# ENTERING THE IN BETWEEN LAND

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**Master thesis**
The implementation of “The Entrance to the Tussenland”. Supporting people with an incurable disease in their journey to the in-between-land.

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# PREFACE

A ten for wellbeing, that was the mindset how I started this project nine months ago. I think that overall, with a few exceptions in the end, I can conclude this was achieved. These nine months showed me how much I had learned as a Strategic and Integrated Product Design student, but also how I developed myself as a Social Impact designer during these years. I am glad that I was able to work on this project from all these perspectives.

During my bachelor and masters I found out that I have an affinity for social design, particularly designing around taboos. I always have found it fascinating how something that is such an integral part of life, is so hidden in the Dutch culture. That is why I want to embed death literacy more in our culture: the knowledge and skills to gain access to, understand and make informed choices about end-of-life and death care options.

Although this thesis was an individual project, I had the help from a big group of people who contributed to the result.

I would like to thank my supervisor team, Marieke and Caroline, for their guidance and inspiration during this project. If I had to sum our meetings up, it would consist of 25% of guidance, 25% of inspiration and 50% of laughter. And I wouldn't want it any other way. I also want to thank you for constantly challenging me, in a way that I was also able to exceed my own expectations.

Moreover, I want to thank Christiaan from Hospice Bardo for his dedication and enthusiasm in this project. You always made sure to clear your schedule whenever needed, and kept on inspiring me with nice articles and books.

I want to thank Mieke for helping me out throughout this whole project and during the big milestones. Your advice helped me to get a better grip on the whole system in this project.

A special thanks goes out to all the tussenlanders, loved ones, care professionals, experts and the hack-a-thon team that helped me in this process. Thank you for your honesty, your dedication and showing your vulnerability. All these conversations formed this project.

I want to thank the VR Zone for guiding me in the world of Virtual Reality, and helping me with creating my prototype.

And last but not at least I want to thank my friends and family for supporting me and making sure that I will at least score a ten for well-being in this project.

So brace yourself, and get ready to immerse yourself in the entrance to the in-between-land!

Zhenja

# EXECUTIVE SUMMARY

## THE BRIEF & THE IN-BETWEEN-LAND

The moment a patient receives the diagnosis of an incurable disease, it often feels like their whole world collapses. One patient explained this feeling as entering the in-between-land, or in dutch 'het tussenland', the transition period from ending curative care and entering the end-of-life care. The in-between-land is a world and experience people enter when they find out they have an incurable disease. For everyone, this in-between-land can be experienced differently. However, it has one thing in common, it feels like entering an unknown land where you do not know the way and do not speak the language. Entering the in-between-land can be scary and lonely for a patient. Unfortunately, this period is hardly supported in practice in our daily lives. Hospice Bardo does provide palliative care for the patients in the last few weeks to months. However, hospice Bardo expressed an interest in fulfilling this need at an earlier stage in patients' lives, using the technology Virtual Reality. Therefore, this thesis aims to create a place for people where they can safely land in these tumultuous times. To make people feel welcome to engage and open up to the 'in-between land' using Virtual Reality.

## RESEARCH & DESIGN GOAL

During this thesis, various research activities have been performed to get insight into the patient's wishes and needs. Literature research and explorative interviews were performed to get insight into the patient's journey after the diagnosis of an incurable disease. The interview panel consisted of patients, loved ones, care professionals, and experts in the palliative world. The insights of this research have been clustered and led to fourteen criteria that support the design goal.

## IDEATION & CO-CREATION

The criteria have been used as an inspiration for the ideation. The research till this point has been used to create a brief for a Hack-a-thon of Young Medical Delta, where four students worked on this project for three days. They were able to bring all the insights of this thesis back to one core insight: After the diagnosis, patients feel lost. Therefore, they need a warm place to go to, to feel heard, and to be connected. The team created a framework that complemented this research, which led to the final design. This framework consists of five worlds that all answer to a different need: The forest (the need to safely land), the library (the need for answers), the home (the need to feel at home), the communal space (the need for connection) and the beach (the need to engage existential matters).

## THE FINAL DESIGN | THE ENTRANCE TO HET TUSSENLAND

The Tussenland is a digital platform and service that will be introduced to the patient after the bad news conversation by the supporting team. This supporting team exists out of the hospital's palliative team and hospice Bardo's team and volunteers.
The supporting team will explore the wishes and needs of the patient together with the patients so that the concept can be customised. The concept The Tussenland acknowledges that there is a land for them where they can feel part of a group they can identify themselves with. In this thesis, only a part of The Tussenland will be conceptualised: 'The Entrance to The Tussenland'.
'The Entrance to The Tussenland' will be the first worldmentioned in the framework: the forest. The four other worlds in the framework will be developed in a future stage. "The Entrance to The Tussenland" is a forest-like environment in Virtual Reality where people are welcomed and shown around by a guide. The forest was chosen as the entrance to The Tussenland because the forest shows the patient that it is a place where they are part of, where they can identify themselves with. The patients own a tree where their

experiences and memories grow as blossoms on their tree. The patient can share their tree, enabling others to enter this world, comment on these experiences, and leave messages. It is a lowkey tool that enables people to be there for each other. It is also a personalised tool where patients can learn from the experiences of other patients, and maybe find the answers to their questions.

## EVALUATION

For the final design, a use scenario and a prototype were created in Unreal engine that was shown to the panel.
The panel gave positive reviews and was pleased about the meaningful interactions that were created in "The Entrance to The Tussenland". It felt like a safe way to let people be welcomed and immersed in this new magical world. The participants felt like it was a tool that enabled them to express their thoughts, give them information and offer consolation in a meditative world.

## IMPLEMENTATION

A service system map and roadmap were created to look at the future development of "The Entrance to The Tussenland". Three milestones are discussed: starting a pilot, launching "The Entrance to The Tussenland", and further development of The Tussenland.

## DISCUSSION & LIMITATIONS

A long road is ahead as there is a limited image of palliative care in society. Therefore, many pain points could be possible barriers to this design. The tone of voice in this design can make it or break it. Therefore, this design should be discussed in convergence with all the stakeholders involved with great sensitivity in mind. Moreover, the deliverable is a limited version of the VR application.
It needs to be developed as a full-service application, as it is now a demonstration of what it could look/feel/sound like.

"The Entrance to The Tussenland" is not a concept meant for everyone. Every patient will enter the in-between-land, but that does not mean that every patient wants to engage in the in-between-land. In this thesis, some differences between patients are briefly discussed, but many factors were not considered (age, culture, upbringing and more). Patients who are open to engage the in-between-land are most likely the users of "The Entrance to The Tussenland".

## CONCLUSION

It can be concluded that the platform and service "The Entrance to The Tussenland" supports patients after the bad news conversation by making them feel less lost. It acknowledges that there is a warm place for them they feel part of, feel heard and connected.

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# PART 1 START

# 01

# PROJECT OUTLINE

*This chapter introduces the project by presenting the context, goal and approach of the project.*

### CHAPTER 1.1

# CONTEXT OF THE PROJECT

*"We not only live longer, we also die longer",* These are the words, Rene Gude, a Dutch philosopher, spoke of. Due to medical developments, it is not weird anymore to reach the age of eighty years or more. However, this development goes hand in hand with the phenomenon that death and dying tend to become medicalised events.

Part of the quality of our end-of-life is determined by how well we are prepared for it. This preparation is a joint effort, regards ourselves and the inner circle of care and the care professionals we are surrounded by. However, the question is: how and when do we prepare? The transition period from ending curative care and entering the end-of-life care, while not being terminally ill yet, is a challenging period. This period is also referred to as 'entering the in-between land (het tussenland)' by writer and experience expert Jannie Oskam. She and her book have been the inspiration for this project. In her book, she illustrates that for people facing a life-threatening/incurable disease, the 'in-between land' can feel like an unknown land where people do not know the way and do not speak the language. Unfortunately, this period is hardly supported in practice.

Palliative care is a form of care with a holistic view, that does focus on the patient's quality of life and the people next to them. Within palliative care, the quality of life is an essential topic as it aims to make the end-of-life more natural and a social and meaningful part of our lives.
However, palliative care is not a widespread and widely known type of care in Dutch society. It is often associated with the terminal phase, the last weeks or months that a person lives. Palliative care already starts from the moment of the diagnosis of an incurable disease until the bereavement care after the person's end-of-life. This timespan can differ from months to multiple years.

Hospices are care facilities where people can receive palliative care. The care at hospices provides compassionate care for people in the last phases of an incurable disease that focuses on the quality of life for people with a life-threatening disease and their caregivers. Hospice Bardo is a Dutch-based hospice that provides palliative care at the hospice in Hoofddorp and palliative home care.
The goal of hospice Bardo is to guide people with a life-threatening disease in this whole process, by supporting a meaningful life of high quality. Hospice Bardo offers care to people in the last stage of their life. Most patients in a hospice stay a few weeks to several months, but not often longer than that. While Hospice Bardo is already doing meaningful work, it wishes to reach more people in an earlier stage where they may need palliative care. Hospice Bardo believes that offering palliative care at an earlier stage can create more meaning in the lives of people with a life-threatening disease and normalise palliative care in our society.

In a joint project called "Hart en Tech' with several Hospices in the Netherlands, including Hospice Bardo, together with Marieke Sonneveld, founder of the end-of-life lab at the TU Delft, hospice Bardo looked at what (new) technologies could mean for hospice care. The outcome of this project was that within hospice care, they saw possibilities in the technology Virtual Reality. Therefore, Hospice Bardo, in particular Palliative Doctor Christiaan Rhodius, was very interested in exploring these possibilities of Virtual Reality, which brings us back to this thesis.
Thus, this thesis will look at how Virtual Reality can create a more meaningful life for people with a life-threatening disease, where hospice Bardo can reach these people earlier before entering the hospice.

### CHAPTER 1.2

# GOAL OF THE PROJECT

In the case of patients with an incurable disease, their life embarks on a new direction: the in-between-land. The in-between-land is a place where the quality of life and the quality of death is important. For many people, the diagnosis of an incurable disease, often referred to as 'the bad news conversation' (het slecht nieuws gesprek), is an extremely vulnerable period. They enter a world where they do not know the way, do not speak the language and feel lost in many ways. It is a world where they have many questions that are not always answered.

However, people are diverse, so the in-between-land can look different for all of them. What does this in-between-land look like, and how can we guide them in this place? How can we create a place where we can both find out the meaning and value of life and learn about our mortal side and deal with that?

Therefore, this project aims to design a product or service supporting the patient's journey in the in-between-land. The design must be integrated into palliative care, so that hospices can contribute to improving the quality of the remaining life and face the nearing death. The design should fit the context of palliative care, where technology might be experienced as inappropriate. The goal is to let people experimentally engage with this topic using the technology Virtual Reality.

As dying is a social happening, this project also aims to investigate how the environment of a patient, their loved ones, caregivers, hospices and society, can form a secure base that can support the patient. As the Dutch poet Jules Deelder (2011) mentioned: '*De omgeving van de mens is de medemens*' (the surroundings of mankind is the fellow man). Moreover, as English poet John Donne (1624) declares: '*no man is an island*'.

As it is a delicate topic that touches many people in our society, the solution must be designed with great sensitivity in mind. Therefore, it must fit in the whole system around the hospitals, hospices, our society and the current market.

People that face a life-threatening disease, should be seen as who they are, and not be defined by their sickness. Therefore, in this thesis, people with a life-threatening disease will not be referred to as patients, but as tussenlanders (people who live in the in-between-land).

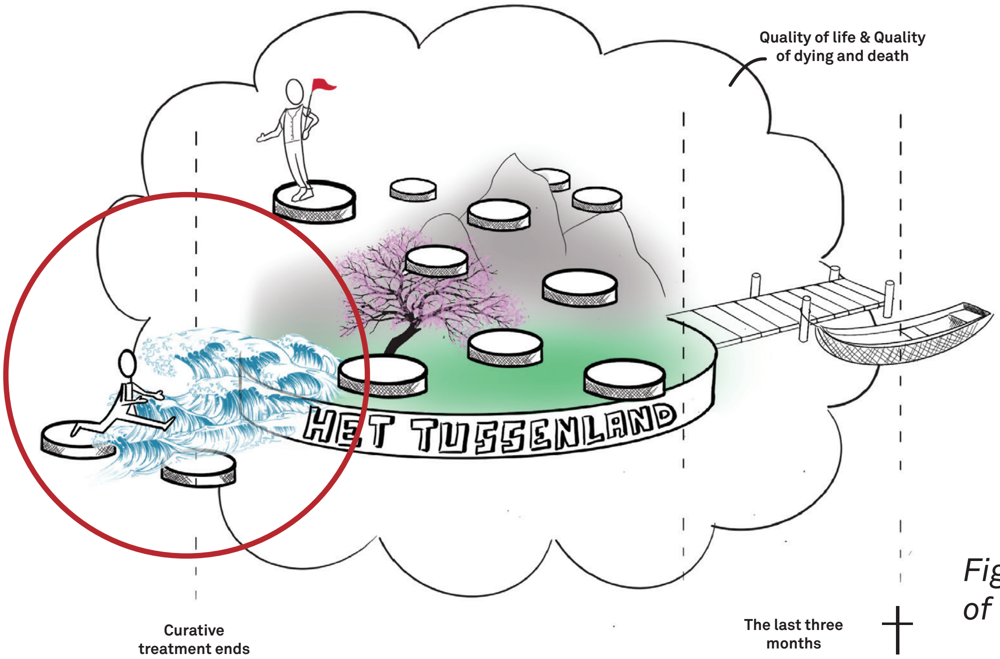


*Figure 1. Visualisation of the assignment*

### CHAPTER 1.3

# APPROACH OF THE PROJECT

The approach of the project is divided into the following phases of the double diamond.

**Literature exploration and interviews**
The literature exploration and interviews aim to find the answer to the research question:

**Research question:** *How can design support and guide people facing a life-threatening disease and their loved ones on their journey through the in-between-land that can be integrated into palliative care within a hospice?*

The following subquestions were created to answer the research question:

**Subquestion 1:** *What does the in-between-land look like for tussenlanders and their loved ones? (desirability)*
**Subquestion 2:** *How can Virtual Reality guide the tussenlander and their loved ones through the in-between-land? (feasibility)*
**Subquestion 3:** *How is palliative care perceived in our culture? (viability)*

The goal is to gain insight into the experiences and the needs and wishes of tussenlanders and their loved ones. After this phase, there will be a better understanding of palliative care in the Netherlands and how the quality of life and quality of dying and death are perceived in the Dutch culture.

The participants for the interviews will be selected from different disciplines in palliative care to create a comprehensive and more complete perspective on these topics. From tussenlanders to loved ones, from social workers to game designers. For this phase, a research plan was made that can be found in appendix A.

**Data analysis**
The data analysis aims to collect all the insights from the literature exploration and interviews to connect the dots so that these insights can be categorised into driving forces. For the Data analysis, the VIP method (Vision in Product) created by TU Delft professors Paul Hekkert and Matthijs van

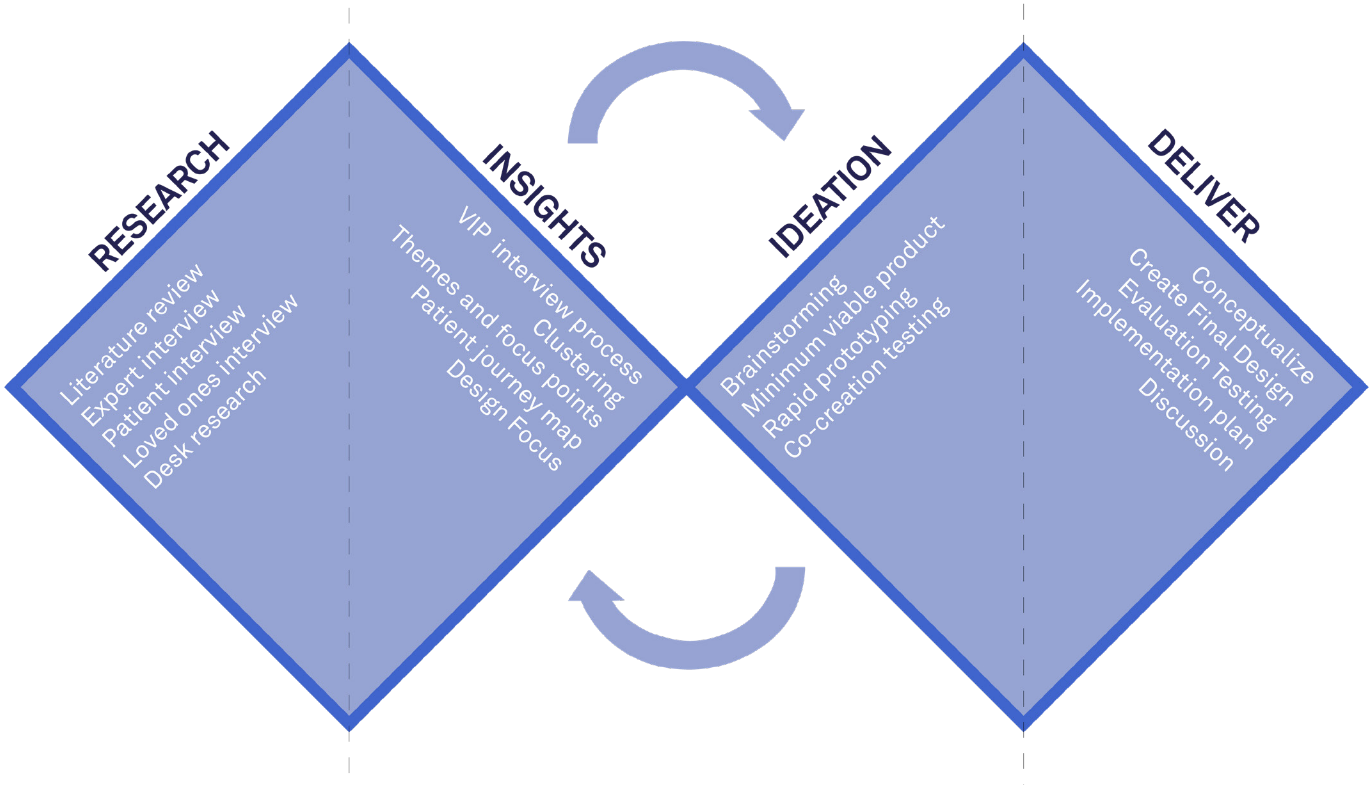


*Figure 2. Double diamond approach*

Dijk was followed.

### Design Focus

The requirements and design goals will be more specified and sharpened in the design focus. After this phase, there will be a better understanding of what criteria the final design must comply with.

### Ideation & Conceptualization

The aim is to explore and ideate in various idea directions, to create a wide variety of ideas. The ideas with the most potential will be combined and conceptualised into one final concept. This final concept will undergo many iterations that lead to the final design. Brainstorm sessions and co-creation sessions are performed to get the final design.

### Final Design

The final design and its different elements will be elaborated in this phase. A prototype is created, showing a demonstration of the final design.

### Evaluation and implementation

The goal of the evaluation is to determine the impact and influence of the final design. The stakeholders will review the prototype. Moreover, an implementation plan will be presented that shows how the final design fits the current system within palliative care.

### Discussion

The discussion aims to discuss what the contributions of the final concept are to the problem definition mentioned at the start of this project. Based on the final evaluation, the recommendations and limitations of this project will be presented. In conclusion, a reflection will be written to elaborate on the (personal) goals and to what extent they are met.

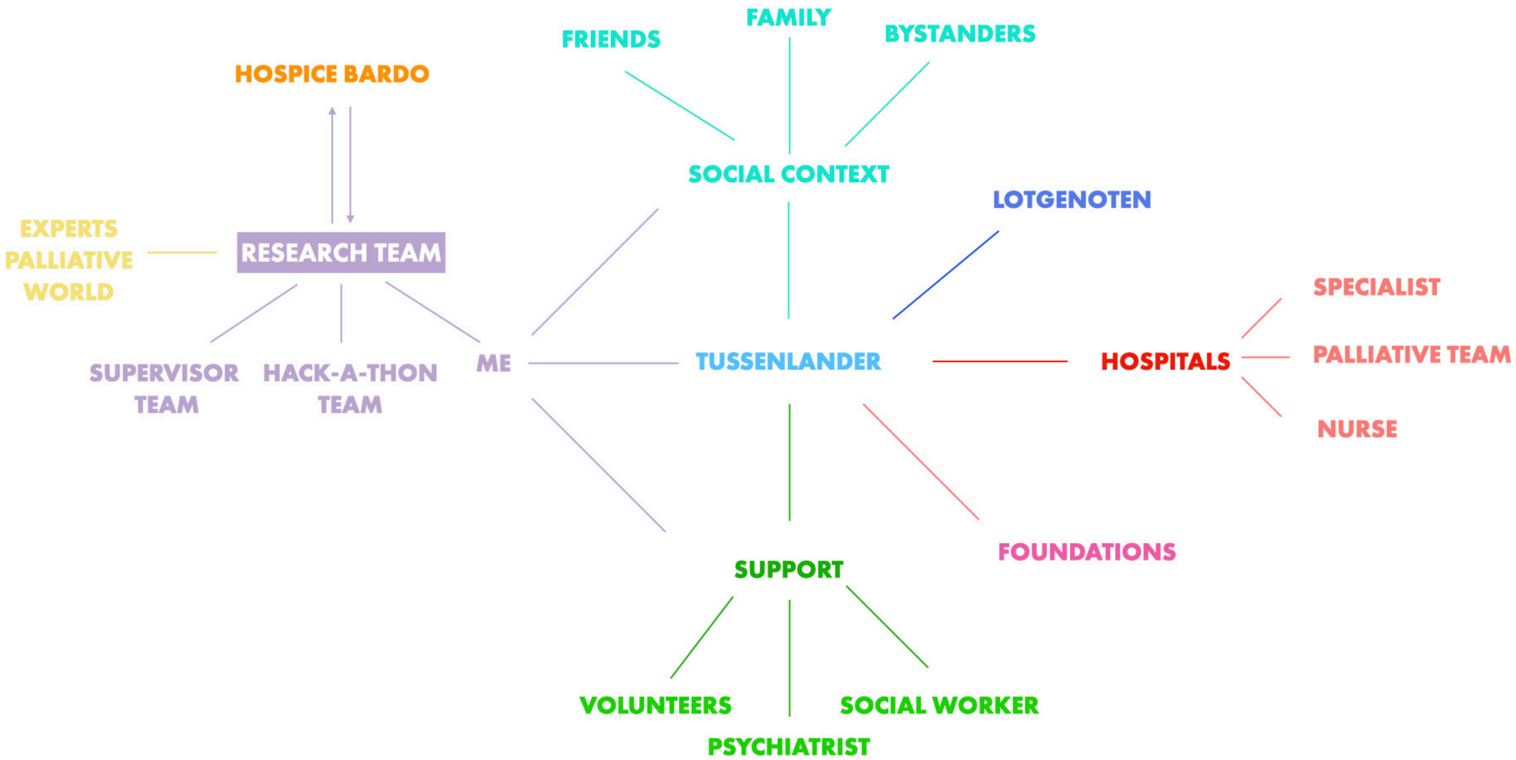


*Figure 3. Stakeholdermap of the thesis*

# PART 2 FRAMING

# 02

# EXPLORATORY LITERATURE REVIEW

*This chapter explores the domains of palliative care, the five styles of dying, Virtual Reality in the palliative care and the concept of compassionate communities with the help of literature research.*

CHAPTER 2.1
# OVERVIEW

An exploratory literature review has been performed to understand the context of this project. This chapter aims to find the answer to the following questions:

- *How is palliative care perceived in our culture?*
- *How can Virtual Reality guide the tussenlander and their loved ones through the in-between-land?*

These questions led to the exploration of the following research questions :

**PALLIATIVE CARE**
- *What is palliative care?*
- *What is the role of palliative care in the Netherlands?*
- *What are the different phases of palliative care?*

**THE FIVE STYLES OF DYING**
- *What characterises the different styles of dying (the rational, inhibited, social, proactive and trusting types)?*

**VIRTUAL REALITY IN PALLIATIVE CARE**
- *What are the effects of VR?*
- *What are viable uses of VR in care?*
- *What are the powers and the pitfalls of VR?*
- *What are product examples of VR in care?*

**COMPASSIONATE COMMUNITIES**
- *What are compassionate communities?*
- *What is the importance of compassionate communities?*

CHAPTER 2.2
# PALLIATIVE CARE

### THE DEFINITION OF PALLIATIVE CARE

The most common understanding society has of palliative care derives from the definition of the World Health Organization (2020):

*Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.*

The definitions get more defined with time, although this may not always be the case. The European Association for Palliative Care created a definition in 1998 that seems more complete compared to the definition from the WHO:

*Palliative care is the active, total care of the patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of social, psychological and spiritual problems is paramount. Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital. Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.*

The interesting part of this definition is how it shows that palliative care does not only encompass the tussenlander and the family, but also the whole community in its scope. Dying as a social happening, is one of the core beliefs palliative care stands for, as we humans are relational beings. It is not without reason that love and belonging are one of the needs, according to Maslow (1943).

The majority of the tussenlanders in need of palliative care have chronic diseases such as cardiovascular diseases, cancer, chronic respiratory diseases, AIDS and diabetes. Other diseases that may require palliative care are kidney failure, chronic liver disease, multiple sclerosis, Parkinson's disease, rheumatoid arthritis, neurological diseases, dementia, congenital anomalies and drug-resistant tuberculosis (*World Health Organization, 2020*)

**PALLIATIVE CARE IN THE NETHERLANDS**
In the Netherlands, an estimation of 150.000 people die every year, where 80% of these cases are not unexpected. Every year an amount of 120.000 tussenlanders require palliative care. (*Ministerie van Volksgezondheid, Welzijn en Sport, 2019*).

Although it has been more than twenty years, since palliative care was initiated in the Netherlands, it is still in its infancy. In the last twenty years, there have been many changes in the practice of palliative care. Nevertheless, the large conceptual ideas about care in the last phase of our lives have stayed more or less the same (*Kwaliteit in Zorg, 2015*). This may occur because the Netherlands has been a cradle of euthanasia since the first of April in 2002. The Netherlands became the first country that regulated the 'Termination of Life on Request and Assisted Suicide'. (*ZonMw, 2016*). However, during these heated discussions, some parties contradicted 'euthanasia or palliative care'. This example shows a knowledge gap about palliative care, as palliative care and euthanasia are aligned and sometimes even go hand in hand.
Many people in the Netherlands do not know about palliative care. Furthermore, if they have heard about it, often it is associated with the terminal phase, the last stage.

Saskia Teunissen, Professor Hospicecare at UMC Utrecht, explains that palliative care has been enshrined insufficiently in medical care. (*Kwaliteit in Zorg, 2015*) This can explain the knowledge gap in palliative care, as society mainly associates their health and professional care with the care they receive at hospitals or from general practitioners.

However, Corry Tol, who was closely involved in the nineties with the establishment of the first hospices, does experience some incremental changes: 'It is a positive experience that there is more

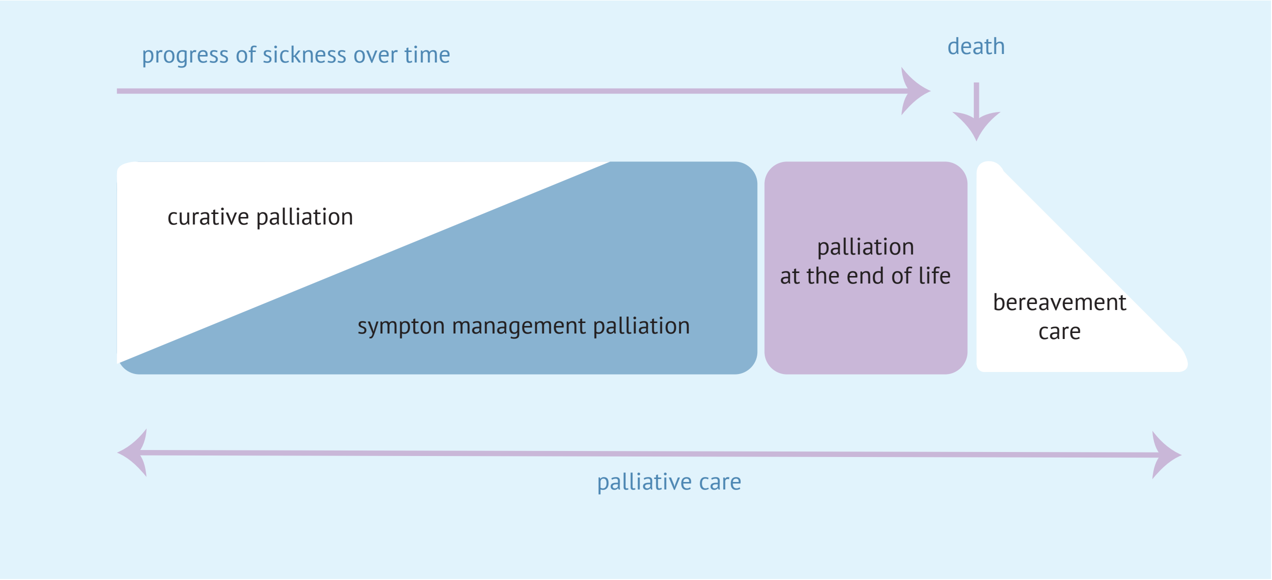


*Figure 4. the four stages of palliative care*

acknowledgement for the hospice concept (*Kwaliteit in Zorg, 2015*). The concept of hospice care has also been embedded in more hospitals and first-line care. There are more options now in the end-of-life care.

## PALLIATIVE PHASE

Many people associate palliative care with the last weeks to months, the terminal phase. However, palliative care covers more than that. In figure 4, the various stages of palliative care can be seen (*Murray, 2005*).

The four phases are respectively:
1. Curative palliation: The disease is being treated without any prospects of being cured.
2. Symptom management palliation: Enlightenment and control of the symptoms.
3. Palliative care at the end-of-life: The attention moves from the quality of life to the quality of dying. Most of the time, this phase has a short duration of a few days, the last days before end-of-life.
4. Bereavement care: The aftercare that focuses on the care for the people close to the tussenlander.

Figure 4 is an overview of what palliative care could look like for a tussenlander. This can differ per tussenlander. The journey of some tussenlanders could take five years, while for other tussenlanders, the journey only might

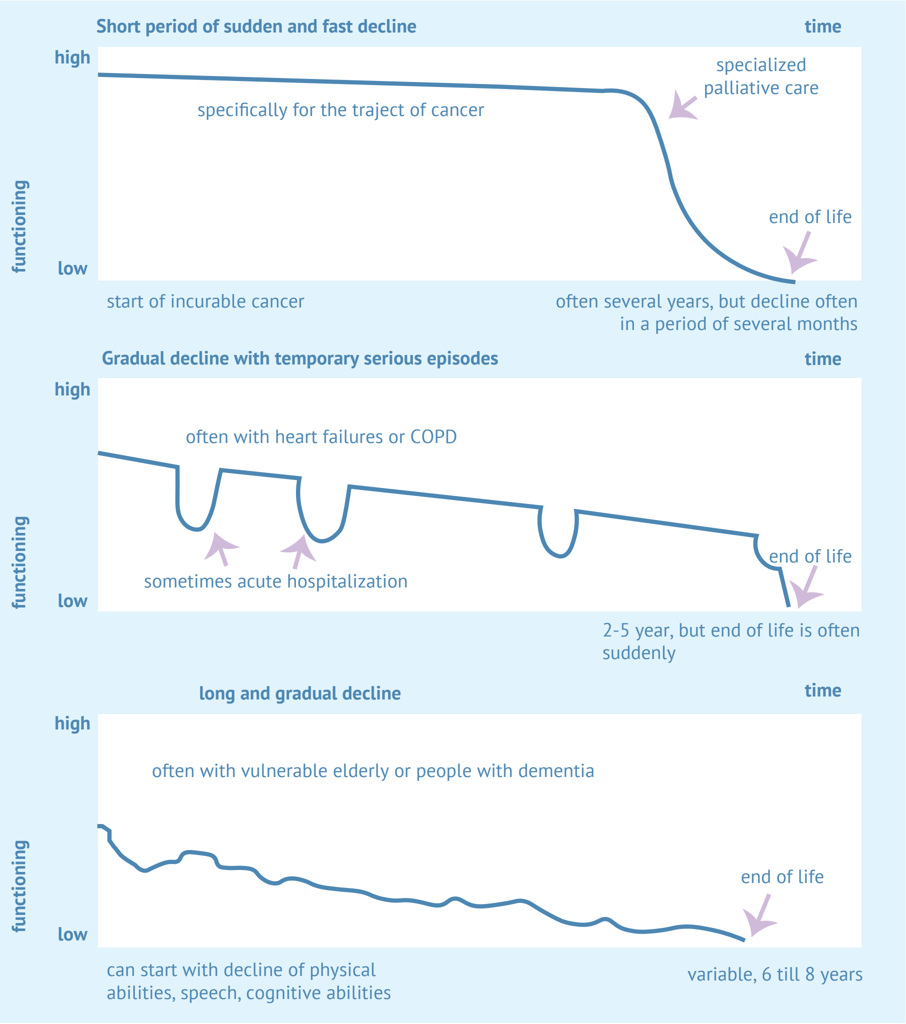


*Figure 5. the progress of different diseases (Murray, 2005)*

be five months or less.

## DIFFERENT PROGRESS PALLIATIVE PHASE

For every tussenlander, the palliative phase can look different. Moreover, there is also a clear distinction in the progress of the palliative phase in terms of the disease. In figure 5, the progress of the diseases cancer, heart failures and COPD, vulnerable elderly and dementia are presented.

The progress of cancer is often characterised by a long period of high functioning with a sudden and fast decline in the last months. The progress of heart failures and COPD is characterised by a gradual decline with temporary periods of decline with a sudden end-of-life.
A slow and gradual decline often characterises the progress of vulnerable elderly and dementia.

## THE KUBLER ROSS MODEL

The Kubler Ross Change Curve is a model introduced by Elisabeth Kubler Ross(1969), a Swiss-American Psychiatrist. It is also known as the five stages of grief, consisting of various levels and stages of emotions experienced by a person approaching the end-of-life.
These five stages exist of denial, anger, bargaining, depression and acceptance (*Kubler-Ross, 2009*).

### *Denial*

This stage is often a short-lived period filled with shock and denial. In this phase, one may not want to believe what is happening. Often this is channelled into a dip in productivity and a dip in the ability to think and act. The first phase of shock is often followed by denial. Some people remain in this state of denial for a long time, losing touch with reality.

### *Anger*

Anger characterises this stage after realising that the end-of-life is coming sooner than they thought. This anger is often expressed

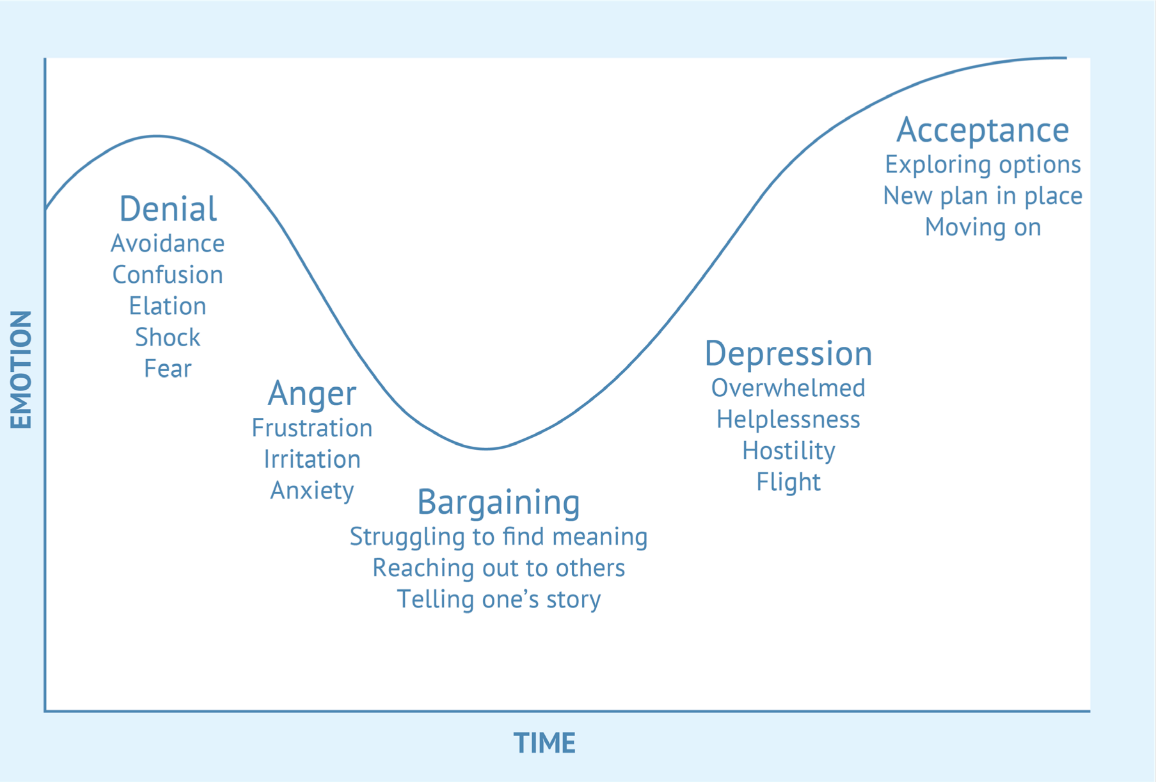


*Figure 6. The Kubler-Ross Change Curve (2009)*

as frustration, irritation and anxiety. It can be directed at themselves, while others take out their anger towards those around them.

***Bargaining***
In this phase, people may start thinking about postponing the inevitable. This is expressed in a search where they are looking for a different or a less traumatic outcome. They may try to process this (traumatic) experience by setting new goals. They try to engage this by reaching out to others and telling one's story.

***Depression***
Depression is a stage where the emotions of sadness and grief overrule. They feel overwhelmed, helpless, fear and other negative emotions. It is a stage where all these negative emotions overrule the perspective of a meaningful life.

***Acceptance***
After a particular moment, the person finds out that they cannot walk away from the truth anymore. People come to terms with this 'new' reality in this phase. This does not mean that there are no bad days anymore, but the person has more space to explore new options in this phase.

This model looks like a linear model, that describes steps or phases that follow up on each other. However, it would be incorrect and wrong to interpret the feelings of a tussenlander as a linear model. Kubler Ross noted that the emotions that are described in her model could be experienced in every different order over a more extended period. That is also how this model is viewed in this thesis, fitting the complexity of the tussenlander's feelings.

### CHAPTER 2.3

## THE FIVE STYLES OF DYING

Stichting STEM( STerven op je Eigen Manier) is a Dutch organisation that shines light upon the end-of-life. The organisation aims to make the end-of-life an integral part of our lives and society. Stichting STEM investigated how people can cope and engage with this end-of-life, which resulted in five styles of dying (*Stichting STEM, n.d.*). In this chapter, these five styles of dying will be elaborated on.

### THE RATIONAL TYPE ('rationele type')

**Description**
The rational type is often male, with often a secondary level education and often non-religious or non-spiritual. There is a fear of pain, and medical care and privacy are important. Status is essential for them, and they value their family and friends. So taking care of everything so that the bereaved will be left behind 'properly' is of utter importance to them.

**The view on the end-of-life**
For them, death is a taboo, that one might think about but never speak of. So they often have difficulties in showing their vulnerability.
They would instead look for information and rationality.

### THE UNHIBITED TYPE ('onbevangen type')

**Description**
The rational type is often male and young, and lives with their parents or family. They have had a higher education, and their

income is rarely below average. Moreover, their spirituality and practice of religion are below average. The uninhibited type is young and tolerant, with a high affinity for friendships. Their family plays a minor role in their social life.

**The view on the end-of-life**
The uninhibited type is less afraid for the last phase of life, but does not know what he would wish or need in terms of help or rituals, and has almost not arranged anything for that phase. They like to enjoy their life, and are playful, but death is something that is eliminated from their daily life.

## THE SOCIAL TYPE ('sociale type')

**Description**
The social type, the largest group, often lives together and is low educated. Their income is often below average, and a large part of this group consists of Catholics and Muslims. They often have a low information literacy level, are risk-averse and look for safety.

**The view on the end-of-life**
The social type is more scared of the end-of-life than the average person. There is a need for pain relief and control when needed. They appreciate the company of family and friends, and practical help with housekeeping, transport and chores. With regards to the end-of-life, the social type often is in denial.

## THE PROACTIVE TYPE ('pro-actieve type')

**Description**
The proactive type is often female, older than 45 years, with often a secondary level education. More than average, the proactive type lives alone, and has a spiritual mindset. Their fears are dementia, loss of dignity and dependency on caregivers. They would like to be in charge of the process to their end-of-life.

**The view on the end-of-life**
The end-of-life is part of their lives and not taboo for this group. This group does wish to be in charge till the end, and wants to die an authentic death, preferably at home.
Their wish in the last phase is to be healthy in body and mind, to be able to decide the moment of dying, with little pain and a little suffering. Compared to all the other groups, the proactive has arranged the most for the end-of-life.

## THE TRUSTING TYPE ('vertrouwende type')

**Description**
The trusting type is often married and higher educated. They are often religious. They think more of others than themselves. The trusting type views family, following the rules, duties and caring as important.

**The view on the end-of-life**
The trusting type is less afraid of the end-of-life than the average person, because they feel supported by their religion and loved ones. They do not talk about death, as it is just part of life. This group would like to be completely conscious, to be able to say goodbye to everyone, and do not want to be a burden to others. They do prefer professional help.

These five dying styles are not absolute, meaning that only these five styles exist in our population. However, they indicate how the views on end-of-life can differ. They show how people all have different defence mechanisms in times of need and how they all approach the end-of-life differently. Often, people belong to a mix of 'types'. This makes it challenging to design something for people with many different needs. Therefore, this must be considered when defining the scoped target group for this project.

### CHAPTER 2.4

# VIRTUAL REALITY IN PALLATIVE CARE

Virtual Reality (VR) is a technology that enables you to enter a virtual world. Wearing special VR glasses, where the computer-generated image is embedded, feels like a 3D reality.
The use of VR in general care is not something new. It has already been used for educational and rehabilitation purposes. However, evidence for VR in a palliative care setting is sparse (*Perna, 2021*). VR is often associated with and understood as a replacement of the care, which is hard to connect with the warm and holistic care a hospice offers (*de Beer, 2021).*

In the project 'met Hart en Tech', the Dutch association of hospice care and Marieke Sonneveld from the Technical University of Delft, with several other experts, looked at how hospice could innovate with specific technologies. In this project, the potential was found in VR technology, especially by Hospice Bardo. This thesis uses this thought of potential as a starting point to investigate how this expectation can be met.

## THE EFFECTS OF VIRTUAL REALITY

Virtual Reality is an approach that can desensitise the source of the autonomic reflexes that have now deteriorated into anxiety and panic (*Ashwell, 2019*)

VR can engage the aberrant state of mind via:

1. Acclimatisation: Fear, anxiety, and panic can be softened through the repetition of immersive environments that are naturally reassuring and comfortable for a patient. *(Rothbaum, 2009*)

2. Distraction: For fear of pain, distraction can re-allocate much of one's recognition to other realms of thought. (*Boyd, Wetterneck, Hart, 2013)*

## VIABLE USES OF VIRTUAL REALITY

This paragraph shows the viable uses of Virtual Reality in care situations according to literature.

- Palliation in painful procedures (pain, wound management). VR effectively mitigates the subjective perception of pain, both acutely and chronic *(Hoffman, Doctor, Patterson, Carrougher, & Furness, 2000)*.
- Calming in fearful situations. VR is effective in calming patients undergoing procedures within confined spaces (MRI). A VR "run-through" is excellent preparation for the experience *(Hoffman,2004)*.
- Mental excursions during therapy (e.g. chemotherapy, radiation therapy). VR has been shown to make chemotherapy and other lengthy, recurrent treatments more tolerable and seem shorter in duration *(Schneider, Prince-Paul, Allen, Silverman, & Talaba, 2004)*.
- Introduction to environments that cause apprehension (hospice, hospital, surgery, SNF, burn units, etc.). Serially increasing exposure via VR exposure therapy (VRET) immersion to feared social situations, is an alternative to the standard exposure therapy to virtual environments that result in social phobias *(Klinger, Bouchard, Légeron, Roy, Lauer, Chemin, & Nugues, 2005)*.
- Anxiety disorders. VRET demonstrates a dose-response relationship in improving anxiety disorders *(Opris, Pintea, García-Palacios, Botella, Szamosközi., & David, 2012)*.

These examples show how VR has contributed to treatments in hospitals. The following paragraphs explore the power and the pitfalls of VR in general, not necessarily related to a medical environment.

## THE POWER OF VR

1. It enables people to forget the reality for a moment, the reality of being sick.
2. It can close people off from the daily fuss and rush instantly, wherever they are, enabling them to enter a new reality *(Lee,*

*Hsiao & Chen, 2020).*
3. In 2D or movies, people can imagine the interactions and the world, but with VR, they can experience it themselves and be immersed in this world *(Tian & Zhang, 2021).*
4. People can create their own narratives. Due to the controllers, people are in charge of their own stories *(Ostrin, Frey & Cauchard,2018).*
5. VR can evoke physical reactions from the body that would happen in actual situations, as the brain is susceptible to social reactions *(Wiersma & van Duinen, 2021).*
6. The actions in VR feel more natural and intuitive because of a better perception of depth and similarities with the real world.
7. VR can enable people to 'physically' visit places, sceneries or situations that would not have been possible by certain handicaps.

### THE PITFALLS OF VR

1. People, in general, love the interaction experienced in reality *(Wiersma & van Duinen, 2021)*, for example, holistic care. Therefore, the use of VR should not be a replacement for the current care but something that complements the care.
2. The technology is not comfortable enough yet; the size of the glasses, nausea and headaches *(Elmqaddem, 2019; Wiersma & van Duinen, 2021)*.
3. Social interactions do not flow naturally yet. Examples are the synchronisation of the lips and facial and body expressions *(Wiersma & van Duinen, 2021)*.
4. It initially is a technology with a high threshold for digital illiterate people, especially the elderly.

### EXAMPLES OF VR IN CARE

#### VRiendje

*Figure 7. The VRiendje (HorusVR, 2020)*

The VRiendje is a 360 degrees camera, that enables people to attend activities, or occasions they cannot attend due to treatments or physical reasons. The 360 degrees camera will be placed where the tussenlander should be, while the tussenlander is wearing the VR glasses. Whenever the tussenlander turns its head, the camera will move accordingly, making it feel like they are in the same space. It is one of the solutions to fight the social isolation many tussenlanders deal with.
This design gives people the feeling that they do not have to feel left out, as they still will be able to be present during an event and look around as they would usually do.

*Figure 8. The DreamDiVR in use (DreamDiVR,2019)*

A pitfall is that it only is a camera. Therefore, the tussenlander cannot communicate with other people. This can make them still feel excluded from the event.

**DreamDiVR**

DreamDiVR are Virtual Reality underwater goggles that enable people to be immersed in the underwater world. The goggles are waterproof, which allows to wear them underwater to simulate the underwater feeling for the ultimate immersion. With the DreamDiVR, people do not need to travel far away for snorkelling and diving, but they can experience it at their local swimming pool or even their bathtub. It allows people to enter a different reality that would not have been possible without these goggles.

The power of these underwater goggles is that it allows them to be immersed through vision, touch, feeling, and warmth. It allows them to be transported and immersed in the sea.

While the views are breathtaking, the question is for how long it will stay interesting, as it does not offer extensive interactions. So it would be interesting to explore all the possibilities in the underwater scene. A pitfall could be that, of course, it is a particular niche, underwater VR.

**Playground VR**

Playground VR is a virtual playground for children who cannot play outside. These children can play together with other children in a hospital and their families. The Playground enables the children to relax and have fun under challenging times.

The power of the Playground VR is the interactions that it brings with it, and that it allows children to do the one thing that characterises them: playing. So this application gives them the feeling of themselves back: to be a kid.

*Figure 9. Little girl using PlaygroundVR (2021)*

*Figure 10. The virtual world of PlaygroundVR (n.d.)*

### CHAPTER 2.5

# COMPASSIONATE COMMUNITIES

In the literature review, the Compassionate communities theory was often linked to palliative care. A study by Julian Abel (2018) in the *Clinical Medicine,* suggests the following: Compassionate communities as part of the public health approach to end-of-life care, offers a possibility of solving the inequity of the difference in provision of care for those with an incurable disease (Abel, 2018). In this chapter the definition and the importance of the Compassionate communities theory will be explained.

## DEFINITION OF COMPASSIONATE COMMUNITIES

Compassionate communities are based on the understanding that the care for another at times of crisis and loss is not solely a task for health and social services but everyone's responsibility *(Kellahear, 2013).*

The care for tussenlanders is now widely viewed as the family's responsibility or of health services *(Kellahear, 2013)*. This polarised view of care for older people, tussenlanders and the bereaved is the consequence of the following cultural developments. In Western European culture, there has been a growing disconnect between the basic family unit and their wider connection with extended family and broader community networks in the last century. Moreover, there is also a rise in dependency on professional health services *(Gottlieb, 1994)*.

## IMPORTANCE OF COMPASSIONATE COMMUNITIES

This polarised view presents a false representation of what communities can mean for the tussenlander, the family and health services. Allen Kellahear (2013) explains why the concept of compassionate communities is important to implement in our culture and health services.

1. The 95% rule. A dying or grieving person spends less than 5% of their time with a doctor or a health professional. This means that 95 percent of this time is spent alone or with friends, family, and co-workers. It is spent with the community.
2. It is not dying or grieving that is the problem. The problem is the co-morbidities; it is what accompanies dying and grieving. It is the anxiety, the depression, the loneliness, the social isolation, the stigma, the social rejection, the lost workdays, lost school days. These are the real problems.

Nowadays, harm reduction and early intervention have become watch-words in the best cure for these co-morbidities (*Kellahear, 2013*).
However, instead of medicine, these people need support. They need their first line of support. In theory, when people think of their first line of support, they think of their care professionals. However, in practice, the people around them, with whom they spend 95% of their time, are the first line of support.

The research agency ABF Research analysis showed that the care professional shortage will multiply by three in 2031(*Sondermeijer, 2022*). This means that there will be a shortage of over 140.000 care professionals in nine years in the Netherlands. This shortage can result in a higher workload for care professionals, leading to insufficient care. Therefore, it would be recommended to explore what could contribute in providing tussenlanders with the care they need.
Using the concept of compassionate communities and implementing that in the care for a tussenlander, can relieve the care professionals of their high workload, and support the tussenlander.

# 2.6 KEY TAKEAWAYS

### PALLIATIVE CARE

The way palliative care is presented in the Dutch culture does injustice to palliative care. Palliative care is often associated with the last months to weeks of a tussenlander. Therefore, one of the goals of this project is to explore how palliative care can be implemented in an earlier phase than the last months to weeks, and create more awareness of the existence and the true meaning of palliative care.

### THE FIVE STYLES OF DYING

Stichting STEM defined five styles of how people can approach the end-of-life: the rational type, the inhibited type, the social type, the proactive type and the trusting type. These styles all have different needs, which shows the complexity of designing something for a more significant part of society (that involves more than one style of dying). The diversity that exists in different types of tussenlanders must be considered. The design cannot be a one size fits all. Because everyone does enter the in-between-land, but not everyone wants to engage in this in-between-land. Though, most likely, the pro-active type will be most open to engage with the in-between-land. However, these five styles are not absolute, people can belong to a mix of types. Thus, the focus in this project will be mainly on the pro-active type, but still be open to exploring the other styles.

### VIRTUAL REALITY IN PALLIATIVE CARE

Virtual Reality is shown to have much potential, with its powers and its pitfalls. Virtual Reality enables them to enter a new reality, something that is valuable for tussenlanders in these tumultuous times. However, it also shows inconsistencies with the physical world, thus not allowing it to replace interactions. The power of VR in this project is not to replace any interactions, people or things but to use the technology Virtual Reality to reinforce the interactions that happen in the physical world.

### COMPASSIONATE COMMUNITIES

The concept of compassionate communities can help out so many people in so many ways. We live in a world compassed by individualism. However, suppose we can look out for each other in the form of a compassionate community. In that case, the tussenlander benefits from it, and it will relieve the care and social services sector.

# 03

# EXPLORATIVE STUDY

*This chapter presents the insights of the user interviews to investigate the experiences, needs and wishes of a tussenlander. These insights are presented in a patient journey map followed by several opportunities.*

CHAPTER 3.1

# OVERVIEW

This chapter aims to get insight into the experiences, needs, and wants of a tussenlander after the diagnosis of an incurable disease.

***Research question***: *What does the in-between-land look like for tussenlanders and their loved ones?*

All these insights will be used to present the journey of the tussenlander. By mapping out this journey, this chapter aims to get insight into the crucial moments in the journey when the tussenlander needs support the most.

The explorative study of this project exists out of in-depth user interviews with a panel of different types of stakeholders: Tussenlanders, their loved ones, care professionals and experts in the field of palliative care. A variety of participants was chosen to understand what the in-between-land looks like and what the journey in the in-between-land exists of. Tussenlanders and their loved ones are interviewed to determine their needs and wishes when they have just entered the in-between-land and how they experience the time they already have spent in the in-between-land.

Experts like care professionals and important frontrunners in the world of palliative care were interviewed to understand their role in the lives of tussenlanders. Moreover, their perception of the needs, wishes and hurdles in the lives of a tussenlander, is taken into consideration.

The base of every interview was built around a metaphor, the participant could relate to. In literature about palliative care, many tussenlanders expressed their feelings and experiences in the form of a metaphor, like Jannie Oskam, the owner of the Tussenland metaphor, which became the inspiration for this project. Not everyone can express all their feelings, thoughts and emotions in words, while a metaphor can convey the complexity of these feelings, thoughts and emotions.

For every interview, an interview guide was created beforehand. This guide served as a base for the interviews. However, as

**INTERVIEW PANEL**

| TUSSENLANDERS | LOVED ONES | CARE PROFESSIONALS | EXPERTS |
|---|---|---|---|
| TUSSENLANDER JANNIE | SON OF TUSSENLANDER S. | SOCIAL WORKER | ROB BRUNTINK |
| TUSSENLANDER DVD | DAUGHTER OF TUSSENLANDER M. | ONCOLOGY SUPPORT CONSULTANT | TEUN AALBERS |
| TUSSENLANDER MINNIE | SON OF TUSSENLANDER M. | | PEIK SUYLING |
| TUSSENLANDER CECILIA | | | |
| TUSSENLANDER LUBBERT | | | |

*Figure 11. Overview interview panel*

every story and narrative for every person is different, this occasionally led to new iterative variations of the interview guide. The complete interview guides can be found in appendix B.
By using the metaphors and the insights from the interviews, the journey of a tussenlander is formed in a Patient Journey Map

### CHAPTER 3.2

# INTERVIEW GUIDE

## TUSSENLANDERS

**Goal**
The goal of the interviews was to gain insight into the following topics:
- The journey of the tussenlander in terms of activities, experiences and needs.
- The different actors that play a role in the journey of the tussenlander.
- The metaphor that represents their view of the in-between-land.

**Method**
The interviews consist of three parts. The first part focused on the personality and mindset of the tussenlander. This part of the interview looks beyond their status as a patient, and tries to grasp and understand the tussenlander as a human being.

In the second part of the interview, the tussenlander is asked to elaborate more about the moment they received the diagnosis of an incurable disease. The following research questions are asked to achieve the research goals:
- How does the tussenlander experience the communication of the diagnosis?
- What experiences take place during and shortly after the diagnosis?
- What are the tussenlander's needs for each experience?

The third part of the interview focuses on the experiences of the tussenlander when they have landed for a more extended period in the in-between-land. The following research questions are some of the questions that were asked to achieve the research goals:
- What are the experiences for the tussenlander after the diagnosis until the present?
- What are the tussenlander's needs for each activity?
- What are important values in the in-between-land?
- How did it change the life of the tussenlander in terms of family, friends, work, financially, physically and in society?

Every interview was concluded with the following question:
- What does the ideal in-between-land look like for you?

The last question may be interpreted as a difficult question, because what makes something ideal? However, for this research, people were encouraged to still have the ability to think of a dream situation. Christiaan Rhodius, the palliative doctor at Hospice Bardo, explained that at Hospice Bardo, they always try to answer the needs of the tussenlander, no matter how absurd the request. Hospice Bardo likes to think in possibilities, which is a mindset incorporated into this project.

Two participants were recruited through Hospice Bardo and three participants through palliative organisations. These participants differ in age (53-78 y/o), gender (60% female), disease and progression of the disease. Even though these differences exist, they all have one thing in common: they have entered the in-between-land.

The interviews were held online on zoom due to the COVID measures and offline when it fitted the schedule of the tussenlander.
The interviews were recorded and transcribed. The insights of these interviews are included in the database (Airtable) that will be used for the data processing in chapter 4.

## LOVED ONES

**Goal**
The lives of the tussenlander and their loved ones are so intertwined that they will be able to show the journey of a tussenlander from their perspective. The goal is to determine how the loved ones envision the in-between-land. Therefore the interviews gain insight into the following topics.

- The journey of the loved one in terms of activities, experiences and needs.
- The metaphor that represents their view of the in-between-land.
- How the disease affected the relationships between the tussenlander and the loved one.

**Method**
The interviews consist of two parts. The first part focuses on the experiences and memories of the loved one after the diagnosis.
The following research questions are asked to achieve the research goals:

- How does the loved one experience the moment of diagnosis?
- What was something the loved one needed at that moment?
- What are the tussenlander's needs for each activity?

The second part of the interview focuses on how the disease affected the relationship with the tussenlander. The following research questions are some of the questions that were asked to achieve the research goals:

- How did the roles between the tussenlander and the loved one change?
- Could the loved one specify a special moment between the tussenlander and loved one? Explain why.
- What were the fields of tension between the tussenlander and the loved one?

Every interview was concluded with the following question:

- What does the ideal in-between-land look like for you?

All the participants are children of tussenlanders. The three participants (24-29 y/o) recruited all have a different situation in terms of in which phase the tussenlander is. For two participants, the tussenlander is near the end-of-life. The third participant is the son of a tussenlander who deceased in 2016.

The interviews were held online on zoom due to the COVID measures and offline when it fitted the schedule of the loved ones. The interviews were recorded and transcribed. The insights of these interviews are included in the database (Airtable) that will be used for the data processing in chapter 4.

## CARE PROFESSIONALS

**Goal**
The goal of the interviews was to gain insight into the following topics:

- The journey of the tussenlander, from the viewpoint of the care professional, in terms of activities, experiences and needs.
- The available means to support the tussenlander (treatments, therapies).
- The 'best' and 'worst' practices.
- The metaphor that represents their view of the in-between-land.

**Method**
The interview was divided into two parts. The first part focused on mapping the care professional's activities in more detail. The following research questions are asked to

achieve the research goals:

- What is the care professional's profession about?
- How would the care professional explain their role towards the tussenlander?
- What tools and approaches does the care professional use to support the tussenlander?

The second part of the interview focuses on the experiences the care professionals had with tussenlanders. More importantly, what we can learn from these experiences: the best and worst practices. The following research questions are some of the questions that were asked to achieve the research goals:

- What is something that gives the tussenlander support/energy?
- Which tussenlanders do you still remember clearly? Can you elaborate on why?
- What is something you struggled with dealing with these tussenlanders?

Every interview was concluded with the following question:

- What does the ideal in-between-land look like for you?

The two recruited participants have much experience in guiding tussenlanders daily, as a social worker and oncology support consultant. The interviews were held online on zoom due to the COVID measures and offline.

The interviews were recorded and transcribed. The insights of these interviews are included in the database (Airtable) that will be used for the data processing in chapter 4.

## EXPERTS

**Goal**

The goal is to obtain experiences and practices of palliative care from different types of experts in our society. Therefore, the interviews gain insight into the following topics:

- The perception of palliative care in our culture.
- Forms of therapy and digital applications in palliative care.

**Method**

The three participants that were recruited all have a different expertise. Therefore the interview research questions differ from each other. One participant is Rob Bruntink, an expert on palliative care in our society. The following research questions were asked to achieve the research goals:

- What is so typical about the palliative care in the Dutch culture?
- How is the quality of life and quality of death perceived?

The two other participants both have an expertise in a specific type of treatment. Peik Suyling is an artist, designer, and owner of 'alswoordenbloemenworden'. Teun Aalbers is one of the owners of Gainplay, where they developed the design of the 'wijsheidscoach', a design that supports the tussenlander.

The following research questions were asked to achieve the research goals:

- What is the therapy/treatment about?
- In what way does this therapy/treatment support the tussenlander?

Every interview was concluded with the following question:

- What does the ideal in-between-land look like for you?

The interviews were held online on zoom due to the COVID measures. The interviews were recorded and transcribed. The insights of these interviews are included in the database (Airtable) that will be used for the data processing in chapter 4.

CHAPTER 3.3

# INTERVIEW RESULTS

## TUSSENLANDERS

### Disruptiveness of the diagnosis

The participants explained that the diagnosis completely disrupted their lives, where it felt like they had lost their grip on their lives. There was an urgent need for palliative care in the first phase after the diagnosis.

*‘In het begin is het beangstigend. Je wordt gekatapulteerd, als je van de ene op de andere dag de diagnose krijgt. Je bent je lichaam, je levensperspectief, je gezinssituatie, je maatschappelijke positie en ook vaak in je materiele omstandigheden iets kwijt’*
*- Jannie, Tussenlander*

*“Heleboel dingen zijn langs me heen gegaan in die periode. Ik zat vaak als een dood vogeltje in de stoel natuurlijk.”*
*-Cecilia, Tussenlander*

*“Ik ben helemaal vergeten wat er gebeurde. Er gebeurde zoveel, maar ik kon dat niet allemaal goed op een rijtje zetten. Ik was een soort van verdoofd”*
*-Minnie, Tussenlander*

The participant explained that it felt like an earthquake when she got the diagnosis, a state where they could not think clearly. This enormous amount of information on treatments, therapies, and literature can be experienced as overwhelming for the tussenlander. On top of that, it felt like an information overload after they receive the diagnosis, because many things in their life will change. One tussenlander explained how a specialised nurse took charge of this and acted as a sort of case manager:

*‘Een gespecialiseerde verpleegkundige heeft het roer overgenomen voor alle behandelingen. Dat heeft ze achter de schermen gedaan, en ik heb dat enorm gewaardeerd. Ik was daar zelf niet toe in staat’. Zij heeft gewoon voor comfort gezorgd zodat ik kon herstellen en daarna verder kon gaan’*
*-Jannie, Tussenlander*

The participant explains how this nurse guided her in her darkest moments, so that she could heal to go on and make the decisions herself eventually.

### The need for attention

The need that was still missing in daily practice was an unwavering form of attention. There is a need for a genuine and constant form of attention, that goes deeper than a simple question of formality.

*“Ik vind het moeilijk dat mensen je geen aandacht geven in de zin van, hoe gaat het met je en je ziekte, waar denk je aan wat houdt je bezig? Meestal is het een aandacht in de vorm van bezorgdheid.”*
*-Jannie, Tussenlander*

*“Dat mensen bij me blijven komen. Niet dat op een gegeven moment als het heel lang gaat duren dat de aandacht verslapt. Want ik heb toch heel erg de mensen nodig, ik ben namelijk veel op mezelf, en ik kan dat makkelijker als ik weet dat er anderen voor mij zijn. Dat vind ik heel belangrijk. Dat ik altijd de ruimte en vrijheid kan blijven voelen. Bij mezelf en ook bij de mensen om me heen”*
*-Minnie, Tussenlander*

### Position in society changes

One of the insights of the tussenlanders was how it changed his position as a person in society. Where in the past, he would be described as a successful businessman, devoted father and husband and the breadwinner, he felt deprived of these labels. The only thing left was a patient that only caused suffering for his surroundings.

*“het was op twee fronten oorlog voeren. ik moest mijn positie verdedigen als persoon, maar ik moest ook overleven in belang voor*

*mijn gezin"*
*-DVD, Tussenlander*

*"Ik moest mijn plek binnen het gezin afstaan. 6 jaar lang. omdat je alleen maar aan het vechten bent tegen die verdomde ziekte"*
*-DVD, Tussenlander*

The tussenlanders want to be seen as a person and not as a patient, which unfortunately happens in reality.
The following was an experience that left an impact on the tussenlander at a smaller hospital. They address him with his first name at this hospital and not as a patient. It is already this tiny detail that can change an experience altogether.

**Will to live for loved ones**
The topic that ran like a thread in the interviews was the will to live. This will to live was endorsed by improving the quality of life for their loved ones:

*"Het is mijn laatste taak om ze goed achter te laten."*
*-DVD, Tussenlander*

The love for his family was intense, like a fire inside him burning. It was for him the incentive to keep making memories together.

*"Liefde is zo sterk, niks is te veel"*
*-DVD, Tussenlander*

**New changes**
For the tussenlanders, the disease also opened new doors. It gave them more insights into their priorities in life and also enabled them more space and time to focus on themselves.

As the disease also creates beautiful moments, one must not forget to be realistic: there is something in their body that is slowly destroying parts of their body. This must be taken into consideration when they shape and plan their life.

*"Mijn langste planning scoping is 3 maanden. Op basis daarvan maak ik de plannen. Want ik ben al een keer teleurgesteld dat het weer enorm terugkwam. Toen kon mijn hele planning in de prullenbak"*
*-DVD, Tussenlander*

**Lotgenoten contact**
One of the tussenlanders emphasised the great support of lotgenotencontact (contact with people in similar situations):

*"Het fijne aan lotgenotencontact is dat je niet iedere keer dingen hoeft uit te leggen, iedereen begrijpt het wel hoe je je voelt, de vervelende en mooie dingen. Je leert ook heel veel van andere over alle behandelingen die nog mogelijk zijn"*
*-Cecilia, Tussenlander*

**Unexpressed emotions**
An experience that helped a tussenlander was at the Helen Downing centre, where the tussenlander and her husband went together. Tensions in the household ran high, and even though both parties felt the same emotions, they were never discussed aloud. A session at the Helen Downing centre showed them how important it was always to speak their mind:

*"Ze vroegen bijvoorbeeld aan hem: ben je bang om je vrouw te verliezen. Ja zei hij. Kijk we weten het van elkaar, om dit echt uit te spreken, is wel echt confronterend. Tuurlijk weet je het van elkaar dat je bang bent om elkaar te verliezen, maar als je het ook echt hoort, dat komt wel aan."*
*-Cecilia, Tussenlander*

**Incomplete information**
The tussenlander indicated that alternative treatments are inferior to medical treatments

in current practice. At the same time, many of his symptoms and complaints could not be tackled and addressed by the medical circuit. Therefore, there is a need for a complete range of treatments.

## LOVED ONES

### No future perspective

One of the biggest struggles mentioned was the difference in mindset and perspective between the loved ones and the tussenlanders. The life of the loved one is mainly focused on the present and the future. In contrast, for tussenlanders in the terminal phase, it feels like there is no future perspective.

*"Je hebt de wereld van mijn leven, maar dan is er ook de wereld van mijn vader. De eigenschappen van die werelden zijn zo verschillend dat ze moeilijk te verenigen zijn. Mijn wereld is heel erg op het nu en vooral op de toekomst gericht en heeft een bepaald tempo en urgentie, een bepaalde frequente van interacties met andere mensen. En zijn wereld, hij heeft gewoon geen toekomstperspectief."*
*-s. son of a tussenlander*

This is not always the case, as many tussenlanders still have many years to live. However, for one of the loved ones, whose father is near the end-of-life, it felt like they only had the past left, and no space for creating new things.

*"Sommige dingen zijn altijd, horen altijd bij het verleden. Maar als iemand ziek wordt en doodgaat, dan blijft alleen dat verleden over, dan kan er geen nieuwe dingen meer bijgemaakt worden. Dat is waar ik mee zit."*
*-s. son of a tussenlander*

### Using painting as a means of communication

Some loved ones indicated that they had difficulty expressing their emotions to deal with this situation. One of the loved ones expressed that painting was the way to convey his emotions and thoughts for him.

*" Ik denk dat het een manier is om verbintenis te zoeken. Het is een manier van communicatie zou ik bijna willen zeggen.Ik kon bepaalde dingen niet uitdrukken met woorden hoe meestal mensen dat doen. Ik had daar een andere uitdrukkingsvorm voor gevonden".*
*-s. son of a tussenlander*

### Need for community

From the loved one's perspective, there is a need for a community. We live in an era of compartmentalisation, individualisation and distance between people.

*"Ik merk dat ik dat heel erg het gevoel van gemeenschap mis in het tussenland en in het dagelijks leven. Als alles goed gaat, maakt niet uit, want dan ga je gewoon naar je werk en dan heb je niemand nodig, maar als het niet goed gaat, dan heb je ineens heel veel mensen nodig, en die zijn er niet"*
*-s. son of a tussenlander*

### Need for timelessness

One of the insights was that there was a need for timelessness in these dark times. The feeling of being together in the woods:

*"Dus een soort vacuüm in dat tussenland. Dat je de ruimte hebt om alles even te laten vallen om alles uit die tijd te halen en niet zozeer dat je ineens 1000 dingen moet gaan plannen. Maar al is het, je gaat gewoon alleen maar series kijken met elkaar, dat er een cultuur heerst waarin waar tijd niet bestaat"*
*-Myron, son of a deceased tussenlander*

There is a need for a place and a moment where one cannot do anything else than feel. ('op dat moment niks anders dan voelen").

### Different needs

The loved one indicated that the definition of comfort could differ for the tussenlander and the loved one.

*“Ik denk dat er niks zo erg is in een familie om te zien dat het niet goed gaat. Maar soms als diegene achteruit gaat, is het beter voor diegene”*
*-Maude, daughter of a tussenlander*

Seeing someone’s physical and mental functions deteriorate can be life-breaking for the loved ones, but for the tussenlander, her mind was more at peace, and she seemed less unhappy. This example shows how sometimes the most complicated changes do not immediately imply a negative outcome for the tussenlander.
What also happens is that the focus stays on the tussenlander, whereas the needs of the loved one fade into the background.

*“Wat er snel gebeurt, is dat iemand die heel ziek is, die wordt een soort van zon in dit zonnestelsel waar alles om heen draait.*
*Ik merkte wel in dat proces dat mijn eigen behoeftes naar de achtergrond verdwenen”*
*-s. son of a tussenlander*

## CARE PROFESSIONALS

### Be selfless

The insights of the care professionals showed how selfless care professionals have to be while treating a tussenlander. As a non-tussenlander, one must always concur with the tussenlander wishes and needs.

*‘ Sluit je altijd aan waar de persoon is. Dit is hun reis, niet mijn reis. Je moet luisteren met elke vezel in je en je moet alle zintuigen gebruiken die je hebt. Je moet egoloos zijn”*
*- Nettie, specialized oncology social worker*

The story of the professor in figure 12 also

### The story of the professor

The professor had been receiving curative treatment for cancer for years. However, one morning he woke up and could not move his whole body. The doctors diagnosed that the tumour had spread and that the disease was incurable. After this diagnosis, the first person he spoke to was a social worker called Nettie. When he saw her, he started screaming and swearing at her. Who do you think that you are, trying to talk to me. I cannot do anything, I cannot decide how to live my life, I’m completely dependent of others. Nettie heard all of this, and the only thing that she could say was: You are right, I’m just me and I cannot solve anything for you. But she looked around: he was lying in a shared room with 6 others. She saw that he hated being in this room, because it felt that he had no choice. So she said to him: I’m giving you the choice to come with me this afternoon, I’ll bring a wheelchair and then we’ll take a stroll. And so they did, he was very silent when they walked around. ***She asked him if he wanted a smoke, as she had already noticed a faint smell of cigarette smoke around him.*** So they went to the smoking area, and when he lit the first cigarette, he started crying uncontrollably. He asked her: “how to die, how do I do this? I don’t know anything about it, and I feel so scared and lonely. And I know that there are many others, but how do I reach out to them.

***So she started to map out the social context of the professor and showed him what possibilities he had***: that he could ask for a private room, have personal belongings that are dear to him in this room, and reach out to the people close to him. The next day Nettie came back, and when she looked for him she found him in a private room with tons of bottles of wine. His friends all visited him and decorated the whole room with books and photos. And he told Nettie: Yesterday I decided with all my friends, that I will be going to a hospice, where they all will visit me and where we will party like there is no tomorrow, and celebrate my life.

*Figure 12. Story of the professor*

portrays this selflessness. The professor insulted the social worker, but she saw right through it. She completely understood how she had to treat him. She gave him something he was missing by offering him a cigarette to feel like himself.

**Tone of voice**
Unfortunately, in practice, care professionals still tell tussenlanders that they cannot be treated anymore ("U bent uitbehandeld"). The use of this kind of sentence can traumatise tussenlanders and deprive them of their hope. This means that one cannot deprive a tussenlander of its hope when they are not ready for it yet. Therefore, the tone of voice and the manner of breaking the news matter.

**Mean something for other tussenlanders**
Moreover, the power of meeting other people is precious for tussenlanders, where they can mean something to each other. It can be an outlet where they can share their feelings and an environment where they can enjoy their lives together.

## EXPERTS

**Palliative care fragmented in Dutch culture**
One of the main insights was that Rob perceived palliative care in the Dutch culture as fragmented. Many organisations exist parallel to each other. Thus, there is no central place for people to go to. Moreover, every type of organisation is more directed internally. A country we could learn a lot from is Ireland, where the Irish Hospice Association already is mobilising and including the society in their organisation. That is precisely what needs to happen in the Netherlands.

*"Sterven is een sociaal gebeuren. Heel concreet gezien zijn zorgverleners hooguit 5% van de tijd in nabijheid van de patient en 95% van de tijd zijn die patienten alleen of hebben ze hun partner, kinderen, ouders of andere mensen om zich heen."*
*-Rob Bruntink*

The experiences of Teun Aalbers corresponded with the experiences of Rob. During the development of the 'wijsheidscoach', he experienced how fragmented the palliative care in the Netherlands is. This was also reinforced by the complexity of the large group of people who enter palliative care.

*"Groepen zitten in verschillende stadia en stadia van acceptatie"*
*-Teun Aalbers*

**VR should not replace the physical world.**
Teun noted a vital insight regarding the use of VR.

*"Het gaat om het leren met de pijn dealen als de VR bril afgaat. Want als je de bril afzet, dan heb je weer de ramp van terugkomst van pijn."*
*-Teun Aalbers*

Therefore, the goal with VR is not only to decrease the pain whenever the tussenlander uses it, but the use of VR must also ensure that the tussenlander has a better quality of life whenever they remove the VR glasses.

**Creating in silence**
Peik started the therapy 'alswoordenbloemenworden', where tussenlanders paint different types of flowers in complete silence. The combination of creating something and the silence worked in this therapy.

*"Bloemen zijn een expressie van levenskracht en vergankelijkheid. Van hoop en herinnering"*
*-Peik Suyling*

For this therapy, the silence was a requirement for it to work.

*"In stilte een nieuwe werkelijkheid creeren, Je*

*creeert samen een bubbel die je kan delen met een nieuwe werkelijkheid"*
*-Peik Suyling*

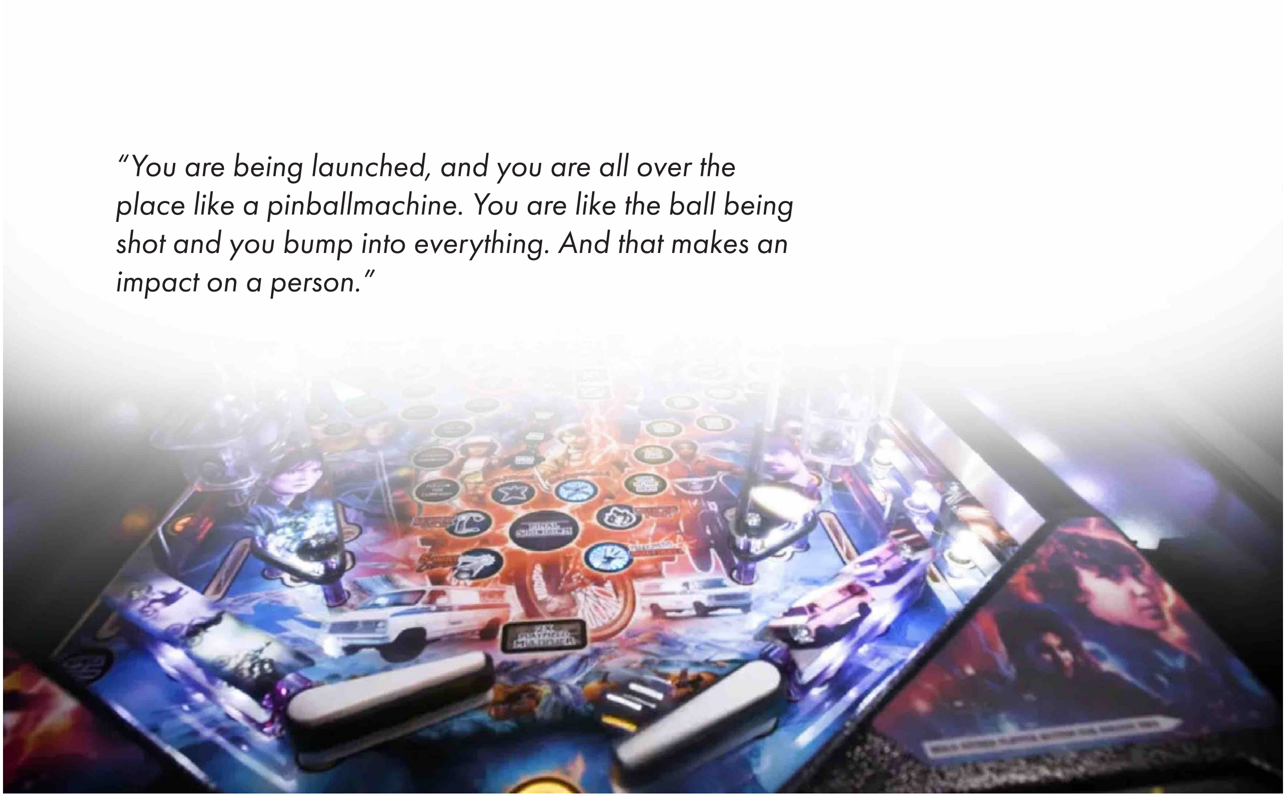
More extensive results of the interviews can be found in appendix C. The translation of the quotes can be found in Appendix D.

### CHAPTER 3.4

# METAPHORS

As explained in the approach of this chapter, the base of every interview was built around a metaphor. It was interesting to see how some participants were initially hesitant to think of a metaphor, but they expressed a metaphor during the conversation without knowing themselves. Some participants even came up with multiple metaphors.

This use of metaphors enabled the participants to share the complexity of their feelings, thoughts and emotions. One of these metaphors also inspired the journey in the next chapter (see figure 14). A complete overview of all the other metaphors can be found in Appendix E.



*"You are being launched, and you are all over the place like a pinballmachine. You are like the ball being shot and you bump into everything. And that makes an impact on a person."*

*Figure 13. The pinball metaphor*

### CHAPTER 3.5

# JOURNEY THROUGH A METAPHOR

All people are different and have their individual traits. Therefore a linear patient journey map was challenging, as it is not a linear process. The life of a patient is filled with uncertainties. The following figure is a metaphor of a pinball machine that explains what these uncertainties look like. There are only three moments that are fixed, which are A) the launch of the pinball (diagnosis of incurable disease), B) the pinball flowing through the path (start trajectory hospital treatment plan) and L) the end of the game (end-of-life). All the moments in between are not in chronological order. The order can be completely random and repeated multiple times.

**A. Diagnosis of an incurable disease**
The moment the patient gets the diagnosis that their disease is incurable. It feels like they are launched into an unknown world, where they have lost grip on their lives.

**B. Start trajectory hospital treatment plan**
After the diagnosis, the doctors start informing the patient about the treatment plan to control the symptoms. It feels like the hospital is taking control of the patient's life.

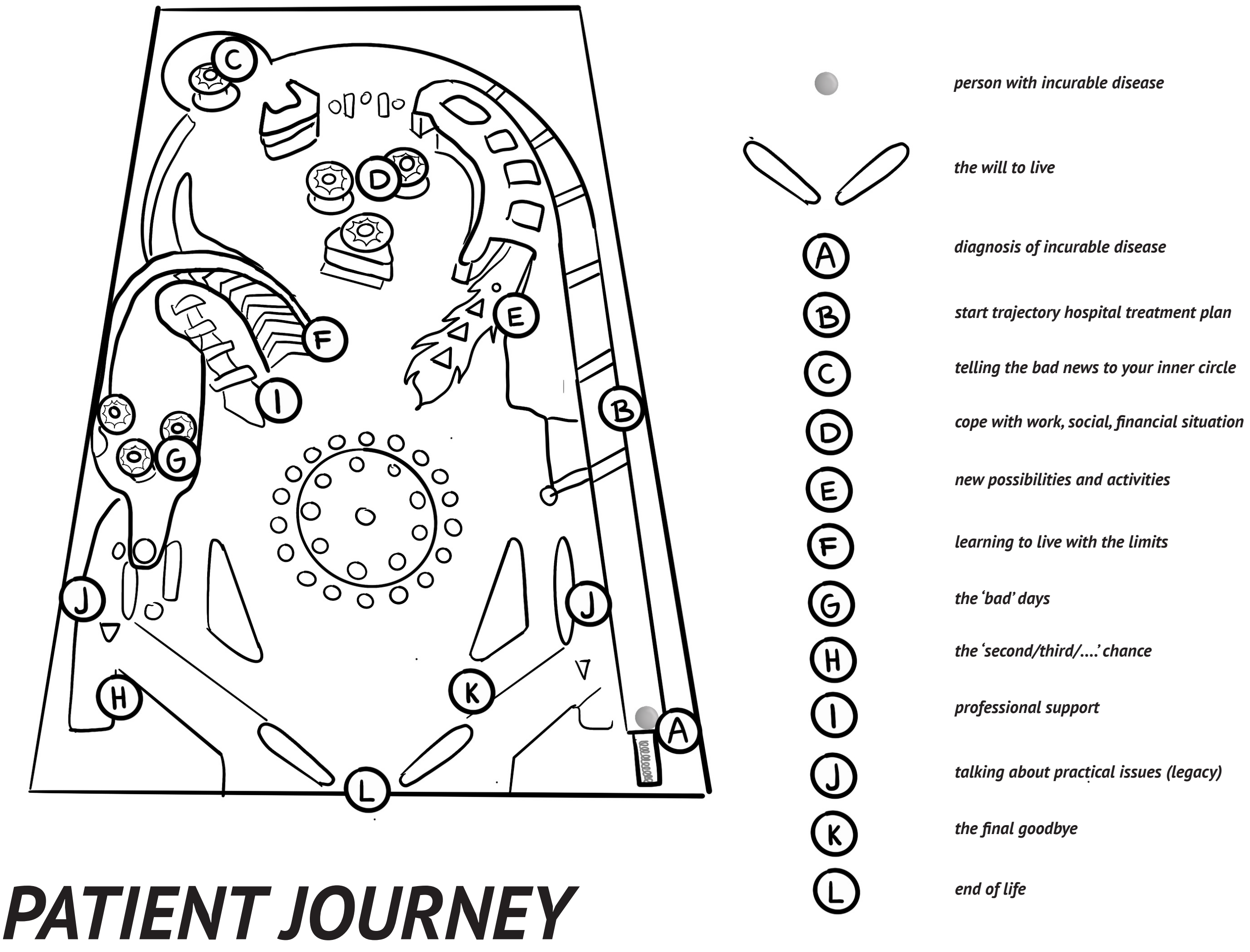


*Figure 14: The journey through the pinball metaphor*

The hospital determines their pace, how they fill their days, and decides what medicine they have to take. The hospital decides everything, and it is difficult for the patient to deal with this transition. It feels like they have lost their autonomy.

### C. Telling the bad news to your inner circle

The moment the patient breaks the news to their inner circle is an emotional rollercoaster. It can be experienced differently by everyone. Some people seek consolation and comfort in each other. However, many patients already have enough on their plates. They do not have enough space for other peoples' emotions. By not expressing these emotions, some fields of tension can arise.

### D. Cope with work, social, financial situation

After the diagnosis, the patient's mind is all over the place. The things they felt secure about in life, like work, social life and financial situation, have been shaken up. Some people lose their jobs, and people start treating them differently, the costs start piling up, they have difficulties paying the mortgage of their house and more new difficulties. So not only their bodies are fighting the disease, but arising problems also overload their mind and soul. It feels like the patient is fighting a war on two fronts.

### E. New possibilities and activities

The diagnosis can also have a positive influence on the patient's life. It can give them the realisation to live life to its fullest, and do what they enjoy. Things they felt they never had any time for due to work or other obligations. This can differ from following new passions and hobbies to spending more time and connecting with their loved ones. As human beings, we constantly urge to work on our personal growth and development, but we also want to create valuable memories.

### F. Learning to live with the limits

Patients have to learn how to deal with the new limits in their lives. Due to medication and symptoms, they have to live a healthy life. They cannot go back into their old habits. They cannot exercise or work as much as they used to. Planning activities can not be as spontaneous as it used to be. Some patients keep their disease a secret, as they do not want people to treat them differently.

### G. The 'bad' days

Even when the patient tries his best to adapt to his new life, they will always have the 'bad' days. The days when they have to stay in bed due to the symptoms, have nightmares about dying, and have to stay in the hospital. They get 'hospital-sick' at a particular moment because they cannot handle the grief and sorrow around them.

### H. The' second/third/..' chance

Even though the doctor gives a life expectancy, the duration of the patient's life is still uncertain. Medical miracles do happen, but they can also quickly turn around. Even on the brink of death, people can still recover and live many years. It feels like they have been given a second chance and live in 'bonus time'. This uncertainty in life expectancy ensures that patients only pay attention to their own scoping and time framing. For example, one patient only looks ahead for three months, not further than that.

### I. Professional support

Patients can get physical, psychological, social and spiritual support from different professionals. Some people get support from people with the same experiences, while others speak with professionals individually or together. Not everything applies to everyone, but it can give them a lot of guidance and support on their journey.

**J. Talking about practical issues (legacy)**
An issue that always arises is talking about practical issues. What will happen after the death of the patient? What kind of funeral is preferred? What will happen with the possessions? What are their last wishes? How people deal with this can differ significantly. Some people already have planned everything, while others do not even want to think about the idea of death and therefore postpone it till it is too late.

**K. The final goodbye**
This final goodbye is the last moment the patient is conscious. It is an emotional moment as they have to say goodbye to their loved ones and a moment of peace as they can finally be at rest.

**L. End-of-life**
The end-of-the life of the patient.

**M. Bereavement care**
After the end of the patient's life, practicalities like the funeral will come up. However, this phase also focuses on the care for the bereaved.

### EVALUATION

This customer journey was shown to the participants of the panel. While some participants resonated with the pinball metaphor, for some participants, their experiences did not correspond with this metaphor. The metaphor of the pinball being launched, is someone's experience and not factual information. Therefore, in the next chapters, a Patient Metro Map will be created to look for the factual touchpoints in the journey of the Tussenlander.

CHAPTER 3.6

# METROMAP

This chapter presents a Metro Map that illustrates the journey of the Tussenlander. Metro Mapping, a service design method, maps the complexity of a medical care path and shows a better overview and understanding of the care path. The touchpoints in the Metro Map will be used for the Patient Journey Map that gives a representation of the journey of the Tussenlander.

The Metro Map in figure 15 presents the tussenlander's journey starting from the bad news conversation to the bereavement care after the end-of-life of the tussenlander. The metro map is not linear, as some touchpoints can be experienced several times. Sometimes multiple cycles can happen, where people have already been admitted to a hospice, but still, go back home for undergoing new treatments.

The metro map shows two major points or moments of decision. The first one is whether a tussenlander decides to undergo (palliative) treatment or not. After the first decline, the second point of decision is whether the tussenlander will choose not to change the living situation or start thinking of a care home, hospice or hospital. The figure shows a missing part between the entrance to the home care/hospital/care home/hospice and the final decline. For this part, four journeys have already been created in the Master Thesis of Willemijn Boere (2021), where she focused on the journey of family caregivers.

The touchpoints of this metro map will be used for the Patient Journey in the next chapter.

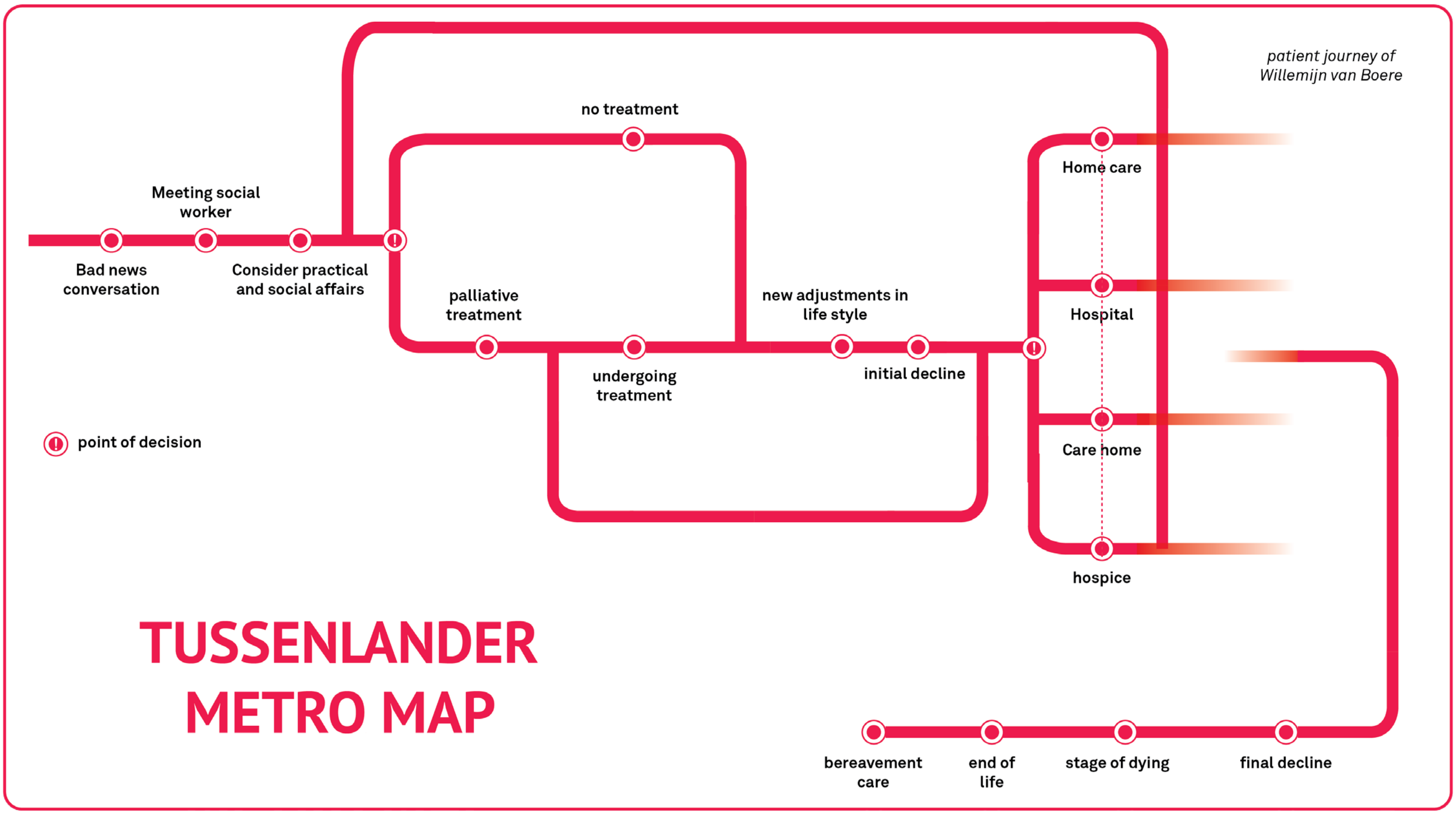


Figure 15: Metro Mapping of journey tussenlander

CHAPTER 3.7

# PATIENT JOURNEY MAP

This chapter shows a Patient Journey Map, using the touchpoints of the metro map in chapter 3.5 and the results of the interviews. The journey uses the experiences of the tussenlanders, loved ones and care professionals. This patient journey fits the journey of the pro-active type the most. Most of the tussenlanders interviewed fitted he description of the pro-active type.The Patient Journey map can be found in Appendix F.

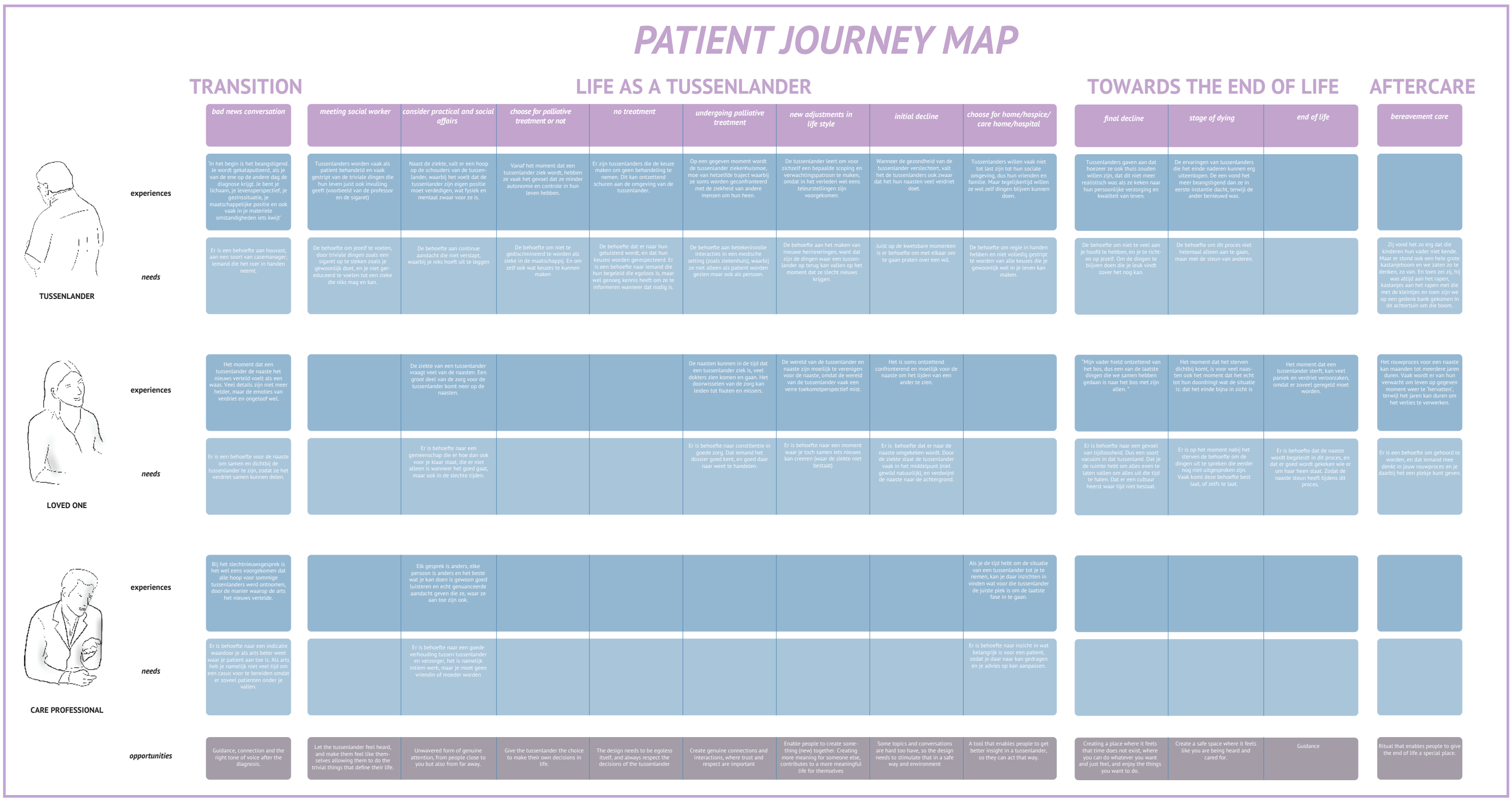
## THE JOURNEY

### Transition

The journey starts with the transition period when the tussenlander has the bad news conversation. For the tussenlander and their loved ones, this is a tumultuous period where they need to process this event together and individually. At the start of this journey, there is a strong need for guidance in this new and uncertain world. From a care professional's perspective, this is a challenging period. The challenge is to set the right tone in the bad news conversation, while telling them the truth but at the same time not depriving them of hope.

### Life as a tussenlander

The moment after the diagnosis, tussenlanders have a lot on their plate; will they get (palliative) treatment or not? What happens to their job? Who do they tell and who not? The lives of tussenlanders undergo many changes in the physical, psychological, social and spiritual dimensions. At the same time, this also has a significant impact on the people surrounding the tussenlander, the loved ones. In this period, there is a strong need for unwavering attention from the people around them, meaningful interactions and the power and freedom to make their own decisions. From a care professional's perspective, it is essential to put their feelings aside and listen to the tussenlander.



PATIENT JOURNEY MAP

| | | TRANSITION | LIFE AS A TUSSENLANDER | | | | | | | | TOWARDS THE END OF LIFE | | | AFTERCARE |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | *bad news conversation* | *meeting social worker* | *consider practical and social affairs* | *choose for palliative treatment or not* | *no treatment* | *undergoing palliative treatment* | *new adjustments in life style* | *initial decline* | *choose for home/hospice/ care home/hospital* | *final decline* | *stage of dying* | *end of life* | *bereavement care* |
| TUSSENLANDER | **experiences** | 'In het begin is het beangstigend. Je wordt gekatapulteerd, als je van de ene op de andere dag de diagnose krijgt. Je bent je lichaam, je levensperspectief, je gezinssituatie, je maatschappelijke positie en ook vaak in je materiele omstandigheden iets kwijt' | Tussenlanders worden vaak als patient behandeld en vaak gestript van de triviale dingen die hun leven juist ook invulling geeft (voorbeeld van de professor en de sigaret) | Naast de ziekte, valt er een hoop op de schouders van de tussenlander, waarbij het voelt dat de tussenlander zijn eigen positie moet verdedigen, wat fysiek en mentaal zwaar voor ze is. | Vanaf het moment dat een tussenlander ziek wordt, hebben ze vaak het gevoel dat ze minder autonomie en controle in hun leven hebben. | Er zijn tussenlanders die de keuze maken om geen behandeling te nemen. Dit kan ontzettend schuren aan de omgeving van de tussenlander. | Op een gegeven moment wordt de tussenlander ziekenhuismoe, moe van hetzelfde traject waarbij ze soms worden geconfronteerd met de ziekheid van andere mensen om hun heen. | De tussenlander leert om voor zichzelf een bepaalde scoping en verwachtingspatroon te maken, omdat in het verleden wel eens teleurstellingen zijn voorgekomen. | Wanneer de gezondheid van de tussenlander verslechtert, valt het de tussenlanders ook zwaar dat het hun naasten veel verdriet doet. | Tussenlanders willen vaak niet tot last zijn tot hun sociale omgeving, dus hun vrienden en familie. Maar tegelijkertijd willen ze wel zelf dingen blijven kunnen doen. | Tussenlanders gaven aan dat hoezeer ze ook thuis zouden willen zijn, dat dit niet meer realistisch was als ze keken naar hun persoonlijke verzorging en kwaliteit van leven. | De ervaringen van tussenlanders die het einde naderen kunnen erg uiteenlopen. De een vond het meer beangstigend dan ze in eerste instantie dacht, terwijl de ander benieuwd was. | | |
| | ***needs*** | Er is een behoefte aan houvast, aan een soort van casemanager; iemand die het roer in handen neemt. | De behoefte om jezelf te voelen, door triviale dingen zoals een sigaret op te steken zoals je gewoonlijk doet, en je niet gereduceerd te voelen tot een zieke die niks mag en kan. | De behoefte aan continue aandacht die niet verslapt, waarbij je niks hoeft uit te leggen | De behoefte om niet te gediscrimineerd te worden als zieke in de maatschappij. En om zelf ook wat keuzes te kunnen maken | De behoefte dat er naar hun geluisterd wordt, en dat hun keuzes worden gerespecteerd. Er is een behoefte naar iemand die hun begeleid die egoloos is, maar wel genoeg kennis heeft om ze te informeren wanneer dat nodig is. | De behoefte aan betekenisvolle interacties in een medische setting (zoals ziekenhuis), waarbij ze niet alleen als patient worden gezien maar ook als persoon. | De behoefte aan het maken van nieuwe herinneringen, want dat zijn de dingen waar een tussenlander op terug kan vallen op het moment dat ze slecht nieuws krijgen. | Juist op de kwetsbare momenten is er behoefte om met elkaar om te gaan praten over een wil. | De behoefte om regie in handen hebben en niet volledig gestript te worden van alle keuzes die je gewoonlijk wel in je leven kan maken. | De behoefte om niet te veel aan je hoofd te hebben, en je te richten op jezelf. Om de dingen te blijven doen die je leuk vindt zover het nog kan. | De behoefte om dit proces niet helemaal alleen aan te gaan, maar met de steun van anderen. | | Zij vond het zo erg dat die kinderen hun vader niet kende. Maar er stond ook een hele grote kastanjeboom en we zaten zo te denken, zo van. En toen zei zij, hij was altijd aan het rapen, kastanjes aan het rapen met die met de kleintjes en toen zijn we op een gedenk bank gekomen In de achtertuin om die boom. |
| LOVED ONE | **experiences** | Het moment dat een tussenlander de naaste het nieuws verteld voelt als een waas. Veel details zijn niet meer helder, maar de emoties van verdriet en ongeloof wel. | | De ziekte van een tussenlander vraagt veel van de naasten. Een groot deel van de zorg voor de tussenlander komt neer op de naasten. | | | De naasten kunnen in de tijd dat een tussenlander ziek is, veel dokters zien komen en gaan. Het doorwisselen van de zorg kan leiden tot fouten en missers. | De wereld van de tussenlander en naaste zijn moeilijk te verenigen voor de naaste, omdat de wereld van de tussenlander vaak een verre toekomstperspectief mist. | Het is soms ontzettend confronterend en moeilijk voor de naaste om het lijden van een ander te zien. | | "Mijn vader hield ontzettend van het bos, dus een van de laatste dingen die we samen hebben gedaan is naar het bos met zijn allen. " | Het moment dat het sterven dichtbij komt, is voor veel naasten ook het moment dat het echt tot hun doordringt wat de situatie is: dat het einde bijna in zicht is | Het moment dat een tussenlander sterft, kan veel paniek en verdriet veroorzaken, omdat er zoveel geregeld moet worden. | Het rouwproces voor een naaste kan maanden tot meerdere jaren duren. Vaak wordt er van hun verwacht om leven op gegeven moment weer te 'hervatten', terwijl het jaren kan duren om het verlies te verwerken. |
| | ***needs*** | Er is een behoefte voor de naaste om samen en dichtbij de tussenlander te zijn, zodat ze het verdriet samen kunnen delen. | | Er is behoefte naar een gemeenschap die er hoe dan ook voor je klaar staat, die er niet alleen is wanneer het goed gaat, maar ook in de slechte tijden. | | | Er is behoefte naar constitentie in goede zorg. Dat iemand het dossier goed kent, en goed daar naar weet te handelen. | Er is behoefte naar een moment waar je toch samen iets nieuws kan creeren (waar de ziekte niet bestaat) | Er is  behoefte dat er naar de naaste omgekeken wordt. Door de ziekte staat de tussenlander vaak in het middelpunt (niet gewild natuurlijk), en verdwijnt de naaste naar de achtergrond. | | Er is behoefte naar een gevoel van tijdloosheid. Dus een soort vacuüm in dat tussenland. Dat je de ruimte hebt om alles even te laten vallen om alles uit die tijd te halen. Dat er een cultuur heerst waar tijd niet bestaat. | Er is op het moment nabij het sterven de behoefte om de dingen uit te spreken die eerder nog niet uitgesproken zijn. Vaak komt deze behoefte best laat, of zelfs te laat. | Er is behoefte dat de naaste wordt begeleidt in dit proces, en dat er goed wordt gekeken wie er om haar heen staat. Zodat de naaste steun heeft tijdens dit proces. | Er is een behoefte om gehoord te worden, en dat iemand mee denkt in jouw rouwproces en je daarbij het een plekje kunt geven. |
| CARE PROFESSIONAL | **experiences** | Bij het slechtnieuwsgesprek is het wel eens voorgekomen dat alle hoop voor sommige tussenlanders werd ontnomen, door de manier waarop de arts het nieuws vertelde. | | Elk gesprek is anders, elke persoon is anders en het beste wat je kan doen is gewoon goed luisteren en echt genuanceerde aandacht geven die ze, waar ze aan toe zijn ook. | | | | | | Als je de tijd hebt om de situatie van een tussenlander tot je te nemen, kan je daar inzichten in vinden wat voor die tussenlander de juiste plek is om de laatste fase in te gaan. | | | | |
| | ***needs*** | Er is behoefte naar een indicatie waardoor je als arts beter weet waar je patient aan toe is. Als arts heb je namelijk niet veel tijd om een casus voor te bereiden omdat er zoveel patienten onder je vallen. | | Er is behoefte naar een goede verhouding tussen tussenlander en verzorger, het is namelijk intiem werk, maar je moet geen vriendin of moeder worden | | | | | | Er is behoefte naar inzicht in wat belangrijk is voor een patient, zodat je daar naar kan gedragen en je advies op kan aanpassen. | | | | |
| | ***opportunities*** | Guidance, connection and the right tone of voice after the diagnosis. | Let the tussenlander feel heard, and make them feel like themselves allowing them to do the trivial things that define their life. | Unwavered form of genuine attention, from people close to you but also from far away. | Give the tussenlander the choice to make their own decisions in life. | The design needs to be egoless itself, and always respect the decisions of the tussenlander | Create genuine connections and interactions, where trust and respect are important | Enable people to create something (new) together. Creating more meaning for someone else, contributes to a more meaningful life for themselves | Some topics and conversations are hard too have, so the design needs to stimulate that in a safe way and environment | A tool that enables people to get better insight in a tussenlander, so they can act that way. | Creating a place where it feels that time does not exist, where you can do whatever you want and just feel, and enjoy the things you want to do. | Create a safe space where it feels like you are being heard and cared for. | Guidance | Ritual that enables people to give the end of life a special place. |

*Figure 16: Patient Journey Map*

**Near the end-of-life**
When the health of the tussenlander starts deteriorating, it can be a sign that they enter the period near the end-of-life. During this period, they start preparing for the inevitable: the patient's end-of-life. In most cases, they have already prepared many practicalities (the funeral, the will), and many things are still unspoken. There is a strong need to be together with the people that matter during this period. For the tussenlander, their biggest worry is that they leave their loved ones behind most of the time. Therefore, bereavement care for the bereaved is something that must not be underestimated. It can take years of guidance for some bereaved to give the end-of-life a place in their lives.

Based on these results, a list of opportunities arose for the design.

## OPPORTUNITIES

1. Guidance, connection and the right tone of voice after the diagnosis.
2. Let the tussenlander feel heard, and make them feel like themselves, allowing them to do the trivial things that define their life.
3. Unwavered form of genuine attention from people close and far away.
4. Give the tussenlander a choice to make their own decisions in life.
5. The design needs to be egoless itself, and always respect the decisions of the tussenlander
6. Create genuine connections and interactions, where trust and respect are important.
7. Enable people to create something (new) together. Creating more meaning for someone else, contributes to a more meaningful life for themselves.
8. Some topics and conversations are hard to have, so the design needs to stimulate that in a safe manner and environment.
9. A tool that enables people to get a better insight into a tussenlander to act accordingly.
10. Creating a place where it feels that time does not exist, where they can do whatever they want and just feel, enjoying the things they want to do.
11. Ritual that enables people to give the end-of-life a special place.

# 3.8 KEY TAKEAWAYS

### TUSSENLANDER INTERVIEWS

•The tussenlander wants to be seen as a person and not as a patient.
•The diagnosis is a vulnerable and crucial moment, where the tussenlander needs support.
•The tussenlander can feel overwhelmed by the enormous but not complete collection of information. This influences their decision-making but also their mental and physical health.
•The tussenlander needs a figure of guidance that organises and guides them in the in-between-land.
•The connections with loved ones and lotgenoten contribute to the will of life.
•The disease has a significant impact on the daily lives of a tussenlander in terms of social position.
•Living in the in-between-land is learning to live with adjustments and a new shape of life (planning wise).
•By creating more space and time for themselves, it can lead to more resilience in terms of the new life in the in-between-land.

### LOVED ONE INTERVIEW

•The tussenlander's world and the loved one's world clash, because in one world, the perspective of a future is missing.
•The needs of a loved one can quickly fade to the background.
•There is a need for a place where time does not exist, where they can simply only feel.
•The right decision for the tussenlander, may not always feel like the right decision for the bystanders.

### CARE PROFESSIONAL INTERVIEW

•When treating a tussenlander, one must be selfless and always concur with the tussenlander's wishes and needs.
•The tone of voice and the manner of breaking the news matter.
•The power of meeting other tussenlanders and meaning something to each other, is valuable.

### EXPERT INTERVIEW

•Palliative care in the Netherlands is too fragmented. A central place is needed that is embedded in our society.
•Dying is a social happening.
•The use of silence can enable the creation of a new reality.
•Within the group of tussenlanders, everyone can be in a different stadia.
•With the use of VR, one must also foresee the influence of the use, whenever the tussenlander leaves the "digital world" and enters the physical world again.

### OPPORTUNITIES PATIENT JOURNEY MAP

1. Guidance, connection and the right tone of voice after the diagnosis.
2. Let the tussenlander feel heard, and make them feel like themselves, allowing them to do the trivial things that define their life.
3. Unwavered form of genuine attention, from people close and far away.
4. Give the tussenlander a choice to make their own decisions in life.
5. The design needs to be egoless itself, and always respect the decisions of the tussenlander.
6. Create genuine connections and interactions, where trust and respect are important.
7. Enable people to create something (new) together. Creating more meaning for someone else, contributes to a more meaningful life for themselves.
8. Some topics and conversations are hard to have, so the design needs to stimulate that in a safe manner and environment.
9. A tool that enables people to get a better insight into a tussenlander to act accordingly.
10. Creating a place where it feels that time does not exist, where they can do whatever they want and just feel, enjoying the things they want to do.
11. Ritual that enables people to give the end-of-life a special place.

# PART 3 REFRAMING

# 04

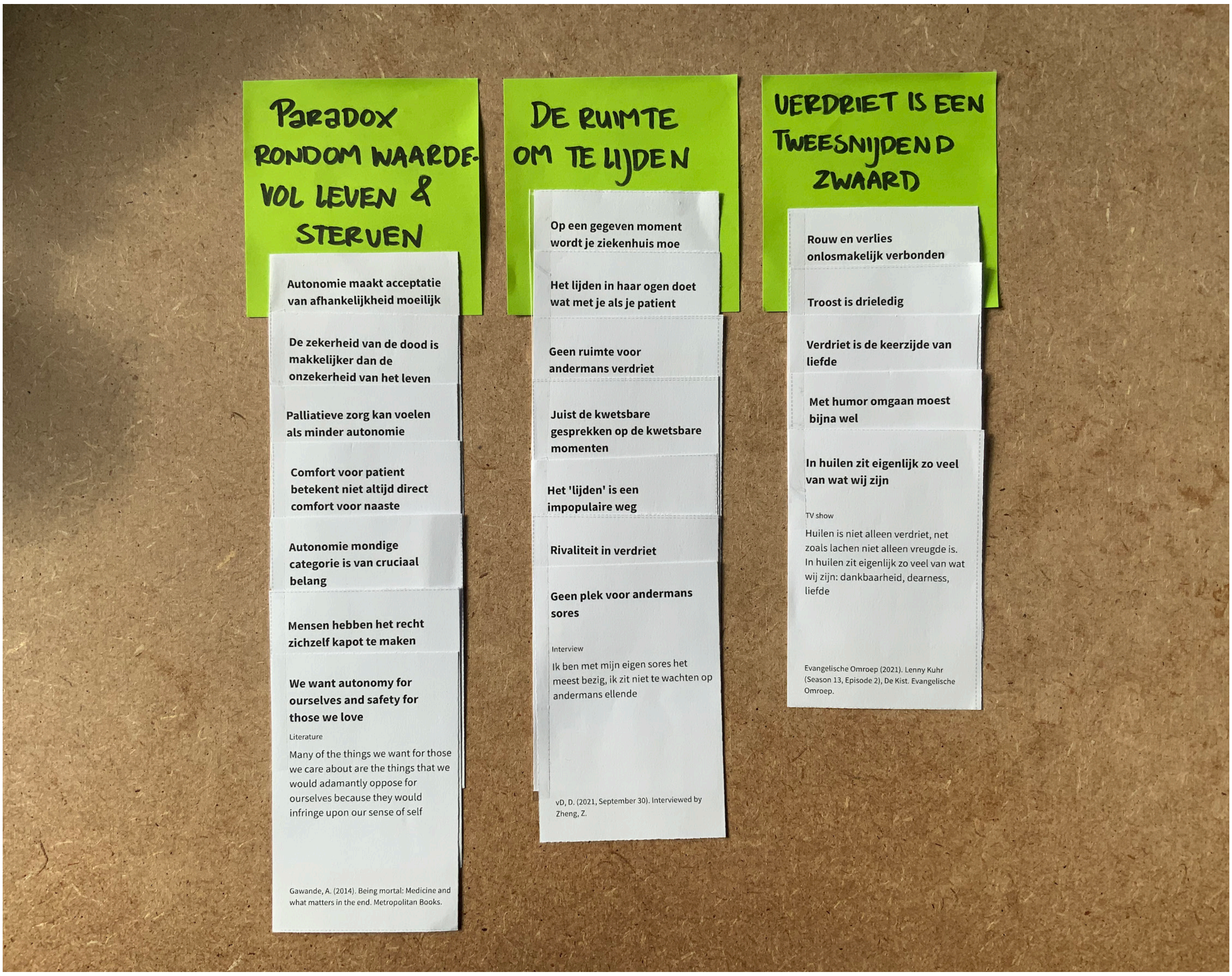
# DESIGN FOCUS

*In this chapter, all the exploratory literature review and study insights are clustered into 22 driving forces. These driving forces are used to scope the project and revise the design goal. This chapter concludes with the criteria the final design should comply with.*

### CHAPTER 4.1

# CLUSTERING

In the literature research and interviews, the transcripts and data are analysed for important factors; factors that are constantly changing(trends and developments), and factors that are not bound to change (states and principles). The VIP method (*Hekkert & van Dijk, 2011*) was followed for this part of the data collection. After the data collection of interviews, literature and desktop research, all the factors were stored in the online database Airtable. In a clustering session, connections were made between the factors to determine what Driving Forces exist in this theme. Driving Forces are personal drivers or motivators that answer the WHY question. So Driving Forces explain a person's motivating factors and 'why' someone does what they do. All the factors were printed out on cards and clustered into 22 Driving Forces. From there, these 22 Driving Forces were clustered into six main themes. The six themes and 22 driving forces can be found in Appendix G and H. These clusters were used as an inspiration for the criteria in chapter 4.5.



PARADOX RONDOM WAARDEVOL LEVEN & STERVEN

**Autonomie maakt acceptatie van afhankelijkheid moeilijk**

**De zekerheid van de dood is makkelijker dan de onzekerheid van het leven**

**Palliatieve zorg kan voelen als minder autonomie**

**Comfort voor patient betekent niet altijd direct comfort voor naaste**

**Autonomie mondige categorie is van cruciaal belang**

**Mensen hebben het recht zichzelf kapot te maken**

**We want autonomy for ourselves and safety for those we love**

Literature

Many of the things we want for those we care about are the things that we would adamantly oppose for ourselves because they would infringe upon our sense of self

Gawande, A. (2014). Being mortal: Medicine and what matters in the end. Metropolitan Books.

DE RUIMTE OM TE LIJDEN

**Op een gegeven moment wordt je ziekenhuis moe**

**Het lijden in haar ogen doet wat met je als je patient**

**Geen ruimte voor andermans verdriet**

**Juist de kwetsbare gesprekken op de kwetsbare momenten**

**Het 'lijden' is een impopulaire weg**

**Rivaliteit in verdriet**

**Geen plek voor andermans sores**

Interview

Ik ben met mijn eigen sores het meest bezig, ik zit niet te wachten op andermans ellende

vD, D. (2021, September 30). Interviewed by Zheng, Z.

VERDRIET IS EEN TWEESNIJDEND ZWAARD

**Rouw en verlies onlosmakelijk verbonden**

**Troost is drieledig**

**Verdriet is de keerzijde van liefde**

**Met humor omgaan moest bijna wel**

**In huilen zit eigenlijk zo veel van wat wij zijn**

TV show

Huilen is niet alleen verdriet, net zoals lachen niet alleen vreugde is. In huilen zit eigenlijk zo veel van wat wij zijn: dankbaarheid, dearness, liefde

Evangelische Omroep (2021). Lenny Kuhr (Season 13, Episode 2), De Kist. Evangelische Omroep.

*Figure 17: Clusters| Three of the 22 driving forces*

### CHAPTER 4.2

# SOLUTION SPACE

Based on the research done, it became clear, that designing for palliative care is a complex challenge because every tussenlander can experience the in-between-land differently. A tussenlander can even experience it differently day by day. Moreover, the concept of the ‘in-between-land’ for palliative care has not been used yet in the design world. The notion that a tussenlander is not living in the same world as others and not in the world of the deceased, but in a completely new world is something that sparks an interest. This new world has its own rules and characteristics with ups and downs. Furthermore, even though many hardships will be on their path, many beautiful things in the form of love and connection will be waiting for them too.

Looking at the findings of the study, two major causes complicate the life of a tussenlander.

1. Every participant expressed how the diagnosis was traumatizing for them. For some, it felt like an earthquake. For others jumping in an empty pool. Especially the moment after the diagnosis is an uncertain time where life passes them by. They feel numb and are not able to continue normally with their life.

2. Tussenlanders cannot always get the proper means to support them. The (palliative) care system is so fragmented that they have a lot of unanswered questions and uncertainties.

The findings of the study also suggest some positive effects in the life of a tussenlander.

1. The tussenlanders spoke about the unexpected interactions that arose after the diagnosis of an incurable disease. While some relationships were broken, some relationships only grew stronger. These interactions contributed to the will of life of a tussenlander. Moreover, the disease also created new relationships with people from angles they did not expect.

2. For some tussenlanders, the diagnosis of an incurable disease changed their priorities in life. The knowledge that their life is ending soon, was a wake-up call that urged them to reflect on their lives and think about how to create meaning in their life. This resulted in Tussenlanders spending more time with their family and doing things they always wanted to do.

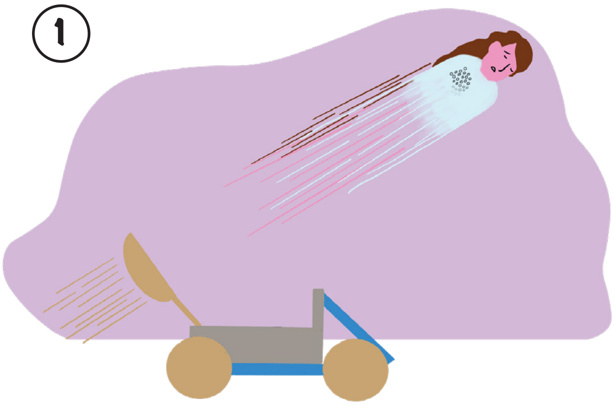
CHAPTER 4.3

# PROBLEM ANALOGY

The metaphor created by Jannie Oskam about the in-between-land presented a new perspective on perceiving the palliative phase of a patient. Therefore, the problem analogy of Oskam is being introduced and explored to support the creation and see the existing problem through the lens of a different domain (*Van Boeijen et al., 2014*). The analogy that illustrates this problem is as follows:

*It feels like entering an unknown foreign land, where you do not speak the language and do not know the way. It feels like a different planet. You feel completely lost and do not know what to do. (Oskam, 2021)*

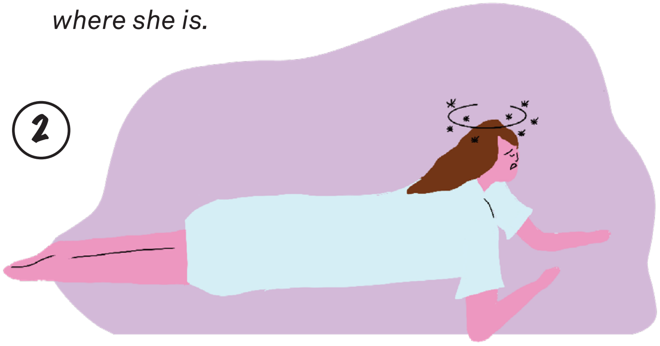
It is important to mention, that tussenlanders do not voluntarily enter the in-between-land. So it is not their own choice. Rather than voluntarily entering, it feels more like they are being catapulted into this unknown foreign land. The tussenlander needs some grip and certainty, because there is much to explore in this land. However, it can be hard to find or grasp by the tussenlander. There is a need for a map that outlines the possibilities in the unknown land, so that they do not have to be afraid they will end up in dangerous areas. They need to be guided by someone who has had prior experience in this foreign land that can accompany and welcome them.



*When the tussenlander gets the bad news diagnosis, it feels like they are being catapulted into another world.*

This analogy focuses mainly on the first part, the transition, of the patient journey map in chapter 3.7. This analogy shows the hurdles that arise after the bad news conversation. In the patient journey map, the experiences of the tussenlanders show little to no support and guidance for this phase, and throughout the patient journey, this need for guidance and support continues.
It could be meaningful for the tussenlander to get this support and guidance from the moment they need it, after the bad news conversation.

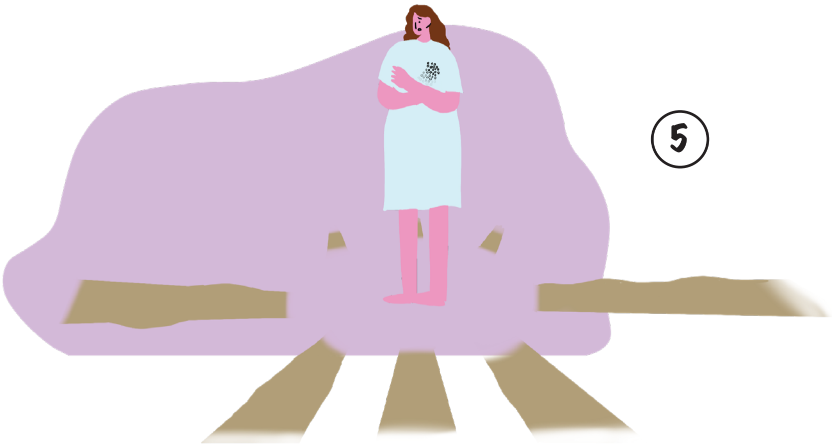
*She falls in the in-between-land and has no clue where she is.*



*She looks around, and it is so foggy that she cannot see a thing.*

④

*She walks closer to some roadsigns, but when she reaches them she does not understand the signs.*



⑤

*She sees all those paths around her, but she has no clue where they all lead to.*

⑥

*She feels so lonely and scared. Isn't there anyone else there? And how to find them?*

⑦

*She has so many questions. How to survive in this new land?*

CHAPTER 4.4

# DESIGN BRIEF

## DESIGN GOAL

The goal for this design challenge is a product service that will allow Hospice Bardo (and thereby other end-of-life care organisations) to support people in entering the ‘in-between land’, and exploring what it means to them. This case aims to create a place for people where they can safely land in these tumultuous times and feel welcome to engage and open up to the ‘in-between land’. So how can the design create light for them in these dark times, and invite them to enter this Virtual Reality. Nevertheless, how can a patient’s environment, so their loved ones, caregivers, hospices and society, form a secure base that can support the patient? The in-between-land is an endless world with many different needs, layers, and possibilities, as someone’s stay in the in-between-land can vary from a few weeks to several years. In this research, the number of people that mentioned they needed something or someone after the diagnosis, was remarkable. Therefore, this project will focus on the entrance to the in-between-land, and how to design an invitation so that people can safely land:

*How can an invitation be designed for people who enter the in-between-land, to engage with this new context of their life emotionally?*

As explained in the key takeaways in chapter 2.6, the design cannot be a one size fits all. Not every tussenlander wants to emotionally engage with this new context. Among the styles of dying from Stichting STEM, the pro-active type, is most likely open to engage this new context.

## DESIGN STATEMENT

A design statement is created to capture what the design should do and its characteristics (*van der Vorst, 2018*).For target audience (1), product category (2) will offer product attributes (3) that, functional benefits (4) and give emotional benefits (5) to be self-expressive benefits (6).

FOR **PEOPLE WITH AN INCURABLE DISEASE** AND **THEIR LOVED ONES**[1], THE CONCEPT WILL OFFER A VR-SOLUTION[2] THAT WILL **WELCOME** AND **INVITE** THEM TO ‘HET TUSSENLAND’[3], HELPING THEM **EXPLORE** HET TUSSENLAND[4], MAKING THEM **FEEL LESS LOST**[5], TO BE ABLE TO FEEL AND BE SEEN LIKE THEMSELVES AND NOT ONLY A PATIENT[6]

## CHAPTER 4.5

# CRITERIA

The insights from the research and the design goal are summarised and grouped in the following criteria categories: a place for questions, for connection, for rest, for their own priorities and the preferred interaction qualities.

### A PLACE FOR QUESTIONS

**Access to information**
The final design should allow tussenlanders to get all the information they want.

**Guidance after the diagnosis**
The final design should guide the tussenlander after the diagnosis of an incurable disease, as it is a vulnerable and crucial moment, where the tussenlander needs much support.

**No explanation needed**
The final design should empathise with the tussenlanders feelings and emotions. It should give them the feeling that they do not have to explain anything to anyone.

### A PLACE FOR CONNECTION

**Easy contact with people in similar situations**
The final design should create an environment that enables easy contact between people in similar situations.

**Leave memories**
The final design should be able to leave memories for the bereaved.

**The right tool to support**
The final design should function as a tool for the social context of the tussenlander to support the tussenlander.

**Conversation starter**
The final design should be a conversation starter between the tussenlander and its social context.

### A PLACE FOR REST

**Rest**
The final design should create a place where one can rest and get peace of mind.

**Timelessness**
The final design should create an atmosphere where timelessness exists.

**Just feel**
The final design should create a place where one can simply only feel and follow their emotions.

### A PLACE FOR THEIR OWN PRIORITIES

**Tool to reflect**
The final design should support the tussenlander to reflect on his/her life.

**Control**
The final design should enable the tussenlander to regulate and be in control of their own social context.

**Feel like yourself, not just a patient**
The final design should let Tussenlanders feel like themselves and not only be reduced to only a patient.

**Weight of your shoulders**
The final design should take some tasks of the tussenlanders plate to enable them to have more space in their life/head.

### INTERACTION QUALITIES

**Inviting**
The final design should be inviting to create an environment where the tussenlanders feel safe to share their experiences without feeling judged.

**Openness**
The final design should not impose thoughts or ideas on the tussenlander, but create an open interaction so that the tussenlander can solely focus on their own thoughts and emotions.

These criteria will be used for inspirational purposes in the ideation phase and to evaluate the final design.

# PART 4 DESIGN

# 05

# IDEATION

*The ideation phase is started based on the criteria. The four most potential ideas are elaborated on in this chapter. Moreover, a hack-a-ton took place where four enthusiastic students worked on this project based on the design goal and criteria, and created a concept and framework that has been proven to be of value in the ideation process.*

CHAPTER 5.1

# OVERVIEW

The criteria formed in the last chapter are used as an inspiration for the ideation phase. By brainstorming and combining some of these criteria, ideas were generated.

After this idea generation, a hack-a-thon from Young Medical Delta took place, where this project was one of the cases. Four dedicated students from medical and technical backgrounds worked on this case, which complemented the core value of this project. These students contributed by sharpening the design focus, and bringing all the research together to the core values that the final design should embody.

The outcome of the hack-a-thon was used to map the ideas from the first idea generation. By combining the results of the hack-a-thon and the most promising ideas, a framework was created that will be used in the final design.

CHAPTER 5.2

# IDEATION

Based on the criteria and the interview insights, fifteen ideas were generated. The full elaboration on these ideas can be found in Appendix I. In dialogue with some tussenlanders it became clear that there already was a preference and interest in specific ideas. These ideas will be elaborated on in this chapter.

### THE TREE OF LIFE

The tree of life shows the patient's mood and hope in their journey. The colours of the blossoms on the tree indicate the emotion and the well-being of the tussenlander. Loved ones and care professionals can visit this place to understand the patient's mood and act according to this knowledge. When people visit, around the tree of life, flowers will pop up and gradually disappear over time ( a way of showing that you still care).

**Criteria**

The Tree of Life complies with seven out of the fourteen criteria.

+ The final design should create a place where one can simply only feel, and follow their emotions.

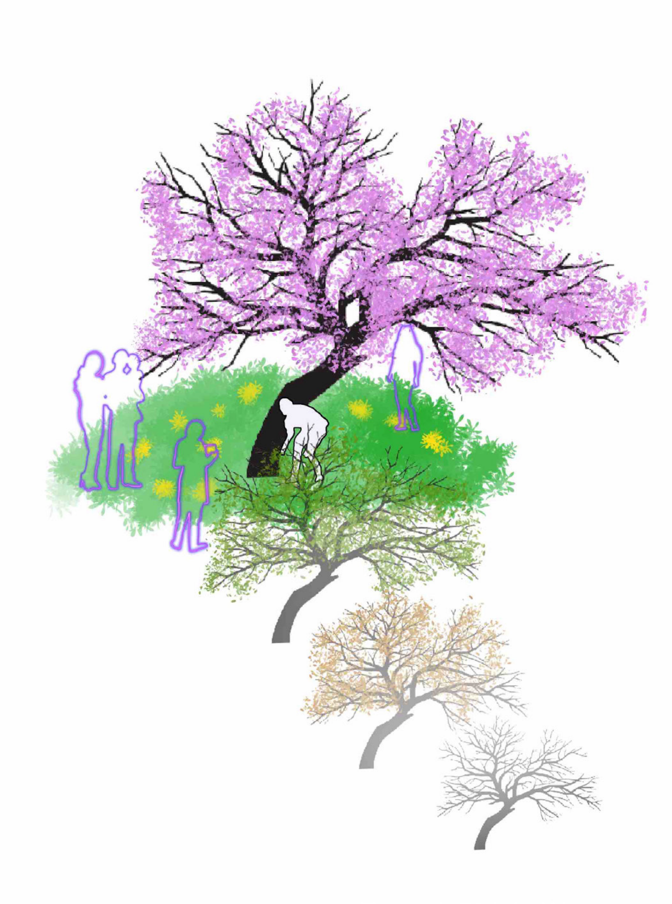


*Figure 18. Idea | the tree of life*

+ The final design should function as a tool for the social context of the tussenlander to support the tussenlander.

+ The final design should support the tussenlander to reflect on his/her life.

+ The final design should empathise with the tussenlander's feelings and emotions, as understanding is a step that is too hard to achieve if one has not been in a similar situation. It should give them the feeling that they do not have to explain anything to anyone.
+The final design should let Tussenlanders feel like themselves and not only reduced to only a patient.
+The final design should create a place where one can rest and get peace of mind.
+The final design should create an atmosphere where timelessness exists.

## ALL THAT

People with an incurable disease are more than patients. They are individuals with their own story. The idea 'all that' shows not only the medical road but their whole life story. So that we can provide them with the personalised care that they need and deserve. With 'all that' specialists, doctors, nurses, and the whole social context of the tussenlander will be able to virtually visit every path and part of the tussenlander's life to get a better and holistic understanding.

### Criteria

'All that' complies with six out of the fourteen criteria.
+ The final design should function as a tool for the social context of the tussenlander to support the tussenlander.
+ The final design should support the tussenlander to reflect on his/her life.
+ The final design should empathise with the tussenlander's feelings and emotions, as understanding is a step that is too hard to achieve if one has not been in a similar situation. It should give them the feeling that they do not have to explain anything to anyone.
+The final design should let Tussenlanders feel like themselves and not only reduced to only a patient.
+ The final design should be able to leave memories for the bereaved.
+The final design should function as a conversation starter between the tussenlander and its social context.

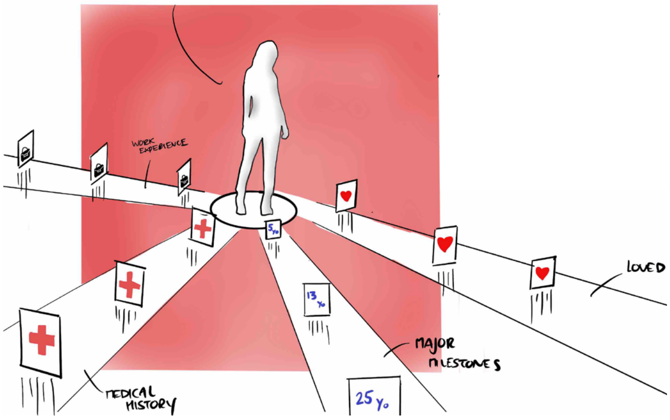


*Figure 19. Idea | all that*

## COMPANION

*Figure 20. Idea | companion*

The users are being guided in a virtual world by an avatar companion that is created out of the experience of other tussenlanders, showing them the hurdles and activities they might encounter in their life.

### Criteria

'Companion complies with six out of the fourteen criteria.

+ The final design should guide the tussenlander after the diagnosis of an incurable disease, as it is a vulnerable and crucial moment, where the tussenlander needs much support.
+ The final design should empathise with the tussenlander's feelings and emotions, as understanding is a step that is too hard to achieve if one has not been in a similar situation. It should give them the feeling that they do not have to explain anything to anyone.
+The final design should let Tussenlanders feel like themselves and not only reduced to only a patient.
+The final design should allow Tussenlanders to get all the information that they want
+ The final design should take some tasks of the tussenlanders plate to enable them to have more space in their life/head.
+ The final design should create an environment that enables easy contact between people in similar situations.

## TREASURE HUNT

Treasure hunt is a virtual environment that a tussenlander can visit with their loved one. In every treasure chest, a question waits for them with a question they perhaps already know the answer to but is still unspoken. These can be personal questions about their relationship in the past but also how the disease affects their relationship in the future. These questions can be: 'what do you still regret?' or 'How do you think life will look without me?'.

### Criteria

'Treasure Hunt' complies with five out of the fourteen criteria.
+The final design should support the tussenlander to reflect on his/her life.
+ The final design should be able to leave memories for the bereaved.
+ The final design should function as a conversation starter between the tussenlander and its social context.
+The final design should create an atmosphere where timelessness exists.
+The final design should create a place where one can simply only feel, and follow their emotions.

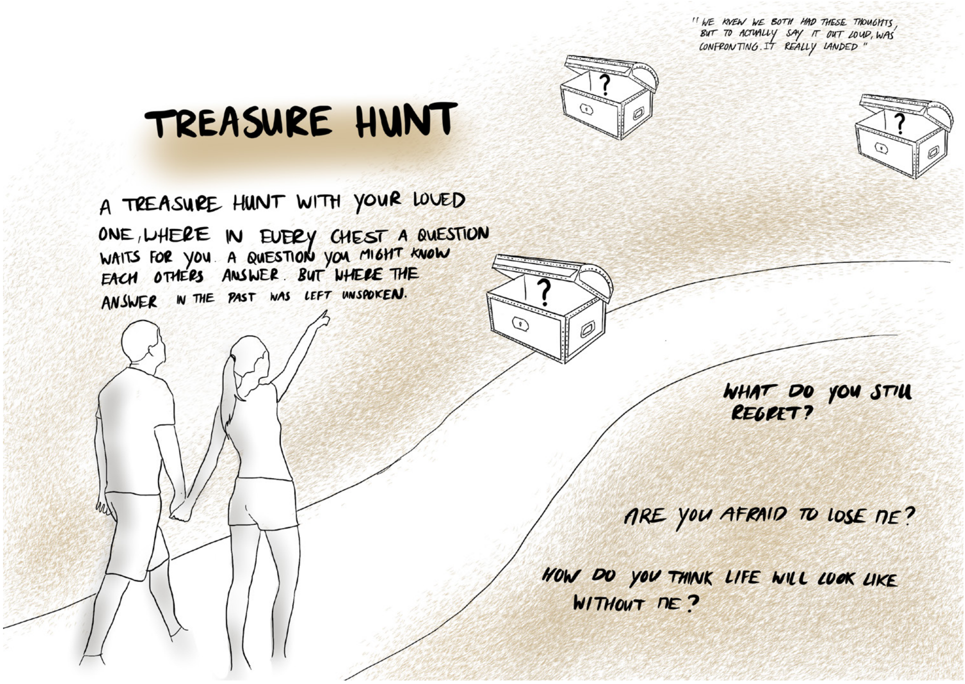


*Figure 21. Idea | Treasure hunt*

### CHAPTER 5.3

# HACK-A-THON

After the idea generation, a hack-a-thon from Young Medical Delta took place halfway through this project. During this event, challenging cases on health technology-related topics were executed by interdisciplinary teams. One of the cases during this weekend was this thesis project. In a 'pressure cooker', the students worked on this project.

In preparation for this hack-a-thon, a case description was submitted containing the problem definition, competencies, proposed solution and company/organisation description. The submitted case description can be found in Appendix J. The case descriptions were sent to the students in advance. At the opening of the hack-a-thon, the cases were introduced one more time by the case owners. The rest of the schedule can be found in appendix K. Four dedicated students chose this case and came to great insights in these few days.

*Figure 22. The hack-a-thon student team*

## THE PROBLEM DEFINITION

The team looked at the problem definition and the needs of the user. They came to the following results:

**The issue: People who enter the in-between-land feel lost and have many questions.**

**The need: a warm place to go to, to feel heard and connected.**

## THE CONCEPT

### Buddy

There will be a 'buddy' joining the tussenlander (not yet defined, it could be a dog or a person that guides them throughout the game, but they have the choice to send it away). The buddy will explain the goal and possibilities of the platform and will be there to answer their questions and guide them through the platform.

### The framework

A framework was created with five different environments that all answered to different kinds of needs of the tussenlander:

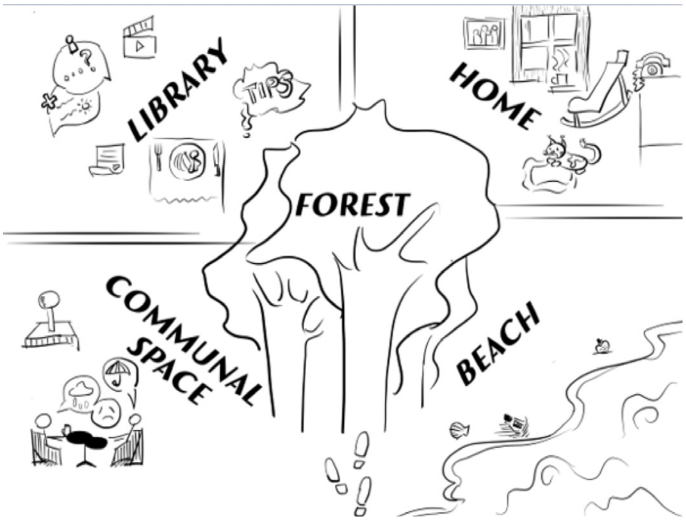


*Figure 23. The five different environments envisioned by the hack-a-thon team*

### The forest

The forest is a place where (ex-)patients can be vulnerable and share their stories/emotions/questions anonymously regarding their disease through their own tree or leaf messages. This is all passive/indirect interaction! They can either share it with other tussenlanders/specialists/non-personal relatives or personal relatives.

**The library**
An offline environment that does not include real interaction with other persons. Its main goal is to answer all health-related concrete questions and provide tips to improve their life/and what they can do in the short term.

**The communal space**
It is a communal space where they can meet new people by playing games, having public conversations, and one-on-one conversation. Tussenlanders and relatives are both able to enter this world.

**Home**
Their own house in which they choose whether to or not to invite people over. This is a place where they are not anonymously anymore.

**The beach**
A peaceful and silent beach with waves and a starry night. This is a place to feel comfortable and think about nothing.

A more extensive overview of the hack-a-thon results can be found in Appendix L.

**INSIGHTS OF HACK-A-THON**
•The team was able to capture the feeling of the tussenlander: When they enter the in-between-land, they feel lost and have many questions.
•The concept should be a warm place where they have the choice to explore the world.
•The concept should be a central place where they can go for questions, rest and connections.
•The concept should have a buddy that does not know the answers but does know the way and how to show them around.
•The ideas formed in the first idea generation complement the world the hack-a-thon team envisioned. Not knowing any of the ideas, they created an environment containing many ideas combined.

*Figure 24. The hack-a-thon team presenting the concept through roleplay*

# 5.4 KEY TAKEAWAYS

**IDEATION**

Fifteen ideas were generated in the ideation phase inspired by the criteria and opportunities of the patient journey map in chapter 4. The four most promising ideas based on the criteria were elaborated on: The tree of life, All that, Companion and Treasure hunt.

**HACK-A-THON**

The hack-a-thon team created a framework that would answer the needs of the tussenlander. It is a concept that is a central place where they can go for questions, rest and connections. In this concept, they are guided by a buddy who will show them around. The promising ideas generated in the ideation phase correspond with this framework. So they will be both combined and worked out as a concept in the next chapter.

# 06

# CONCEPT CREATION

*This chapter shows the iterations that have been made in the concept creation. This chapter starts with the knowledge from the framework acquired during the Hack-a-thon. This chapter will show the steps that led to the chosen concept.*

CHAPTER 6.1

# CONCEPT ELABORATION

The following paragraphs will explain how the envisioned framework, from the hack-a-thon team in chapter 5.3, plays a role in the concept creation.
In this thesis, the framework in figure 25 presents what the concept The Tussenland can look like and consist of. This chapter explains how the needs and wishes of the tussenlander are answered in the concept The Tussenland.
However, this chapter concludes that the focus will be placed on the invitation to the Tussenland, and not the entire journey in The Tussenland. Therefore, only "The Entrance to the Tussenland" will be conceptualised and developed in detail.

## FRAMEWORK OF THE TUSSENLAND

The Tussenland is a virtual world and space where tussenlanders can safely land after the diagnosis. It is a platform where they are being welcomed, when they feel lost after the bad news conversation. The Tussenland shows them that there is a whole new land where they can live and expore.
This is a world created especially for them that can answer their questions, find new possibilities, meet new people and create space and time to adjust to their new lifestyle. It is an environment that ensures that they do not feel lost anymore, and feel heard and connected.

**The buddy/guide**
**The need that is answered**: To let the tussenlander know that they are not alone in this world and that they do not have to do it alone.

One of the most important aspects of the Tussenland is the buddy that welcomes them into this new world. The buddy guides them through the Tussenland, explains where they are and shows them what it offers. So throughout the whole journey, there will always be one stable factor that will always be with them: their buddy. It will welcome

Figure 25. The framework of The Tussenland (and the scope of this thesis: the entrance)

them every time they enter the Tussenland and let them safely land and help them out when needed.

The Tussenland consists of five different environments, where the forest is the starting point when they enter the Tussenland.

**The forest**
**The need that is answered:** A place where the tussenlander can safely land. In the forest the tussenlander can reflect on their thoughts and emotions after the bad news conversation and share this with their social context on their own terms.

The forest is inspired on the following ideas from chapter 5.2 : The Tree of Life and All That.
In the forest, the tussenlander is welcomed by the buddy that brings them through the forest to a designated tree: a tree and place that is entirely theirs. At this tree they can share their experiences and emotions. The more experiences they share, the more their tree grows. The leaves symbolise all the stories/emotions and questions they have. Generally, their experiences are anonymous, but they can choose to share them with fellow tussenlanders, their loved ones and care specialists. So whenever they feel like it, this tree can show their context how they are feeling without explaining it every time. Since it is a forest, their tree is not the only tree. All the other trees are other tussenlanders. Therefore, they can choose to walk around through the forest, look at other trees, or just sit against their own tree. It is all up to them, in this environment the tussenlander is the only one present. It is a virtual environment that will keep growing, as more trees will grow in this forest. Even after the end-of-life, these trees will not cease to exist, creating a lifelong legacy of someone's experiences during these times.

This buddy has the option that it will show them around, but they can also decide to send the buddy away, to explore the other worlds themselves.

**The library**
**The need to be answered:** To find the answers to all the questions of the tussenlander and to show all the possibilities.

When entering the library, some different bookshelves and sections are categorised in the following topics:
- Medical-related topics (treatments, surgeries and therapies)
- Health-related topics (exercise and diet)
- Work-related topics
- Administrative topics (notary, insurances)
- Financial topics
- Sex and intimacy

The tussenlanders can walk to the designated section and grab a book. Whenever a tussenlander opens the book, the following can happen:
1. They can read the information/ recommendation
2. They get drawn into the book and can watch a video that answers their question
3. They see a referral to a particular organisation, specialist, book, or podcast.

The content in the library is something that is replenished constantly. It combines Google, videos, literature, and expert input. Whenever they cannot find the right book, they can summon their buddy to help them look for the answer.

**Home**
**The need to be answered:** To create a place where the tussenlander feels at home. The tussenlanders will be able to prioritise the important things in their life here.

Home is the place where they decide how to set up their time, share their space and manage their possessions.

The virtual interface of a living room enables them to put personal pictures or posters to personalise it. Initially, home is solely for them, but they can choose to invite people inside.
This is where they can explore how all these adjustments influence their lives in peace. It is the place where they scope their own agenda and where they can create an advanced care planning for themselves (together with others).

### Cafe

**The need to be answered:** To create a place where people can have meaningful interactions together.

The cafe is a place where they can share their experiences with fellow tussenlanders, friends and family and create new memories. It is a place where they can continuously get the attention they need and feel understood. Whenever they enter the cafe, it is divided into three areas:

1. An area where they can share their stories and experiences with others. A place of conversation
2. A place where they can play games together (rec room style: Pictionary)
3. A make-a-wish kind of place, that can change. It is a place where they can do memorable experiences together like diving, safari, hot air balloon flight.

### The Scenery

**The need to be answered:** Allowing tussenlanders the time and space to pay attention to existential matters.

A place where they can come to peace. This is a place only the tussenlander can enter, a place that enables them to have enough space and time just solely to focus on themselves. Research indicates that tussenlanders who received palliative care, express the need to speak about spiritual matters, the purpose of life, relationships and their thoughts about death (*Huber 2016; ZonMW 2016*). It is a place in nature (beach, mountain top, a lake) where they can meditate and focus on their body and mind. It is a place where time does not exists, where only moments exist where one can simply only feel.

### DESIGN FOR THE ENTRANCE

As explained in the introduction of this chapter, this thesis focuses only on the Entrance to the Tussenland. The development of the entire Tussenland is too ambitious for the period of this thesis.

For “The Entrance to the Tussenland”, the buddy and the forest are chosen. While the needs of every world are significant, the need for the forest was something that tussenlanders longed for. Entering the in-between-land can be scary and lonely for a tussenlander. The strength of “The Entrance to the Tussenland” is that it acknowledges that there is a place and a land for them where they can feel part of a group which they can identify themselves with. That is why the forest was chosen with the trees full of experiences. The experiences and narratives of the tussenlanders in the forest contribute to this feeling of identification, creating a community where tussenlanders can feel part of. It is a place where they are not only seen as a patient but as a human being, where they can share all their experiences, thoughts and emotions. It is a place that allows them to get the unwavering form of attention and allows them to manage their own social interactions with their social context. So from now onwards, the concept “The Entrance to the Tussenland” will be developed in this thesis. When tussenlanders enter “The Entrance to the Tussenland”, they will enter through the forest. While standing in the forest, the other worlds are visible from afar. The potential development of the four other worlds will be further explored in chapter 8, the design implementation.

CHAPTER 6.2

# CRITERIA | THE ENTRANCE

The criteria of chapter 4.5 are revised to fit the concept “The Entrance to the Tussenland”.
The criteria are summarised in the following category: The content qualities, the form qualities and the interaction qualities.

## CONTENT QUALITIES

**Part of community**
The final design should make the tussenlander feel recognised and part of the group of tussenlanders, where they do not feel lonely anymore.

**Guidance after the diagnosis**
The final design should guide the tussenlander after the diagnosis of an incurable disease, as it is a vulnerable and crucial moment, where the tussenlander needs much support.

**Tool to reflect**
The final design should support the tussenlander to reflect on his/her life.

**Control**
The final design should enable the tussenlander to regulate and be in control of their own social context.

**Feel like yourself, not just a patient**
The final design should let Tussenlanders feel like themselves and not only be reduced to only a patient.

## FORM QUALITIES

**Timelessness**
The final design should create an atmosphere where timelessness exists.

**Just feel**
The final design should create a place where one can simply only feel, and follow their emotions.

**A land to explore**
The final design should show that there is more to explore in the land than in the forest and more possibilities.

## INTERACTION QUALITIES

**Inviting and welcoming**
The final design should be inviting to create an environment where the tussenlanders feel safe to share their experiences without feeling judged.

**Safe landing**
The final design should allow the tussenlander to take its time and space to land in the in-between-land safely.

**Openness**
The final design should not impose thoughts or ideas on the tussenlander, but create an open interaction so that the tussenlander can solely focus on their own thoughts and emotions.

**No explanation needed**
The final design should empathise with the tussenlanders feelings and emotions. It should give them the feeling that they do not have to explain anything to anyone.

### CHAPTER 6.3

# FIRST PROTOTYPE

A first prototype was created of “The Entrance to the Tussenland”, containing the forest and the guide, in Unreal Engine. A 25-second long video was exported and used for the concept evaluation in the next chapter. In this prototype, the user falls into this world and is led by a deer to a specific tree. The purpose of creating this first prototype is to convey the tone of voice of the concept, showing the vibe and atmosphere of this world.

*Figure 26. First prototype of the Entrance to the Tussenland in Unreal engine*

CHAPTER 6.4

# CONCEPT EVALUATION

## DATA COLLECTION

For the first concept evaluation, the same group of participants was invited as in the research phase. The last time these participants were introduced to this project had been several months ago. At that moment, they indicated that they all wanted to be kept in the loop about this project. Therefore, the concept evaluation consists of the following three parts:

**Problem definition and interview insights**
The problem definition was illustrated in the form of a storyboard to show the struggles of the tussenlander clearly. The participants were asked if it resonated with their own experiences.
Afterwards, an overview of the interview insights was presented. To make it more organised, the insights were categorised into four categories.

**The concept of "The Entrance to the Tussenland"**
The concept is explained verbally using the prototype in chapter 6.2, videos, and pictures to give an overall expression.

**The interaction and the entrance to the Tussenland**
The participants were asked to answer a few questions regarding the interaction and their entrance into the Tussenland. For these questions, a few examples were prepared beforehand where they could choose from, but they were also prompted to give additional answers. The questions were as follows:

- If you put your VR glasses on, what do you see when entering "The Entrance to the Tussenland"? (Entrance)
- What does your buddy look like? (buddy)
- How does the buddy approach you at the first moment? (first contact)
- Does the buddy walk in front of you of next to you (in front of next to you)
- What do you hear around you? (sounds)

The evaluations were conducted online through zoom using Miro as a whiteboard to showcase the results. For the complete overview of the Miroboard go to Appendix N.

## DATA RESULT

The concept evaluations were summarised after the interviews. These evaluations are summarised in tips and tops. In Appendix O, the data results can be found per participant.

**Problem definition and interview insights**
*Tops*
The participants mentioned that they could all identify with the illustration of the problem definition. The aspect that differed from other problem definitions is that in this problem definition, it is not the tussenlanders' choice to enter the in-between-land, it is something that is not in their hands. So they are literally being launched into this land. The participants indicated that especially this part was what made the problem definition strong.

*Tips*
The interview insights focus significantly on the reality that focuses on their disease and death. However, the tussenlanders are living in two realities, so also the reality where they live their life to the fullest. The life that gives them happiness, pleasure and meaningful interactions. The participants indicated they would want to see more of the latter in the final concept.

**The concept of "The Entrance to the Tussenland"**
*Tops*
The participants were very optimistic about the concept. They noted that many people are so lost and confused that they cannot formulate and put their experiences in words. This tool could assist them.

*"There are a lot of conversations and things that you wish you had talked about with your*

*loved one. But I did not feel fully equipped to sense that I had these needs, while you knew at that time it is now or never. So some guidance in engaging these topics could be really helpful."*
*-Son of a deceased tussenlander*

The participants felt that "the Entrance to the Tussenland" was a unique way of giving people information and offering consolation. They could also imagine that this world could be meditative.

*"The basis of giving someone a world in VR, where they can come to their senses and where they can ask their questions, is incredible. Especially because you can share it with your loved ones."*
*- Rob Bruntink*

*"I am overwhelmed, I think it is a beautiful concept. It seems like a beautiful form of a diary or blog, where others can comment on. Very playful and approachable"*
*- Tussenlander*

Some participants were positive about using the technology VR, as it enables someone to completely shut off from our busy world and enter a magical-like world. Without VR they could not visualise these things.

*"I think that you found the right tone, it is not too gloomy and not too bright."*
*-Rob Bruntink*

*"In this world the magical touch is important, the fairy tale-like touch. I think it is a safe way to let people be immersed in this world. If there is magic which is embedded with carefulness, respect and time and you find a way to convey this in images, movements and interactions, then this will definitely work."*
*- Peik Styling*

*Tips*
Many participants mentioned that the tussenlander should have the power and the choice to adjust or change things in the concept. So the tussenlander should be able to choose itself if the content of the tree is private or open. Maybe, there needs to be a possibility to build different layers in the tree so that they do not have to share their diary-like thought but share more factual information like a field trip with their daughter. Nevertheless, the core of the message was that the tussenlander should be able to be in control of their own tree.

*"If you are going to build a tree, you would also want the option to first educate people in what is needed. Or the possibility to remove comments."*
*-Christiaan Rhodius, palliative doctor*

*"It would be nice to propose different layouts of the world: woods, beaches, dunes"*
*-Tussenlander*

As one of the participants saw the positive side of VR, another participant saw the barriers that VR causes.

*"A lot of people, especially the elderly are digitally illiterate. A foundation that provides educational digital cafes can be an initiative that educates digital illiterate people. It is also beneficial that it can operate from a safe and trusted space."*
*-Tussenlander*

In the data results of the problem definition, it was already mentioned that there was a need to focus on both realities in "The Entrance to the Tussenland", the nearing death and the life you live. There was a desire to implement more of the latter in the concept.

*"It would be nice if you could integrate other VR applications in this world, like a VR world where you can travel, go the beach, your birth city etc. It would be nice to have an*

*escape-like path where you can get to these experiences”*
*- Rob Bruntink and Tussenlander*

This platform with the tree full of memories and experiences also has ethical implications as it contains much sensitive data.

*“It is tricky to have an open platform with cybercrime in mind. There is a lot of sensitive data.”*
*-Tussenlander*

## The interaction and the entrance to Het Tussenland

### Entrance

The majority of the participants indicated that they preferred to immediately stand in The Entrance to the Tussenland”, for psychological and physical reasons. People want to feel in control whenever they enter this world, not a world of panic and uncertainty. Moreover, for different diseases, the entrance into the in-between-land can differ.
Moreover, large displacements in VR can trigger headaches and feelings of motion sickness.

### Guide

On what the Guide would look like, the opinions were divided. Overall, from all the participants, most of them thought that an animal that suits the environment (deer/butterfly, bird) or moving flower petals/leaves would suit the best. However, since the platform already expresses a magical feeling, it would be nice if the Guide would have the same charge.
The Guide has to contain a combination of magical and realistic interactions.
So using a talking animal as a buddy would be magical, but not realistic to our perception of animals. One participant mentioned the following:

*“Maybe a guiding voice is enough. The most magical part of this world is your own fantasy. Whenever you give something a physical entity, it can lose this part of your fantasy”*
*-Son of a tussenlander*

### First contact

The interactions must be close to the interaction in reality.

*“So I would not want the tool to immediately know my name, but that it gradually will learn my name. It is key that it doesn’t feel automated. You must be in charge in what you do and experience. “*
*-Tussenlander*

The tone of voice of the Guide is essential. It must not address the tussenlander in an all-knowing tone.
Furthermore, the Guide must welcome them and help them understand where they have landed.

### In front of next to them

Initially, the Guide must walk in front of the tussenlander, because he knows this world. He clearly is the guide. Gamewise, that works the best. When the tussenlander has been in this world for a more extended period, the Guide can gradually transform into a partner/buddy and walk next to them.

### Sounds

Sounds of nature are a must. It is essential to create immersion. Maybe some soft music can be used, but watch out for selecting the right music as it can create an aversion for some people.

# 6.5 KEY TAKEAWAYS

## CONCEPT ELABORATION

The focus will be placed on the invitation to the Tussenland. Therefore only the forest and the buddy will be elaborated on in the final design, called “The Entrance to the Tussenland”.

## CRITERIA| THE ENTRANCE

The criteria have been revised to “The Entrance to the Tussenland”. The criteria are categorised in content, form and interaction qualities. These criteria will be used for the evaluation of the final design.

## THE EVALUATION

### Problem definition

Tussenlanders live in two realities: the reality of the disease and the nearing death, and the reality where they live their lives to the fullest. The final design should contain more of the latter.

### The concept

•The participants were positive about the concept. They felt like it was a tool that enabled them to express their thoughts, give them information, and offer consolation and a meditative world.

•The atmosphere was almost magical in the prototype. Furthermore, this magical touch is crucial. It is a safe way to let people be immersed in this world.

•The final design should enable the tussenlander to have the power and choice to adjust and change things in the platform.

•Extra support should be provided for using this technically advanced platform for digital illiterate people.

•In the final design, the data must be handled with great sensitivity on this platform.

### The interaction and entrance

•In the final design, the tussenlander immediately stands in “The Entrance to the Tussenland” when they put the glasses on.

•In the final design, the buddy must have a magical touch but also have realistic interactions.

•The human interactions in “The Entrance to the Tussenland” must be close to the interactions in reality.

•The buddy initally walks in front of the tussenlander and can gradually over time, walk next to them.

•In the final design, nature sounds are a must.

•In the final design, a personalised set of information will be presented that allows the tussenlander to find the answer to his questions.

# PART 5 END RESULT

# 07

# FINAL DESIGN

*In this chapter, the final design of the service and the platform "the Entrance to the Tussenland" will be elaborated.*

### CHAPTER 7.1

## OVERVIEW

The past chapters showed the progress that led to the creation of this service and platform. In this chapter, the final design will be presented. First, the platform in Virtual Reality will be explained, and the most essential functions will be highlighted. Second, as the final design, “The Entrance to the Tussenland,” is a comprehensive platform and service, it will be presented in a use scenario to understand how the service fits in the life of a tussenlander. Lastly, a digital prototype of “The Entrance to the Tussenland” is made to demonstrate the first entrance to Het Tussenland. This chapter will be concluded with an evaluation of the criteria for the entrance in chapter 6.2.

### CHAPTER 7.2

## THE PLATFORM THE ENTRANCE TO THE TUSSENLAND

“The Entrance to the Tussenland” is a virtual world tussenlanders enter after they are recently diagnosed with an incurable disease. After this diagnosis, tussenlanders often feel lonely and lost. “The Entrance to the Tussenland” shows that there is a land for them where they can live, where they do not have to feel alone. It is a magical environment where tussenlanders receive the undivided attention that they deserve and need. “The Entrance to the Tussenland” is a world to explore. The main characteristics in this world are embodied by the Guide, the Tree of Life and the Box of Memories.

### THE GUIDE WHO SHOWS THEM AROUND

The tussenlander puts the VR glasses on and arrives in “The Entrance to the Tussenland”. The Guide, a female voice called Ava, welcomes the tussenlanders and explains where they are. A female voice embodies the Guide due to two reasons. First of all, giving the Guide not a physical entity, maintains the magical atmosphere in this land. By giving it a physical entity, people can easily associate it with objects or entities in their daily lives. Second, a female voice is already embodied in many situations in our lives: navigation, public transport, commercials in the supermarket, and applications like Siri, Google home. So the sound of a female voice in a digital application can feel familiar.
Ava has no physical appearance, but “The Entrance to the Tussenland” will be filled with deer wandering around. Ava will explain that tussenlanders can find her through the deer that wander in “The Entrance to the Tussenland”. The deer will bring and lead them whenever they feel lost in “The Entrance to the Tussenland”. So whenever the tussenlander wants to find Ava, the tussenlanders simply have to approach one of the deer in “The Entrance to the Tussenland”.

The purpose of Ava is to welcome tussenlanders and show them around in this world and make them feel less lost. Ava explains that they do not have to explore this land all by themselves, but that they can do it together. Ava explains to tussenlanders,they have entered the entrance of the entire Tussenland, the forest where they can safely land. Standing in the forest, “The Entrance to the Tussenland”, tussenlanders can already see the other worlds that can be explored, far away.

### THE TREE OF LIFE

In “The Entrance to the Tussenland” all the trees represent tussenlanders. So when a tussenlander walks in “The Entrance to the Tussenland”, the tussenlander can also find its own tree. This tree is their personal tree of life where their memories and experiences during this whole period grow as cherry blossoms on the tree. The tree is initially filled with green leaves, but every time the tussenlander experiences something new, a pink blossom will grow that represents this experience. It can serve as a tool for the tussenlander to reflect on their life and to express all their thoughts and emotions. In this tree every branch symbolises a different topic in their lives. These topics can vary from experiences of treatments and memories with loved ones to private thoughts and fears. So whenever the tussenlander has experienced a nice beach day with her family, it will grow as a cherry blossom on the 'memories with loved ones'-branch.

The content of the Tree of Life is initially only for the eyes of the designated tussenlander. However, the tussenlander can choose to share their tree. In this scenario, there are two options. The first option is that they decide that the content of the tree is open to all the other people on the platform, meaning that other tussenlanders can also see the content of their tree. The second option is that the tussenlander decides only to share the content of the tree with a designated group using a passcode, meaning that when someone has received the passcode from the tussenlander, they will be able to see the content. The tussenlander is also able to share only parts of their tree. It is understandable that they would be open to sharing the branch about the experiences of treatments, but that they would be less willing to share the branch about their private thoughts and fears.

**Entering "The Entrance to the Tussenland" as a loved one**

As a loved one, they can also enter "The Entrance to the Tussenland". The platform has a different model for the tussenlander than for a loved one, where the mode of the loved one will be less extensive. The Guide Ava will welcome the loved one and explain the possibilities. A loved one can see the content of the Tree of Life when the tussenlander has given permission, reply to the memories/experiences or leave a message for the tussenlander. The loved one can be there for the tussenlander, but still give the tussenlander enough space. Whenever the tussenlander arrives back in "The Entrance to the Tussenland" to their Tree of Life, these new messages will light up as unread messages. It is suggested to create an app for mobile or tablet applications, where loved ones can easily enter "The Entrance to the Tussenland". Loved ones can easily leave messages for the Tussenlander, without having to enter this whole land again.

### THE BOX OF MEMORIES

Before a tussenlander enters "The Entrance to the Tussenland", the tussenlander will have a meeting with a palliative worker who will determine important questions, worries, values and themes in the life of the tussenlander through conversation. In "The Entrance to the Tussenland" a number of boxes float in the landscape, where every box represents a specific theme that is of importance to the tussenlander. These themes can vary from practical (e.g. health, treatments, work, financial, administrative) to more personal themes (e.g. loneliness, father-son relationships, sex). In the Box of Memories, these themes return.

When they open the box, memories and experiences of other tussenlanders will appear about this theme. So what changed for them and how did they deal with this?

Offering the tussenlanders memories and experiences can stimulate or inspire them to think about what these themes mean to them in the physical world. The Box of Memories floats around in "The Entrance to the Tussenland". The tussenlander can decide not to open it if they are not ready for it. If the tussenlander does not feel any connection with the box, they can shove it away, and it will simply disappear. The benefit of the Box of Memories is that it provides a customised set of information for the tussenlander.

**Leaving a legacy**

When the tussenlander comes close to the end-of-life, the tussenlander will be asked to decide what should be done with the content of the tree. If they want to share parts of their tree, these memories and experiences will be placed in the designated Box of Memories to inspire and support future tussenlanders.

After the end-of-life, the bereaved will be able to visit the tree the tussenlander. It is also possible to convert the tree in a book or a photo.

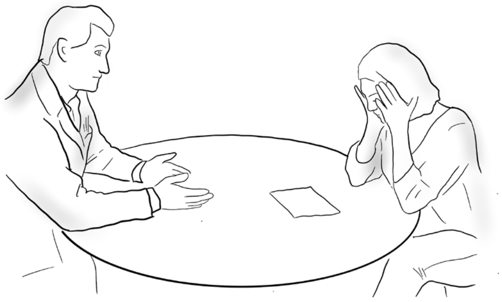
CHAPTER 7.3

# THE USE SCENARIO

The use scenario shows how the platform and service play a role in the life of the tussenlander after their diagnosis of an incurable disease. The use scenario is divided into 6 phases: The onboarding, The first time in “The Entrance to the Tussenland”, Back to reality, In “The Entrance to the Tussenland”, Preparing for the end-of-life and After the end-of-life.

## THE ONBOARDING

①

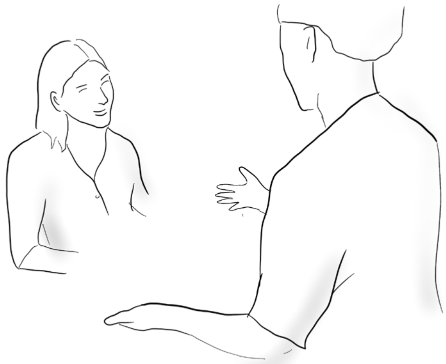


After the bad news conversation at the hospital, the specialist will refer the tussenlander to the Palliative Team. The palliative doctor introduces the platform to the tussenlander.

②

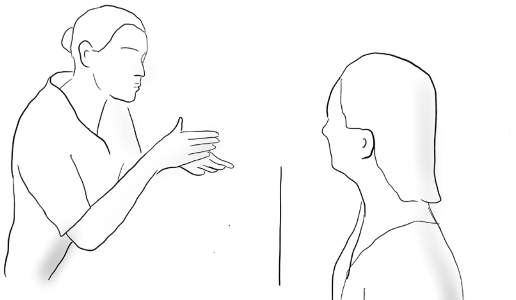
The palliative doctor explains that it is a Virtual Reality platform that might help to feel less lost and let them find the answers to their questions. If the tussenlander is interested, an appointment will be made for a next meeting (for example when they also have to go for a treatment to the hospital).

③



A few days later the tussenlander has an appointment with a palliative worker at the hospital. The palliative worker explains what is possible in “The Entrance to the Tussenland”.

④



During this same meeting the palliative worker asks several questions to determine important themes that play a role in the tussenlander’s life. This data will be communicated back stage to the software developers. This is the end of the meeting.

5

A new meeting with a volunteer from hospice Bardo is made. The volunteer will assist the tussenlander on their first time in “The Entrance to the Tussenland”.

6

The volunteer already installed all the hardware and will explain how the VR Gear works. After that the tussenlander will put the VR glasses on.

## THE FIRST TIME IN ‘THE ENTRANCE TO THE TUSSENLAND”

7

The tussenlander puts the glasses on, and stands in the virtual forest. The guide called Ava, which is a voice and has no physical entity, introduces herself and asks you if you want to take a walk together.

⑧ Ava tells that right now you are standing in the forest, “The Entrance to the Tussenland”. She explains that the world around you is the Tussenland, and next to the forest, there is more to explore in this land.
All the other trees in the forest represent other tussenlanders. She shows that you also have a tree that belongs to you.

⑨ Ava asks you if you want to see your tree. If yes: Ava will tell you that a deer will lead you to your tree. If No: Ava explains that it is fine, but lets you know that if you have questions, you will find Ava by approaching a deer.

⑩ After you are brought to your tree by a deer, Ava explains how your tree of life works. She explains that by touching the tree and talking at the same time, a memory will be created in the form of a blossom.

while that branch can exist of memories with your family.

⑪ Ava explains that you can categorise your experiences and memories in branches. So every branch stands for a category, like treatments, or special moments with the family.

⑫ As an example, a first blossom appears that represent the first memory in “The Entrance to the Tussenland”: the entrance of the tussenlander in this world.

⑬ Ava explains that family and friends, can also enter this world and leave a message for you in and around your tree. But it is your choice to keep your tree private or public.

If you don't want it, pluck the blossom and let it go.

⑭ Ava explains how you can also delete an experience or a message from the tree by removing a blossom.

⑮ Now the tussenlander can explore “The Entrance to the Tussenland”. Whenever the tussenlander walks around in “The Entrance to the Tussenland”, it might encounter the Boxes of Memories that float in this world. When the tussenlander comes near such a box, Ava will give an explanation.

⑯ Ava explains that these boxes contain memories of people that could be useful for the tussenlander. Every box represents a certain theme that was determined in the meeting with the palliative worker in the beginning.

⑰ Ava emphasizes that these memories are experiences of past tussenlanders that maybe went through the same journey. But it is the choice of the tussenlander if they want to open the box. If they do not want to see this box any time soon, they can simply shove it away and it disappears .

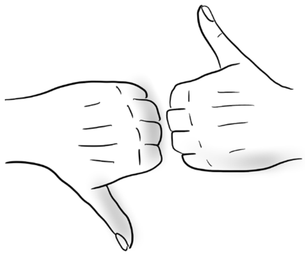
⑱ When the tussenlander touches the box, it will open and a memory will pop out (video or audio). After the memory is finished the tussenlander can choose to look at another memory, but also choose to close the box.

⑲ When the tussenlander decides to leave the virtual world, Ava tells the tussenlander goodbye.

## REALITY

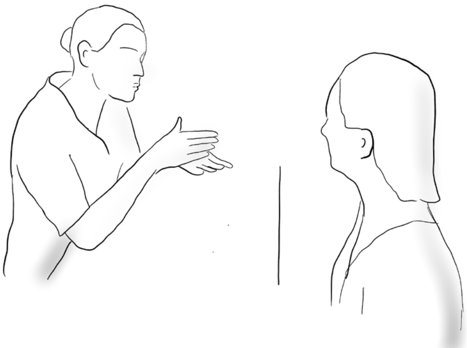
⑳

The volunteer helps the tussenlander to save the platform and asks the tussenlander how they perceived the platform.



㉑

If the tussenlander indicates to be interested in the platform, the application for the service will be started. If the tussenlander is not interested, the volunteer will ask why to determine what could be possible barriers.



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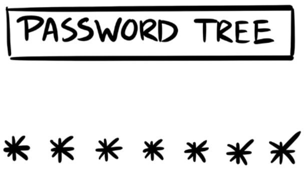
The volunteer will ask if the Box of Memories corresponded to the tussenlander's needs. If not, additional questions will be asked to get the right themes.



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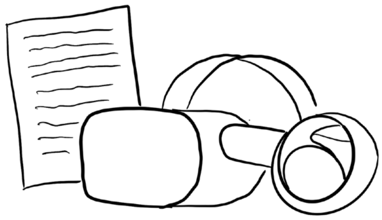
The volunteer lets the tussenlander choose a code/password for their tree. Initially the tree with their memories in the platform is anonymous. By giving the code to loved ones and friends, they will be able to see the content of the tussenlander's tree.



㉔

A few days later a kit is prepared for the tussenlander that contains the gear and printed instructions that will also lead them to the (online) helpdesk. This kit can be picked up or delivered at home.

㉕

If the tussenlander has a question about the platform they can go to the online helpdesk (website). There will also be events organised for extra support for digital iliterate people.

## BACK IN THE ENTRANCE TO THE TUSSENLAND

26

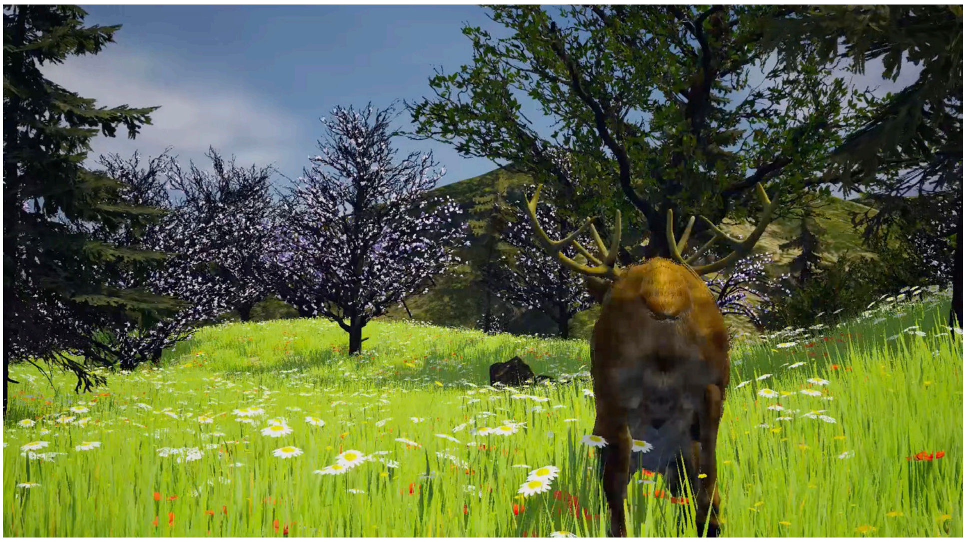
Ava welcomes the tussenlander back. The tussenlander will be able to walk around by themselves.

27

The tussenlander will be able to create memories at their Tree of Life, look at experiences in trees of other tussenlanders, open a Box of Memories, or simply just wander around and rest.

㉘

When someone has left a message at the tree for the tussenlander the blossom or flower will light up.

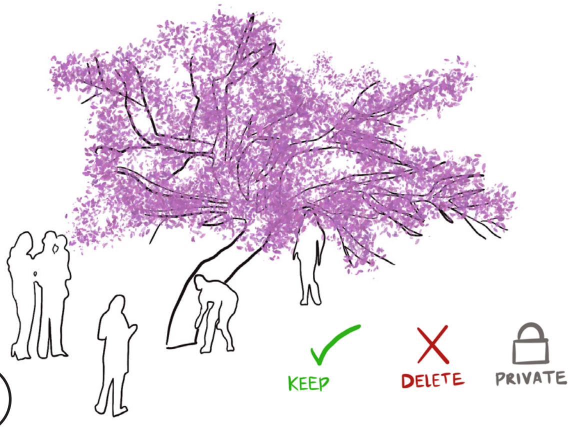


㉙

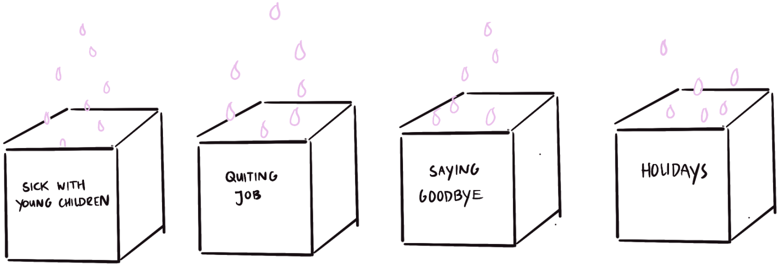
Whenever the tussenlander has a question, they can stop one of the wandering deers and Ava will be present again to help you.

30 When the tussenlander decides to leave. Ava will say goodbye.

## Preparing for the end-of-life*



31 A ritual will be organised where the tussenlander can enter “The Entrance to the Tussenland together with their loved ones, where they can decide together what should happen with all the memories and experiences. Will they be public for everyone, only for loved ones or completely deleted.

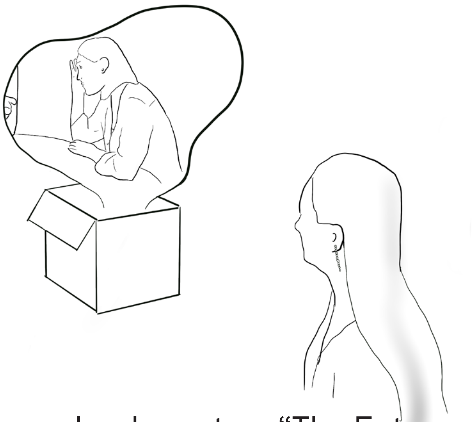


32 All the memories that will be public, will be scattered over all the Boxes of Memories, and will be used for future tussenlanders. The tussenlander can also leave a message of wisdom to future tussenlanders (that are not in their tree) in the Box of Memories.

## After the end-of-life

㉝

The bereaved can always enter this world whenever they want and visit the tree.
If the tussenlander enabled it in the last step, the bereaved will also be able to open the messages the tussenlander left them.
There is a possibility to convert the virtual world into a physical product. The tree can be converted into a photograph or a book that contains all these experiences.



㉞

New tussenlander enters “The Entrance to the Tussenland” and may see and learn from the experiences of the last tussenlander.

*** DIGITAL LEGACY: ETHICAL IMPLICATIONS**
The phase ‘Preparing for the End-of-Life’ addressed what should happen with the content of the tree. But it is not unevitable that a crisis will strike and that the death of a tussenlander comes sooner than expected. Then the questions arises, what should happen with all this sensitive data? It is a phenomenon that palliative expert Rob Bruntink sees a lot, where the bereaved are left with the digital legacy (social media pages, pictures, documents, bitoins etc.) of the deceased tussenlander.
Due to the sensitivity of this data, it would be unethical to make this decision for the tussenlander. Therefore, whenever the tussenlander does not finish the ‘Preparing for the End-of-Life’ phase, all the data of the Tree of Life will be deleted.

CHAPTER 7.4

# EVALUATION

In this chapter, the main features of “The Entrance to the Tussenland” were evaluated by the interview panel: the Tree of Life and the Box of Memories. Furthermore, the concept “The Entrance to the Tussenland” was evaluated using the criteria of chapter 6.2.

### EVALUATION INTERVIEW PANEL

The evaluation results by the interview panel are summarised in the following points.

**The Tree of Life**

- The tree is almost like a Christmas tree, they can decorate together. It is a medium that can be used to support someone in an accessible way.
- Building something together, enabling people to create something together in this stage, is very valuable.

**The Box of Memories**

*Tops*

- The forest of questions is new. This kind of onboarding, seems a safe way to reflect on the tussenlander’s issues. It is important though, that the experiences people see should correspond with their own experiences.
- The Box of Memories offers a whole new layer of traceable information in this magical world.

*Tips*

- Different people fight different demons. So older people are maybe more occupied with topics like patient-doctor communication, while younger people might be more interested in how the topic of sex changes for them. In this concept, it could be nice to connect a psychologist who can introduce and guide these themes and look at what would fit every individual.
- One of the things in the in-between-land is that the needs constantly change. So it would be nice if the themes in the box of questions would change now and then.
- For the box of questions, it would be nice that something can lead the tussenlander to the correct box immediately if the tussenlander already had a specific question beforehand.

### EVALUATION CRITERIA

To conclude if the platform and service meets the design goal, the design is evaluated using the criteria for “The Entrance to the Tussenland”.

***The final design should make the tussenlander feel recognised and part of the group of tussenlanders, where they do not feel lonely anymore.***

“The Entrance to the Tussenland” acknowledges that there is a land, especially for tussenlanders. Moreover, the use of shared stories, experiences and memories contribute to the feeling of a community where they can feel “part-off.”

***The final design should guide the tussenlander after the diagnosis of an incurable disease, as it is a vulnerable and crucial moment, where the tussenlander needs much support.***

The tussenlanders will be welcomed by the guide Ava in “The Entrance to the Tussenland”, who invites them to explore this land together. Ava will explain to them what this world has to offer. Whenever the tussenlanders feel lost, the deer in the forest will help them find their way.

***The final design should support the tussenlander to reflect on his/her life.***

The Tree of Life is a tool that the tussenlander can use to reflect on his/her life.

***The final design should enable the tussenlander to regulate and be in control of their own social context.***

The function of the Tree of Life, to be private or shared with others, gives the tussenlander the control to share their experiences with whom they want. Whenever they allow their social context to enter their tree and leave messages, the tussenlanders can read these messages at their own pace.

***The final design should let Tussenlanders feel like themselves, and not only be reduced to only a patient.***
“The Entrance to the Tussenland” does not look at the tussenlander like they are a medical record, but at all the themes and values that make the tussenlanders who they are.

***The final design should create an atmosphere where timelessness exists.***
“The Entrance to the Tussenland” tried to recreate the feeling whenever one is in nature, completely cut off from the hustle and bustle of the city. Some participants explained it as a place where time does not exist. Therefore, the forest was chosen for the entrance of the Tussenland.

***The final design should create a place where one can simply only feel, and follow their emotions.***
The answer to this criterion corresponds to the answer to the last criterion of timelessness. Moreover, using the experiences and memories of other tussenlanders as a learning tool enables the tussenlanders to feel more identified with each other, allowing them to open up emotionally.

***The final design should show that there is more to explore in the land than the forest and more possibilities.***
The final prototype that is shown in the use scenario shows that the landscape in “The Entrance to the Tussenland” is more extensive than only the forest. So it is visible that there is more to explore, but it does not give a clear overview of the possibilities. The land is now defined by a landscape filled with mountains, trees and grass. However, it does not show the other worlds described in the framework of chapter 6.1.
The reason for this decision was that these other worlds have not been designed yet, making it difficult to create these worlds. However, this leads to the limitation that standing in “The Entrance to the Tussenland” does not give a clear overview yet of what the Tussenland can offer.

***The final design should be inviting to create an environment where the tussenlanders feel safe to share their experiences without feeling judged.***
“The Entrance to the Tussenland” allows the tussenlander to share their experiences with their Tree of Life. If the tussenlander decides to share it with other tussenlanders, their loved ones or their care professionals, it cannot be guaranteed that the tussenlander will not feel judged by them. The tussenlanders are in charge with whom they share their experiences.

***The final design should allow the tussenlander to take its time and space to land in the in-between-land safely.***
The need that is answered in “The Entrance to the Tussenland” (the forest) is that it allows tussenlanders to land in the Tussenland safely. The Tussenland still can offer more possibilities for the tussenlander. However, “The Entrance to the Tussenland” was designed for the tussenlander to safely land, so that they will be able to explore the rest of the Tussenland.

***The final design should not impose thoughts or ideas on the tussenlander, but create an open interaction so that the tussenlander can solely focus on their own thoughts and emotions.***
The dialogue and speech of the guide Ava have been iterated multiple times to ensure an open interaction that does not insinuate or impose specific thoughts.

***The final design should empathise with the tussenlanders feelings and emotions. It should give them the feeling that they do not have to explain anything to anyone.***
By creating a tree with experiences and memories that tussenlanders can share with their social context, they can simply let others enter their tree instead of having to repeat and explain their story repeatedly.

# 08

# DESIGN IMPLEMENTATION

*This chapter proposes an implementation plan for the platform and service Het Tussenland. As set of limitations and recommendations are suggested, followed by a personal reflection. This is followed up by the final part of the project which includes the final reflection that discusses the insights and conclusions of the project.*

### CHAPTER 8.1

# OVERVIEW

This chapter proposes a way to implement the platform and service "The Entrance to the Tussenland". First, a service system map is presented to show in a single frame all the actors that are involved and the different service flows. A roadmap will propose the next steps in the future for "The Entrance to the Tussenland".

### CHAPTER 8.2

# SERVICE SYSTEM MAP

The service system map clarifies how all the different service components, organisations, and actors connect (*Morelli, 2007*). This system map is created to understand the service dynamics, highlighting the values they exchange.

## SERVICE FLOWS

The system map shows how the service components can be divided into five different service flows:

- **Labour Performance Flow**
- **Data/Information Flow**
- **Supporting flow**
- **Material Flow**
- **Financial Flow**

## ORGANISATIONS

The different organisations that are involved in the service and platform are:

**The organisation of the platform**

The hospital and hospice Bardo are part of the organisation, and will work together to

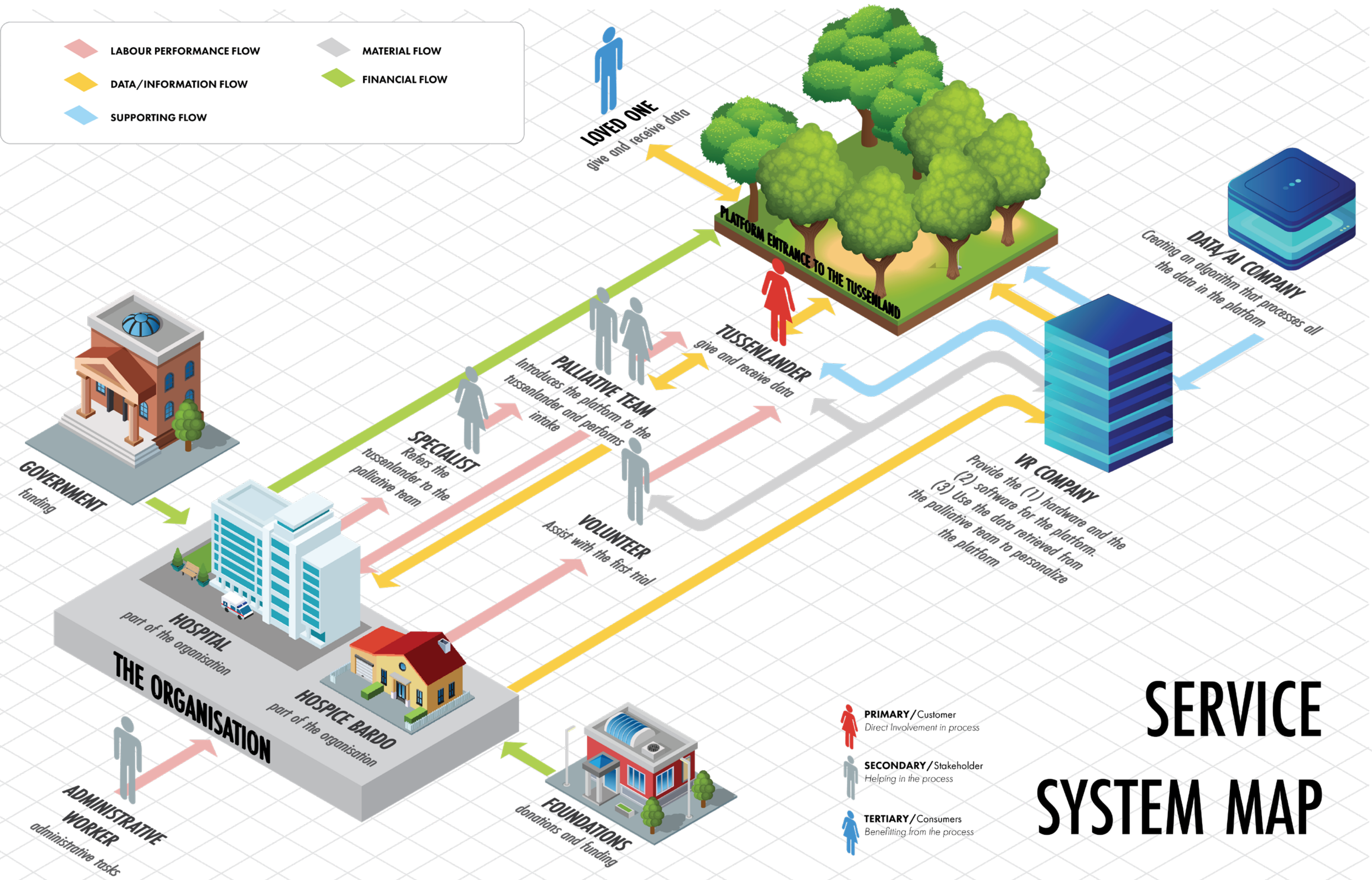


*Figure 27. Service System Map of Het Tussenland*

provide a better quality of life for people who enter the palliative phase. These organisations have an extensive network with many resources that are valuable for "The Entrance to the Tussenland". Their staff (specialist, palliative team, volunteers, social workers, mental health professionals, administrative workers, etc.) is essential for onboarding this service and platform. All the administrative tasks are performed to ensure that the service and platform work. These are tasks like: setting up the application of the service, contacting organisations, and transferring data. The administrative workers will also assist tussenlanders whenever they have any questions.

**Hospital**
The hospital is part of the organisation of this platform together with the Hospice (Bardo). The hospital is an environment where tussenlanders can be located in the early stage of palliative care. Moreover, this is also a tool that enables the care professionals at the hospital to get a better understanding of their patients. It could be a possibility for the patient to also share their tree with a care professional. So instead of looking at their patient record, the care professional will be able to see the bigger picture and offer holistic care to the Tussenlander. The staff (specialists and palliative team) is also involved in the first part of the service.

**Hospice Bardo**
Hospice Bardo is part of the organisation together with the hospital. They work together in close collaboration. Hospice Bardo has expressed interest in meaning more for Tussenlanders in an early stage of their disease. In the Dutch culture, hospices can be associated with end-of-life care. Therefore, at the start of the service Hospice Bardo will play a backstage role. It can be frightening for a new tussenlander to be immediately confronted with a hospice worker when the representation of a hospice is often linked to the end-of-life. Therefore, the hospice staff will be involved in the service, but initially in a more backstage role that can gradually develop into a front stage role. At the start, Hospice Bardo does provide the volunteers that will assist the tussenlander in the process.

**Foundations**
Several foundations (e.g. 'stichting Vrienden Van', 'stichting Hematon') are connected to the hospices. The needs and the benefits of the service and platform "The Entrance to the Tussenland" will be presented to them. The goal is to receive donations that can be used to develop "The Entrance to the Tussenland".

**Government**
In an ideal situation, the government also sees the benefit "The Entrance to the Tussenland" can offer tussenlanders, and how it can improve the care at hospitals. Funding from the government would be an enormous boost to develop "The Entrance to the Tussenland".

**VR Company**
It is suggested that a VR company will provide the hardware and the software of the service.

**AI/Data company**
It is recommended that an AI/Data company will provide the knowledge and the skills to build an automated AI solution that processes the incoming data on the platform. The AI/Data company will assist the VR company in building the platform.

**ACTORS**
The actors are categorised as follows:

**Primary | Customer (red)**
This is the tussenlander who has direct involvement in the process.

**Secondary | Stakeholders (grey)**
The stakeholders that help the process: the palliative team, specialist and volunteers.

**Tertiary | Consumers (blue)**
The loved ones who are not the primary user but do benefit from the process.

### LABOUR PERFORMANCE FLOW

The Labour Performance Flow shows all the frontstage labour activities that are performed to ensure the service.
It starts with the specialist at the hospital that refers the tussenlander to the palliative team. The palliative introduces the platform to the tussenlander. If the tussenlander indicates that they are interested in the platform, the palliative team will inform the organisation that starts the application for the service. At the same time, the organisation will send a signal to the volunteers who will assist the tussenlander with the first trial in “The Entrance to the Tussenland”. The tussenlander can choose if they want to have the trial at their home or a more communal area like the hospital or a community centre.
When the tussenlander is interested in the platform, the administrative workers of the organisation of the platform will set up the application for the platform and service and start contacting the involved organisations.

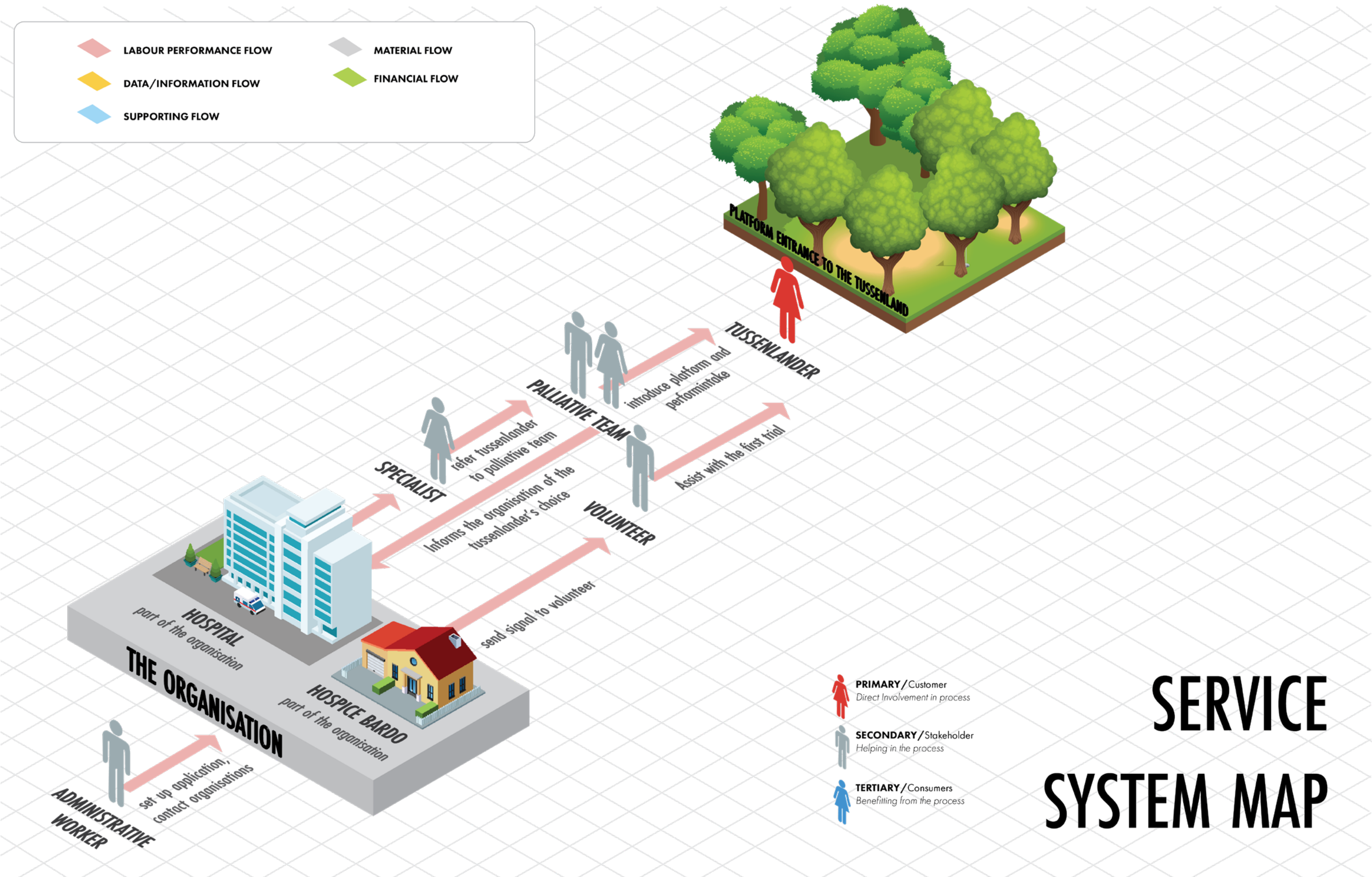


*Figure 28. Labour Performance Flow*

## DATA/INFORMATION FLOW

The Data/Information Flow shows all the data that flows through the service system. The platform's content relies on this data so that future tussenlanders can benefit from this feature.

The service starts when the palliative team has the second meeting with the tussenlander, where they have a conversation to determine the essential themes and values in the life of the tussenlander. The palliative team reports this data to the organisation. The office then directs it to the VR company, which will use this data to personalise the content of "The Entrance to the Tussenland" to the tussenlander's need. The tussenlander and loved ones give the platform data by building a tree with memories and experiences. At the same time, they receive data from the platform through the experiences of others. As tussenlanders and loved ones will continue to give and receive experiences, this is a data platform that keeps growing.

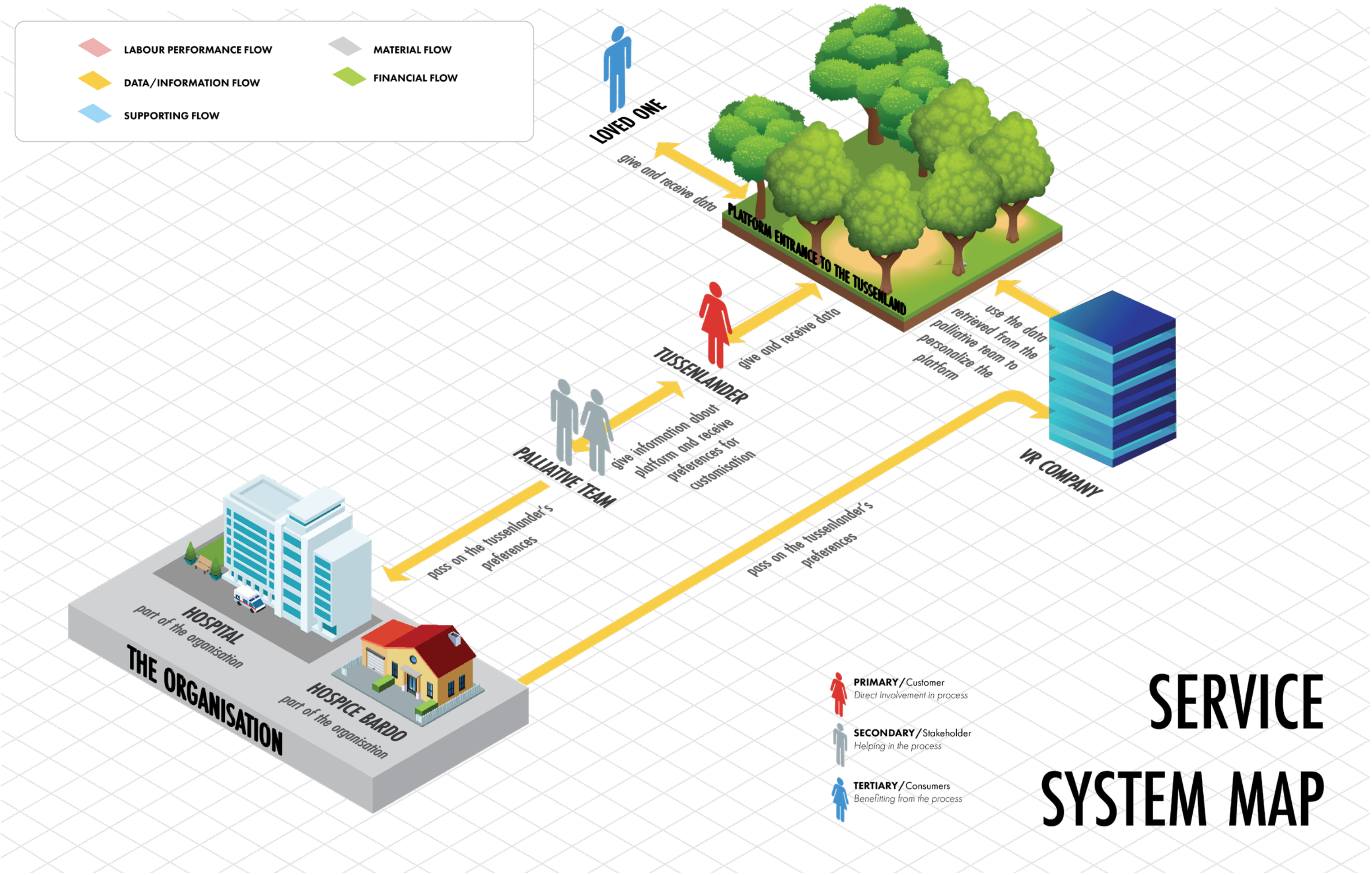


*Figure 29. Data/Information Flow*

## SUPPORTING FLOW

The supporting flow shows all the supporting services in “The Entrance to the Tussenland”. This supporting flow exists out of the development and maintenance of the platform.

### Development and maintenance

The platform’s maintenance is in the hands of a VR company and an AI/data company. A VR company will provide the software for the platform, and build the platform environment. The VR company will also provide the hardware (see material flow). The maintenance of the VR kit will also go through them.
The AI/data company will be responsible for creating a model using Artificial Intelligence that will be able to categorise all the incoming data so that every tussenlander will get the right experiences that fit their needs.

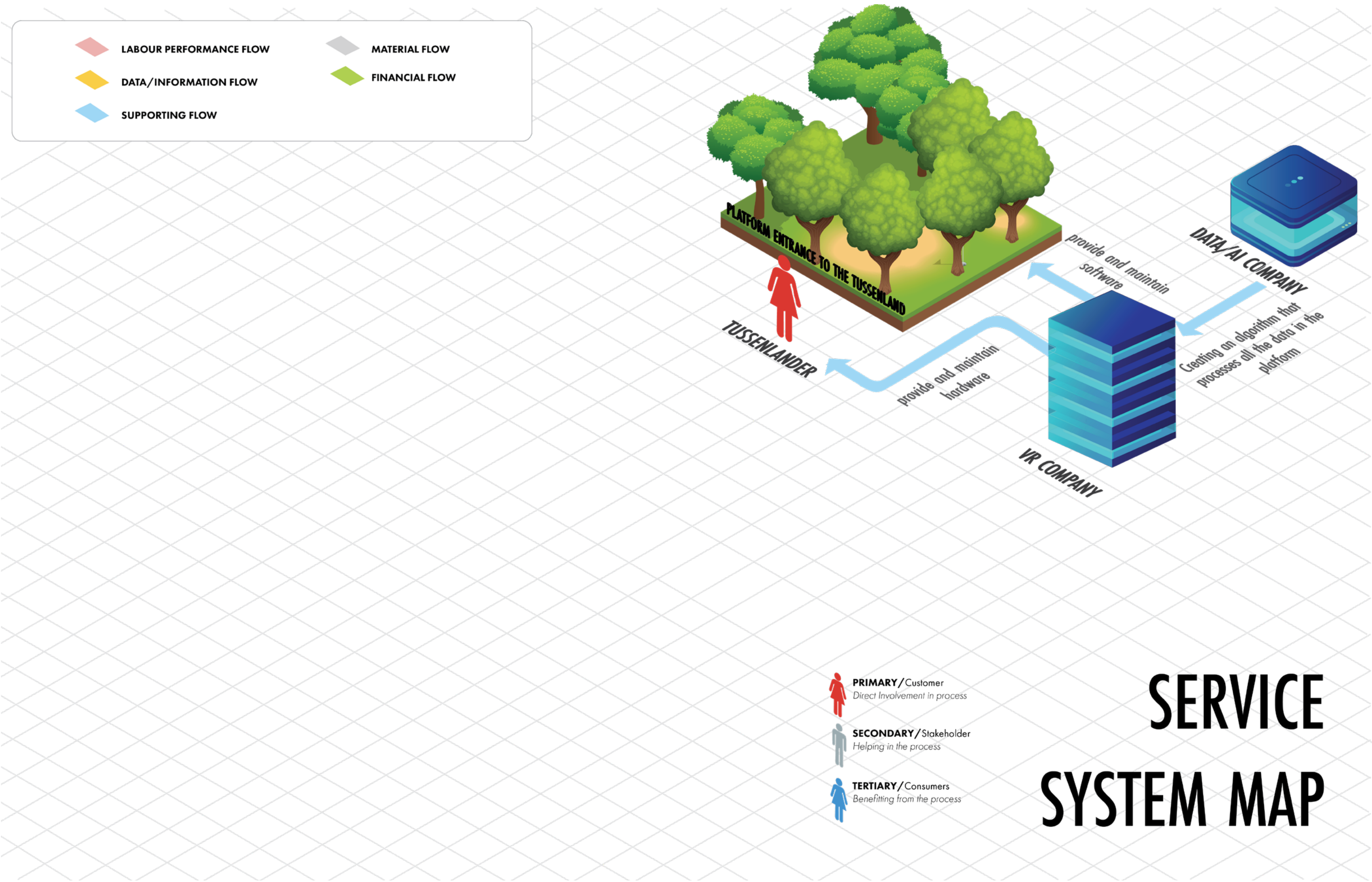


*Figure 30. Supporting Flow*

**MATERIAL FLOW**
The material flow shows the physical material that goes around in the service.

When the tussenlander decides to try the platform, a signal will be sent by the administrative worker to the VR company. After the VR company receives this signal, they will prepare a VR kit (glasses and handhelds) and hand it to the volunteers. The VR company will send a VR kit to the tussenlander. When the VR-kit needs some maintenance or will not be used anymore, it will go back to the VR company. The volunteers will use these VR kits for the first trial with the tussenlander when the tussenlander decides to engage the service.

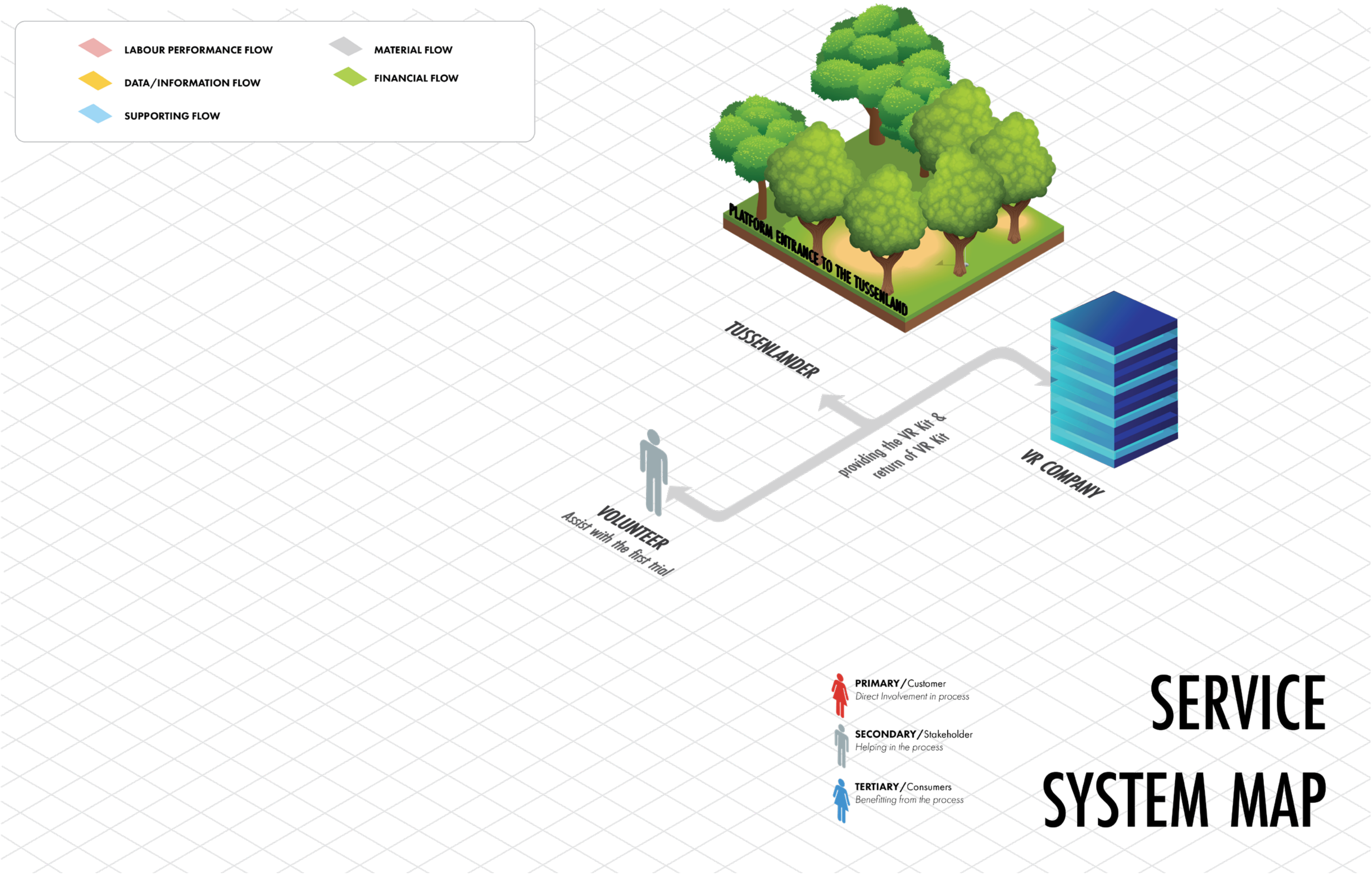


*Figure 31. Material Flow*

**FINANCIAL FLOW**
The financial flow shows how the platform will be financed.

In this flow, it would be recommended to use the network and resources of the hospital and hospices, as they have connections with various foundations and the government. In an ideal situation, part of the system would be financed through donations from foundations, and funding from the government.

The revenue model of “VRiendje”, the VR application that was mentioned in chapter 2.4, is based on a monthly subscription (*Zorginnovatie, 2017*). In the subscription, all the costs will be included (hardware, software, hosting, training and support). Care organisations like hospitals and hospices will purchase the product, to offer it to their patients. This revenue model could be used as an inspiration for “The Entrance to the Tussenland”.

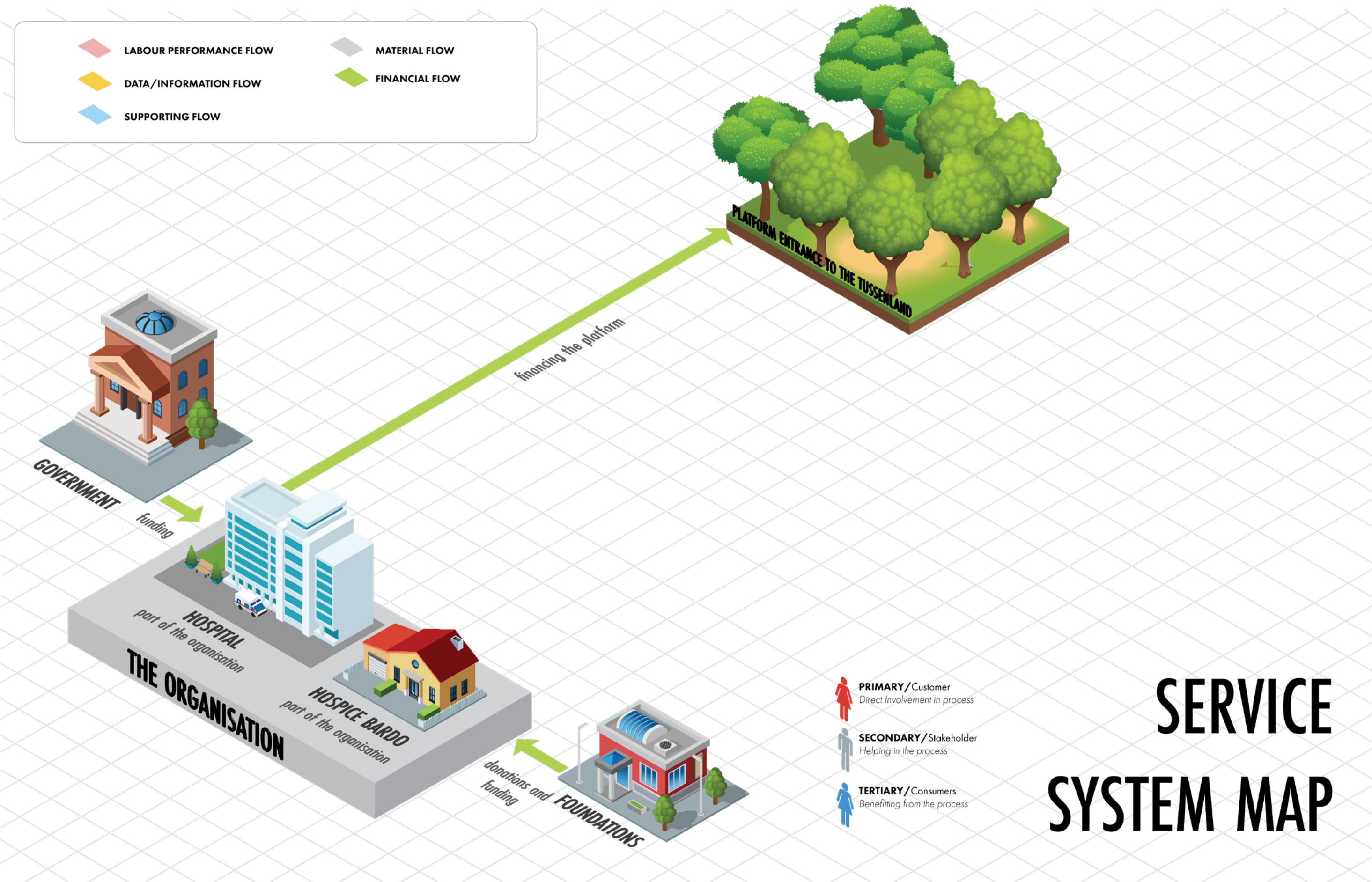


*Figure 32. Financial Flow*

### CHAPTER 8.3

# ROADMAP

This chapter discusses how to implement “The Entrance to the Tussenland” and in what time frame. The end result of this thesis is a framework of the Tussenland, where “The Entrance to the Tussenland” has been conceptualised and translated into a video demonstration. A roadmap will be presented that shows the next steps that must be taken to launch the platform “The Entrance to the Tussenland” officially. The roadmap shows three milestones: start the pilot, launch “The Entrance to the Tussenland”, and further development of the Tussenland. The following steps for the first milestone will be more extensive than the second and third milestones. The right stakeholders are not involved yet, which makes it difficult to make recommendations in the second and third milestones.

## MILESTONE 1| start pilot

The goal of the first milestone is to start the pilot for the platform. By conducting a pilot, the effectiveness of the platform can be investigated. The following steps must be executed in order to start the pilot.

### Finding the right stakeholders

The goal of the first step is to find the right stakeholders. The stakeholders need to be enthusiastic and dedicated pioneers willing to engage with this platform. The required stakeholders are Hospice Bardo, a hospital, a VR company and an AI/Data company. Hospice Bardo has already been involved in this project and has shown an interest in pursuing this project. It is recommended to find a hospital connected to Hospice Bardo, like Spaarne Gasthuis. The Spaarne Labs, the innovation lab of Spaarne Gasthuis, has been

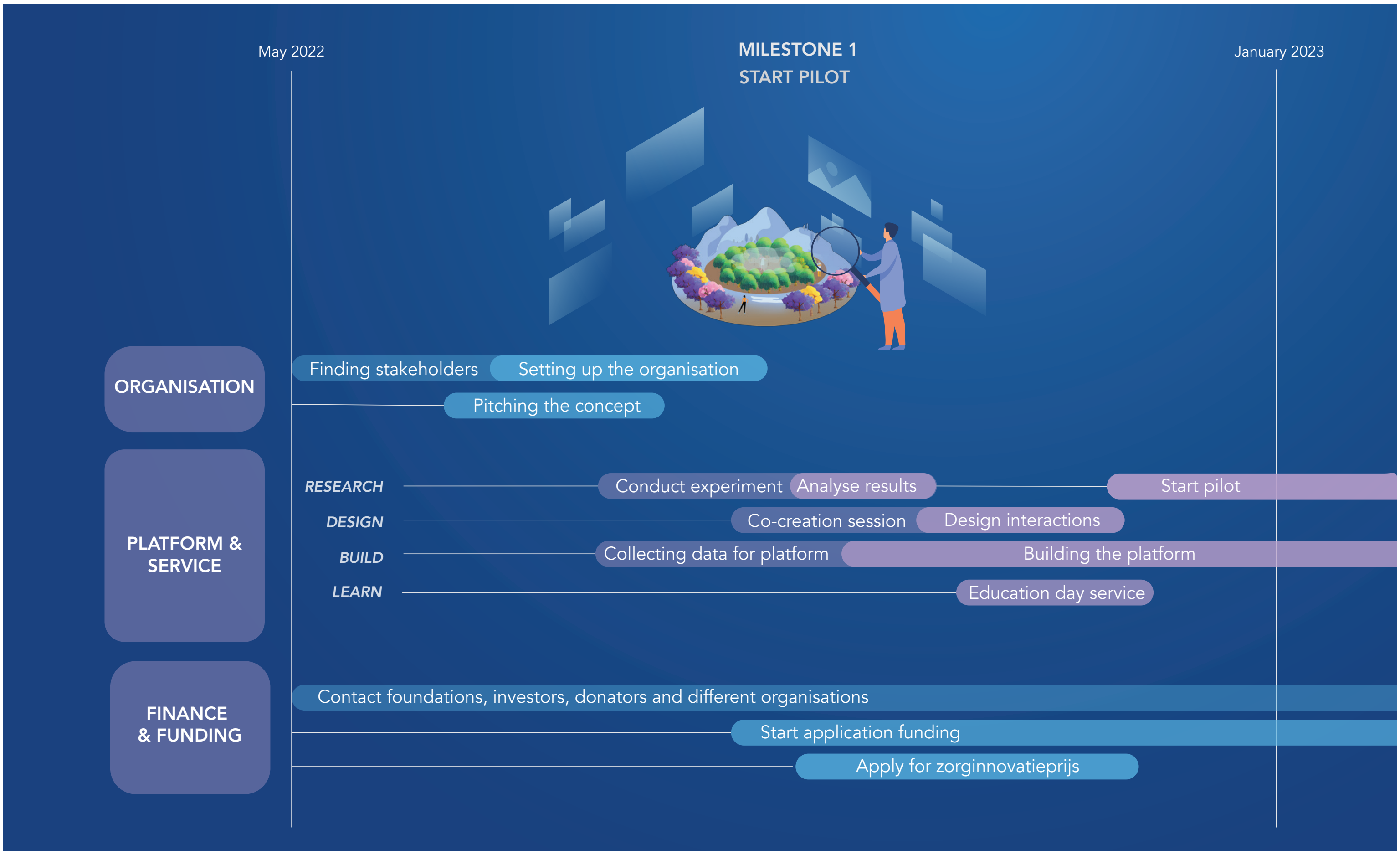


*Figure 33. Roadmap: first milestone*

contacted to explore further development. The latest update is that The Spaarne Labs has replied and that they are interested in the story behind “The Entrance to the Tussenland”.

The VR company and the AI/data company will be collaborating. Thus, it is recommended first to find a VR company. When the right VR company has been found, this company may already have partnerships with certain AI/data companies.
SyncVR, a pioneer in Virtual Reality in medical situations, was contacted for further exploration for the VR company. The founder of SyncVR indicated that they had no time the coming months to commit to an external project. Therefore, it is recommended to approach other medical VR companies like HorusVR or UnboundVR.

**Pitching the concept to the stakeholders**
This step focuses on sparking the stakeholders’ interest. The video demonstration of the concept, can be used as input for the conversation with the stakeholders. In these meetings, the framework of the Tussenland will be introduced, and the final design “The Entrance to the Tussenland” will be presented.
Moreover, the evaluation of the platform from the interview panel will be presented to the stakeholders. It will be recommended to the stakeholders to conduct an experiment with the target group. It is proposed to find participants who have just been diagnosed with an incurable disease, and who are open to engaging with “The Entrance to the Tussenland”. These participants can be found through the hospital.

**Contact foundations, investors, donators and different organisations**
This step aims to look for partners who can financially invest in the platform and create more presence in the palliative circuit. The platform will be presented to different kinds of foundations (e.g. stichting Vrienden Van, Stichting hematon), investors and organisations (e.g. Patio Erasmus). This step needs to be executed during the whole roadmap.

**Setting up the organisation**
This step aims to form the base of the organisation of the platform. The organisation consists of a team of workers that hospice Bardo and the hospital will distribute. This team of workers will consist of administrative workers (administrative tasks, like setting up the application), care professionals (specialists, palliative workers, social workers, psychologists) and volunteers.

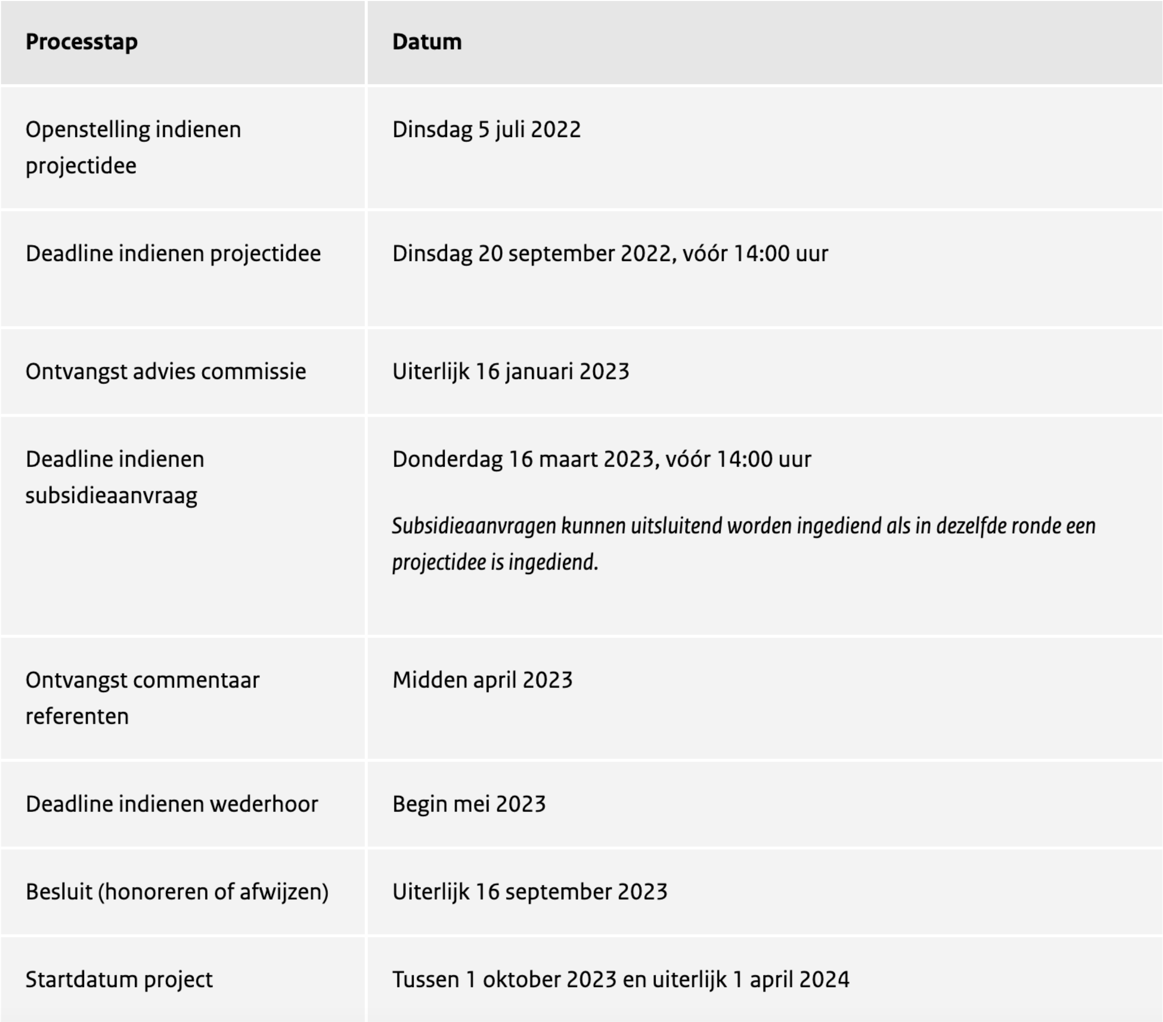
**Conducting the experiment**
This step aims to evaluate the concept with the right target group. For this evaluation, the video demonstration can be shown to the tussenlanders. In this step it is essential to create a safe environment where the target group is willing to enter this concept. It is recommended to find tussenlanders of the pro-active type (Stichting STEM), who are most willing to engage with this topic. If the concept receives positive feedback in the experiment, these results can form the support for the following steps.

**Collecting data**
This step aims to collect the data for the Box of Memories in the “The Entrance to the Tussenland”. The idea of the concept “The Entrance to the Tussenland” is that it keeps generating data from the input of the tussenlanders (the user of the platform). However, at the start, there has not been any user activity. Therefore, the experiences and thoughts of tussenlanders will be collected beforehand, so that a base will already be present for the Box of Memories. This data can be collected through two channels.
The first channel is lotgenotencontact (contact with people in similar situations).

These people are already willing to share their experiences with others. It is advised to contact organisations that provide lotgenotencontact, to find tussenlanders that want to share their experiences.
The second channel is through the media that already exists. So experiences of tussenlanders in literature, tv shows (e.g. over mijn lijk), documentaries, and the internet.

**Co-creation session with all the stakeholders**
This step aims to improve and iterate the platform. By conducting co-creation sessions, the first iteration of the design will take place based on the feedback and insights. These co-creation sessions must be prepared and will be led by a moderator. It would be recommended that every stakeholder puts 1-2 representatives forward to participate in the session. The Spaarne labs has experience in conducting these kinds of co-creation sessions. Therefore, it would be wise to contact them.

**Design the interactions**
The goal of this step is to design the guide and the interactions. First of all, the right voice for the guide Ava has to be found. Second, it would be recommended to re-enact the dialogue with actors and care professionals to see what could be improved. When care professionals are educated, they often already had to practice the bad news conversation with actors. These actors can also be used for this purpose.



| Processtap | Datum |
|---|---|
| Openstelling indienen projectidee | Dinsdag 5 juli 2022 |
| Deadline indienen projectidee | Dinsdag 20 september 2022, vóór 14:00 uur |
| Ontvangst advies commissie | Uiterlijk 16 januari 2023 |
| Deadline indienen subsidieaanvraag | Donderdag 16 maart 2023, vóór 14:00 uur<br>*Subsidieaanvragen kunnen uitsluitend worden ingediend als in dezelfde ronde een projectidee is ingediend.* |
| Ontvangst commentaar referenten | Midden april 2023 |
| Deadline indienen wederhoor | Begin mei 2023 |
| Besluit (honoreren of afwijzen) | Uiterlijk 16 september 2023 |
| Startdatum project | Tussen 1 oktober 2023 en uiterlijk 1 april 2024 |

*Figure 34. application process of the subsidary/funding*

**Building the platform**
This step aims to create a working prototype that can be used for a pilot. A VR company will be working together with an AI/Data company to create the platform's software.

**Education day for the service**
This step aims to ensure that everyone, who is involved with the procedure of the service, knows what their role is. Actors will also be present during this education day to test the flow of the service.

**Start application for subsidiary/funding**
The goal is to start the application for a subsidiary/funding by the Zorginstituut Nederland and ZonMw. The research program "Potentially Promising Care" gives the opportunity to offer temporary funding for potentially promising interventions that are not reimbursed from the Dutch standard health care package (*Ministerie van Volksgezondheid, Welzijn en Sport, 2021*). This funding is only granted under the following conditions. High-quality research data must be collected during the subsidy period, which can be used in the future to assess the (cost)effectiveness of the project. The subsidy is granted for a maximum of six years. Within six months before the project has ended, an assessment will take place where Zorginstituut Nederland will determine whether or not the treatment can be reimbursed from the Dutch Standard health care package.

The procedure of the application can be seen in figure 34. The deadline for submitting the project idea is on 20 September 2022. The project idea is a short version of the research proposal, a concise description of the project that shows the argumentation, the effects, the safety and the relevance of the idea. An advisory committee will judge the submission on 16 January in 2023. If the project gets selected, the deadline for the funding application is on 16 March 2023. The project's start date will be between 1 October 2023 and 1 April 2024.

**Start application for Zorginnovatieprijs**
This step aims to apply for the 'Zorginnovatieprijs' (care innovation prize) in November 2022. This will create more publicity, but the prize is also something that can kickstart this platform. Next to prizemoney, the winner also receives professional coaching for the platform, which would be helpful.

**Start pilot**
The pilot's goal is to determine the effects of the platform and service, e.g. how do tussenlanders perceive the Guide, the environment, the Tree of Life and the Box of Memories. Moreover, is the platform user friendly.
In this pilot, it would be interesting to investigate how the five different styles of dying of Stichting STEM would react to the platform and service.
In this pilot hospice Bardo will work together with a connecting hospital (e.g. Spaarne Gasthuis). It would be recommended to create five focus groups (for the five types of Stichting STEM) with 5-10 participants. Thus, the total amount of participants will be around 25-50.
By conducting a pilot that provides scientific results, it also enlarges the possibility to obtain specific funding or grants.

**MILESTONE 2| Launch "The Entrance to the Tussenland"**
The goal of the second milestone is to officially launch "The Entrance to the Tussenland". The following steps must be executed in order to launch the platform.

**Conduct pilot**
After achieving the first milestone that started the pilot, the pilot will continue at the start of the second milestone.

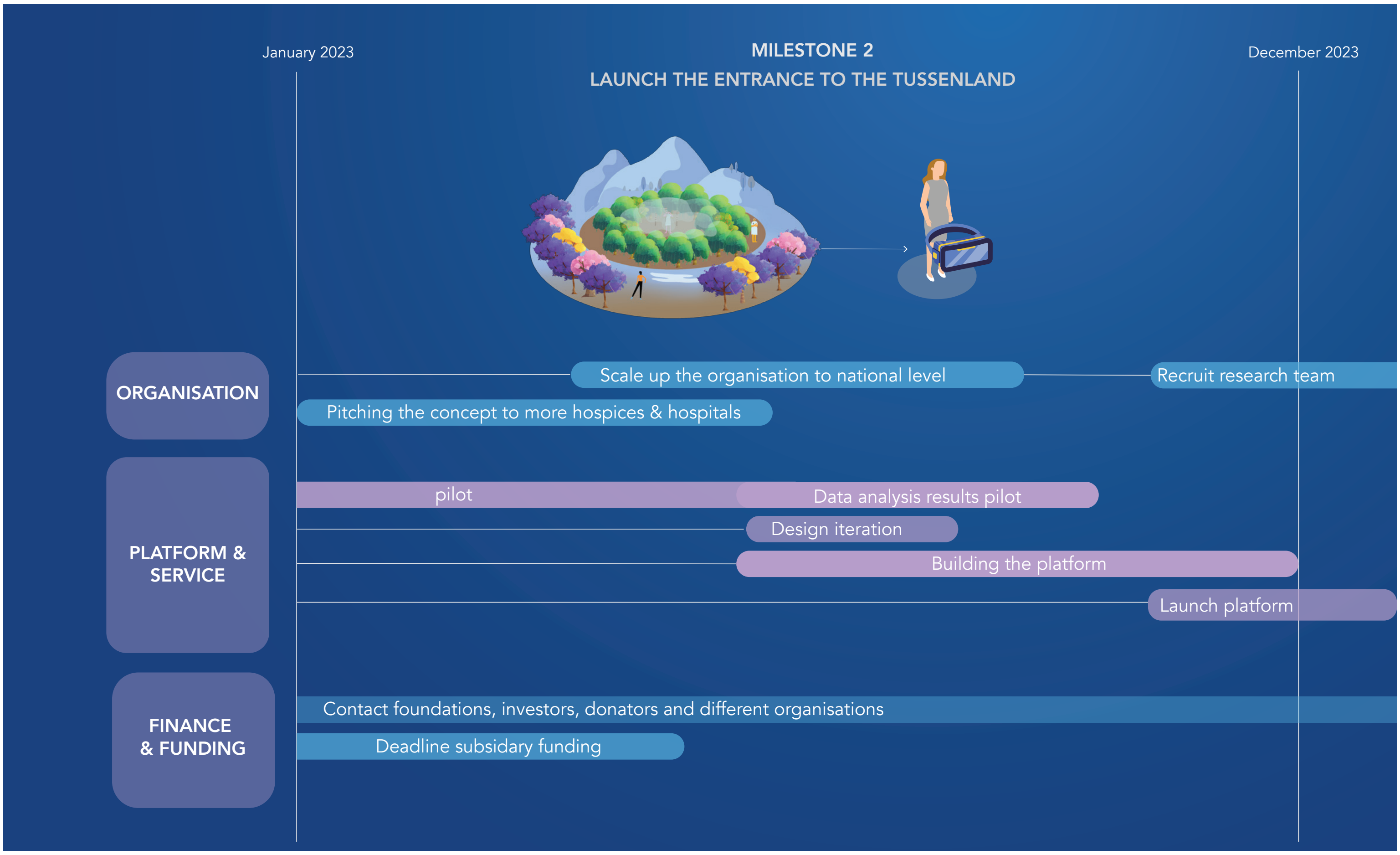


*Figure 35. Roadmap: Second milestone*

**Pitching the concept to more hospices/ hospitals**
The platform has only been introduced to hospice Bardo and the connecting hospitals for the pilot. In this step, it is the goal to pitch the concept to more hospices and their connecting hospitals.

**Scale-up organisation**
This step aims to scale up the organisation to a national level, as more hospices/ hospitals will be involved in the project. An infrastructure needs to be built that regulates the service collaborating with multiple hospitals and hospices.
The central department will be appointed to overview the entire organisation nationally. Subdepartments will be created for every hospice and their connecting hospitals locally.

**Deadline subsidiary funding**
This step aims to finish the application for the subsidiary/funding for the programme "Potentially Promising Care". In the first milestone the project idea was submitted. For this milestone , if this project gets selected, the deadline for the funding application will be on 16 March 2023.

**Data analysis results pilot**
This step aims to show the effectiveness of "The Entrance to the Tussenland" by analysing the results of the pilot. Ideally, a research paper or report will be written about this pilot to share its findings.

**Design iteration**
The goal of this step is to conduct a new design iteration. The results of the pilot likely suggest some design changes. These design changes lead to an improved concept of "The Entrance to the Tussenland".

**Building platform**
This step aims to implement the new design changes in the platform.

**Launch platform**
The goal is to launch the platform by the end of the year 2023.

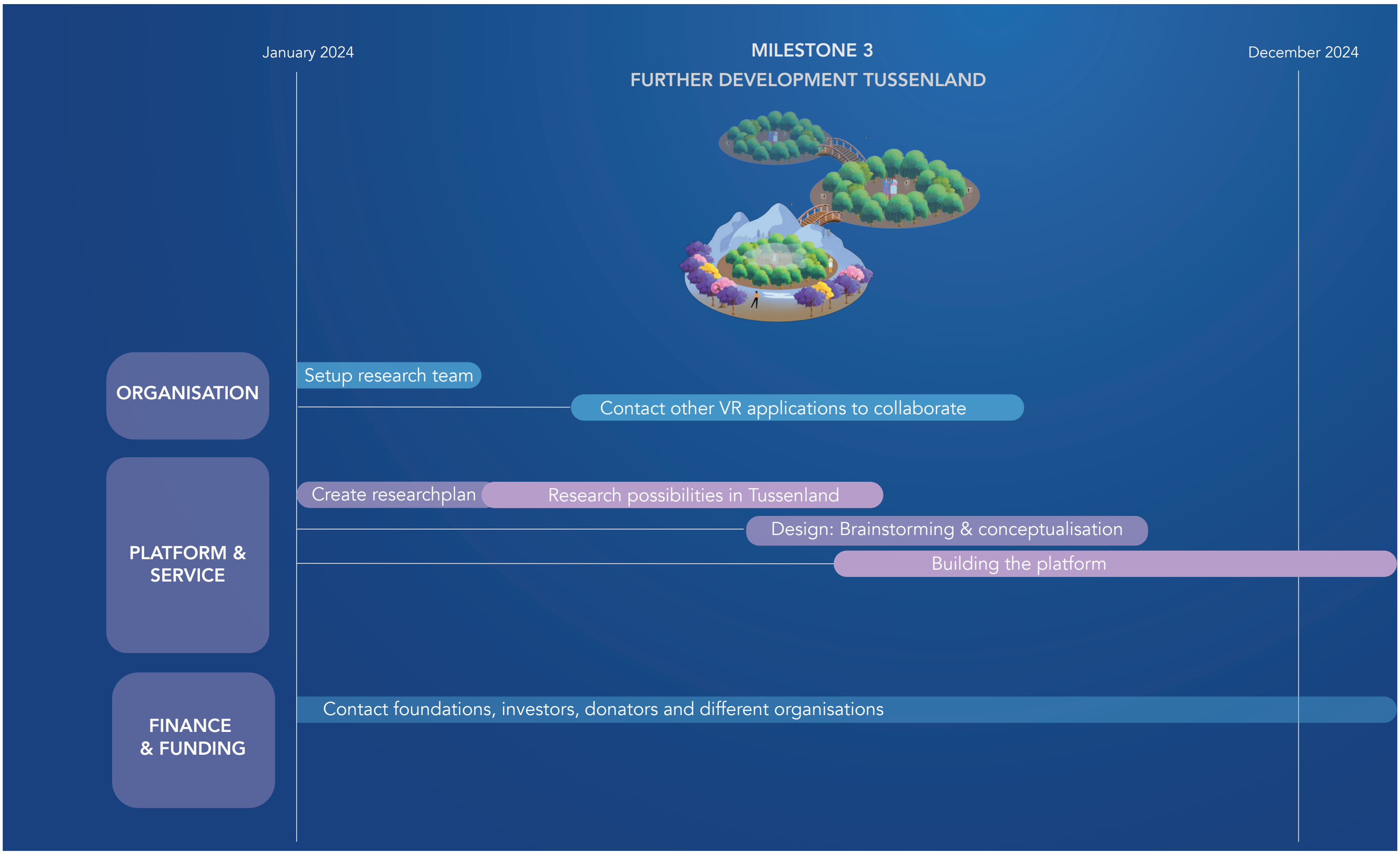


*Figure 36. Roadmap: Third milestone*

**Recruit research team**
This step aims to start the recruitment for the research team. This step serves as a preparation for the next milestone.

### MILESTONE 3| Further development Tussenland

The goal of the third milestone is to conceptualise the entire Tussenland. This thesis has conceptualised the entrance, and presented a framework of what the rest of the Tussenland could look like. The following steps must be executed to develop the Tussenland further.

**Setup research team**
The goal is to set up the research team to develop the platform. For this an organisation like The Spaarnelabs can be contacted. It can also be a possibility to recruit a graduate student from the faculty of Industrial Design Engineering to develop this platform further.

**Create research plan**
The goal is to create a research plan to investigate what is needed in the Tussenland for the tussenlander.

**Research possibilities in Tussenland**
The goal is to determine the needs and the possibilities in the Tussenland, not only the entrance. The research will be performed through exploratory literature reviews and studies. For the exploratory study, the participants will not only exist out of the pro-active type but also the other dying styles from Stichting STEM. The needs of every group regarding the platform will be distinguished from each other.

**Design: brainstorm & conceptualise**
The goal is to design and conceptualise the rest of the Tussenland. The design process will consider the following need: the need for the Tussenland to face the nearing end-of-life and the life they are living by creating new memories. After landing in “The Entrance in the Tussenland” they will be able to explore the rest of the Tussenland, where they can explore these new places and enjoy new

activities.
For this step, it is recommended to participate in a hack-a-thon (e.g. Young Medical Delta), or organise a hack-a-thon with students. The results in chapter 5.3 show how valuable the hack-a-thon was in this design process.

**Contact other VR applications**
The goal is to create a collaboration with other VR applications. In the medical and entertainment category of VR, many applications already exist. These applications could be a nice extension for the Tussenland. For example, the application that was described in chapter 2.4, PlaygroundVR, could be an extension of the Tussenland. Parents could enter the Tussenland together with their children, and visit the PlaygroundVR.

**Build the platform**
The goal is to expand the platform in VR, and implement the results from the research and design phase.

# PART 6 FINAL WORD

# FINAL REFLECTION

## REFLECTION ON INITIAL BRIEF

The initial brief of this thesis was to investigate how the technology Virtual Reality can create a more meaningful life for people with a life-threatening disease, where Hospice Bardo can reach these people in an earlier stage. In this thesis, it became clear that the wish of Hospice Bardo had not to be interpreted literally. Hospice Bardo wants to disassociate itself from the idea that the care for a tussenlander is divided and fragmented in different organisations and institutions (e.g. hospitals, hospices, clinics). Hospice Bardo views that all these organisations and institutions can offer a holistic form of care together for the tussenlander. As an institution, Hospice Bardo does not literally want to reach tussenlanders in an earlier stage. However, Hospice Bardo wants to enable tussenlanders to receive the palliative care that can be offered. That is something that could be seen in practice. During the concept development, it was initially envisioned that Hospice Bardo would play a more significant role in the onboarding of the platform. However, then Christiaan spoke the following words:
***'Unfortunately, many tussenlanders still associate palliative care with the end-of-life, so it can be extremely terrifying and confronting for tussenlander to already meet a hospice worker that early'.***
This reminded me of the statement of Nettie, the specialised oncology social worker, that one always has to be in line with the tussenlander's needs. A care professional has to be egoless.

There are no winners or losers in the world of palliative care. Every stakeholder in this project has one goal together: to create more meaning in the lives of people with an incurable disease. This is where the concept of compassionate communities from Alan Kellahear(2013) returns where the care is not only in the hands of health and social services, but where it is the responsibility of every stakeholder.

## REFLECTION ON DESIGN BRIEF

After the literature and exploratory research, a revised design brief was created, looking at how we could design an invitation for people who enter the in-between-land to engage with this new context for their lives emotionally. The strength of "The Entrance to the Tussenland" is that it is a different approach and perspective to look at the palliative phase. Instead of closing the door, "The Entrance to the Tussenland" opens new doors for them, by acknowledging that there is a land for them where they can explore all the possibilities.

A theory that embodies this transition is the rites of passage model of Van Gennep (1960), where he presents a ritual that deals with the change of an individual's group or status in society. In this model, Van Gennep distinguishes three stages that can be viewed from the narrative of a tussenlander. The first stage is the rites of separation, where Van Gennep (1960) speaks of a departure and disengagement from the social world. For the tussenlander this is the moment when they get the diagnosis of an incurable disease, where they feel removed from the group they initially belonged to. This is followed up by the second stage: the rites of liminality, where people find themselves in a transcendent state, between heaven and earth. This corresponds with the experience of Jannie Oskam, who felt that life after the diagnosis was divided into two paths: the path of the nearing death (heaven), and the path of the life they are living (earth). The third and final stage is the rites of reaggregation, where Van Gennep speaks of a return and re-engagement with the social world. The stage where the individual is recognised in this new group and category *(Van Gennep, 1960)*. Acknowledging that there is a new land called "The Entrance to the Tussenland", that is there solely for them and that they belong somewhere, can be very meaningful for a tussenlander. That is why "The Entrance to the Tussenland" is all about sharing experiences and narratives, as people need to be part of something that they can identify with.

### REFLECTION ON THE COMPLEXITY OF THE PROJECT

It was described in chapter 2.6, that the focus and the target group for this project will be mostly the pro-active type of Stichting STEM. But that it would keep the option open to explore the other four styles. In practice, especially during the interviews in the exploratory study, it showed that the proactive type was the only one who would be open to engaging this topic and this project. It is true that after the bad news conversation everyone enters the in-between-land, but that does not mean that everyone needs to engage with this in-between-land. The majority of the participants in this study fit the description of the pro-active type. Therefore, the needs that are answered in "The Entrance to the Tussenland" do not always correspond with the other types. It was also mentioned that the dying styles from Stichting STEM are not absolute, showing that people can also be a mix of these styles. One of the participants in the study fit the description of the rational type, but his view on the end-of-life fit the pro-active type. This shows that even after creating these five different dying styles, people still differ from each other.
The topic of the end-of-life deals with the complexity and the diversity of a tussenlander. This thesis briefly described the diversity in terms of styles of dying, and type of disease. But there are so many factors that influence the end-of-life: age, gender, culture, religion, education, upbringing and much more.

In the design focus in chapter 4, the design decision was made to support the tussenlander after the diagnosis of an incurable disease. In literature and the exploratory study, almost every tussenlander expressed that this was a difficult moment for them, with emotions of sadness, disbelief and shock. Exploring this moment with a more diverse group of tussenlanders with different needs would be interesting. In this thesis, it is assumed that the needs of the pro-active type were collected in the exploratory study.

Thus, "The Entrance of the Tussenland" is not for everyone, only for the people who want to engage the in-between-land. The people who feel lost after the bad news conversation, but are open to find their way back.

### RELEVANCE FOR FIELD OF DESIGN

It can be seen as a provocative design, a form of design that challenges the status quo through products that expose assumptions and stimulate discussion (*Ozkaramanli & Desmet, 2016*). Thus, in this thesis, "The Entrance to the Tussenland" is not a finished product yet, but the starting point to engage tussenlanders in a world that belongs to them.

# LIMITATIONS AND RECOMMENDATIONS

During this thesis, a set of limitations have been encountered. This chapter will elaborate on these limitations. Furthermore, future recommendations are given that could improve the final design.

## LIMITATIONS

### Limited participants research and evaluation

The panel that has been interviewed throughout the whole process consisted of five tussenlanders, three loved ones, two care professionals and three experts. Due to the limited number of participants per category the insights might not represent every group. Moreover, as this thesis focuses on people who just got the diagnosis of an incurable disease, it would have been interested to speak to tussenlanders who are in this phase. And evaluate the final design with them. The tussenlanders that were part of this project were already past this phase, and have known for years that they had an incurable disease. These tussenlanders were willing to talk and thus were more open and enthusiastic about The Entrance to the Tussenland.

### VR testing

The scope of this thesis was to look at how the technology Virtual Reality could be implemented to create more meaning in the lives of people with an incurable disease. This thesis looked at all the possibilities that VR has and used this technology in the final design. However, for the evaluation, a video was created for the prototype to evaluate the final design. Although, the prototype explains the final design, it is not the same as experiencing it as a VR experience. Thus, the insights of the final design evaluation may not be representative for the VR experience of The Entrance to the Tussenland.

### Time to land

It needs time to land. This can be interpreted in two ways, first for the tussenlander. After the tussenlanders gets the diagnosis of an incurable disease, they need time to land. The concept of time changes, and their pace is entirely different than the pace of people who are not in The Entrance to the Tussenland. There could be a possibility that the pace of the Guide Ava is not in line with the pace of the tussenlander. The second thing that needs time to land is this whole platform. Because it connects elements that we know of (e.g. VR, the end-of-life, sharing stories, having conversations), but combining them into one final design is something that people are not familiar with. So it is a different approach to engage the topic end-of-life and death literacy.

## RECOMMENDATIONS

### Research of Interaction guide

It is recommended to investigate the tone and the interaction of the Guide. There is still so much to explore in voice, tone, intonations and pace. It would be interesting to continue this project with a Design For Interaction graduation student at the IDE faculty together with the End-of-life Lab and the Expressive Intelligence Lab. The End-of-Life Lab could give the expertise around the end-of-life, while the Expressive Intelligence Lab is the expert for the embodied intelligent agent (the Guide) and its expressiveness.

### Explore other needs

In chapter 6.1, a framework was presented with different worlds that represent the different needs of the tussenlander. Only the first world (the forest) was elaborated for this thesis. Therefore, it is recommended to also explore the other needs as these worlds also could have much potential, and expand the platform Het Tussenland.

### Testing

It is recommended to test the Virtual Reality experience The Entrance to The Tussenland with a representative group, tussenlander, who just got the diagnosis of an incurable disease. For this, it would be interesting to determine if there are significant differences for tussenlanders that vary in age, disease and palliative phase.

# PERSONAL REFLECTION

I think that I would not be exaggerating if I would say this project exceeded all my expectations. I met the most wonderful people, had the most real and sincere conversations, and besides learning as a student, all those people taught me many life lessons. I guess that is inevitable in a topic like the end-of-life.

## UNEXPECTED LEARNING LESSONS

At the start of the project my main goal was to improve the quality of life of the tussenlander through my design.  But throughout the process Christiaan remarked that it can already create a positive effect by conducting these interviews with the tussenlanders. And I felt that after every conversation I had. Beforehand, I told every participant that the interview would have a duration of one hour. But everyone stayed longer, willing to talk more about their experiences, emotions, and thoughts. Sometimes we even talked for three hours, not only about this research but also about other topics. Of course, I do not exactly know what they felt afterward, but **I think they felt heard and seen. Not as a patient, but as themselves.**

## PERSONAL LEARNING AMBITIONS

At the beginning of the project, I had a set of personal learning ambitions. Firstly, I wanted to achieve in-depth knowledge of palliative care and the end-of-life to make it **more approachable and less taboo** in our society. I think that at the start I still had to warm up, but after the user interviews, I was able to engage the complexity of this topic. Thanks to this I was able to create a design that makes the topic of end-of-life more approachable.
In my second learning ambition, I wanted to **define my own personal work method**. In this process I found what worked for me, taking all my past learnings with me. For example, the data collection method that I learned at Reframing Studio helped me to structurise all the information that was found in my research.
I also wanted to determine if **a long individual project** was something that suits me. I think in some ways it did, as it allowed me much freedom (e.g. to go to Suriname). But in this project, I was not always completely alone due to interesting conversations I had. So I think I have it in me to work on individual projects, but would also benefit from working with people together to stay grounded.
Lastly, I wanted to determine what it takes for **an idea to be implemented**. Beforehand, I underestimated the complexity of this project. Therefore, it is impossible to make a set of rules to determine if something can be implemented or not. But I did learn that being constantly in contact with all the stakeholders and listening to their input, is what increases the chance for implementation.

## IMPORTANCE OF BEING IN CONTROL

In my kick-off document, I spoke of the competencies that I have yet to develop and want to improve in the detailing and the finishing touch of the project. This is something that played a role in the last weeks before the deadline. The combination, of the weeks that I lost before the greenlight meeting, and the complexity of the project, resulted that at a certain point I lost a bit of control. When I am in control, what I usually am, I am able to convey what I want to say. But when I am not in control, the storyline which is so clear in my head does not land with others. This was a big learning moment for me. As I have been working on this project for nine months, of course, the storyline is clear to me. But for someone who is not as invested as me in this project, my reasoning was hard to understand. It made me realise that I had to go back to the core of my project, think of the narrative, and be back in control. And after this realisation, I was able to regain that control.

All in all, I think I learned more in these last 130 days than I would have initially expected, and that I not only created something meaningful for the tussenlander but also for myself.

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# APPENDICES

Master thesis | Zhenja Zheng | april 2022
Integrated Product Design and Strategic Product Design
Delft University of techology

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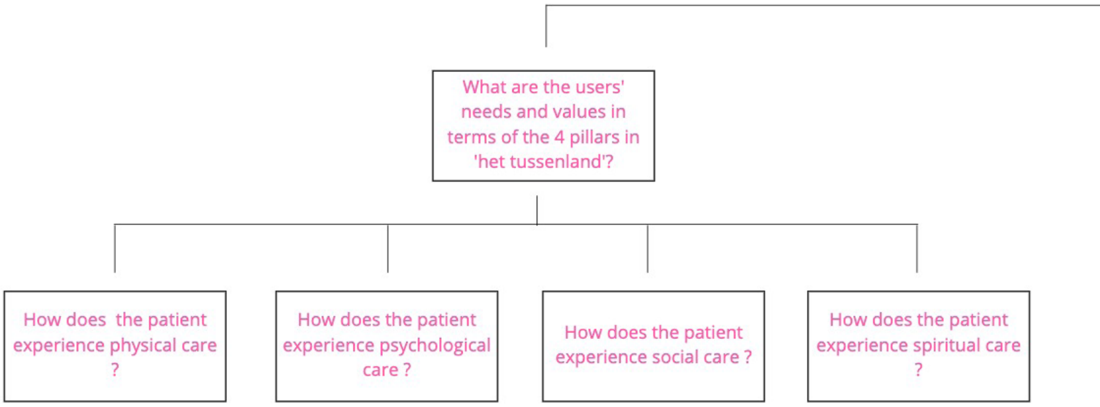
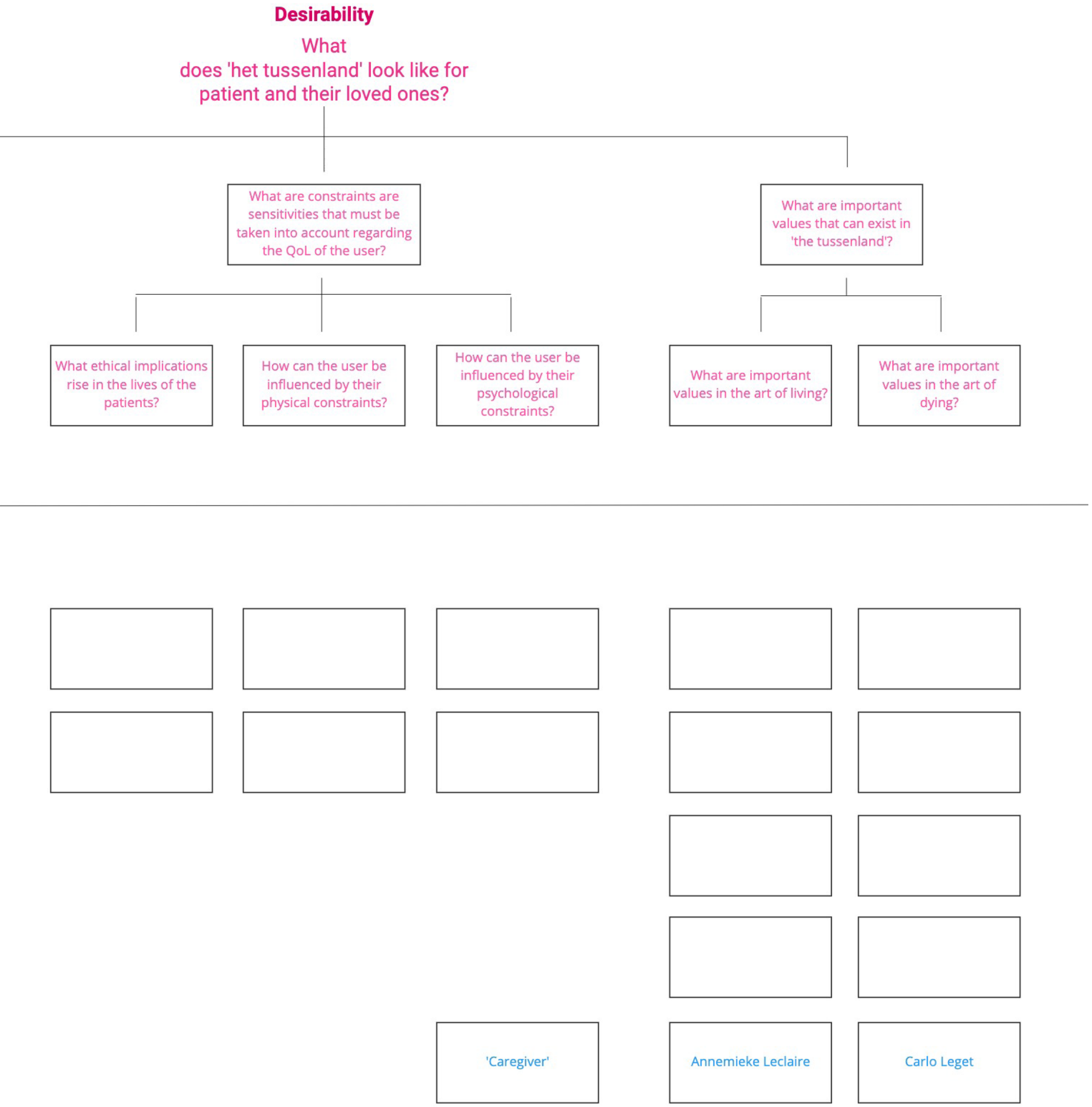
### APPENDIX A

# RESEARCH PLAN



| | How does the patient experience physical care ? | How does the patient experience psychological care ? | How does the patient experience social care ? | How does the patient experience spiritual care ? |
|---|---|---|---|---|
| **Literature review** | | Helpen bij verlies en verdriet. | | Van levenskunst tot stervenskunt. |
| **Desktop research** | | | | |
| **Patient** | | | | |
| **Loved one ('naaste')** | | | | |
| **Expert** | Jannie Oskam, 'Caregiver', | Jannie Oskam, 'caregiver' | Jannie Oskam, 'caregiver' | Jannie Oskam |



**Desirability**

What does 'het tussenland' look like for patient and their loved ones?

What are constraints are sensitivities that must be taken into account regarding the QoL of the user?

- What ethical implications rise in the lives of the patients?
- How can the user be influenced by their physical constraints?
- How can the user be influenced by their psychological constraints?

What are important values that can exist in 'the tussenland'?

- What are important values in the art of living?
- What are important values in the art of dying?

'Caregiver'

Annemieke Leclaire

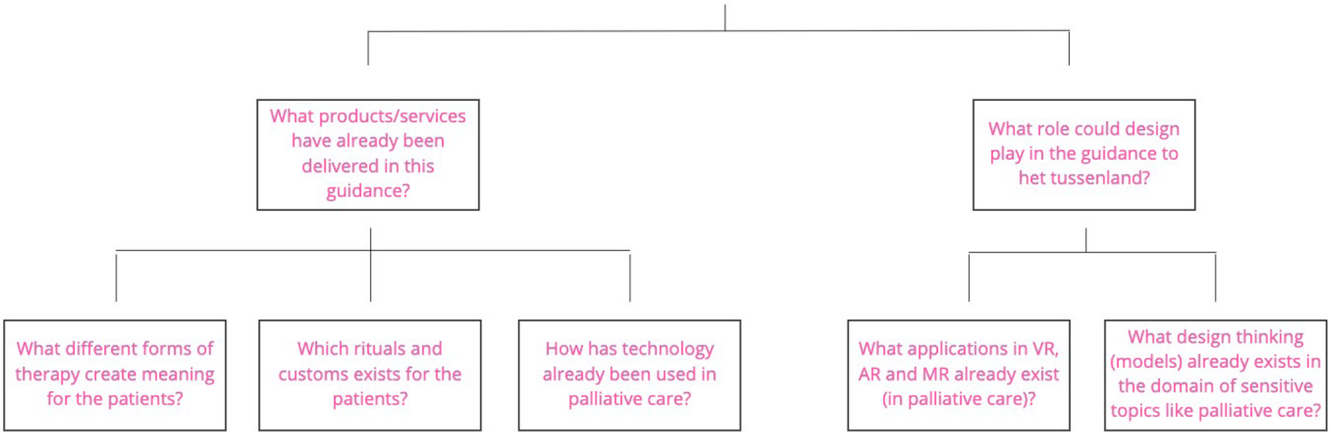
Carlo Leget

# ONDERZOEKSPLAN

**Main question:** ***How can design support and guide people who are facing a life threatening disease and their loved ones on their journey through 'het tussenland' that can be integrated in the palliative care within a hospice***

## Feasibility

How can a product and/or service guide the patient and their loved ones through 'het tussenland'



- What products/services have already been delivered in this guidance?
  - What different forms of therapy create meaning for the patients?
  - Which rituals and customs exists for the patients?
  - How has technology already been used in palliative care?
- What role could design play in the guidance to het tussenland?
  - What applications in VR, AR and MR already exist (in palliative care)?
  - What design thinking (models) already exists in the domain of sensitive topics like palliative care?

---

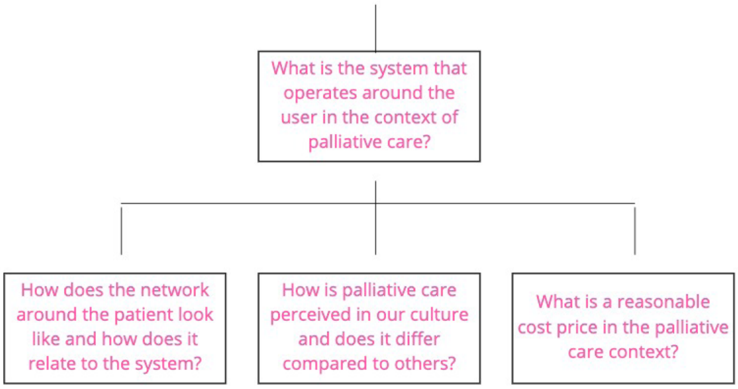
Exploration design toolkits

Peik Suyling,

Teun Aalbers, professor medesign

## Viability

### What does a culture, where palliative care and hospices are more imbedded in society, look like?



What is the system that operates around the user in the context of palliative care?

How does the network around the patient look like and how does it relate to the system?

How is palliative care perceived in our culture and does it differ compared to others?

What is a reasonable cost price in the palliative care context?

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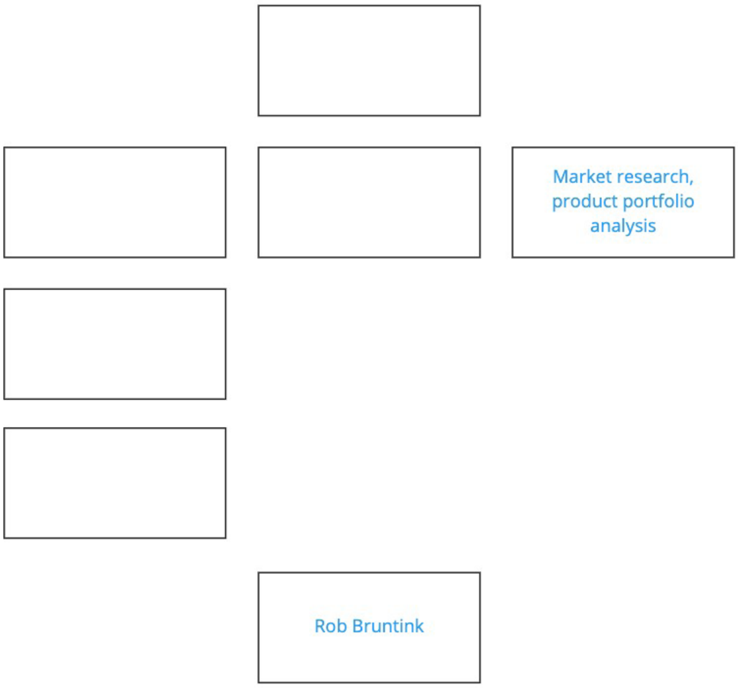


Market research, product portfolio analysis

Rob Bruntink

## APPENDIX B

# INTERVIEW GUIDE

*Eerst ben ik toch benieuwd wie jij bent, Cecilia. Dus zou ik je nogmaals willen vragen om jezelf te introduceren. Wie ben jij verder en hoe sta jij in het leven? Hoe zou jij jezelf en je karakter omschrijven?*

**Diagnose**

1. Op moment dat je de diagnose kreeg van een ongeneeslijke ziekte, Wat gebeurde er allemaal met je? Hoe was die overgang voor jou?(lege patient customer journey)
2. Hoe ervaarde jij die activiteiten?
3. Wat gaf je steun/energie op dit moment? Wat hielp juist helemaal niet?
4. Deze gebeurtenissen die je net beschreef, dus het moment dat je de diagnose hoorde, zou jij dat kunnen beschrijven in vorm van een metafoor? Dus waar doet het je aan denken? Hebben jij en je gezin of vrienden hier soms jullie eigen terminologie voor? Hebben jullie hier een codewoord voor? (voorbeeld met de zwarte hond) Doet het je misschien denken aan een boek, of een film die je ooit heb gezien? Of aan een of andere situatie?

**In het Tussenland**

5. Nadat je de diagnose kreeg, wat gebeurde er allemaal met je? Wat voor activiteiten speelden toen een rol in jouw leven? Wat was de gang van zaken?
6. Hoe ervaarde jij die activiteiten?
7. Wat gaf je steun/energie op dit moment? Wat hielp juist helemaal niet?
8. Deze gebeurtenissen die je net beschreef, dus de periode vanaf dat je de diagnose hoorde, zou jij dat kunnen beschrijven in vorm van een metafoor? Dus waar doet het je aan denken? Hebben jij en je gezin of vrienden hier soms jullie eigen terminologie voor? Hebben jullie hier een codewoord voor? (voorbeeld met de zwarte hond) Doet het je misschien denken aan een boek, of een film die je ooit heb gezien? Of aan een of andere situatie?

   **eigen interpretatie van het tussenland laten zien**
   **praten over de patient journey map**

9. Wat zijn waarden in *metafoor* die van jou van belang zijn?

10. Een waarde die vaak te vinden is in het tussenland, is hoop? Wat betekent hoop voor jou? Of in ieder geval waar hoop je op? Is die hoop ook veranderd?
11. Op wat voor vlakken heeft het jouw leven veranderd? Hoe is jouw rol veranderd in jouw leven? In de maatschappij, als persoon, als gezinslid. Werk, gezinssituatie, financieel, sociale behoefte, fysiek? En hoe is de rol veranderd voor jouw naasten?
12. Voor iedereen betekent het tussenland ook dat je je moet aanpassen: dus adaptatie. Dit kan je vanuit verschillende perspectieven bekijken. Je zou het kunnen bekijken van een kant dat je minder dingen mag doen. Maar ik zie ook juist een kant bij veel mensen waarbij het nieuwe paden opent voor ze. Hoe ligt dat bij jou?
13. Hoe zou jij je zinsgeving beschrijven in het dagelijks leven?
14. Wat ik zie is dat verbondenheid en liefde 1 van de sterkste dingen is dat leeft in het tussenland, wat levenskracht bevordert en de wil om te leven. Waarbij het verzorgen

van een nalatenschap van belangrijke waarde kan zijn. Geldt dit ook voor jou, en hoe ben jij hiermee bezig? (in nalatenschap met betrekking van mijn gezin)

15. Wie zijn de mensen die jou hebben gemaakt tot wie je nu bent? Wie hebben zo’n stempel op jou gedrukt dat ze een (on)zichtbaar deel van jou zijn? Kan je meer vertellen over deze bijzondere interacties?
16. Welke vormen van zorg heb je ontvangen, hoe was je ervaring met deze zorgverleners? Individueel, samen met familieleden? Vrienden?

Hoe zou het ideale tussenland er voor jou eruit zien? Hoe wil jij worden gezien, en wat zijn jouw behoeftes hier binnen?

APPENDIX C

# INTERVIEW RESULTS

## TUSSENLANDERS

### Key findings

***Jannie | 60 y/o | writer, wife and mother, and tussenlander living with breastcancer***

The participants explained the diagnosis completely disrupted their lives, where it felt that they lost the grip in their lives. There was an urgent need for palliative care in the first phase after the diagnosis.

*'In het begin is het beangstigend. Je wordt gekatapulteerd, als je van de ene op de andere dag de diagnose krijgt. Je bent je lichaam, je levensperspectief, je gezinssituatie, je maatschappelijke positie en ook vaak in je materiele omstandigheden iets kwijt'*

The participant explained that it feels like an earthquake when she got the diagnosis, a state where you are not able to think clearly. On top of that, for tussenlanders it felt like an information overload after they receive the diagnosis, while at the same time a lot changes for them. This enormeous amount of information of treatments, therapies, literature etc. can be experienced as overwhelming for the tussenlander. One tussenlander explained how a specialised nurse took charge of this and acted like a sort of case manager:

*'Een gespecialiseerde verpleegkundige heeft het roer overgenomen voor alle behandelingen. Dat heeft ze achter de schermen gedaan, en ik heb dat enorm gewaardeerd. Ik was daar zelf niet toe in staat'. Zij heeft gewoon voor comfort gezorgd zodat ik kon herstellen en daarna verder kon gaan'*

The participant explains how this nurse guided her in her darkest moments, so that she could heal to eventually go on and make the decisions herself.

The need that was still missing in daily practice was an unwavering form of attention. There is a need for a genuine and constant form of attention, that goes deeper than simple formality question.

*"Ik vind het moeilijk dat mensen je geen aandacht geven in de zin van, hoe gaat het met je en je ziekte, waar denk je aan wat houdt je bezig? Meestal is het een aandacht in de vorm van bezorgdheid."*

***DvD | 53 y/o | project manager, husband and father, and tussenlander with the disease of Kahler.***

One of the insights of the tussenlanders was how it changed his position as a person in society. Where in the past, he would be described as a succesful businessman, devoted father and husband and the breadwinner, he felt deprived of these labels. The only thing that was left, was a patient that only caused suffering for his surroundings.

*"het was op twee fronten oorlog voeren. ik moest mijn positie verdedigen als persoon, maar ik moest ook overleven in belang voor mijn gezin"*

*"Ik moest mijn plek binnen het gezin afstaan. 6 jaar lang. omdat je alleen maar aan het vechten bent tegen die verdomde ziekte"*

An experience that really left an impact for the tussenlander at a smaller hospital was the following. At this hospital they address him with his first name and not as a patient. It is already this small detail that can change an experience completely.

The topic that ran like a thread in this interview was the will to live, how this was endorsed by to improve the quality of life for his loved ones:

*“Het is mijn laatste taak om ze goed achter te laten.”*

The love for his family was so strong, like a fire inside of him that keeps burning, keeps making memories together.

*“Liefde is zo sterk, niks is te veel”*

For the tussenlander this disease also opened new doors. It gave him more insights on the priorities in life and also enabled him more space and time for new hobbies.

As the disease also created beautiful moments, one must not forget to be realistic: there is something in your body that is slowly destroying parts of your body. This must be taken into consideration when you shape and plan your life.

*“Mijn langste planning scoping is 3 maanden. Op basis daarvan maak ik de plannen. Want ik ben al een keer teleurgesteld dat het weer enorm terugkwam. Toen kon mijn hele planning in de prullenbak”*

***Cecilia | 59 y/o | wife and mother, and tussenlander with breast cancer***

One of the tussenlanders emphasized on the great support of lotgenotencontact:

*“Het fijne aan lotgenotencontact is dat je niet iedere keer dingen hoeft uit te leggen, iedereen begrijpt het wel hoe je je voelt, de vervelende en mooie dingen. Je leert ook heel veel van andere over alle behandelingen die nog mogelijk zijn”*

The tussenlander explained how in the years as a person you learn how to deal with this new lifestyle, and even reach a point that some moments the disease moves to the background. But this is in contrast with the beginning:

*“Heleboel dingen zijn langs me heen gegaan in die periode. iK zat vaak als een dood vogeltje in de stoel natuurlijk.”*

An experience that really helped the tussenlander was at the Helen Downing center where the tussenlander and her husband went to together. Tensions in the household ran high, and even though both parties felt the same emotions, they were never discussed out loud. A session at the Helen Downing center showed them how important it was to always speak your mind:

*“Ze vroegen bijvoorbeeld aan hem: ben je bang om je vrouw te verliezen. Ja zei hij. Kijk we weten het van elkaar, om dit echt uit te spreken, is wel echt confronterend. Tuurlijk weet je het van elkaar dat je bang bent om elkaar te verliezen, maar als je het ook echt hoort, dat komt wel aan.”*

***Lubbert | 78 y/o | widow, and tussenlander with disease of Waldenstrom***

The tussenlander indicated that in current practice, alternative treatments are inferior to medical treatments. While, a lot of his symptoms and complaints could not be tackled and addressed by the medical circuit. Therefore, there is a need for a more complete range op treatments.

What was remarkable in this interview, was his positive and optimistic view, in these dark times. He explained that he followed the ITIP, an educational institute that focuses on topics like, self knowledge, vigor and the trust to make decisions that correspond to your deepest self. This experience enabled him to have more time and space to focus on himself.

*“De ITIP opleiding hielp bij overgang. Nu voel ik me zoveel vrijer mede door die ITIP opleiding.*

*Dit is mijn ultieme vrijheid."*

***Minnie | 70 y/o | Tussenlander***

Minnie's mindset was focused on openness. But by addressing the diagnosis by its name, for her it deprived her of hope and openness in het tussenland. That is why in this interview, topics like the diagnosis and death are initially avoided, but not completely out of our minds.

Minnie explained that there are a lot of needs in het tussenland that are not always answered. But a lot of these needs are answered in the hospice she stays. These needs are as followed:

- Minnie wants to be seen as a person and not as a patient. She noted that she felt seen in the hospice as who she was, but that in her daily life it was still missing.
- In the hospice she found the time and space to focus on herself
- The moment she entered the hospice, important objects from her own home were transported. The hospice room was personalized and felt more comfortable.
- The need for continuous and genuine attention
- A place where time does not exist.

An experience that really supported her was her little sister that really guided and supported her in the beginning. During the diagnosis she felt numb and gobsmacked and was not able to continue by herself.

**Conclusion**

- The tussenlander wants to be seen as a person and not as a patient
- The diagnosis is a vulnerable and crucial moment, where the tussenlander needs support.
- The tussenlander can feel overwhelmed by the enormeous but not complete collection of information. This influences their decisionmaking but also their mental and physical health.
- The tussenlander is in need for a figure of guidance that organizes and guides them in het tussenland
- The connections with loved ones and lotgenoten contributes to the will of life
- The disease has a huge impact on the daily lives of a tussenlander in terms of social position.
- Living in the tussenland is learning to live with adjustments and a new shape of life (planning wise)
- By creating more space and time for yourself, it can lead to more resillience in terms of the new life in het tussenland.

## LOVED ONES

### Key findings

***S. | 28 y/o | son of a patient with the disease of Waldenstrom***

< How my and my dad's worlds collided

"*Je hebt de wereld van mijn leven, maar dan is er ook de wereld van mijn vader. De eigenschappen van die werelden zijn zo verschillend dat ze moeilijk te verenigen zijn. Mijn wereld is heel erg op het nu en vooral op de toekomst gericht en heeft een bepaald tempo en urgentie, een bepaalde frequente van interacties met andere mensen. En zijn wereld, hij heeft gewoon geen toekomstperspectief."*

< How music brings me back into the moment

" *Dus er zijn nog een paar muzieknummers als ik die hoor, dan ga ik meteen janken. Merk het nu zelfs als ik daar over die tijd denk. Toen we met z'n vieren samen waren en dan in de auto naar David Sammy Junior of Dire straits* *luisterden"*

< You only have the past left, but no space for creating new things

"*Sommige dingen zijn altijd, horen altijd bij het verleden. Maar als iemand ziek wordt en doodgaat, dan is eigenlijk, blijft alleen dat verleden over, dan kan er geen nieuwe dingen meer bijgemaakt worden. Dat is waar ik mee zit."*

< My own needs faded into the background

"*Wat er snel gebeurt, is dat iemand die heel ziek is, die wordt een soort van zon in dit zonnestelsel waar alles om heen draait.*
*Ik merkte wel in dat proces dat mijn eigen behoeftes naar de achtergrond verdwenen"*

< Using painting as a means of communication

" *Ik denk dat het een manier is om verbintenis te zoeken. Het is een manier van communicatie zou ik bijna willen zeggen.Ik kon bepaalde dingen niet uitdrukken met woorden hoe meestal mensen dat doen. Ik had daar een andere uitdrukkingsvorm voor gevonden".*

< One of the most beautiful special moments -> in chaos, complete harmony

" *Ik heb heel duidelijke moment voor ogen. Dat is van vorig jaar, mijn moeder was even boodschappen doen. En ik ging met mijn vader en mijn broertje iets te eten maken.*
*We waren met zijn drieën in de keuken en mijn vader was echt iets debiels aan het doen. Dus mijn ouders, die hebben een stoomoven en dan heb je van die schaaltjes waar het vocht in landt en daar hadden we dan bieten in. En hij moest van de ene kant van de keuken, naar de andere kant van de keuken het bietenvocht in de wasbak doen. Heel veel dingen kan hij niet zo heel goed meer, dus het bietensap ging alle kanten op en toen moesten we vet hard lachen. We waren met z'n drieen en niemand was echt sad of aan het denken aan de ziekte, er was geen ruzie, het was gewoon als vanouds.*

*En wat er heel mooi aan is was waar we het eerder over hadden. Dat er dus niet zo veel nieuws meer kan worden gecreerd, want het eindigt zo snel. Dit was eigenlijk een blik in de toekomst bijna. Het was heel harmonieus.*

< Medical failures that were made in the process

< Hospital and the doctors play an enormous part in your life when you are this sick

*"D'r spelen allerlei interpersoonlijke interacties dus hè? Ik heb een interactie met mijn vader in mijn gezin. Maar hij heeft ook een interactie met de apotheker of met de doktersassistent of met de dokter en die wordt geïnformeerd door zijn achtergrond en de achtergrond van de dokter. En als dat niet helemaal lekker gaat. Dan gaat die interactie niet lekker en vervolgens gaat de behandeling ook niet goed.'*

< How longer the period, how bigger the chance that things shift on the care side or the family side

< The ideal in-between land

*"Meer een gevoel van gemeenschap.*
*Want wij leven In het tijdperk van ongelofelijke verkokering en individualisering en afstand tussen mensen dan voel je dat extra veel.*
*Dan komt het bijvoorbeeld helemaal neer op mijn moeder en dan deels ook op mijn broertje. En die zorg, dat is een soort van ding in de verte, die af en toe een pot pillen over de schutting gooit. En veel mensen durven niet te bellen, want dat vinden ze eng*

*Ja dus toch in dit ideale tussenland heb je toch een soort gemeenschap, en dan zie.*
*Ik dat voor me als een soort van binnenplaats die soms zelfs open is naar de straat toe. Ja, omheen heb je dan een gebouw met balkons, zoals de Jordaan vroeger.*
*Die functie van dat verbindende weefsel of het nou architectuur is of dat het mensen zijn. Ik merk dat ik dat heel erg mis in het tussenland en in het dagelijks leven. Als alles goed gaat, maakt niet uit, want dan ga je gewoon naar je werk en dan heb je niemand nodig, maar als het niet goed gaat, dan heb je ineens heel veel mensen nodig, en die zijn er niet. "*

***Myron | 24 y/o | son of a deceased tussenlander***

One of the insights was that in these dark times there was a need for timelessness. The feeling of being together in the woods:

*"Dus een soort vacuüm in dat tussenland. Dat je de ruimte hebt om alles even te laten vallen om alles uit die tijd te halen en niet zozeer dat je ineens 1000 dingen moet gaan plannen. Maar al is het, je gaat gewoon alleen maar series kijken met elkaar, maar dat er een cultuur heerst waarin waar je een tijd niet bestaat"*

There is a need for a place and a moment where one cannot do anything else than feeling. ('op dat moment niks anders dan voelen").

***Maude | 25 y/o | Daughter of a tussenlander with Multiple Sclerose***

The loved one indicated that the definition of comfort can differ for the tussenlander and the loved one.

*"Ik denk dat er niks zo erg is in een familie om te zien dat het niet goed gaat. Maar soms als diegene achteruit gaat, is het beter voor diegene"*

Seeiing someone's physical and mental functions detoriate can be life-breaking for the loved ones, but for the tussenlander her mind was more at peace and she seemed less unhappy. This example shows how sometimes the hardest changes does not immediately imply a negative outcome for the tussenlander.

**Conclusion**

- Music is a means of connection and reliving precious memories
- The worlds of a tussenlander and a loved one collide, because in one world the perspective of a future is missing
- The needs of a loved one can easily fade to the background
- There is a need for a place where time does not exist, where you can simply only feel
- The right decision for the tussenlander, may not always feel as the right decision for the bystanders.

### 3.2.3 CARE PROFESSIONALS

#### Key findings

***Nettie | Specialized oncology social worker***

The interview with Nettie really showed beautiful examples of good practices in the world of palliative care. These practices are more elaborated in figure FIXME.

The main insights from all these experiences are as following. As a non-tussenlander you must always concur with the tussenlander wishes and needs.

*' Sluit je altijd aan waar de persoon is. Dit is hun reis, niet mijn reis. Je moet luisteren met elke vezel in je en je moet alle zintuigen gebruiken die je hebt. Je moet egoloos zijn"*

This also means that you cannot deprive a tussenlander of its hope when they are not ready for it yet. Therefore, the tone of voice and the manner of breaking the news, really matters.
Moreover, the power of meeting other people, is something that is very valuable for tussenlanders. It can be a outlet where they can share their feelings but als an environment where they can simply enjoy their lives together.
Lastly, being surrounded by things from their own home that they are familiar with really helps them to feel at ease in medical areas.

***Susan | Oncology patient consulent***
xxxxx

**Conclusion**
xxxxx

### 3.2.4 EXPERTS

**Goal**
The goal is to obtain experiences and practices of palliative care in our society by different types of experts. Therefore the interviews gain insight in the following topics

- The perception of palliative care in our culture
- Forms of therapy and digital applications in palliative care

**Method**
The three participants that were recruited all have a different expertise, therefore the interview research questions differ from each other. One participant is an expert on palliative care in our society. The following research questions were asked to achieve the research goals:

- What is so typical about the palliative care in the Dutch culture?
- How is the quality of life and quality of death perceived?

Two participants both an expertise in a certain type of treatment. The following research questions were asked to achieve the research goals:

- What is the therapy/treatment about?
- In what way does this therapy/treatment support the tussenlander?

Every interview was concluded with the following question:

- How does the ideal tussenland look like for you?

The interview were held online on zoom due to the COVID measures.
The interviews were recorded and transcribed. The insights of these interviews are included in the database (Airtable) that will be used for the data processing in chapter 4.

**Key findings**

***Rob Bruntink | Writer and expert palliative care***

One of the main insights was that Rob perceived the palliative care in the Dutch culture als fragmented. Many organisations exist parallel from each other. Thus, there is no central place for people to go to. Moreover, every type of organisation is more directed internally. A country we could learn a lot from is Ireland, where the Irish Hospice Association already is mobilising and including the society in their organisation. And that is exactly what needs to happen in the Netherlands.

**“***Sterven is een sociaal gebeuren. Heel concreet gezien zijn zorgverleners hooguit 5% van de tijd in nabijheid van de patient en 95% van de tijd zijn die patienten alleen of hebben ze hun partner, kinderen, ouders of andere mensen om zich heen.”*

***Peik Suyling | Social designer and owner 'alswoordenbloemenworden'***

Peik started the therapy 'alswoordenbloemenworden', where tussenlanders paint different types of flowers in complete silence. The combination of flowers and the silence was something that really worked in this therapy.

*"bloemen zijn een expressie van levenskracht en vergankelijkheid. Van hoop en herinnering"*

For this therapy, silence really was a requirement for it to work.

*"in stilte een nieuwe werkelijkheid creeren, Je creeert samen een bubbel die je kan delen met een nieuwe werkelijkheid"*

***Teun Aalbers | Game designer of the 'wijsheidscoach'***

The experiences of Teun corresponded with the experiences of Rob Bruntink. During the developement of the 'wijsheidscoach', he experienced how fragmented the palliative care in the Netherlands is. According to him, this was also reinforced by the complexity of the big group of people who enter palliative care.

*"Groepen zitten in verschillende stadia en stadia van acceptatie"*

Thus, Teun dreams of an open and accesible system:

*'Systeem waarin zo min mogelijk poespas en intakeachtige dingen kunt identificeren. Zodat je de optimale route komt zodat mensen met het juiste onderwerp in aanraking komen. En daar moet dan een overkoepelende visuele metafoor voor ontwikkeld worden die eigenlijk vanuit een soort van zelflerend systeem onderwerpen omhoog brengt en vragen, liedjes of herinneringen die een intern dialoog of gesprek faciliteert tussen naasten, familie of eventueel medische professionals. Ook dat mensen op de hoogte houdt van je leven, dat je als mantelzorger kan checken in de app van hoe hangt de vlag er op dit moment. Of is papa verdrietig wakker geworden of heeft hij een goede dag. En op een gegeven moment dat als iemand komt te overlijden, dan moet het hele systeem op de een of andere manier uitgepoept worden als een soort van digitale, fysieke nalatenschap van die persoon.'*

Teun noted an important insight regarding the use of VR.

*"Het gaat om het leren met de pijn dealen als de VR bril afgaat. Want als je de bril afzet, dan heb je weer de ramp van terugkomst van pijn. "*

Therefore, the goal with VR is not only to decrease the pain whenever the tussenlander uses it, but the use of VR must also ensure that the tussenlander has a better quality of life whenever they remove the VR glasses.

**Conclusion**

- Palliative care in the Netherlands is too fragmented. A central place is needed that is embedded in our society
- Dying is a social happening
- The use of silence can enable the creation of a new reality
- Within the group of tussenlanders, everyone can be in a different stadia
- With the use of VR, we must also foresee what the influence of the use will be, whenever the tussenlander leaves the "digital world" and enters the physical world again.

APPENDIX D

# QUOTE TRANSLATIONS

***'In het begin is het beangstigend. Je wordt gekatapulteerd, als je van de ene op de andere dag de diagnose krijgt. Je bent je lichaam, je levensperspectief, je gezinssituatie, je maatschappelijke positie en ook vaak in je materiele omstandigheden iets kwijt'***
*In the beginning it is frightening. When you get the diagnosis it feels like you are being catapulted. You have lost your body, your perspective on life, your family situation, your societal position and often also material things.*

***"Heleboel dingen zijn langs me heen gegaan in die periode. Ik zat vaak als een dood vogeltje in de stoel natuurlijk."***
*A lot of things passed me by in that period. I sat often in that chair like a dead bird.*

***"Ik ben helemaal vergeten wat er gebeurde. Er gebeurde zoveel, maar ik kon dat niet allemaal goed op een rijtje zetten. Ik was een soort van verdoofd"***
*I totally forgot what had happened. So much happened, but I could not figure it all out. I felt numb.*

***'Een gespecialiseerde verpleegkundige heeft het roer overgenomen voor alle behandelingen. Dat heeft ze achter de schermen gedaan, en ik heb dat enorm gewaardeerd. Ik was daar zelf niet toe in staat'. Zij heeft gewoon voor comfort gezorgd zodat ik kon herstellen en daarna verder kon gaan'***
*A specialised nurse took charge over all the treatments. She did that behind the scenes, and I really appreciated that. I simply was not in the state to do it myself. She provided the comfort for me to heal and to go on.*

***"Ik vind het moeilijk dat mensen je geen aandacht geven in de zin van, hoe gaat het met je en je ziekte, waar denk je aan wat houdt je bezig? Meestal is het een aandacht in de vorm van bezorgdheid."***
*I find it hard that people won't give you attention in the sense of, how are you and how is the disease, what are you thinking of? Often it is attention in the form of concern.*

***"Dat mensen bij me blijven komen. Niet dat op een gegeven moment als het heel lang gaat duren dat de aandacht verslapt. Want ik heb toch heel erg de mensen nodig, ik ben namelijk veel op mezelf, en ik kan dat makkelijker als ik weet dat er anderen voor mij zijn. Dat vind ik heel belangrijk. Dat ik altijd de ruimte en vrijheid kan blijven voelen. Bij mezelf en ook bij de mensen om me heen"***
*That people keep coming. Not that at a certain moment when it takes too long the attention will disappear. Because I need people around me. I always keep to myself, and I can do that with the notion that there are people there for me. That is what I find important. That i can always feel the space and the freedom, with myself and also with the people around me.*

***"het was op twee fronten oorlog voeren. ik moest mijn positie verdedigen als persoon, maar ik moest ook overleven in belang voor mijn gezin"***
*It was like a two front war. I had to defend my position as a person, but I also had to survive for the sake of my family.*

***"Ik moest mijn plek binnen het gezin afstaan. 6 jaar lang. omdat je alleen maar aan het vechten bent tegen die verdomde ziekte"***
*I had to give my position in the family for six years, because you only have to fight against the bloody disease.*

***"Het is mijn laatste taak om ze goed achter te laten."***
*It is my last duty to ensure that they are left behind well cared for.*

***"Liefde is zo sterk, niks is te veel"***
*Love is so strong, nothing is too much*

***"Mijn langste planning scoping is 3 maanden.***

***Op basis daarvan maak ik de plannen. Want ik ben al een keer teleurgesteld dat het weer enorm terugkwam. Toen kon mijn hele planning in de prullenbak"***
*My longest scoping is three months. Based on that I make my plans. Because I already have been disappointed when it returned. I could throw my whole planning in the bin.*

***"Het fijne aan lotgenotencontact is dat je niet iedere keer dingen hoeft uit te leggen, iedereen begrijpt het wel hoe je je voelt, de vervelende en mooie dingen. Je leert ook heel veel van andere over alle behandelingen die nog mogelijk zijn"***
*The nice thing about "contact with people in similar situations" is that you don't have to explain everything the whole time. Everyone understand how you feel, the annoying and the beautiful parts. You also learn a lot from others about all the treatments that are possible.*

***"Ze vroegen bijvoorbeeld aan hem: ben je bang om je vrouw te verliezen. Ja zei hij. Kijk we weten het van elkaar, om dit echt uit te spreken, is wel echt confronterend. Tuurlijk weet je het van elkaar dat je bang bent om elkaar te verliezen, maar als je het ook echt hoort, dat komt wel aan."***
*They asked him: are you afraid of losing your wife. He said yes. Look, we know it from each other, but to really say it out loud, was really confronting. Of course you know from each other that you are scared to lose each other, but if you hear it out loud, then it really lands.*

***"Je hebt de wereld van mijn leven, maar dan is er ook de wereld van mijn vader. De eigenschappen van die werelden zijn zo verschillend dat ze moeilijk te verenigen zijn. Mijn wereld is heel erg op het nu en vooral op de toekomst gericht en heeft een bepaald tempo en urgentie, een bepaalde frequente van interacties met andere mensen. En zijn wereld, hij heeft gewoon geen toekomstperspectief."***
*You have the world of my life, but then there is also the world of my father. And the characteristics of these worlds are so different that it is difficult to unite them. My world is focused on the now and the futue and has a certain pace and urgence, a certain frequent interaction with other people. And his world, it has no future perspective.*

***"Sommige dingen zijn altijd, horen altijd bij het verleden. Maar als iemand ziek wordt en doodgaat, dan blijft alleen dat verleden over, dan kan er geen nieuwe dingen meer bijgemaakt worden. Dat is waar ik mee zit."***
*Some things are forever,always belong to the past. But when someone is sick and dies, then only the past is left. There is no possibility to create something new, that really bugs me.*

***" Ik denk dat het een manier is om verbintenis te zoeken. Het is een manier van communicatie zou ik bijna willen zeggen. Ik kon bepaalde dingen niet uitdrukken met woorden hoe meestal mensen dat doen. Ik had daar een andere uitdrukkingsvorm voor gevonden".***
*I think it is a way to find connection. It is almost a way of communication. I could not express certain things that people would express in words. I found a different form to express that.*

***"Ik merk dat ik dat heel erg het gevoel van gemeenschap mis in het tussenland en in het dagelijks leven. Als alles goed gaat, maakt niet uit, want dan ga je gewoon naar je werk en dan heb je niemand nodig, maar als het niet goed gaat, dan heb je ineens heel veel mensen nodig, en die zijn er niet"***
*I notice that the feeling of community really misses in the in-between-land and in daily life. When everything goes well, it doesn't matter, because then you just go to your work and you don't need anybody. But when your life doesn't work out, then suddenly you need a lot of people, but they are not there.*

***“Dus een soort vacuüm in dat tussenland. Dat je de ruimte hebt om alles even te laten vallen om alles uit die tijd te halen en niet zozeer dat je ineens 1000 dingen moet gaan plannen. Maar al is het, je gaat gewoon alleen maar series kijken met elkaar, dat er een cultuur heerst waarin waar tijd niet bestaat”***
*A sort of vacuum in the in-between-land. That you have the space to drop everything and to make the best of your time, and that you do not need to plan 1000 things. Even if it is just watching a series together, that there exists a culture where time does not exist.*

***“Ik denk dat er niks zo erg is in een familie om te zien dat het niet goed gaat. Maar soms als diegene achteruit gaat, is het beter voor diegene”***
*I think that nothing is as bad in a family to see that it isn’t going well. But sometimes for the only who is detoriating, it is actually better.*

***“Wat er snel gebeurt, is dat iemand die heel ziek is, die wordt een soort van zon in dit zonnestelsel waar alles om heen draait. Ik merkte wel in dat proces dat mijn eigen behoeftes naar de achtergrond verdwenen”***
*What often happens, is that someone who is really sick, becomes some kind of sun in the solar system where everything revolves around. I noticed that my own needs faded in the background during the process.*

***‘ Sluit je altijd aan waar de persoon is. Dit is hun reis, niet mijn reis. Je moet luisteren met elke vezel in je en je moet alle zintuigen gebruiken die je hebt. Je moet egoloos zijn”***
*Always allign to where that person it at that moment. This is their journey, not my journey. You have to listen with your whole being, and use all the senses you have. You have to be egoless.*

***“Sterven is een sociaal gebeuren. Heel concreet gezien zijn zorgverleners hooguit 5% van de tijd in nabijheid van de patient en 95% van de tijd zijn die patienten alleen of hebben ze hun partner, kinderen, ouders of andere mensen om zich heen.”***
*Dying is a social happening. Concretely, care professionals are only 5% of the time in the proximity of the patient, and 95% these patient are alone, or surrounded by their partner, children, parents or other people.*

***“Groepen zitten in verschillende stadia en stadia van acceptatie”***
*Groups are in different stadia and in different stadia of acceptance.*

***“Het gaat om het leren met de pijn dealen als de VR bril afgaat. Want als je de bril afzet, dan heb je weer de ramp van terugkomst van pijn.***
*It is about learning to deal with the pain when you take off the VR glasses. Because when you take of the glasses, the disaster of the return of the pain happens.*

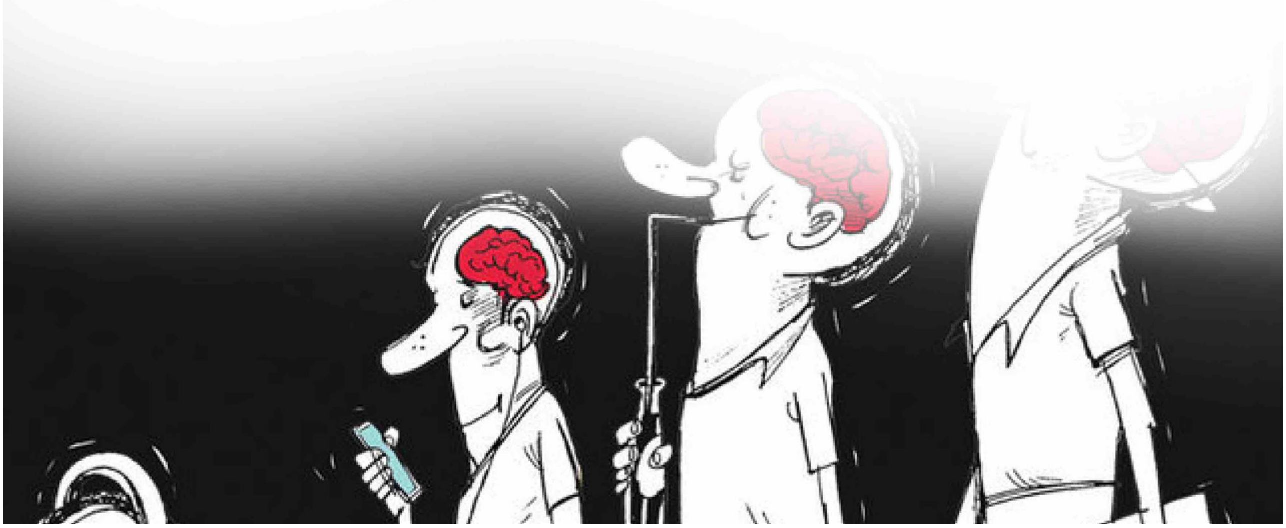
***“bloemen zijn een expressie van levenskracht en vergankelijkheid. Van hoop en herinnering”***
*Flowers are an expression of power of life and transience. Of hope and memory.*

***“in stilte een nieuwe werkelijkheid creeren, Je creeert samen een bubbel die je kan delen met een nieuwe werkelijkheid”***
*In silence you create a new reality. Together you create a bubble you can share with this new reality.*

## APPENDIX E

# METAPHORS

*"Officieel ben ik overleden op 2015, 21 april. Want dat is de eerste dag dat ik chemo kreeg. Het is de weg naar herstel. Maar de oude ik is overleden. Je praat nu met een verbeterde versie, want de 1.0 heeft het niet gered. Nu praat je met de 2.0 en daar zijn alle bugs eruit en die is wel stabiel. Eigenlijk is dit de beste versie van mezelf."*



*"De weg van diagnose naar dood is eigenlijk een soort kluwen. misschien is het 1 lijn, maar soms zitten daar knopen in. Soms ga je een bepaalde weg, dan wordt die knoop alleen maar strakker. Soms ga je een bepaalde weg op en dan lukt het je om de knoop losser te maken en hem misschien zelf nog uit elkaar te halen."*

*"Energie vergaat niet, ook al ga je dood. Ik geloof dat energie blijft bestaan. Een beetje zoals een herinnering. Het vergaat niet. Het blijft altijd bij je, ook al gaat het niet goed."*

*"Mijn vader hiled ontzettend veel van het bos. Het voelt als een soort wandeling waar langzaam takken en bladeren vallen, waar het drassig is, waar het een beetje kil is, maar tegelijkertijd ook fris en verhelderend. Er is op dat moment niks anders dan voelen. Je stapt heel bewust uit alles waar je mee bezig was. De buitenwereld is roerig, maar hier loop je ineens rustig en is het stil."*

*Het is net een hike (bergwandeling/wandeling). Je weet niet of je naar boven gaat of naar beneden, dus of het goed of slecht is. En soms is het zwaar maar je kan altijd wel iets moois vinden als een uitzicht of een plek, als je er open voor staat."*

*"Ik dacht dat ik nooit bang zou zijn voor de dood, maar op de een of andere manier werd ik heel onzeker alsof ik door een tunnel ging. Daar werd ik heel benauwd van en ik heb dat nooit gerealiseerd. Ik dacht het wordt mooi met het licht aan het eind van de tunnel. Maar nu dacht ik god. Ik kom in een smalle tunnel, en ik weet niet wat daarachter zit."*

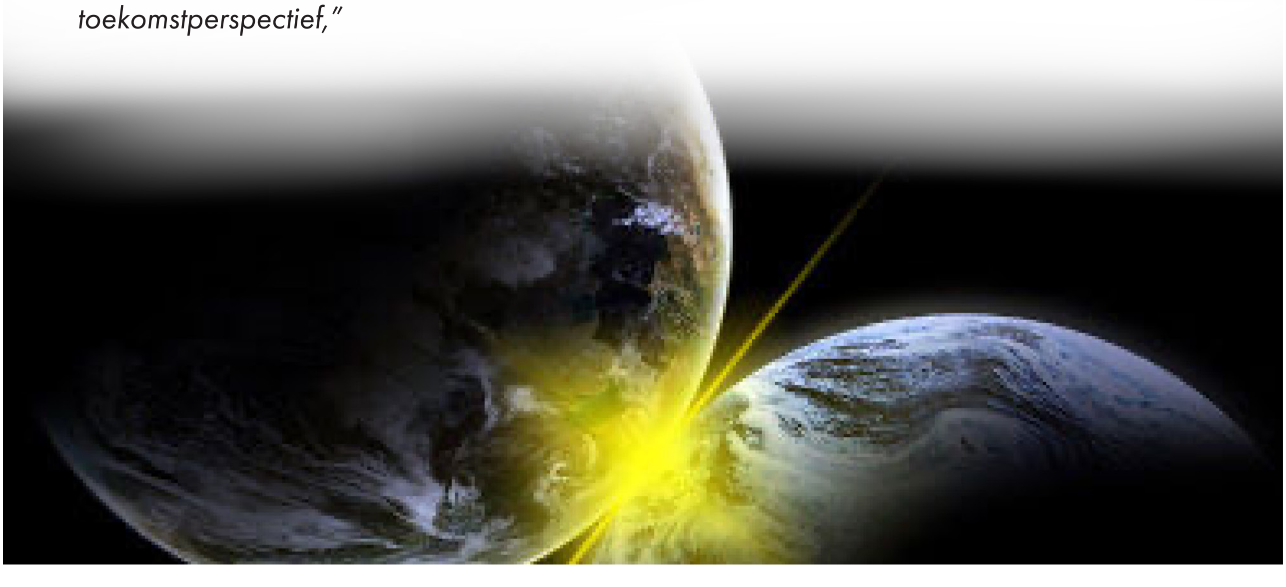
*Het is net een hike (bergwandeling/wandeling). Je weet niet of je naar boven gaat of naar beneden, dus of het goed of slecht is. En soms is het zwaar maar je kan altijd wel iets moois vinden als een uitzicht of een plek, als je er open voor staat."*

*" In het leven leeft iedereen in een speedboot, en in die speedboot kijkt iedereen voor zich uit en ga je snel. En als je de diagnose krijgt, dan stap je van die speedboot af, stap je in een roeboot en die roeiboot, die gaat heel langzaam en je kijkt de andere kant op. Je kijkt terug eigenlijk"*

*"Ik zie het nu als een kans. Ik geloof ook wel in vorige levens waarbij dit leven wat intensiever is. Maar dan ben ik nu wel ene stukje verder als ik straks een nieuw leven moet beginnen"*

*"Je moet je emoties zien als een groot vat, met angst, verdriet, boosheid en blijheid allemaal in dat vat. Maar als dat vat te vol zit, en dan explodeert het. En dat vat zat toen ook vol met verdriet, daardoor kwam het als boosheid naar buiten.Dus je moet je moet je emoties uiten en niet in je houden."*

*"Het gaat erover dat je allerlei werelden hebt. Je hebt bijvoorbeeld de wereld van mijn leven. Maar dan is er ook de wereld van mijn vader die door de pandemie helemaal in isolatie is gebracht. Als ik naar mijn ouders ga, dan clashen die werelden soms een beetje. Soms stapt hij in mijn wereld, en wordt hij heel moe en dat is moeilijk. Soms stap ik in zijn wereld, maar is het moeilijk want dan raak ik afgeleid of is het ook heel confronterend. De eigenschappen van die werelden zijn zo verschillend dat ze moeilijk te verenigen zijn. Mijn wereld is heel erg op het nu en vooral op de toekomst gericht en heeft een bepaalde urgentie, een bepaald tempo en een bepaalde frequentie van interactie met andere wereld. En zijn wereld: Hij heeft gewoon geen toekomstperspectief,"*



*"Ik vergelijk het met op reis zijn. Dat je oude leven op een moment stil staat en er niet meer toe doet. Als je 3 maanden ergens naar toe bent, dan maak je je niet druk over dat je belastingsaangifte moet doen of dat je naar de tandarts moet. Het is niet perse een zorgeloos bestaan, maar je hebt eigenlijk 1 ding waar je je op focust. Dus het was eigenlijk ook erg simpel. Het is een soort van op reis gaan met een klein gezelschap, waarbij je dicht naar elkaar toe groeit en heel sterk op elkaar aangewezen bent, een soort parallele realiteit waar de alledaagse beslommeringen niet relevant zijn."*

*"Ik zie de wereld echt als een sprookje voor me . Dat de wereld mooi is, dat het mooi weer blijft. Dat ik nog mooie dingen samen mag beleven, met familie, lotgenoten en vrienden. Maar dat er ook ruimte is voor mij in een holle boom alleen. En al is het een sprookje, ik blijf wel met beide benen op de grond."*

*"In het begin loop je in de mist. Je weet niet wat boven en onder is. Je merkt dat er allemaal mensen zijn die je overeind helpen wanner je valt, maar je ziet ze nog niet, je kent ze nog niet. En op een gegeven moment trekt de mist op. Dan zijn er dagen dat je de wonderbare schoonheid ontdekt: hoge bergen, diepe dalen, donderende watervallen . In niet-materiele woorden vind je liefde en heel veel aandacht."*

*"Het eerste wat me te binnenschoot was toch een bootje en de rivier Styx. Een bootje die ahterstevoren aan het peddelen is. Waarbij je voortdurend naar het deel van het leven kijkt dat al achter de rug is. De boot kan je alle kanten op laten gaan, naar voor, naar achter, links, rechts. Je kunt zelfs zinken. De ene boot kan snel. De ander kan hard. Je hebt roeispanen of een motor. Of je hebt ze in situaties waarin je aan alle elementen wordt blootgesteld. Dit kan in het twentekanaal zijn, maar je hebt ook allerlei zeeen met hoge golven. Dat typeert misschien ook het leven tussen diagnose en dood."*

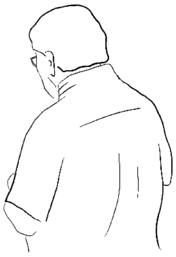
## APPENDIX F

# PATIENT JOURNEY MAP

## PATIEN

## TRANSITION

## LIFE AS A TUSSENLA

|  |  | *bad news conversation* | *meeting social worker* | *consider practical and social affairs* | *choose for palliative treatment or not* | *no treatment* | *undergoing palliat treatment* |
|---|---|---|---|---|---|---|---|
|  **TUSSENLANDER** | **experiences** | 'In het begin is het beangstigend. Je wordt gekatapulteerd, als je van de ene op de andere dag de diagnose krijgt. Je bent je lichaam, je levensperspectief, je gezinssituatie, je maatschappelijke positie en ook vaak in je materiele omstandigheden iets kwijt' | Tussenlanders worden vaak als patient behandeld en vaak gestript van de triviale dingen die hun leven juist ook invulling geeft (voorbeeld van de professor en de sigaret) | Naast de ziekte, valt er een hoop op de schouders van de tussenlander, waarbij het voelt dat de tussenlander zijn eigen positie moet verdedigen, wat fysiek en mentaal zwaar voor ze is. | Vanaf het moment dat een tussenlander ziek wordt, hebben ze vaak het gevoel dat ze minder autonomie en controle in hun leven hebben. | Er zijn tussenlanders die de keuze maken om geen behandeling te nemen. Dit kan ontzettend schuren aan de omgeving van de tussenlander. | Op een gegeven moment w de tussenlander ziekenhuis moe van hetzelfde traject w ze soms worden geconfront met de ziekheid van ande mensen om hun heen. |
|  | ***needs*** | Er is een behoefte aan houvast, aan een soort van casemanager; iemand die het roer in handen neemt. | De behoefte om jezelf te voelen, door triviale dingen zoals een sigaret op te steken zoals je gewoonlijk doet, en je niet gereduceerd te voelen tot een zieke die niks mag en kan. | De behoefte aan continue aandacht die niet verslapt, waarbij je niks hoeft uit te leggen | De behoefte om niet te gediscrimineerd te worden als zieke in de maatschappij. En om zelf ook wat keuzes te kunnen maken | De behoefte dat er naar hun geluisterd wordt, en dat hun keuzes worden gerespecteerd. Er is een behoefte naar iemand die hun begeleid die egoloos is, maar wel genoeg kennis heeft om ze te informeren wanneer dat nodig is. | De behoefte aan betekenis interacties in een medisc setting (zoals ziekenhuis), w ze niet alleen als patient wo gezien maar ook als perso |
|  **LOVED ONE** | **experiences** | Het moment dat een tussenlander de naaste het nieuws verteld voelt als een waas. Veel details zijn niet meer helder, maar de emoties van verdriet en ongeloof wel. |  | De ziekte van een tussenlander vraagt veel van de naasten. Een groot deel van de zorg voor de tussenlander komt neer op de naasten. |  |  | De naasten kunnen in de tij een tussenlander ziek is, v dokters zien komen en gaan doorwisselen van de zorg leiden tot fouten en misse |
|  | ***needs*** | Er is een behoefte voor de naaste om samen en dichtbij de tussenlander te zijn, zodat ze het verdriet samen kunnen delen. |  | Er is behoefte naar een gemeenschap die er hoe dan ook voor je klaar staat, die er niet alleen is wanneer het goed gaat, maar ook in de slechte tijden. |  |  | Er is behoefte naar constite goede zorg. Dat iemand dossier goed kent, en goed naar weet te handelen |
|  **CARE PROFESSIONAL** | **experiences** | Bij het slechtnieuwsgesprek is het wel eens voorgekomen dat alle hoop voor sommige tussenlanders werd ontnomen, door de manier waarop de arts het nieuws vertelde. |  | Elk gesprek is anders, elke persoon is anders en het beste wat je kan doen is gewoon goed luisteren en echt genuanceerde aandacht geven die ze, waar ze aan toe zijn ook. |  |  |  |
|  | ***needs*** | Er is behoefte naar een indicatie waardoor je als arts beter weet waar je patient aan toe is. Als arts heb je namelijk niet veel tijd om een casus voor te bereiden omdat er zoveel patienten onder je vallen. |  | Er is behoefte naar een goede verhouding tussen tussenlander en verzorger, het is namelijk intiem werk, maar je moet geen vriendin of moeder worden |  |  |  |
|  | ***opportunities*** | Guidance, connection and the right tone of voice after the diagnosis. | Let the tussenlander feel heard, and make them feel like themselves allowing them to do the trivial things that define their life. | Unwavered form of genuine attention, from people close to you but also from far away. | Give the tussenlander the choice to make their own decisions in life. | The design needs to be egoless itself, and always respect the decisions of the tussenlander | Create genuine connections interactions, where trust a respect are important |

# T JOURNEY MAP

## ANDER

## TOWARDS THE END OF LIFE

## AFTERCARE

| *ive* | *new adjustments in life style* | *initial decline* | *choose for home/hospice/ care home/hospital* | *final decline* | *stage of dying* | *end of life* | *bereavement care* |
|---|---|---|---|---|---|---|---|
| vordt moe, aarbij teerd ere | De tussenlander leert om voor zichzelf een bepaalde scoping en verwachtingspatroon te maken, omdat in het verleden wel eens teleurstellingen zijn voorgekomen. | Wanneer de gezondheid van de tussenlander verslechtert, valt het de tussenlanders ook zwaar dat het hun naasten veel verdriet doet. | Tussenlanders willen vaak niet tot last zijn tot hun sociale omgeving, dus hun vrienden en familie. Maar tegelijkertijd willen ze wel zelf dingen blijven kunnen doen. | Tussenlanders gaven aan dat hoezeer ze ook thuis zouden willen zijn, dat dit niet meer realistisch was als ze keken naar hun persoonlijke verzorging en kwaliteit van leven. | De ervaringen van tussenlanders die het einde naderen kunnen erg uiteenlopen. De een vond het meer beangstigend dan ze in eerste instantie dacht, terwijl de ander benieuwd was. | | |
| volle he aarbij orden oon. | De behoefte aan het maken van nieuwe herinneringen, want dat zijn de dingen waar een tussenlander op terug kan vallen op het moment dat ze slecht nieuws krijgen. | Juist op de kwetsbare momenten is er behoefte om met elkaar om te gaan praten over een wil. | De behoefte om regie in handen hebben en niet volledig gestript te worden van alle keuzes die je gewoonlijk wel in je leven kan maken. | De behoefte om niet te veel aan je hoofd te hebben, en je te richten op jezelf. Om de dingen te blijven doen die je leuk vindt zover het nog kan. | De behoefte om dit proces niet helemaal alleen aan te gaan, maar met de steun van anderen. | | Zij vond het zo erg dat die kinderen hun vader niet kende. Maar er stond ook een hele grote kastanjeboom en we zaten zo te denken, zo van. En toen zei zij, hij was altijd aan het rapen, kastanjes aan het rapen met die met de kleintjes en toen zijn we op een gedenk bank gekomen In de achtertuin om die boom. |
| d dat veel n. Het kan ers. | De wereld van de tussenlander en naaste zijn moeilijk te verenigen voor de naaste, omdat de wereld van de tussenlander vaak een verre toekomstperspectief mist. | Het is soms ontzettend confronterend en moeilijk voor de naaste om het lijden van een ander te zien. | | “Mijn vader hield ontzettend van het bos, dus een van de laatste dingen die we samen hebben gedaan is naar het bos met zijn allen. ” | Het moment dat het sterven dichtbij komt, is voor veel naasten ook het moment dat het echt tot hun doordringt wat de situatie is: dat het einde bijna in zicht is | Het moment dat een tussenlander sterft, kan veel paniek en verdriet veroorzaken, omdat er zoveel geregeld moet worden. | Het rouwproces voor een naaste kan maanden tot meerdere jaren duren. Vaak wordt er van hun verwacht om leven op gegeven moment weer te ‘hervatten’, terwijl het jaren kan duren om het verlies te verwerken. |
| ntie in het l daar . | Er is behoefte naar een moment waar je toch samen iets nieuws kan creeren (waar de ziekte niet bestaat) | Er is behoefte dat er naar de naaste omgekeken wordt. Door de ziekte staat de tussenlander vaak in het middelpunt (niet gewild natuurlijk), en verdwijnt de naaste naar de achtergrond. | | Er is behoefte naar een gevoel van tijdloosheid. Dus een soort vacuüm in dat tussenland. Dat je de ruimte hebt om alles even te laten vallen om alles uit die tijd te halen. Dat er een cultuur heerst waar tijd niet bestaat. | Er is op het moment nabij het sterven de behoefte om de dingen uit te spreken die eerder nog niet uitgesproken zijn. Vaak komt deze behoefte best laat, of zelfs te laat. | Er is behoefte dat de naaste wordt begeleidt in dit proces, en dat er goed wordt gekeken wie er om haar heen staat. Zodat de naaste steun heeft tijdens dit proces. | Er is een behoefte om gehoord te worden, en dat iemand mee denkt in jouw rouwproces en je daarbij het een plekje kunt geven. |
| | | | Als je de tijd hebt om de situatie van een tussenlander tot je te nemen, kan je daar inzichten in vinden wat voor die tussenlander de juiste plek is om de laatste fase in te gaan. | | | | |
| | | | Er is behoefte naar inzicht in wat belangrijk is voor een patient, zodat je daar naar kan gedragen en je advies op kan aanpassen. | | | | |
| s and and | Enable people to create something (new) together. Creating more meaning for someone else, contributes to a more meaningful life for themselves | Some topics and conversations are hard too have, so the design needs to stimulate that in a safe way and environment | A tool that enables people to get better insight in a tussenlander, so they can act that way. | Creating a place where it feels that time does not exist, where you can do whatever you want and just feel, and enjoy the things you want to do. | Create a safe space where it feels like you are being heard and cared for. | Guidance | Ritual that enables people to give the end of life a special place. |

### APPENDIX G

# CLUSTERING

In the literature research and interviews, the transcripts and data are analysed for important factors; factors that are constantly changing(trends and developments), and factors that are not bound to change (states and principles). For this part of the data collection the VIP-method (Hekkert & van Dijk, 2011) was followed. After the data collection of interviews, literature and desktop research, all the factors were stored in the online database Airtable. In a clustering session, connections were made between the factors to determine what Driving Forces exist in this theme. Driving Forces are personal drivers or motivators, that answer the WHY-question. So Driving Forces explain a person's motivating factors and 'why' someone does what they do. All the factors were printed out on cards and clustered in 22 Driving Forces. From there, these 22 Driving Forces were clustered in six main themes, which are as followed:

## Theme 1 | The current position of palliative care

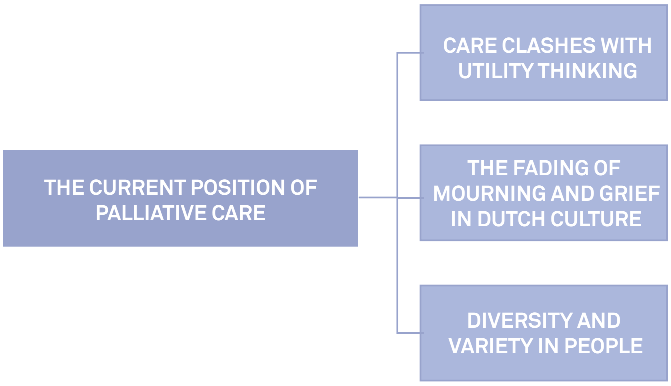


*Figure FIXME: Cluster theme | the current position of palliative care*

### Driving Force 1 | Required care clashes with utility thinking *('gewenste zorg botst met nuttigheidsdenken')*

The Dutch culture is characterised by a tendency to act instead of resigning oneself (Leget, 2012). But the boundaries when to act are very blurred in terms of maintaining quality of life. The care system is still mainly focused on healing, while in many cases especially in palliative care, it is more about pain reduction and symptom reduction.

### Driving Force 2 | The fading of mourning and grief in dutch culture *('vervaging rouw en verdriet in cultuur NL')*

On the one hand mourning and grief is slowly disappearing in public and our society. A lot of mourning rituals disappeared, which resulted that it is not self-evident anymore for people to meet each other in our society and public around topics like grief(Keirse, 2017).
On the other hand mourning and grief are two terms that are being used interchangeably. But to mourn does not automatically mean that one must grief. The confusion of these two terms can lead to a lot of misunderstood situations.

### Driving Force 3 | Diversity and variety in people *('Diversiteit en verscheidenheid van mensen')*

People can differ from each other. Even for the same person, the in-between-land can look different every day. Therefore, it is allright to learn the theory, but put the theory aside when you get into contact with every human being. In that moment you have to listen to what every singular person experiences as comfortable, supporting and insightful

## Theme 2| The possibilities: making the best out of it ("roeien met de riemen die je hebt")

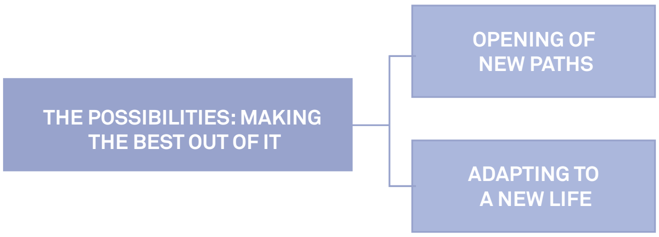


*Figure FIXME: Cluster theme | the possibilities, making the best out of it*

### Driving Force 4 | Opening of new paths *('openen van nieuwe paden')*

After the diagnosis of an incurable disease, for some people new possibilities arise. They find new triggers and find the space and time to experience new things.

### Driving Force 5 | Adapting to a new life *('adaptatie naar het nieuwe leven')*

While for some people it is hard to accept, their lives will never be the same as before the diagnosis of an incurable disease. So for a lot of people their new life is about learning to live with the limitations that are caused by the disease. They simply have to adapt to the new circumstances.

## Theme 3| The hurdles during the transition to the tussenland

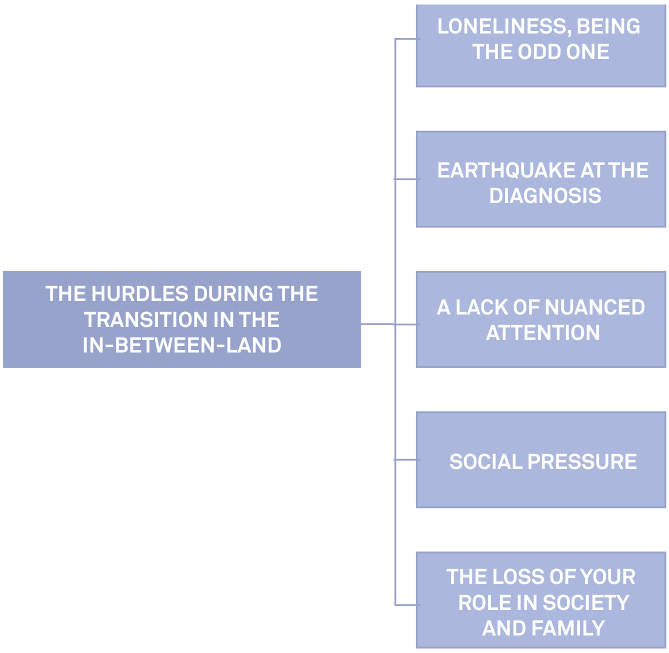


*Figure FIXME: Cluster theme | the hurdles during the transition in the in-between-land*

### Driving Force 6 | Loneliness, being the odd one *('eenzaamheid: de vreemde eend in de bijt')*

For a lot of people the in-between-land can be very lonely. A lot of people in there don't know other people. It also happens a lot that other people don't know how to talk to you.

### Driving Force 7 | Earthquake at the diagnosis *('aardschok bij de diagnose')*

The period during and after the diagnosis of an incurable disease has an enormous impact on the tussenlander. For the tussenlander it often feels like their whole world collapses.

### Driving Force 8 | Lack of nuanced attention *('gebrek aan genuanceerde aandacht')*

There is a need for continuous attention whenever you have a disease. Currently, tussenlanders still experience a lack of nuanced attention. So not only attention in the form of concern, but also genuine questions about someone's mental wellbeing.

### Driving Force 9 | Social pressure *('sociale druk')*

Life can feel like fighting a war on two fronts. So on the one hand it feels like they have to fight their disease, but on the other hand it also feels like they are being discriminated by society as a sick person. It feels like they are not part anymore, and that has an enormous impact.

### Driving Force 10 | The loss of your role in society and family *('verlies rol in maatschappij en familie')*

For many people the diagnosis of an incurable disease meant that they could not fulfill the role they used to fulfill. People had to quit their job or it felt like they were not part of their family anymore. Many tussenlanders experienced that they were being sucked into isolation.

## Theme 4| Connectedness

### Driving Force 11 | The power of love *('de kracht van liefde')*

The period of sickness also has some beautiful aspects. Many tussenlanders experienced a form of love, where no request was too absurd. Tussenlanders really felt supported by the people around them.

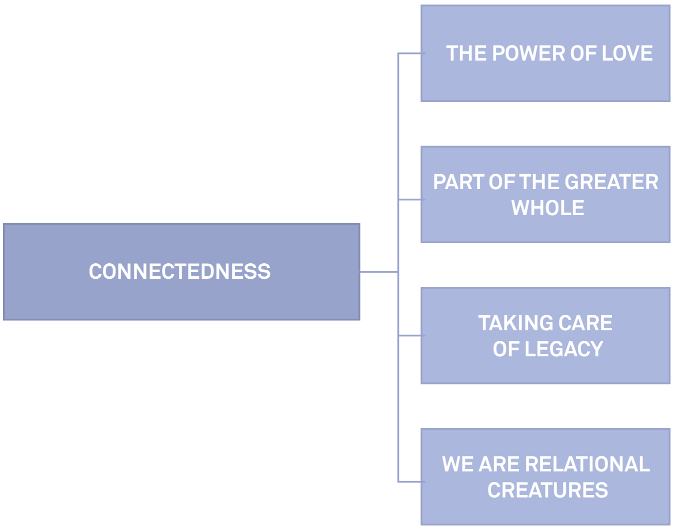


*Figure FIXME: Cluster theme | connectedness*

### Driving Force 12 | Part of the greater whole *('onderdeel van het groter geheel')*

The belief that we human beings are part of something greater. Also the notion that more and more tussenlanders will enter the in-between-land.

### Driving Force 13 | Taking care of legacy *('verzorgen nalatenschap')*

One of the biggest concerns for a lot of tussenlanders was to ensure that the people they leave behind are well cared for. This goal really contributed to their will to live.

### Driving Force 14 | We are relational creatures *('relationele wezens')*

We human beings are relational creatures. And dying is a social happening. So people also want to be treated that way, It can make a huge difference when you are being adressed by your name and not as Patient X. Despite of the sickness, as a tussenlander you build up relationships and interaction with people, some that will stick for life.

## Theme 5| Elements that are required in the in-between-land

### Driving Force 15 | The balance between body and mind *('balans tussen geest&lichaam')*

It is important to create a balance between body and mind, as these two things are interconnected. For example, walking can relieve your mind and also build up resistance.

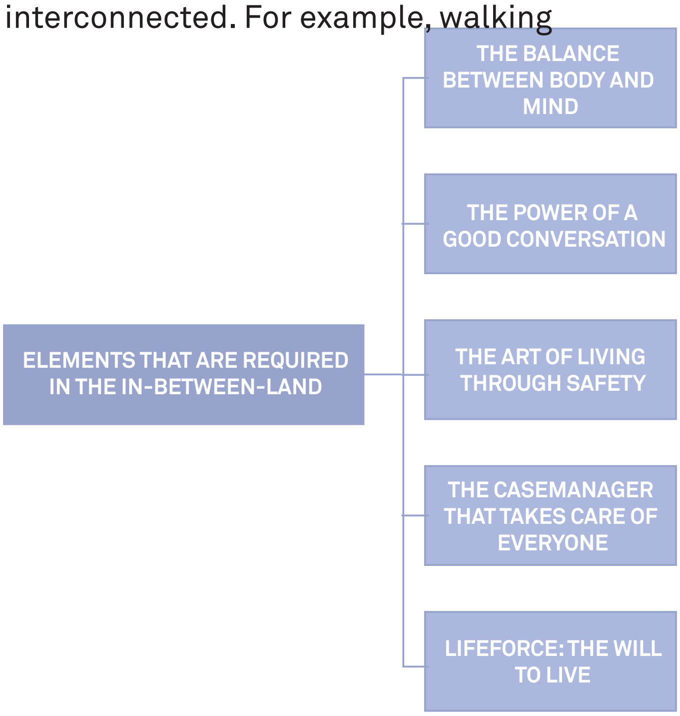


*Figure FIXME: Cluster theme | elements that are required in the in-between-land*

### Driving Force 16 | The power of a good conversation *('de kracht van een goed gesprek')*

Nobody regrets it to talk about dying and death, although it can feel uneasy in the beginning due to the death literacy in the Netherlands.. But openness in a conversation lead to more openness.

### Driving Force 17 | 'The art of living', through safety *('Levenskunst door veiligheid')*

A good quality of life for tussenlanders exists there where they feel safe. So in their own house surrounded by loved ones, in a hospice where dedicated professionals work, in a hospital or nursing home where the form of care is not suffocated by protocols and lack of staff. The place where you feel safe, is the place where your own priorities hold sway.

### Driving Force 18 | The casemanager that takes care of everyone *('de casemanager die zich om iedereen ontfermd')*

There is a need for something or someone, like a casemanager, that is there to take care of everything and everyone. Not only physically, but also psychologically, socially and spiritually.

### Driving Force 19 | Lifeforce: the will to live *('levenskracht: de wil om te leven')*

The will to live, is a kind of like a force of nature, it is something that can be strong within a tussenlander. A lot of times this is accompanied by a re-appreciation for life, as the longer you are in the in-between-land, the more nuanced attention and love you encounter.

## Theme 6| Different interpretation of space for the tussenlander

### Driving Force 20 | Paradox of a meaningful life and death *('paradox rondom waardevol leven en sterven')*

There exists a paradox around living a meaningful life and having a meaningful death, as we want autonomy for ourselves and safety for those we love. Many of the things we want for those we care about are the things that we would adamantly oppose for ourselves because they would infringe upon our self of self.

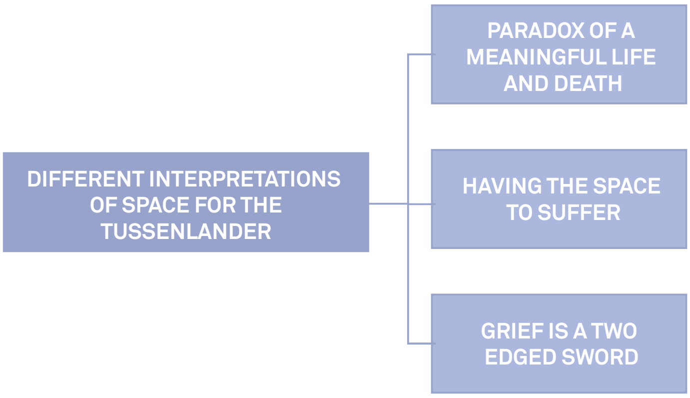


*Figure FIXME: Cluster theme | different interpretations of space for the tussenlander*

### Driving Force 21 | Having the space to suffer *('de ruimte om te lijden')*

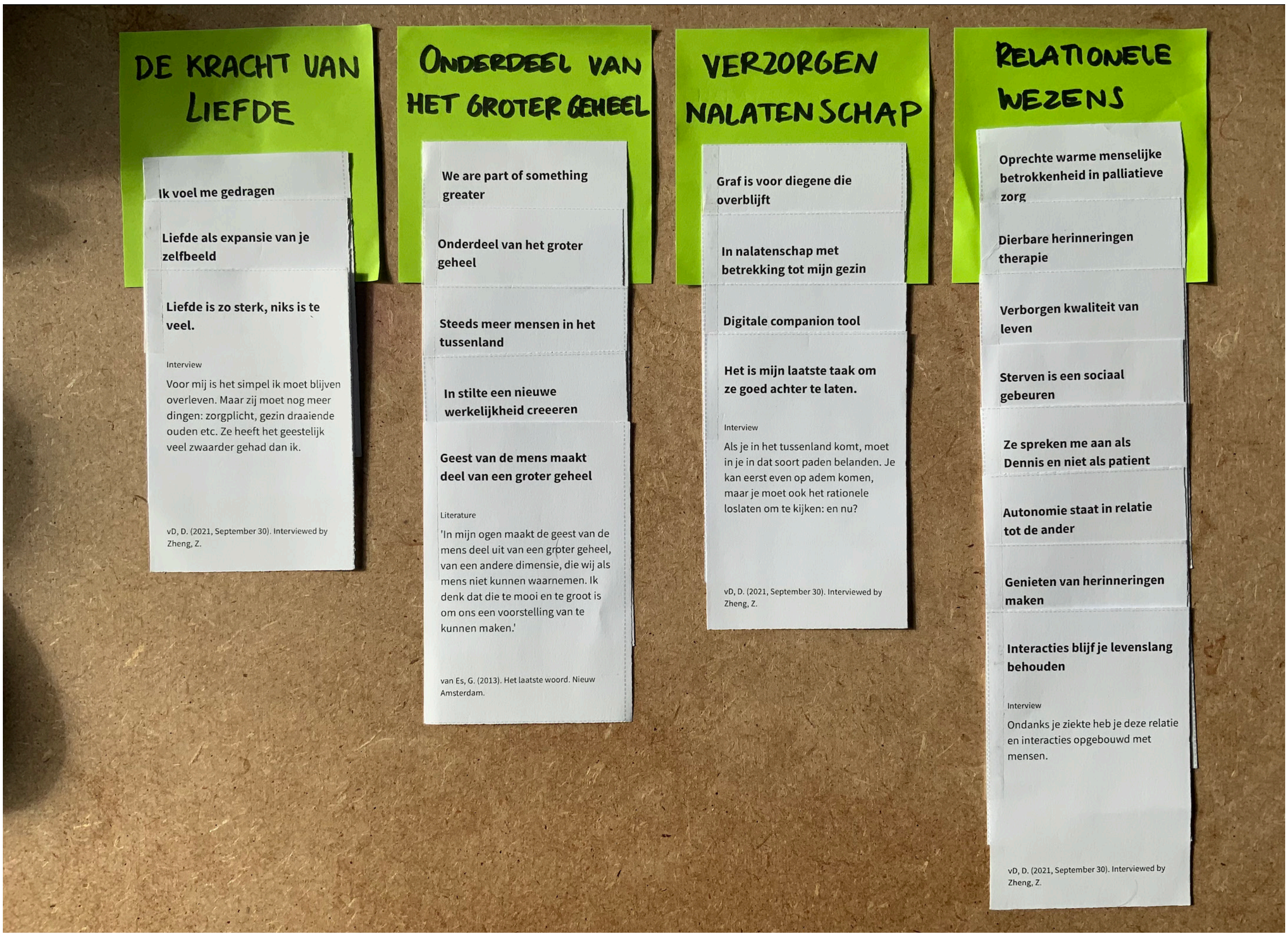
As a tussenlander you need the space and time for your own suffering. At some moments it can be so intense that you don't have space for the sadness and grief of others. Moreover, it can be confronting to see other tussenlanders because it feels like they are holding a mirror in front of you, that this could be you in a matter of time. A lot of tussenlanders also mentioned that for that reason they felt 'hospital-tired' ('ziekenhuismoe').

### Driving Force 21 | Grief is a two edged sword *('verdriet is een tweesnijdend zwaard')*

Crying is not only grief and sadness, just like laughter is not only happiness. Crying embodies so much of who and what we are: thankfulness, dearness, love. Grief and sadness can also be experienced as the flipside of love. To grief, one must first be able to love.

APPENDIX H

# CLUSTERING OVERVIEW



DE KRACHT VAN LIEFDE

**Ik voel me gedragen**

**Liefde als expansie van je zelfbeeld**

**Liefde is zo sterk, niks is te veel.**

Interview

Voor mij is het simpel ik moet blijven overleven. Maar zij moet nog meer dingen: zorgplicht, gezin draaiende ouden etc. Ze heeft het geestelijk veel zwaarder gehad dan ik.

vD, D. (2021, September 30). Interviewed by Zheng, Z.

ONDERDEEL VAN HET GROTER GEHEEL

**We are part of something greater**

**Onderdeel van het groter geheel**

**Steeds meer mensen in het tussenland**

**In stilte een nieuwe werkelijkheid creeeren**

**Geest van de mens maakt deel van een groter geheel**

Literature

'In mijn ogen maakt de geest van de mens deel uit van een groter geheel, van een andere dimensie, die wij als mens niet kunnen waarnemen. Ik denk dat die te mooi en te groot is om ons een voorstelling van te kunnen maken.'

van Es, G. (2013). Het laatste woord. Nieuw Amsterdam.

VERZORGEN NALATENSCHAP

**Graf is voor diegene die overblijft**

**In nalatenschap met betrekking tot mijn gezin**

**Digitale companion tool**

**Het is mijn laatste taak om ze goed achter te laten.**

Interview

Als je in het tussenland komt, moet in je in dat soort paden belanden. Je kan eerst even op adem komen, maar je moet ook het rationele loslaten om te kijken: en nu?

vD, D. (2021, September 30). Interviewed by Zheng, Z.

RELATIONELE WEZENS

**Oprechte warme menselijke betrokkenheid in palliatieve zorg**

**Dierbare herinneringen therapie**

**Verborgen kwaliteit van leven**

**Sterven is een sociaal gebeuren**

**Ze spreken me aan als Dennis en niet als patient**

**Autonomie staat in relatie tot de ander**

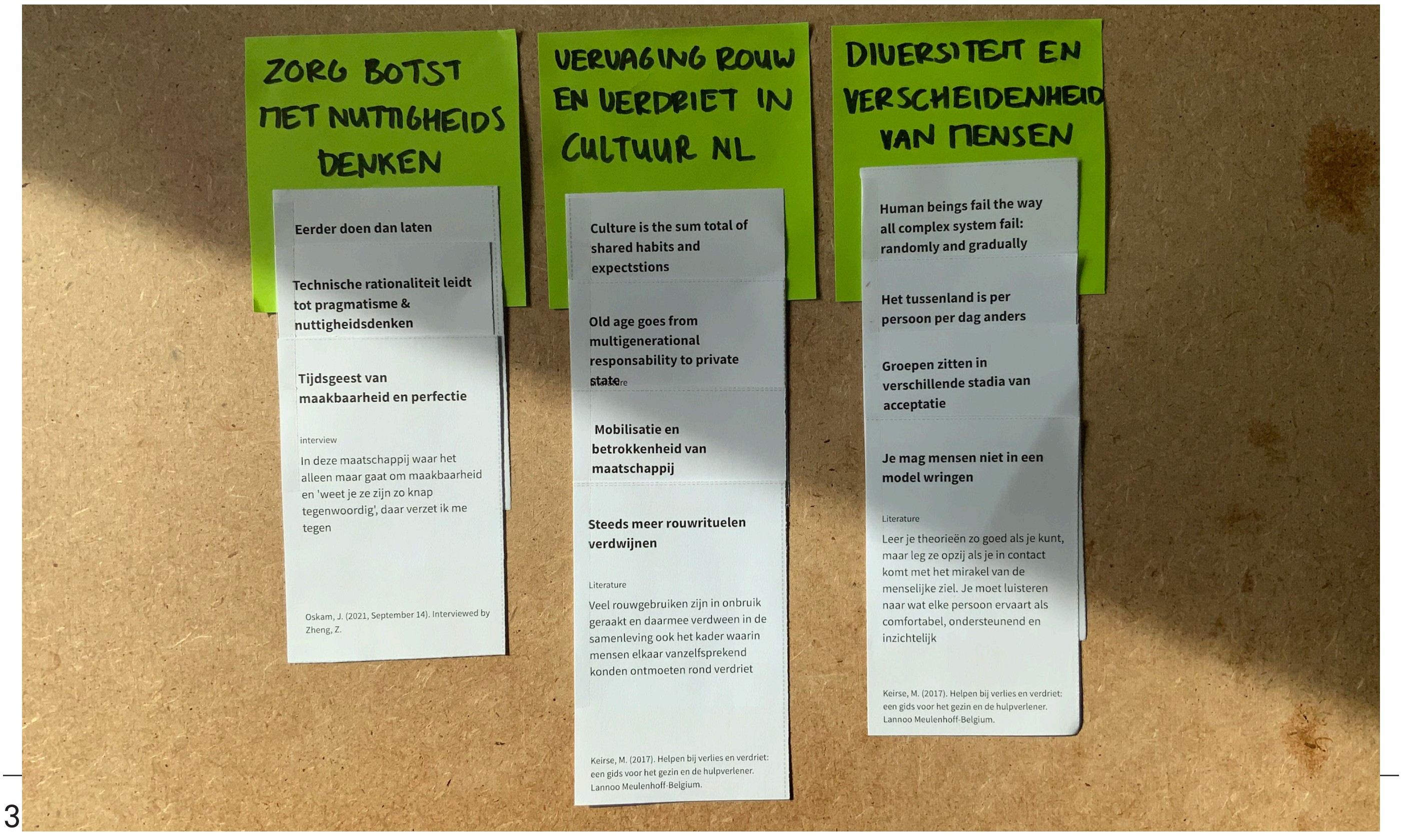
**Genieten van herinneringen maken**

**Interacties blijf je levenslang behouden**

Interview

Ondanks je ziekte heb je deze relatie en interacties opgebouwd met mensen.

vD, D. (2021, September 30). Interviewed by Zheng, Z.



ZORG BOTST MET NUTTIGHEIDS DENKEN

**Eerder doen dan laten**

**Technische rationaliteit leidt tot pragmatisme & nuttigheidsdenken**

**Tijdsgeest van maakbaarheid en perfectie**

interview

In deze maatschappij waar het alleen maar gaat om maakbaarheid en 'weet je ze zijn zo knap tegenwoordig', daar verzet ik me tegen

Oskam, J. (2021, September 14). Interviewed by Zheng, Z.

VERVAGING ROUW EN VERDRIET IN CULTUUR NL

**Culture is the sum total of shared habits and expectstions**

**Old age goes from multigenerational responsability to private state**

**Mobilisatie en betrokkenheid van maatschappij**

**Steeds meer rouwritualen verdwijnen**

Literature

Veel rouwgebruiken zijn in onbruik geraakt en daarmee verdween in de samenleving ook het kader waarin mensen elkaar vanzelfsprekend konden ontmoeten rond verdriet

Keirse, M. (2017). Helpen bij verlies en verdriet: een gids voor het gezin en de hulpverlener. Lannoo Meulenhoff-Belgium.

DIVERSITEIT EN VERSCHEIDENHEID VAN MENSEN

**Human beings fail the way all complex system fail: randomly and gradually**

**Het tussenland is per persoon per dag anders**

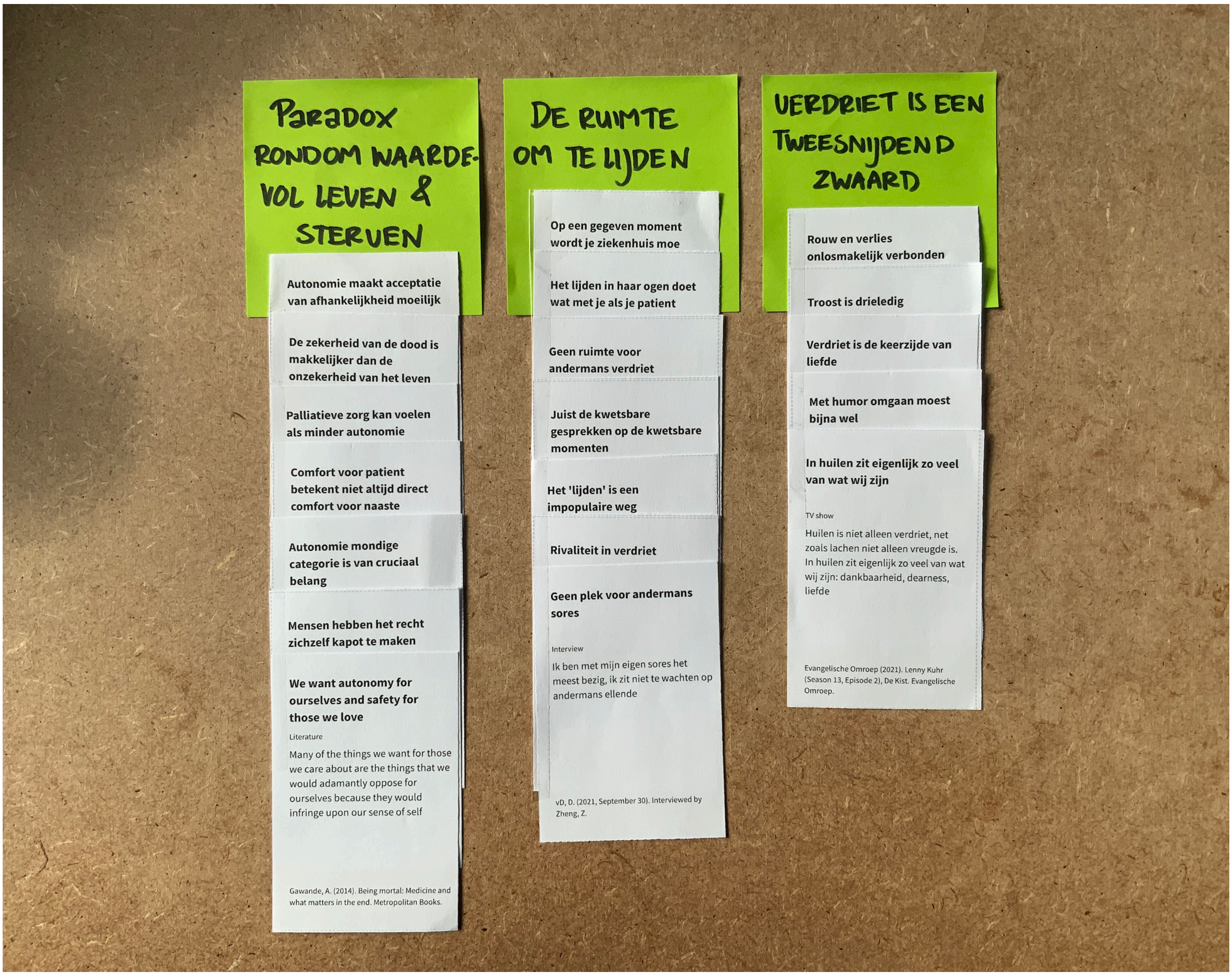
**Groepen zitten in verschillende stadia van acceptatie**

**Je mag mensen niet in een model wringen**

Literature

Leer je theorieën zo goed als je kunt, maar leg ze opzij als je in contact komt met het mirakel van de menselijke ziel. Je moet luisteren naar wat elke persoon ervaart als comfortabel, ondersteunend en inzichtelijk

Keirse, M. (2017). Helpen bij verlies en verdriet: een gids voor het gezin en de hulpverlener. Lannoo Meulenhoff-Belgium.



**PARADOX RONDOM WAARDEVOL LEVEN & STERVEN**

**Autonomie maakt acceptatie van afhankelijkheid moeilijk**

**De zekerheid van de dood is makkelijker dan de onzekerheid van het leven**

**Palliatieve zorg kan voelen als minder autonomie**

**Comfort voor patient betekent niet altijd direct comfort voor naaste**

**Autonomie mondige categorie is van cruciaal belang**

**Mensen hebben het recht zichzelf kapot te maken**

**We want autonomy for ourselves and safety for those we love**

Literature

Many of the things we want for those we care about are the things that we would adamantly oppose for ourselves because they would infringe upon our sense of self

Gawande, A. (2014). Being mortal: Medicine and what matters in the end. Metropolitan Books.

**DE RUIMTE OM TE LIJDEN**

**Op een gegeven moment wordt je ziekenhuis moe**

**Het lijden in haar ogen doet wat met je als je patient**

**Geen ruimte voor andermans verdriet**

**Juist de kwetsbare gesprekken op de kwetsbare momenten**

**Het 'lijden' is een impopulaire weg**

**Rivaliteit in verdriet**

**Geen plek voor andermans sores**

Interview

Ik ben met mijn eigen sores het meest bezig, ik zit niet te wachten op andermans ellende

vD, D. (2021, September 30). Interviewed by Zheng, Z.

**VERDRIET IS EEN TWEESNIJDEND ZWAARD**

**Rouw en verlies onlosmakelijk verbonden**

**Troost is drieledig**

**Verdriet is de keerzijde van liefde**

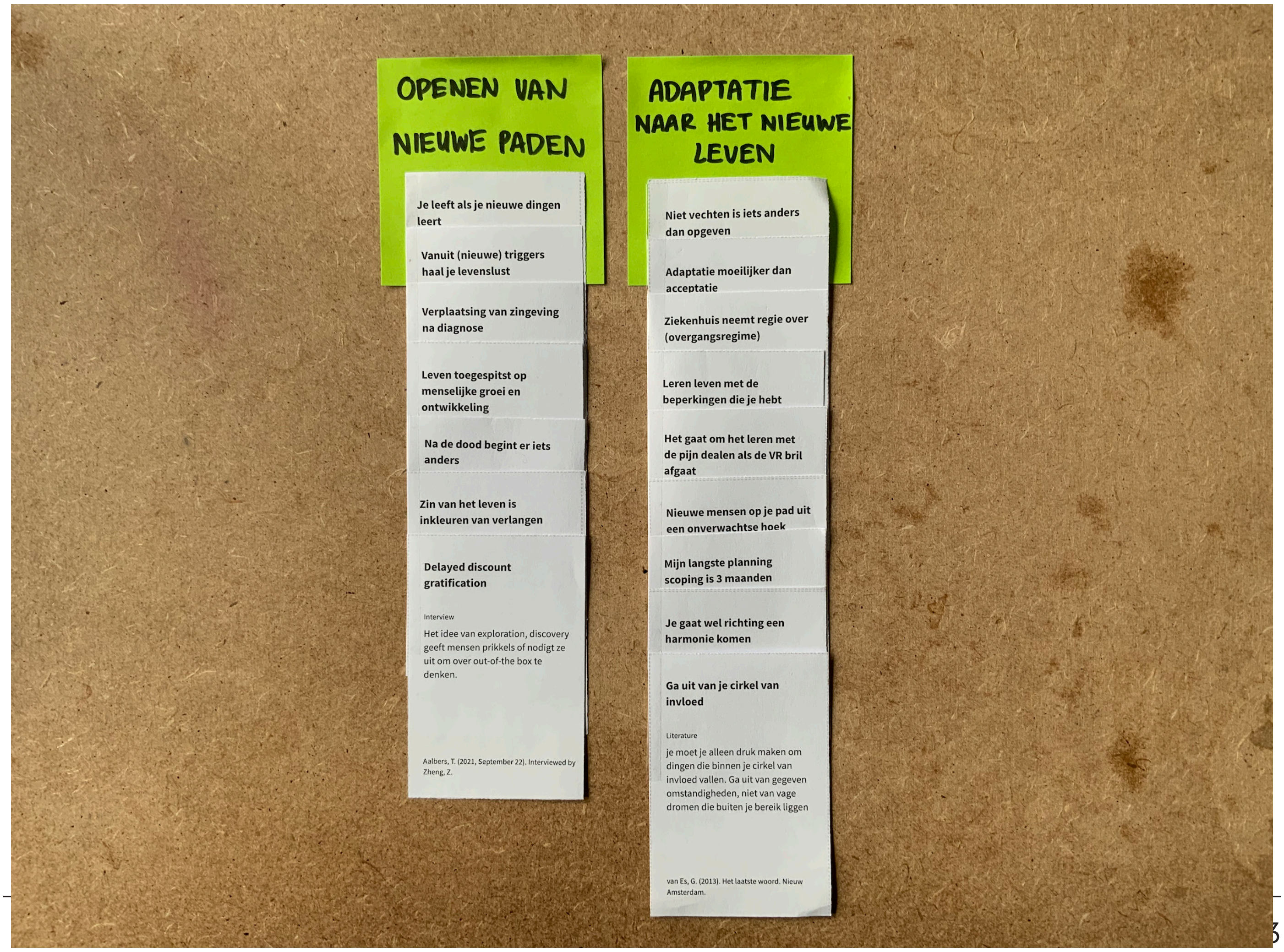
**Met humor omgaan moest bijna wel**

**In huilen zit eigenlijk zo veel van wat wij zijn**

TV show

Huilen is niet alleen verdriet, net zoals lachen niet alleen vreugde is. In huilen zit eigenlijk zo veel van wat wij zijn: dankbaarheid, dearness, liefde

Evangelische Omroep (2021). Lenny Kuhr (Season 13, Episode 2), De Kist. Evangelische Omroep.



**OPENEN VAN NIEUWE PADEN**

**Je leeft als je nieuwe dingen leert**

**Vanuit (nieuwe) triggers haal je levenslust**

**Verplaatsing van zingeving na diagnose**

**Leven toegespitst op menselijke groei en ontwikkeling**

**Na de dood begint er iets anders**

**Zin van het leven is inkleuren van verlangen**

**Delayed discount gratification**

Interview

Het idee van exploration, discovery geeft mensen prikkels of nodigt ze uit om over out-of-the box te denken.

Aalbers, T. (2021, September 22). Interviewed by Zheng, Z.

**ADAPTATIE NAAR HET NIEUWE LEVEN**

**Niet vechten is iets anders dan opgeven**

**Adaptatie moeilijker dan acceptatie**

**Ziekenhuis neemt regie over (overgangsregime)**

**Leren leven met de beperkingen die je hebt**

**Het gaat om het leren met de pijn dealen als de VR bril afgaat**

**Nieuwe mensen op je pad uit een onverwachtse hoek**

**Mijn langste planning scoping is 3 maanden**

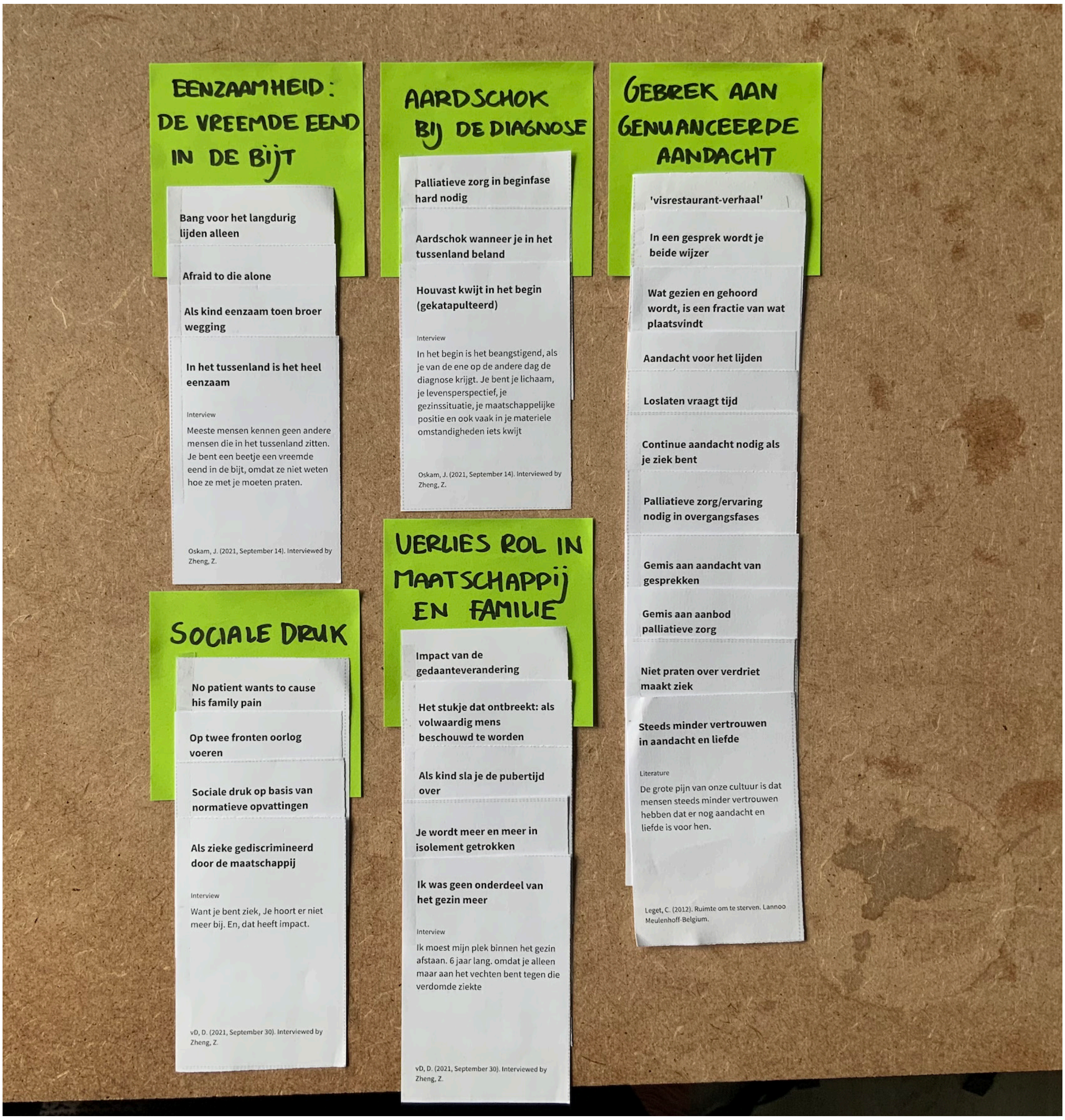
**Je gaat wel richting een harmonie komen**

**Ga uit van je cirkel van invloed**

Literature

je moet je alleen druk maken om dingen die binnen je cirkel van invloed vallen. Ga uit van gegeven omstandigheden, niet van vage dromen die buiten je bereik liggen

van Es, G. (2013). Het laatste woord. Nieuw Amsterdam.



EENZAAMHEID: DE VREEMDE EEND IN DE BIJT

Bang voor het langdurig lijden alleen

Afraid to die alone

Als kind eenzaam toen broer wegging

In het tussenland is het heel eenzaam

Interview

Meeste mensen kennen geen andere mensen die in het tussenland zitten. Je bent een beetje een vreemde eend in de bijt, omdat ze niet weten hoe ze met je moeten praten.

Oskam, J. (2021, September 14). Interviewed by Zheng, Z.

SOCIALE DRUK

No patient wants to cause his family pain

Op twee fronten oorlog voeren

Sociale druk op basis van normatieve opvattingen

Als zieke gediscrimineerd door de maatschappij

Interview

Want je bent ziek, Je hoort er niet meer bij. En, dat heeft impact.

vD, D. (2021, September 30). Interviewed by Zheng, Z.

AARDSCHOK BIJ DE DIAGNOSE

Palliatieve zorg in beginfase hard nodig

Aardschok wanneer je in het tussenland beland

Houvast kwijt in het begin (gekatapulteerd)

Interview

In het begin is het beangstigend, als je van de ene op de andere dag de diagnose krijgt. Je bent je lichaam, je levensperspectief, je gezinssituatie, je maatschappelijke positie en ook vaak in je materiele omstandigheden iets kwijt

Oskam, J. (2021, September 14). Interviewed by Zheng, Z.

VERLIES ROL IN MAATSCHAPPIJ EN FAMILIE

Impact van de gedaanteverandering

Het stukje dat ontbreekt: als volwaardig mens beschouwd te worden

Als kind sla je de pubertijd over

Je wordt meer en meer in isolement getrokken

Ik was geen onderdeel van het gezin meer

Interview

Ik moest mijn plek binnen het gezin afstaan. 6 jaar lang. omdat je alleen maar aan het vechten bent tegen die verdomde ziekte

vD, D. (2021, September 30). Interviewed by Zheng, Z.

GEBREK AAN GENUANCEERDE AANDACHT

'visrestaurant-verhaal'

In een gesprek wordt je beide wijzer

Wat gezien en gehoord wordt, is een fractie van wat plaatsvindt

Aandacht voor het lijden

Loslaten vraagt tijd

Continue aandacht nodig als je ziek bent

Palliatieve zorg/ervaring nodig in overgangsfases

Gemis aan aandacht van gesprekken

Gemis aan aanbod palliatieve zorg

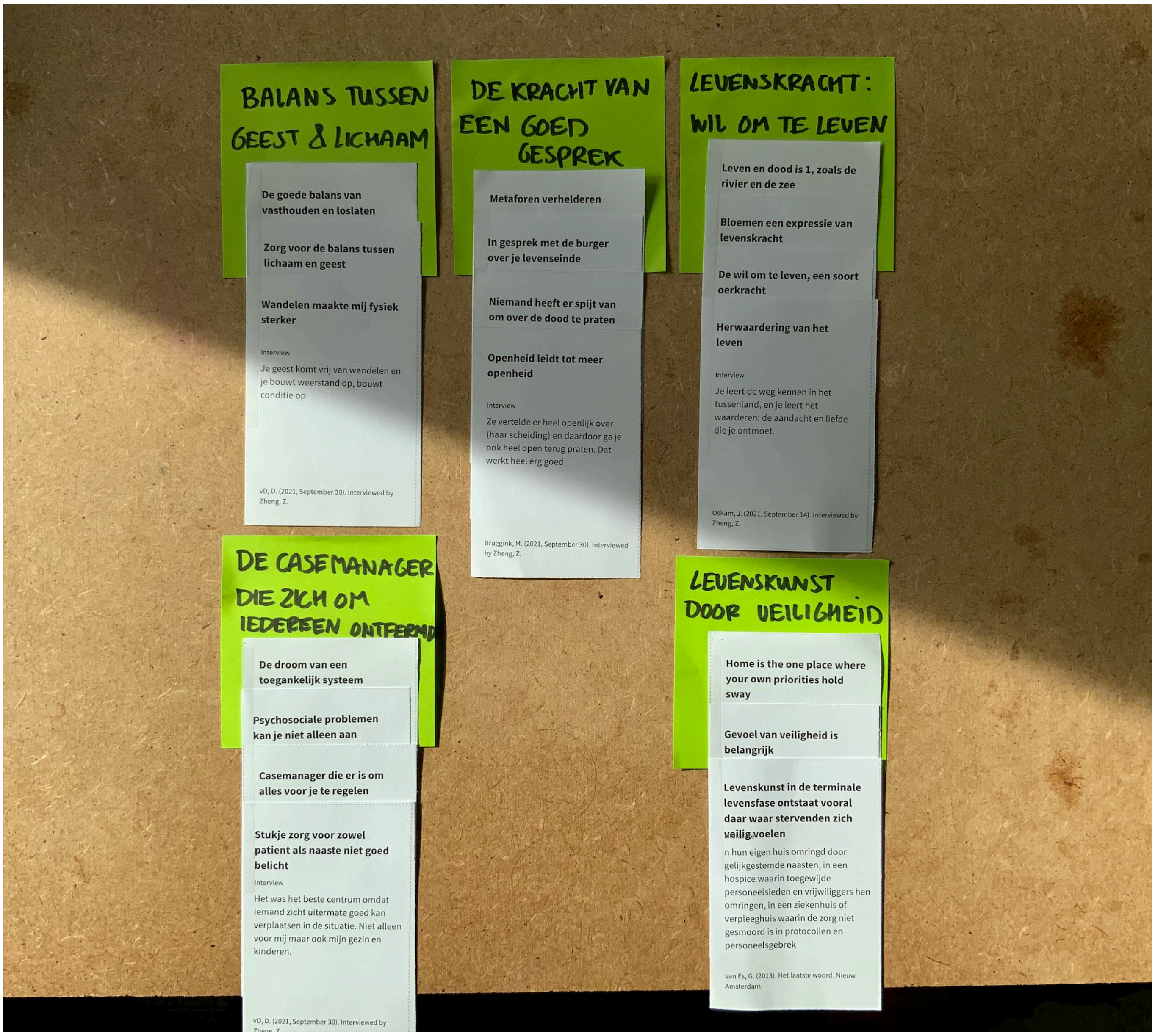
Niet praten over verdriet maakt ziek

Steeds minder vertrouwen in aandacht en liefde

Literature

De grote pijn van onze cultuur is dat mensen steeds minder vertrouwen hebben dat er nog aandacht en liefde is voor hen.

Leget, C. (2012). Ruimte om te sterven. Lannoo Meulenhoff-Belgium.



**BALANS TUSSEN GEEST & LICHAAM**

De goede balans van vasthouden en loslaten

Zorg voor de balans tussen lichaam en geest

Wandelen maakte mij fysiek sterker

Interview

Je geest komt vrij van wandelen en je bouwt weerstand op, bouwt conditie op

vD, D. (2021, September 30). Interviewed by Zheng, Z.

**DE KRACHT VAN EEN GOED GESPREK**

Metaforen verhelderen

In gesprek met de burger over je levenseinde

Niemand heeft er spijt van om over de dood te praten

Openheid leidt tot meer openheid

Interview

Ze vertelde er heel openlijk over (haar scheiding) en daardoor ga je ook heel open terug praten. Dat werkt heel erg goed

Bruggink, M. (2021, September 30). Interviewed by Zheng, Z.

**LEVENSKRACHT: WIL OM TE LEVEN**

Leven en dood is 1, zoals de rivier en de zee

Bloemen een expressie van levenskracht

De wil om te leven, een soort oerkracht

Herwaardering van het leven

Interview

Je leert de weg kennen in het tussenland, en je leert het waarderen: de aandacht en liefde die je ontmoet.

Oskam, J. (2021, September 14). Interviewed by Zheng, Z.

**DE CASEMANAGER DIE ZICH OM IEDEREEN ONTFERMD**

De droom van een toegankelijk systeem

Psychosociale problemen kan je niet alleen aan

Casemanager die er is om alles voor je te regelen

Stukje zorg voor zowel patient als naaste niet goed belicht

Interview

Het was het beste centrum omdat iemand zicht uitermate goed kan verplaatsen in de situatie. Niet alleen voor mij maar ook mijn gezin en kinderen.

vD, D. (2021, September 30). Interviewed by

**LEVENSKUNST DOOR VEILIGHEID**

Home is the one place where your own priorities hold sway

Gevoel van veiligheid is belangrijk

Levenskunst in de terminale levensfase ontstaat vooral daar waar stervenden zich veilig voelen

n hun eigen huis omringd door gelijkgestemde naasten, in een hospice waarin toegewijde personeelsleden en vrijwilligers hen omringen, in een ziekenhuis of verpleeghuis waarin de zorg niet gesmoord is in protocollen en personeelsgebrek

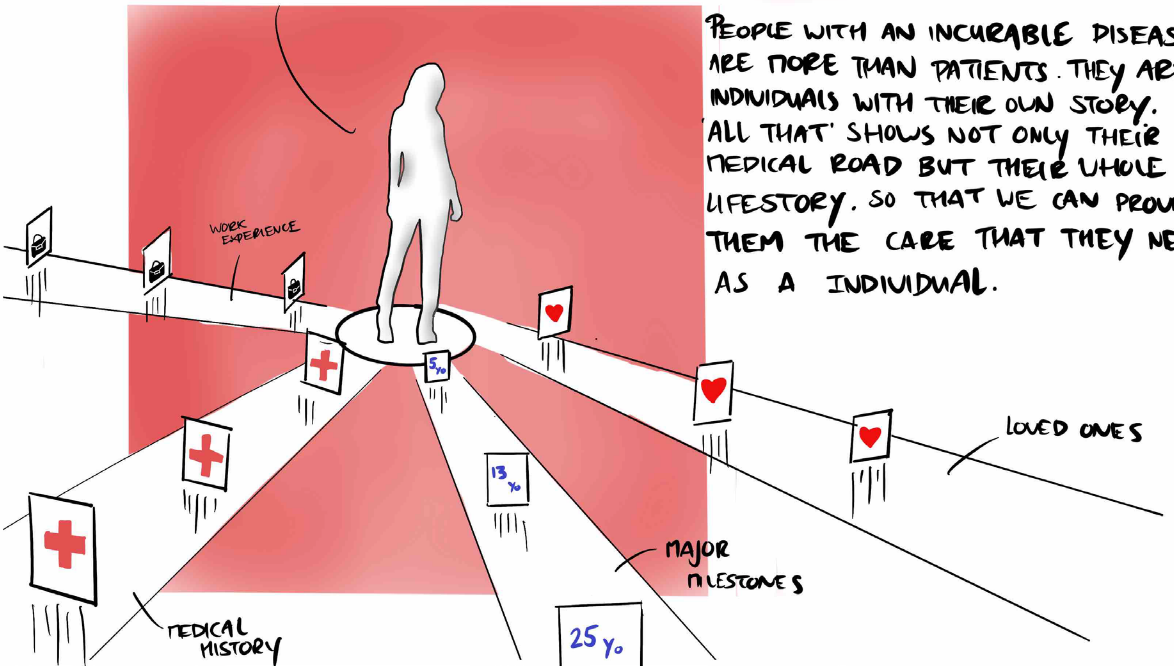
van Es, G. (2013). Het laatste woord. Nieuw Amsterdam.

APPENDIX I

# IDEA GENERATION

## ALL THAT

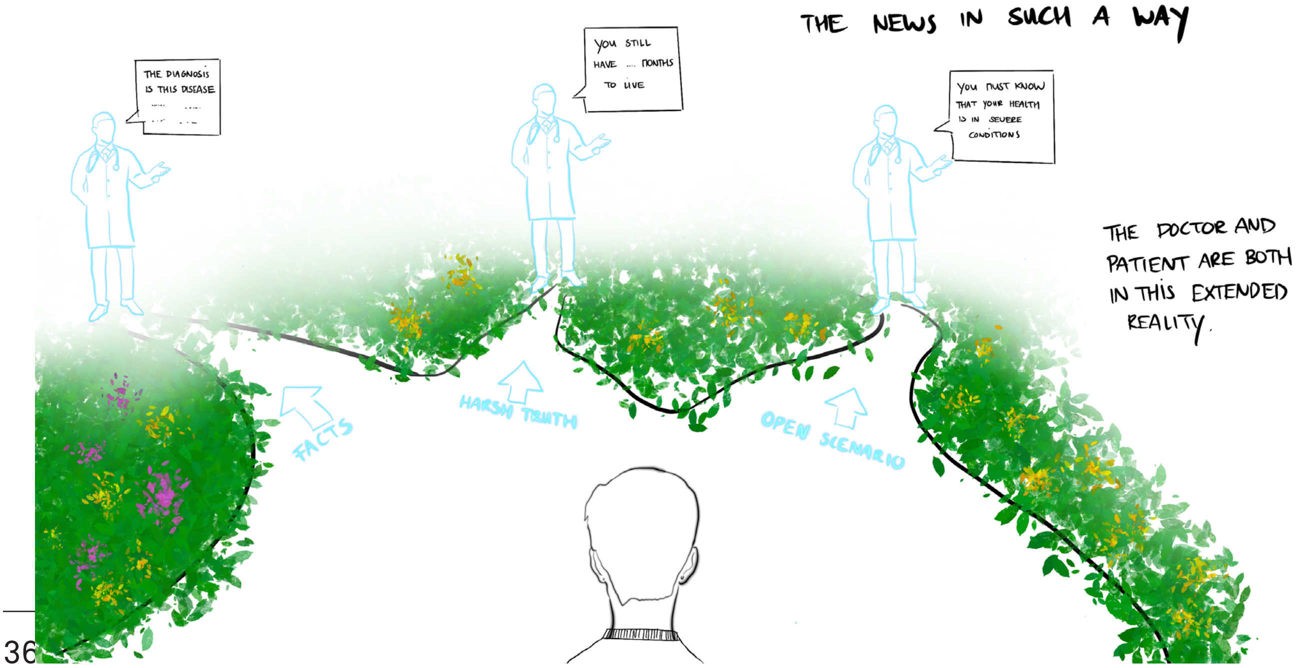
THE PERSON WITH AN INCURABLE DISEASE, LOVED ONES AND CARE PROFESSIONALS CAN ENTER THIS WORLD.



PEOPLE WITH AN INCURABLE DISEASE ARE MORE THAN PATIENTS. THEY ARE INDIVIDUALS WITH THEIR OWN STORY. 'ALL THAT' SHOWS NOT ONLY THEIR MEDICAL ROAD BUT THEIR WHOLE LIFESTORY. SO THAT WE CAN PROVIDE THEM THE CARE THAT THEY NEED AS A INDIVIDUAL.

## BREAKING NEWS

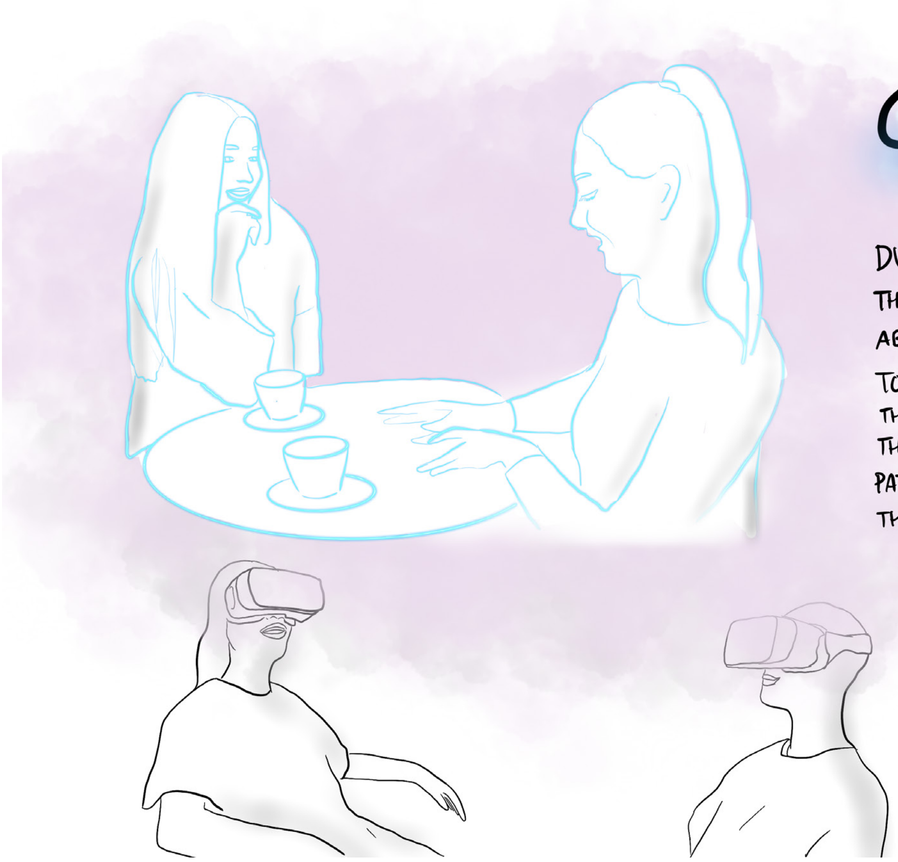
THE PATIENT CHOOSES ITS OWN PATH OF THE DIAGNOSIS. BEHIND EVERY ROAD IS THE SAME DOCTOR BUT DEPENDENT ON THE PATH THAT IS CHOSEN, THE DOCTOR WILL BREAK THE NEWS IN SUCH A WAY



THE DOCTOR AND PATIENT ARE BOTH IN THIS EXTENDED REALITY.

# COFFEE BREAK

DURING TREATMENTS AT THE HOSPITAL, PATIENTS ARE ABLE TO HAVE A COFFEEBREAK TOGETHER IN A VIRTUAL REALITY. THIS MAKES THEM FORGET THAT THEY'RE IN A HOSPITAL AS A PATIENT AND ENJOY THE LITTLE THINGS IN LIFE



"I JUST CAN'T STAND SEEING ALL THE SUFFERING IN THE HOSPITAL"

FOR PEOPLE WITH AN INCURABLE DISEASE SOMETIMES THESE SETTINGS DISAPPEAR AS THEIR APPETITE HAS DISAPPEARED.

# THE LAST SUPPER

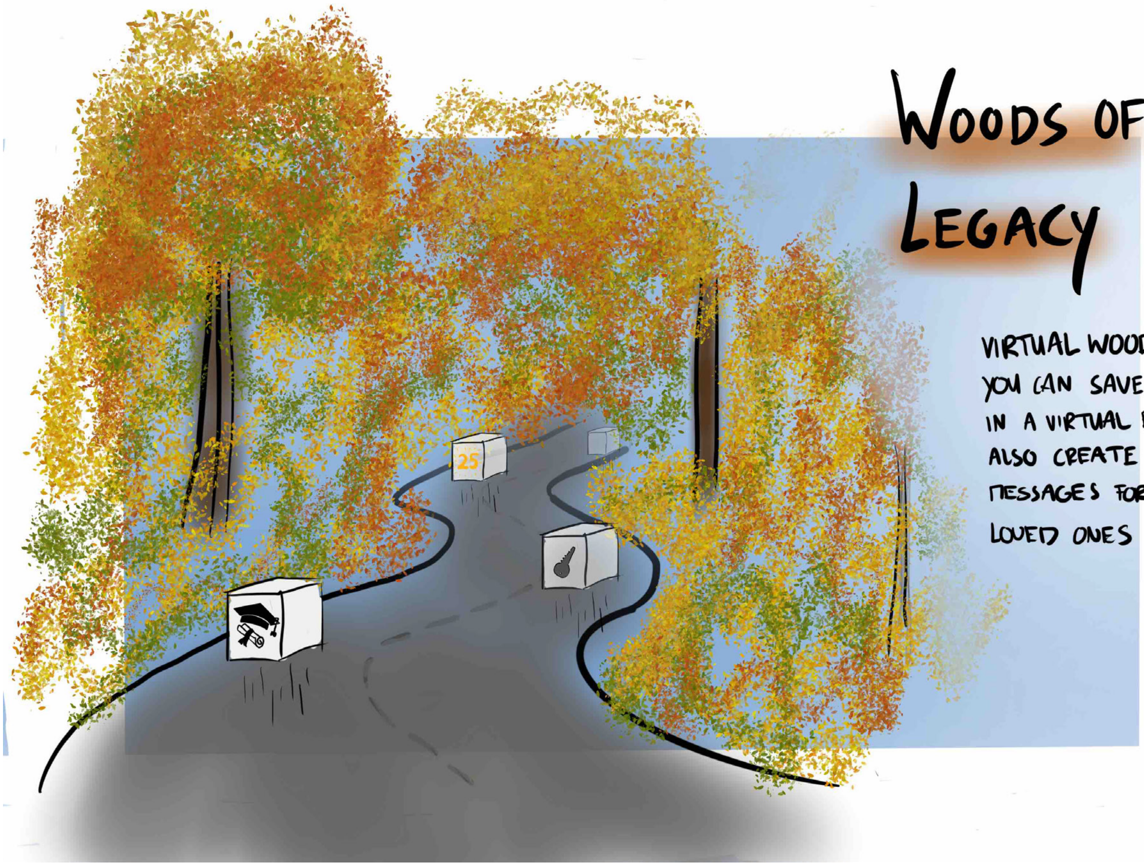
BASED ON DEATH OVER DINNER, TAFEL VOOR 2

AN IMMERSIVE EXPERIENCE WHERE YOU CAN HAVE DINNER AGAIN WITH YOUR FRIENDS AND/OR QUESTION. A PLACE WHERE YOU CAN SHARE LAUGHTER, JOY BUT ALSO GRIEF AND SADNESS.

TARGETED FOR PEOPLE WHO ARE HOSPITALIZED OR HAVE MANY TREATMENTS

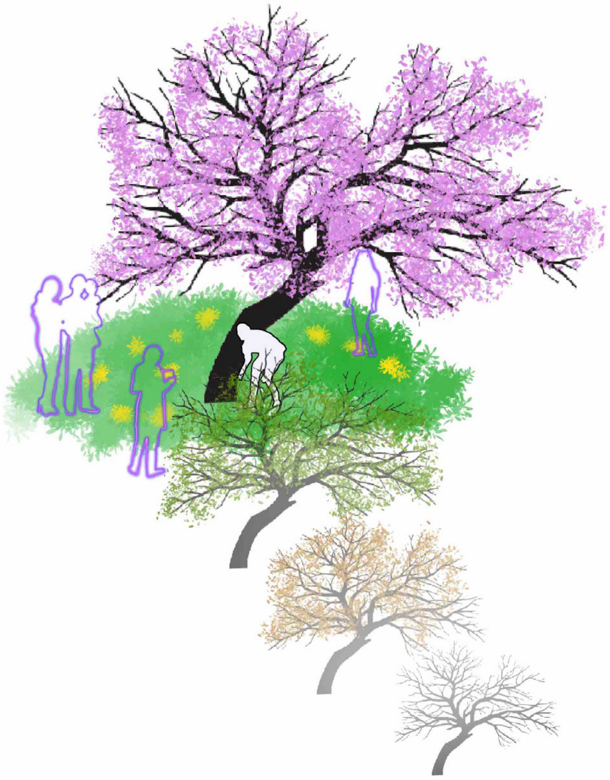
YOU CAN CHOOSE TO TALK ABOUT YOUR NORMAL TOPICS BUT YOU CAN ALSO ACCESS THE "DEATH OVER DINNER" TEMPLATE

HOME-LIKE SETTING
DIMMED LIGHTING, CANDLES



# WOODS OF LEGACY

VIRTUAL WOOD WHERE YOU CAN SAVE MEMORIES IN A VIRTUAL BOX AND ALSO CREATE FUTURE MESSAGES FOR YOUR LOVED ONES



# TREE OF HOPE

THE TREE OF HOPE SHOWS THE PATIENT'S MOOD AND HOPE IN THEIR JOURNEY. LOVED ONES & CARE PROFESSIONALS CAN VISIT THIS PLACE TO UNDERSTAND THE PATIENTS MOOD AND ACT ACCORDING TO THIS KNOWLEDGE

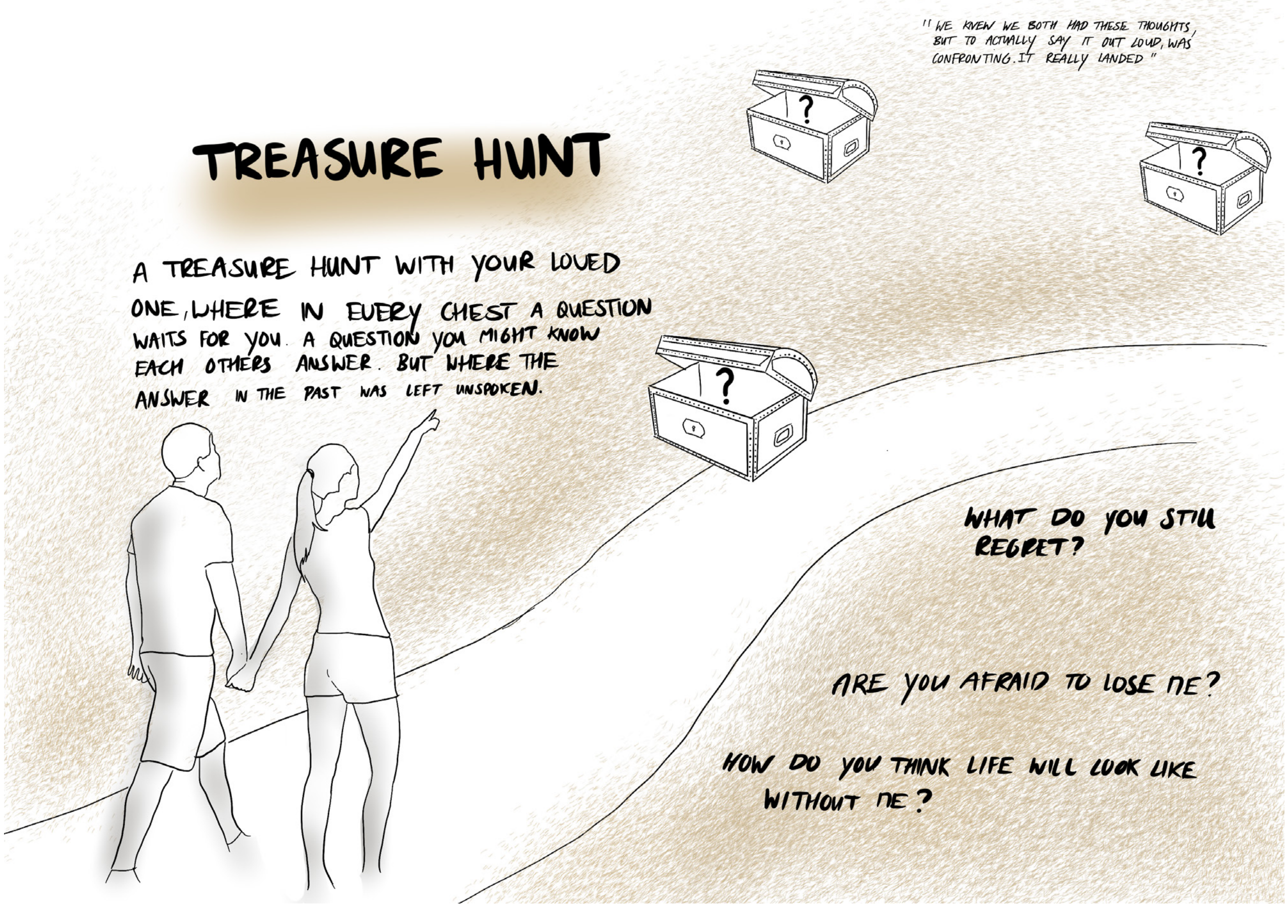
WHEN PEOPLE DO VISIT, AROUND THE TREE OF HOPE FLOWERS WILL POP UP AND GRADUALLY DISAPPEAR OVER TIME.

A WAY OF SHOWING THAT YOU STILL CARE

## TREASURE HUNT

A TREASURE HUNT WITH YOUR LOVED ONE, WHERE IN EVERY CHEST A QUESTION WAITS FOR YOU. A QUESTION YOU MIGHT KNOW EACH OTHERS ANSWER. BUT WHERE THE ANSWER IN THE PAST WAS LEFT UNSPOKEN.

" WE KNEW WE BOTH HAD THESE THOUGHTS, BUT TO ACTUALLY SAY IT OUT LOUD, WAS CONFRONTING. IT REALLY LANDED "

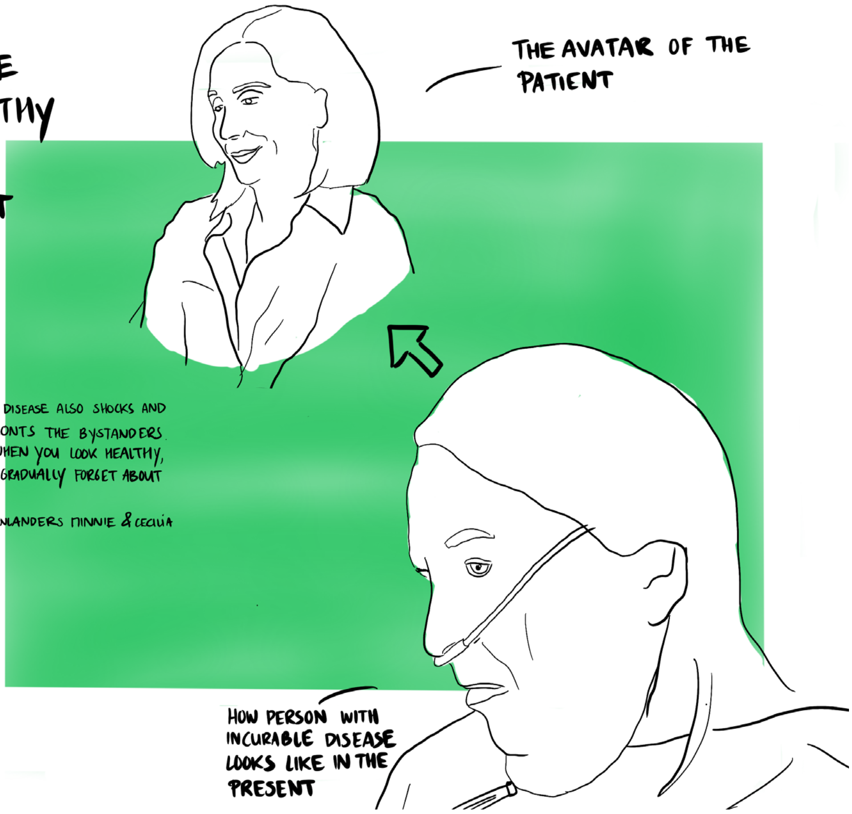


A PLACE WHERE TIME DOES NOT EXIST. WHERE YOU LOOK LIKE YOUR HEALTHY SELF, AND WHERE YOU AND OTHERS CAN FORGET YOUR DISEASE FOR A MOMENT

" YOUR DISEASE ALSO SHOCKS AND CONFRONTS THE BYSTANDERS. BUT WHEN YOU LOOK HEALTHY, YOU GRADUALLY FORGET ABOUT IT "

- TUSSENLANDERS MINNIE & CECILIA

## TIMELESS



# Companion

YOU ARE BEING GUIDED BY AN AVATAR COMPANION THAT IS CREATED OUT OF THE EXPERIENCE OF FELLOW PAST COMPANIONS. SHOWING YOU THE HURDLES & ACTIVITIES YOU MIGHT HAVE TO TACKLE

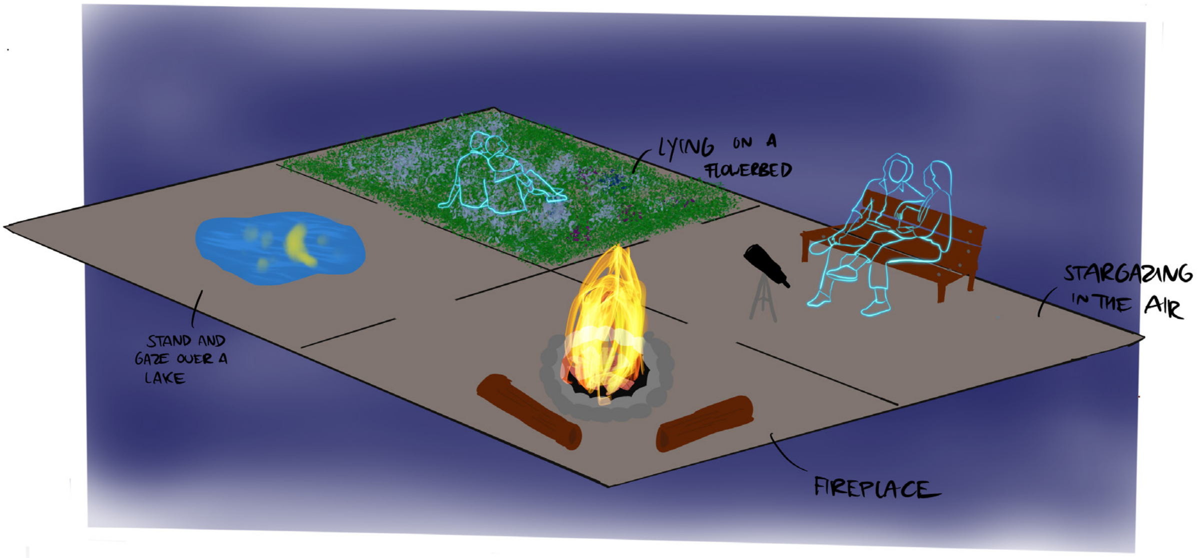
# Forest of Harmony

IN THE FOREST OF HARMONY YOU LET YOURSELF BE GUIDED. AND IMMERSED IN SOUND & SILENCE. THE HOMEBASE IS ALWAYS THE LAKE OF SILENCE WHERE YOU CAN HAVE A MOMENT FOR YOURSELF.

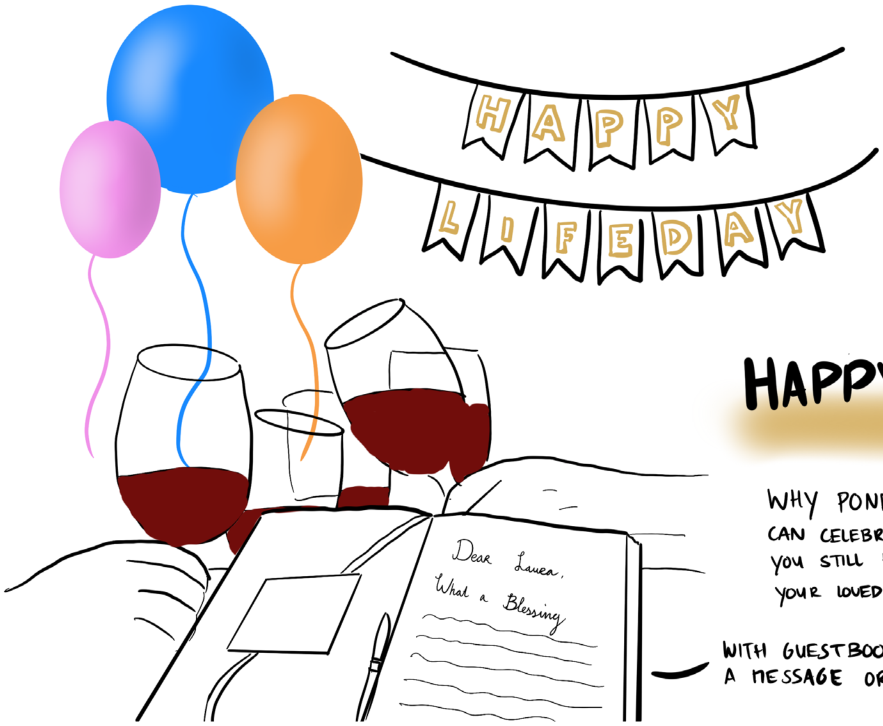
BUT YOU CAN ALSO BE GUIDED BY MUSIC (SENT BY CLOSE ONES, OR YOUR FAVOURITE SONGS) THAT GETS YOU BACK TO THAT SPECIAL MOMENT.

# ELEMENTS OF HONESTY

THE PLACE YOU CAN WANDER AROUND FOR A SPECIAL TALK. WITH THE RIGHT INTIMATE ATMOSPHERE



CREATING A NEW RITUAL IN DEATH WHERE PEOPLE ARE NOT RELUCTANT TO ENTER.

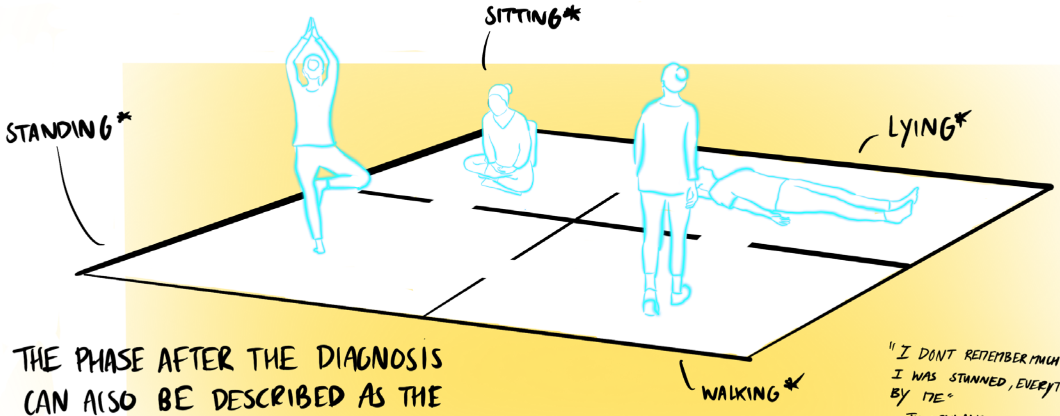


# HAPPY LIFEDAY

WHY PONDER OVER LIFE WHILE YOU CAN CELEBRATE LIFE. ENJOY THE MOMENTS YOU STILL HAVE AND CELEBRATE IT WITH YOUR LOVED ONES.

WITH GUESTBOOK WHERE GUEST CAN LEAVE A MESSAGE OR SPECIAL MEMORY

# THE FUZZY FRONT

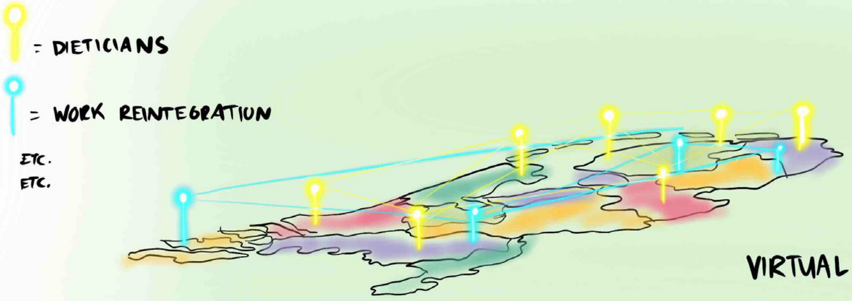


THE PHASE AFTER THE DIAGNOSIS CAN ALSO BE DESCRIBED AS THE FUZZY FRONT END: A PERIOD WHERE EVERYTHING GOES PAST YOU. THE "FUZZY FRONT" OFFERS YOU 10 MIN TO MEDITATE AND TO LAND BACK FROM THIS FOGGY PERIOD

"I DONT REMEMBER MUCH FROM THE BEGINNING, I WAS STUNNED, EVERYTHING WENT PAST BY ME"
— TUSSENLANDERS CECILIA & MINNIE

*BUDDHA'S FOUR MEDITATION POSTURES

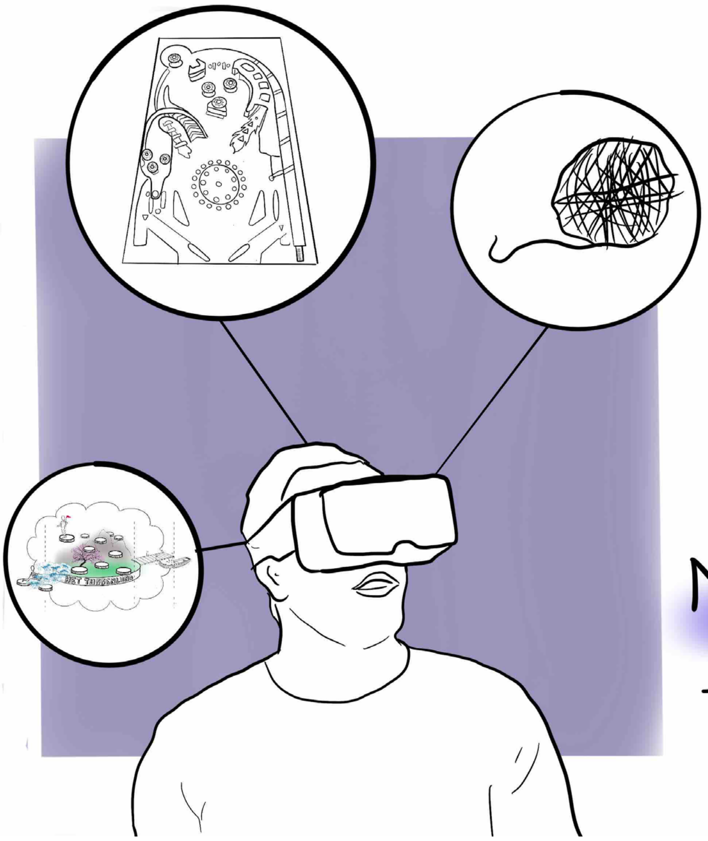
# My Way



VIRTUAL OVERVIEW OF THE NETWORK & INFRASTRUCTURE AROUND A PATIENT.

TO GIVE A CLEAR OVERVIEW OF ALL THE POSSIBILITIES

BEFOREHAND FILL IN SOME STATEMENTS TO DETERMINE THE AREAS OF TENSION



A COLLECTION OF METAPHORS OF WHAT PATIENTS EXPERIENCE SO THAT OTHER PATIENTS AND LOVED ONES AND CARE PROFESSIONALS CAN IMMERSE IN THIS EXPERIENCE.

BASED ON THIS EXPERIENCE NEW PATIENTS CAN ALSO ADD A METAPHOR TO THE COLLECTION: A MEMORY AND METAPHOR THAT WILL NEVER DIE

THE SECOND DEATH -> WHEN YOU DISAPPEAR FROM THE LAST MEMORY

# METAPHOR YOU

THE MEMORY THAT STICKS

APPENDIX J

# HACK-A-THON CASE DESCRIPTION

## Entering the In-between land

*Delf design End-of-Life Lab and Hospice Bardo*

### Problem Definition

Part of the quality of one's end of life is determined by how well prepared one is. This preparation is a joint effort, and regards the person as well as the inner circle of care one is surrounded by.

The transition period from ending curative care and entering the end-of-life care, while not being terminally ill yet, is a challenging period, often referred to as 'entering the in-between land (het tussenland)'. However, this period is hardly supported in practice.

This project will address the question: how can design support people who are facing a life-threatening/incurable disease and their loved-ones on their journey through the' in-between land'.
More specifically: how can we make people aware of this in-between land, and of the issues and questions that are face and raised during that journey?

### Competencies

- Being interested in end-of-life questions and personal development
- Being empathic
- Making rapid prototypes and iterations
- Sketching and storyboarding
- Desktop research
- User involvement

### Contact

Marieke Sonneveld
m.h.sonneveld@tudelft.nl

### Proposed Solution

The solution space for this design challenge is a product-service that will allow Hospice Bardo (and thereby other end-of-life care organizations) to support people in making them aware of the in-between land, and exploring what it means to them. This can be an interactive game, a VR solution, an installation somewhere in public space, anything that will allow people to engage with the topic in an experiential way, moving beyond providing mere information (through folders, books, etc).

At the kick off, we will show some examples of designs, and discuss what might work and what might not work, to give further directions to the project.

### Company / Organization

The Delft design for End-of-Life Lab explores how design in its broadest sense can contribute to the quality of life in its final stage. Developing end of life literacy (knowledge and skills regarding end-of-life decisions and behavior) is an important part of this exploration. This end-of-life literacy can be addressed on different levels: on personal, inter-personal, communities and societal levels.

Hospice Bardo offers care to people who are in the last stage of their life as well as care to people who have an incurable disease which will in time (up to years) result in death. In addition, they offer education and awareness creation around end-of-life topics. Again, this is addressed on different levels in our society.

## APPENDIX K

# HACK-A-THON SCHEDULE

| TIME | FRIDAY | SATURDAY | SUNDAY |
|---|---|---|---|
| 9:00 | | | |
| | | Walk-in | Walk-in |
| 10:00 | | Opening | Opening |
| | | **Workshop**<br>*Collaboration* | **Work**<br>*Finalise & Prepare pitch* |
| 11:00 | | | |
| | | **Work**<br>*Problem Analysis* | |
| 12:00 | | | |
| | | Lunch | |
| 13:00 | | | Pitches |
| | | **Work**<br>*Brainstorming* | **Lunch**<br>*Jury Discussion* |
| 14:00 | | | |
| | | | Winner Announcement |
| 15:00 | | | Drinks |
| | | | |
| 16:00 | | **Work**<br>*Conceptualisation* | |
| | Walk-in | | |
| 17:00 | Opening & Cases | | Closing |
| | **Dinner**<br>*Choose a case* | | |
| 18:00 | | Dinner | |
| | Team Up | | |
| 19:00 | **Workshop**<br>*Design Thinking* | **Work**<br>*Finalisation* | |
| | | | |
| 20:00 | | | |
| | **Work**<br>*Problem Analysis* | | |
| 21:00 | | | |
| | Closing | Closing | |

### APPENDIX L

# HACK-A-THON TEAM RESULTS: CONCEPT

- The issue: feeling lost and lots of question --> the need: a warm place to (literally) go to, to feel heard&connected.
- the solution: exploring the in-betweenland by choice.
- Sidenote: There will be a ‘buddy’ joining you (not yet defined, could be a dog or a person that guides you throughout the game, but you have the choice to send it away). The buddy will explain the goal and possibilities of the platform and will be there to answer your questions/guide you through the platform.
-
- So what is this concept?
- (middle bottom)
- 1st environment: the forest
- -this is the entering room of the platform/ serious game
- -There’s no other people: you will always be by yourself in this room
- -The buddy will show you one tree: this is ‘YOUR tree’, this tree will represent your story, experiences and thoughts. You have the choice whether to share it online or not.
- -Then the buddy tells you to look around. You are in a forest. The other trees represent the stories of other people. You can engage in their stories and respond anonymously.
- -There are also leafs that function as a ‘blog’. You can freely and anonymously write down questions concerning (emotional) thoughts, or health issues, and will receive anonymous answers (you can also answer yourself to other leafs).
- -Summarised: the forest is a place where (ex-)patients can be vulnerable and share their stories/emotions/questions anonymously regarding their disease, either through their own tree or via leaf-messages. This is all passive/indirect interaction! They have the options of whether to share it to other patients/ specialists/non-personal relatives or personal relatives
- 2nd environment: The hospital setting
- (top left)
- -It is offline, it does not include real interaction with other persons.
- -Its main goal is to answer all health-related concrete questions and providing tips to improve your life/what you can do yourself on short-term.
- It is divided into 3 main areas.
- -Area 1: the medical explanations: this will be a fictive specialist that will answer questions such as ‘how long will I live?’ ‘what is my disease?’ ‘what are the side-effects?’ The specialist is also enabled to enter this room passively, offering him/her the chance to have an overview in what sort of questions patients are dealing with
- -Area 2: the explanations/simulation of medical interventions such as diagnostics or therapies. This will take away possible fears and make them more comfortable with the setting
- -Area 3: the lifecoach. She will answer questions regarding short-term questions on how to improve you’re life and what you are capable of doing. The will give advice concerning healthy lifestyle, healthy food, possibilities you can undertake yourself and offers tools for psychological rest such as mindfulness and meditation.
-
- 3rd environment: the anonymously public setting
- (bottom left)
- -first area: You have the ability to meet new people, either being patient (avatars coloured in blue) or relative (avatars coloured in red) in the bar/restaurant
- -second area: playing mini-games (chess,tennis,golf)
- -third area: 1-1 conversation
-
- 4th environment: personal space
- (top left)
- -1st area: an own house in which you have the choice whether to or not to invite people over. This is a place where you are

NOT anonymously anymore.

- -2nd area: a peaceful and silent beach with waves and the starry night. This is a place to feel comfort and think about nothing.

### APPENDIX M

# CONCEPT ELABORATION PART 2

In this paragraph a second concept elaboration was performed to show the development of the concept.

**NEED FOR RIGHT INFORMATION**
The concept evaluation showed that the panel was positive about the concept of the forest and the trees. Although the whole framework in paragraph 6.1 was not presented in these concept evaluation, at the end some participants expressed the need to be able find the right information about practical topics like treatments, finance, administrative tasks, but also more personal topics like loneliness and sex. This brought me back to the need of the library, that finds the answers to all the questions of the tussenlander and show all the possibilities there are.

**POWER AND PITFALL OF THE 'LIBRARY'**
The power of the world 'the library' was that it is a central place where all the information lies for a tussenlander. But the pitfall of the library is that there exists so much information around palliative care, that it can easily be experienced as an information overload. Moreover, not everyone knows exactly what they are looking for. Especially in the beginning, when you are new to everything. A lot of tussenlanders mentioned that at their first specialist appointments, they did not know what to ask or where to pay attention on. But the longer you live in the in-between-land the more you acquinted you are. And even if you know what questions you have, sometimes it is not the right timing to engage these questions.

**REVISED CONCEPT**
In Het Tussenland, a personalised set of topics that are important for the tussenlander will be presented to them. They will appear in Het Tussenland like a treasure hunt, where they can explore for these topics, like in the idea Treasure Hunt in figure FIXME. It is up to the tussenlander if they want to engage these topics.

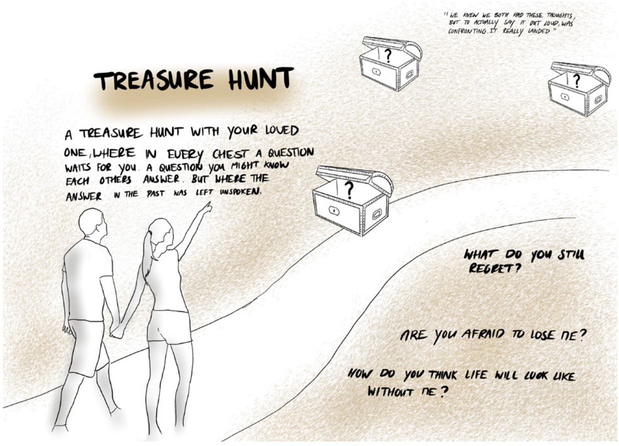
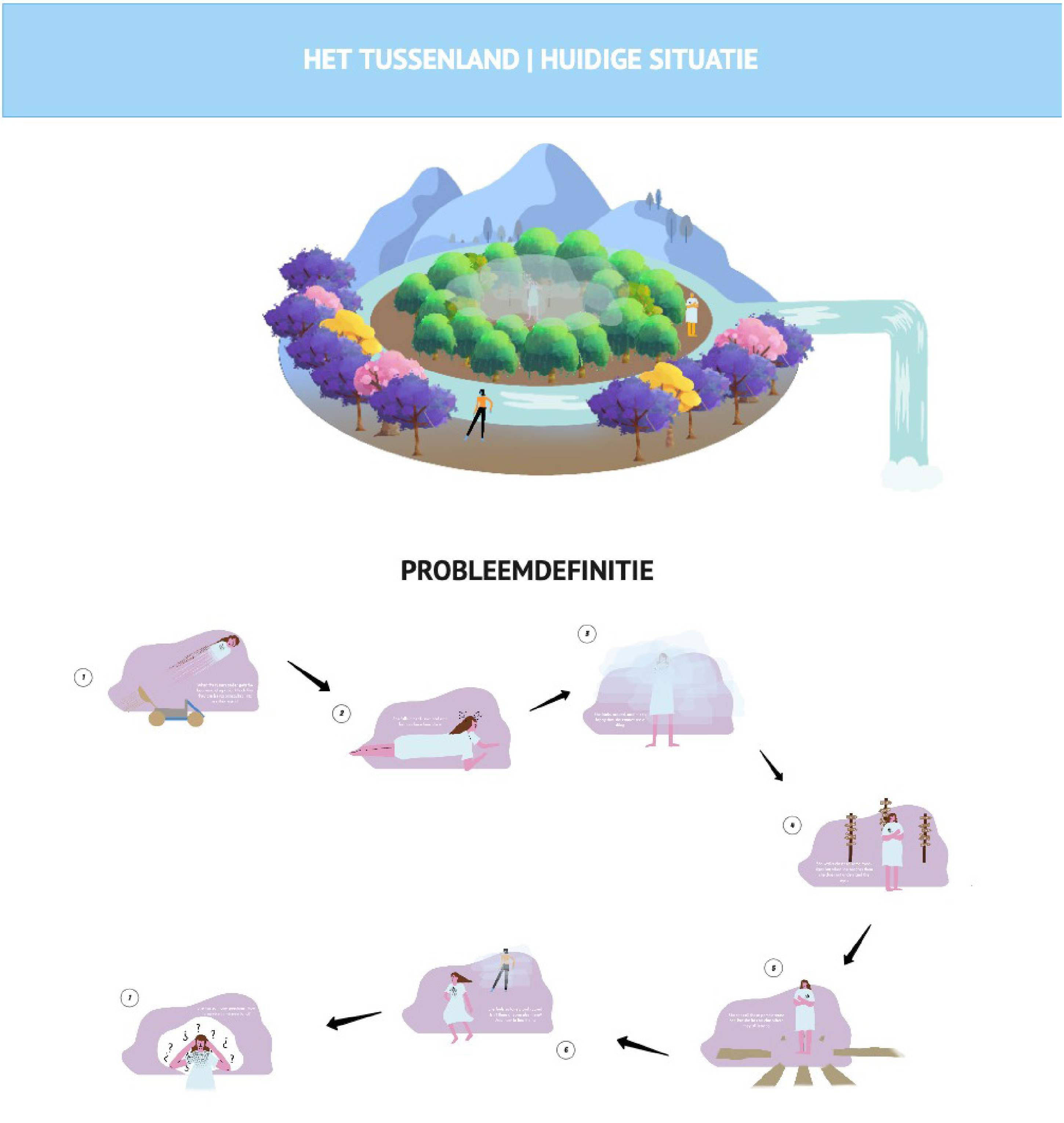


*Figure FIXME: Idea | Treasure hunt*

These boxes will be filled with experiences of other tussenlanders that have experienced these topics. The benefit of using experiences of other tussenlanders is that the tussenlander can easily relate to it. The power of 'lotgenotencontact' is that you don't have to explain anything to each other, you just simply understand becauase you are both in the same boat. By using experiences of other tussenlanders, it does not feel like a question or answer is imposed on the tussenlanderm, but it can rather be a form of inspiration to allow the tussenlander to think about this topic in a safe environment.

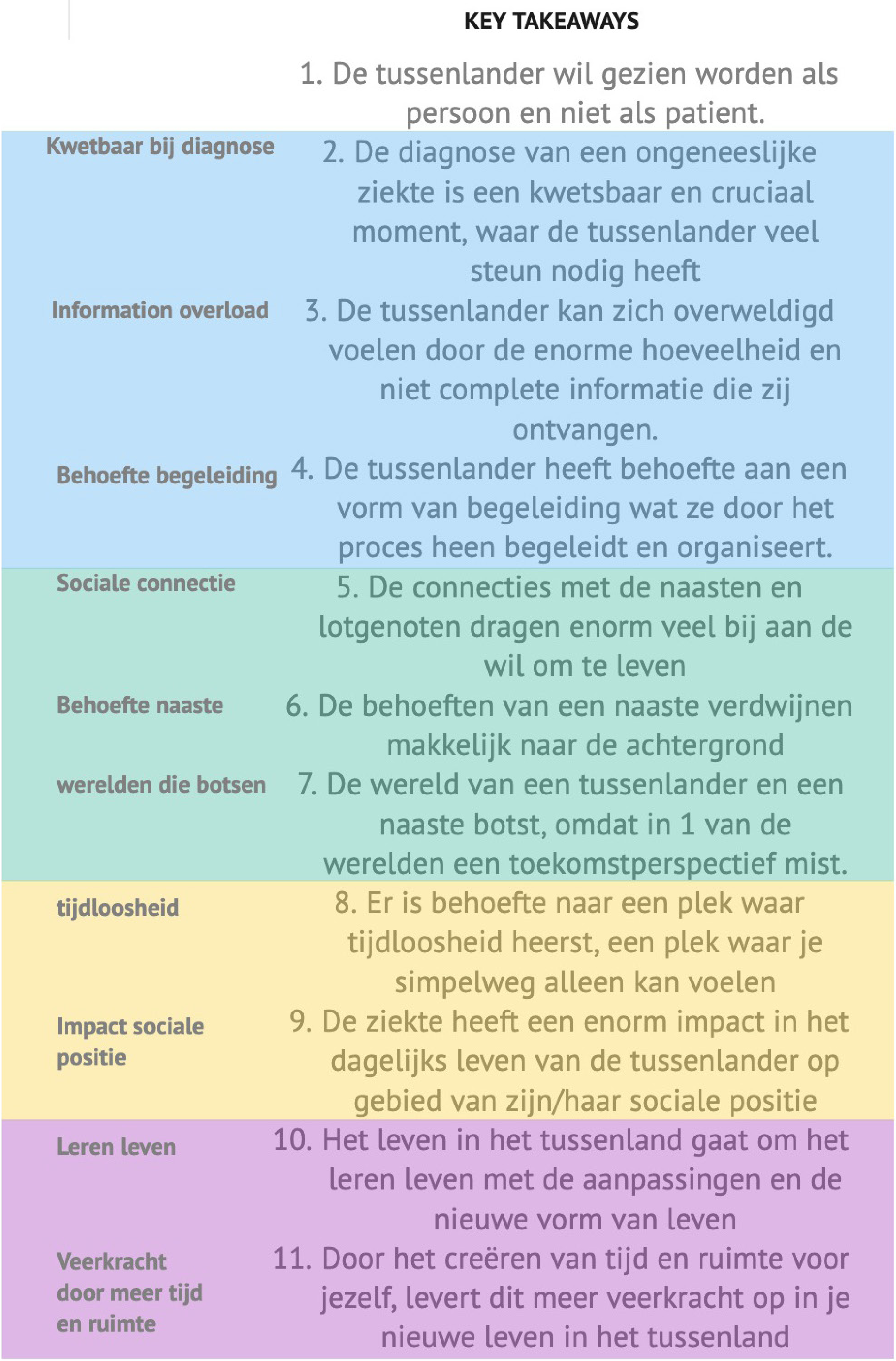
APPENDIX N

# CONCEPT EVALUATION MIRO



HET TUSSENLAND | HUIDIGE SITUATIE

PROBLEEMDEFINITIE

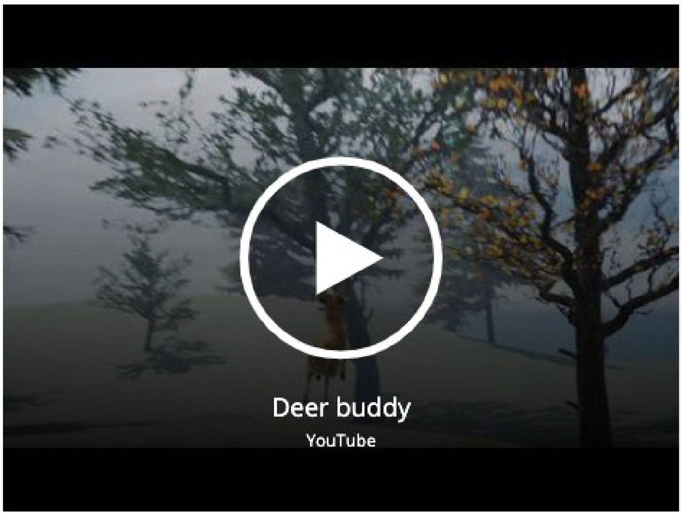


## KEY TAKEAWAYS

| | |
|---|---|
| | 1. De tussenlander wil gezien worden als persoon en niet als patient. |
| **Kwetbaar bij diagnose** | 2. De diagnose van een ongeneeslijke ziekte is een kwetsbaar en cruciaal moment, waar de tussenlander veel steun nodig heeft |
| **Information overload** | 3. De tussenlander kan zich overweldigd voelen door de enorme hoeveelheid en niet complete informatie die zij ontvangen. |
| **Behoefte begeleiding** | 4. De tussenlander heeft behoefte aan een vorm van begeleiding wat ze door het proces heen begeleidt en organiseert. |
| **Sociale connectie** | 5. De connecties met de naasten en lotgenoten dragen enorm veel bij aan de wil om te leven |
| **Behoefte naaste** | 6. De behoeften van een naaste verdwijnen makkelijk naar de achtergrond |
| **werelden die botsen** | 7. De wereld van een tussenlander en een naaste botst, omdat in 1 van de werelden een toekomstperspectief mist. |
| **tijdloosheid** | 8. Er is behoefte naar een plek waar tijdloosheid heerst, een plek waar je simpelweg alleen kan voelen |
| **Impact sociale positie** | 9. De ziekte heeft een enorm impact in het dagelijks leven van de tussenlander op gebied van zijn/haar sociale positie |
| **Leren leven** | 10. Het leven in het tussenland gaat om het leren leven met de aanpassingen en de nieuwe vorm van leven |
| **Veerkracht door meer tijd en ruimte** | 11. Door het creëren van tijd en ruimte voor jezelf, levert dit meer veerkracht op in je nieuwe leven in het tussenland |

# HET TUSSENLAND | NIEUWE SITUATIE

Het tussenland is een platform in een virtuele wereld die je betreedt wanneer je net de diagnose hebt gekregen van een ongeneeslijke ziekte. Het is een (bijna magische) omgeving en bos, waar je de onverdeelde aandacht krijgt die je verdient. Een plek voor **vragen**, voor **verbinding**, voor **rust** en ook helemaal alleen voor jou, zodat jij **je eigen prioriteiten** kan stellen. Je kan deze wereld alleen betreden, maar ook samen met een naaste vanuit welke locatie je bent, ongeacht of je samen of alleen bent.

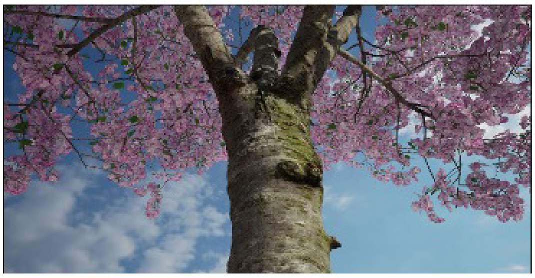


### GIDS DIE JE WEGWIJS MAAKT

Wanneer je je bril opzet en het tussenland voor het eerst binnenvalt, vangt je je buddy je op en legt uit waar je bent. De buddy benadrukt dat je die er is om het samen met je te ontdekken. De buddy is er niet om de antwoord op je vragen te vinden, dat moet je namelijk zelf doen. De buddy is er om je **wegwijs te maken in deze nieuwe wereld**, zodat je weet wat er te verwachten valt.

### LEVENSBOOM VAN ERVARINGEN EN HERINNERINGEN

Je wordt door een bos geleid, naar een boom (zonder blaadje). Elke ervaring die je meemaakt, groeien als blaadjes aan je boom. Dit kunnen ervaringen zijn zoals behandelingen, maar ook momenten zoals dat je met je werk moet stoppen, of dat je een mooie dag hebt gehad met je dochter.

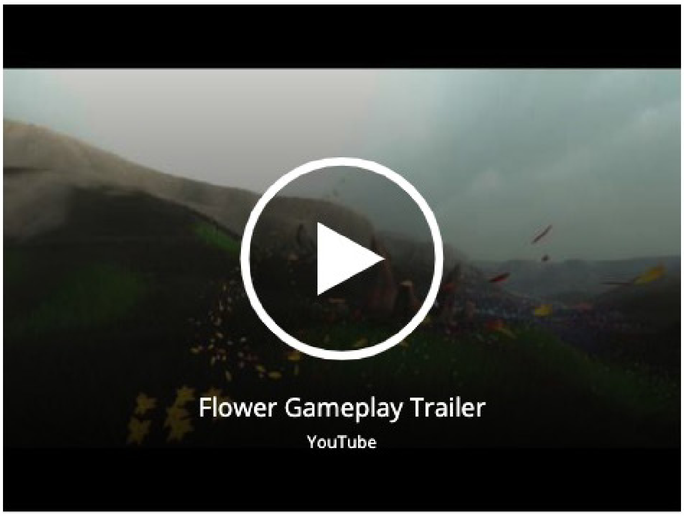


### SAMEN CREEREN VAN EEN NALATENSCHAP

Als niet-tussenlander, dus als naaste kan je ook in deze wereld komen en op deze ervaringen antwoorden of een mooie herinnering delen. Deze herinneringen verschijnen in de vorm van gekleurde bloesems in de bomen.

Je boom is ook verbonden met een app, zodat je ziet wanneer je er nieuwe blaadjes groeien, dus wanneer mensen een boodschap achter hebben gelaten,

Wanneer het minder goed gaat met de tussenlander, wordt het gras rondom de boom wat doffer en slapper. Net zoals bomen in een echte bos, zullen de bomen rondom passen op de zieke boom. Andere tussenlanders (en naasten) kunnen deze ‘zieke boom aanraken. Bij de aanraking ontstaat er een nieuw bloempje rondom de boom, waardoor het gebied wat gezonder wordt. Dit kan anoniem, maar ook met een berichtje. Zo kunnen tussenlanders elkaar (anoniem) steun bieden.



### HET BOS DER VRAGEN

Verder in het bos zijn er thema's te vinden van vragen die er allemaal spelen wanneer je ongeneeslijk ziek bent. Je kan samen of alleen deze thema's aangaan wanneer je dat wilt. Dit zijn praktische thema's zoals gezondheidsvraagstukken, werkgerelateerd, financieel, administratief, relaties etc. Maar ook persoonlijke levensvragen die je voor elkaar hebt, de vragen die meestal worden uitgesteld tot het sterfbed

### AAN BOD STELLEN VAN THEMA'S DIE ER TOE DOEN

Wanneer je een doos samen opent, zullen er ervaringen rondom dit thema tevoorschijn komen. Wat veranderde er voor anderen op financieel vlak, en hoe gingen zij hiermee aan de slag? Maar ook vragen zoals: hoe denk je dat het leven straks zonder mij zal zijn? Of zijn er nog dingen waar je spijt van hebt? Uiteindelijk ontstaat er een database aan ervaringen en verhalen waaruit je veel kan leren en je eigen conclusies kan trekken. Ervaringen die je misschien prikkelen om het hier met je eigen naaste over te hebben.

# DE JUISTE INTERACTIE IN

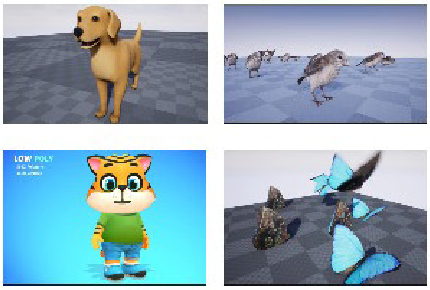
## HOE BELAND JE/KOM JE AAN IN

A. je valt erin

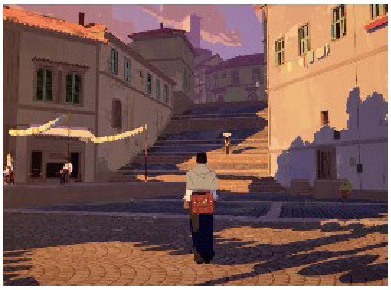
B. het is donker om je heen, en het wordt steeds lichter

C. je staat er al in, als j opent 🟩

## HOE ZIET JE BUDDY



A. dier (vlinder, hond, kat, vogel, hert)



B. mens

C. voorwerp

## JE BUDDY INTRODUCEERT

A. je naam te noemen 🟩

B. je hand vast te pakken en je overeind te helpen

## DE BUDDY LOOP

A. voor je 🟩

## OM JE HEEN HOO

A. muziek

# HET TUSSENLAND

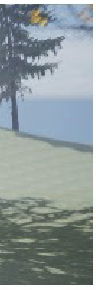
HET TUSSENLAND?

[✓ je je ogen]

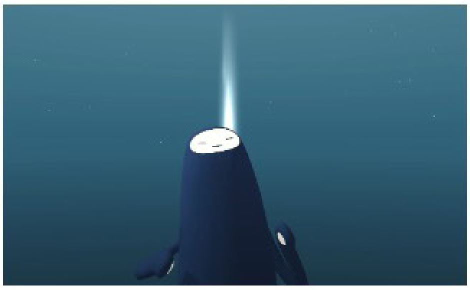
D. je wordt erin geschoten zoals een katapult

E. een mist die minder dik wordt

ERUIT?



[✓ D. natuurverschijnsel (lichtje/bloemblaadje)]



E. fictieve animatie

ZICH DOOR...

C. je uit te leggen waar je bent

[✓ D. met gebaren aan te wijzen waar je naar toe kunt.]

T ....

B. naast je

R JE...

B. bosgeluiden

APPENDIX 0

# FIRST CONCEPT EVALUATION RESULTS

***DvD | 53 y/o | project manager, husband and father, and tussenlander with the disease of Kahler.***

**The current situation in het Tussenland**

- The relationship between you and your loved one depends in which stage you are of the disease.
- One of the first question people have in het tussenland is how much time they have.

**The envisioned concept**

- It is tricky to have an open platform with cybercrime in mind. There is a lot of sensitive data.
- Privacy law with medical data can differ the process. It would be beneficial and more safe to connect the platform to (academic) hospitals.
- A lot of people, especially elderly are digitally iliterate. A foundation that provides educational digital cafes can be an initative that educates digital iliterate people. It is also beneficial that it can operate from a safe and trusted space.
- It would be smart to sponsor the VR hardware by academic hospitals, because they have a great network and are high-secured. An additional feature for the people who regularly visit the hospital is that this concept offers a platform where they can easily meet other tussenlanders where they can share their stories.
- It would be nice to a three layered security level. One for the tussenlanders, one for the loved ones, and one of the interested people.
- The woods can be scary, it could come back in your dreams. It would choose for a beach, with dunes and soothing sounds of the birds and waves.
- In our webinar for Hematon, the wants and needs of the patient are used for discussion with care professionals. It is a different kind of interaction, where different disciplines can shed light on an unambiguous topic together
- With this platform you can help people explore this world, but also give training where care professionals in your community can give tips and tricks
- Different people fight different demons. So elderly people are maybe more occupied with topics like patient-doctor communication, while younger people might be more interested in how the topic of sex changes for them. In this concept it could be nice to connect a psychologist, that can introduce and guide these themes and also look what would fit every individual.
-

**The preferred interaction**

- The beginning scene of the matrix, where everything around the persons stands still. Because that is how it feels when you get the diagnosis of an incurable disease.
- In the movie Philadelphia, the man walks next to the skyline of Philadelphia, from dusk to down, rain to sun. So when someone is sick, it feels like the world stands still. But that is not the case in real life, it even feels like everyone around you is going faster than ever.
- It would be nice if the guide would be a combination of an object and a natural phenomenon, like a leaf. A leaf can float through a whole landscape, and get in contact with a lot of elements. It goes on for 4 seasons.
- Humans are part of nature. We can be a seed that is part of a tree. When the seeds grows out into a tree, you get the diagnosis. As a leaf, the tussenlander literally is an unwritten plain leaf. And from that notion you can share your experiences but also get them
- In the first phase the guide must welcome you and stand in front of you and greet you warmly: how do you want me to address

you? How do you feel at this moment? Are you open to make the walk with me?

***Jannie | 60 y/o | writer, wife and mother, and tussenlander that has breastcancer***

**The current situation in het Tussenland**

- In your life there are two roads, the road as a patient, but also the road where you are living, that gives your happiness and pleasure. I would like to see more of that second road

**The envisioned concept**

- The role of other tussenlanders is too big. I would look more into the role of care professionals, they are the ones who your interact with, that guide you and give your the information you want to know,

**The preferred interaction**

- Preference for catapult interaction, because it really emphasizes the fact that this is something that overcame you.
- A dog is a fitting guide, because it is such a loyal subject. You need a buddy that follows you and can lead you
- A natural phenomenon can be a beautiful way to convey certain processes that people endure and experience.
- The guide definitely needs to call your name and help you understand where you landed.

***S. | 28 y/o | son of a patient with the disease of Waldenstrom***

**The envisioned concept**

- The tree is almost like a christmas tree, that you can decorate together. I think it is a medium that you can support someone in an accessible way
- The boxes with questions really appeals to me, because addressing these questions is too loaded in our environment.
- This world can still seem very lonely to me
- Important question is our heritance. My dad has a lot of stuff, some of emotional worth that contain a lot of stories. These stories will disappear whenever he dies. It would be nice to have something that could help to collect these stories.

**The preferred interaction**

- People can be very digitally iliterate, so i recommend that your are already at your tree immediately when you put on the glasses. You want people to feel control whenever they enter this world, not a world of panic and uncertainty.
- Maybe a guiding voice is enough. The most magical part of this world is your own fantasy. Whenever you give something a physical entity, it can lose this part of your fantasy,
- Other people can look like butterflies. It is beautiful insect, that has not any strong associations, that you can easily customize (colours, pattern, size etc)
- Very important to call your name and explain where you are
- Preferably the guide would walk next to you, because then it is more in your hands how to engage this world.

***Teun Aalbers | Game designer of the 'wijsheidscoach'***

**The envisioned concept**

- Is it relevant for non-tussenlanders to be in this VR world, can they join from behind their desktop.
- The notion that you can build something together, so that you can still create something together in this stage, that is very valuable
- Whenever you facilitate a certain behaviour or feature, you give people the expectation that they should behave this way. This can scare of people and deprive them of they autonomy.
- The box of questions is something that is

new. This kind of onboarding, seems a safe way to reflect on your own issues. It is important though that these experiences people see should correspond with their own experiences

**The preferred interaction**

- I would not do the catapult, because it is something that comes to close, to hurried. I would choose the option that you are already in this world when you put your glasses on
- An animal or natural phenomenon would fit this world the best, in terms of style. I would choose an animal as it can offer more interaction.
- It would be nice to hear your name, unless it is spoken like a robot. So you need to find AI that can transform text into reasonable natural speech.
- All the characters in this world could be deers, but that you can customize one thing. So a deer could get a big hat, or mustache so that you can easily recognize the person with a simple gimmick.

***Myron | 24 y/o | son of a deceased tussenlander***

**The envisioned concept**

- The idea of the woods seems conceptually strong to me. But I cannot really imagine if an VR experience can be as spiritual and immersive as being in real woods.
- There are a lot of conversations and things that you wish you had talked about with your loved one. But I did not feel fully equiped to sense that I had these needs, while you knew at that time it is now or never. So some guidance in engaging these topics could be really helpful.

**The preferred interaction**

- Large displacements can cause nausea for new VR-users
- The catapult or falling simulates the moment of diagnosis. I don't know if you want to evoke these feelings again. It would be better to start the game in a soft and tranquil way, so the user knows that he or she is in good hands.
- The mist is for me the most interesting one. The mist can slowly fade away, and slowly the world starts opening up.
- In my mind the buddy cannot speak. As a designer I always find it elegant when the guide does not need any language. That it can build trust based on the way it looks, mimes and sounds.
- Initially the buddy must walk in from of you. Gamewise that works the best. You have to give the user the time and space to find out yourself where to go in this world. So at a certain moment the buddy can walk next to you, but at first the user needs an objective.
- Sounds of the woods are a must. The sound is very important.

***Rob Bruntink | Writer and expert palliative care***

**The current situation in het Tussenland**

- Not finding the connection with your loved ones after diagnosis can lead to existential loneliness ('existentiele eenzaamheid').
- I miss the notion that tussenlanders are living in two realities: the reality that focuses on their disease and death and the reality where they live their life to the fullest.

**The envisioned concept**

- Unique way of giving people information but also offer consolation. I can also imagine that this world can be a meditative world.
- The basis of giving someone a world in VR, where they can come to their senses and where they can ask their questions, is incredible. Especially because you can share it with your loved ones.
- Maybe in the box of questions you can

also add the topic of digital legacy. So what will happen to your social media account, with your bitcoins etc.
- It gives tussenlanders peace of mind when they already arranged certain practicalities. It also unburdens the bereaved, which also unburdens the worries of the tussenlander in some sense
- Maybe nice if you could give it a name, so that you can also place it in your personal world.
- It would nice if you could integrate other VR applications in this world, like a VR world where you can trael, go the beach, your birth city etc. It would be nice to have an escape-like path where your can get to these experiences
- Into what extent is it possible for the tussenlander in this VR world to add any elements?
- Without VR you could not visualize these things. I think that you found the right tone, it is not too gloomy and not too bright.

**The preferred interaction**
- You would fall in immediately. I would not choose the catapult and the mist. But it would be nice to have some form of transition, so that you would not immediately be in this world.
- The guide should call out your name in combination with and explanation where your are. it is a complete new world, so it would be nice to have an explanation
- The guide has to walk in front of you in the beginning, because he knows this world so he clearly is the guide. When you are longer in this world, he can gradually transform into a partner/buddy and walk next to you.
- Nature sounds are always good, music can create aversion from certain people

***Peik Suyling | Social designer and owner 'alswoordenbloemenworden'***

**The current situation in het Tussenland**
- For people with an incurable disease their sense of time changes. You have the rational time, the timeline we are used to. But you also have the 'lived time'. These two forms of time co-exist, where in the 'lived time' people are aware that they spend their times so that they can experience beautiful moments.

**The envisioned concept**
- The metaphor of a tree where connections happen seems like a good goal to me. It feels safe, and doable for the users.
- If you open the information of your tree to other tussenlanders, it has to be your own choice. Maybe you should give them the option to keep it open or private. And build different layers in it, so that you don't have to share your diary-like thought, but share more factual information like a fieldtrip with your daughter.
- For the box of questions it would be nice that if you already had a certain question beforehand, that something can lead you to the right box immediately.
- I think that the boxes of question will work, because you have a whole new layer of information that is traceable in this magical world.
- In this world the magical touch is important, the fairy tale like touch. I think it is a safe way to let people be immersed in this world. If their is magic which is embedded with carefulness, respect and time and you find a way to convey this in images, movements and interactions, then this will defintely work.

**The preferred interaction**
- If I would arrive in het tussenland, I would want to immediately arrive in the woods, I don't see any value in letting people

experience the feeling of their diagnosis again. But you could use this metaphor of the diagnosis to show people that this is the route a past tussenlander experienced, to explain you why and how you land in het tussenland.
- For the buddy/guide a deer seems suitable to me, a magical creature. Or a butterfly or bird. Your tool already expresses a magical feeling and it would be nice if the buddy would have the same charge.
- The interactions must be close to the interaction in reality. So I would not want the tool to immediately know my name, but that it gradually will learn my name. It is key that it doesn't feel automated. You must be in charge in what you do and experience.
- The buddy can walk in front of me. It gives a kind of promise of a magical world that leads to something.

***Christiaan Rhodius | Palliative care doctor***

**The current situation in het Tussenland**
- After the diagnosis you are also not sure what you want.
- Maybe it not hard to find other people, but how to find them and connect to them at the same time.
- Instead of surviving in het Tussenland, it rather is how to make it the most beautiful and meaningful. So it is not about trying to get rid of things, but also about adding new elements.

  Quote: 1 van de dingen die ik graag benadruk in de palliatieve geneeskunde is dat je niet alleen wegpoetst, maar ook iets weet toe te voegen"

**The envisioned concept**
- The power of this platform is that you empower people to add something valuable to this platform
- It is possible that non-tussenlanders can leave negative comments or remarks. Remarks with a good intention, can be experienced as ill-mannered.
- If you are going to build a tree, you would also want the option to first educate people in what is needed. Or the possibility to remove comments.
- By remarking beforehand that some people don't know the right words to convey something, that also might take the sting out already.
- In the hospice we make use of the metaphor of stones that we connect to a painful memory. By addressing this memory and by taking a distance from it, it can take a huge load from someones shoulder.
- It would be nice if the tree would not only contain the beautiful parts of life, but also the process of the sad parts in life, e.g. that you finally had the courage to talk to your daughter about how her life would look like without you.
- In the box with questions a careprofessionals can walk around and see what their patients struggle with.
- A lot of people are lost and confused, that they cannot formulate and put their experiences in words. This tool could assist them.
- One of the things in het tussenland is that your needs constantly change. So it would be nice if the themes in the box of questions would change every now and then.

**The preferred interaction**
- For the entrance in het Tussenland it is important where it begins. Who hands the glasses over to you?
- The kind of disease influences how people land in het tussenland. For people with cancer it feels like they are catapulted, while for elderly people it feels completely different.
- For the buddy I have preference for an

animal or a natural phenomenon, that seems most in place in this world.

- It is important that the buddy says your name. The tone of voice of the buddy is important. It must not address you in an all-knowing tone: “ anderen zijn jou voorgegaan en die hebben me een aantal dingen geleerd en hebben me gevraagd dit door te geven. Gegeven alle verhalen en ervaringen van andere mensen, is dit denk ik het beste wat we je kunnen bieden.
- Emphasize that the experiences you give, also brings a big contribution in welcoming new tussenlanders in the future.

***Cecilia | 59 y/o | wife and mother, and tussenlander with breast cancer***

**The envisioned concept**

- I am overwhelmed, I think it is a beautiful concept. It seems like a beautiful form of a diary or blog, where others can comment on.
- Too me it looks approachable and playful
- I would like to receive experiences of other people by a voice over telling the story.
- My own experiences I would like to convey them through writing, but also have the option to make a voice over when needed.

**The preferred interaction**

- I would choose that whenever you put your glasses on, that you are immediately in that world.
- For the buddy the natural phenomenon, so the flower petals, are the number one. Because it is light, magical and mysterious.
- The buddy has to walk in front of you
- I would primarily go for the nature sounds.

Designing for the journey of palliative care patients to 'Het Tussenland' project title

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

start date 26 - 08 - 2021

07 - 04 - 2022 end date

## INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

Bardo is a Dutch high care hospice where palliative care is offered 24 hours a day. Their team focuses on improving the quality of life for the patient and their loved ones. The care they provide is inspired on the 4 pillars of palliative care: physical care (e.g. pain or symptom relieving), psychological care (e.g. anxiety, sadness, depression), social care (e.g. social support, connectedness) and spiritual care (e.g. value and meaning of life, connection to religion or nature). For many people this type of care is of inestimable value. But still many patients, doctors, nurses and also our society associate palliative care with death, while palliative care is much more than reaching the end of your life, as it is also about how to make the remaining time as comfortable and meaningful as possible. In the four phases of palliative care, it can be seen that the longest timeframe consists of the disease-oriented palliation and the symptom-oriented palliation, two phases that overlap and gradually flow into each other (see fig. 1). These phases explain how the type of palliative care develops over time. But what this figure does not explain is how the patient experiences it. From the moment a patient's disease is incurable, they arrive in 'het Tussenland' ('in-Between-Land'), a place where on the one hand they experience and feel their normal life, and on the other hand are occupied with their disease and death. Many people live in this 'Tussenland', but miss guidance to this new place. What does it look like for them? And how to live and act in this 'Tussenland'?

There are certain barriers that prevent patients and doctors to integrate palliative care in an early stage, as many doctors are educated to heal a patient physically. Their approach is medical-technical, while some patients are in need of a human-social conversation. Not only will this integration of palliative care in an early stage improve the quality of life for a patient, it can also save money. By looking at the patient with a palliative care-mindset it can prevent over-treatment or unnecessary hospitalization. Another barrier is that death is still a topic that we rather not talk about in our society. And as palliative care is often related to death, it is something that patients and their loved ones rather not think or talk about. But talking about the topic death is very important, as a deeper understanding can improve the palliative care and the quality of life of patients.
Design could support such conversations between caregivers and caretakers about this in between land. However, such a design should fit the context of palliative care. Digitalization in the care sector has improved the medical care for the patient for the better. Medical digital devices (e.g. heart monitors, oxygen pumps) are of inestimable value and the digitalization in care offers more opportunities in offering optimal care despite time and place. But the use of technology is a double-edged sword. In our culture technology and care can be perceived as opposites (see figure 2). How our culture thinks and operates is dominated by a form of technical rationality that leads to pragmatism and utility thinking (Leget C., 2012). The type of technology that is currently embraced on a bigger scale in hospices are more based on the physical care pillar (medical digital devices). Although design has already been used as a means to improve the quality of life regarding all 4 pillars, a lot of these toolkits or initiatives could not be fully integrated in the palliative care. Bardo has expressed its interest in designing with new technologies like virtual reality, as it has proved to have a positive impact on the patients. Therefore, I want to to find this connection that enables a digital product/service to be fully integrated in the palliative care. Through this connection I want to enable barco and palliative care in general, to be more embedded in our society. To reach this scope, digitalization and new technologies (with the focus on virtual reality, augmented reality and mixed reality) can accelerate this transformation in palliative care.

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Initials & Name Z.J. Zheng Student number 4397592

Title of Project Designing for the journey of palliative care patients to 'Het Tussenland'

introduction (continued): space for images

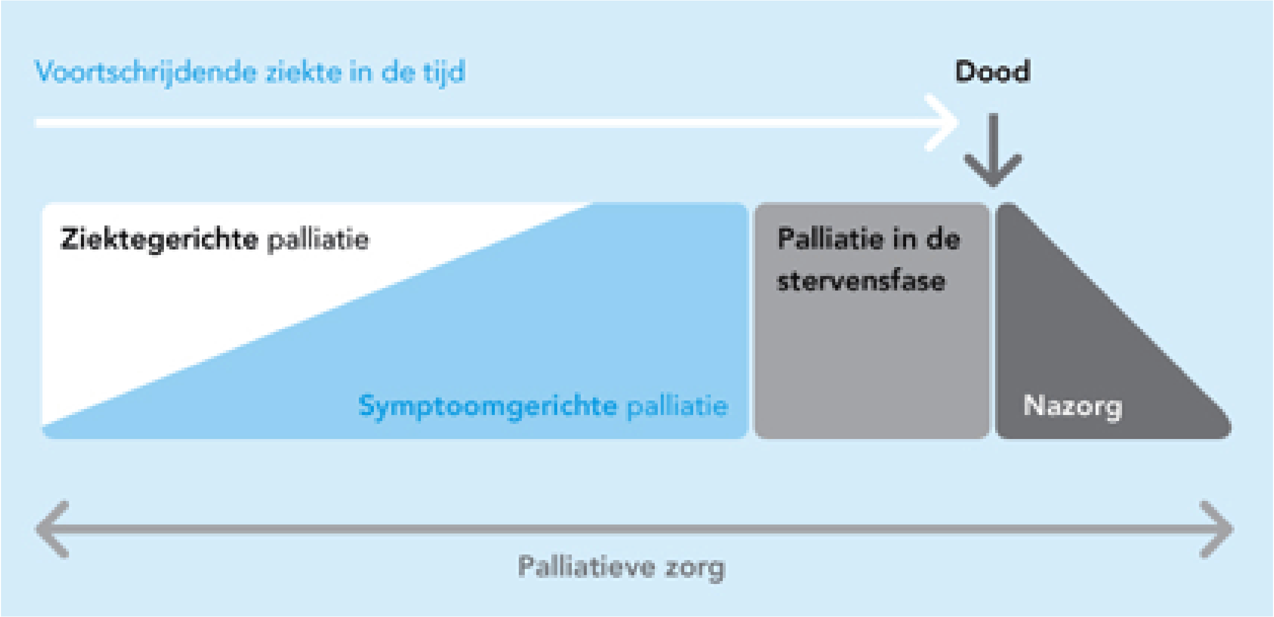
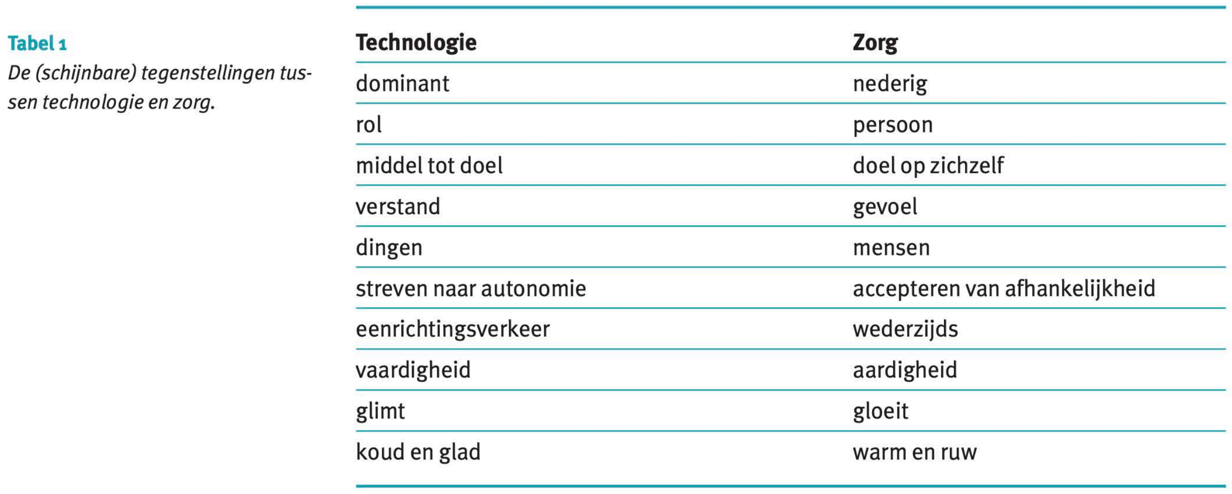


image / figure 1: The four phases of palliative care



**Tabel 1**
*De (schijnbare) tegenstellingen tussen technologie en zorg.*

| **Technologie** | **Zorg** |
|---|---|
| dominant | nederig |
| rol | persoon |
| middel tot doel | doel op zichzelf |
| verstand | gevoel |
| dingen | mensen |
| streven naar autonomie | accepteren van afhankelijkheid |
| eenrichtingsverkeer | wederzijds |
| vaardigheid | aardigheid |
| glimt | gloeit |
| koud en glad | warm en ruw |

image / figure 2: The (perceived) contradictions between technology and care (Zorgtechnologie, 2002)

## PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

In the case of patients with an incurable disease their life embarks on a new direction: 'Het Tussenland'. This is a place where quality of life is very important, but also the quality of death. But people are diverse, so 'Het Tussenland' can look different for all of them. How does this 'Tussenland' look like, and how can we guide them to this place. How can we create a place where we can both find out about the meaning and value of life but also learn about our mortal side and deal with that.

As it is a very delicate topic that touches a lot of people in our society, the solution must be designed with great sensitivity in mind. Therefore, it must fit in the whole system around the hospices, our society and the current market.
These issues let to the following main question:
How can design support and guide people who are facing a life-threatening/incurable disease and their loved ones on their journey through 'het Tussenland' that can be integrated in the palliative care within a hospice?

This main question can be divided in the following sub-questions:
1. How and what does 'het Tussenland' look like for patients and their loved ones?
2. How can a product and/or service guide the patient and their loved ones to and in 'het Tussenland'?
3. How can the product and/or service be implemented in a broader scope where palliative care and hospices are connected to society?

What must be taken into consideration is that the context of palliative care can be hesitant in implementing new technologies in general. Therefore, I want to take this into account, without being discouraged from the use of any technologies like VR, AR and mixed reality

## ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, ... . In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

Design a product and/or service that contributes to the journey of the patient to 'het Tussenland' (the transition area between life and death) that can be integrated in the palliative care within a hospice in order to improve the quality of the remaining life but also face the nearing death. The design should fit the context of palliative care, where technology might be experienced as inappropriate

As it will be a double degree graduation project, the assignment can be divided between two sub-aims that are intertwined with each other, where both of the masters are present. The first aim is to define how people with a life-threatening or incurable disease and their loved ones can explore and create their own 'Tussenland', where all 4 pillars (physical, psychological, social and spiritual) of palliative care are present. How can design guide them in this journey through 'het Tussenland'. The solution that is expected is a product or a product-service system, where ergonomics, technology, aesthetics and culture play a big role. To achieve the first sub-aim the following sub-aim is of utter importance. To understand the problem's scope, there should be an understanding of the context factors and all the stakeholders to reach new possibilities. It is important to perceive the whole system, and understand how patients, loved ones, caregivers, doctors, hospices etc. relate to palliative care in our society and culture. So a strategy will be proposed how the product would fit in a system where the interconnections and feedbacks are identified so that we reach a complete understanding of the behavior of the network around the patient. I strive to create a strategy and product that can be implemented on a bigger scale, where other hospices besides Bardo will be able to use it.
This whole project will be an iterative process where co-creation, literature reviews, expert sessions will contribute to the validation of the design.

Initials & Name Z.J. Zheng Student number 4397592

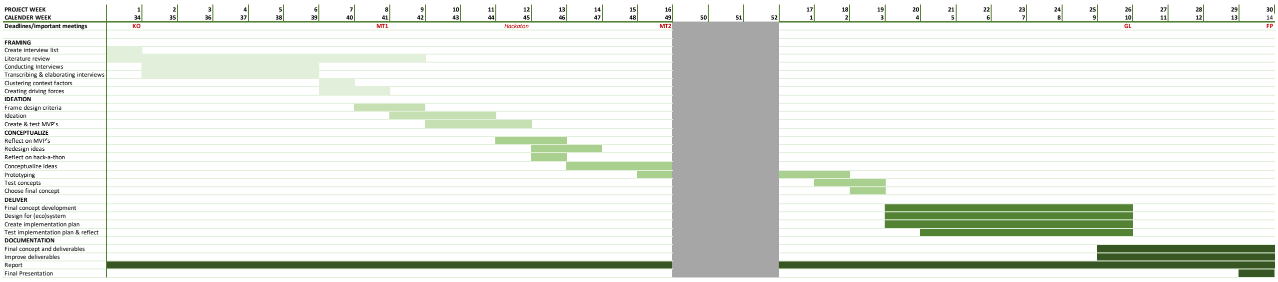
Title of Project Designing for the journey of palliative care patients to 'Het Tussenland'

## PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and 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 activities.

start date 26 - 8 - 2021

7 - 4 - 2022 end date



For my graduation project, I am combining the learnings from my bachelor with my internship: on the one hand the double diamond method and the iterative processes learned in PO1 and PO2, and on the other hand my internship where they made use of the Reframing method (VIP). I chose to only incorporate a part of the VIP method (the first phase framing) because this is the part of the method that I have the most positive experience with. For me in the past the research part was lacking in structure, so this will really help me out. I will proceed with the phases ideation, conceptualize and deliver. As I explained before this is not a linear process, but an iterative process. As the graduation project is a double degree master, I decided to have two Milestones instead of one Midterm, to have a better grasp and control on time for my project.

## MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, ... . Stick to no more than five ambitions.

As a social impact designer, I always found it interesting to design for the topics that are painful or uncomfortable to talk about, but necessary and needed in our society. One of these topics is the end-of-life. It is something that everyone in life has in common, which is part of your life, but so difficult to talk about. In the past I also wrote a short paper for my chair Marieke Sonneveld for the course Context and Conceptualization about this topic and it showed me that there was so much more to explore in this topic.
People in the palliative care already know that the end-of-life is nearing, and are put in the impossible situation and threshold between life and death. My personal motivation is to improve their quality of life, as it is already a stressful and painful situation. I believe that more recognition of the end-of-life also improves our ability to design for the end-of-life.

I think one of the best acquired competences that I learned during my Bachelor degree, Master degree and internship was my empathetic and deep interest to really understand the topic and see it from different perspectives. This enabled me to dive deeper, and really find the pain areas in our society that are so obvious but still not designed for. In a topic as complex as the end-of-life I feel that I need to really implement this competence but also use it in a responsible and ethical manner. This mindset also enabled me to out-of-the-box brainstorming, the area of design where I feel most comfortable with.

Competences that I have yet developed and want to improve is detailing and the finish touch of the project. I noticed that in some projects that I have zero difficulties with starting a project, but I have difficulties to maintain the same level at the end of the project as there are more 'restrictions' and requirements to stick to. This detailing also means that I want to improve my way of presenting the end result in terms of style and aesthetic.
Moreover I want to improve the viability of my project, as I feel that I quite control the desirability and feasibility part.

My personal learning ambitions are as followed:

1. Achieve in-depth knowledge on palliative care and the end-of-life to make it more approachable and less taboo in our society
2. Define my personal work method, where I will be able to combine my SPD and IPD knowledge officially for the first time on a project. In this personal work method, also aspects learned from my internship will be present (the Reframing method)
3. Determine if a long individual project, is something that suits me, as I am considering the possibilities of freelancing after graduation
4. Determine what it takes for an idea to be actually implemented. So not only design for the desirability for a single user group, but see how it fits within the whole system or ecosystem

## FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

Initials & Name Z.J. Zheng Student number 4397592

Title of Project Designing for the journey of palliative care patients to 'Het Tussenland'