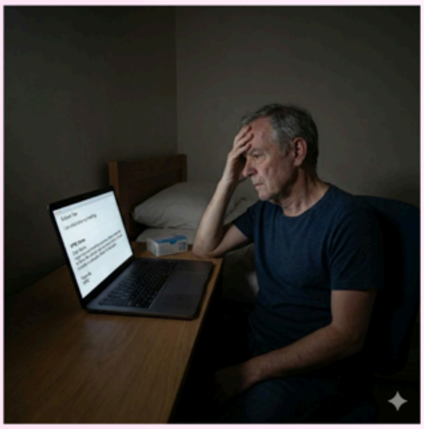
**Result**: Hans is not able to answer himself and is treated as a passive object. It makes him feel like an ‘observer’. Control over his own personal story disappears.

## 2. Functionality over Personality

**The situation**: Because Henk (palliative HNC patient) his communication is limited to nodding yes or no because of his speech loss, the VPKC asks only yes/no questions.

**Result**: He can no longer share a little sarcasm, his humor or his opinions. His personality is erased because there is no room for the nuances that make someone unique. Henk feels like he becomes a sort of 'collection of symptoms', instead of a human being

## 3. Blocking the right, emotional support



**The situation**:
Marco experiences severe fear at night that he might suffocate because of his tracheostoma. He wants to talk to his VPKC about this because he feels unsafe. However, he cannot call. He has to explain his deep, existential fear in an email. Since typing costs him a lot of energy, he keeps his message short and writes: "I am afraid about my breathing."

**Result**: The VPKC interprets the message as a medical problem and replies with instructions on how to clean the cannula. Henk's real need (emotional support and recognition of his fear) remains unmet. As a result, he feels like a medical case instead of being seen as Marco, the person.

## 4. Emotional disconnection caused by technology

Current aids (such as an electrolarynx) can feel alienating.

**The situation**: A patient wants to say an emotional or comforting word to their partner in the final stage of life, but the voice sounds mechanical, and emotionless.

**Result**: The voice does not match the patient's personality. The patient does not want to sound like that at all, but he can't control it. Not only does this result in a lack of autonomy, but also of relatedness: for those around him, it feels like they are talking to a machine; the emotional meaning does not come across

*Figure 6: Scenarios where severe speech difficulties negatively impact the wellbeing of a patient (Images generated with Gemini)*

## 3.2 Design Vision and Goal

**VISION**
*"I envision a future where patients transition from a place of isolation to feeling deeply connected to their environment and loved ones, having a convenient life where they feel in charge. Instead of being treated as a 'medical case', they are recognized as human beings, seen and heard for who they truly are. Their personal essence is present as they express themselves and their thoughts and feelings exactly when and how they choose. They feel in charge, connected, and like themselves again."*

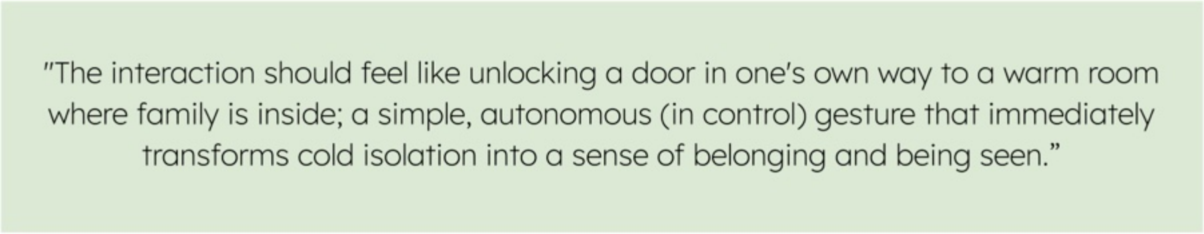
**GOAL**
*My goal is to design an intervention that supports the feeling of autonomy, relatedness and comfort of palliative HNC patients with severe speech difficulties during synchronous verbal communication. I want them to have a convenient life and to feel in control again and feel included in a conversation instead of being an observer. The design should feel like an extension of their identity, ensuring that even in the final stage of life, the patient can communicate in a way that feels personal. By being able to communicate in their own personal way, I aim to support their sense of autonomy and relatedness with those around them.*

The **design goal** therefore is:

"To create a communication tool that enables palliative HNC patients with severe speech difficulties to express themselves autonomously in a personal way, supporting meaningful synchronous communication while strengthening their sense of *autonomy* and *relatedness.*"

## 3.3 Interaction Vision

An interaction vision (see Figure X) is created to define the intended 'feel' of the relationship between the user and the design. It serves as a guiding star for the next phase, ensuring that every design choice evokes the right emotional experience and atmosphere.



"The interaction should feel like unlocking a door in one's own way to a warm room where family is inside; a simple, autonomous (in control) gesture that immediately transforms cold isolation into a sense of belonging and being seen."

*Figure 7: The Interaction Vision (Image generated with Gemini)*

## 3.4 List of Requirements and How-To’s

Based on the previous analysis and the defined design vision and goal, a list of requirements has been developed. These requirements serve as a practical framework to ensure the final design effectively supports the patient's needs and translates the interaction vision into a functional solution. To support brainstorming and idea generation in the next phase, these requirements were translated into several 'How-To' questions.

### 3.4.1 List of requirements

R1: The design must be usable for patients with **severe speech difficulties**.
The focus group is palliative patients with severe speech difficulties, like having almost to no voice. This requirement ensures that the design remains accessible for this group.

R2: The design must facilitate **synchronous communication**, allowing the patient to take an **active role** rather than being reduced to an 'observer'.
This requirement focuses on enabling real-time interaction, where the patient can respond and contribute as the conversation happens. By facilitating autonomous participation, the design prevents the patient from drifting into a passive role, ensuring they remain an active and valued member of the dialogue.

R3: The design must support the patient’s **sense of autonomy**.

The patient should remain in control of what is communicated and when. A sense of control is deeply linked to autonomy; it is the power to decide independently whether, when, and what to share in a synchronous conversation. By removing the barrier to meaningful communication caused by speech impairments, the design ensures that patients can actively steer the conversation rather than being forced into silence by their condition.

R4: The design must enable patients to **personalize** their communication.

This requirement ensures that the design goes beyond functional messaging by allowing patients to express their unique personality and identity. The patient can ensure their message is understood as they intended, preserving their individual character in every interaction.

R5: The design must support a **sense of relatedness** with loved ones.

By enabling active participation rather than passive observation, the design naturally fosters a deeper emotional connection between the patient and others. When patients can contribute to the conversation in real-time, it reaffirms their significance within the social circle and restores the feeling that they truly matter. By enabling patients to speak for themselves, the design aims to reduce their sense of being a burden and restores a balanced relationship where the partner no longer has to act as their voice.

R6: The design must be **intuitive** and **usable without requiring extensive learning effort**.

The interaction should feel intuitive and/or familiar, so the patient doesn't have to 'solve a puzzle' before they can speak. This with the consideration that a palliative patient has a short time to live and as the primary demographic often consists of individuals aged 60 and older, the design must prioritize familiar interaction patterns to avoid the burden of a steep learning curve.

R7: The design must require **minimal cognitive and physical effort**, appropriate for the capacity and energy levels of a palliative patient

Given that palliative patients often deal with fatigue and pain, as mentioned, the interaction must be as effortless as possible to prevent further exhaustion. By keeping the interface simple and the physical movements small, the use of the design should feel effortless.

R8: The design must feel **natural**, ensuring social integration by avoiding a medical or stigmatizing appearance

To prevent the patient from feeling like an outsider, the design must avoid looking or acting like a disruptive medical device. By ensuring the interaction feels as natural as a regular conversation, the design lowers the social threshold and minimizes any feelings of awkwardness.

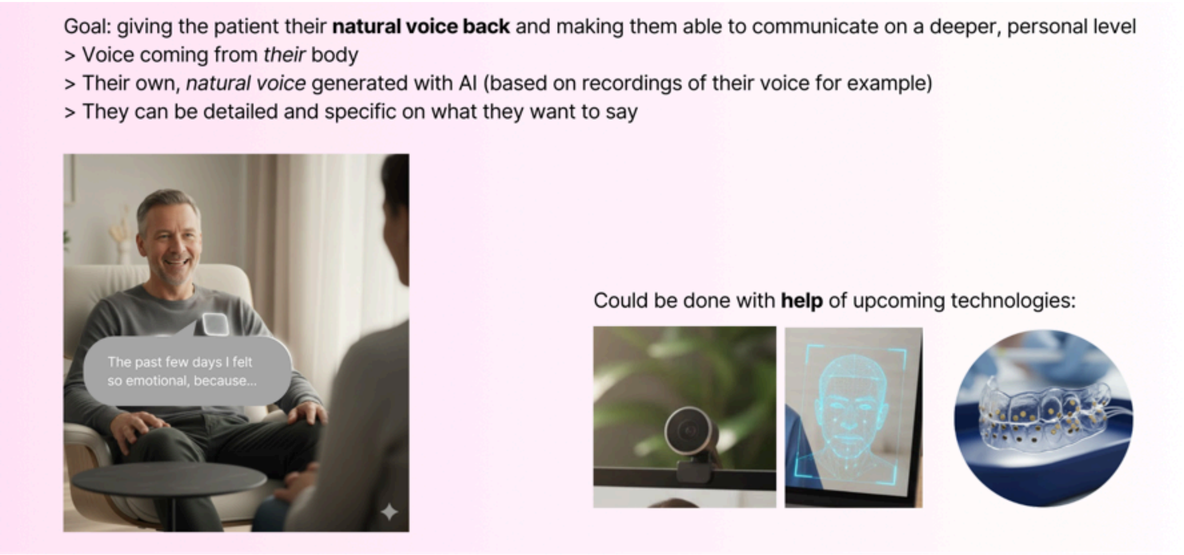
### 3.4.2 How-To’s

- How to… enable the patient to take an active role in the conversation and feel included?
- How to… ensure the patient maintains autonomy over their messages and choices?
- How to… enable patients to communicate in a personal way/personalize messages, when speech is impossible or difficult?
- How to… create a strong feeling of relatedness between the patient and others?
- How to… ensure a communication tool is easy to use for this specific user group?

## 3.5 Explorative Concept and Feedback of Erasmus MC

During an initial ideation phase, an exploratory concept emerged. Since a meeting with Erasmus MC was already scheduled, it was decided to present this idea immediately to gather early-stage feedback.

### 3.5.1 Explorative Concept



Goal: giving the patient their **natural voice back** and making them able to communicate on a deeper, personal level
> Voice coming from *their* body
> Their own, *natural voice* generated with AI (based on recordings of their voice for example)
> They can be detailed and specific on what they want to say

Could be done with **help** of upcoming technologies:

*Figure 8: Explorative concept*

The core of this idea is to empower patients to communicate through their own natural, AI-generated voice, preserving their sense of self. It targets patients who retain the ability to articulate but have lost their vocal strength. The design converts facial movements into a synthesized version of their own pre-recorded voice via a wearable speaker, ensuring that patients can express themselves with precision, depth and personal nuance. By reclaiming their 'voice', patients can transition from passive observers to active participants, as they can speak for themselves, strengthening their autonomy and improving the relational balance with their partner by lowering the patient's feeling of being a burden to them.

### 3.5.2 Translating Feedback of Erasmus MC into Design Actions

Following the presentation of the initial concept, the meeting with Erasmus MC provided insightful feedback that led to a shift in design focus.

**Broadening the target group**

It was noted that the concept focused heavily on patients with total speech loss. Although I had found quite an amount of literature regarding patients who lose their speech entirely, feedback from Erasmus MC revealed that this is actually a very small group, and expressed a preference for focussing on a broader population of palliative HNC patients. While this niche remains an important group to design for, I expanded the target demographic to include a broader range of patients to align with the priorities of Erasmus MC and ensure the final design would be effective for a larger group of patients.

**Focus on home care setting**

While the initial concept aimed to support both domestic settings and clinical consultations with the VPKC, Erasmus MC emphasized that the core objective of remote care is to support wellbeing specifically within the home environment. Consequently, the project scope was narrowed to focus exclusively on the patient's personal living space, which led to the addition of a new requirement:

R9: The design must be optimized for and functional within the **home care setting**.

**A holistic view on communication and redefining autonomy**

With the feedback of the concept being 'too technical' in mind and by narrowing the context to the home setting, I started thinking more about the complete picture of communication (within the home setting). I realized that my previous focus had been very heavily centered on the technical restoration of speech, but not so much on the social dynamics of a conversation. This phase marked a pivotal realization: communication is not solely the mechanical act of speaking, but consists of multiple components:

1. **Physical (Technical):** This refers to the physical production of speech (mouth, tongue, vocal cords) but also the patient's overall physical capacity to be able to communicate. In a palliative context, patients often face low energy levels or rapid cognitive overload, making the physical act of speaking significantly more taxing.

2. **Social Dynamics:** This concerns the flow and pace of interaction. It is the ability of the patient to remain an active participant in a group setting, preventing them from drifting into the role of a 'passive observer' due to the *speed* of the conversation.

3. **Content:** What the topic of the conversation is (such as end-of-life); the actual exchange of information.

4. **Identity (Personal Expression):** The *'how'* of communication. It encompasses nuance, humor, and the unique sound of one's voice. Without this element, a patient risks feeling like a 'collection of symptoms' rather than an individual with a distinct personality.

Therefore, since a conversation is a shared interaction rather than a monologue, the design must support the patient's ability to navigate social dynamics. In this context, **autonomy was redefined**: it is no longer solely about the *functional act of speaking independently*, but rather about *maintaining agency* over the conversation's dynamics and content. By investigating further why palliative HNC patients can withdraw from social settings, the design now aims to ensure they remain engaged and valued participants rather than passive observers.

### Focus on conversation facilitation

Erasmus MC emphasized the importance of the psychosocial reality of palliative patients, who often face **psychosocial barriers** to communication regarding end-of-life topics within the home setting. Reasons they mentioned were that patients could struggle to articulate deep feelings or not knowing how to initiate conversations regarding end-of-life topics. Therefore, they advocated for a shift toward a *proactive communication facilitator* for patients and family, centered on the ***content*** of communication (end-of-life topics), and not necessarily focus on the ***technical aspect*** of communication.

However, ignoring the technical aspect of communication would diverge from my research findings, which identify physical impairments as primary drivers of social withdrawal. Consequently, I had maintained the project's focus on the technical enablement of communication, but if there would be room in the design for it, I was definitely willing to add the end-of-life conversation facilitation. Therefore, I included this as a 'wish' (W1) in my list of requirements:

W1: The design should **provide proactive, psychosocial support** by **facilitating end-of-life conversations** between patient and next of kin.

## 3.7 Broadening the Target Group and Refining the Design Goal

To align with Erasmus MC's wish for a more inclusive design, the target group was expanded beyond total voice loss to encompass a broader spectrum of HNC-specific physical barriers to communication. The design now moves beyond the technical restoration of speech to actively support the social dynamics and processes of verbal communication. It moves beyond individuals with severe speech impairments (where talking is mechanically (almost) impossible) to include all palliative patients facing communication difficulties due to physical impairments (inherent to the palliative state) that lead to involuntary withdrawal of a conversation.

Maintaining focus on these physical aspects remains essential in my opinion, as these, as identified in the literature, are critical characteristics of the HNC population. Ultimately, the ability to actually have a conversation about a certain topic (end-of-life), the physical capacity to sustain participation in a conversation is necessary. Without this functional foundation, patients are effectively barred from the dialogues Erasmus MC aims to facilitate.

### 3.7.1 Reasons for Withdrawal in a Conversation

There are multiple reasons why a palliative HNC patient can withdraw from a conversation. This withdrawal is rarely caused by a single factor; rather, it is the result of a 'high cost of entry' created by the following four pillars. This list was compiled based on the knowledge acquired during the project, as well as what was considered to be the logical consequences of those insights.

**1. Physical effort caused by speech difficulties**
Specific to HNC patients, physical impairments make the act of speaking and being understood a high-effort task. The kinds of speech difficulties are discussed in chapter 3.1, but to give a short summary of what could be the effects of it:

*Physical strain of speaking:* Speaking can be physically painful, difficult or exhausting. This means the patient has a limited 'budget of words' before they have to stop talking. It is even harder in loud or busy places or where conversations go fast. In those situations, the patient has to speak louder to be heard, which can take too much physical effort and results in withdrawal.

*Lack of speech clarity:* When it is hard for others to understand the patient (for example, due to unclear articulation or a very soft voice) the need to repeat words doubles the physical effort. This leads to frustration or a feeling of being a 'burden' to the listener.

**2. Low Energy & Fatigue**
A characteristic aspect of the palliative phase is that palliative patients often face general fatigue, as described in Chapter 2.1.1.

*The energy price:* Every interaction has an 'energy price.' Because palliative patients usually already have little energy, caused by the illness and/or treatment, and talking takes so much effort, the cost of a conversation is often too high. This can force them to choose rest over social engagement.

**3. Cognitive Overload**
Difficulty speaking can make it mentally taxing to stay engaged in a conversation, especially considering the overall low energy levels of the patient.

*The pace of conversation:* Normal social interactions can move (too) fast. The assumption is that when a patient needs more time to process information or say something, they could quickly lose the thread of the conversation, leading to withdrawal where they become passive observers.

**4. Psychological Impact & Embarrassment**
The fear of how one is perceived can be a decisive reason to withdraw.

*Loss of identity:* Previous chapters have highlighted how speech impairments can negatively impact a patient's sense of self. Patients can also feel embarrassed because their voice has changed. For example, using an electrolarynx can make them sound 'robotic,' or they may struggle with mouth movements. These changes make them feel less like themselves, which can lead to avoiding conversations.

### 3.7.2 Adjusted Design Goal

“To design a communication tool that empowers palliative HNC patients with *communication difficulties* to engage in synchronous conversations with low effort in a personal way within the home care setting, thereby strengthening their sense of autonomy and relatedness.”

## 3.8 Conclusion and Project Implications

This chapter represents a shift in the design direction. While the initial focus centered on patients with severe speech difficulties like total speech loss, feedback from Erasmus MC revealed that this group was too limited: they had wished for an intervention that would be effective for a broader group of palliative HNC patients. Therefore, the design direction has shifted from a niche focus on speech loss to addressing the broader physical communication barriers faced by a wider range of palliative HNC patients.

As I realized that focusing solely on technical sound production overlooks the **social dynamics** and high 'cost of entry' of synchronous conversations, the project now addresses the holistic reasons why palliative HNC patients can withdraw from a conversation and can become ‘passive observers’.

Given the imbalance between high cognitive and physical load and the patient’s limited energy reserves, **energy efficiency** is a critical design driver. To ensure sustained social engagement, the interaction must be optimized to achieve maximum social engagement with minimal physical or verbal effort. By lowering the threshold for participation in a conversation, the intervention aims to empower patients to remain active participants in conversations and stay effortlessly in control of the dynamics of a conversation, while being able to express their true identity.

While the primary focus remains on supporting the critical needs of *autonomy*, *relatedness*, and *comfort* by making it easier for palliative HNC patients to communicate with their next of kin in the home setting, the ideation phase will also **explore if and how the facilitation of sensitive end-of-life topics** (W1) can be integrated as a secondary feature.

Despite the shift, the **core requirements** remain largely the same, with minor adjustments to reflect the broader focus on ‘communication barriers’ rather than only ‘severe’ speech difficulties.

# 4. Develop

During this stage, concepts were developed aligned with the new design direction and the needs of the expanded focus group.

## 4.1 Ideation

To translate the previous insights into tangible solutions, ideas were generated using methods such as braindrawing, brainwriting, and discussions for inspiration with others. During this ideation phase, the 'How-To' questions served as a guide, while the focus was placed on the social dynamics during a conversation within the home setting.

A primary objective was to determine how to slow down the conversational pace, as this was identified as critical for enabling patients to remain engaged and maintain agency while requiring minimal energy output. This led to two key design directions:

- **Reducing the conversation speed**: The design must facilitate a consistently slower interaction to better match the patient's reduced energy level and physical output capacity.

- **Low-effort 'interrupter'**: There is a requirement for a tool that allows the patient to actively enter or pause a conversation with minimal physical or cognitive effort. This ensures they maintain control without reaching physical exhaustion.

From the generated ideas, three concepts were developed. These concepts were subsequently presented to Erasmus MC for feedback.

## 4.2 Three Concepts

### 1. The Personal Voice

*This concept focuses on providing a low-threshold way to stay an active participant in a conversation while allowing the patient to express their personality with minimal effort.*

When a conversation moves too quickly or a patient wishes to contribute, they can use a dedicated device to trigger a sound cue to effortlessly pause the conversation and get their attention. This signal removes the need for the patient to physically 'overpower' the others talking or struggling with vocal strain. Once the conversation is paused, the patient has the floor to share their thoughts.

If the patient is able, they can use their own voice; however, they also have the option to type on a tablet to conserve energy. What makes this tool unique is its focus on identity:

rather than a generic robotic output, the system allows the patient to use their prerecorded voice *and* select the tone and nuance of the voice. By adding emotional depth to the synthesized speech, the patient's individual character is supported.

This concept allows the patient to maintain agency (*autonomy*) over the conversation in a low-effort and more *personalized* manner, fostering a deeper sense of *relatedness* through active participation.

**Core Elements of the Concept**:

- **Personalization**: The use of a personal, synthesized voice that includes emotional and volume nuances, supporting the patient's sense of *identity*.
- **Supporting Autonomy**: Using an interruptor can easily pause a conversation and gain the attention of the group, resulting in more room for input and steering the conversation, supporting the patient's sense of *autonomy*.
- **Supporting Relatedness**: By lowering the energy threshold required to participate, this concept enables the patient to stay part of the conversation more easily. By being able to stay part of the conversation more easily, this supports the feeling of *connection.*

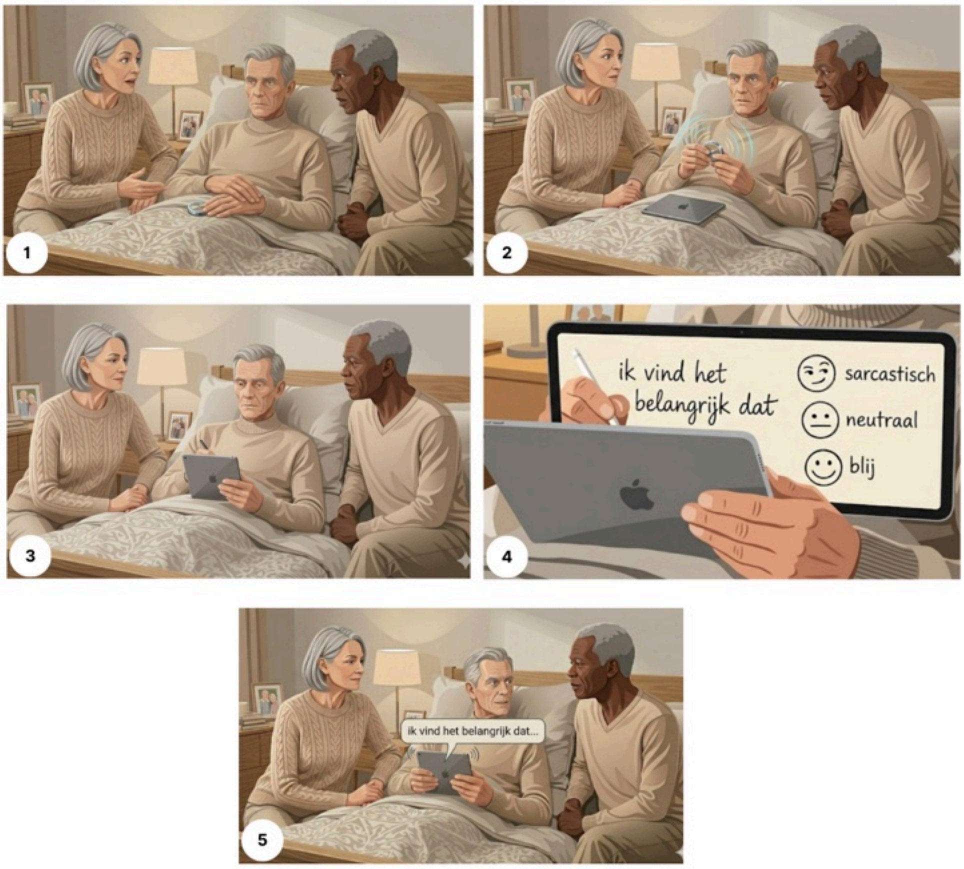


*Figure 9: Concept 1 - The Personal Voice*

## 2. The Communication Cards

*The second concept provides a low-threshold way for patients to maintain control over a conversation through a set of tangible cards and a bell used as a physical interrupter.*

The design allows the patient to effortlessly pause or slow down an interaction using a bell. This signal removes the need for the patient to physically ‘overpower’ others or struggle with vocal strain and pain. This concept goes beyond simple interruption; it utilizes a variety of cards to provide detailed control over the conversation's flow.

To remain agency in a conversation, the cards allow the patient to steer a conversation with minimal physical or cognitive effort, fitting their limited energy reserves. As seen in the provided image, the cards are categorized to support different needs:

- **State (Staat):** Communicating whether they want to listen or share something.
- **Pace (Tempo):** Managing the speed of the interaction by asking others to slow down or repeat themselves.
- **Opinion (Mening)**: Quickly and effortlessly sharing agreement or disagreement, which allows for immediate personal expression.
- **Addition (Toevoegen)**: Using "What I want to say..." or personalized cards to contribute content without needing to use their voice if it is painful or exhausting.

*Figure 10: Concept 2 - Communication Cards*

The use of familiar, physical cards ensures the interaction feels intuitive and natural, lowering the social threshold for participation. Furthermore, this concept directly addresses the wish from Erasmus MC by incorporating ‘Theme Cards’. These cards can proactively introduce sensitive topics, such as "my goals in life," facilitating meaningful end-of-life discussions in the home setting. Should this concept be pursued for further development, what exactly will be the topics of the theme cards is something that remains to be decided.

**Core Elements of the Concept:**

- **Supporting Autonomy**: Using the bell as a physical interrupter allows the patient to effortlessly pause a conversation and gain the group's attention. This is combined with a variety of cards to provide detailed control over the conversation's flow. Together, these tools create immediate room for input and enable the patient to steer the interaction at their own pace, directly supporting the patient's sense of autonomy.

- **Personalization**: The inclusion of opinion cards and customizable "free to fill in" cards allows the patient to express their unique character and personal nuances. By choosing how and when to use specific cards, the patient’s individual identity is preserved in every interaction.

  **Supporting Relatedness**: By lowering the energy threshold required to participate, this concept enables the patient to stay part of the conversation more easily. This *continuous* engagement fosters a deeper feeling of *connection* and prevents the patient from feeling like an isolated observer.

- **The possibility of facilitating end-of-life topics**: The addition of specialized theme cards could introduce end-of-life subjects, helping the patient and their loved ones navigate difficult discussions in a supportive way within the home setting.

An optional addition to this concept can be found in the Appendix D.

## 3. Conversation Circle

*The third concept provides a low-threshold way for patients to maintain control over a conversation through a 'Circle' that changes the social dynamics of a conversation by making use of 'speech turns'. It contains multiple elements.*

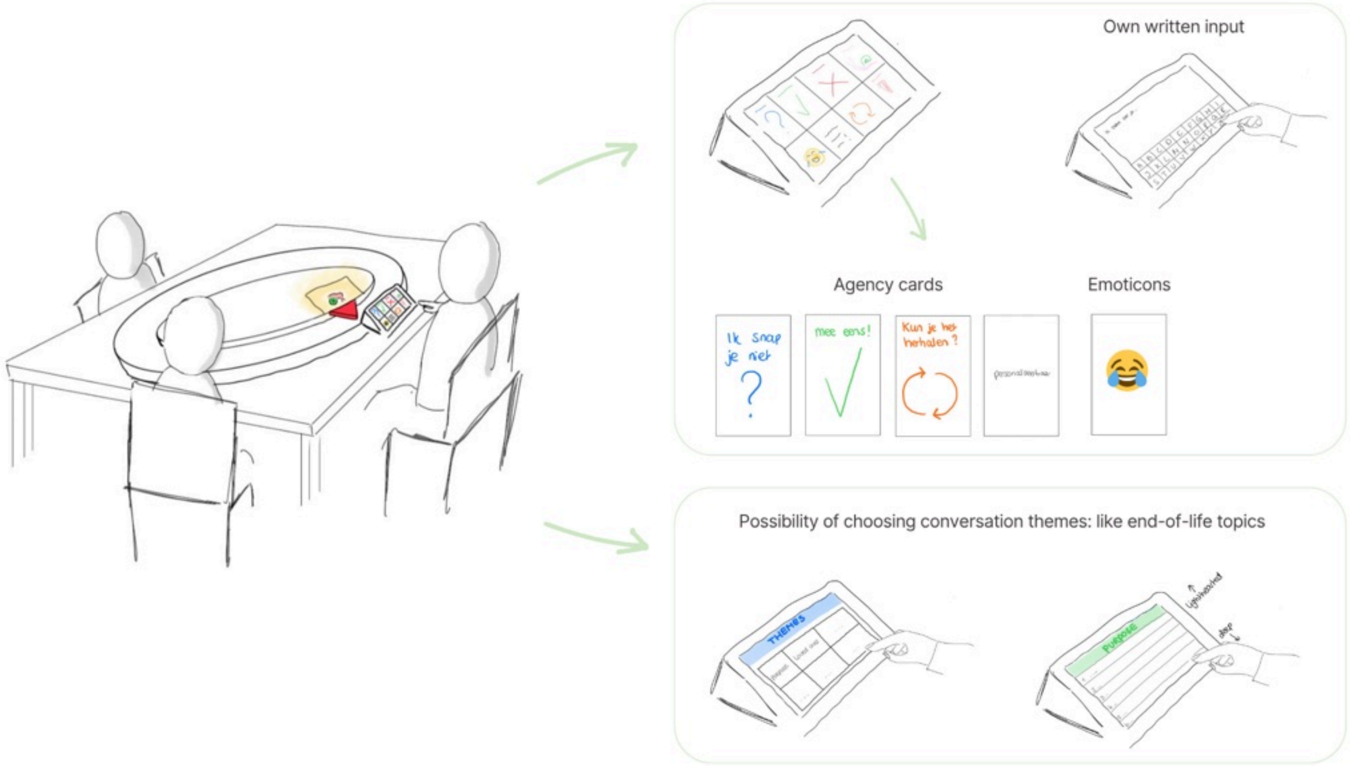


*Figure 11: Concept 3 - Conversation Circle*

The "Conversation Circle" is a tabletop intervention designed to fundamentally shift the social dynamics of group interactions. It centers on a physical rotating circle with an integrated display placed in the middle of the table. To speak, participants rotate the arrow toward themselves, granting them the speaking turn. This mechanism enforces clear turn-taking and naturally slows the pace of the interaction, creating a calmer environment.

Patients use a separate digital interface (such as a tablet) to select "Regie kaarten" or personal comments, which then appear on the central display. This interaction requires only a single click, ensuring it remains a low-energy task. To further assist the group, the circle uses color-coded lights to signal specific needs, such as a request to slow down, providing immediate non-verbal cues to everyone present. Finally, the system incorporates digital conversation starters focused on end-of-life topics (a specific request from Erasmus MC).

**Core Values of the Concept:**

- **Social Dynamics:** By implementing a physical turn-taking system, the design prevents the patient from being overwhelmed and ensures a manageable conversation speed.

- **Supporting Autonomy:** The digital interface allows the patient to effortlessly steer the conversation and slow down the pace with a single click. The visual signals ensure that their requests for input or changes in tempo are immediately understood by the group, giving the patient more control over the flow of dialogue.

- **Supporting Relatedness:** Since all participants follow the same rules, the patient is included as an equal member. This shared experience fosters a sense of belonging.

- **Identity & Expression:** The ability to add emojis or custom comments allows the patient's unique personality and humor to shine through.

- **Facilitating Sensitive Topics:** The integrated theme cards provide a proactive, personal way to initiate difficult end-of-life conversations within the home setting.

## 4.3 Concept Feedback Meeting with Erasmus MC

Before selecting the best concept, a feedback meeting was held with Erasmus MC to present and discuss the three proposed directions. During this meeting, Erasmus MC noted that the focus still remained heavily on the 'technical' (physical) aspects of communication and clarified that their priority lay almost exclusively with the facilitation of *content* (end-of-life topics), rather than the technical or physical obstacles that have been identified as critical for HNC patients in this project.

It was initially assumed that broadening the patient demographic meant moving beyond a niche focus on speech loss to target a larger group of patients. The approach was to achieve this by addressing a wider range of physical communication barriers. However, Erasmus MC clarified that with 'broadening', they specifically meant shifting the focus toward the content of the conversation; particularly end-of-life topics, which are inherent to the palliative phase.

They expressed a clear preference for *Concept 2 (The Communication Cards)*, specifically because of the inclusion of 'Theme Cards' designed to facilitate conversations about a certain theme, as the topics of these cards could be about end-of-life topics. Additionally, the physical bell was recognized to possibly be a valuable addition to the concept, providing a simple way for patients to gain attention and manage the conversational flow.

To maintain the integrity of my research while meeting the stakeholder's needs, I redefined the project's scope to address 'communication barriers' on two levels:

→ **The practical layer**: Focusing on physical barriers to communication.

→ **The psychosocial layer**: Focusing on the content: the difficulty of initiating and navigating end-of-life conversations with their families.

> This combination makes the project focus even more uniquely suited for the ***palliative HNC population***. While a focus purely on physical barriers could apply to curative cases as well, the addition of end-of-life topics makes the research specifically relevant to the palliative group.

## 4.4 Choosing the most promising concept

After the meeting with Erasmus MC and reflection, a concept was chosen.

### Refining the list of requirements

Two of the concepts (Communication Cards and Conversation Circle) had strong potential to include this wish. The requirements list was extended with Requirement 10:

R10: The design should provide **proactive psychosocial support** by facilitating conversations about end-of-life

### Choosing the best concept

Although Concept 2 was the preferred choice for Erasmus MC due to the theme cards and I recognized that R10 would significantly strengthen the concept, a Weighted Objective analysis (Van Boeijen et al., 2013) was performed to determine its overall strength, based on the other requirements as well (see Appendix E). This ensured that the final decision was grounded not only in stakeholder preference but also on the requirements defined by my research.

Concept 1 was discarded as it showed the least alignment with the requirements. By looking at all the plusses and minuses of Concept 2 and 3 (see Table 1), a synthesis was performed between those. The specific strengths and weaknesses of each concept, which informed this synthesis, are detailed in the PMI (Van Boeijen et al., 2013) analysis below.

|  | PLUSSES + | MINUSES - |
|---|---|---|
| 2 - Communication Cards | ● Can be used anywhere, anytime<br>● Can be very personalized<br>● Option to add in desire of Erasmus MC (by adding Theme Cards): supporting proactive psychosocial support<br>● Best concept according to Erasmus<br>● Very accessible and convenient, because of:<br>○ **Portability**: Cards are easy to pick up and use in any setting, making them highly practical for daily use.<br>○ **Approachable Appearance**: The cards are familiar and might create a subconscious association with a game (such as a card game), which makes the idea of using it seem more positive and less weighted, giving it an accessible and familiar feel. Because games are typically associated with social connection and lightheartedness, the tool feels less intimidating. Furthermore, the use of familiar elements (such as the card format and the bell) increases the sense of recognition and ease.<br>○ **Lowered Threshold for Conversation**: Since the card "asks" the question, it lowers the barrier to discussing sensitive topics. This functions similarly to the questions found on tea tags of Pickwick; a person can bring up a "heavy" or "awkward" topic because the card suggests it. This shifts the responsibility from the individual to the tool, making the user feel less like the 'inventor' of the question, which reduces the emotional burden of starting the conversation. | ● Need something to put the cards/bell on<br>● There should not be too many cards, as this can make it chaotic |
| 3 - Conversation Circle | ● Having a 'turn to speak' slows the conversation pace, making it much more accessible for palliative patients.<br>● A screen requires minimal effort: a single tap is enough to 'say' something.<br>● Easily add emojis or reactions. | ● Might be too 'intense', heavy and big<br>● You need a table to use it<br>● Not familiar at all |

*Table 1: Plusses and Minuses of Concept 2 and 3*

Based on feedback from Erasmus MC, the Weighted Objectives, and an evaluation of each concept's strengths and weaknesses, a **refined version of Concept 2: The Communication Cards** was chosen to proceed with. By analyzing the pros and cons of each design, it was explored how to combine the most effective elements from the different concepts.

For instance, a key feature of the Communication Circle is the **'turn-taking' mechanism**. Integrating this element into Concept 2 ensures that the conversation pace remains naturally slow, as everyone actively participates in this structure. This is beneficial because:

- **It requires less energy** for the patient to remain engaged in the conversation.
- **The patient feels less like an 'interrupter'** in a fast-paced conversation. Instead of having to halt a dynamic flow (which can feel like an emotional burden) this creates a shared conversation dynamic that fosters a stronger connection.

Adding **'emoticons'** from Concept 3 is a valuable addition, as they allow users to express emotion without using words and significantly enhance the expression of personality. Compare it with texting a message on your phone: the text gets a different ‘personality’ when (not) using (specific) emoticons.

### Theme Cards as conversation starters about end-of-life

The Theme Cards of the concept could function as conversation starters about end-of-life. While a deep psychological investigation into *why* patients don’t talk about end-of-life topics at home falls outside this project's scope, the project addresses only the practical **hurdle of initiation**: patients that *want* to talk about the topics, but just don’t know how to *start* the conversation or find the right words.

Given the project’s condensed timeline, the content of these Theme Cards had to be developed using a combination of *literature* provided by Erasmus MC and the *best possible assumptions*. After that, to ensure the intervention would remain grounded in reality despite a lack of direct patient access, experts in the field would be asked to review the topics of the cards to gain their professional feedback.

## 4.5 Refining the Concept

To build a strong concept, first its **core elements** were identified by evaluating which parts of the initial concept should be retained, modified, or added. This process was primarily based on own insights and assumptions, supplemented by feedback from Erasmus MC. Low-fidelity prototypes were then used to make the concept tangible.

### 4.5.1 Deciding the Core Elements

This resulted in the following core elements of the concept:

Card Set
For the patient to maintain **agency** of the conversation and the **topics**, including customizable cards for personalization.

'Speaking turn' object
For conversation dynamics: a physical object symbolizing the **speaking turn**. This ensures a calm pace and allows the holder to finish speaking without being interrupted.

Interrupter
An accessible tool for the patient to **claim a speaking turn** or temporarily pause the conversation.

Emoticons
Enables the patient to **express personality** by adjusting the intent and nuance of a message on the card, but also share emotions without needing many words.

Box / Packaging
To **store** all the elements in.

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*An explanation of how this selection was reached and the design questions that followed:*

Card Set

It has been decided to implement three types of cards: Agency Cards (Regie kaarten), Barrier Cards (Blokkade kaarten), and Wish Cards (Wens kaarten). Agency cards support the steering of the conversation, the barrier and wish cards facilitate the content of the conversation: end-of-life topics.

**Agency Cards (Regie kaarten)**
These allow the patient to maintain agency over the conversation with minimal effort. The primary goal is to strengthen the patient's sense of autonomy. Compared to Concept 2,

the variety of Agency cards has been reduced or integrated into other elements. This simplification ensures that the tool remains clear and manageable for palliative patients.

- **'Opinion' cards** have been replaced by emoticons (see 'Emoticons' section).
- **'Status' cards** have been removed as they were originally intended for a conversation dynamic where people talk over each other. With the introduction of the 'Speaking turn' object, it is inherently clear if the patient wants to talk or not as holding or asking for the object reveals the patient wants to say something.
- **The 'Add' card** was discarded because its focus was on patients who were completely unable to speak. However, as the target group focus has shifted toward patients who *can* speak but prefer to minimize verbal output (due to energy depletion or pain), the goal of these cards has shifted. The focus is now on maximum energy conservation while directing the flow of the conversation.

### Barrier Cards (Blokkade kaarten)

These cards lower the threshold for discussing difficult end-of-life themes at home. Instead of waiting for a clinical consultation, patients can use these tools to initiate sensitive conversations with loved ones. These cards provide an accessible way to start the dialogue by helping patients articulate their worries, ensuring important matters are shared with loved ones rather than left unsaid.

### Wish Cards (Wens kaarten)

A key aspect of end-of-life is how a patient chooses to spend their remaining time. The Wish cards are designed to help the patient think about and share how they want to give meaning and purpose to this final stage; what still matters most and what they still wish to do or experience. Instead of focusing on limitations, these cards invite a positive perspective on the time that remains and how to best tailor it to the patient's wishes.

### Blanco Cards

To support the personalization of communication, each category includes blank cards. These provide space for personal themes or agency-related actions that fall outside the standard set. This is necessary because communication is inherently dependent on both context and the individual, meaning a predefined set can never fully cover every unique situation or person.

*Design questions:*

- How can the cards be easily distinguished from one another (e.g., through shape, size, or color)?
- What material (e.g., weight and thickness) should the cards be made of?
- Should the cards use text, visuals, photos, or a combination?
- What specific content will be featured on the cards?
- What will be the 'tone' of the cards?
- What final names or titles will be assigned to the cards?

### ‘Speaking turn’ object

Normal conversations can move (too) quickly, making it difficult or exhausting for a patient to remain an active participant. To maintain a calm and structured conversation for the patient, a clear speaking turn-taking system is introduced using a physical object. By sharing a collective object, the assumption is that it will foster a deeper sense of connection, as everyone shares the same item.

*Design Questions:*

- What will the object look like (material, shape, etc.)?
- How can the object minimize energy consumption for the patient: should it be held, or can it be placed on a surface?

### Interrupter

The interrupter serves as the signal for the patient to claim their turn to speak. The assumption is that a sound signal is essential to immediately capture the attention of everyone present, regardless of their line of sight. For example, when NOK starts talking only to each other. This tool is intended to minimize the threshold for joining the conversation: instead of requiring physical or verbal effort to break in, a single sound is sufficient to claim the floor.

*Design Questions:*

- What will the object look like (material, shape, etc.)?
- What type of sound should be used?

### Emoticons

Emoticons can often convey at a glance what would otherwise require many words. They are intended to clarify intent and add nuance to an agency card, allowing the patient to add personality to the interaction in an energy-efficient way. This can be compared to messaging on your phone: texts gain character when emoticons are used in a unique and personal manner.

*Design Questions:*

- Which emoticons will be used?

### Box / packaging

Of course, the packaging for all components must also be considered.

*Design Questions:*

- What will it look like (material, shape, etc.)?

### 4.5.2 Answering the Design Questions

This section describes the concept and demonstrates how the design questions were addressed for all parts of the design.

#### Card Set

*The following design choices apply to all cards.*

**Material**
The material chosen for the entire card set is cardstock (similar to the material used for playing cards). This choice ensures that the cards remain lightweight, requiring minimal physical effort from the patient to pick up and hold, (in line with Requirement 7).

**Differentiation between cards**
To ensure clear differentiation between the Agency Cards and the Content Cards (Wish and Barrier Cards), each category uses a unique color and size. Testing physical dimensions (See Appendix F) showed that making Agency cards smaller makes them feel less invasive and more subtle, supporting a low threshold of use. Conversely, larger Content cards were chosen to accommodate the elderly target group, who generally prefer larger text and visuals for better readability.

The selected dimensions are:
Agency Card: 9 x 6,5 cm
Content Cards: 12,5 x 8,5 cm

**Visual Design**
Guided by Requirement 7 (minimal cognitive effort), a minimalist design was chosen to keep the cards simple and clear. Each card combines a recognizable visual with a small amount of text, ensuring the patient can grasp the meaning quickly without using much energy or mental effort. These visualizations make the cards instantly recognizable and emotionally accessible, while the concise text provides added clarity

**Tone**
The visuals on the cards use a calm, accessible and warm tone as this suits the vulnerable target group. The visuals are suggestive rather than literal, as this prevents confronting patients with images of activities they may no longer be able to perform because of their illness. This ensures the tool remains inclusive regardless of a patient's health status. In case a patient wishes to create a personal tone, blank cards (and adding tokens) allow for further personalization.

**Content of the Cards**
The content of the cards will be explained per each category and is derived from literature provided by Erasmus MC, assumptions and the 13 FPN. The phrasing is

designed to guide the conversation topic while leaving room for individual interpretation and response.

## Agency Cards

While several agency cards were originally based on assumptions, research specifically concerning palliative HNC patients reinforced the decision to include them (see Table 2). The literature served as inspiration for the text on the cards.

| **Goal** | **Literature** | **Text on card** | **Visual Inspiration** |
|---|---|---|---|
| **Tempo verlagen** | Fatigue and cognitive strain make conversations difficult. Patients sometimes have trouble processing information and are not always able to keep up with the pace on their own. (Van den Besselaar et al., 2025; Saghafi et al., 2023) | "Iets langzamer graag" |  |
| **Om herhaling van iets vragen** | Patients can feel overwhelmed by information. What is said does not always get through or is not fully understood. (Van den Besselaar et al., 2025; North et al., 2021)* | "Kun je het herhalen?" | 2X |
| **Op iets terugkomen** | Important topics sometimes come up later, once the initial shock has passed. Patients want to be able to indicate that they'd like to come back to something without interrupting the conversation. (Van den Besselaar et al., 2025) | "Hier wil ik later graag op terugkomen" |  |
| **Onderwerp niet nu bespreken** | Not every topic can be discussed at any given moment. Patients sometimes want to be able to set a topic aside without it disappearing. (North et al., 2021; Lang et al., 2013) | "Over dit onderwerp heb ik het nu liever niet" |  |
| **Niet begrijpen** | Complex information can create barriers to understanding. Patients do not always feel comfortable admitting that they have not understood something. (North et al., 2021) | "Ik begrijp het niet, kun je het in andere woorden uitleggen?" | ? |
| ***Blanco kaart, zelf in te vullen*** | - | *Zelf in te vullen* | - |

*Table 2: Agency cards: the goal of each card and the text + visual on them*

Some cards made, to illustrate the back, visual tone and content:

*Figure 12: First version of Agency Cards*

**Color of inner edges**
A conscious decision was made to keep the inner edges the same color as the card type (in this case, blue), so that the card is immediately recognized as an “Agency card”

**Blanco cards**
The blank cards are left completely open to allow for maximum personalization. This gives the user full control over the content, whether they choose to add a single line of text, a specific visual, or a combination of both.

> *"With an old friend, they used to shout 'Too long!' if someone kept talking; you could easily write an inside joke like that on a blank card." — Family member*

**Number of cards**
To minimize cognitive load (in line with Requirement 7), a compact set of **5 base cards** was selected. This ensures that the patient can quickly identify the appropriate card during a conversation. **3 Blanco cards** have been added to provide the patient with sufficient space for personalized content.

## Barrier Cards

The barrier cards address themes that palliative HNC patients often struggle with and may find difficult to discuss (see Table 3). The topics on the cards are based on topics discussed in literature. By identifying with these topics, patients are provided with a concrete starting point to discuss them with their loved ones.

| **Topic** | **Literature** | **Text on card** | **Visual inspiration** |
|---|---|---|---|
| **Uncertainty and waiting** | Patients want to know what the future holds, but are reluctant to ask, either out of fear of the answer or so as not to burden the healthcare provider. Questions about prognosis are rarely discussed spontaneously. (North et al., 2021; Van den Besselaar et al., 2025) | “Er zijn dingen die ik eigenlijk graag wil weten, maar ik durf er niet naar te vragen" |  |
| **Fear of the future** | Patients are afraid of what lies ahead (North et al., 2021; Van den Besselaar et al., 2025) | “Ik ben bang voor de toekomst” |  |
| **Lonely in the illness** | The loss of everyday activities (eating, speaking, working, socializing) is a profound experience, but one that is difficult to explain to people who have not gone through it. (Lang et al., 2013; Saghafi et al., 2023) | “Ik vind het moeilijk uit te leggen wat ik allemaal meemaak, omdat ik het gevoel heb dat mensen me niet *echt* (kunnen) begrijpen” |  |
| **Unwillingly downplaying complaints** | Patients tend to downplay their symptoms when speaking with healthcare providers. (Lang et al., 2013; Saghafi et al., 2023) | “Ik minimaliseer mijn klachten vaak (tegenover zorgverleners)” |  |
| **Reluctant to share all their feelings** | Patients sometimes view their feelings as ‘luxury problems’ that they are not allowed to acknowledge. (Lang et al., 2013; Saghafi et al., 2023) | “Ik ben terughoudend in het delen van *al* mijn gevoelens, omdat het voelt alsof het ‘overdreven’ overkomt“ |  |
| **Giving meaning to the experience** | Patients seek meaning and reassess what matters to them. At the same time, they do not always want to talk about their illness or come across as somber, but they do not know how to bring up this subject. (Lang et al., 2013; Saghafi et al., 2023) | “Ik wil niet altijd over de ziekte praten, maar ik weet niet goed hoe ik dat zeg” |  |

|  |  |  |  |
|---|---|---|---|
| **To feel burdened** | Patients feel like a burden to their loved ones and withdraw to protect them, even though what they truly long for is genuine connection. The care provided by their loved ones feels like an additional burden to bear. (North et al., 2021; Lang et al., 2013) | "Soms voel ik mij een last" |  |
| **Finding a way/balance between the 'present' and the 'future'** | Patients are unsure whether it is okay to look ahead or make plans. Some consciously live in the present; others struggle with a frustrated longing for normality. (Lang et al., 2013; North et al., 2021) | "Ik vind de balans vinden tussen in het 'nu' leven en bezig zijn met de toekomst lastig" |  |
| **Acceptance and letting go** | "Acceptance and letting go are the hardest parts of the illness" (No Pictures, 2024) | "Ik heb moeite met acceptatie en loslaten" |  |

*Table 3: Barrier cards: the goal of each card and the text + visual on them*

Some cards made, to illustrate the back, visual tone and content:

*Figure 13: First version of Barrier Cards*

**Blanco card**

The existing cards can inspire patients to identify personal topics of concern that are not directly covered by the standard set. In such cases, the blank card provides the necessary space to write these down and share them with loved ones.

**Number of Cards**

The set consists of **9 base cards** based on common struggles found in research, with **3 Blanco cards**. This quantity was chosen to ensure the set remains manageable and clear.

## Wish Cards

The wish cards are intentionally open-ended (see Table 4). This provides patients with full freedom for personal input, ensuring the cards align perfectly with how they wish to shape their remaining life.

### Inspired by the 13 Fundamental Psychological Needs

Although Chapter 2 identified which needs are often prioritized for palliative patients, that analysis narrowed the focus to needs that frequently remain unfulfilled in practice. For the wish cards, it was decided to return to the full spectrum of the 13 FPN as a source of inspiration for the content.

The rationale is that every fundamental need, regardless of its general priority, can serve as an essential source of meaning for an individual in the final stage of life. The cards focus on a positive ‘wish perspective’: the goal is not to identify unmet needs, but to explore and share personal desires regarding how to spend this final phase.

Literature regarding palliative HNC was synthesized with the 13 FPN to maintain a clear focus on the target group and the unique clinical and personal context of these patients.

| Fundamental Need | Literature | Text on card | Visual Inspiration |
|---|---|---|---|
| **Autonomy** | Patients want to continue making their own choices about treatment and daily life, even as they become more physically dependent. Maintaining agency is seen as essential. (Mayland et al., 2021; Saghafi et al., 2023) | “Ik wil zelf kunnen beslissen over…” or<br>“Ik wil de controle houden over…” |  |
| **Relatedness** | Patients sometimes feel like a burden to their loved ones but long for genuine connection; not just care. (North et al., 2021; Lang et al., 2013) | “Wat ik nog heel graag samen zou willen doen is…” or<br>“Wat ik graag nog voor jou wil betekenen, is…” |  |
| **Purpose** | Patients reassess what truly matters. Life goals and meaning shift; some focus on small pleasures, while others focus on what they still want to experience. (Lang et al., 2013; Saghafi et al., 2023) | “Mijn doelen in het leven zijn..” or<br>“Wat ik graag nog wil in het leven: …” |  |
| **Security** | Fear of (a difficult) death and of what remains unspoken is big. (North et al., 2021; Van den Besselaar et al., 2025) | “Ik wil graag zekerheid als het gaat om…”<br>or<br>“Ik wil me graag veilig voelen als het gaat om…” |  |

| | | | |
|---|---|---|---|
| **Recognition** | Patients want to be seen as people, not just as patients. (Lang et al., 2013) | “Ik wil dat mensen mij zien als…” |  |
| **Community** | Connecting with peers is a significant unmet need: 50% of patients want to talk to someone who has been through the same experience. (Ferri et al., 2024) | “Ik zou graag nog met deze mensen in contact komen:…” |  |
| **Comfort** | Patients are afraid of what lies ahead, affecting their piece of mind. Fatigue and cognitive strain make conversations and daily life difficult. Patients seek rest, simplicity, and clarity. (Van den Besselaar et al., 2025; Saghafi et al., 2023) | “Wat voor mij het leven makkelijker zou maken, is…”<br>or<br>“Wat mij mentale rust geeft, is…” |  |
| **Morality** | Patients struggle with treatment decisions that conflict with their own values. (Mayland et al., 2021; North et al., 2021) | “Een behandelproces dat goed bij mij zou passen, is…”<br>or<br>“Ik zou graag willen dat het behandelproces in lijn is met mijn eigen waarden” |  |
| **Competence** | Complex medical information often acts as a cause to lack the feeling of competence, leaving patients feeling inadequate and helpless (Ferri et al., 2024; Saghafi et al., 2023) | “Wat ik graag beter wil begrijpen, is…” |  |
| **Stimulation** | Small pleasures become big ones. Patients rediscover the joy in everyday things and seek out what still matters to them. (Lang et al., 2013; Saghafi et al., 2023) | “Iets wat me nog echt plezier geeft, is…” |  |
| **Fitness** | Illness and treatment cause profound changes to the body. Problems with eating, speaking, and appearance are prominent. (Hazzard et al., 2019; Lang et al., 2013) | “Wat ik graag nog zou willen doen dat lichamelijk nog kan, is…” |  |
| **Beauty** | Patients seek harmony and aesthetic meaning in their surroundings, even when their lives are in turmoil. (Lang et al., 2013) | “Wat ik om me heen mooi vind, is…” |  |

| | | | |
|---|---|---|---|
| **Impact** | Patients reflect on their legacy and the people they have made a meaningful impact on. A shift in priorities from work to relationships and legacy. (Lang et al., 2013; Saghafi et al., 2023) | "Wat ik graag wil nalaten, is..." |  |
| *Open wens, zelf in te vullen* | - | "Mijn wens:"<br>*Zelf in te vullen* | - |

Table 4: Wish cards: the goal of each card and the text + visual on them

Some cards made, to illustrate the back, visual tone and content:

Figure 14: First version of Wish Cards

**Blanco card**
The cards can inspire patients to formulate their own wishes that are not directly covered by the predefined set. In such cases, the blank card provides the necessary space to write down these personal wishes and share them with loved ones.

**Number of cards**
A set of **13 base cards** was chosen (inspired by the 13 FPN), with **3 Blanco cards**.

## Talking stick

Using a physical stick is a proven technique to structure dialogue by giving speaking turns. In line with Requirement 7, bamboo was selected because it is lightweight and ergonomic, ensuring minimal physical effort for the patient. Having a talking stick (see Figure 15) in this shape and size, ensures a clear visual reminder of the speech turn for everyone using it without being too prominent.

**Material**
To prevent the talking stick from being perceived as an isolated component, visual unity was sought throughout the entire set. Incorporating bamboo into various components creates a material connection, making the entire set feel like a unified whole.

*Figure 15: Illustration of the Talking Stick*

## The Bell

The bell (see figure 16) is a non-verbal tool used to claim the talking stick. As a universally recognized object, its clear and not-to-miss sound immediately captures attention, allowing the patient to claim the talking stick at any point in the conversation with very low effort.

**Material**
Bamboo is also used for the base of the bell, ensuring clear material consistency within the concept. This allows the bell to form a visual unity with the other components of the set.

*Figure 16: Illustration of the Bell*

## Tokens

The primary role of the tokens (see Figure 17) is to facilitate the design goal 'expressing personality'. By adding tokens to agency cards, patients can soften or nuance their message; for example, adding 🥰 to an Agency card makes the request feel more personal and less direct. Patients are free to decide how and if they use the tokens. Whether they choose a single 👍 or an expressive combination like 🥰❤️👍, they remain in control of the tone of the interaction. Ultimately, the way the tokens are used serves as a direct reflection of the patient's personality.

*Figure 17: Illustration of the Emoticon Tokens*

Tokens can also function as a mood indicator.
By simply placing a token nearby, the patient can communicate their current state of mind, helping loved ones instantly grasp the emotional context.

## The Box

The Box would be made of bamboo, where ale elements are stored, and would be designed to be both aesthetic and user-friendly, with a focus on accessibility. Bamboo provides a neutral, inviting look while remaining lightweight. Crucially, the box must remain compact; a large, bulky design would likely increase the barrier to use. Due to time constraints, the exact looks, measurements and a manual for this design still had to be explored.

## Flexible Use

Because a patient's (physical) circumstances can vary and communication is deeply personal, the set is designed to be used **at the patient’s discretion.** There are no fixed rules; patients are free to use as much or as little of the set as they wish; every element is **entirely optional.** The assumption is that this **optionality** strengthens the patient's sense of **autonomy and identity:** after all, you decide what and when to use it (autonomy), but also how to use it (identity).

For instance, while tokens allow for personalization and blank cards offer space for unique input, their use is entirely optional. If the setting does not require the bell, the patient can leave it in the box. Patients can decide which and how many topics to discuss in each session. Beyond the content, the timing and context of use are also at the patient's discretion: whether used daily, with specific people, or only for a few minutes. Ultimately, every element is tailored to the user's preference; it is *their* conversation.

### 4.5.3 Scenario Example of Use

A scenario has been illustrated to demonstrate product usage. Although the box is smaller in reality, it has been enlarged here for visual clarity. This scenario should be viewed as an **example of how to use it**; the strength of the concept lies in the patient's freedom of use of all elements. This illustration serves purely to show how the tools can be used collectively and the role the Nurse Specialist (VPKC) can play in this process.

**Hans** = Palliative HNC patient, **Anita** = Hans’ wife, **Ben** = Hans’ son

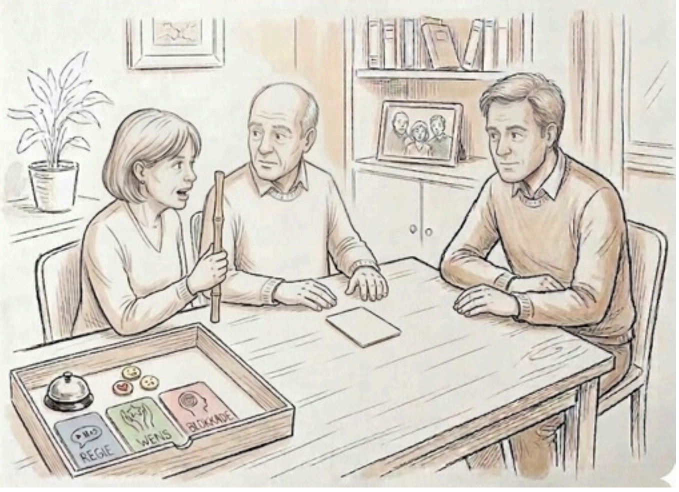
**1. The Introduction** Hans and Anita visit the VPKC (Specialist Oncology Nurse). The nurse explains how the concept works and encourages them to try it at home. She mentions that during their next follow-up call, she will ask them about their experience with it.

**2. Starting the Conversation** Later that day, their son Ben visits. Ben provides a lot of care for his father since Hans got sick and is curious about the appointment. Hans and Anita tell him about the box they received and suggest trying it out together. Hans agrees, and they place the box on the table.

**3. Identifying Blockades** They begin by laying out the **'Blockade cards.'** Anita asks Hans, "Do you recognize yourself in any of these?" Hans points to a card that describes exactly how he feels.

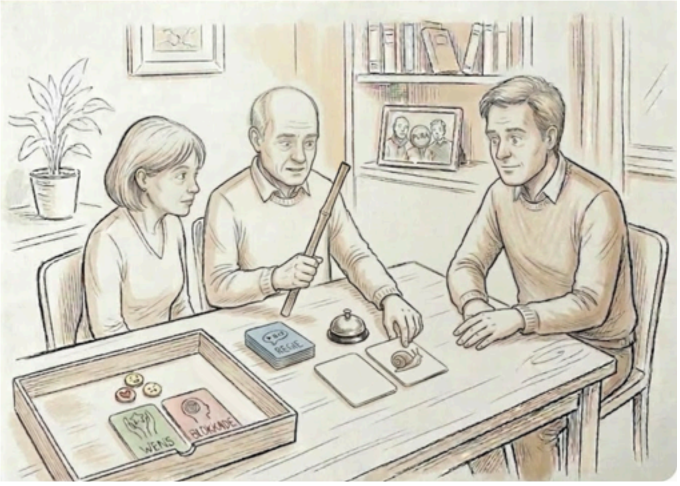
**4. Finding the Right Pace** Hans picks up the **Talking Stick** to start sharing. Although speaking is physically painful for him, the tool creates a calm conversation: Hans is the only one allowed talking.

**5. Anita replies** Anita waits for him to finish and then asks for the stick, so she can respond. Hans notices that because the **pace of the conversation** is lower than usual, it takes him much less effort to stay focused and engaged.

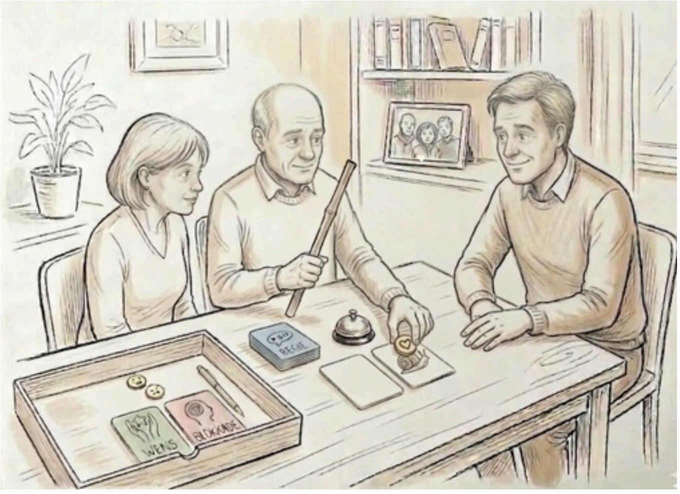


**6. Using the Bell** When Ben takes the stick, he starts talking very fast, something he often does when he is enthusiastic or worried. Hans wants him to slow down a bit. Normally, Hans would find it difficult to interrupt because he is low in his energy, but now he simply **rings the bell**. Ben stops immediately.

**7. Using the Regie Cards** Hans then places the *'Snail'* card (slower, please) on the table.



**8. Adding tokens** Because Hans doesn't want to seem too commanding, he adds a '*Heart*' token to show he appreciates Ben. Ben smiles and says, "Sorry Dad, I forgot I was going too fast." He continues his story more slowly. They continue to have a conversation in this way: the person who has the talking stick talks and if Hans wants to interrupt, he rings the bell and gets the talking stick back.



**9. Asking for Clarification** Later, Ben uses some complicated terms. Hans feels lost but doesn't want to give up. He rings the bell again to claim the Talking Stick. He looks through his **Regie cards** and places the '*Question Mark*' in front of Ben, which says: *"I don't understand"* Again, he adds a heart token to show his appreciation. Ben simplifies his explanation, and Hans feels included again.

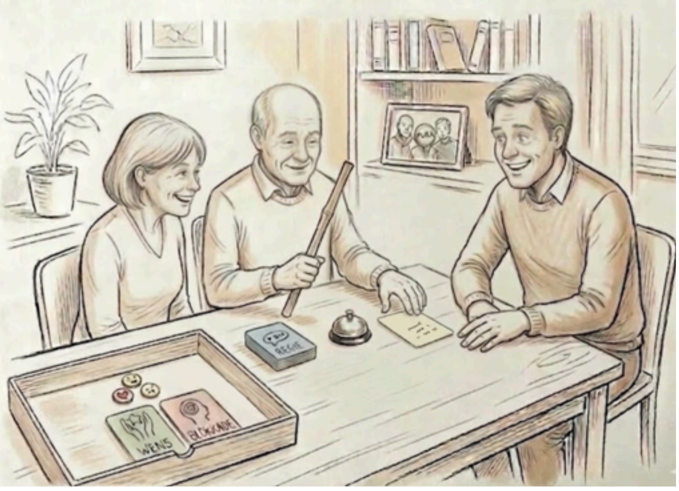
**10. Using the Blank card** After a while, Hans is done with the conversation about the topic. He wants to keep the atmosphere positive, so he uses a **Blanco card** he customized himself. It says: *"En nou is t mooi geweest!"*; a classic family phrase they use to jokingly end a conversation. It's a lighthearted and very personal way for him to signal his limits.

**11. Sharing a Wish** Before they finish, Hans is curious about the **'Wish cards.'** He picks one from the stack:

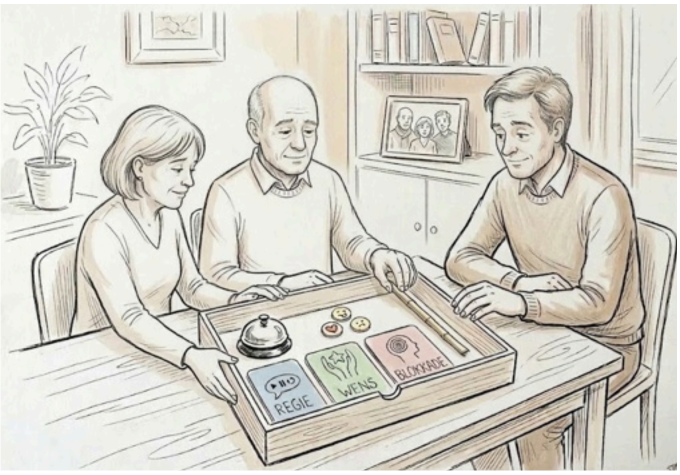
**12. Sharing the wish** *"Something I would still love to do together is..."* He thinks quietly while Anita and Ben wait patiently. In a normal conversation, they might have filled the silence for him, but now he feels the space to think. He finally shares his wish: he wants to go to an outdoor cinema together. He had been afraid to ask, thinking it would be too much trouble for them.

**13. A Positive Outcome** Ben and Anita are thrilled by the idea. Ben asks for the stick and says, "Dad, that's amazing! I'll book the tickets tonight." Hans is surprised and happy that his wish was received so well.

**14. Ending the Session** Although he is happy, Hans is now exhausted. Speaking has taken all his energy. He rings the bell one last time, places his *"En nou is 't mooi geweest!"* card on the table.

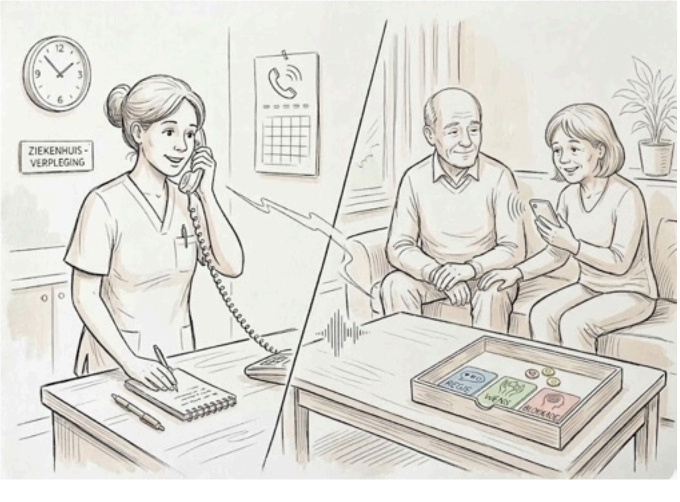


**15. Putting the box away** Hans puts the Talking Stick back in the box. This is the signal for Anita and Ben that Hans is done for now.



**16. Feeling good** While Anita and Ben continue chatting in the background, Hans leans back and enjoys the sound of their voices, feeling peaceful, in control and strong connection with his loved ones.

**17. Call with the VPKC** The VPKC calls Hans and Anita again to check in on Hans and ask how they liked using the cards. Because Hans finds it difficult to speak, Anita speaks on his behalf. She shares that they have had several interesting and meaningful conversations together and explains Hans' wishes and needs. Hans is relieved that Anita can express what is going on in his mind. The nurse is pleased to hear this progress and provides them with tailored care.



### 4.4.4 Lowering the Barrier to Use

While the Content cards themselves are designed to lower the threshold on starting a conversation about these topics, here are a few suggestions to encourage people to actually start using them:

- **The role of the VPKC:** The VPKC introduces the tool and explains its use, making the start feel less overwhelming. By following up during subsequent consultations, they provide motivation as this could be seen as a friendly ‘stok achter de deur’: it allows patients to shift the ‘reason’ for starting to the VPKC (e.g., *"The nurse suggested we try this"*), lowering the emotional threshold to begin.

- **Start with Wish Cards:** Beginning with the positive, lighter topics found in the Wish Cards creates a low-pressure entry point. Once patients and loved ones are comfortable using the set, the transition to the Barrier Cards becomes more natural.

- **Initial initiative by loved ones:** Since the topics can be confronting, it may be easier if loved ones take the lead initially. Their barrier to starting might be lower because the focus is not directly on their own process. By removing the burden of initiative from the patient, the conversation becomes more accessible. Over time, as the tool becomes familiar, the patient might feel more confident starting the dialogue themselves.

- Include an **instruction booklet/ manual** that explains how the elements can be used and emphasizes the flexibility of use.

### 4.4.5 Benefits for Erasmus MC

The concept not only provides proactive psychosocial support - aligning with Erasmus MC’s objectives - but also facilitates valuable feedback for the VPKC, enabling them to better understand the needs and feelings of the patient. When the tool is used at home, partners can better understand and articulate the patient’s state of mind and needs of the patient to the VPKC. This addresses the ‘*communication gap*’ between patient and VPKC earlier defined in Chapter 2.2.2. This tool offers an opportunity to gain deeper insight into those needs.

## 4.6 Feedback by Experts

Feedback sessions provided new insights that led to further design adjustments.

### The Experts

The concept was discussed with four experts:

- **Medical Specialist in palliative care**
- **A palliative representative:** a palliative HNC patient who is also a board member of a patient association, and could therefore speak on behalf of the broader patient community as well.
- **Practical Nurse**
- **General Practitioner**

### Method

These were open feedback conversations. First, experts were asked about their experiences regarding communication barriers and the psychological impact of the physical limitations that patients may face. Furthermore, experts' initial impressions of the concept and its elements - using a photo of the prototype (see figure 18) and the scenario as a reference - were asked and whether they could envision the target group using this concept. Additionally, feedback was requested on the content of the cards, using table 2, 3 and 4 and the overall tone of the cards, themes and the phrasing, using Figure 12, 13 and 14. Due to circumstances, these interviews were all conducted online.

*Figure 18: Prototype of concept, shown to experts*

### Results

**Design Goal**

All experts recognized the tool as a valuable instrument for both maintaining agency during a conversation and discussing sensitive topics. A patient representative even emphasized that the design '**hits the nail on the head**' by acknowledging how physical barriers in communication is such a struggle for HNC patients and often lead to exhaustion and involuntary withdrawal. It was emphasized how this can lead to isolation and loneliness. Overall, the experts clearly envisioned this product being used by the target group.

> “This really ‘hits the nail on its head’ when it comes to head and neck cancer” - Patient

### General Concept

Experts agreed that the tool is highly applicable in practice. However, they noted that its success should be tested further and **depends on the patient’s personality and openness**. For instance, it’s possible that patients won’t want to use it because of religious beliefs, or simply because they don’t want to talk about their feelings in general.

### Content and Language

***Agency Cards***: The cards were described as clear and intuitive. The patient suggested including an ‘*end of conversation*’ card. It was also emphasized that these cards must contain text; since the target group often struggles with short-term memory, icons alone may be insufficient.

***Content of the Theme cards***: Together with the experts, the sentences written on the theme cards were discussed and improved together based on their feedback.

***Wording***: Phrases should remain ‘open’, to avoid leading the patient toward a specific answer and allowing for personal interpretation. For example, remove words like ‘because’. It was also noted that word choice is critical; for example, phrases like ‘goals in life‘ can be interpreted negatively by patients as this suggests that they have a long life to live. Therefore, the wording is crucial.

***Name of the Barrier cards***: The term ‘Blokkade’ was considered too heavy to most experts. The alternative, *‘Drempelkaart’* was received positively.

***Language Level***: To ensure accessibility for patients with lower literacy, which was mentioned many HNC patients are, the text must be at a B1 level: short, powerful, and clear.

> "I would use this! It could spark many beautiful, important, and valuable conversations between patients and those close to them." - Patient

### Tone and Social Connection

The ‘game-like’ format was praised for making discussing heavy topics more accessible. This approach allows for a lighter tone, where the wish cards can even be used for positive bonding. Furthermore, the tool fosters relatedness, as loved ones can also answer the questions, turning the experience into a shared activity. Experts valued the flexibility of the set, noting it can be used in various social contexts (e.g., with a partner, child, or grandchild).

> "What I like is how accessible it is; it almost feels like a game, which makes it very approachable. For example, you could even discuss the wish cards in a relaxed evening setting over a glass of wine." - Patient

### Physical Design and Usability

***The Box***: Feedback indicated that the box design shown in the prototype and scenario appeared too bulky. It needs to be a more compact, attractive format to lower the barrier to use.

***Tokens***: Their meaning must be unmistakable. Seniors do not always recognize WhatsApp emojis (e.g., mistaking 'crying with laughter' for 'sadness'). Ergonomically, they should be larger than a €2 coin to be easily handled.

***Guidance***: Professional guidance is essential. Experts suggested that the VPKC should introduce the tool. Beyond a written manual, a short instructional video was recommended to make the starting process as low-threshold as possible.

***Number of elements***: Although an expert suggested that the number of elements could be overwhelming, this is mitigated by the principle of optionality. Since patients are under no obligation to use the entire set, they can simply select the parts that feel right for them.

***Might feel 'childish':*** The components all together might feel childish. This was also given as feedback by one of the Palliative Care Researchers of Erasmus MC. Whether this is the case, needs to be tested with the target group.

## Conclusion: what needs to be adjusted

Some aspects of the feedback are based on testing with the actual target group. For example, if it will come across as 'childish' or 'is the tone approachable for this specific group'. However, some adjustments can already be made:

- **Content of the cards**: based on the feedback, change the phrases content and wording wise. Make the text very clear, shorter, not confronting and B1 level.

- **Name of the 'Blokkade' card**: change it to a less heavy word, like 'drempel'.

- **Add a manual and a video for guidance**: so patients and NOK can read and watch this before using the tool, to lower the threshold and make everything very clear.

- **Use very clear emoticons**: there should not be a possibility of misunderstanding the meaning of an emoticon

- **Adjust box size**: make the box a size that feels and looks approachable.

Of course, this eventually needs to be tested with the target group as well, but by adjusting these elements based on expert feedback, the design is more likely to be successful.

# 5. The Design - “*Wat ik zeggen wil*”

Based on all the feedback received, own insights and assumptions, the design was developed.

## The Name: *Wat ik zeggen wil*

A good name of the tool is essential, as it sets the tone for the entire design. An accessible title was chosen to keep the barrier to use low and reflect the patient’s need for communication and agency. The title implies that the patient wants to share something, and with this tool they can explain what.

## Theme Cards

Both the Barrier cards as the Wish cards were optimized.

Figure 19: The back of Barrier cards

### Barrier Cards

*Difficult-to-discuss topics palliative HNC patients can struggle with.*

The back of all Barrier cards is shown in Figure 19. The content of all Barrier cards are shown in Figure 20.

Figure 20: Content of all Barrier cards

Figure 21: The back of Barrier cards

## Wish Cards

*Open-ended questions for the patient to complete regarding how they wish to spend the final phase of their life.*

The back of all Wish cards is shown in Figure 21. The content of all Wish cards are shown in Figure 22.

Ik wil graag de **regie** houden over...

Wat ik nog heel graag **samen** zou willen doen is...

Wat ik om me heen **mooi** vind, is...

Wat ik graag beter wil **begrijpen**, is...

Ik zou graag nog met deze mensen **in contact** komen:

Wat mij **mentale rust** geeft, is...

Wat ik nog graag **zelf** zou willen **doen**, is...

Wat ik graag nog **wil** in mijn leven:

Wat ik heel **belangrijk** vind in mijn **zorg** en **behandeling**, is...

Wat ik graag wil **nalaten**, is...

Ik wil graag me **veilig** voelen als het gaat om...

Iets wat me nog echt **plezier** geeft, is...

Ik wil dat mensen mij **zien als**...

Mijn wens:

Mijn wens:

Mijn wens:

*Figure 22: Content of all Wish cards*

# The Agency elements

Figure 23: The back of Agency cards

## Agency Cards

*For the patient to use to keep agency in conversations and remain an active participant*

The back of all Agency cards is shown in Figure 23. The content of all Agency cards are shown in Figure 24.

Figure 24: Content of all Agency cards

### Placing of the cards

The idea is that you can place these cards on the table in front of you wherever you like and simply point to them. The assumption is that this is a very low-threshold and quick way to use the set. Furthermore, it offers the freedom to decide exactly where to place the cards, as well as which ones and how many to use.

## Talking Stick and the Bell

*These elements remained the same.*

### The Stick

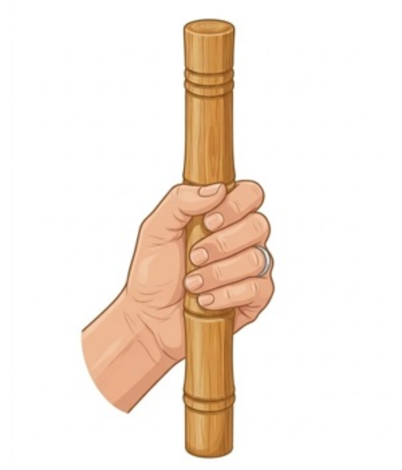


*Figure 25: The Talking Stick*

### The Bell

*Figure 26: The Bell*

## Tokens

The **selection** of emoticons:

*Figure 27: The Bell*

A personal assumption was that these emoticons are often used by people and are hard to be mistaken for what they mean.

**Size**: diameter of 4 cm.

## The Box

A box (Figure 28 and 29) with a simple and approachable design, made of bamboo. Although the original idea was to divide the box in a specific way (see Appendix G), a smaller size was ultimately chosen when making the high fidelity prototype of the design, to make it more approachable, where the assumption was this smaller size would be more likely to be put and kept on the table. The final dimensions are: **24x16,5x7 cm**

Figure 28: The box open with all elements inside, with manual

Figure 29: The box closed

## Guidance

**Step 1**: A VPKC explains the elements and use of the tool and facilitates a first session to demonstrate its practical application.

**Step 2**: The box contains a manual (see Figure 30) that explains how the tool can be used and what each element is designed for. The manual also includes a QR code, that will send you to a video you can watch for a demonstration on how to use the tool.

*Wat ik zeggen wil*

Voor waardevolle gesprekken met elkaar

**Inleding**

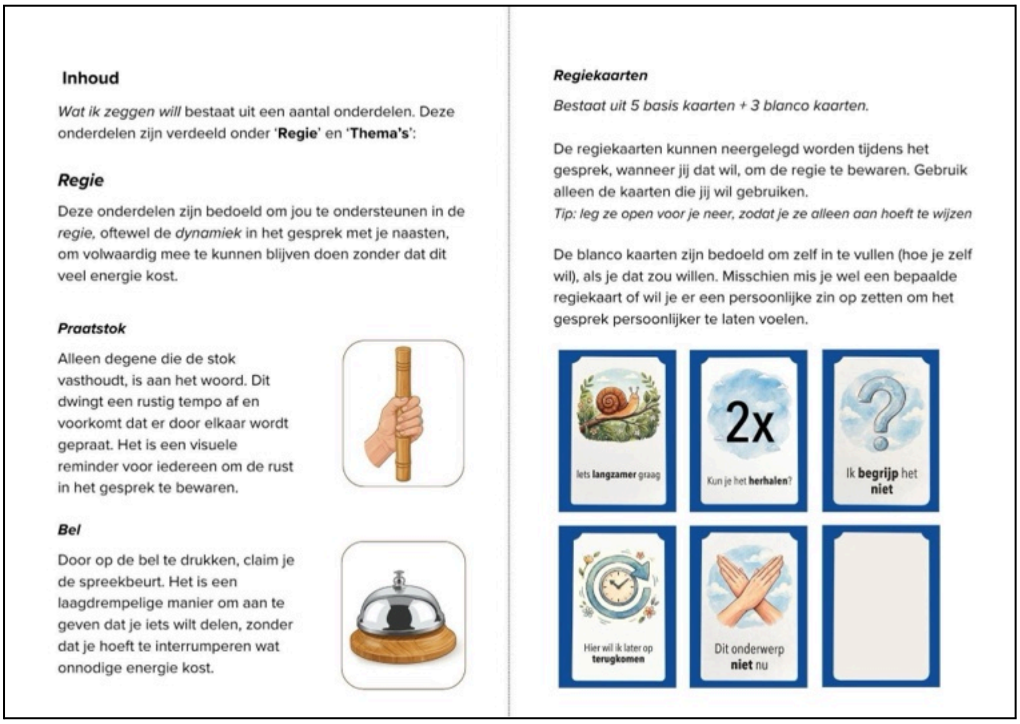
Goed kunnen communiceren is zeker in de palliatieve fase voor veel mensen belangrijk. Maar soms kan dit kan lastig zijn. Zo kan praten fysiek vermoeiend zijn, waardoor het lastig is om deel te blijven van een gesprek. Maar ook kunnen onderwerpen die de palliatieve fase met zich mee brengt simpelweg zwaar aanvoelen, of weet je niet zo goed hoe je erover moet beginnen. Dit ontwerp is er om jou en je naasten te ondersteunen om thema's met betrekking tot jouw situatie bespreekbaar te maken terwijl jij zelf de regie houdt over het gesprek zonder dat dit veel energie kost.

In *Wat ik zeggen wil* staat één ding centraal:

**Niets moet, alles mag**

Dat wil zeggen: alle onderdelen in de doos zijn geheel vrijblijvend en op jouw eigen manier te gebruiken. Ze dienen ter *ondersteuning* daar waar jij dat wil. Dit is geen spel met vaste regels, maar een gereedschapskist die jij opent wanneer jij dat wilt, op de manier die bij jou past:

Het is *jouw* gesprek.



**Inhoud**

*Wat ik zeggen will* bestaat uit een aantal onderdelen. Deze onderdelen zijn verdeeld onder '**Regie**' en '**Thema's**':

***Regie***

Deze onderdelen zijn bedoeld om jou te ondersteunen in de *regie*, oftewel de *dynamiek* in het gesprek met je naasten, om volwaardig mee te kunnen blijven doen zonder dat dit veel energie kost.

***Praatstok***

Alleen degene die de stok vasthoudt, is aan het woord. Dit dwingt een rustig tempo af en voorkomt dat er door elkaar wordt gepraat. Het is een visuele reminder voor iedereen om de rust in het gesprek te bewaren.

***Bel***

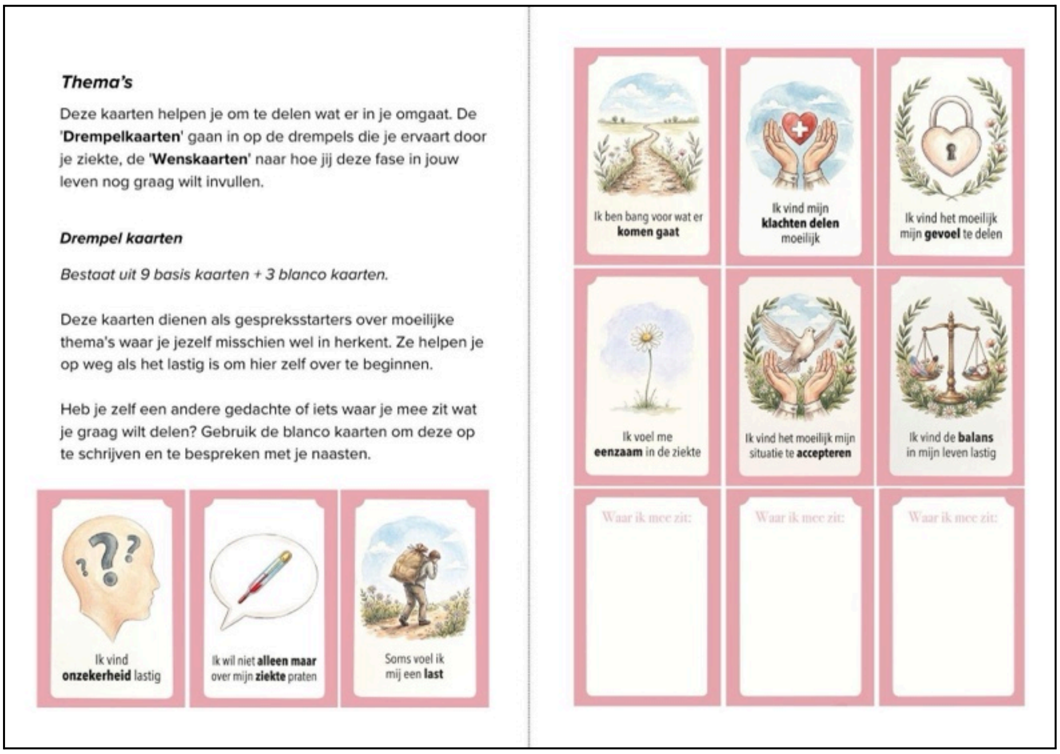
Door op de bel te drukken, claim je de spreekbeurt. Het is een laagdrempelige manier om aan te geven dat je iets wilt delen, zonder dat je hoeft te interrumperen wat onnodige energie kost.

***Regiekaarten***

*Bestaat uit 5 basis kaarten + 3 blanco kaarten.*

De regiekaarten kunnen neergelegd worden tijdens het gesprek, wanneer jij dat wil, om de regie te bewaren. Gebruik alleen de kaarten die jij wil gebruiken.
*Tip: leg ze open voor je neer, zodat je ze alleen aan hoeft te wijzen*

De blanco kaarten zijn bedoeld om zelf in te vullen (hoe je zelf wil), als je dat zou willen. Misschien mis je wel een bepaalde regiekaart of wil je er een persoonlijke zin op zetten om het gesprek persoonlijker te laten voelen.



### *Thema's*

Deze kaarten helpen je om te delen wat er in je omgaat. De '**Drempelkaarten**' gaan in op de drempels die je ervaart door je ziekte, de '**Wenskaarten**' naar hoe jij deze fase in jouw leven nog graag wilt invullen.

### *Drempel kaarten*

*Bestaat uit 9 basis kaarten + 3 blanco kaarten.*

Deze kaarten dienen als gespreksstarters over moeilijke thema's waar je jezelf misschien wel in herkent. Ze helpen je op weg als het lastig is om hier zelf over te beginnen.

Heb je zelf een andere gedachte of iets waar je mee zit wat je graag wilt delen? Gebruik de blanco kaarten om deze op te schrijven en te bespreken met je naasten.

Ik vind **onzekerheid** lastig

Ik wil niet **alleen maar** over mijn **ziekte** praten

Soms voel ik mij een **last**

Ik ben bang voor wat er **komen gaat**

Ik vind mijn **klachten delen** moeilijk

Ik vind het moeilijk mijn **gevoel** te delen

Ik voel me **eenzaam** in de ziekte

Ik vind het moeilijk mijn situatie te **accepteren**

Ik vind de **balans** in mijn leven lastig

Waar ik mee zit:

Waar ik mee zit:

Waar ik mee zit:

### *Wenskaarten*

*Bestaat uit 13 basis kaarten + 3 blanco kaarten.*

Deze bevatten open zinnen die je uitnodigen om na te denken en te delen hoe jij de laatste fase van je leven wilt invullen. Heb je een eigen wens die niet op de kaarten staan: voel je vrij om een blanco kaart in te vullen met jouw wens.

Wat ik om me heen **mooi** vind, is...

Wat ik graag beter wil **begrijpen**, is...

Wat ik nog graag **zelf** zou willen **doen**, is...

Ik zou graag nog met deze mensen **in contact** komen:

Wat ik graag nog **wil** in mijn leven:

Wat mij **mentale rust** geeft, is...

Wat ik heel **belangrijk** vind in mijn **zorg** en **behandeling**, is...

Wat ik graag wil **nalaten**, is...

Iets wat me nog echt **plezier** geeft, is...

Ik wil graag de **regie** houden over...

Wat ik nog heel graag **samen** zou willen doen is...

Ik wil graag me **veilig** voelen als het gaat om...

Ik wil dat mensen mij **zien als**...

Mijn wens:

Mijn wens:

***Fiches***

De fiches zijn bedoeld voor extra personalisatie en nuance.

- Leg ze bij een specifieke (regie)kaart om je boodschap persoonlijker te maken. Je mag er zo veel (of weinig) gebruiken als je wil: ze dienen ter ondersteuning van het uiten van jezelf.

*Voorbeeld: Misschien dat je de kaarten wel veel te direct vindt; dan kun je er bijvoorbeeld een fiche bij leggen van het hartje: jouw naasten weten: jij bedoelt het liefdevol.*

- Gebruik ze om je algehele 'mood' aan te geven aan het begin van een gesprek.

*Tip: Spreek van tevoren met je naasten af wat een fiche voor jou betekent, om misvattingen te voorkomen.*

**Suggesties hoe te gebruiken**

- *De selectie:* Wil je één kaart per keer bespreken of liever een stapeltje? Pak je blind een kaart of leg je de kaarten voor je neer en kies je er een om te bespreken?
- *Regiekaarten*: Leg ze voor je op tafel, zo hoef je ze niet vast te houden maar alleen maar aan te wijzen.
- *Themakaarten*: Leg ze open op tafel en kies, trek er een van de stapel of neem er een mee naar buiten.
- *De interactie*: Beantwoord jij als enige de kaarten, of nodig je je naaste uit om ook hun gedachten hierover te delen?
- *Fiches*: Gebruik je 1, meerdere tegelijk, of helemaal geen fiches per kaart? Gebruik je ze alleen om bij de kaart te leggen, of gebruik je ze om je gemoedstoestand aan te geven?

Voor een voorbeeld hoe *Wat ik zeggen wil* te gebruiken is, scan de QR code:

*Figure 30: The manual*

**Feasibility and viability**

The ‘low-tech’ nature of the design makes it highly feasible. Most elements and the box already exist in different shapes or forms and are fairly easy to produce, it does not contain any new, complicated technologies or digital infrastructure. This allows for immediate production and implementation, ensuring that support can reach the patient quickly.

Because of the low-tech nature, the product has a fairly low production cost. Depending on the budget available, this is beneficial for Erasmus MC. The design suits the remote care system and the objective of Erasmus MC, as it provides proactive psychosocial support from home. Next to that, it could support even better quality of care when follow-up consultations are implemented.

# 6. Evaluation

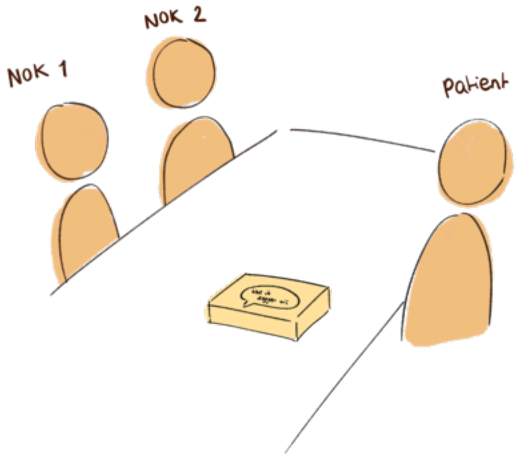
*Done by testing the interaction and a second round of feedback by experts.*

## 6.1 Testing the interaction

Two interaction tests were conducted with six healthy participants, divided into two groups of three. As it was not possible to test with the actual target group, the primary goal of these sessions was to identify general usability hurdles and observe interaction patterns by evaluating the intuitiveness and physical use of the product in general. The insights gained could be used to optimize the product and provide direction for further development.

### Setting

The two interaction tests were conducted with two different families, both at their own homes. In both cases, the interaction was done at a dinner table in the evening. Participants were free to choose their own seating positions at the table to create a realistic family conversation setting. Each group consisted of three people: one participant acting as the patient and two as next of kin. Group 1 included a mother (the patient), her son, and her daughter. Group 2 included a mother (the patient) - recovering from chemotherapy, so had a reduced energy level -, her partner, and their son.



*To simulate the physical communicative barrier, the participant in the patient role was only allowed to whisper.*

### Method

The test session followed a three-step process:

**Introduction**: First, the context of the design was explained, focusing on its purpose for palliative HNC patients. All design elements were introduced and explained, including their intended goal and potential ways to interact with them. It was strongly emphasized that all elements could be used flexibly and in any way the participants felt comfortable with.

**Observation**: Participants were then asked to use the product independently. During this 20-minute session, their interactions were observed to identify how they navigated the tool and which elements were most or least utilized.

**Evaluation**: The session concluded with an evaluation that combined questions for the participants (based on predefined questions and observation), with room for general feedback from the participants. This allowed them to reflect on their overall experience and their interaction with the design elements, providing qualitative insights into the designs usability and intuitiveness.

Figure 31: Test 1

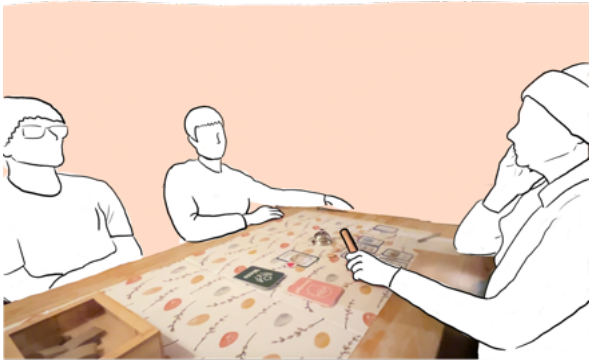


Figure 32: Test 2

## Results

The following section presents the key findings and insights gathered during the tests.

### General usability and intuition

- **Guidance**: In both groups the manual was not used once; instead, participants relied on the researcher's explanation and explored the design through hands-on interaction. This led to occasional seeking of validation from the researcher ("*Is this right?*"), which conflicts with the tool's goal of total flexibility and freedom of what and how to use it. Although mentioned multiple times, it was not 100% clear there is not one 'correct' way to use the design.

- **Visual Clarity**: The illustrations on the 'agency' cards were considered so clear that patients did not feel the need to read the text. This reduced their cognitive load.

> *"I recognized the cards immediately based on the visual, I did not need to read them anymore"* - Patient 1

- **Design of the box**: The 'tea box' aesthetic was perceived as positive and approachable. The design fits well into a domestic setting, as it reminded the participants of a 'tea box' and would be likely to be put and kept on the table, which may increase the likelihood of (regular) use.

## Conversational dynamics and feeling of Autonomy

According to both ‘patients’, the talking stick and the bell were considered *essential* to keep agency in the conversation. These elements changed the dynamics and the feeling of agency for the patient in the conversations, in multiple ways:

### The Talking Stick

- **Created a calm pace of the conversation**: This ensured that patients did not feel rushed and were given the time they needed to speak. This allowed them to remain active participants with minimal physical effort.

> *“The calm pace is essential to minimize cognitive load and stay an active participant”* - Patient 2

- **Different attitudes towards the talking stick**: While the NOK perceived the talking stick as a barrier to spontaneity and a 'natural' conversational flow, patients viewed it as an essential tool for inclusion. For the patients, the structured security of being heard clearly outweighed the desire for a 'natural' conversational flow.

> *“In a ‘normal’ conversation flow, I would not have been heard. The talking stick made sure I was”* - Patient 2

- **Shared Responsibility**: A collective awareness emerged in both groups. Not only the patient but also (especially) the next of kin corrected one another if the talking stick was forgotten. This ensured that it was not just the patient who had to worry about this, which contributed to saving the patient's energy.

- **Usability**: In the beginning, the talking stick felt a bit ‘strange’, as it was new to everyone. However, after a very short while (+/-3 minutes) both groups got used to it already. It was very clear to them how to use it. However, the NOK sometimes felt uncertain when providing short feedback (like only saying 'I agree'); they didn't know whether to request the talking stick for it or say it without having the stick. Sometimes, the NOK got a little frustrated when they weren't allowed to say something if they did not have the stick.

> *“I sometimes struggled a bit when I wanted to respond briefly but didn’t want to claim the talking stick just for that”* - NOK

### The Bell

- **Used as interruptor**: The bell was especially considered crucial in the second testgroup. It provided the patient with an effortless way to claim attention when the NOK were talking (too fast) to each other, without having to physically talk over others. The bell was used twice in the second group and while the bell was not used in the first group, it was mentioned that they all could imagine an interruptor would most likely be used sometime.

> *“The bell was essential for me to break into the conversation at the start.”* - Patient 2

- **Looks and sound**: Where the second test group felt very comfortable with the sound and looks of the bell, the first test group would have preferred a more gentle sound and a less ‘game-like’ element: especially the loud noise prevented the patient from using it.

> *“I found the bell too intrusive; I would have used it if the sound had been gentler.”* - Patient 1

Use of the tokens

- **Added value when used with themecards**: In the second test, the patient used the tokens with the theme cards instead of the agency cards. Although this was not the intended use, it provided a valuable insight: the tokens helped facilitate the conversation by making it easier for her to talk about the topics.

> *“The emoticon made it easier for me to explain my thoughts on this topic”* - Patient 2

- **Not clear to everyone what they mean and how to use**: Some emojis appeared nearly identical to the participants or meant something else in their opinion. Also, a misunderstanding occurred when Participant 2 used emojis to emphasize her emotions regarding the *theme card content*. The NOK were confused by this placement, as they expected the tokens to indicate *how* the patient wanted to communicate, in line with the initial instructions.

> *“To me, these [points to two] emoticons mean basically the same”* - NOK

- **Wish of use**: Participants mentioned they would have liked if the NOK would have tokens as well, to give quick feedback without having to ask for the talking stick. The patient mentioned she would have liked that as well, to get a bit more feedback from the NOK when she was talking.

### Lowering Emotional Barriers

- **The Card as a mouthpiece**: The agency cards acted as a safe barrier, according to both patients. Patients noted that it was easier to show a card than to speak the words themselves. The card "says" it for them, which lowers the emotional threshold.

> *"I'm not sure if I would've said this if there wasn't a card for it"* - Patient 2

- **Randomly picking vs choosing a theme card**: While the patient during Test 1 first looked into all the cards and then chose a specific theme card which supported her feeling of autonomy, it was felt as overwhelming for the patient in Test 2. The patient of Test 2 therefore preferred picking cards blindly.

### Mental Load and mitigating the barrier

Although the tool saves physical energy, the mental and emotional load can remain high.

- **Energy levels**: Participants emphasized that these conversations should not be held late at night. The weight of the topics requires all parties, especially the patient, to be well-rested.

- **Equality**: The patient-centered focus of many elements, (unintentionally) increased the mental load of patient 1, highlighting her 'different' status. Making elements, such as the cards or tokens, more inclusive for the NOK could mitigate this feeling. However, Group 2 did not experience this particular issue at all.

> *"I felt quite a pressure, as the theme cards were focussed on me mainly and I felt my NOK expected something from me"* - Patient 1

- Need for **lightness** in the beginning: There is a clear need for lightness in the beginning when it comes to the topics. Group 1 mentioned it would be nice to have 'practice rounds' with lighter topics first, to become familiar with the use of the design before discussing difficult subjects. Group 2 started with the 'wish cards', as they were seen as 'positive' and therefore lighter to start with.

> *"Learning the tool while also going through all cards and immediately discuss those heavy topics was mentally overwhelming"*- Patient 1

- **Conversational depth and flow**
  The quality of the dialogue was found to be highly dependent on the questioning skills of the NOK. Without effective follow-up questions, there is a risk that the conversation will lose its flow or remain superficial. This indicates that the tool's effectiveness currently relies on the relative's communicative competence or the patient's own level of input.

## 6.2 Feedback Sessions with two VPKC's and an ENT-resident of Erasmus MC

A second round of feedback was conducted with three experts in total, divided in two sessions:

***Feedback session 1***: Two VPKC's from Erasmus MC
***Feedback session 2***: One ENT-resident of Erasmus MC

The goal was to gain more professional input that could further improve the design and guide the recommendations for future development. While previous sessions with experts (Chapter 4.6) focused on the general concept idea and improving the content of the cards, this evaluation served three specific purposes:

- ***Physical interaction and usability***: Experts were able to physically hold and see the design in real life. This allowed them to evaluate the tool's feel and looks and its fit within both clinical and domestic settings.

- ***Feedback on the refined design***: Since the design significantly improved based on earlier feedback sessions with experts, this round served as a second evaluation on the tone and content and if it is clinically appropriate in their opinion.

- ***Implementation reality for Erasmus MC***: By involving experts working at Erasmus MC, the research gained valuable insights into if and how the tool could actually be introduced and used in practice for Erasmus MC in their opinion.

### Insights

*From these feedback sessions, some new interesting insights emerged.*

**General impression**
All experts liked the design and the goal of it and confirmed that palliative HNC patients can struggle with communication in these ways. They recognized the tool's potential to support a sense of agency in a conversation and agreed that facilitating conversations around these themes is valuable.

**The 'stubborn' target group**
The experts praised the initiative, but their biggest 'concern' was that HNC patients are often a very stubborn demographic who don't (want to) talk about emotions in general. Therefore they questioned the tool's reach across the entire demographic, but concluded it could serve as a very useful opening for patients who are open to and wish to speak about these topics, but lack the means to initiate it.

*"I really like the concept. However, the main challenge is whether this demographic will actually use it, as they are typically quite stubborn and tend to avoid emotional conversations in general"* - VPKC

**Introduction of the tool**
The VPKC's were not entirely sure how this tool should be introduced to the patient group: they mentioned this should not be forced on patients, but rather offered as an option only if they wish to use it themselves.

*"I think it's a great tool when people ask for it themselves"* - VPKC

**Visual tone and content of the cards**
The illustrations on the cards were highlighted as a major strength, as they felt very calm, clear and approachable. Experts consistently validated the 'barrier cards' content, identifying the themes as highly relevant to their patient demographic. They liked that the 'wish cards' acted as a positive stimulation on deep reflection and would encourage patients to think about their needs and desires. You might even use them on your own.

*"I think the barrier cards are very suitable and the wish cards contain really beautiful questions. It encourages deep reflection, even if you would use this on your own"* - VPKC

**The tokens**
The experts expressed uncertainty regarding whether patients would use the tokens, as they were unsure if the target group would intuitively understand their meaning and purpose. However, because the use of any element of the tool is entirely voluntary, they acknowledged the tokens as a valuable addition for those inclined to use them. The experts emphasized that for these tokens to be effective, their intended meanings must be very clear. Furthermore, they suggested expanding the emotional spectrum to include 'anger' and 'confused,' as these would better reflect the complex reality of the palliative phase when using tokens in conjunction with the theme cards.

*"When using them for content, I really miss the 'anger' and 'confused' emoticons, as these are emotions patients often experience"* - ENT-resident

**Practicality of the box**
From a practical standpoint, one VPKC recommended making the physical box more compact for better portability.

**Post-conversation documentation**
One expert noted the potential value of documenting the discussion outcomes. This would assist patients in remembering their insights when the VPKC follows up at a later date. Since several weeks might pass between sessions, having a written record prevents valuable information from being forgotten.

## 6.3 Synthesis of Findings and Conclusion

Table 5 shows a synthesis of findings of the interaction tests and feedback sessions with experts from Erasmus MC.

| **Design element** | **What works well** | **Points for improvement** |
|---|---|---|
| **Physical design** | The 'tea box' aesthetic is approachable and fits a domestic setting. | The box could be more compact for portability, if desired by patients. |
| **Talking stick** | Ensures a calm pace, which reduces the cognitive load. Considered essential to patients to remain agency and an active participant with very low physical effort. | Did make the conversation feel like an ‘interview’, rather than a natural conversation for the NOK. NOK struggled with giving quick feedback. |
| **Bell** | Considered essential to patients to remain agency and an active participant with very low physical effort when NOK would start talking to each other. | The sound might feel too harsh to some users. Also, to some, the bell felt too game-like, which didn't align with the tool’s true depth and goal. |
| **Agency cards** | Clear visuals, the addition of blanco cards were considered useful, the cards lowered the barrier to ‘say’ what’s on the card. The visuals are clear and reduce cognitive load. All cards were used or expected to be used. | Some missed an ‘end of conversation’ card. |
| **Tokens** | Nice addition to express personality, if patients wish to use them. | Not completely clear on when and how to use them and what the exact meaning of all emoticons is. Also, some emoticons were considered too identical. |
| **Theme cards** | Content theme cards were considered suitable for this group of patients by experts, 'wish cards' stimulate positive reflection and the look and visuals were considered very nice, approachable and suiting by everyone. | There is a strong need for light topics to start with. Also, going through the cards first and then choosing one can feel overwhelming and can result in avoiding talking about certain topics |
| **Guidance** | Having a clear explanation and guidance is essential. Emphasizing that everything can be used flexibly and without obligation was also considered essential. The idea of guidance by a VPKC or another professional was considered important. | Some participants had a feeling there was a ‘right way’ to use the design, which is not the case. Also, too much information at once was considered overwhelming to some participants. |
| **Equality** | The talking stick created a shared responsibility (lowering the patient's energy drain) and feeling of connectedness as everyone used it. Also, some cards were answered by patients as well. | Since the cards and some tools are focused on/only used by the patient, it might create a sense of being 'different' from the group. Because the cards focus primarily on the |

| | | |
|---|---|---|
| | | patient, it can cause the patient to feel a sense of pressure. |
| **Implementation** | Experts see it as a valuable opening for patients who want to talk but lack the means. | The 'stubborn' nature of the target group most likely creates a very high threshold for use. |
| **Post-conversation** | VPKC's noted that follow-ups to discuss outcomes of the conversations could motivate usage and they felt this was a feasible to implement | Missed the post-conversation documentation |

*Table 5: Synthesis of results of the interaction tests and the feedback sessions with experts*

### Conclusion

In general, the design was perceived positively, with participants praising both its functionality and visual appeal. However, several aspects of the design could be improved before testing it with the actual target group. The points for improvement provided the basis for a new **design iteration** and **recommendations for further development**, which will be explained in the following chapter.

# 7. Further Development

This chapter discusses proposed design refinements based on the results of the tests and feedback sessions in the previous chapter and recommendations for further developments of the design.

## 7.1 Proposed Design Refinements

While testing with the target group is essential (detailed in ‘Recommendations’) for further development, certain design adjustments can be made beforehand, based on the insights gained from the recent tests and expert feedback.

### Add agency cards

Add: “*Ik wil het gesprek stoppen*”, to end the conversation.
Add: “*Hoe denk jij daar over?*” to stimulate equality and therefore decrease the possible pressure on the patient, but keeping the agency with the patient.

### Tokens

***Broaden the emotional spectrum****:* Add ‘anger’ and ‘confused’ emoticons to better reflect the patient's reality.

***Using with theme cards as well:*** Enable patients to attach tokens to theme cards as well if it makes it easier for them to express specific feelings about a topic

***Clarify meanings****:* Ensure the meaning of each emoticon is discussed and recorded beforehand to prevent confusion.

***Next of Kin (NOK) support****:* Design specific tokens for relatives so they can provide quick, silent feedback without interrupting.

### Add ‘light topic’ theme cards

Add a category of lighter topics to be used first. This allows users to get used to the tool's mechanics in a less overwhelming way before discussing difficult subjects.

### Add follow up questions

Give more guidance on follow-up questions. Add questions such as “Why do you feel this way?” or “When do you experience this?”. This ensures the depth of the conversation does not depend solely on the users' communication skills, which is especially important since speaking can already be difficult for this group.

### Post-conversation documentation

Record insights by writing down answers or outcomes. This ensures that important reflections are not forgotten and can be easily discussed during follow-up sessions with the VPKC.

## 7.2 Recommendations

While the current design refinements provide a foundation, the most critical next step is to conduct qualitative testing with the actual target group: palliative HNC patients and their next of kin. This testing should be structured around the following key areas:

**Reaching the goal**

Determine whether the tool effectively contributes to the patient's sense of *autonomy*, *piece of mind* (comfort), *expressing personality* and *relatedness*, in an energy efficient way.

**User Experience & Physical Design**

***Use of elements:*** Explore which elements are considered necessary to the patients and why, and if, how, when and why they are (not) used.

***The optimal box size***: Research whether a more compact, portable version is preferred or if the current 'tea box' size and look is essential for its inviting presence on the dinner table.

***Auditory and visual experience of the interruptor***: Test different types of sound and looks for the interruptor, as the bell might seem too 'aggressive' and game-like to some people.

***Tone***: Examine how the overall aesthetic (visuals, wording, and feel) is perceived by the actual target group to ensure it aligns with their situation and feelings.

***Picking theme cards***: Explore the balance between randomly picking vs. consciously choosing theme cards. Research whether random picking prevents the avoidance of difficult topics or if it feels too overwhelming for the patient.

**Content of the cards and tokens**

***Theme relevance***: Confirm if the current themes on the cards resonate with the target group and identify any missing topics that are crucial for their specific circumstances.

***Refinement of tokens***: Test the clarity and use of tokens with patients. Determine which emoticons are most intuitive and necessary for their daily communicative needs.

**Equality for lowering threshold of use**

Investigate if the tool requires more 'equality' by providing specific cards or tokens for the NOK as well and if this is crucial to lowering the threshold of use.

### Implementation & Guidance

***Introduction of the tool***: In collaboration with VPKCs, explore the most effective way to introduce the tool. Research the timing (when to offer it) and the method (e.g., as a proactive suggestion) to ensure it feels supportive rather than pushy. It is also important to make an instruction video which explains the use of the tool, for users to watch at home.

***Instructional clarity***: explore the most effective way of explaining the tool. A careful balance is required to ensure instructions are complete without becoming overwhelming or feeling like a set of 'rules'.

***(Professional) Involvement***: Explore who is, next to family, best suited to use (and introduce) the tool with the patient; the VPKC, a social worker, a GP, or someone else. Also, examine the impact of VPKC follow-ups as a motivation for families to keep using the tool.

### Long-term impact

Conduct a longitudinal study to observe how the tool is used over a longer period. Does it become a recurring ritual, or is more required to maintain active usage over time?

> In addition to usability testing, research is needed to define the tool's **actual reach.** While it is designed for those who ***want*** to talk but don't know ***how***, some patients may face deeper psychological barriers. For example, underlying factors could include cultural taboos, religious beliefs, not interested in talking about emotions and feelings, or a fear of vulnerability. Future research should explore if patients with deeper psychological barriers can be motivated without being forceful, as use must always remain voluntary. This will clarify if the tool is primarily suited for a receptive subgroup or if more intensive psychological support is required for others.

# 8. Conclusion and reflection

## 8.1 Conclusion

The primary objective of this project has been to **support the wellbeing of palliative HNC patients** by supporting their unfulfilled critical needs. The design aims to do this by facilitating meaningful communication with their loved ones, by addressing the two dimensions of communication barriers: the physical communication barrier and the psychosocial communication barrier.

- **The physical dimension**: Based on this research, the tool is expected to help palliative HNC patients remain active participants rather than becoming ‘observers’ in conversations by lowering the ‘cost of entry’ to conversations. The results from proxy testing and expert consultations indicate that the tool supports the critical fundamental needs of **Autonomy**, **Relatedness**, and **Comfort**. It allows patients to manage the social dynamics and to decide not only **what** they want to say and **when**, but also **how** they express it, which directly aligns with the goal of allowing patients to express their personality into a conversation. Being able to communicate better without a lot of effort creates convenience and peace of mind (comfort) and going from isolation to feeling included again, strengthens the feeling of Relatedness.

- **The psychosocial dimension**: On a psychosocial level, the tool addresses the emotional difficulty of starting end-of-life conversations patients can experience. The design acts as a conversation facilitator for patients and loved ones who would like to talk about these topics, but lack the words or means to initiate these.

It must be noted that the success of this design will depend heavily on the **patient's mindset**. The tool is designed for those who are **open to communication** about these topics, but struggle with the '**how**.' Many patients might be too stoic to discuss these topics in general, which could limit the tool's reach. Future testing is therefore essential to evaluate for which part of the patient population this tool is genuinely desirable.

Next to providing proactive psychosocial care to their patients, the tool is also beneficial for **Erasmus MC** as it could deepen the understanding of the needs and wishes of patients that have difficulty explaining this (physically but also mentally), when follow-up sessions -regarding the conversations held with the tool between patients and loved ones- are implemented. This likely could even further improve the quality of care.

Although further testing with the actual target group is essential to evaluate its impact, the findings of this project suggest that this tool has the potential to support the wellbeing of HNC patients.

## 8.2 Limitations

**Limited access to target group**
As access to the actual target group was very limited, much of the research and design development was based on literature, expert consultations, and personal insights. Although experts work closely with the target group and can provide a professional perspective, they lack the direct ‘lived experience’ of the patient, which could cause a different view on certain aspects.

Limited access also caused the **interaction tests** to be conducted with healthy participants as proxies. While this helped identify general intuitive use and usability hurdles, the specific physical and emotional realities of palliative HNC patients cannot be fully replicated by healthy individuals. As the palliative themes were not personally relatable for these participants, this lack of personal urgency might have influenced the conversational flow, use of the product and the participants' willingness to engage deeply with the design.

**Time**
Available time for a master thesis also played a role in this project. While I would have liked to spend more time on certain aspects, sometimes final decisions had to be made to move forward to the next stage to ensure the project was completed on time.

**Single test session**
The tests were conducted in a single, 20 minute session. In practice, a patient would have more time to process the tool’s purpose and use it at their own pace. The condensed nature of the test may have made the tool feel more overwhelming than it would be during voluntary integration in a domestic setting.

**Small Sample Size for Testing**
The interaction tests included only six participants, which limits the ability to generalize the findings. While these tests helped uncover some initial usability issues, a larger group of testers might have revealed more 'general' hurdles that remain undiscovered in this small-scale study.

**Researcher Presence**
The presence of the researcher during the testing sessions likely influenced participant behavior. Observation often leads to the ‘Hawthorne Effect’, where participants act more ‘correctly’ or seek validation from the researcher, which would not occur if the tool were used privately at home.

## 8.3 Personal reflection

During this graduation project, I learned a lot as a designer but as a person as well. I would like to reflect on a few aspects of this project.

**The topic**
I've learned a lot about head and neck cancer and everything that comes with it: I started the project knowing nothing about it, but I've gained a great deal of knowledge; not just about what it involves, but especially about the ways it can affect a person's wellbeing. It has made me realize how crucial communication is for human connection, and how this disease can be a huge obstacle to that. I've come to appreciate much more the privilege of simply being able to speak: the ability to speak is something we often take for granted.

**The process**
I very much enjoyed doing this project, as with each new step I took I learned new things. At the beginning, personal circumstances made it hard for me to maintain a clear structure for this project, as planning didn't go as smoothly as I'm used to. Planning was challenging not only because of my personal situation but also due to the limited availability of some experts.
In the beginning of the project, I had expected to be able to have more contact with the target group. However, it turned out I was going to have very limited access to the target group, which felt a bit like a setback to me, as connecting with the target group (doing interviews and testing) I mostly enjoy doing as a designer. Because of this limited access to the target group, I had to adjust my process and methods. Even though it felt like a setback in the beginning, it turned out to be a valuable lesson and I grew as a designer: I learned how to deal with things that are out of my hands and how to still deliver a high-quality project.

**Collaborating with a third party**
I am very grateful to Erasmus MC for the opportunity to collaborate with them on this project. It was highly valuable to speak with experts on this subject and to conduct interviews with patients myself (one interview with a patient of Erasmus MC and one that was made possible through Erasmus MC). Preparing, conducting, and reflecting on these interviews has significantly increased my confidence in my interviewing skills. Furthermore, I learned how to work together toward solutions when expectations were not entirely aligned.

**The end result**
I am very satisfied with and proud of the result. I feel deeply grateful for the opportunity to have worked on this project, as I truly believe it could support those who need it most. Especially given the positive feedback I received on the design, I can see its potential to make a meaningful difference for people with head and neck cancer.

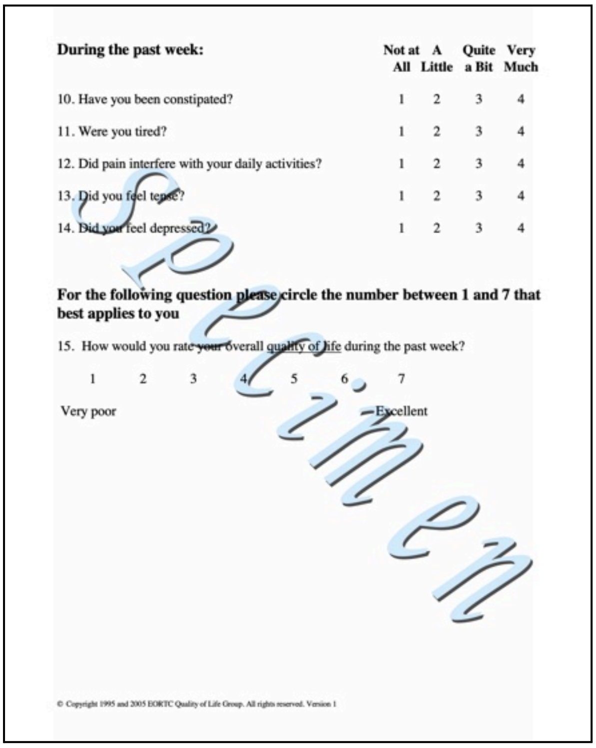
What I value most about this design is its **flexibility of use** and its **non-obligatory** nature. Communication should feel personal and I believe that by granting patients the flexibility to choose which elements to use and when, the tool facilitates an experience that feels authentic and tailored to the individual. The tool can be used by any patient (if they are open to it of course), as the use is entirely adaptable to one's personal situation and preferences.

### Development as a designer

During this project, I've learned, tried out, and practiced many new things, such as conducting interviews, carrying out a project with minimal access to the target group, research through design, collaborating with a third party, and navigating the challenge of balancing a highly structured project when personal matters get in the way and planning becomes complicated. I realized how much I want to uncover people's true feelings and motivations, because this is crucial for me to design for emotion and wellbeing. Before I started this project, I had the idea that Design for Emotion and Well-being would be a great fit for me. After this project, I've become even more convinced of this and as a designer, I would like to make a positive impact on the people who truly need it.

# Appendices

## Appendix A - EORTC QLQ-C15-PAL Questionnaire

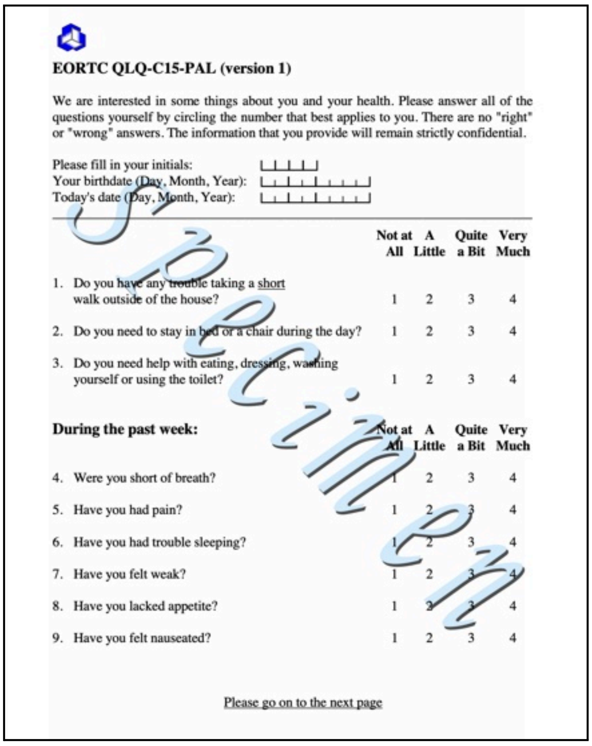


| During the past week: | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|
| 10. Have you been constipated? | 1 | 2 | 3 | 4 |
| 11. Were you tired? | 1 | 2 | 3 | 4 |
| 12. Did pain interfere with your daily activities? | 1 | 2 | 3 | 4 |
| 13. Did you feel tense? | 1 | 2 | 3 | 4 |
| 14. Did you feel depressed? | 1 | 2 | 3 | 4 |

**For the following question please circle the number between 1 and 7 that best applies to you**

15. How would you rate your overall quality of life during the past week?

| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
|---|---|---|---|---|---|---|
| Very poor | | | | | | Excellent |



**EORTC QLQ-C15-PAL (version 1)**

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials:
Your birthdate (Day, Month, Year):
Today's date (Day, Month, Year):

| | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|
| 1. Do you have any trouble taking a short walk outside of the house? | 1 | 2 | 3 | 4 |
| 2. Do you need to stay in bed or a chair during the day? | 1 | 2 | 3 | 4 |
| 3. Do you need help with eating, dressing, washing yourself or using the toilet? | 1 | 2 | 3 | 4 |

| During the past week: | Not at All | A Little | Quite a Bit | Very Much |
|---|---|---|---|---|
| 4. Were you short of breath? | 1 | 2 | 3 | 4 |
| 5. Have you had pain? | 1 | 2 | 3 | 4 |
| 6. Have you had trouble sleeping? | 1 | 2 | 3 | 4 |
| 7. Have you felt weak? | 1 | 2 | 3 | 4 |
| 8. Have you lacked appetite? | 1 | 2 | 3 | 4 |
| 9. Have you felt nauseated? | 1 | 2 | 3 | 4 |

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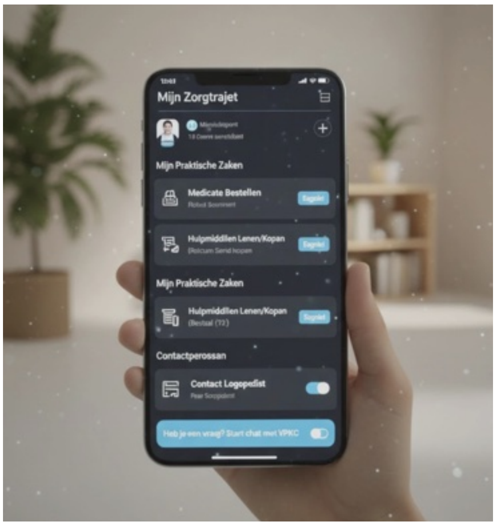
## Appendix B - Explorative Concept



*An app where an AI agent can guide patients through practical things (like where to buy a wheelchair, how to fix all your financial matters, etc.) independently.*

## **Appendix C** - Detailed causes of speech difficulties

→ Verwijderen van Larynx (strottenhoofd)

→ zwelling in hoofdhalsgebied door:
- operatie
- radiotherapie

→ Tumorgroei in mondholte / keelholte / strottenhoofd
  ↳ vervorming spraakorganen
  ↳ zenuwschade (verlamming stembanden)
  ↳ blokkade spraakorganen

→ Glossectomie (verwijderen vd tong)

→ Mandibulectomie (verwijderen (deel) vd kaak)

→ Fibrose (verstijving tong, kaak, stembanden)

→ Xerostomie (droge mond)

## **Appendix D** - Optional addition to Concept 2

A recording system records the conversation and the text is shown on a screen. The patient can refer back to things the NOK has said during the conversation, and can then use the cards if he wants to add something in the conversation.

## **Appendix E** - Weighted Objectives

| Concept ➡<br>Requirements ⬇ | *Weight* | *1. Personal voice* | *2. Communication Cards* | *3. Conversation Circle* |
|---|---|---|---|---|
| **R1** | 10 | 10 | 10 | 10 |
| **R2** | 10 | 8 | 10 | 10 |
| **R3** | 10 | 6 | 9 | 9 |
| **R4** | 10 | 8 | 8 | 8 |
| **R5** | 10 | 6 | 8 | 8 |
| **R6** | 10 | 5 | 8 | 6 |
| **R7** | 10 | 4 | 8 | 8 |
| **R8** | 10 | 4 | 8 | 6 |
| **R9** | 10 | 10 | 10 | 10 |
| **R10** | 10 | 0 | 10 | 10 |
| **Total score** | | **610** | **890** | **850** |

## **Appendix F** - Testing out different element sizes

*This is about the **size** exploration, not the content*

Regie kaart:

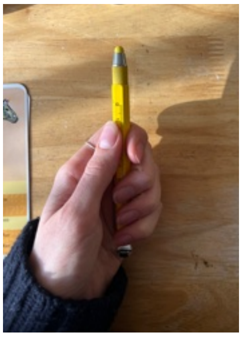
Wenskaart & Blokkade kaart:

*Alle kaartsoorten even groot:*

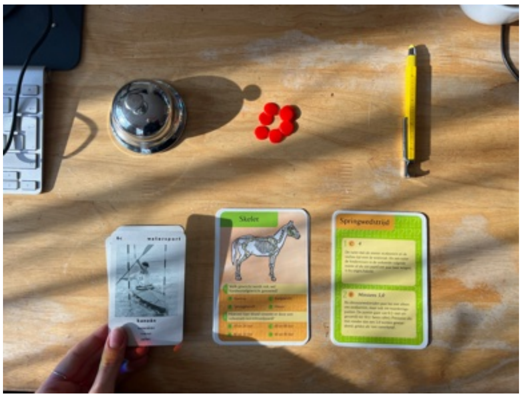
*Regiekaart kleiner dan wens en blokkade kaarten:*

*Trying out sizes for the tokens*

*Trying out sizes for the Talking stick*

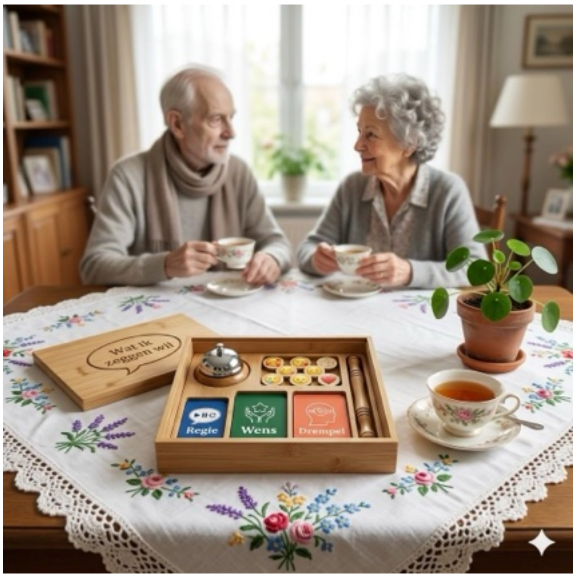


*Trying out all elements together*



*Making prototypes of elements based on the sizes*

## **Appendix G** - Initial Box design



# **Appendix H** - Project Brief

## Personal Project Brief – IDE Master Graduation Project

**Name student** Olga Bogaerts

**Student number** 5,335,531

**PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT**
Complete all fields, keep information clear, specific and concise

**Project title** Redesigning meaningful end-of-life for palliative Head and Neck Cancer patients at home

*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)*

Palliative Head and Neck Cancer (HNC) patients often face psychological challenges. The inability to perform certain activities in their daily life at home can negatively impact their psychological well-being, which can lead to serious consequences such as depression, anxiety, and emotional distress.

At the moment, Erasmus MC provides limited support for the psychological wellbeing of their palliative HNC patients. They use the so-called 'health monitor', where patients can update Erasmus MC on their overall health by filling in surveys with questions about their health remotely. Patients are generally satisfied with most aspects of (remote) palliative care, but highlight the need for improvement in psychological support [1]. For this reason, Erasmus MC approached the Faculty of Industrial Design at TU Delft to initiate a collaboration aimed at designing interventions that fulfill the psychological needs of patients receiving palliative cancer care to support their wellbeing. Erasmus MC is particularly interested in the 13 Fundamental Psychological Needs [2] by Pieter Desmet and seeks to find out how this typology could contribute to supporting the psychological wellbeing of their patients. Their goal is to provide proactive and compassionate care addressing both physical and psychosocial needs of HNC patients and family members throughout their palliative phase, enabling them to stay with an optimal quality of life in their trusted home environment.
One important consideration, and potential limitation, is that the user group is very vulnerable, which may pose challenges in conducting interviews, user testing, and other forms of direct engagement.

[1] van den Besselaar, B. N., van Hof, K. S., Sewnaik, A., de Jong, R. J. B., & Offerman, M. P. (2023). Experience with eHealth in the palliative care pathway for head and neck cancer patients: A mixed-methods study. Research Square. https://doi.org/xxxx

[2] Desmet, P., & Fokkinga, S. F. (2020). Thirteen fundamental psychological needs (p. 20).

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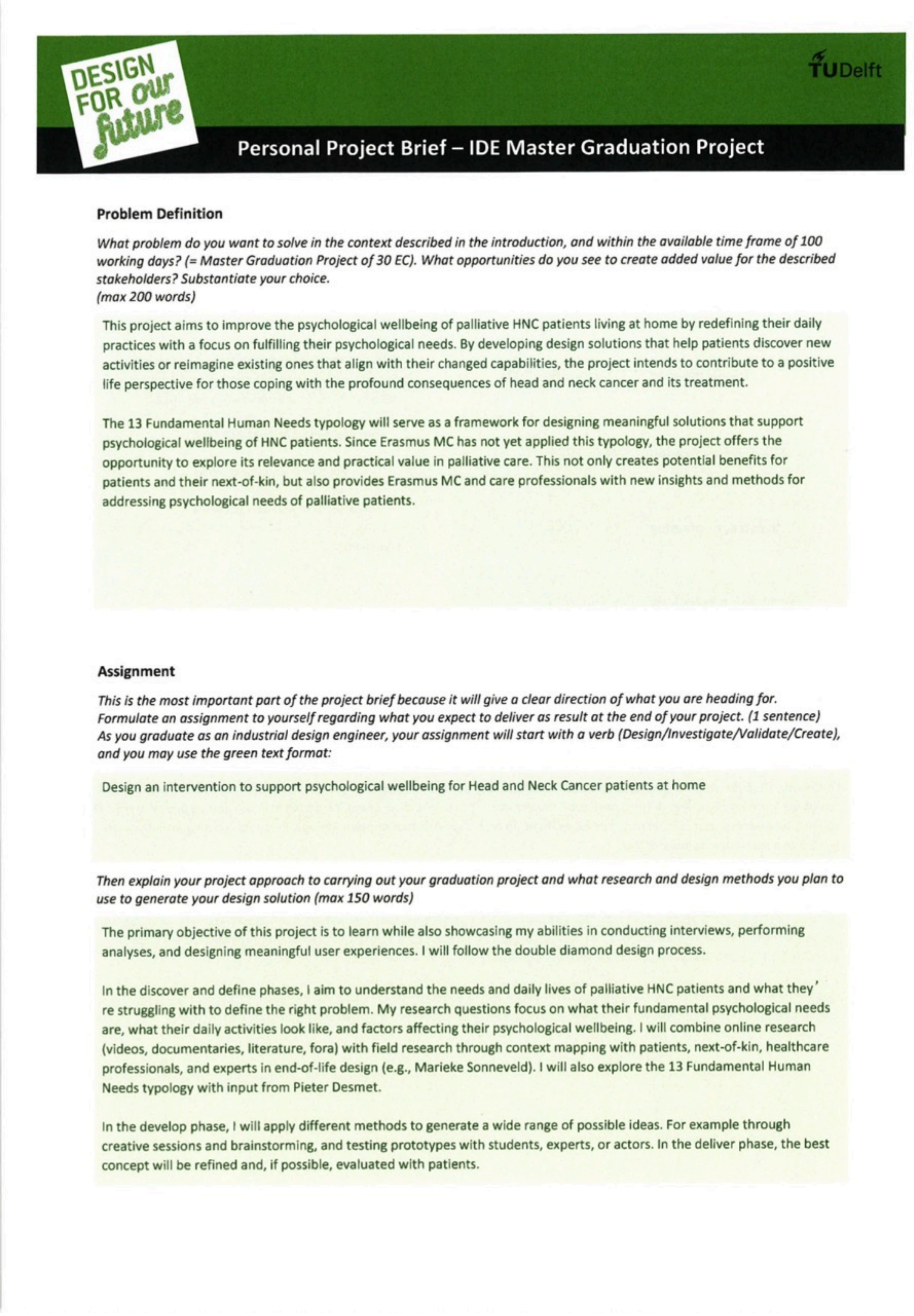


TUDelft

DESIGN FOR our future

**Personal Project Brief – IDE Master Graduation Project**

**Problem Definition**

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

This project aims to improve the psychological wellbeing of palliative HNC patients living at home by redefining their daily practices with a focus on fulfilling their psychological needs. By developing design solutions that help patients discover new activities or reimagine existing ones that align with their changed capabilities, the project intends to contribute to a positive life perspective for those coping with the profound consequences of head and neck cancer and its treatment.

The 13 Fundamental Human Needs typology will serve as a framework for designing meaningful solutions that support psychological wellbeing of HNC patients. Since Erasmus MC has not yet applied this typology, the project offers the opportunity to explore its relevance and practical value in palliative care. This not only creates potential benefits for patients and their next-of-kin, but also provides Erasmus MC and care professionals with new insights and methods for addressing psychological needs of palliative patients.

**Assignment**

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

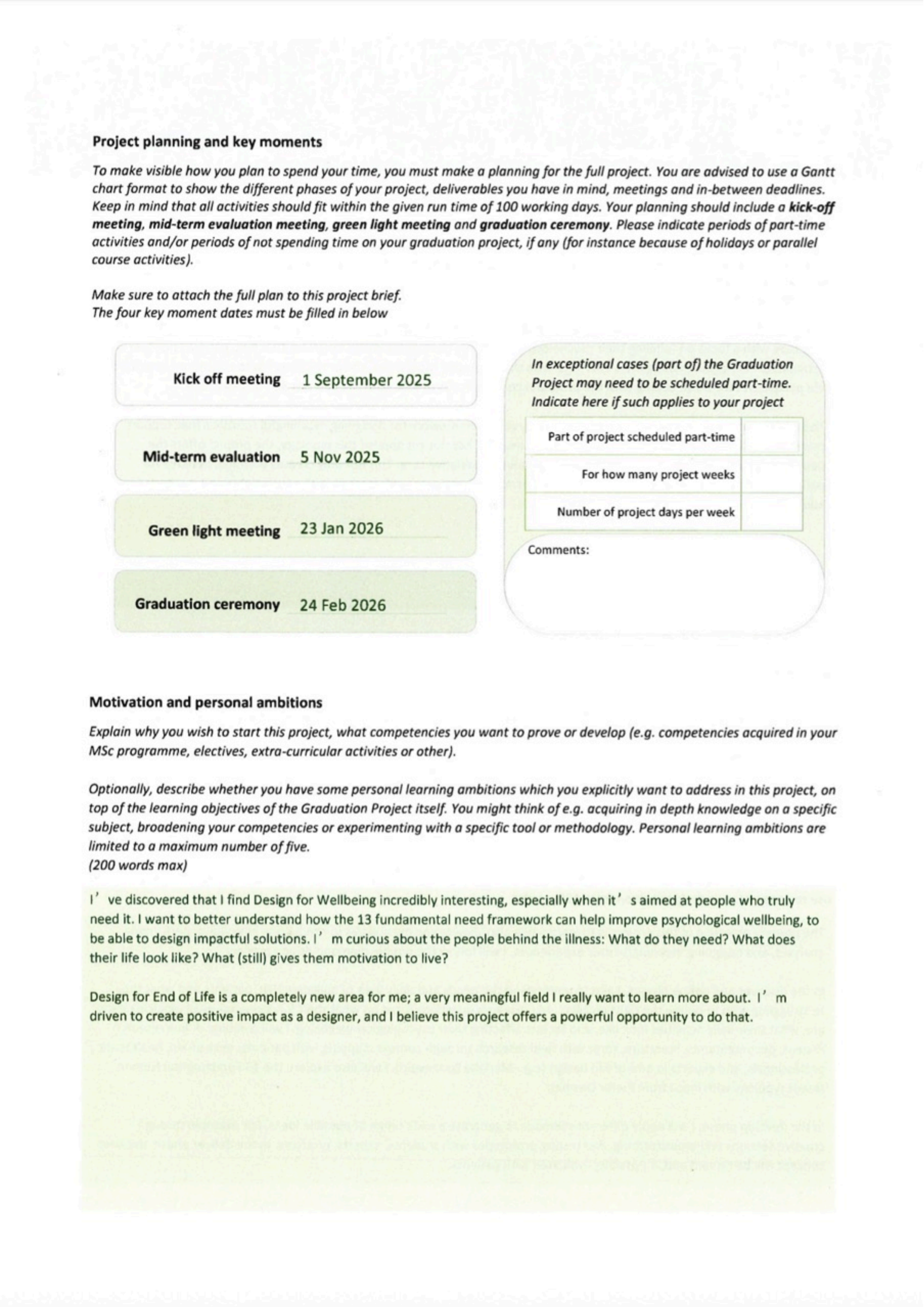
Design an intervention to support psychological wellbeing for Head and Neck Cancer patients at home

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

The primary objective of this project is to learn while also showcasing my abilities in conducting interviews, performing analyses, and designing meaningful user experiences. I will follow the double diamond design process.

In the discover and define phases, I aim to understand the needs and daily lives of palliative HNC patients and what they're struggling with to define the right problem. My research questions focus on what their fundamental psychological needs are, what their daily activities look like, and factors affecting their psychological wellbeing. I will combine online research (videos, documentaries, literature, fora) with field research through context mapping with patients, next-of-kin, healthcare professionals, and experts in end-of-life design (e.g., Marieke Sonneveld). I will also explore the 13 Fundamental Human Needs typology with input from Pieter Desmet.

In the develop phase, I will apply different methods to generate a wide range of possible ideas. For example through creative sessions and brainstorming, and testing prototypes with students, experts, or actors. In the deliver phase, the best concept will be refined and, if possible, evaluated with patients.



**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** 1 September 2025

**Mid-term evaluation** 5 Nov 2025

**Green light meeting** 23 Jan 2026

**Graduation ceremony** 24 Feb 2026

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

| | |
|---|---|
| Part of project scheduled part-time | |
| For how many project weeks | |
| Number of project days per week | |

Comments:

**Motivation and personal ambitions**

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

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

I’ve discovered that I find Design for Wellbeing incredibly interesting, especially when it’s aimed at people who truly need it. I want to better understand how the 13 fundamental need framework can help improve psychological wellbeing, to be able to design impactful solutions. I’m curious about the people behind the illness: What do they need? What does their life look like? What (still) gives them motivation to live?

Design for End of Life is a completely new area for me; a very meaningful field I really want to learn more about. I’m driven to create positive impact as a designer, and I believe this project offers a powerful opportunity to do that.

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