LIBRA CARE

An interactive tool that stimulates **ACTIVE PATIENT PARTICIPATION** to create **CUSTOMIZED CARE PLANS** that contribute to trauma patients

QUALITY OF LIFE

Master Graduation Project
MSc Strategic Product Design (TU Delft)
Author: Lynn Broos
Supervisors: Lianne Simonse & Paula Melo Signerez
Client: Kolonel Henk van der Wal
Company: Civil-Military Centre of Expertise for Trauma Care (CETC)
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Faculty of Industrial Design Engineering

Delft University of Technology

Contents

Summary

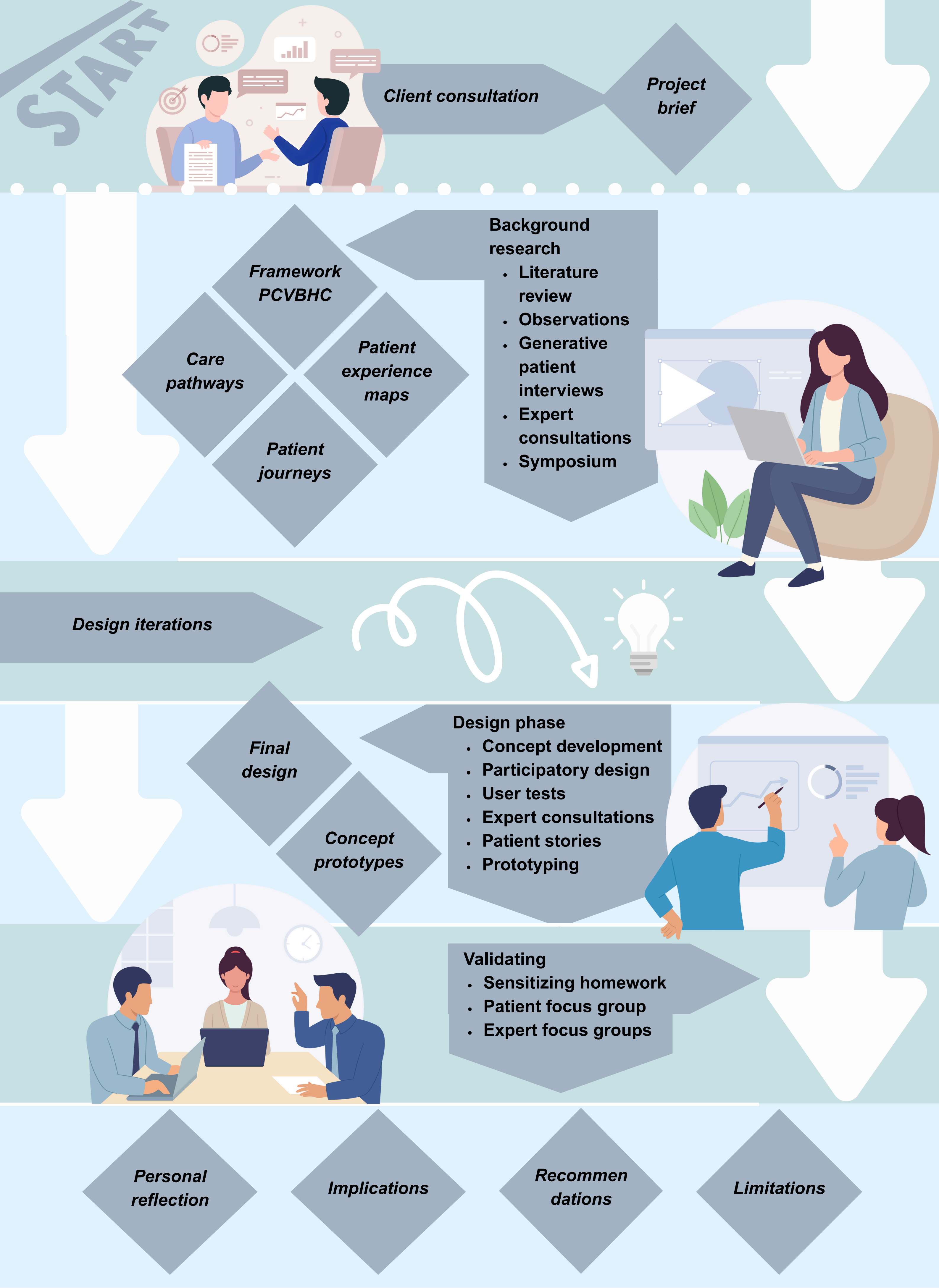
This Strategic Product Design graduation project is carried out on behalf of the Civil-Military Centre of Expertise for Trauma Care (CETC). Based on insights from the research phase, the design direction iterated two times and evolved into *‘an interactive tool that supports person-centred value based health care (PCVBHC) during trauma rehabilitation, by making patients more actively involved in the design of their customized care plan and by facilitating effective interdisciplinary goal-setting. Additionally, the tool aims to help patients with acceptance, as this makes an essential contribution to quality of life’.*

The designed tool is called Libra Care, which refers to *‘care that is in balance’*. This means that the optimal customized care plan is created with medical input from the health care provider, but also with personal input from the patient. Patients are the only ones that can determine the value of various health outcomes for their quality of life. And therefore, Libra Care provides support for patients to actively participate in the process of aligning care provision with their personal values, goals and preferences.

Libra Care uses a guided exercise in combination with generative techniques and mind-switching to elicit personal values and the things that are important in the life of this patient. These techniques are used to extract deeper and more valuable personal information. The generated ‘What matters to me’-dossier is the starting point for consultation with different health care providers, and supports expectation management, shared decision-making and personal goal-setting. All goals a patient works towards with different health care providers are documented in relation to the overarching goal and patient reported outcome measurements (PROMs) they support. This ensures that health care providers can align their care, facilitating effective interdisciplinary collaboration. Regular patient reported outcome measurements (PROMs) ensure continuous patient involvement and evaluation.

The information in the dossier can also be used by psycho-social workers to support conversations about acceptance. The dossier helps to broaden a patient's perspective, by making them realize that most of what is important to them remains unaffected by the trauma injury. Personal goal-setting focuses on what is still possible for the patient (or could be possible in the future).
Libra Care provides patients with the opportunity to explore the coping strategies of other patients. This will help them to realize that quality of life can be achieved in many ways and that their losses can often be mitigated or compensated. Within Libra Care, patients can share their experiences, concerns, and emotions. Feeling supported and connected with other patients supports mental, physical and emotional health, and it improves the capacity to cope with losses.

Although the desirability and value of the tool was proven during patient and expert focus groups, the project and design have some limitations. Therefore, recommendations have been provided for further research and testing. The implications of this project offer actionable insights for transforming health care practices and policies, ensuring that care remains person-centered and value-driven, despite the challenges posed by increasing healthcare demands.



Client consultation

Project brief

Background research

- Literature review
- Observations
- Generative patient interviews
- Expert consultations
- Symposium

Framework PCVBHC

Care pathways

Patient experience maps

Patient journeys

Design iterations

Design phase

- Concept development
- Participatory design
- User tests
- Expert consultations
- Patient stories
- Prototyping

Final design

Concept prototypes

Validating

- Sensitizing homework
- Patient focus group
- Expert focus groups

Personal reflection

Implications

Recommendations

Limitations

Figure 1: Visual overview master graduation project

Chapter 1: Introduction

This Strategic Product Design (Delft University of Technology) graduation project is carried out on behalf of the Civil-Military Centre of Expertise for Trauma Care (CETC).

1.1 The client

The CETC is a collaboration between the Dutch Ministry of Defense and the University Medical Centre of Utrecht. This partnership between military and civilian sectors aims to contribute to improving trauma care. On one hand, civil trauma care enables new technologies and innovations to be tested and developed. Eventually, the new tools, procedures, and treatments can be transferred to the military trauma context. Additionally, military surgeons are trained within the civilian trauma care chain before they do practical work on deployment. On the other hand, the civilian trauma care sector benefits from the hard-won lessons from the battlefield. It has happened before that procedures and methods from the battlefield have been adopted by the civilian care sector. By integrating the military and civilian trauma systems, the CETC aims to achieve zero avoidable mortality and minimize disability after injury for both military personnel and civilians.

The CETC focuses on the research domains of complex acute care, psychotrauma and value based health care, as well as the themes of data, education and patient participation. This graduation project contributes to the domain of value based health care and the theme of patient participation.

“By applying the principles of value based health care to the trauma care chain, we contribute to improving the quality of life of patients. By using patient reported outcome measurements (PROMs) and stimulating patient participation, we gain insight into what is really important for patients and give them and active role in optimizing trauma care” (vision CETC, 2025)

1.2 Why strategic product design?

In order to contribute to the above vision, the CETC aims to develop an interactive and generative tool that contributes to value based trauma care, by giving the patient a more active role within their care pathway. The tool empowers patients to actively participate in the customization of their care plan and facilitates health care systems to transition towards person-centred and value based health care. In short, there is a need for the development of an innovative design intervention that creates meaningful impact for both trauma patients and healthcare providers. The inspiration for this assignment was the Metro Mapping tool, a service design tool developed and validated by a team of designers in collaboration with health care providers and patients. But since this tool is not suitable for the complexity of (poly)trauma care, there is a need to develop a tool specifically suitable for the domain of trauma care, both for military and civilian patients.

Strategic product design is a field where design meets strategic innovation. It aims to co-design meaningful innovative interventions and transitions that create a positive impact, aligning with the desire of the CETC to develop an innovative design intervention that creates meaningful impact for both trauma patients and health care providers. Strategic product design recognizes the importance of close collaboration with multiple stakeholders to gain control over complex contexts and co-create future visions, strategies and value propositions from a multi-stakeholder perspective. And this is exactly what you will encounter when reading this report. During the exploration of the context, there was close collaboration with multiple stakeholders, including generative patient interviews, which led to two iterations of the design direction (as will be explained in chapter 9). But also during the design phase there was close collaboration with various stakeholders in a process of co-creation, resulting in multiple design iterations (part 3). And lastly, during the validation phase (part 4), I worked with patients and experts in focus groups to map the value of the tool and make recommendations (part 5). In total, 21 people were involved in this graduation project.

1.3 Project brief

Within the initial project brief the following design goal was formulated: ‘to develop an interactive tool that stimulates and enables shared decision-making for polytrauma patients, in this way contributing to person-centred value based acute trauma care’. However, during the exploration of the context it turned out that such a tool was not suitable for this specific context for multiple reasons. Therefore, the design direction made two iterations based on strong argumentation from literature review, observations, expert interviews and patient interviews (this will be explained in depth in chapter 9). Eventually, the design goal became to create ***‘an interactive tool that supports PCVBHC during trauma rehabilitation, by making patients more actively involved in the design of their customized care plan and by facilitating effective interdisciplinary goal-setting. Additionally, the tool aims to help patients with acceptance, as this makes an essential contribution to quality of life’.***

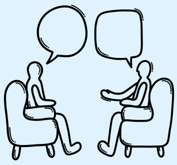
Figure 2: Logo CETC

Part 1: Research phase

BACKGROUND RESEARCH

Literature review

- *Shared decision-making*
- *Value based health care (VBHC)*
- *Person-centred health care (PeCHC)*
- *Health equity*
- *Person-centred value based health care (PCVBHC)*

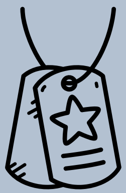


Research civilian burns care pathway

- *Desk research burns*
- *Observation Maasstad Burn Center (Rotterdam, the Netherlands)*
- *Expert interview, burn specialist at Maasstad Burn Center*
- *2 generative patient interviews (Map My Experience Trauma Care Tool)*
- *Burns patient journeys*
- *Visitor Symposium Extreme Trauma Care (MEDEX/CETC)*

Research civilian crush injury care pathway

- *Desk research crush injury*
- *Observation annual exercise Calamiteiten Hospital*
- *Expert interview, trauma surgeon Central Military Hospital*
- *1 generative patient interview (Map My Experience Trauma Care Tool)*
- *Crush injury patient journey*
- *Visitor Symposium Extreme Trauma Care (MEDEX/CETC)*



Research military trauma care pathway

- *Desk research military trauma care chain*
- *Expert interview, trauma surgeon Central Military Hospital*
- *Expert interview military nurse*
- *1 polytrauma patient interview*
- *Insights from own military medical training*
- *Visitor Symposium Extreme Trauma Care (MEDEX/CETC)*
- *Consultation Military Rehabilitation Center Aardenburg*

Chapter 2: Design research method

To explore the context, literature review, observations, generative patient interviews and expert interviews were performed. This chapter discusses the methods used. The insights gained from these methods will be discussed later in chapters 3 to 7. For the observations and interviews, qualitative research with a phenomenological-hermeneutic approach was exploited. This approach is oriented to the description and interpretation of the fundamental structures of the lived experience, and to the recognition of the meaning of this experience (Miles et al., 2013).

The objectives of the design research were:

1. To gain a deeper understanding of the civilian trauma care pathways for burns and crush injury
2. To gain a deeper understanding of the military trauma care pathways for burns and crush injury
3. To gain a deeper understanding of the NATO standards for military trauma care
4. To find the main differences between civilian and military trauma care
5. To explore the feasibility, desirability and viability of an interactive and generative tool that supports PCVBHC by supporting active patient participation and effective interdisciplinary collaboration.

2.1 Literature review

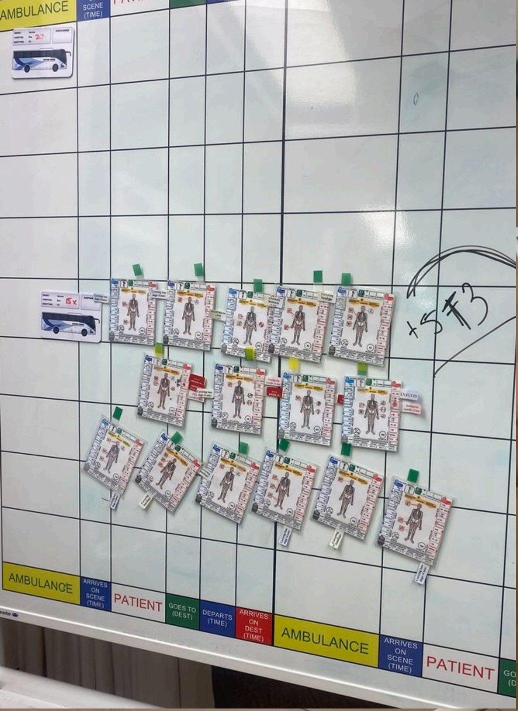
Based on the objectives stated above, literature review was performed. Articles were selected that provided a clear definition of relevant concepts, as will be explained in chapter 3. Additionally, literature review was performed with a focus on the trauma care pathways of burns and crush injury, both for civilians and military personnel, as will be described in chapter 4 and 5.

2.2 Observations

Three observations were performed to get a deeper understanding of the expectations and experiences of the health service, and to observe interdisciplinary collaboration within the trauma care pathways (see table 1 and Figure 3). For more pictures, see Appendix C.

Table 1: Observations

Observation	Observation of what?	Why?	Location
1. Annual trauma disaster exercise (Nov 9, 2024)	Observation of the annual trauma disaster exercise, in which multiple severely injured trauma patients have to be treated urgently within the Calamiteiten Hospital.	To get a better understanding of the acute trauma care context and the procedures and the protocols maintained around medical triage, which is higly relevant in the context of war victims (often large numbers).	Calamiteiten Hospital Utrecht (Dutch emergency hospital)
2. Medical Response to Major Incident Training (Nov 8, 2024)	Medical Response to Major Incident training. A major incident was simulated by the use of medical cards and health care providers had to anticipate on this scenario.	To get a better understanding of the acute trauma care context and the procedures and the protocols maintained around medical triage, which is higly relevant in the context of war victims (often large numbers).	Calamiteiten Hospital Utrecht (Dutch emergency hospital)
3. Observation interdisciplinary collaboration in burn center (Nov 15, 2024)	Observation of the interdisciplinary consultation and care provision at the Maasstad Burn center. Due to the complexity of burns, close interdisciplinary collaboration is required.	To get a better understanding of interdisciplinary collaboration within trauma care.	Maasstad Burn Center Rotterdam

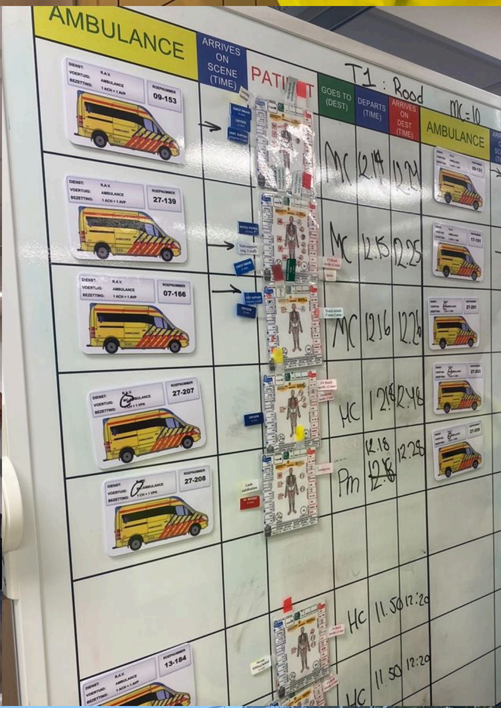

AMBULANCE
ARRIVES ON SCENE (TIME)
PATIENT
GOES TO (DEST)
DEPARTS (TIME)
ARRIVES ON DEST (TIME)
AMBULANCE
ARRIVES ON SCENE (TIME)
PATIENT
6x
+5 #3


Neck stabilis. (5 min)
IV.fluid (needle +2 min)
B BREATHING
C CIRCULATION
164
ROEPNUMMER
17-101
AMBULANCE
1 ACH + 1 AVP


AMBULANCE
ARRIVES ON SCENE (TIME)
PATIENT
GOES TO (DEST)
DEPARTS (TIME)
ARRIVES ON DEST (TIME)
T1 : Rood
MC = 10
HC = 30
AVP
ACH


EMERGENCY DEPARTMENT
WAITING ROOMS
T2


Waiting for transport
T2
Symbols
Triage
URO
ABIEL
END


AMBULANCE
ARRIVES ON SCENE (TIME)
PATIENT
GOES TO (DEST)
DEPARTS (TIME)
ARRIVES ON DEST (TIME)
T1 : Rood
MC = 10
AMBULANCE
09-153
27-139
07-166
27-207
27-208
13-184
MC 12.14 12.24
MC 12.15 12.25
MC 12.16 12.26
HC 12.29 12.46
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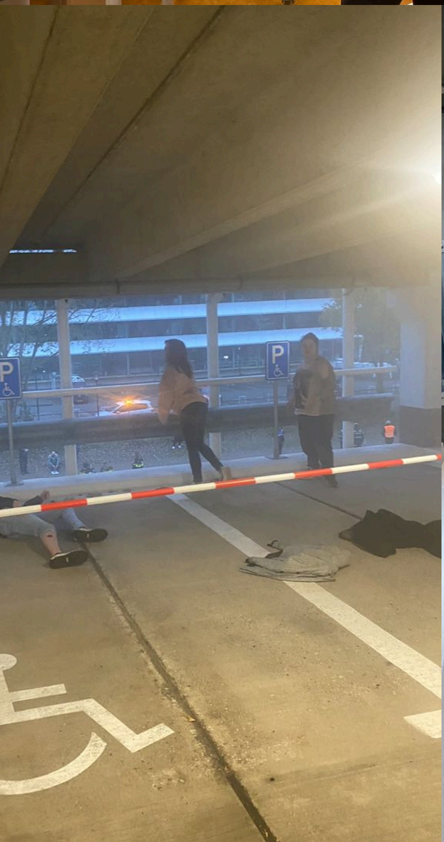
HC 11.50 12.20



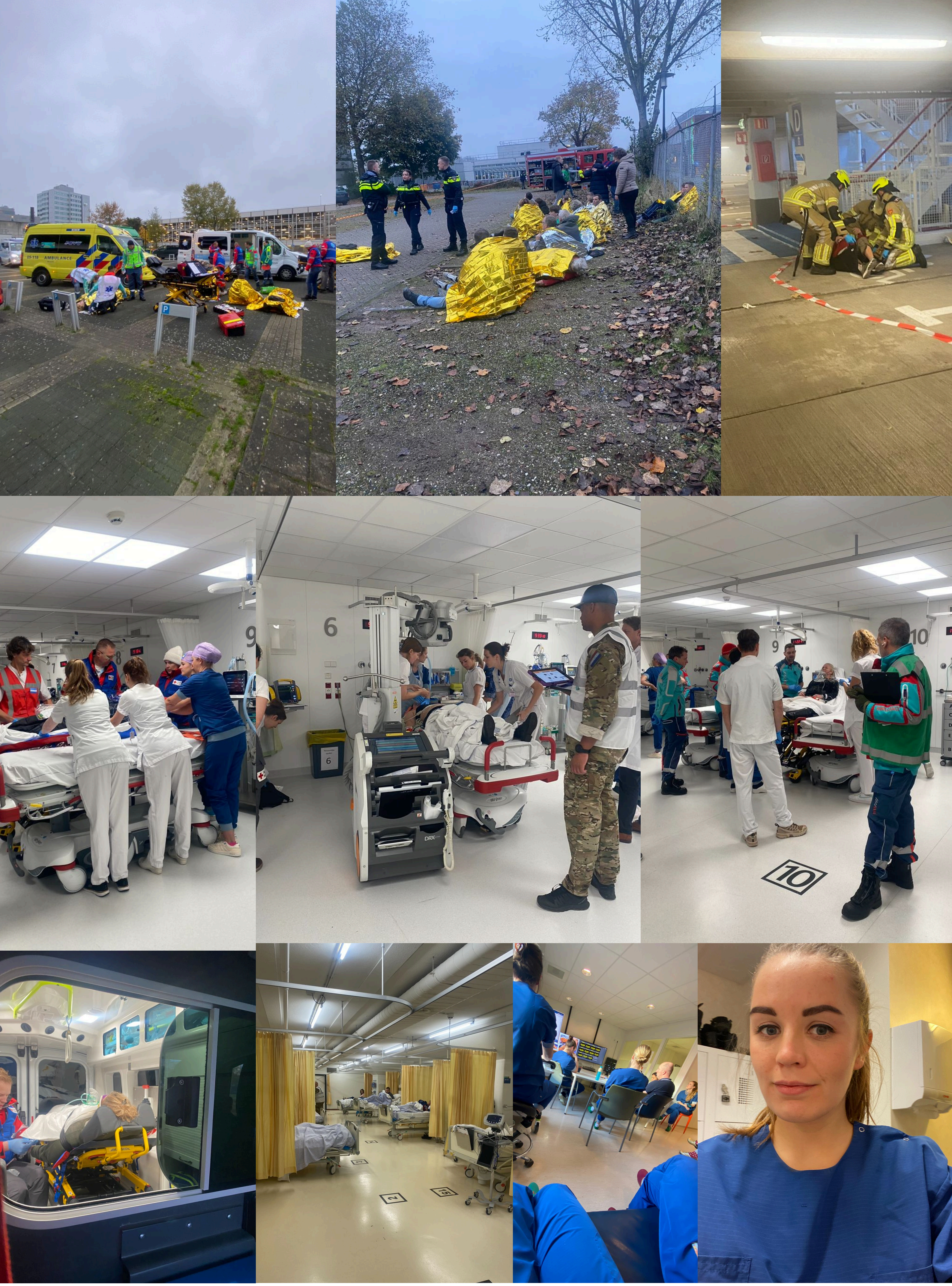


Figure 3: Observations

3.2 Interviews overview

To explore the context and analyze patients experiences, 10 interviews were performed.

Table 2: Interviews during the research phase

Interview number	Respondent	Main reason interview
1. Nov 5, 2024	Civilian Burn Patient	Generative patient interview to explore patient experiences with the trauma care pathway of burns
2. Nov 6, 2024	Civilian Burn Patient	Generative patient interview to explore patient experiences with the trauma care pathway of burns
3. Nov 15, 2024	Burn Medical Specialist *Maasstad Burn Center*	To discuss the burns care pathway and the interdisciplinary care provision for burns
4. Nov 18, 2024	Trauma Surgeon 1 *Central Military Hospital*	Consultation about the desirability of the first design direction and to gain insights for further development
5. Nov 20, 2024	Military nurse	To explore and discuss expert experiences of the military trauma care chain (both during deployment and during service in the Netherlands)
6. Nov 24, 2024	Civilian Crush injury patient	Generative patient interview to explore patient experiences with the trauma care pathway of crush injury
7. Nov 27, 2024	Military Polytrauma patient	Generative patient interview to explore patient experiences with the military trauma care chain. Also, consultation about the desirability of the second design direction and to gain insights for further development
8. Nov 27, 2024	Trauma surgeon 2	Consultation about the desirability of the second design direction and to gain insights for further development
9. Dec 11, 2024	Rehabilitation clinician *Military Rehabilitation Center Aardenburg*	Consultation about the desirability and viability of the final design direction and to gain insights for further development
10. Dec 11, 2024	Head R&D *Military Rehabilitation Center Aardenburg*	Consultation about the desirability and viability of the final design direction and to gain insights for further development

2.4 Generative Patient interviews

For the patient interviews, a generative approach was used to elicit memories and evoke emotions and feelings (Sanders, 2000). Generative techniques help people to express themselves on a deeper level than possible by just asking them a question, since some feelings, desires or thoughts are hard to articulate (tacit knowledge) (Sleeswijk Visser et al., 2005). Generative research focuses on exploring, understanding and revealing the needs, behaviors and preferences of patients (Blitzllama, 2024). To capture the patient experience data in a rich way, a patient experience ,apping Tool for trauma care was developed. In addition, the methodology of Simonse et al. (2019) was used to create patient journeys. Purposive sampling was used to select participants who had experienced the trauma care journeys of interest. The selection criteria used were that the patients had to be treated in the Netherlands and that their injuries had to be severe enough for treatment in trauma centers.

2.4.1 Map My Experience Trauma Care tool

The National Health Council (NHC) developed a Patient Experience Mapping Tool (PEMT) to help researchers capture patient experience data more holistically and in a standardized manner across chronic diseases (National Health Council, z.d.). The tool helps the researcher to collect patient experience data including the impact of the disease/condition/therapy/investigation and the patient preferences with respect to different treatment options. The collection of patient experience data can be used to create shared decision-making tools that contribute to person-centred and value based health care. The Patient Experience Mapping Tool (PEMT) is developed especially for patients with chronic diseases. However, the tool can be tailored for specific health conditions. For this graduation project, I tailored the tool to make it suitable for acute trauma care patients. I named this new tool the Map My Experience Trauma Care (MMETC) (see Figure 2). The adjusted tool includes the following phases: moment of accident, first aid and transportation, examination, treatment and surgeries, after care at hospital, and after care at home. Similarly, the MMETC uses textual and visual cues to capture patient experience data. All cues, as well as the life factors, are assessed and adjusted in terms of importance for the study about acute trauma care. Additionally, a tailored interview guide was developed. For a more detailed explanation of the tool, the legend and the interview guide that I have developed, see appendix D and E.

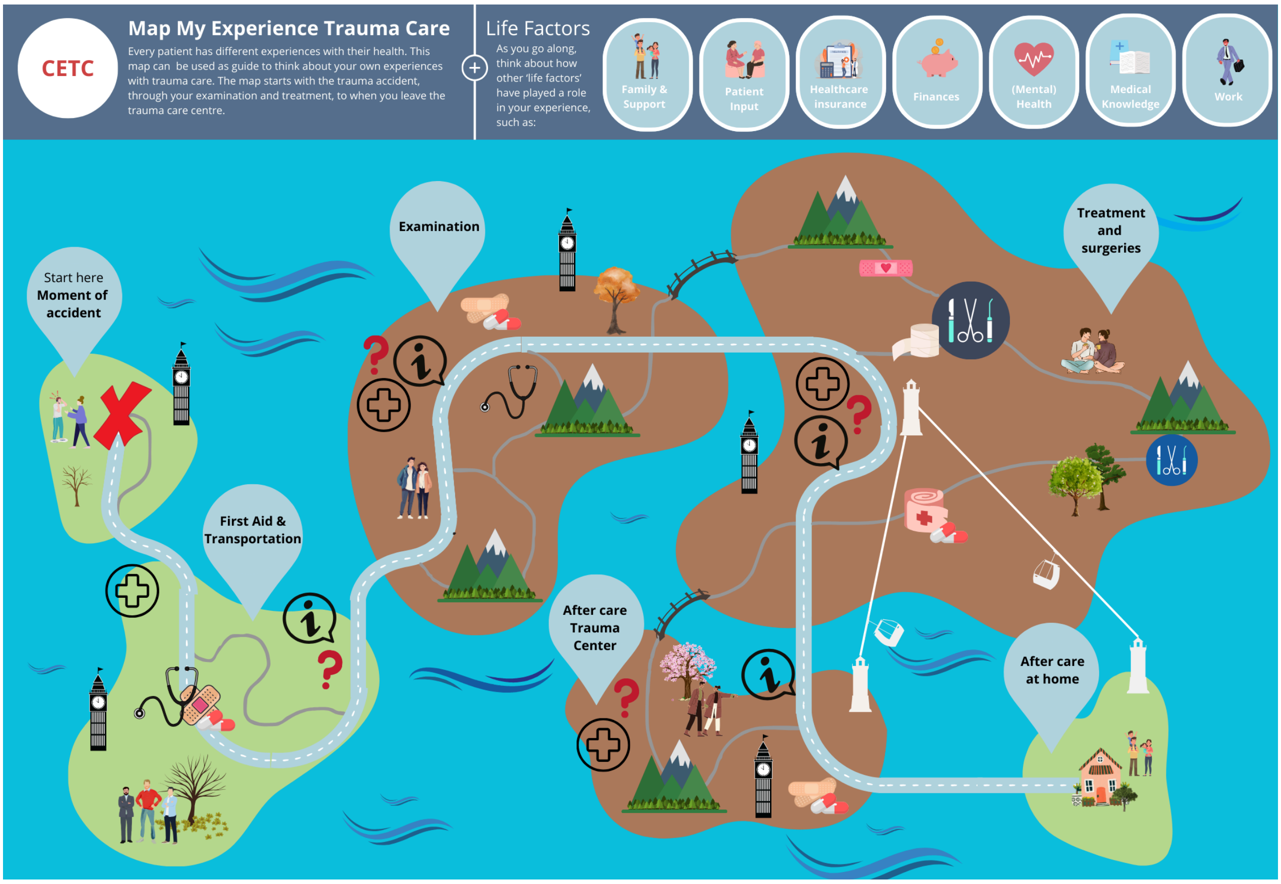


Figure 4: Map My Experience Trauma Care tool

2.4.2 Patient Journeys

Patient journeys were developed by the methodology as described in the article of Simonse et al. (2019). A patient journey is defined as *‘a comprehensible representation of a health service and its procedures, including relationships and feelings from a patient perspective’*. With this methodology patient journeys are created based on desk study, observations, patient interviews, and validation. The created patient journey template can be found in Figure 5.

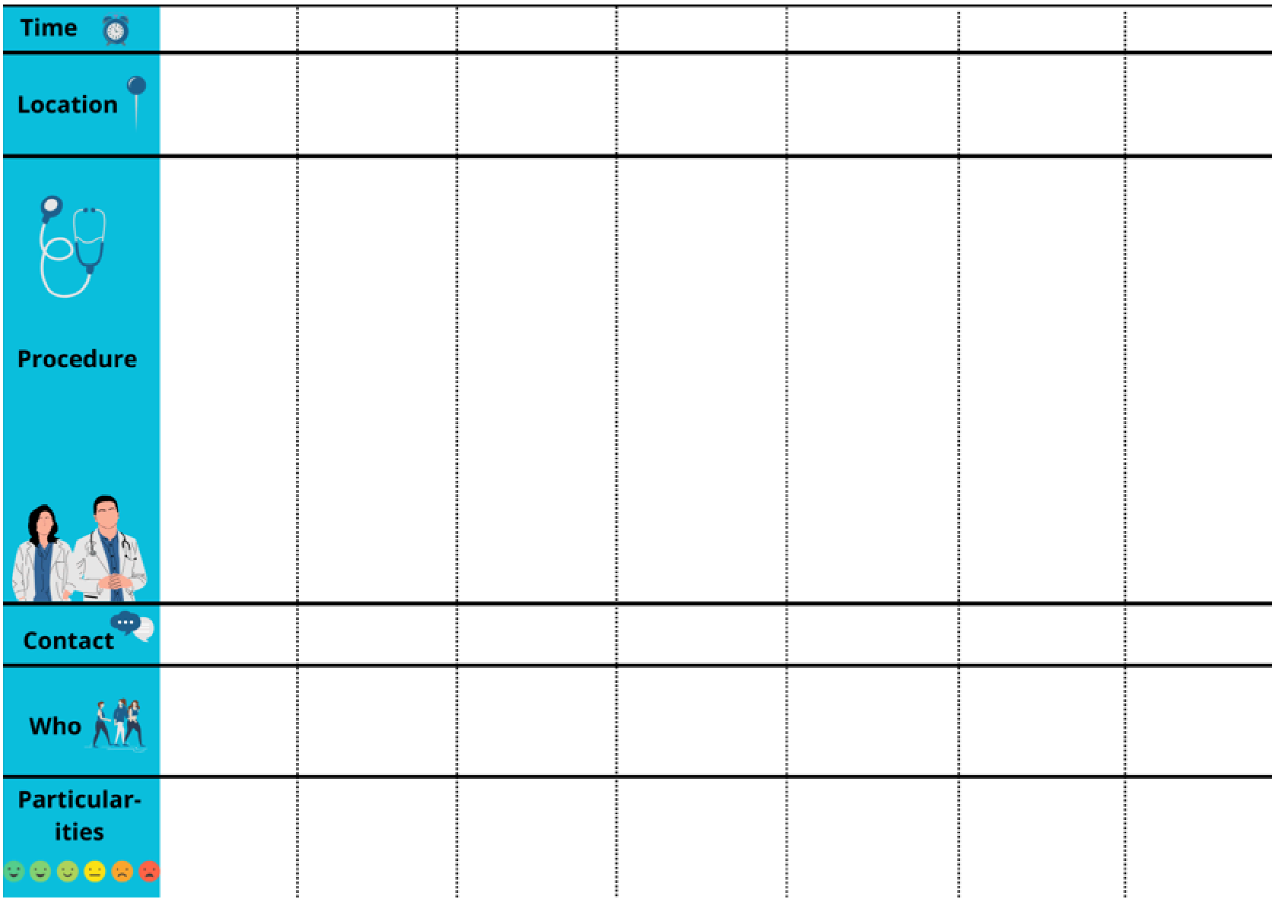


Figure 5: Patient Journey Template

2.5 Expert interviews

Expert interviews were conducted during the research phase with the following two objectives: (1) to gain a deeper understanding of the military trauma care chain and (2) to test the viability of the design direction(s).

2.5.1 Military trauma care chain

Although the literature review provided a clear overview of the procedures and protocols used within the military trauma care chain, it remained hard to find details about experiences within this care chain. Therefore, interviews were conducted with a military trauma surgeon and military nurse (see Appendix H). During those open discussion interviews we did a deep-dive into the context of military trauma care during deployment and after medical evacuation to the Netherlands (as explained in detail in chapter 6). The main objective was to gain insight into the organizational structure of the military trauma care chain, from the moment of injury during deployment to final rehabilitation. In addition, we discussed the main challenges and barriers to delivering trauma care within the standards of NATO regulations and compared the differences with the regular Dutch care system, as described in chapter 7.

2.5.2 Viability of the design directions

Expert consultations were crucial to validate the viability of the different design directions, as I, as a strategic product designer, did not have in-depth knowledge of the complexities of trauma care. Each expert consultation led to valuable insights and was fundamental to the iterations of the design direction, as will be explained in chapter 9.

Chapter 3: Relevant concepts

In this chapter different concepts that have been fundamental for the design of the tool are explained. The information in this chapter results from literature review.

3.1 Shared decision-making (SDM)

Shared decision-making is *'an approach where health care providers and patients share the best available evidence when faced with the task of making decisions. Patients are supported by the health care provider to consider options and to achieve informed preferences'* (Elwyn et al., 2010). Shared decision-making rests on the goal of individual self-determination and health care providers need to support patients with information and options to achieve this goal (Elwyn et al., 2012). The study of Elwyn et al. created a simplified shared decision-making model that consists of three different steps: choice talk, option talk, and decision talk (2012). During choice talk the patient is informed about the reasonable options available. During option talk patients are provided with more detailed information about those options. And finally, during decision talk patients are supported during the process of considering preferences and deciding their final preference.

3.2 Value based health care (VBHC)

Value based health care (VBHC) consists of cost effective and evidence based care to meet health outcomes that are important to the patient. This is important because the preferred clinical outcomes are not always equal to the outcomes that are important to the patient (Australian Health care and Hospitals Association, 2022). The goal of VBHC is to enable the health care system to create more value for patients (Teisberg et al., 2019). This value is defined as health outcomes against the costs of delivering those outcomes (Catalyst, 2017). This means that value can increase by lowering the health care costs or improving the health outcomes, or both (Porter & Tiesberg, 2006). By focusing on the outcomes that matter most to patients, value aligns care with how patients experience their health (Teisberg et al., 2019). VBHC uses standardized outcomes and cost measurements to monitor and compare performance between organizations (Srur et al., 2024). Health outcomes can be divided into capability, comfort, and calm. Capability refers to the patient being able to do what defines him/her as an individual. Comfort refers to the relief from physical and emotional suffering and/or discomfort. Calm refers to the ability to live normally while receiving care (Teisberg et al., 2019). The standardized outcomes can be captured by patient-reported outcome measurements (PROMs), such as general health, experienced symptoms, and aspects of physical and mental health (Kidanemariam, 2025). In VBHC, PROMs are used at the aggregate level for value improvement and at the individual patient level. The PROMs are used as input during consultations, to support shared decision-making and discuss the patients' needs (Kidanemariam et al., 2024).

3.3 Person-centred health care (PeCHC)

Person-centred health care (PeCHC) originated as a response to disease-oriented care, where the focus is mainly on biological aspects and functional or medical outcomes. This disease-oriented approach does not include the patient's unique context and experiences with the disease (PCVBHC Project Team* et al., 2021; Eklund et al., 2018). Person-centered care highlights the importance of knowing the person behind the patient, in order to engage the person as an active partner in his/her care and treatment (Ekman et al., 2011). PeCHC does not focus on functional or medical outcomes, but on a meaningful life as the desired outcome of the care. It is about understanding what matters to people and what they value in their life (PCVBHC Project Team* et al., 2021; Eklund et al., 2018). Dimensions of PeCHC are shared decision-making, acknowledgement of the person as a unique individual, a holistic view, respectful communication and building trust and alliance, coordinated and integrated care, and qualities of health care providers like empathy and self-awareness (Eklund et al., 2018; Langberg et al., 2019). PeCHC encourages meaningful involvement of the person receiving care in the design of the care delivery.

3.4 Person-centred value based health care (PCVBHC)

VBHC is based on the use of standardized outcomes measurements for benchmarking, which also leads to standardising definitions of health outcomes success. However, those standardized success measurements do not always align with the goals and preferences of individual people (Kidanemariam, 2025; Kamal et al., 2018; PCVBHC Project Team* et al., 2021). Additionally, it does not take into account that patients attribute different relative importance to health outcomes. As such, VBHC may well lack alignment with PeCHC. Additionally, both VBHC and PeCHC have a lack of recognition that resources are finite and therefore, it is not possible for everyone to receive all the care they want (PCVBHC Project Team* et al., 2021). This touches upon the principle of health equity, referring to the absence of unfair, avoidable and remediable differences in health status among groups of people, when everyone can attain their full potential (World Health Organisation, 2025). As explained in the report of the PCVBHC project team, an international community of experts representing health care stakeholders stated that there is a need to bring together VBHC, PeCHC and health equity (PCVBHC Project Team* et al., 2021). This new concept is called Person-centred value based health care (PVBHC).

“Person-centred value based health care links the personal values, goals and preferences in PeCHC with the principle of standardized measurement and benchmarking in VBHC, underpinned by the equitable allocation of finite resources” (Srur et al., 2024).

For this project the concept of PCVBHC is especially relevant on the micro level, where the concept focuses on care provision for individual patients. Health care teams need to decide how to achieve personal goals and preferences, within the funded resources available (PCVBHC Project Team* et al., 2021).The process of shared decision-making helps to elicit personal values, goals and preferences and to create a shared understanding between patient and health care providers. Patients are stimulated to actively participate in their own care, and should be supported to do so (Kidanemariam, 2025). Patient reported outcome measurements (PROMs) can be used to incorporate patients' perceptions of their health and medical condition within the care pathway (Field et al., 2019). Personal goals assist the development of customized care plans and they support patients in maintaining a sense of purpose and control (Mandel et al., 2016). To support goal-setting, patients must be informed about their health condition, prognosis, and treatment options. Health care providers that perform consultations with patients and are responsible for the creation of a suitable care plan, must be trained in shared decision-making and goal-setting, and sufficient time must be allocated to this purpose. When possible, personal goals should be recorded in the health record and should be reviewed regularly. Personal goals and preferences should be linked (where possible) to standardized outcomes measures (Kidanemariam, 2025). By linking personal goals to PROMs, the principles of VBHC and PeCHC are aligned and a customized care plan that actually contributes to the patients quality of life is created. Health care providers should provide care that matches or supports the personal goals of the patients, within the constraints of limited resources (Kidanemariam, 2025).

On the macro level, health care organizations have to decide which products and services they want to invest in, based on cost effectiveness analysis (CEA) and on the principles of equity. It is important to state that Person-centred value based health care is an emerging concept and it will take time for health to successfully transition to this concept. This graduation project aims to develop a tool that supports PCVBHC and the creation of a customized care plan, as explained in chapter 11, facilitating this transition.

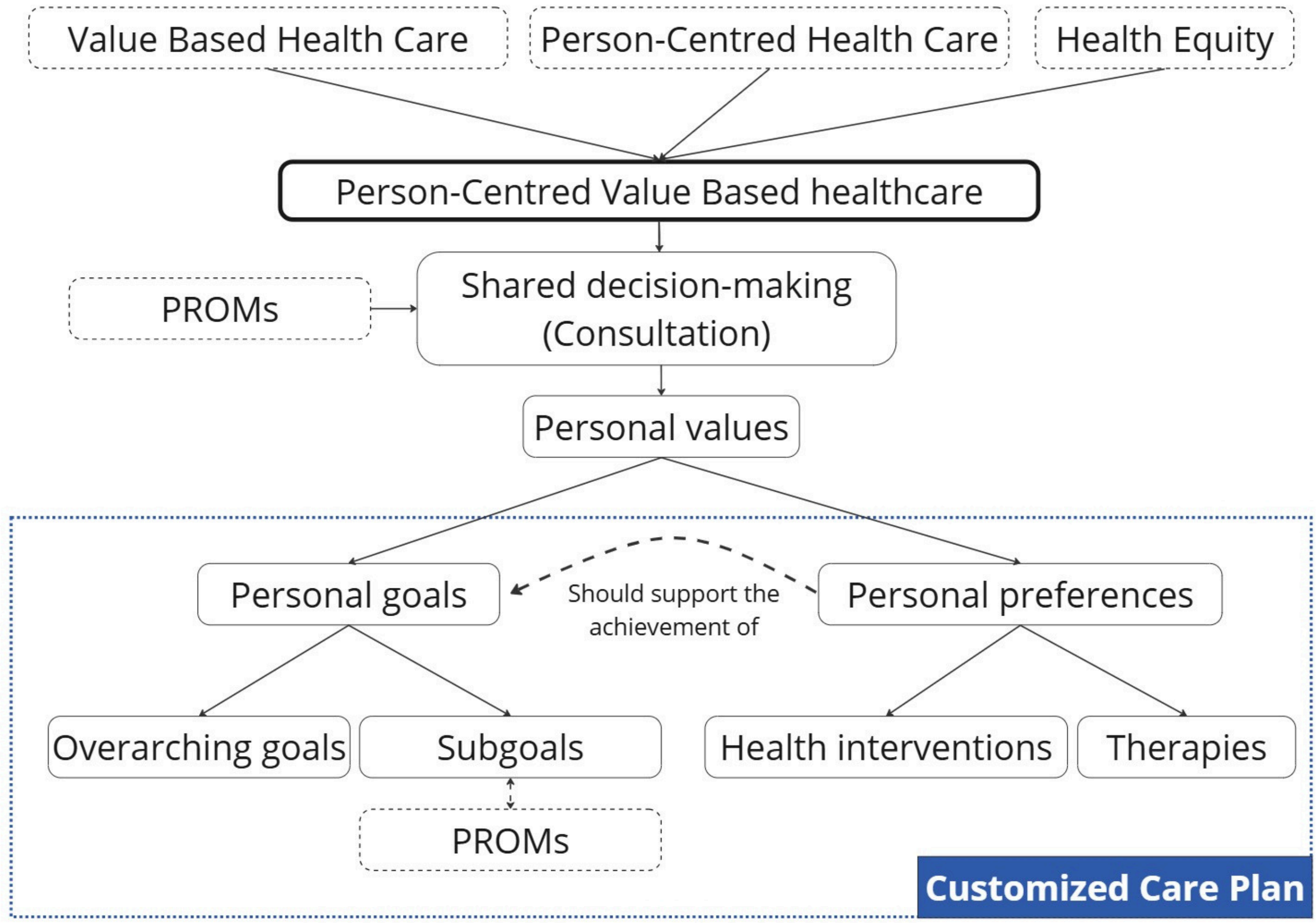


Figure 6: Framework PCVBHC. During consultation the health care provider and patient create a customized care plan, by using the principles of PCVBHC. A recent PROM should be filled in by the patient before consultation. And ultimately, the personal goals should be linked to PROMs (problem areas), to create a customized care plan that actually contributes to the patients quality of life.

Table 3: Definitions supported by examples

	Definition	Examples
Personal values	Personal values are what drives us, acting as the basis for our beliefs and bringing meaning to our lives. Personal values tend to remain stable over time.	*'I value family life and personal independence'* *'I value giving back to society, for example through volunteering.'*
Personal goals	Goals reflect a desired end state that is typically consistent with an individual's underlying personal values. There are overarching goals and subgoals, with subgoals supporting the achievement of an overarching goal.	Overarching goal: *'I want to be fully independent and not dependent on others to do the activities that are important to me.'* Subgoals: *'I want to be able to continue to work and to be able to walk my dog in the park each day.'*
Personal preferences	Preferences refer to the care that people are willing and able to do or to receive, that is aligned to their values and that supports them in achieving their goals.	*'I don't want to have surgery because there is a risk that it will stop me from being able to walk... and walking my dog each day in the park is something I don't want to risk losing.'*

Note: from the report 'Enabling people accessing care and their clinicians to collaborate in a shared goal-setting and decision making process to align care to personal values, goals and preferences' (Srur et al., 2024)

Chapter 4: Trauma care chain of burns

To get a deeper understanding of the trauma care context, the trauma care pathways of burns and crush injury (next chapter) were investigated. Literature review, observations and patient interviews were performed.

4.1 Treatment of burns in the civilian context

A burn is an injury to the skin or other organic tissue primarily caused by heat or due to radiation, radioactivity, electricity, friction or contact with chemicals (World Health Organization: WHO, 2023). As a result, the skin and underlying tissues can be damaged (OLVG, 2024). Burns can be divided into three classifications:

1. First-degree (superficial burns): first-degree burns affect only the outer layer of the skin. The burn site is red, dry, and painful. There are no blisters. Long-term tissue damage is rare (Johns Hopkins medicine, 2024). The burns usually heal within several days, without leaving severe scars. There is no need to be treated in a healthcare facility (OLVG, 2024).
2. Second-degree (partial thickness) burns: second-degree burns affect the upper layer of the skin and the underlying layer. The burn site appears red, blistered, and may be swollen and painful (Johns Hopkins medicine, 2024). For superficial second degree burns the treatment in a healthcare facility is not needed. The burns usually heal within two weeks, without leaving severe scars. Deeper second degree burns should be treated in the specialized burn center (OLVG, 2024).
3. Third-degree (full-thickness) burns: Third-degree burns damage the different layers of the skin and may even damage the underlying bones, muscles, and tendons. The burn site appears white or charred There is no feeling in the area since the nerve endings are destroyed (Johns Hopkins medicine, 2024). Third-degree burns are always treated in a specialized burn center. The burns always lead to scars and patients often receive skin transplantation surgery (OLVG, 2024).

Non-fatal burns are a leading cause of morbidity, including prolonged hospitalization, disfigurement and disability. Hospitalization for burns varies by country, but in Western countries burn care is well organized and the treatment of burn victims is centralized in burn centers or units (World Health Organization: WHO, 2023; Handboek Brandwondenzorg, z.d.). Because so many functions and systems of the body can be affected by severe burns, burn patients need the highly specialized services of health care professionals who work together in multidisciplinary teams (Johns Hospik medicine, 2024). A multidisciplinary approach leads to better recovery, better processing of the trauma, limiting post-traumatic stress syndrome, and to acceptance and resocialization (Handboek Brandwondenzorg, z.d.).

Treatment

When providing first aid for burns it is important to reduce the temperature of the burn with lukewarm softly flowing water for 10-20 minutes (Het Nederlandse Rode Kruis, 2023). Never apply ice, because it deepens the injury (World Health Organization: WHO, 2023). To reduce the chances of hypothermia, only cool the burnt skin and not the rest of the body. Remove clothes and jewelry from the burnt skin. Do not touch the burn to reduce the risk of infection. In the case of an open wound or blisters, you can wrap it in cling film or greasy gauze (OLVG, 2024). In the case of severe burns, emergency services can be called after cooling of the burn.

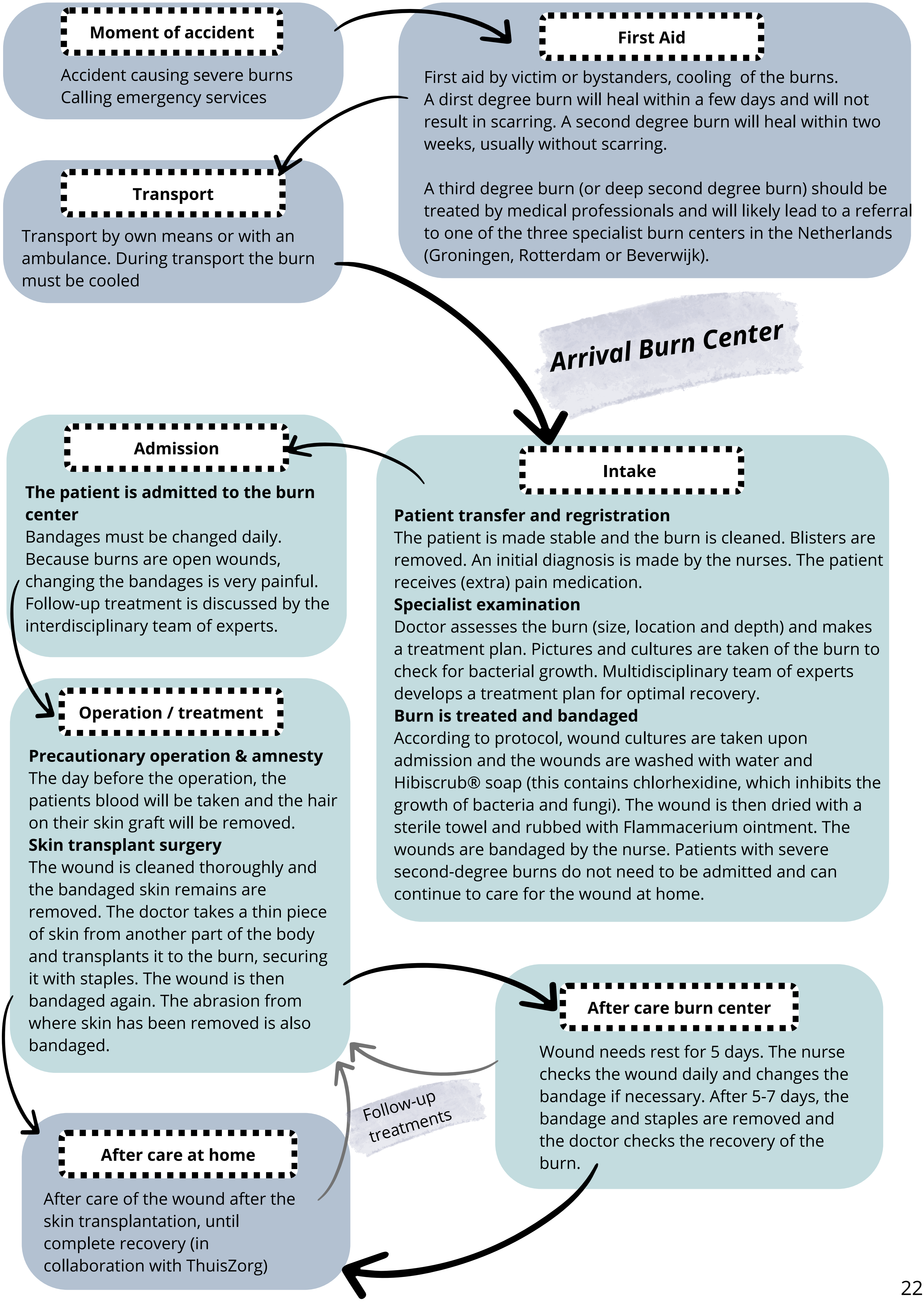
Patients with severe burns are transferred to a specialized burn center. During the intake in this facility, the patient is made stable and the wound is cleaned. Blisters are removed from the wound. An initial diagnosis is made. Possibly (extra) pain relief is provided.

A burn specialist assesses the wound (size, location and depth) and makes a treatment plan. Pictures and cultures are taken of the wound to check for bacterial growth. A multidisciplinary team of experts assesses the treatment plan for optimal recovery (Brandwondenzorg Nederland, 2024).

According to protocol, wound cultures are taken upon admission and the wounds are washed to reduce the chances of infection. The wound is then dried with a sterile towel and rubbed with Flammacerium ointment (Hartlief, 2018). The wounds are bandaged by the nurse after assessment. Some patients will be admitted to the burn center for a longer period of time. Their bandages must be changed daily. Because burns are open wounds, changing bandages is a very painful procedure.

In case a burn does not heal on its own or if the healing process takes too long, patients receive skin transplantation surgery (Brandwondenzorg Nederland, 2024). Operated areas generally result in more subtle scars. For this operation the patient is put under general anesthesia. During the surgery, the wound is cleaned thoroughly and the bandaged skin remains are removed. The doctor takes a thin piece of skin from another part of the body and transplants it to the burn, securing it with staples. The wound is then bandaged again. The abrasion from where skin has been removed is also bandaged. The wound needs rest for 5 days. The nurse checks the wound daily and changes the bandage if necessary. After 5-7 days, the bandage and staples are removed and the doctor checks the recovery of the wound (Brandwondenzorg Nederland, 2024). To reduce the itchy feeling during recovery, the patient can wear pressure clothing (Hartlief, 2018).

BURNS CIVILLIAN CARE PATHWAY



Moment of accident

Accident causing severe burns
Calling emergency services

First Aid

First aid by victim or bystanders, cooling of the burns. A dirst degree burn will heal within a few days and will not result in scarring. A second degree burn will heal within two weeks, usually without scarring.

A third degree burn (or deep second degree burn) should be treated by medical professionals and will likely lead to a referral to one of the three specialist burn centers in the Netherlands (Groningen, Rotterdam or Beverwijk).

Transport

Transport by own means or with an ambulance. During transport the burn must be cooled

Arrival Burn Center

Intake

Patient transfer and regristration
The patient is made stable and the burn is cleaned. Blisters are removed. An initial diagnosis is made by the nurses. The patient receives (extra) pain medication.
Specialist examination
Doctor assesses the burn (size, location and depth) and makes a treatment plan. Pictures and cultures are taken of the burn to check for bacterial growth. Multidisciplinary team of experts develops a treatment plan for optimal recovery.
Burn is treated and bandaged
According to protocol, wound cultures are taken upon admission and the wounds are washed with water and Hibiscrub® soap (this contains chlorhexidine, which inhibits the growth of bacteria and fungi). The wound is then dried with a sterile towel and rubbed with Flammacerium ointment. The wounds are bandaged by the nurse. Patients with severe second-degree burns do not need to be admitted and can continue to care for the wound at home.

Admission

The patient is admitted to the burn center
Bandages must be changed daily. Because burns are open wounds, changing the bandages is very painful. Follow-up treatment is discussed by the interdisciplinary team of experts.

Operation / treatment

Precautionary operation & amnesty
The day before the operation, the patients blood will be taken and the hair on their skin graft will be removed.
Skin transplant surgery
The wound is cleaned thoroughly and the bandaged skin remains are removed. The doctor takes a thin piece of skin from another part of the body and transplants it to the burn, securing it with staples. The wound is then bandaged again. The abrasion from where skin has been removed is also bandaged.

After care burn center

Wound needs rest for 5 days. The nurse checks the wound daily and changes the bandage if necessary. After 5-7 days, the bandage and staples are removed and the doctor checks the recovery of the burn.

Follow-up treatments

After care at home

After care of the wound after the skin transplantation, until complete recovery (in collaboration with ThuisZorg)

4.2 Generative patient interviews

Two generative patient interviews were performed with civilian burn patients. During the generative interviews, the Map My Experience Trauma Care tool was used in combination with an interview guide (see appendix E). In this section, the experience maps and patient journeys are presented. Additionally, combined insights from the interviews are discussed.

4.2.1 Burn patient interview 1

Below the experience map and patient journey of the first burn patient interview can be found. The generative interview was performed in the patients native language (Dutch), to elicit information in the most detailed and rich way (see appendix F). For the presentation in this report, the original map is presented with highlights of positive and negative experiences (smiley icons). Additionally, the patient's notes on every island are documented under the map.

Map My Experience Trauma Care map (burns 1)

Figure 7: Burn patient 1 map

Moment of incident

- *Feb 14, 2022 Friday night, clothing caught fire at a party. Immediately put in the shower by bystanders. No conscious memory of the incident itself, many gaps in the memory of that night.*
  "I had a total blackout from the moment of the burn incident until the acute phase was over. Months later, after doing EMDR therapy some memories returned".
- *Drove to the local hospital by the boy next door. On site within half an hour. Her first active memory is of her waiting for the car and being in a lot of pain.* ***(☹ lot of pain)***.

First aid & transportation

- *Upon arrival at the ER, she is immediately put under the shower for another 15 minutes. She is treated by an ICU nurse and a doctor. She cannot be referred to the Maasstad Burn Center because it is full.*
- *Because her nose hairs were singed she was admitted to the ICU, since this could indicate inhalation trauma. Her parents are called and are there within 2 hours* ***(🙂 arrival of parents)****. They sleep somewhere else in the hospital.*
- *She is in terrible pain and is given cooling pads and morphine* ***(☹️ lot of pain)****.*
- *She is told that her thumb is circularly burned, a diagnosis that ultimately turns out to be incorrect. This ER does not have the correct knowledge about burns. They are constantly calling the Maasstad burn center for advice.*
- *The next morning she only realizes the seriousness of her situation after she sees her mother's reaction and the face ID on her phone no longer recognizes her face. This is the first time that she feels real emotions of fear in addition to pain* ***(☹️ she realizes the seriousness of her medical situation and feels fear****). “I was really shocked when Face ID did not recognize my face”*
- *The next morning she was transferred by ambulance to the Maasstad burn center. Her mother was allowed to go with her in the ambulance and this went smoothly and quickly* ***(🙂 ambulance transfer experienced as positive)****.*

Examination

- *In Maasstad they don't know about her arrival and that's why there is no specialist burns doctor present.* ***(😐 bad transfer!)*** *Fortunately, they were eventually able to arrange a replacement who could examine her.*
- *In Maasstad she receives a new diagnosis. Her thumb is not circularly burned. The situation is somewhat worse than previously predicted. She has second-degree but most likely also third-degree burns. There is a good chance that a skin transplant is necessary. This is told to her for the first time and feels like a great setback. She experiences fear.* ***(☹️ new diagnosis is worse then first diagnosis provided, she experiences fear).*** *“The new diagnosis was a big disappointment. This was the first time the possibility of a skin transplantation surgery was mentioned.”*
- *The day after, a scan of her skin is made and lab samples are taken for infection research. Every Monday there is an interdisciplinary meeting, in which her situation is discussed.*
- *The scan shows that the situation of her right arm is positive and that it will heal well by itself. This gives her a lot of relief.* ***(🙂 relief by outcome scan).*** *The situation of her thumb and spots on her left arm is still uncertain, they will wait two weeks to see if it heals sufficiently by itself. Otherwise a skin graft will be necessary.*

Treatment

- *She will stay in the burn center for 10 days in total. She will have to wait and see if her wounds heal on their own. She will receive daily wound care and bandages changes (which are painful) and she will receive morphine for the pain.*
- *Her bandages are changed daily and this is a painful experience, but the staff are very knowledgeable and know what they are doing. She is cared for by a nurse and a doctor checks on her every day.*
- *Two people were allowed to visit each day and those were her parents. There were no strict visiting hours and that was very nice.* ***(🙂 relief can visit everyday).*** *She is entertained by the Olympics on TV. “My stay at the center was pleasant. My parents could visit daily and I was entertained by the Olympics.”*
- *During her stay she is treated by a number of doctors who are all well-informed about her situation. The staff is friendly and there is a lot of personal attention. She feels a bond with the care staff.* ***(🙂 positive experience with the staff)****.*
- *The morphine causes negative experiences. She appears to be allergic and has to vomit a lot. She keeps little food in and this is bad for recovery. The morphine in pill form is also a problem. After that, they stopped giving her morphine and switched to another medication.* ***(☹️ allergic to morphine, a lot of vomiting)****.*

- *Because she had eaten so little food, the nutritionist prescribed her fatty food. This was not a good combination with the reaction to the morphine and led to even more vomiting. She felt that this could have been discussed better.*
- *Despite the fact that the bandage change was very painful, she does not have a bad memory of it. This was done very professionally in a special room. She was treated by three nurses so that the bandages could be changed as quickly as possible. As soon as the wounds were clean, a specialist came to see them so that they could be bandaged again as quickly as possible. She was given nasal spray for the pain. This moment was an opportunity to see the progression of recovery. She also saw the necessity of this treatment for her recovery.* ***(😐painful procedure, but not a bad memory)****.*
"Although this was very painful, I knew it was necessary for my recovery. This was also the moment I could see progression."
- *Parents were present at all important conversations.* ***(🙂parents included in important conversations, no pressure from other visitors)****.*
- *Once again she was given morphine, which she had proven to be allergic to. This made her doubt the information transfer between nurses.* ***(🙁 morphine again)****. "I often had doubts about the quality of interdisciplinary collaboration. Once again, I received morphine, which I had proven to be allergic to."*
- *She knew the doctors who treated her well. The nurses sometimes less, but she did not experience this as unpleasant. Within the center you do not really encounter other patients.* ***(🙂 familiar with staff)****.*
- *On the 10th day she was told that she would probably be able to go home that day. At first she was very happy.* ***(😊Notification she might go home today)****. But because of her mother's questions she became more and more anxious. She realized how she could no longer rely on expert staff. She felt very uncertain and doubted whether she wanted to go home. But the doctors assured her that you heal best at home.* ***(🙁 feeling uncertain about going home, away from expert care****).*

After Care Trauma Center

- *After 13 days her chin and right arm have healed. After 2 weeks she still has open wounds on her left arm and thumb. The chance that this will heal itself is small.* ***(🙁some wounds do not heal).*** *Before they switch to a skin transplant they try a special ointment (Terra-Cortril). If this ointment works a skin transplant might not be necessary. There will be a scar anyway. She experiences the information provision as open and honest.*
- *Once a week she returns to the outpatient clinic. She experiences the people and care here as very pleasant. The care is very professional, they have a lot of knowledge and the staff is friendly. Going there was a very pleasant experience!* ***(😊 Best care ever!).***

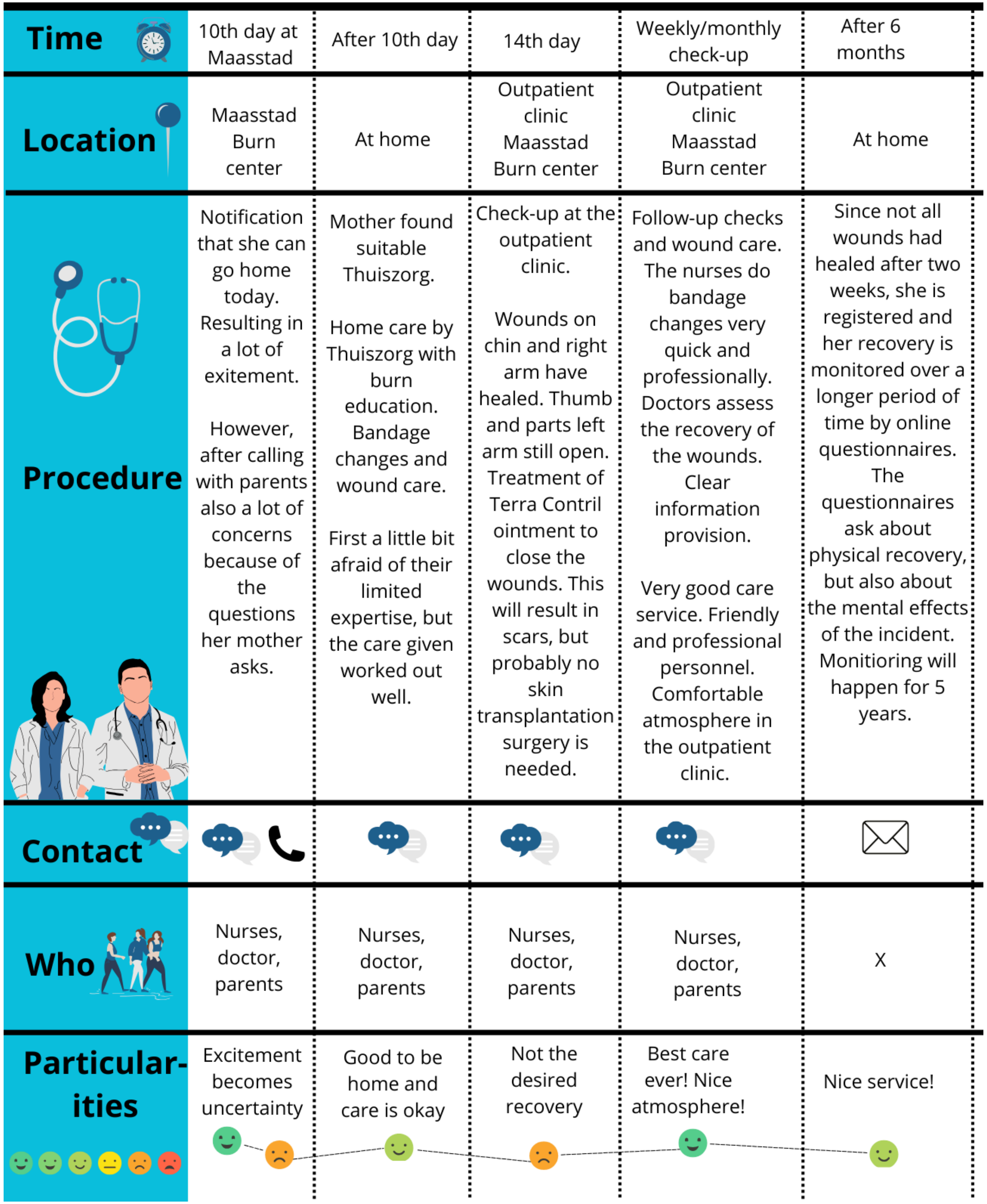
After care at home

- *In addition, she has home care twice a week (her mother had to arrange this). She always found home care a bit scary because they are less experienced with burns. But it is good to be home. She also received a pressure glove so that the scar on her hand would grow more inward and would be less visible.*
- *The photos taken at the beginning helped her a lot later on to appreciate the progress and accept her situation.* ***(🙂 Helps with acceptance).***
- *Because she had burns that were open for more than two weeks, she is registered in a system and regularly receives a survey to ask how she is doing now (for 5 years).*
- *She was eventually referred to EMDR therapy through her university to help her mentally process the incident. During the EMDR treatment an image is retrieved that she sees herself in the mirror immediately after the incident, completely black under the soot. This image was blocked from her memory and returned after the EMDR.* ***(😐neutral feeling about this).***

Patient journey burns 1 (part 1/2)

Time	Friday night	Friday night	Saturday morning	Saturday 11.30-12.00	Saturday after 12.00	Sunday	Monday	Next 7 days
Location	A friends house	Reinier de Graaf hospital Delft	Reinier de Graaf hospital Delft	Ambulance	Maasstad Burn center	Private room & Bandage change room	Maasstad Burn center	Maasstad Burn center
Procedure 	After burn incident put under the shower by friends Transport to Reinier de Graaf hospital in Delft by neighbor's car. While waiting on the car, she is in a lot of pain.	Directly 15 minutes under shower. Direct consultation with Maasstad Burn Center. Cooling cloths and morphine for the pain. Intensive Care monitoring for smoke inhalation. Parents arrived within 2 hours.	Diagnosis: thumb circularly burned and 2nd degree burns on the wrists She realizes the seriousness of her situation mainly because of her mother's reaction. Need to transfer to Maasstad Burn Center.	Transfer to Maasstad Burn Center.	Maasstad is not aware of her arrival, no suitable doctor present. A replacer is called up. Makes swaps for labtesting and examinates burns. New diagnosis, is different from first diagnosis. More severe and they are speaking of possible skin transplantation and serious scars. Burn wound care by nurses.	Daily morning check-in. Changing of the bandages. Due to the location of the burns this is done in the children bandage change room. Everyday two visitors are allowed. Parents visit.	Daily morning check-in & bandages change. Interdisciplinair experts meeting to make a treatment plan. Scans of skin are made: right arm second degree with good recovery. For recovery left thumb and neck wait two weeks.	Daily morning check-in with doctors (three different doctors from the interdisciplinaire team, good relationship with them). Daily bandages change, painful but she knows it necessary and therefore the overall experience is okay . With two nurses to do it as quickly as possible, doctors come at the exact right moment to examine the burns. Morphine for the pain triggers allergic reaction and vomitting. They find out after some time and try morphine pills. Same reaction, then they stop with morphine. By failt Daily amusement by Olympic Winter Competition on television. Parents visit every day.
Contact	💬	💬 ☎	💬	💬	💬	💬	💬	💬
Who	Friends and neighbor	SEH personnal, IC nurses, IC doctor, friend & parents	SEH personnal, IC nurses, IC doctor & parents	Ambulance personnal & mother	Nurses, doctor, mother	Nurses, doctor parents	Nurses, doctor parents	Nurses, doctor parents
Particular-ities 🙂 🙂 🙂 😐 🙁 😞	No clear memory 😞	No idea yet of the seriousness 😐	Realizing the seriousness 😞	Fast transfer, nice personnal 🙂	Incorrect first diagnosis, not expected new information 😞	First time changing bandages 🙁	Reliefed by outcome 🙂	Nice personnal 🙂 Bandages change 😐 Allergic reaction morphine 🙁 Overall days 🙂

Patient journey burns 1 (part 2/2)



Time	10th day at Maasstad	After 10th day	14th day	Weekly/monthly check-up	After 6 months
Location	Maasstad Burn center	At home	Outpatient clinic Maasstad Burn center	Outpatient clinic Maasstad Burn center	At home
Procedure	Notification that she can go home today. Resulting in a lot of exitement. However, after calling with parents also a lot of concerns because of the questions her mother asks.	Mother found suitable Thuiszorg. Home care by Thuiszorg with burn education. Bandage changes and wound care. First a little bit afraid of their limited expertise, but the care given worked out well.	Check-up at the outpatient clinic. Wounds on chin and right arm have healed. Thumb and parts left arm still open. Treatment of Terra Contril ointment to close the wounds. This will result in scars, but probably no skin transplantation surgery is needed.	Follow-up checks and wound care. The nurses do bandage changes very quick and professionally. Doctors assess the recovery of the wounds. Clear information provision. Very good care service. Friendly and professional personnel. Comfortable atmosphere in the outpatient clinic.	Since not all wounds had healed after two weeks, she is registered and her recovery is monitored over a longer period of time by online questionnaires. The questionnaires ask about physical recovery, but also about the mental effects of the incident. Monitoring will happen for 5 years.
Contact	💬 ☎	💬	💬	💬	✉
Who	Nurses, doctor, parents	Nurses, doctor, parents	Nurses, doctor, parents	Nurses, doctor, parents	X
Particularities	Excitement becomes uncertainty	Good to be home and care is okay	Not the desired recovery	Best care ever! Nice atmosphere!	Nice service!

Figure 8: Patient journey burn patient 1

4.2.2 Burn patient interview 2

Below, the experience map and patient journey of the second burn patient interview can be found. The generative interview was performed in the patients native language (Dutch), to elicit information in the most detailed and rich way (see appendix F). For the presentation in this report, the original map is presented with highlights of positive and negative experiences (smiley icons). Additionally, the patient's notes on every island are documented under the map.

Map My Experience Trauma Care map (burns 2)

Figure 9: Burn patient 2 map

Moment of incident

- *On Friday night she spills a cup of tea on her pubic area while watching a movie at a friend's house. She is in insane pain. The friend immediately puts her in the shower for about 18 minutes. (☹ **insane pain)**.*
- *While she is in the shower she sees all the sheets of her skin hanging loose and realizes that this is not good. (☹ **realization of seriousness)**.*
  "When looking down in the shower I directly realized that this was not good, sheets of skin were hanging loose"
- *Meanwhile, her friend tries to call the ER, but she is on hold for a very long time. Finally, she calls her mother (who has a medical background) and she tells her that they need to go to the hospital as soon as possible, because the burns on the pubic area are serious. (☹ **can not reach the ER)**.*
- *After cooling down in the shower, the worst of the pain is gone, but she can barely walk. They take an uber to the nearby hospital, they arrive around 30 minutes after the incident. (☹ **the worst pain is gone, but she is not able to walk).***

First aid & transportation

- *In the hospital she gets triage, because burns on the pubic area are serious.* ***(🙂 triage)***.
- *Her blood pressure is measured and then the nurse puts her in the shower again. The nurse's shift is over and she leaves them with the message that a new nurse will be there soon. She feels abandoned and doesn't know how long she has to wait in the shower. She sits there awkwardly. Fortunately, she has her friend as a distraction.* ***(🙁 she is abandoned and feels forgotten)***.
  "It was a weird situation. I was sitting there naked on a chair in a shower and was left behind. I didn't know how long I had to wait here. Luckily my girlfriend was there to distract me."
- *After 35 minutes, her friend goes to find a nurse. It turns out that they had indeed forgotten her. She had the impression that the personnel were not professional and not expertised.* ***(🙁 negative experience with nurses)***.
- *She has to wait in a room for 10 minutes before a doctor arrives, while she is half-naked and her wounds are still open. While the doctor assesses her burn, she gets the feeling that the doctor has no burn expertise. The doctor has to consult the Maasstad burn center for advice. The doctor makes pictures of her private parts to send to the Maasstad burn center for assessment. This is experienced as awkward.* ***(😐 doctor has no burn expertise & pictures of private parts)***.
- *Then she has to wait for more than an hour before the doctor returns. In the meantime, no updates are provided and she is cold and in an uncomfortable position. Her wounds are still open and this is not pleasant to see for her. She calls her mother to explain what has happened.* ***(🙁 uncomfortable waiting time with no updates)***.
- *After an hour the doctor returns with the message that the sending of the photos went wrong and new photos had to be taken. This gave her a very strange feeling and she worries about what has happened with the first photos of her private parts. The doctor was laconic about it, an unpleasant experience.* ***(☹️ laconic doctor, unpleasant feeling photos lost)***.
  "I felt very uncomfortable with the fact that they had lost the photos of my private parts"
- *After 45 minutes the doctor returns with the message that she can go home, but she has to visit the Maasstad burn center the next day. In this first institution she never receives a clear diagnosis. The nurses clean her wounds and put bandages on her. However, the type of bandages were not suitable for the position of her wounds and kept moving. At midnight, she returns home.* ***(😐 bandages that do not fit correctly)***.
- *The next morning her father brings her to Maasstad burn center since she is not able to walk herself. After arrival, she directly gets the feeling that this is a professional institution with burns expertise.* ***(🙂 feeling of expertise).***

Examination

- *Two nurses take care of her and answer all her questions. She experienced the interaction as friendly with comfortable small talk. They take swabs of the fat lumps on her wounds to check for infections.* ***(🙂 friendly staff).***
- *After 20 minutes a doctor and co-assistant arrive to assess her wounds. It seems that the doctor is in a rush. She tells the nurses how to treat the wounds. The doctor reassures her that everything will be fine. She has seen much worse. There will be scars, but her wounds will probably fully heal by itself in around three weeks.* ***(🙂 reassured by doctor, positive diagnosis!).***
  "This gave me the feeling that the only way is up from now!"

Treatment

- *The nurses cut the loose sheets of skin and treat and bandage the wound. They explain how to do this at home and write it down for her. They provide her with the right equipment. The way they bandage her wounds is very different than it was done by the previous institution. For her, this was proof that the first institution did not really have an idea what to do with severe burns. Around noon she can return home.* ***(🙂 good information provision by doctors)****.*

After care at home

- *She stayed at her parents home and was very dependent on them, since she could not walk. She was not allowed to shower as long as her wounds were open.*
- *She had to change the bandages every other day and let the wounds rest as much as possible. Changing the bandages was hard due to the location of the wounds. She had to watch out specifically for infections. At the beginning the wounds looked really bad because of the fat lumps.* ***(🙁 Changing bandages is hard and the wounds look bad)****.*
- *The fourth day after the incident felt like a changing point. The fat lumps were healed and the wounds looked better. Additionally, she was able to walk independently again. She returned to her student home.* ***(🙂 walk independently again)****.*
- *Every day after that her wounds looked better and she became more mobile. She still has to change the bandages every other day.* ***(🙂 progress every day)****.*

After care at trauma center

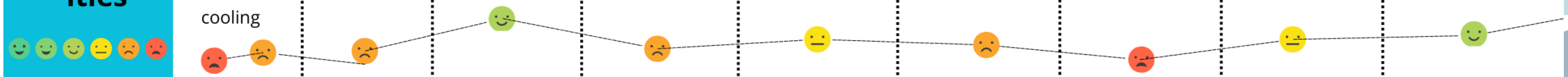
- *One week after the incident she has a check-up at the Maasstad burn center. She has a very good feeling about her situation and this is confirmed by the professionals. The wounds look good and nothing is seriously damaged. The wounds are cleaned and checked and then bandaged again. The nurses provide her with more information for after care at home.* ***(🙂 Good recovery)****.*

After care at home

- *The next two weeks she still has to change the bandages regularly, until the wounds are fully closed. She received access to the 'BeterDichtbij' application to communicate with the nurses of Maasstad. With this application she could ask questions to the nurses and send pictures of her wounds. The nurses provided elaborate answers. This support during the after care at home was experienced as very positive!* ***(🙂 application for contact with nurses during after care at home).***
  "I was able to easily send a photo and ask a question and received an almost immediate response, which was very nice!"
- *Three weeks after the incident her wounds are closed and she can shower again. She has to put oil on the closed wounds to increase the flexibility of the skin. Her recovery was very good and no other after care was needed.*

Patient journey burns 2 (part 1/2)

Time	Friday 19.15	Friday 19:45	Friday 20:00	Friday 20:30	Friday 21:30	Friday 21:45	Friday 22:45	Friday 23:30	Saturday 10.50
Location	At friends home	At friends home	Fransiscus Hospital	Fransiscus Hospital	Fransiscus Hospital	Fransiscus Hospital	Fransiscus Hospital	Fransiscus Hospital	Maasstad Burn Center
Procedure	Watching movie at a friends house and she spilled a mug of thee on herself. Insane pain. Friend did put her directly under the shower for 18 minutes. Relief of the worst pain. Sheets of skin hang from the wound. She realizes the seriousness.	Friend tries to call SEH but is in the wait for a long time. Then mother of friend, who is a doctor, is called. Advise to go dirctly to the hopsital since the burns are on her private parts.	Within 30 minutes arrival with uber at Fransiscus. Brought in by wheelchair (because she could not walk by herself). Triage for burns, she has high priority.	Nurse checks blood pressure and puts her under the shower again. Then leaves her alone because her shift is over. She is left alone and forgotten. After 35 minutes her friends goes to find a nurse. She had the impression the personnal was not professional and not expertised.	Waiting in a room for 10 minutes for the doctor to come. Burns still open and she was half naked. Feeling the doctor had no expertise about burns. She calls Maasstad. Makes pictures of het private parts (uncomfortable) to send to Maasstad and then leaves.	Waiting in the room for more than an hour before the doctor returns. No updates inbetween. She was cold and the position she was in was uncomfortable. Wounds still open. Not pleasant to see the open wounds. Called her mother.	Doctor comes back after one hour with the message that the sending of the photo's went wrong and new photo's needed to be taken. Very strange feeling, what happend with the first photo's of her private parts. Doctor was laconic about it, not pleasant.	After 45 minutes doctor returns. She can go home but has to go to Maasstad the next day. Nurses clean wounds and put bandages on her. The type of bandages was not suitable for the position of her wounds, they kept moving. At 00:30 she can go home.	Father brought her because she could not walk. Immediately the impression that this was a professional institution. Two nurses took care of her and answered her questions. Friendly small talk. Fat lumps on wounds. Swaps to check on infections.
Contact	💬	☎	💬	💬	💬	💬 ☎	💬	💬	💬
Who	Friend	Friend Mother of friend by phone	Friend Nurses	Friend Nurses	Friend Doctor	Friend Mother	Friend Doctor	Friend Doctor	Father Nurses
Particular-ities	Painful and scared, little better after cooling	Not knowing what to do	Priority treatment	Left alone and forgotten	Doctor not experienced	Left alone for long time	Photo's of private parts lost	Bandages do not fit correctly	Friendly and professional staff.



Patient journey burns 2 (part 2/2)

Time	Saturday 11.15	Saturday 11:30	Sunday-tuesday 3 days	Wednesday 4th day	Thursday-Friday	Saturday	The two weeks after check-up	After two weeks
Location	Maasstad Burn Center	Maasstad Burn Center	At parents home	At student home	At student home	Maasstad Burn Center	At home	At home
Procedure	Doctor arrives and assesses the wound. Feeling that she is in a rush. She tells the nurses how to treat the wounds. Also a co-assistent present She is reassured by the doctor. Doctor has seen much worse. There will be scars but it will fully heal probably in three weeks the wounds will close.	Nurses cut the sheets of skin and treat the wound. They explain how to do this at home and write it down. They provide her with the equipment. Different way of bandages binding than at Fransiscus, proves that they did not really know what to do. In generall different information. Around 12:30 she can go home.	Very dependent of het parents since she could not walk. No showering as long as the wounds are open. Change the bandages every other day. Let the wounds rest as much as possible. Watch out for infections. Hard to change the banadages due to the location of the wounds. At the beginning the wounds looked bad due to the fat lumps.	Changing point. Fat lumps are gone, wounds look better and able to move independently. She went back to student home.	Every day more mobile and wounds look better. Still bandage change every other day.	Check-up at Maasstad. Very good feeling about it and this is comfirmed. Wounds look good. Nothing is seriously damaged. Wounds are cleaned and checked. Than bandages are put on it again. Information for after care at home.	Bandages change at home for the next two weeks, until the wounds are closed. She had the 'BeterDichtbij'app to communicate with the nurses. She could ask questions and send pictures. Nurses did send elaborate answers. Very nice experience.	After two weeks the wounds are closed and she can shower again. She has to put oil on the closed wounds for flexibility. Recovery very good and no furher care was needed.
Contact	💬	💬	💬	💬	💬	💬	⚡	
Who	Doctor and co-assistent Nurses Father	Nurses Father	Parents	Housemates	Housemates	Father Nurses Doctor	Nurses	
Particular-ities	Reassured everything will be fine	Good explanation, professional	Hard to change banadages, looked bad. Still painful.	Recovery looks good	Recovery looks good	Confirmed that recovery is good	Contact with nurses via app	After care is done

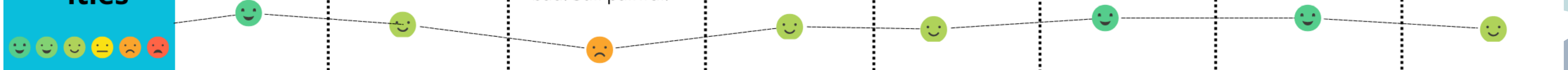
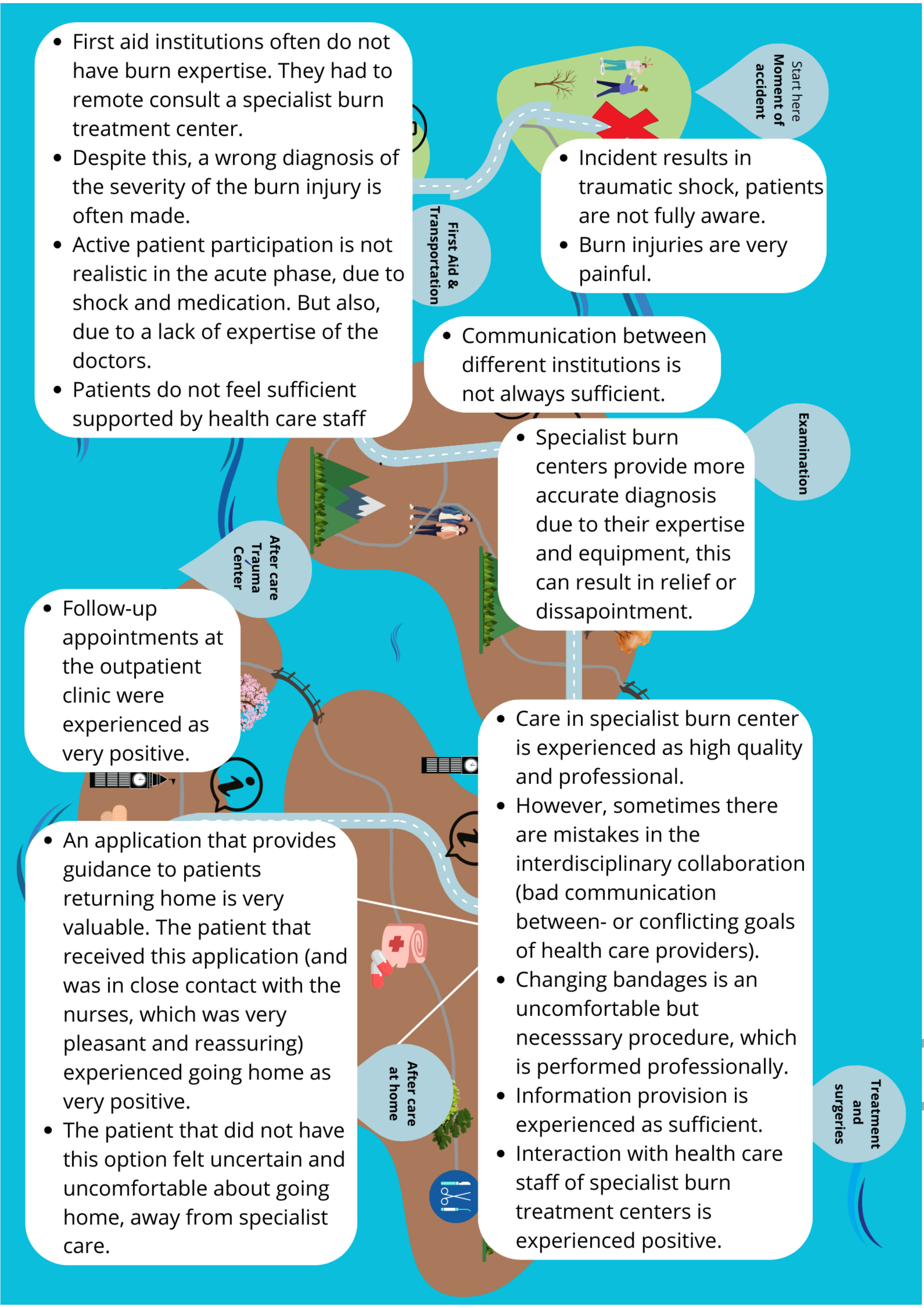


Figure 10: Patient journey burn patient 2

4.3 Combined insights burn patient interviews

The insights retrieved from the burn patient interviews are documented in the map below. Multiple insights contributed to the direction change, as will be explained in chapter 9.



- Incident results in traumatic shock, patients are not fully aware.
- Burn injuries are very painful.

- First aid institutions often do not have burn expertise. They had to remote consult a specialist burn treatment center.
- Despite this, a wrong diagnosis of the severity of the burn injury is often made.
- Active patient participation is not realistic in the acute phase, due to shock and medication. But also, due to a lack of expertise of the doctors.
- Patients do not feel sufficient supported by health care staff

- Communication between different institutions is not always sufficient.

- Specialist burn centers provide more accurate diagnosis due to their expertise and equipment, this can result in relief or dissapointment.

- Care in specialist burn center is experienced as high quality and professional.
- However, sometimes there are mistakes in the interdisciplinary collaboration (bad communication between- or conflicting goals of health care providers).
- Changing bandages is an uncomfortable but necesssary procedure, which is performed professionally.
- Information provision is experienced as sufficient.
- Interaction with health care staff of specialist burn treatment centers is experienced positive.

- Follow-up appointments at the outpatient clinic were experienced as very positive.

- An application that provides guidance to patients returning home is very valuable. The patient that received this application (and was in close contact with the nurses, which was very pleasant and reassuring) experienced going home as very positive.
- The patient that did not have this option felt uncertain and uncomfortable about going home, away from specialist care.

Figure 11: Insights burn patient interviews (in relation to stages on the map)

Chapter 5: Trauma care chain of crush injury

To get a deeper understanding of the trauma care context, the trauma care pathways of burns (previous chapter) and crush injury were investigated. Literature review, observations and patient interviews were performed.

5.1 Treatment of crush injury in the civilian context

Crush injury is defined as compression of extremities or other parts of the body that causes muscle swelling and/or neurological disturbances in the affected areas of the body (Centers for Disease Control and Prevention, 2009). It refers to the damage on a human body resulting directly from a crushing force. Crush injury can be life threatening, even if not involving vital organs (Genthon & Wilcox, 2013). The leading causes of crush injury are motor vehicle accidents, victims trapped under the rubble of collapsing buildings, gunshot or munition wounds, and falls (Strauss & Garcia-Covarrubias, 2008; Bortolin & Ciottone, 2015).

Crush Syndrome

Crush syndrome is the systemic manifestation of breakdown of muscle cells caused by the compression, provoking the releasing of cell contents (creatine kinase, lactic acid, myoglobin, and potassium) into the extracellular fluid and blood circulation (Greaves et al., 2003; Smith & Greaves, 2003). This causes local tissue injury, organ dysfunction, hypovolemia, hyperkalemia, metabolic acidosis, renal hypoperfusion, and ischemia resulting in acute renal failure (Genthon & Wilcox, 2013; Bortolin & Ciottone, 2015). Acute renal failure as a result of crush syndrome is one of the life threatening conditions that can be prevented or reversed (Sever et al., 2006). Since the development of crush injury is directly related to the compression time, victims should be extricated as quickly as possible (Yazici, 2023). During extraction toxic muscle cell components and electrolytes that have been accumulated in the tissues of the crushed body part, start spreading in the blood circulation, possibly resulting in cardiac dysrhythmias (Bortolin & Ciottone, 2015).

Treatment

The most critical therapy in crush syndrome is early and aggressive fluid resuscitation with 0.9% saline to restore circulating blood volume (Genthon & Wilcox, 2013; Yazici, 2023). Imbalance of calcium and potassium in the blood can lead to life-threatening cardiac arrhythmias (Centers for Disease Control and Prevention, 2009; Yayik, 2023). Rapid monitoring of the electrocardiograph (ECG) has high priority, especially to monitor Potassium, Calcium and Phosphorus levels (Genthon & Wilcox, 2013). Additionally, urine is examined and monitored with a catheter for myoglobinuria (which can lead to acute renal failure). If needed, dialysis treatment is performed and waste products and excess fluids are removed from the body (Yayik, 2023; Yazici, 2023). Liver is examined to test for liver shock and coagulopathy (Genthon & Wilcox, 2013). Radiographic imaging or CT are used to detect areas of edema and necrosis, indicating the development of compartment syndrome (muscle swelling within a closed anatomical space) (Genthon & Wilcox, 2014; Yazici, 2023. In the case of compartment syndrome, the patient undergoes fasciotomy surgery (Genthon & Wilcox, 2013). During this operation, a closed wound is turned into an open wound in order to reduce the pressure in the tissue. If a crushed body part cannot be saved, amputation is necessary (Yazici, 2023).

CRUSH INJURY CIVILLIAN CARE PATHWAY

Moment of accident

Accident causing crush injury
Calling emergency services

First Aid

Start with the first aid protocol. Upon liberation of the crushed body part, rapid clinical decline may occur due to the breakdown of the muscle cells (rhabdomyolysis) and the release of toxins from these cells into the bloodstream. This can lead to crush syndrome, which has a high risk of renal failure, local tissue injury, organ dysfunction and metabolic abnormalities, including acidosis, hyperkalemia and hypocalcemia. After performing the Life Support Protocols, it is imperative that early and aggressive fluid resuscitation occurs to restore blood volume to the circulatory system.

Transport

Monitoring of the patient. Continue fluid resuscitation. Imbalance of calcium and potassium in the blood can lead to life-threatening cardiac arrhythmias. Rapid monitoring of electrocardiograph (ECG) is a high priority, especially to monitor Potassium, Calsium and Phosphorus levels. Due to hyperkalia, rapid increase in serum potassium can lead to changes in the ECG.

Arrival Trauma Center

Intake ICU

Patient transfer and regristration
Continue fluid resuscitation. Administer 10-20L for the first 24 hours.

Follow-up examination and treatment
Urine is examined for myoglobinuria which can lead to acute renal failure. Catheter is placed for monitoring. Liver examination to test for liver shock and coagulopathy.
CT scan to detect the development of compartment syndrome (muscle swelling within a closed anatomical space)

Admission

The patient is admitted to the trauma center
All the patient's values are monitored several times a day to check whether the patient is stable.

Operation / treatment

Dialysis
In the case of acute renal failure, the patient is treated with dialysis to remove waste products and excess fluid from the body.
This takes an average of 4 hours and takes place several times a week.

Fasciotomy
In the case of compartment syndrome, the patient undergoes fasciotomy surgery. During this operation, a closed wound is turned into an open wound in order to reduce the pressure in the tissue.

Amputation
If a crushed body part cannot be saved, amputation is necessary. The severity of the crush can be assessed with the 'crushed limb Severity Score' (MESS).

After care trauma center

After care of wounds and evaluation of surgery / treatment.

After care at home

After care of wounds until complete recovery (or rehabilitation).

5.2 Generative Patient Interview

A generative patient interview was performed with a civilian crush injury patient. During the generative interview, the Map My Experience Trauma Care tool was used in combination with an interview guide (see appendix E). In this section, the experience map and patient journey are presented.
The generative interview was performed in the patients native language (Dutch), to elicit information in the most detailed and rich way (see appendix G). For the presentation in this report, the original map is presented with highlights of positive and negative experiences (smiley icons). Additionally, the patient's notes on every island are documented under the map.

Map My Experience Trauma Care tool (burns 2)

Figure 12: Crush injury patient map

Moment of incident

- *As an ambulance worker she comes to someone's home and in the house she misses a step. She falls from the steps and completely shatters her lower leg. She feels extreme pain and knows immediately that this is wrong. Her leg was lying unnaturally and she had enough medical knowledge to see that her leg was crushed.* ***(😞 immense pain)****.*

First aid & transportation

- *They gave her morphine and she was brought to the hospital immediately.*
- *Due to traumatic shock and the morphine, she has no active memory of arriving at the hospital. Later, she heard from others that she was crying hysterically and cursing, and that while she is a strict Christian! She was shocked by the stories.* ***(🙁 shocked by stories)****. "I have no active memory of acute care. Afterwards I heard that I was very upset and swearing, and that while I am a Christian!"*

Examination / treatment

- *At the hospital they made a CT-scan of her head and X-ray images of her leg.*
- *On the second day in the hospital she was operated on her leg by a trauma surgeon. They secured her leg with plates, screws and pins. The expectation was that she would be able to use her leg normally again after recovery.* ***(🙂 expectation of good recovery)****. "With plates, screws and pins they fixed my leg. They thought I would be able to use it normally again, however this was not the case..."*

After care at trauma center

- *After the operation she can go home. She has weekly/monthly check-ups in the outpatient clinic and this is experienced positively.* ***(🙂 satisfied with care)****.*

Follow-up treatments

- *In December she developed sepsis in her lower leg. She is rushed to the hospital by an ambulance. She is in a lot of pain. She received an IV and antibiotics for the inflammation and morphine for the pain. With an operation her leg was opened and the bone was removed. Follow-up surgery is needed.*
- *While waiting at her follow-up surgery (at home), she experiences a tremendous amount of pain. She receives a lot of morphine and even becomes addicted.* ***(😞 immense pain)****.*
- *During her follow-up operation, the leg was opened again and a donor bone was inserted. This operation only had a 15% success rate, because her blood vessel network was severely damaged. Poor blood flow leads to poor recovery. She is now seen in the hospital as a difficult patient who requires a lot of attention. She feels more and more like a burden.* ***(🙁 low success rate)****.*
  "It also happened regularly that I received conflicting advice from different professionals. They had differences of opinion about my care."
- *She still experiences a tremendous amount of pain and becomes more and more addicted to the morphine. She feels tired of all the caregivers and is not satisfied with the hospital care.*
  (😞 immense pain and addicted to morphine)*.*
- *"During rehabilitation you are quite dependent on yourself, a tool that provides guidance in this proces would be valuable!"*
- *Due to the unbearable pain, her leg was amputated in April. This felt like a relief for the patient, she felt liberated. She was happy that she would finally be free of the pain. An artificial knee is attached to her stump.* ***(🙂 finally liberated from the pain)****.*
  "I was happy with the amputation. I had said goodbye to that leg a long time ago. I felt liberated!"

- *She gets a socket prosthesis but experiences a lot of pain with it. The prosthesis tears her skin and causes pressure marks. It hurts so much that she is completely done with it, and is prepared to sit in a wheelchair for the rest of her life. She is also very dissatisfied with the care at Radboud Hospital. There were many miscommunications and disagreements among the doctors about her care. She was also not helped with a suitable prosthetic due to a limited budget. She decides to transfer to Erasmus hospital Rotterdam.* ***(🙁 again a lot of pain, dissatisfied with the care provided)****.*
- *Everything was better in Rotterdam. The healthcare professionals worked well together and agreed with each other. There was also more budget available to give her a suitable prosthetic. In May 2020, she received a click prosthesis. A pin was surgically attached to her leg.* ***(🙂 receives a new prosthetic)****.*

After care at home

- *At home she has to train using the new prosthetic. Slowly pressure on the pin should be increased, until it can carry half her body weight. Only then, she can start practicing walking on the new prosthetic. She experiences training with the new prosthetic as very scary, since she is afraid of falling.* ***(🙁 scared of falling)****.*
- *The prosthetic has to be cleaned twice a day, but that is certainly worth it!*
- *In July, she will also receive a digital knee (funded by healthcare insurance) because she has suffered PTSD from many falls (during accident and rehabilitation). This digital knee can remember her movements and therefore reduces the risk of falling. While they are giving her the new knee, they find out that the knee she received earlier has long been disapproved. She should never have gotten this, it is very dangerous.* ***(🙁 finding out she was given a disapproved knee)****.*
- *She has her last appointment in the outpatient clinic in August. She is very satisfied with the care in Rotterdam and happy with the click prosthesis.* ***(🙂 satisfied with care)****.*
  "The difference between these to health care institutions was enormous, I finally felt heard and received tailor-made care. This was possible since they had other financial procedures."
- *She is now incapacitated. This is not due to her leg disability, but due to her PTSD. They have diagnosed her with a congenital brain injury that means she is no longer able to perform her work normally. This shows what influence the care and rehabilitation process can have on a patient's quality of life. She has done EMDR for her PTSD, this has helped somewhat but is certainly not enough. There are many things she can no longer do, but she focuses on what she can still do. She sets goals for herself that she can work towards, such as being able to walk again with her grandchild in hand. This was her motivation to train hard and recuperate quickly.* ***(🙁 incapacitated due to PTSD from falling).***
  "I have learned to find joy in small things. I focus on what I can still do and set goals for myself. My great motivation was to quickly recuperate so that I could walk again with my grandchild in hand!"

> *"It is certainly valuable to read the experiences of fellow sufferers, in this way someone can be helped to adapt to his/her new situation and has a frame of reference about what is normal within the care pathway".*

Patient journey crush injury (part 1/2)

Time	May 2018	May 2018 Day 1 hospital	May 2018 Day 2 hospital	Weekly/ monthly check-ups	Dec 2018	Jan 2019	Feb 2019	March 2019	April 2019	May 2019 - April 2020
Location	During work at ambulance	Radboud Nijmegen	Radboud Nijmegen	After care outpatient clinic	Radboud Nijmegen	At home	Radboud Nijmegen	At home	Radboud Nijmegen	At home & Radboud Nijmegen
 **Procedure** 	She fall of some stairs and totally crushed her lower leg. She experienced a lot of pain and knew immediately that this was a serious injury. They gave her morphine and she was brought to the hospital immediately.	Patient has no active memory of her arrival at the hospital. She heard from others that she was cursing ans crying. This shocked her since she is a Christian. In the hopsital they made a CT scan of her head and X-ray images of her leg.	At the second day in the hopsital she was operated by a trauma surgeon. They secured her leg with plates, screws and pins. The expectation was that she would be able to use her leg normally again.	Regular check-ups at the outpatient clinic. Patient experienced the information provision as good and the after care of high quality.	In December she developed sepsis in her lower leg. Rushed to hospital by ambulance. She is in a lot of pain. Here she received an IV and antibiotics for the inflammation and morphine for the pain. The leg was opened and the bone removed.	While waiting at her follow-up surgery, she experiences a tremendous amount of pain. She receives a lot of morphine and even becomes addicted.	During her follow-up operation, the leg was opened again and donor bone was inserted. This operation only had a 15% success rate because her blood vessel network was severely damaged. Poor blood flow leads to poor recovery. She is now seen in the hospital as a difficult patient who requires a lot of attention. She feels more and more like a burden.	She still experiences a tremendous amount of pain and becomes more and more addicted to the morphine. She feels tired of all the caregivers and is not satisfied with the hospital care.	Due to the unbearable pain, her leg was amputated in April. This felt like a real relief for the patient, she felt liberated. She was happy that she would finally be free of the pain. An artificial knee is attached to her stump.	She gets a socket prosthesis but experiences a lot of pain with it. The prosthesis tears her skin and causes pressure marks. It hurts so much that she is completely done with it and is prepared to sit in a wheelchair for the rest of her life. She is also very dissatisfied with the care at Radboud Hospital. There were many miscommunications and disagreements among the doctors about her care. She was also not helped with a suitable aid due to a limited budget. She decides to transfer to Erasmus hospital Rotterdam.
Contact	💬	💬	💬	💬	💬	💬	💬	💬	💬	💬 ☎
Who 	Ambulance personnel	Nurses, doctor	Nurses, doctor	Nurses, doctor	Nurses, doctor	Nurses, doctor	Nurses, doctors	Nurses, doctors	Nurses, doctors, private prothesis maker	Nurses, doctors
Particular-ities 🟢 🟢 🟢 🟡 🟠 🔴	Pain! 🔴	No clear memory, shocked by stories 🟠	Expectation of good recovery 🟢	Satisfied with care 🟢	Immense pain 🔴	Immense pain, addicted to morphine 🔴	Low chances of succes, she feels like a burden 🟠	Immense pain, addicted to morphine 🔴	Finally liberated from the pain 🟢	Again a lot of pain, dissatisfied with the care, she feels not heard at al 🔴

Patient journey crush injury (part 2/2)

Time	May 2020	May -June 2020	July 2020	Aug 2020	Aug 2020-dec 2024
Location	Erasmus Rotterdam	At home	Erasmus Rotterdam	Erasmus Rotterdam	At home
Procedure	Everything was better in Rotterdam. The healthcare professionals worked well together and agreed with each other. There was also more budget available to give her a suitable aid. In May 2020, she received a click prosthesis. A pin was surgically attached to her leg.	She should train slowly while increasing the pressure on the pin. She does this by pressing the pin against a scale. The pin must be able to support half her body weight. She can then practice with the prosthesis itself. She built up May and June and learned to use the new prosthesis. The prothesis has to be cleaned twice a day, but that is certainly worth it! she experienced training with the prothesis as very scary, since she was so afraid of falling.	In July she will also receive a digital knee (funded by healthcare insurance) because she has suffered PTSD from many falls (during accidents and rehabilitation). This digital knee can remember her movements and therefore reduces the risk of falling. While they are giving her the new knee, they find out that the knee she received earlier in Nijmegen has long been dissapproved. She should never have gotten this, it is very dangerous. This knee came from a private party. Rotterdam has its own prosthetic making facility internally	She has her last appointment in the outpatient clinic in August. She is very satisfied with the care in Rotterdam and happy with the click prosthesis. She does suffer from PTSD from falling. She dares to walk indoors without a crutch, but not outside	She is now incapacitated. This is not due to leg disability, but due to her PTSD. They have not diagnosed her with a congenital brain injury that means she is no longer able to perform her work normally. This shows what influence the care and rehabilitation process can have on a patient's quality of life. She has done EMDR for her PTSD, this has helped somewhat but is certainly not enough. There are many things she can no longer do, but she focuses on what she can still do. She sets goals for herself that she can work towards, such as being able to walk again with her grandchild in hand. This was her motivation to train hard and recuperate quickly.
Contact	💬	💬	💬	💬	
Who	Nurses, doctor, prosthetic maker	Family	Nurses, doctor, prosthetic maker	Nurses, doctor	
Particular-ities	She receives a new prothesis	Very satisfied with the new prothesis, but during training she is afraid.	Finding out they gave her a rejected knee Receiving a digital knee	Satisfied with service Rotterdam	

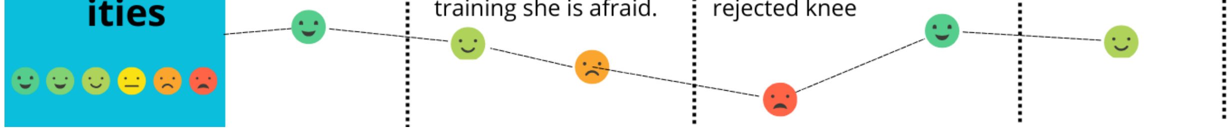
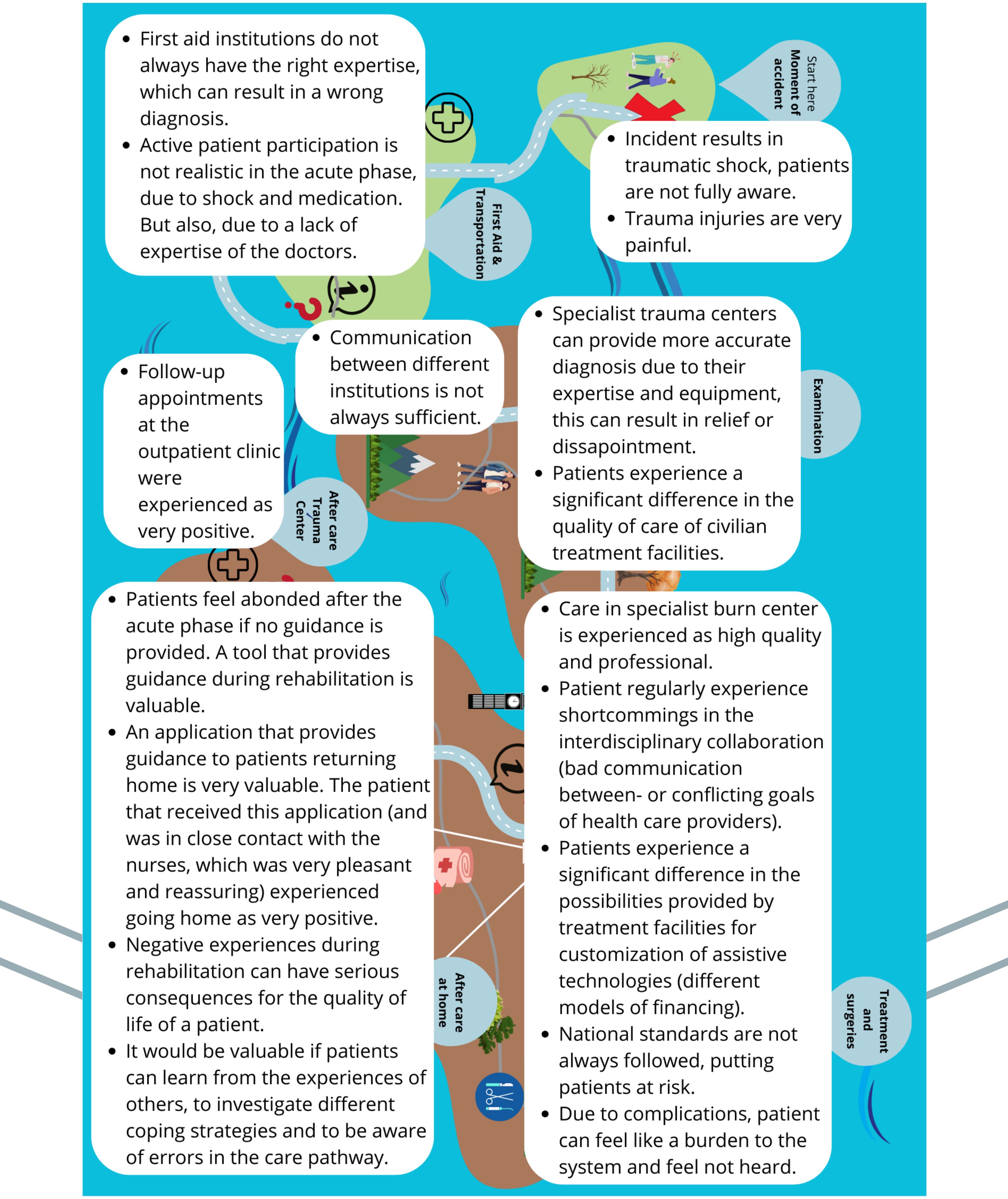


Figure 13: crush injury patient journey

5.3 Combined insights burns and crush injury patient interviews

Finally, the insights from the crush injury interview are combined with the previous insights from the burns interviews, and documented in the map below. The insights contributed to the direction change, as will be explained in chapter 9.



- Incident results in traumatic shock, patients are not fully aware.
- Trauma injuries are very painful.

- First aid institutions do not always have the right expertise, which can result in a wrong diagnosis.
- Active patient participation is not realistic in the acute phase, due to shock and medication. But also, due to a lack of expertise of the doctors.

- Communication between different institutions is not always sufficient.

- Specialist trauma centers can provide more accurate diagnosis due to their expertise and equipment, this can result in relief or dissapointment.
- Patients experience a significant difference in the quality of care of civilian treatment facilities.

- Care in specialist burn center is experienced as high quality and professional.
- Patient regularly experience shortcommings in the interdisciplinary collaboration (bad communication between- or conflicting goals of health care providers).
- Patients experience a significant difference in the possibilities provided by treatment facilities for customization of assistive technologies (different models of financing).
- National standards are not always followed, putting patients at risk.
- Due to complications, patient can feel like a burden to the system and feel not heard.

- Follow-up appointments at the outpatient clinic were experienced as very positive.

- Patients feel abonded after the acute phase if no guidance is provided. A tool that provides guidance during rehabilitation is valuable.
- An application that provides guidance to patients returning home is very valuable. The patient that received this application (and was in close contact with the nurses, which was very pleasant and reassuring) experienced going home as very positive.
- Negative experiences during rehabilitation can have serious consequences for the quality of life of a patient.
- It would be valuable if patients can learn from the experiences of others, to investigate different coping strategies and to be aware of errors in the care pathway.

Figure 14: Combined insights civilian patient interviews (in relation to stages on the map)

Chapter 6: The military trauma care chain

Since the tool will be used by military personnel that got injured during deployment, it is important to be familiar with the military trauma care chain. This trauma care chain starts at the time of injury in the deployment area and ends after rehabilitation in the Netherlands.

6.1 Military trauma patients

When looking at trauma injuries among the military, we can distinguish combat trauma casualties and non-battle trauma injuries. Battle trauma casualties are those that occur as a direct result from combat. Non battle trauma injury can occur during training or daily routines. The study of Hoencamp (2015) about medical repatriation of Dutch military personnel from Afghanistan, showed that 37% of the Dutch repatriated casualties were the result of non-combat injuries. Care under Fire/Threat is the provision of care under circumstances in which there is immediate, life-threatening danger to both the care provider and the victim (Ik 2-22, ministry of Defense). Tactical Field Care is care that is provided when there is no longer any immediate, life-threatening danger, but where there are limited medical options (Ik 2-22, ministry of Defense). In the recent conflicts of Iraq and Afghanistan, explosions were the dominant mechanism of injury among the combat casualties (Hoencamp, 2015; Van Dongen et al., 2016; Owens et al., 2008; Belmont et al., 2012). As a result, lower limb injuries make up the majority of combat related trauma and it often leads to substantial disability (Van Dongen et al., 2016). Between 2006 and 2010, during the operation in Afghanistan, the Dutch military suffered 199 (physical) battle casualties. IEDs were the main mechanism of injury in 74% of the cases and 30% of all injuries were lower limb trauma (Hoencamp et al., 2014). The resulting disability generally undermines the well-being of the victim (Scott et al., 2013). Despite the evolving technical developments and innovations, humans will likely remain irreplaceable in future armed conflicts. Therefore, it is important to study and improve military trauma care.

6.2 Allied Joint Doctrine for Medical Support

The NATO adheres to a standard allied joint doctrine for medical evacuation and treatment, the AJP-4.10. The doctrine should be understood as a guideline and reference for military medical care which can be applied with flexibility and can be adjusted to specific operations and situations. The cycle of military health care follows a continuum of care in a progressive manner, from self and buddy care to definitive treatment, rehabilitation and return to duty (see Figure 15). Roles of care may be bypassed due to patients' needs and operational factors like the workload of medical treatment facilities.

Moment of trauma injury

The doctrine states that within 10 minutes after injury, life-saving first response measures to control severe bleeding and maintain airway, breathing and circulation should be performed, since this significantly improves the likelihood of survival. All military personnel are trained in life-saving skills for the purpose of self and buddy care. This consists of all measures of military care not delivered by dedicated medical service personnel. For the Dutch military the MARCH-protocol is the approach used for first aid (IK 2-22, ministry of Defense). Additionally, all military personnel deployed should be equipped with an individual first aid kit (IFAK) according to NATO standards (AMedP-8.7). Selected trained military personnel should be able to provide advanced and prolonged field care. The pre-hospital phase seems to be the most important phase in the medical support organization to improve the survival and functional outcome for battle casualties (Butler, 2010).

Medevac

Medical evacuation is the process of moving the casualty to or between medical treatment facilities. In the case of combat casualties, medical evacuation teams should be equipped and trained to rescue and evacuate patients out of a hostile and/or remote environment.

Primary health care in role 1 and role 2 Medical Treatment Facility

Role 1 MTF provides primary care, triage, first aid, pre-hospital emergency care, and evacuation. Primary health care consists of diagnosis and nonsurgical lifesaving treatment of trauma (Staudt et al., 2018). Advanced damage control resuscitation and pre-hospital emergency care should be provided within 1 hour after the injury, to restore, stabilize and maintain vital physiological functions of patients in critical conditions. Damage control resuscitation uses advanced trauma life support techniques to minimize blood loss, sustain circulation, secure the airway, provide effective pain management and prevent wound infection and hypothermia. Life, limb, and function preserving surgical and resuscitative care should be provided within 2 hours after injury. Further surgical, resuscitative, diagnostic and specialist care capabilities may be necessary to stabilize the patient for strategic evacuation should be made within 2 hours of tactical evacuation after initial damage control surgery treatment. Role 2 MTF provides primary and secondary care with access to specialist doctor-led resuscitation, surgical stabilization and damage control. Blood transfusions are only possible from the Role 2 MTF, and therefore it is crucial that blood-stopping agents are properly applied in the first phase (Ministry of Defense, 2024). Within role 2, there is access to a limited number of surgical teams, operation tables, intensive care beds and diagnostic capabilities (Staudt et al., 2018). Additionally, there is a moderate holding capacity for patients and limited access to specialist medevac capability. To illustrate, the Role 2 MTF of the Dutch Army in the MultiNational Base Tarin Kowt (Afghanistan) was configured with two emergency resuscitation tables, one operating room, two ICU beds, and 14 regular nursing beds (Hoencamp et al., 2014).

Despite the guidelines of the NATO doctrine we can conclude that in practice it is hard to comply with the time frames. When we look at the medical evacuation situation in Afghanistan, we can conclude that the mean time between injury and medical evacuation for Dutch military personnel was 8 days (Hoencamp, 2015). This mean was reduced to 3,6 days for severe and polytrauma casualties (ISS>15). Shorter transportation intervals might improve morbidity and mortality rates of casualties. Health care during military deployment works according to the same standards and values as civilian care in the Netherlands. The biggest differences are the limited resources and the fact that not all specializations are present within the medical treatment facilities. That is why there is often close collaboration with civilian hospitals (Expert interview military nurse, November 2024).

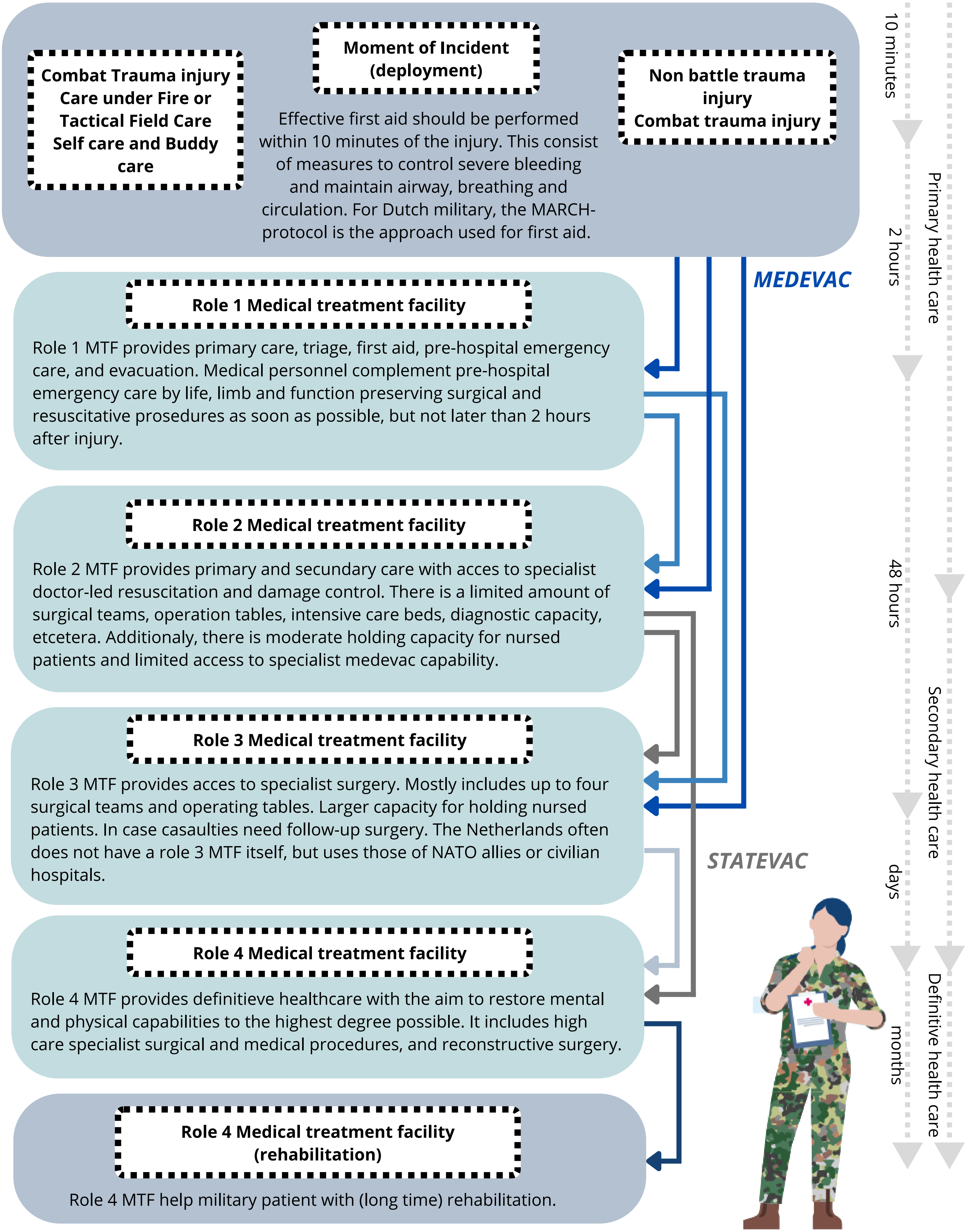
Statevac

Strategic medical evacuation is to be conducted from medical treatment facilities inside the area of deployment towards a medical treatment facility outside this area (usually role 4 MTF). In Afghanistan, casualties were repatriated to the role 4 MTF Central Military Hospital (CMH) and the University Medical Center Utrecht (UMCU) in Utrecht, the Netherlands, for definitive health care.

Rehabilitation

The Military Rehabilitation Center (MRC) Aardenburg is the military treatment and expertise center for rehabilitation, occupational rehabilitation and orthopedic aids. The MRC is for military personnel and civilians. This combination allows the specialists to immediately use the knowledge and experience from one target group for the other target group. For military patients, the goal is to be operationally deployable again. For every patient the goal is to be ‘fit for life’, which means to be able to participate fully in society (Ministerie van Defensie, 2024). After specialised medical rehabilitation, the patient can move on to occupational rehabilitation, which prepares them for specific job requirements such as the Defense Fitness Test (requirement for military personnel) (MRC Aardenburg, 2022).

MILITARY TRAUMA CARE PATHWAY



Combat Trauma injury
Care under Fire or
Tactical Field Care
Self care and Buddy care

Moment of Incident (deployment)

Effective first aid should be performed within 10 minutes of the injury. This consist of measures to control severe bleeding and maintain airway, breathing and circulation. For Dutch military, the MARCH-protocol is the approach used for first aid.

Non battle trauma injury
Combat trauma injury

Role 1 Medical treatment facility

Role 1 MTF provides primary care, triage, first aid, pre-hospital emergency care, and evacuation. Medical personnel complement pre-hospital emergency care by life, limb and function preserving surgical and resuscitative prosedures as soon as possible, but not later than 2 hours after injury.

Role 2 Medical treatment facility

Role 2 MTF provides primary and secundary care with acces to specialist doctor-led resuscitation and damage control. There is a limited amount of surgical teams, operation tables, intensive care beds, diagnostic capacity, etcetera. Additionaly, there is moderate holding capacity for nursed patients and limited access to specialist medevac capability.

Role 3 Medical treatment facility

Role 3 MTF provides acces to specialist surgery. Mostly includes up to four surgical teams and operating tables. Larger capacity for holding nursed patients. In case casaulties need follow-up surgery. The Netherlands often does not have a role 3 MTF itself, but uses those of NATO allies or civilian hospitals.

Role 4 Medical treatment facility

Role 4 MTF provides definitieve healthcare with the aim to restore mental and physical capabilities to the highest degree possible. It includes high care specialist surgical and medical procedures, and reconstructive surgery.

Role 4 Medical treatment facility (rehabilitation)

Role 4 MTF help military patient with (long time) rehabilitation.

Figure 15: Military trauma care chain

6.3 Polytrauma patient Uruzgan

To make the military trauma care chain more concrete, a polytrauma patient was interviewed. During his deployment in Afghanistan, his patrol vehicle drove past a suicide-IED-vehicle-bomb that exploded and resulted in multiple casualties. Care under fire was performed and the casualties were evacuated to medical treatment facilities.

The Map My Experience Trauma Care tool was not suitable for this interview, since it was tailored for the Dutch trauma care chain. It does not fit with the military trauma care chain for deployment, where multiple medical treatment facilities (and modes of transportation) are exploited before returning to the Netherlands. For further research, a tailored Map My Experience Trauma Care tool should be created for the military trauma care chain (for military personnel on deployment).

This patient interview was performed with the objective to create a deeper understanding of the military trauma care chain and to find the main differences with the civilian trauma care chain. The most important insights are documented in Figure 16. A visual representation of the care chain can be found in Figure 17.

Moment of incident

- *Patient is standing on the left front of an armored tracked vehicle when they pass a suicide vehicle IED that explodes. The patient experiences a sensory overload and cannot see or hear anything for some time. When he becomes more aware of his situation, he notices that his head and hand are hurting. He realizes he lays down on someone's lab inside of the vehicle now. This person tries to reassure him that everything will be okay and takes care of his wounds (buddy care - care under fire).*
- *The casualties are loaded into another vehicle and transferred to a wounded nest and placed in a circular guarding formation, since they are still under fire threat.*

Role 1 Medical treatment facility - wounded nest

- *Within the wounded nest primarily health care is provided by Combat Life Savers (Medics). Since they are still relatively close to the fire threat, tactical field care is provided. From the medics he receives pain relief and an oxygen mask. By helicopter he is transferred to a role 2 Medical treatment facility.*

Role 2 Medical Treatment facility - Tarin Kot

- *The patient remembers that he entered the facility on a stretcher and nurses reassured him that he was safe.*
- *At this facility a trauma surgeon performed damage control surgery. His injuries were cleaned and bandaged. His crushed hand is put into plaster.*
- *Only after this first operation does he learn what has happened to him. Before that he was not fully aware of the situation. A day later the family was informed and he was able to call them. The patient remained in the role 2 MTF for a total of 3 days and was then transferred to a role 3 MTF.*

Role 3 Medical treatment facility - Kandahar

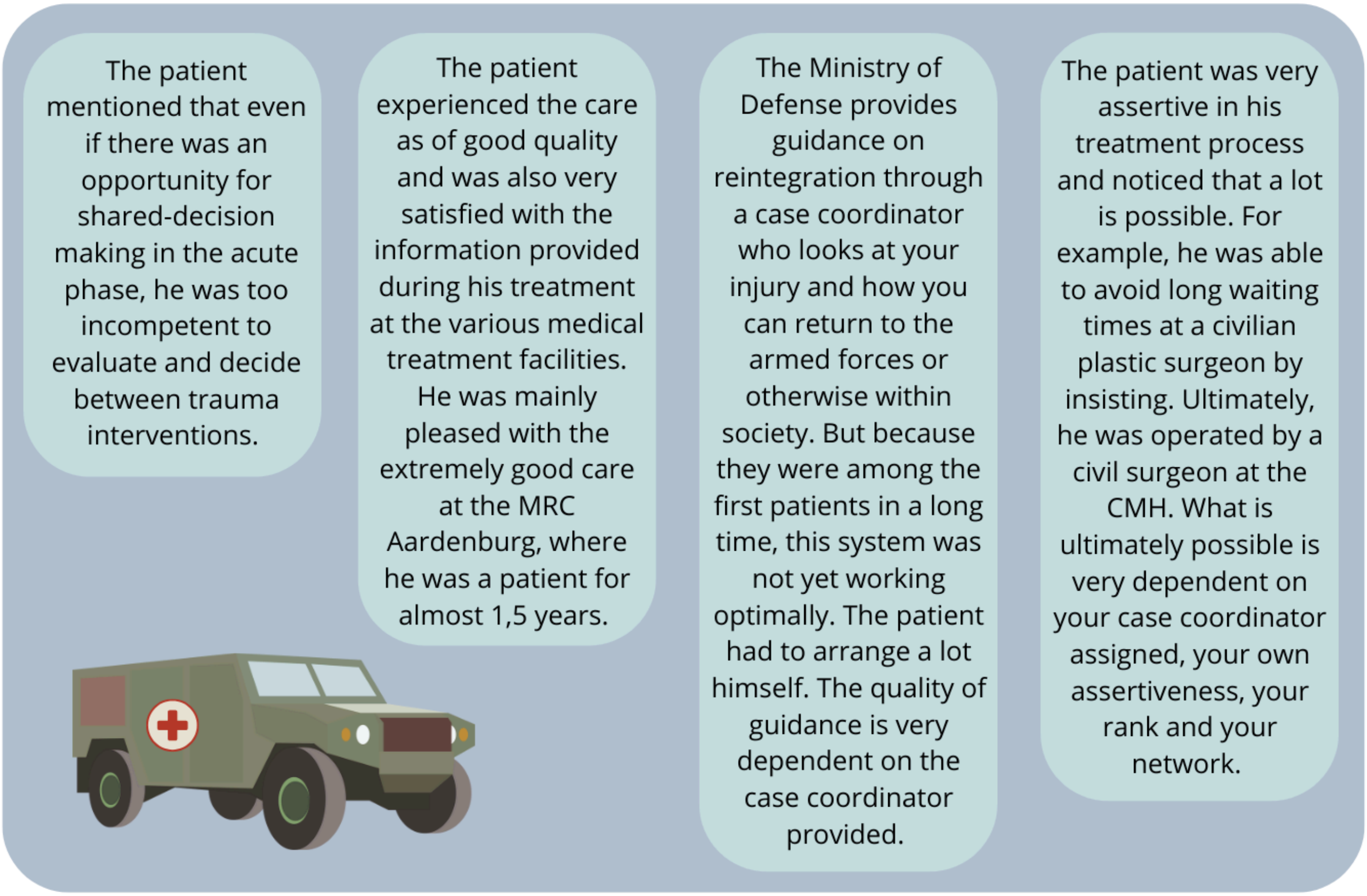
- *In this facility they had the equipment to make a CT-scan of his head injury. It turned out that there was air between his brain and skull, which made flying him to the Netherlands dangerous. As a result, he had to wait for a special medical flight where the air pressure could be maintained at sea level.*
- *At the role 3 facility he mainly received after care. He stayed for a total of 4 days. After that he was transported with a specialized medical flight to Bristol, England. From there, he went with a small plane to Soesterberg and then by vehicle to the role 4 MTF in Utrecht.*

Role 4 Medical treatment facility - Central Military Hospital Utrecht

- *At this facility they fully assessed him again. Here he received his first follow-up treatments. Chances were that he had to amputate two of his fingers, but the surgeons would do everything to prevent this.*
- *Eventually he needed seven follow-up surgeries at the CMH, including two bone transplants. His last operation was 1,5 years after the incident. Quality of care was perceived as good.*

Role 4 Medical treatment facility - Military Rehabilitation Center Aardenburg

- *During the last year of his care pathway he received intense rehabilitation at the military rehabilitation center. The focus was on mental recovery for his brain trauma and physical recovery for his fingers. Because his fingers had been in a cast for over 6 months, he could no longer bend them. He received daily occupational therapy and physiotherapy.*
- *The rehabilitation support was perceived as very positive.*
- *He would no longer be able to perform his previous military function, but was retrained to become a military trauma surgeon himself. This was only possible by continuously proactive insisting. It was not easy to arrange this. The psycho-social and occupational aftercare is very dependent on the case coordinator assigned, your own assertiveness, your rank and your network.*



The patient mentioned that even if there was an opportunity for shared-decision making in the acute phase, he was too incompetent to evaluate and decide between trauma interventions.

The patient experienced the care as of good quality and was also very satisfied with the information provided during his treatment at the various medical treatment facilities. He was mainly pleased with the extremely good care at the MRC Aardenburg, where he was a patient for almost 1,5 years.

The Ministry of Defense provides guidance on reintegration through a case coordinator who looks at your injury and how you can return to the armed forces or otherwise within society. But because they were among the first patients in a long time, this system was not yet working optimally. The patient had to arrange a lot himself. The quality of guidance is very dependent on the case coordinator provided.

The patient was very assertive in his treatment process and noticed that a lot is possible. For example, he was able to avoid long waiting times at a civilian plastic surgeon by insisting. Ultimately, he was operated by a civil surgeon at the CMH. What is ultimately possible is very dependent on your case coordinator assigned, your own assertiveness, your rank and your network.

Figure 16: Insights interview military polytrauma patient

Moment of Incident
Explosion by suicide vehicle

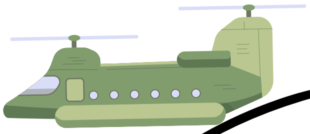
Combat Trauma injury
Buddy care
Care under Fire/Threat

Image retrieved from CNN news website

MEDEVAC

Role 1 Medical treamtent facility - wounded nest

Image retrieved from Kiosk Ministry of Defense



MEDEVAC

Role 2 Medical treamtent facility - Tarin Kot

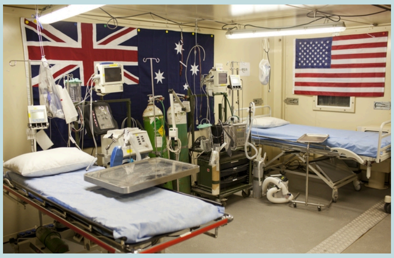
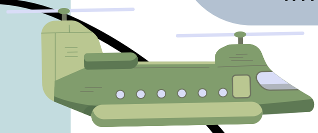


Image retrieved from Australian War Memorial website



MEDEVAC

Role 3 Medical treamtent facility - Kandahar

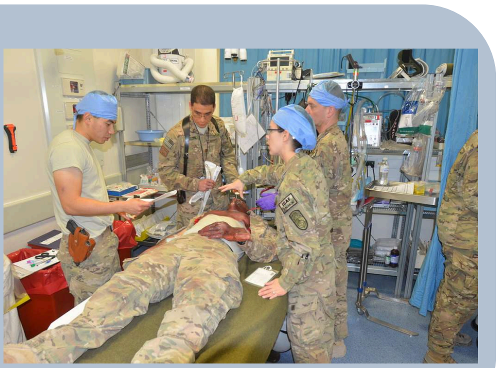


Image retrieved from Kiosk Ministry of Defense

STATEVAC

Role 4 Medical treatment facility - Central Military Hospital Utrecht, the Netherlands

Image retrieved from Kiosk Ministry of Defense

MEDEVAC

Role 4 Medical treatment facility - Military Rehabilitation Center Aardenburg)

Image retrieved from Kiosk Ministry of Defense

Figure 17: Military trauma care chain for a polytrauma patient during deployment in Uruzgan

6.4 Treatment of burns in the military context

Military burns result from either combat or non-combat causes. Most non-combat military burns result from waste burning, ammunition handling, or gasoline (Atiyeh et al., 2007). IED (improvised explosive device) blast related burns are currently the main cause of military burns (Kauvar et al., 2006; Jeevarathnam & Pandya, 2013), and 63% of all combat injuries are the result of explosive devices. In combat related burns, the head and neck are the most commonly affected areas. 60% of the blast burns patients had other injuries as well.

Since burns care is a complex, resource-intensive, multidisciplinary team process it can only be provided to current care standards in specialized burn centers (Cancio et al., 2005). In civilian practice, every burn patient receives emergency care and the patients with severe burns are transferred to a specialised burn center with optimum resources. In combat settings, the tactical situation, logistical limitations, or limited availability of healthcare personnel may reduce the upper limits of what is considered optimal burn care (NATO handbook, 2004). First responders must identify and treat life-threatening injuries before dealing with the burn (MARCH-protocol, 2024). In combat settings, the degree of the burns is not relevant (Ministry of Defense, 2024). The first aid (self care and buddy care) is the same for all types of burns, and consists of cooling the burn with lukewarm running water. It is important that burns are cooled to prevent the consequences from getting worse. The burn should be cooled for up to 20 minutes (Ministry of Defense, 2024).

Treatment of burns on the battlefield consists of bandaging, alleviation of pain, and treatment of shock by intravenous administration of fluids (Michaeli, 1979). With limited burn care resources available, the resources should be applied to the group of patients in whom the greatest benefit will be realized. This means that less attention is paid to those with minor burns (less than 20% total body surface area) or more extensive burns (exceeding 80% total body surface area) (NATO handbook, 2004). Severe burn casualties should be stabilized and evacuated to the role 4 MTF and from there, if needed, be transported to a specialised burn center (Inperson discussion, military nurse, November 2024).

6.5 Treatment of crush injury in the military context

Crush injury represents a spectrum of bodily injuries and can occur in various war settings. Crush injury can be life threatening, even if not involving vital organs (Genthon & Wilcox, 2013). The most important measure available to reduce crush injury is the immediate start of treatment (Li et al., 2020). Direct care at the location of the incident is essential, with a focus on extrication, triage, fluid resuscitation, and transport (Long et al., 2023). In order to reduce the complication of crush injury and syndrome early and aggressive fluid resuscitation is needed in prehospital settings, ideally even before extrication (Genthon & Wilcox, 2013; Yazici, 2023). However, in combat settings it is difficult to diagnose crush syndrome and to start fluid resuscitation on time (Usuda et al., 2023). Additionally, the risk of infections is increased in combat settings.

A tourniquet can be recommended to use in prehospital settings for severe crush injury (Zhang et al., 2014; Gerdin et al., 2012). When it is possible to transfer to a higher level of care, tourniquet application to the crushed limb could serve to prevent loss of life due to the toxic substances in the blood circulation as a result of crush syndrome (WHO EMT Secretariat, 2016). Medical treatment facilities provide initial stabilization and evaluation of crush injury trauma, as well as treatment of any crush syndrome complications (Long et al., 2023). In the role 2 and/or role 3 Medical Treatment Facilities crush injury is treated by trauma surgeons and orthopedic surgeons. Limb amputation is prevented at all costs. Only when the limb cannot be saved due to infections the limb is amputated at the role 4 Medical Treatment Facility (Inperson discussion military nurse, November 2024).

Chapter 7: Differences between the civilian and military trauma care chain

In this chapter the main differences between the civilian and military trauma care chain, as discovered during the research phase, are documented in an analysis table.

Table 4: Differences between the civilian and military trauma care

Topic	Civilian trauma care	Military trauma care
Medical knowledge and equipment	Not all civilians have had medical training. When a traumatic injury happens to someone without basic medical knowledge, this can increase stress and delay correct treatment. In addition, the right resources are not always available, for example to stop serious bleeding.	All military personnel have had basic medical training, therefore they know how to provide first aid to themselves or others. They are better able to assess the seriousness of a medical situation and are (more) able to act correctly. Additionally, military personnel on deployment are equipped with an individual first aid kit (IFAK).
Risk consciousness	Civil trauma usually happens very unexpectedly and people are not prepared for it.	Military personnel increasingly take into account the fact that there is a chance that they will be injured during their work. They have some sort of mental preparedness.
First aid procedure	Civilian first aid works with the most common ABC-procedure (airway, breathing, circulation). The situation around an injury can be dangerous, especially when an accident has happened in traffic. The first objective of first aid providers is to reassure their own safety.	Since most combat casualties die from massive bleeding, the military has a tailored first aid procedure: the MARCH-protocol. Priority of assessment: massive bleeding, airway, respiration, circulation, hyperthermia (and other injuries). Regularly it happens that first aid must be provided while under serious threat (care under fire/threat) (Ministry of Defense, 2024).
Professional help	Ambulance personnel are very experienced with providing primary care, since they practice it in real-life on a daily basis (in person discussion, military nurse, November 2024).	Although every military group has specialized medics, their experience is often limited to training scenarios and simulations (in person discussion, military nurse, November 2024).
Chances of infection	Ambulance personnel are experienced with working sterile and have the right equipment for this (in person discussion, military nurse, November 2024).	Especially during primary care the chances of infection in the military context are high. First aid must be provided in the field, often under serious threat and rush. This reduces the elaborateness for sterile working (in person discussion, military nurse, November 2024).

Triage	In the civilian context scenarios can occur that need triage (multiple casualties - need to make a hierarchy for care), for example the collapsing of a building that results in multiple casualties. However, it is realistic to expect that the civilian medical infrastructure is better equipped to take in a higher number of casualties.	The risk for scenarios that need triage is higher in combat settings. Bombs and other combat weapons often result in multiple casualties at the same time. Due to limited resources and transportation capacities, triage can have serious consequences for the survival rate of casualties.
Medical expertise	All medical expertise is available within the national medical system, however waiting time can be long and a reference for care is required.	Although the most crucial expertise (for example trauma surgeons and orthopedic surgeons) are present on treatment facilities in deployment areas, not all expertise will be available there (in person discussion, military nurse, November 2024).
Mechanisms of injury	Civilian trauma injuries are often less complicated than combat trauma injuries. Explosion injury (which often results in complex mechanisms of injury) is not common in a civilian population.	Military (mainly explosion) injuries have proven to have substantially different mechanisms of injury and surgical pathology compared to civilian trauma (Hoenkamp et al., 2014; Van Dongen et al., 2016).
Treatment facilities	Within the Netherlands trauma patients can be treated in the trauma departments of hospitals. For burns there are three specialized burn centers: Maasstad burn center, Beverwijk burn center and Martini burn center. In those burn centers interdisciplinary teams work on the best care provisions for burns.	On deployment there are different levels of treatment facilities. The facilities closest to combat are the most limited in terms of expertise, equipment and resources. Care provided in the field with limited resources is called Tactical field care. Most treatment facilities are NATO multinational facilities, where care is provided in close collaboration with other NATO countries (and confirm NATO standard). Additionally, the Dutch Ministry of Defense has their own Central Military Hospital (Utrecht, the Netherlands) and Military Rehabilitation Center (Doorn, the Netherlands) (Ministry of Defense, 2024).
Treatment of burns	Based on the degree of the burn a patient is treated at home, in an ER or referred to a specialized burn center.	In combat settings, the tactical situation, logistical limitations, or limited availability of health care personnel may reduce the upper limits of what is considered optimal burns care (NATO handbook, 2004). First responders must identify and treat life-threatening injuries before dealing with the burns (MARCH-protocol, 2024). The first aid is the same for all degrees of burns. Severe burn casualties should be stabilized and evacuated to a specialized burn center in the Netherlands.

Treatment of crush injury	In the civilian context identifying crush injury (and syndrome) is more convenient, due to the type of incidents (collapsing building, motor accidents, etcetera).	In combat settings it is difficult to diagnose crush injury (or syndrome) and the start fluid resuscitation on time (Usuda et al., 2023). Additionally, the risk of infections is increased.
Guidance during after care and rehabilitation	Civilian patients have to arrange their own rehabilitation. There is not a central guidance system. Patients indicate to feel abandoned after the acute care phase (patient interviews). Patients can decide to work with a reintegration supervisor, but have to arrange this themselves. The possibilities for prosthetics and other assistive technologies are dependent on the (financial) system of the civilian treatment facility. Additionally, information provision about this is often limited.	The ministry of Defense has their own rehabilitation center, with all kinds of health care providers available. They provide a service for customized prosthetics and other assistive technologies. The objective of rehabilitation is for the patient to become operational deployable again. If this is not realistic, the patient provides occupational guidance. Every military patient is connected to a case coordinator. The case coordinator is a guide for reintegration within the Ministry of Defense, and otherwise reintegration in society.
Finances	Not all rehabilitation expenses are covered by insurance, and this can hinder optimal physical and mental recovery.	The Ministry of Defense covers the expenses of military trauma care and rehabilitation. Additionally, they provide prosthetics and assistive technologies for their personnel.

Chapter 8: Conclusion research phase

As a closure of part one, the main insights are summarized in this chapter.
Note: the insights from the expert interviews are discussed in chapter 9.

The fundamental concept for this project is PCVBHC, with the aim to create a customized care plan by stimulating active patient participation. Within PCVBHC, the process of shared decision making helps to elicit personal values, goals and preferences during consultation. Patient reported outcome measurements (PROMs) can be used to incorporate patients' perceptions of their health and medical condition during consultation. Health care providers should provide care that aligns with the personal goals and preferences of the patients (within the constraints of limited resources), to create a customized care plan. Personal goals should be linked (where possible) to PROMs to create a customized care plan that actually contributes to the patients quality of life.

From the patient interviews, we could deduce that the acute care phase is not suitable for active patient participation, due to intense pain, traumatic shock and the provision of pain medication. Additionally, patients experienced a significant difference of quality between civilian treatment facilities, in terms of expertise, care provision, information provision, interdisciplinary collaboration and patient guidance after the acute phase. All patients interviewed, had multiple negative experiences within the trauma care pathway. This was due to a wrong diagnosis, provision of wrong medication, inexperienced health care providers or unprofessional medical personnel. Civilian patients can feel abandoned after the acute care phase if no guidance is provided. A tool that provides guidance to burn patients during the after care at home was experienced as very valuable, which indicated the desirability of a tool that provides guidance to patients during rehabilitation. Additionally, patients indicated that it would be valuable to learn from the experiences of other patients, to be inspired by their coping strategies and be aware of errors in the care pathway.

Although the generative Map My Experience Trauma Care tool was suitable for the civilian patient interviews, it was not fitting for the context of military trauma care during deployment. For future purposes, the tool should also be tailored to this specific context.

The military care provision was experienced as of high quality. In contrast to civilian patients, military patients are guided and facilitated during rehabilitation and the expenses are covered by the Ministry of Defense. The ministry of Defense has their own rehabilitation center, with all kinds of health care providers available. They provide a service for customized prosthetics and other assistive technologies. The objective of rehabilitation is for the patient to become operational deployable again and to increase the quality of life. Every military patient is connected to a case coordinator. The case coordinator is a guide for reintegration within the Ministry of Defense, and otherwise reintegration in society. However, the military patient indicated that the possibilities for reintegration after medical treatment are dependent on the case coordinator provided, own assertiveness, rank and own network.

Insights from the research phase contributed to a change in the design direction, as will be explained in the next part of this report.

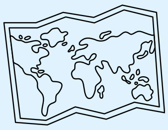
Part 2: Design direction iterations

Design Direction 1

Literature review
Literature reviews was performed to get a better understanding of the context of trauma care and the relevant concepts.

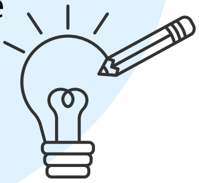
Expert interviews (n=2)
Interviews with a trauma surgeon of the Central Military Hospital and a military nurse.

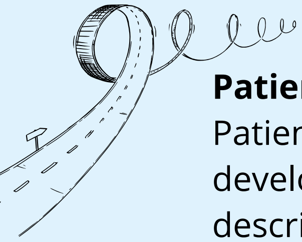
Observations
Multiple observations were performed to get a deeper understanding of the expectations and experiences of the health service (Simonse et al., 2019).



Map My Experience Trauma Care tool
A generative tool was created by tailoring the Patient Experience Mapping Tool (PEMT) from The National Health Council (NHC) This tool aims to help researchers capture patient experience data more holistically and in a standardized manner (National Health Council, z.d.).

Generative Patient interviews (n=4)
For the patient interviews the generative Map My Experience Trauma Care tool was used to captur the patient experience in a richfull manner. Generative techniques help to elicit memories and evoke emotions and feelings (Sanders, 2000).



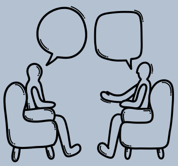


Patient Journeys
Patient journeys were developed by the methodology as described in the article of Simonse et al. (2019). A patient journey is defined as '*a comprehensible representation of a health service and its procedures, including relationships and feelings from a patient perspective*'.

- Burns patient journey (n=2)
- Crush injury patient journey (n=1)

Design Direction 2

Patient & expert interview (n=2)
Interview with a polytrauma patient and trauma surgeon were performed to discover the possibilities of the second design direction



Final Design Direction

Consultation Military Rehabilitation Center (n=2)
Discussion with a rehabilitation clinician and head R&D about the viability of the final design direction

Chapter 9: Iterations of the design direction

As previously described, the initial design direction evolved based on insights from the research phase. This chapter explains the two direction iterations, as well as the reasoning behind them.

9.1 Initial direction

The initial design goal of this graduation project was *‘to develop an interactive tool that stimulates and enables shared decision-making for polytrauma patients, in this way contributing to person-centred value based acute trauma care’.*

Inspiration for this new tool came from the Metro Mapping tool that is commonly used within oncology. Metro Mapping is a service design method with which care pathways can be designed and optimized. The Metro Mapping tool can be used to improve patient experiences and help with clinical challenges, for example, around shared decision-making, value creation for the patient and multidisciplinary collaboration (Metro Mapping, z.d.). The Metro Map is a visual overview of the different options a patient can choose from within a care pathway. Within oncology it is commonly used during deliberation between clinician and patient during the process of shared decision-making (Griffoen, et al., 2022). Inspired by the Metro Mapping tool, the CETC had a desire to develop a similar tool that supports shared decision-making for polytrauma patients in the acute phase. The Metro Mapping tool is not suitable to map the complexity of (poly)trauma and is not focused on the context of acute care.

The new tool will stimulate and guide polytrauma patients in the process of shared decision-making. Since patients have more control and autonomy over their own care process, it is easier to reach health outcomes that are important to them. In this way, the tool contributes to person-centred value based health care. In order to keep the scope comprehensible, it was decided to focus on the trauma care pathways of burns and crush injury, both for civilians and military.

During the research phase, visualizations of the care pathways of burns and crush injury were created, based on literature review, observations, patient interviews and expert interviews (as shown in the previous chapters). Collecting this data was necessary for the development of the tool. But ultimately, the research phase led to insights that required iterations of the design direction.

9.2 Important insights that contributed to the first iteration

In this section the insights from the research phase that contributed to the first iteration of the design direction are described.

Literature review

Literature review was performed to develop the trauma care pathways of burns and crush injury. While doing so, it quickly became clear that there are virtually no defined moments for active patient involvement within the acute trauma phase. There is often a clearly better option, which is better both clinically and for the patient’s ultimate quality of life. If we take the care pathway for third degree burns as an example: the only choice that some patients are given is the option for a skin transplantation surgery. For many patients, this is a procedure that must be done or an option that is not feasible at all. A small proportion of patients are given the choice for this surgery, but in this case choosing the procedure is the better option, both for medical recovery and for the patient's quality of life. A reason for not choosing the procedure is due to religious beliefs (Aflevering RTL Boulevard: Ewout in Kinderbrandwondencentrum, 2024). The cases in which the patient can choose within this care pathway are rare and occur mostly after the acute phase. The same conclusion can be drawn for the crush care pathway (for the acute care phase).

Those findings were confirmed during the MEXMED/CETC symposium, where multiple presentations were given about (military) extreme trauma care and medicine. The following presentations were relevant for this project:

- Prehospital treatment of burns (Kees van der Vlies - Trauma surgeon Maasstad Burn Center)
- Tourniquet syndrome: prevent or accept? (Mark van den Baar - Trauma surgeon Central Military Hospital)
- Casualty collection point Iraq (Henk Emonds - Medic 300 squadron)
- War surgery experiences: Syria, Ukraine, Gaza (Samer Attar - Trauma surgeon)

From these presentations we could conclude that active patient involvement is not realistic during the acute trauma phase, since patients are unconscious, anesthetized or intubated. During this phase, specialists work extremely hard and quickly to save a patient's life or limbs. This complex environment makes the acute phase not suitable for active patient involvement (MEXMED/CETC symposium, December 2024).

Observations

The observation during the Medical Response to Major Incident training gave a clear picture of the complexity of trauma triage and the impact of limited resources. It became obvious that in these complex and overwhelmed situations active patient involvement is not realistic (observation 2: Medical Response to Major Incident, Utrecht).

The observation during the annual exercise of the Calamiteiten hospital was a similar experience. Patients were brought in with urgency and doctors had to act quickly and adequately. Conscious patients were asked about their symptoms, but the patient was not included in the treatment decisions. The situation and severeness of injuries required rapid action from the trauma health care providers and there were many other patients waiting for emergency care (observation 1: Annual Trauma disaster exercise, Utrecht).

The observation in the Maasstad Burns Center showed the close collaboration of a multidisciplinary team of experts. In the interest of the patient, there are two interdisciplinary consultations every week. During the first consultation experts such as a virologist, bacteriologist, surgeon, rehabilitation physician, microbiologist and a neurologist come together to discuss the developments of every patient and plan further treatment. During the second consultation this is repeated, but the focus is on psycho-social care. It is not preferable to have patients present at these meetings. This is mainly because most patients are physically and/or mentally unable to participate and because patients have little knowledge about the medical discussion that is going to take place. However, each patient is spoken to in advance to gather the necessary input and to represent the patient's perspective in the consultation. In this way, the patient is burdened the least, while experts can openly discuss the medical situation (observation 3: Maasstad burn center, Rotterdam).

Patient interviews

When interviewing multiple patients for both burns and crush injuries (both civilians and military), we discovered similar outcomes as mentioned above (interviews 1,2,6 and 7). The patients indicated that there was no room for shared decision-making within their acute care. Although they have alway been well informed about which treatments were done and why, there was never a suitable opportunity to choose between treatments. According to the medical experts, the treatments they received were necessary for their specific injuries.

“There was no need for shared-decision making in my care traject, I prefer it this way” (Burn patient 2)

Additionally, all of the patients interviewed indicate they were not fully competent to make important choices during the acute phase of their care pathway (interviews 1,2,6 and 7). This was due to traumatic shock (n=3), numbness to the environment due to sensory overload (n=1), and the administering of pain medication (n=4).

Patients also expressed concerns about having to actively participate within their trauma care pathway. The patients indicate that they did not wish to have been involved in the medical decisions of the acute phase. They do not feel competent to make such a decision and trust the medical expert to know what is best for them (n=4). One patient experiences a lot of disagreement between different healthcare professionals, with contradictory advice (Interview 6). This makes the situation even more unmanageable for her. *“It also happened regularly that I received conflicting advice from different professionals. They had differences of opinion about my care”.* For her it would be more valuable if the work of these experts were better coordinated, so that everyone worked towards the same goal.

Expert interviews

Metro Mapping is useful for oncology since accurate estimations can be made about different treatment options and the associated results, this is linear and about the same for every patient. Since cancer treatments are not acute and have a major impact on the patient's daily quality of life, it is important that the patient is included in this choice. In this respect, acute trauma care cannot be compared to oncology. Trauma injuries are unique and dependent on many factors, and therefore almost impossible to depict linearly and standardized for patients (in person discussion trauma surgeon Central Military Hospital, November 2024). Additionally, most trauma injuries need acute treatment due to the risk of death or loss of the limb. Within acute trauma care the medical expert must act quickly according to the principle of safe life, safe limb. Due to the physical trauma, patients are always under strong pain medication, in shock, or intubated, and therefore not (fully) conscious or able to process information and make well-considered decisions. Therefore, shared decision-making is not suitable for the context of acute trauma care. In some cases, there are opportunities for shared decision-making later in the care process, when we make choices between treatments based on function recovery.

“Within acute trauma care there is not really space for shared decision-making. The patient is under painkiller and not rational, and the trauma surgeon will always do whatever it takes to save the life and limb” (Trauma surgeon 1)

Expert recommendations

Although the tool is not feasible for the context of acute trauma care, it can be valuable to design a tool for the later phase, when experts and patients have to choose between treatment options based on function recovery (for example the choice between amputation and limb salvage) or rehabilitation. It is important to note that this option is only available in a limited number of trauma cases (Trauma surgeon 1 & 2).

When creating a tool do not focus on polytrauma. In polytrauma, the different injuries influence each other and it is too complicated to reliably handle this in a tool. It is more valuable to create a tool for a specific mono trauma, and later translate it to other traumas (Trauma surgeon 1 & 2).

“It is hard to put polytrauma in a model, since multiple types of trauma influence each other. I would suggest focusing on one specific trauma” (Trauma surgeon 1).

For medical experts it would be helpful if there was a tool that visualised the different treatment options, with outcome scenarios and their recovery percentages. Algorithms can be used to calculate the recovery percentages based on input of the expert and the recovery rates of existing patient cases with a similar injury. Ideally, the tool calculates what the patient’s context does for recovery rates, for example if the patient is a smoker (Trauma surgeon 1).

9.3 Second direction and insights that contributed to the second iteration

Based on the insights a second design direction was explored: the creation of 'a tool that uses algorithms to visualise the different treatment options, with outcome scenarios and calculated recovery percentages'. The tool would use expert input, patient input, PubMed (medical reviews database), and existing patient cases to make reliable estimations.

To explore this direction, literature review was performed on evidence-based medicine, generative AI, PubMed, and Patient reported outcome measures (PROM). Additionally, experts were consulted. It quickly became clear that this direction was not feasiblein the short term and within the scope of a graduation project, based on the following insights:

Patient interviews

When asking a polytrauma patient his opinions about this tool he concluded that the percentages would not influence his initial preferences of saving his limb (patient interview 8).

"It is difficult to attach value to percentages. I would always try to save my limb no matter the odds. The only way that can be different is if I am convinced that amputation leads to a better quality of life. That said, I would be interested in learning about the experiences of fellow sufferers" (Military polytrauma patient)

Expert interviews

For algorithms to calculate reliable chances a lot of data is needed. At this moment there is not enough data of trauma patients available, due to the low number of military casualties and civilian trauma cases in the past years. Additionally, civilian and military trauma are not comparable, due to the severity and complexity of military trauma.

"A lot of data is needed to make reliable chance calculations. We do not have that much trauma data available" (Head R&D Military Rehabilitation Center).

A project team that develops a similar tool that calculates chances for a different context warned that they had a lot of trouble collecting and processing enough data. They have worked on this for already two years with a specialised data team (Personal communication, 13 december 2024).

"To calculate chances you need a data analysis team and a lot of data. We have experienced trouble with this part. It will take years!" (Contributor similar project).

PubMed is not reliable enough for trauma treatments, since randomized controlled trial studies are not possible for trauma injuries. Because of this, systematic review studies about trauma care are biased. Using PubMed as input for the algorithms to calculate success rates is not reliable.

"*PubMed is not that reliable for trauma care, since there are no randomized controlled trials for trauma."* (Trauma surgeon 2).

Consideration must be given whether it is desirable to burden patients with chances and percentages. Processing medical information is already complex enough for patients. For many humans it is difficult to translate chances and percentages into what they mean for their specific contexts. In addition, people have cognitive biases that cause them to attach more value to a small chance of hope than is statistically justified, as explained in the book 'Thinking Fast and Slow' by Daniel Kahnemann. Additionally, expressing the results of treatments in percentages can lead to a lot of patient disappointment when a final undesired result was not expected.

"Showing chances to patients can bring the risk of disappointment and does not add much value for the patient." (Trauma surgeon 2).

Expert recommendations

Leave the clinical diagnosis to the medical expert. The real value of such a tool is to help patients focus on quality of life. What mean the different treatment options for the things that are important in the life to the patient. A medical expert can educate what the medical options are, but an extensive and in-depth translation to the long term quality of life is often missing.

"Leave the clinical knowledge to the experts, and do not incorporate this in the tool. Trauma injuries are unique and dependent on many factors, and therefore almost impossible to depict linearly and standardized for patients". (Trauma surgeon 1).

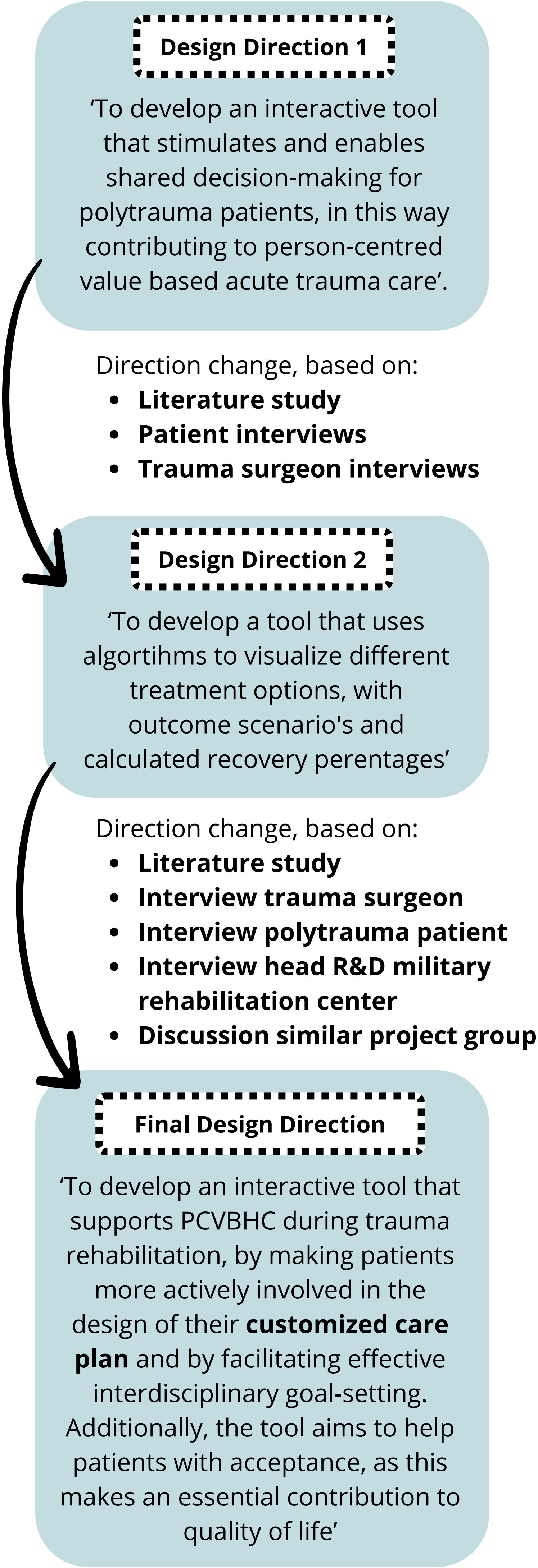
"*The real value of the tool is within the translation from medical options to the patients quality of life"* (Trauma surgeon 2).

Stay away from medical rehabilitation success stories, since it can give patients wrong expectations. However, it is very interesting to make a tool that focuses on the patients quality of life. Suggestion to focus on the coping strategies that patients use to cope with their losses. Coping strategies have an important influence on quality of life. *"It is valuable if patients can learn from the experiences of others, but stay away from the medical success stories! Focus on coping strategies instead."* (Head research & development, Military Rehabilitation Center Aardenburg).

9.4 Final direction

Based on the insights, the final design goal was established: *an interactive tool that supports PCVBHC during trauma rehabilitation, by making patients more actively involved in the design of their **customized care plan** and by facilitating effective interdisciplinary goal-setting. Additionally, the tool aims to help patients with acceptance, as this makes an essential contribution to quality of life'*

This final direction is a result of combining the most important insights. First of all, we have shifted from the acute phase to rehabilitation, as this is more suitable for patient involvement. As advised by experts, it was deliberately chosen to leave the clinical knowledge to the experts and to not incorporate this within the tool. Since the tool does not include the clinical aspects of a trauma, eventually it can be used for all types of trauma. Additionally, the calculation of recovery rates was eliminated, since the limited available trauma data makes those calculations unreliable. The tool will support PCVBHC by stimulating active patient participation and effective interdisciplinary collaboration, as stated in the vision of the CETC and indicated during the interviews. Additionally, the goal of acceptance (contributing to quality of life) was included, since this was a recurring topic in patient and expert interviews. The evolution of the design direction is visualized below (Figure 18).



Design Direction 1

‘To develop an interactive tool that stimulates and enables shared decision-making for polytrauma patients, in this way contributing to person-centred value based acute trauma care’.

Direction change, based on:

- **Literature study**
- **Patient interviews**
- **Trauma surgeon interviews**

Design Direction 2

‘To develop a tool that uses algortihms to visualize different treatment options, with outcome scenario's and calculated recovery perentages’

Direction change, based on:

- **Literature study**
- **Interview trauma surgeon**
- **Interview polytrauma patient**
- **Interview head R&D military rehabilitation center**
- **Discussion similar project group**

Final Design Direction

‘To develop an interactive tool that supports PCVBHC during trauma rehabilitation, by making patients more actively involved in the design of their **customized care plan** and by facilitating effective interdisciplinary goal-setting. Additionally, the tool aims to help patients with acceptance, as this makes an essential contribution to quality of life’

Figure 18: Direction change

"Within acute trauma care there is not really room for shared decision-making. The patient is under painkillers and not rational. The trauma surgeon will always do whatever it takes to save the live and the limb."
(trauma surgeon 1)

"It is hard to put polytrauma in a model, since multiple types of trauma influence each other. I would suggest to focus on one specific trauma!'
(trauma surgeon 1 & 2)

"Pubmed is not that reliable for trauma care, since there are no randomized controlled trials for trauma injuries. Showing chances to patients can bring the risk of disappointment and does not add many value to the patient. The real value of the tool is within the translation form medical outcomes to the patients' quality of life!"
(trauma surgeon 2)

"It is hard to put value on percentages. I would always try to save my limb regardless the chances. Only way otherwise, is when I am convinced that amputation results in better quality of life. I would be interested to learn about the experiences of fellow sufferers'
(polytrauma patient)

"A lot of data is needed to make reliable chance calculations. We do not have that much trauma data available."
(Head R&D Military Rehabilitation Center)

"To calculate chances you need a data analysis team and a lot of data. We have experiences trouble with this part. It will take years!"
(similar project group)

Chapter 10: Barriers to the creation of a customized care plan

Is this chapter the barriers that hinder the creation of a customized care plan are discussed.

10.1 Recap of PCVBHC

“Person-centred value based health care links the personal values, goals and preferences in PeCHC with the principle of standardized measurement and benchmarking in VBHC, underpinned by the equitable allocation of finite resources” (Srur et al., 2024). The process of shared decision-making helps to elicit personal goals and preferences and to create a shared understanding between patient and health care providers about the value of health outcomes. Patients are stimulated to actively participate in their own care, and should be supported to do so (Kidanemariam, 2025). Personal goals assist the development of customized care plans and they support patients in maintaining a sense of purpose and control during treatment (Mandel et al., 2016). Health care providers should provide processes and structures that match or support the personal goals of the patients, within the constraints of limited resources (Kidanemariam, 2025). By linking personal goals to patient reported outcome measurements (PROMs), the principles of VBHC and PeCHC are aligned. With the principles of PCVBHC, a customized care plan can be created that aligns with what matters to the patient.

10.2 Barriers to the creation of a customized care plan

Eliciting personal goals and preferences is the first fundamental step in PCVBHC, to create a shared understanding between the patient and health care providers and to create customized care plans. The community of experts who devised PCVBHC, identified barriers to acting on individuals values, goals and preferences (Srur et al., 2024):

Communication barriers: Eliciting an individual’s values, goals, and preferences depends on high-quality communication between the clinician and patient.

- **Culture:** Differences in culture - in terms of background or beliefs - can hinder qualitative communication, due to wrong assumptions, implicit biases, a lack of shared beliefs and goals, or misunderstanding.
- **Language:** Due to linguistic barriers people may face limitations in fully engaging in the conversation and may experience trouble in conveying their personal values, goals, and preferences. Linguistic barriers make it more difficult for a patient to clearly express their feelings, opinions and thoughts. Additionally, a lack of familiarization with technical/medical terms can hinder discussion.
- **Trust issues:** Patients may be reluctant to share personal values, goals and preferences, for example because they are concerned about their privacy or judgement, or because they feel a certain distance between themselves and the clinician.
- **Communication skill:** Not all health care providers have the skill to engage in qualitative conversations that elicit a patient’s personal values, goals, and preferences. This conversation skill can be hard to master, and many health care providers are still too focused on their medical judgment rather than person-centered.
- **Bias and assumption:** Health care providers may hold implicit biases and assumptions about people based on their age, gender, race, or other factors. This can hinder the ability to understand and act upon individuals’ values, goals and preferences. These biases and assumptions can prevent a clinician from asking the patient for his perspective.

Organizational barriers: Eliciting and using personal values, goals, and preferences to customize the care plan depends also on the organizational structure that can hinder or facilitate.

- **Time constraint:** Busy schedules and high workloads can limit the amount of time health care providers have to engage in in-depth discussion about personal values, goals and preferences with each patient. Time constraints can also hinder relationship- and trust building, which results in a communication barrier (as explained above).
- **Documentation burden:** Extensive documentation requirements can lead to a focus on paperwork over discussions about people's personal values, goals, and preferences. Health care providers need to prioritize what information they document, and this decision is very subjective. It can lead to the information obtained not being properly documented, resulting in a loss of much valuable information.
- **Power dynamics:** Traditionally, the power lies with the health care provider that has medical knowledge and access to treatment options. Patients can feel submissive in the care delivery and be hesitant to share their personal values, goals and preference. Patients are not always aware of how valuable active patient involvement is for the health care provider and for the development of customized care plans (as this is not always implicitly stated).
- **Continuity of care:** Patients sometimes experience a lack of continuity of care. This is the result of part-time working schedules and interdisciplinary care where the patient is in contact with a lot of different health care providers. This phenomenon can lead to an absence of an ongoing relationship between the patient and the different health care providers, hindering relationship- and trust building.

This aligns with the finding of the article of Ekman et al. (2011), which stated that when time is limited health care providers prioritized medical tasks, leading to a focus on the disease rather than on the person. Additionally, it stated that a similar focus on medical details can be found regarding documentation. The personal values, goals and preferences of a patient are rarely documented.

To conclude: in order to successfully implement the principles of PCVBHC and to create the most valuable customized care plan that aligns with what matters to the patient, we need to overcome the barriers stated in this chapter. The tool developed, explained in the upcoming part, aims to tackle those barriers and aims to **support active patient participation in the design of the customized care plan**. Additionally, the tool will facilitate the documentation of person-centred information.

Chapter 11: A tool to support the creation of a customized care plan

For this graduation project, I developed a tool that supports the creation of a customized care plan and that helps to overcome the communication and organizational barriers described in the previous chapter. In this chapter, the three goals of the tool are presented, as well as the barriers they aim to tackle. Finally, the main take-away points of a consultation with the Military Rehabilitation Center are documented.

11.1 Design goals

The tool will be developed aiming for three goals:

1. Generative tool that helps patients elicit personal values, goals and preferences

The tool helps to elicit personal values, goals and preferences. Generative techniques allow patients to express themselves on a deeper level (Goodman et al.. 2012). The elicited information supports the shared decision-making process between patient and health care providers, resulting in health care preferences that align with what matters to this person. The tool helps patients to actively participate in the development of customized care plans.

Since, the tool helps patients with eliciting what matters to them, communication barriers between patient and clinician, time constraints and problems with power dynamic, lack of training and continuity of care are eliminated. Additionally, automatic standardized documentation will reduce the documentation burden of health care providers

2. A tool that supports effective interdisciplinary goal-setting and links those personal goals to patient reported outcome measurements (PROMs).

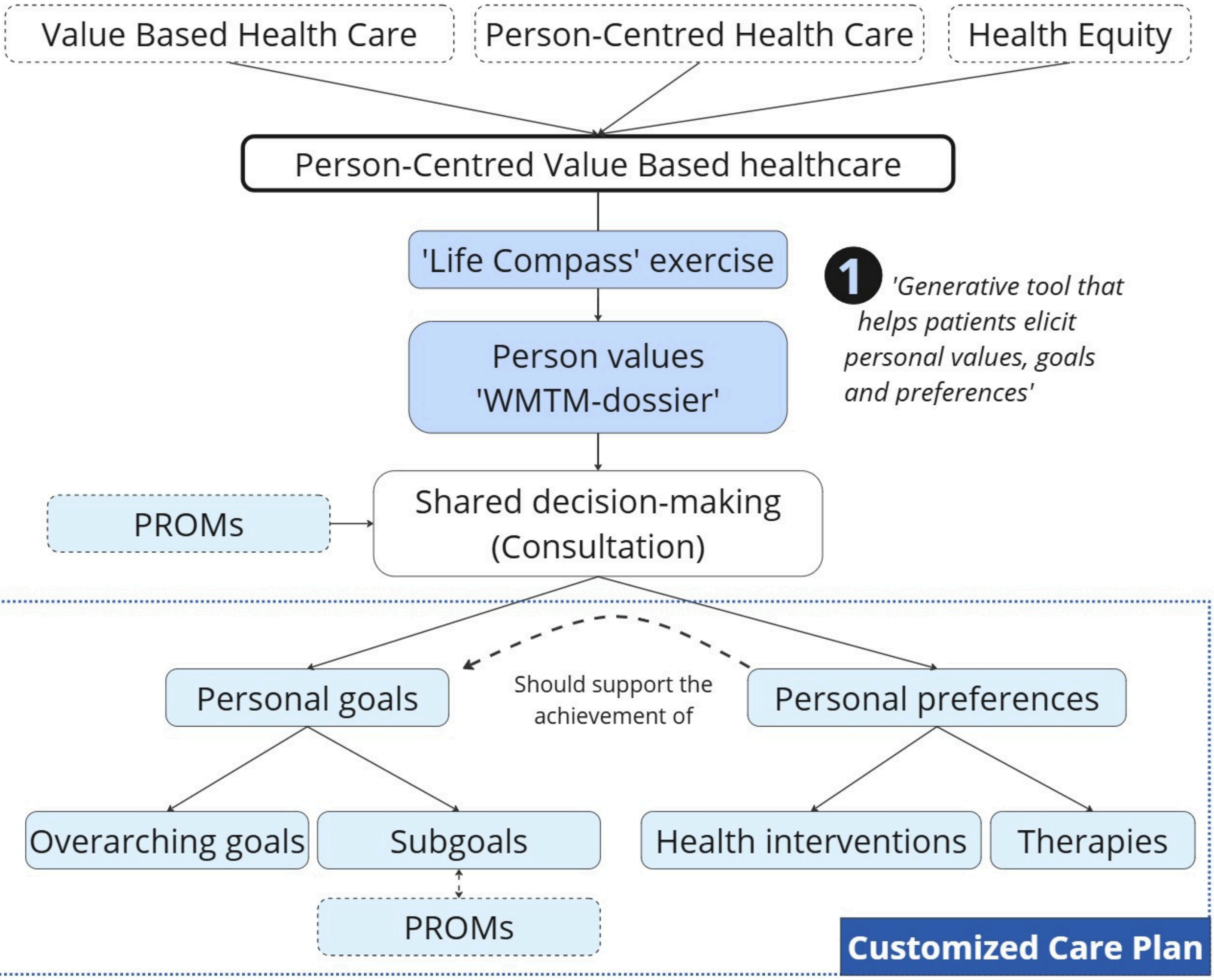
During consultation, personal goals are documented and (when possible) linked to patient reported outcome measurements (PROMs). This combines the principles of PeCHC and VBHC. Based on the personal goals health care providers can provide care processes and structures that match or support those goals, within the constraints of limited resources. Standardized documentation of personal goals results in effective interdisciplinary collaboration.

The tool will support patients and the different health care providers with goal-setting and standardized documentation. Health care providers can align their goals and ensure their goals are not contradictory.

3. Coping tool that helps patient with acceptance

The tool will support patients with coping and accepting their new situation, by making them focus on what they still can, instead of on what is no longer possible. Within the tool, patients can learn from the experiences and coping strategies of other patients. The tool makes them realize that quality of life can be achieved in multiple ways, and their losses can often be mitigated or compensated (by the use of custom-made prostheses or by achieving the same satisfaction with alternative activities).

The first two goals intertwine with the principles of PCVBHC, and are aimed at creating a customized care plan. The third goal is a result of PCVBHC and was suggested during multiple patient interviews (as will be explained in chapter 16). Figure 19 demonstrates how the first two goals of the tool contribute to the creation of a customized care plan.



1 *'Generative tool that helps patients elicit personal values, goals and preferences'*

2 *'A tool that supports efficient interdisciplinary care provision and supports PCVBHC by linking personal goals to PROMS'*

Figure 19: Relation of the tool to PCVBHC, contributing to the creation of a customized care plan. The eliciting of values takes place before consultation, due to the 'Life Compass' exercise.

11.2 Consultation Military Rehabilitation Center (MRC) Aardenburg

The goals of the tool were discussed with a rehabilitation medical expert and the head of the Research and Development department of the Military Rehabilitation Center Aardenburg (in person discussion, December 2024).

Take-away points:

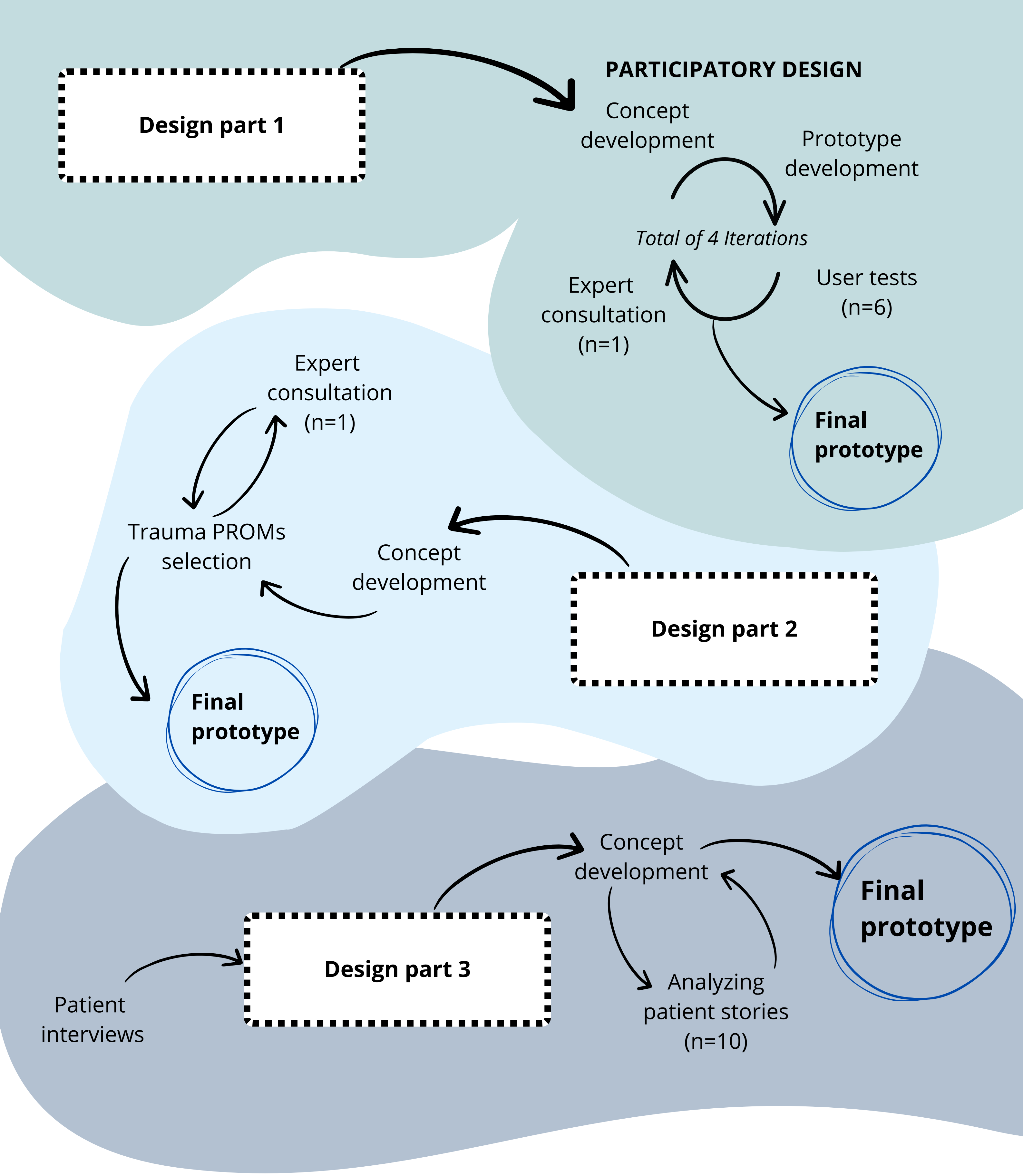
- Not every rehabilitation clinician is experienced in conducting ‘what matters to the patient’ conversations. MRC Aardenburg provides conversation-training to their employees. But still, this skill can be hard to master and should be practiced frequently. Therefore, a tool that helps to elicit the values, goals and preferences of patients can be valuable.
- Sometimes patients open these conversations at inconvenient times for the health care providers, outside of official consultations. This can hinder proper documentation. Incomplete documentation may result in patients having to have this conversation multiple times with different health care providers (rehabilitation is an interdisciplinary care provision). A tool that helps with standardized documentation is desirable.
- With eyes on the future, we cannot expect that our clinicians will always be able to conduct these conversations, since providing care is their main objective. MRC Aardenburg is a military rehabilitation center, and with the increasing tension in the world it is realistic to expect more trauma victims entering the rehabilitation center in the near future. A tool that can successfully complement this process is highly desirable as we prepare for main task 1 (protecting Dutch territory and that of NATO allies). *“A tool that can successfully complement the process of eliciting values, goals and preferences is highly desirable as we prepare for main task 1, when we can expect a very high burden on health care capacity”.* (Head R&D Military Rehabilitation Center).
- The tool must be able to reveal the underlying reason why patients indicate that something is important to them. *“We often see that there are underlying reasons why patients indicate that something is important to them. The tool must be able to reveal these underlying reasons.”* (Rehabilitation clinician).
- It is valuable if patients can learn from the experiences of other patients, but stay away from the medical success stories and focus on coping strategies.
- Take into consideration that the use of the tool should not be a burden to patients or clinicians, therefore try to avoid long questionnaires or a complex design. The tool should be pleasant to use and beneficial. User tests should validate if the tool actually brings value to the patient. *“The tool must be self-explaining and easy to use and understand for both patient and health care provider”* (Head R&D Military Rehabilitation Center).

Chapter 12: Conclusion design direction iterations

Based on insights from the research phase, the design direction iterated two times and evolved into *'an interactive tool that supports PCVBHC during trauma rehabilitation, by making patients more actively involved in the design of their* ***customized care plan*** *and by facilitating effective interdisciplinary goal-setting. Additionally, the tool aims to help patients with acceptance, as this makes an essential contribution to quality of life'*

In order to successfully implement the principles of PCVBHC and to create the most valuable customized care plan that aligns with what matters to the patient, we need to overcome several communicational and organizational barriers. The tool developed aims to tackle those barriers and aims to **support active patient participation in the design of the customized care plan**. Additionally, the tool will facilitate the documentation of person-centred information.

Part 3: Design phase



Design part 1

PARTICIPATORY DESIGN

Concept development

Prototype development

Total of 4 Iterations

User tests (n=6)

Expert consultation (n=1)

Final prototype

Design part 2

Concept development

Trauma PROMs selection

Expert consultation (n=1)

Final prototype

Design part 3

Patient interviews

Concept development

Analyzing patient stories (n=10)

Final prototype

LIBRA CARE

Chapter 13: Libra Care

"Libra Care is an interactive tool that supports PCVBHC during trauma rehabilitation, by making patients more actively involved in the design of their customized care plan and by facilitating effective interdisciplinary goal-setting. Additionally, Libra Care helps patients with acceptance, as this makes an essential contribution to quality of life".

LIBRA CARE

'Libra Care'
The Latin word 'Libra' means balance, often symbolized as a scale. 'Libra Care' refers to care that is in balance. This requires input from the health care providers, but equally input from the patient. The health care provider is the specialist with regard to medical knowledge and available treatment options. The patient is the specialist with regard to what matters in their life, and therefore determines the value of various health care outcomes. PCVBHC is achieved when the health care provider and the patient work together in balance to achieve the most person-centered and value-based outcome(s).

Libra Care can be divided into 3 different design parts, each consisting of different functionalities and targeting one of the tool goals (as explained in chapter 11). When opening the tool, you will arrive at the startpage. From there you can navigate to the different functionalities. In the upcoming chapters, the design parts and tool mechanism are worked out (chapter 14 to 16).

Design part 1: Generative tool that helps patients elicit personal values, goals and preferences. This part exists out of the 'Life Compass' exercise and the 'What matters to me'-dossier.

Design part 2: Documentation and overview tool that ensures effective interdisciplinary goal-setting and links those personal goals to patient reported outcome measurements (PROMs). This part exists out of tracked PROMs, documented overarching- and subgoals, a health care provider overview and an agenda.

Design part 3: Coping tool that helps patients with acceptance. This part exists out stories of other (trauma) patients and an interactive forum.

Chapter 14: Design part 1 - Generative tool that helps patients elicit personal values, goals and preferences

In this chapter the part of the tool that relates to the goal *'to help patients elicit their personal values, goals and preferences'* is described.

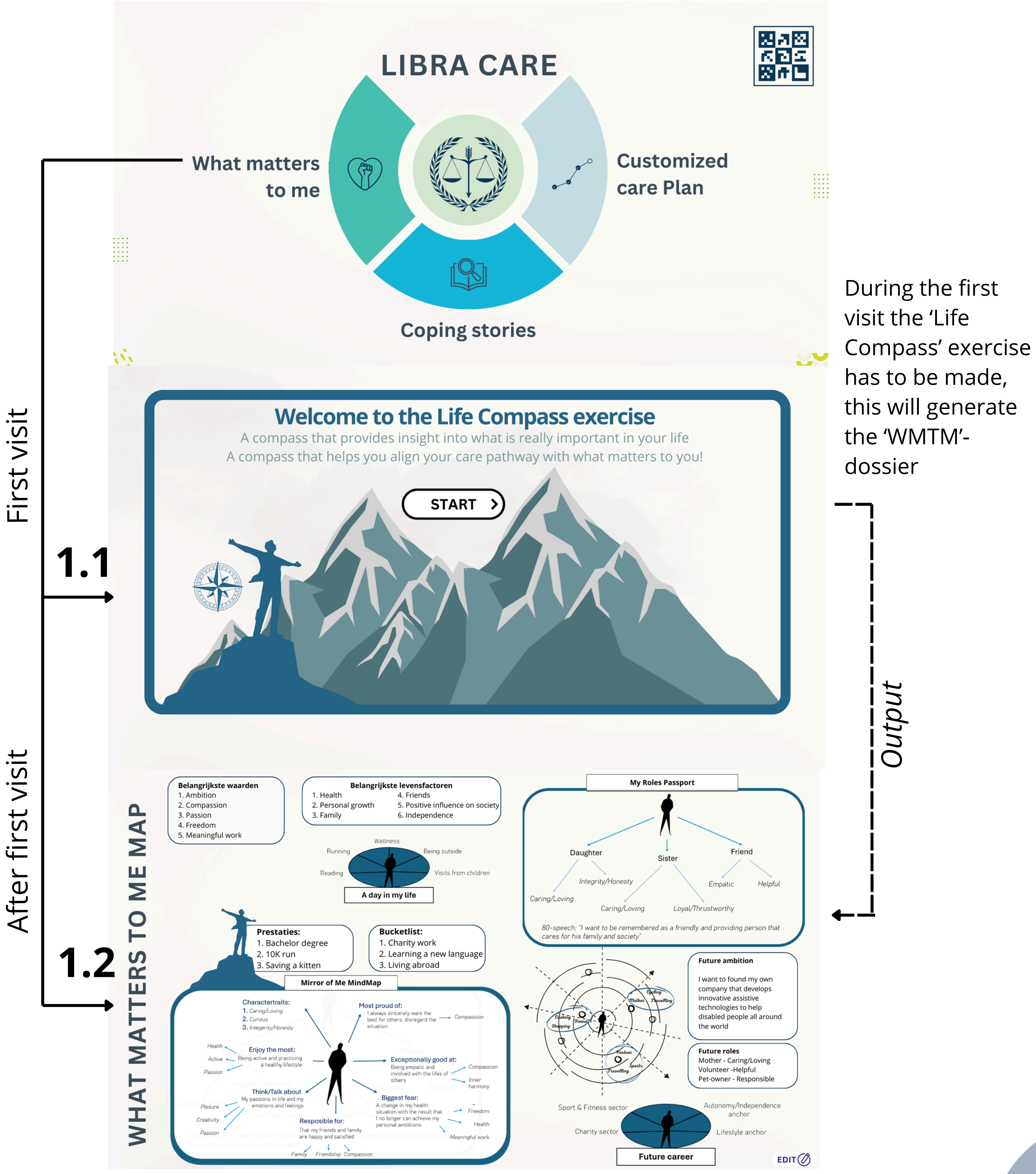
14.1 Objective design part 1

What: Generative tool that helps patients elicit personal values, goals and preferences. The tool empowers people to elicit what really matters to them on a deeper level, by the use of generative techniques and mind-switching.

Why: It is the first step in patients actively participating in the development of their customized care plan. The elicited information supports the shared decision-making process between patient and clinicians, resulting in personal goals and health care preferences that align with what matters to this person.

How: The tool uses a guided exercise, with generative techniques and mind-switching, to elicit latent values and the things that are important in the life of this person. This exercise is called the 'Life Compass'. The generative techniques empower people to elicit what really matters to them on a deeper level. The 'Life compass' exercise generates a 'What matters to me'-dossier that can be used by the patients to be actively involved in the design of their care pathway. The 'What matters to me'-dossier is the starting point for shared decision-making with every health care provider, resulting in personal goals and health care preferences that align with what matters to this person.

14.2 User navigation



During the first visit the ‘Life Compass’ exercise has to be made, this will generate the ‘WMTM’-dossier

LIBRA CARE

Welcome to the Life Compass exercise

A compass that provides insight into what is really important in your life
A compass that helps you align your care pathway with what matters to you!

WHAT MATTERS TO ME MAP

Belangrijkste waarden
1. Ambition
2. Compassion
3. Passion
4. Freedom
5. Meaningful work

Belangrijkste levensfactoren
1. Health
2. Personal growth
3. Family
4. Friends
5. Positive influence on society
6. Independence

A day in my life

Prestaties:
1. Bachelor degree
2. 10K run
3. Saving a kitten

Bucketlist:
1. Charity work
2. Learning a new language
3. Living abroad

Mirror of Me MindMap

Charactertraits:
1. *Caring/Loving*
2. *Curious*
3. *Integerity/Honesty*

Most proud of: I always sincerely want the best for others, disregard the situation → *Compassion*

Enjoy the most: Being active and practicing a healthy lifestyle → *Health*, *Active*, *Passion*

Exceptionally good at: Being empatic and involved with the lifes of others → *Compassion*, *Inner harmony*

Think/Talk about: My passions in life and my emotions and feelings → *Plesure*, *Creativity*, *Passion*

Biggest fear: A change in my health situation with the result that I no longer can achieve my personal ambitions → *Freedom*, *Health*, *Meaningful work*

Resposible for: That my friends and family are happy and satisfied → *Family*, *Friendship*, *Compassion*

My Roles Passport

Daughter → *Caring/Loving*, *Integrity/Honesty*
Sister → *Caring/Loving*, *Loyal/Thrustworthy*
Friend → *Empatic*, *Helpful*

80-speech: “I want to be remembered as a friendly and providing person that cares for his family and society”

Future ambition

I want to found my own company that develops innovative assistive technologies to help disabled people all around the world

Future roles
Mother - Caring/Loving
Volunteer -Helpful
Pet-owner - Responsible

Future career

Figure 20: User navigation ‘What matters to me’ part of the tool
Note: arrow means that the user has to click to reach the next frame

14.3 ‘Life compass’ exercise (1.1)

To facilitate the creation of a customized care plan based on what is important to the patient a ‘Life Compass’ exercise was developed. The ‘Life Compass’ exercise is a guided exercise with generative techniques that helps people to elicit their values and the things that are important in their life.

How does this support the creation of a customized care plan?

As described in chapter 10, the quality of eliciting values, goals and preferences (and therefore the quality of PCVBHC) depends on communication and organizational barriers. By transferring this task from health care providers towards the guided exercise, those barriers can be eliminated. Eliciting values, goals and preferences are no longer dependent on the conversation skills of the health care provider or the patient. Additionally, the guided exercise will be made outside of the consultation, eliminating time-constraints. Patients can use the tool in their private space where they feel comfortable and have time to think about what is important to them. Additionally, family members can be involved in this process, since they can be valuable advocates in communicating a patient's personal values, goals and preferences (Bradley & Green, 2017). The elicited information will be available for all health care providers who treat this patient, resulting in effective interdisciplinary collaboration during rehabilitation (as will be explained in design part 2). Additionally, the ‘Life Compass’ exercise unravels values on a deeper level. It uses mind-switching and several generative techniques to get patients to reveal what matters to them on a deeper level.

Mind-switching

Mind-switching refers to switching a person’s perspective from a medical focus towards a focus on who they are at their core, before asking them what is important in their life. This technique was implemented after consultation with a life coach and victim support worker (In person discussion, January 2025). The implementation of mind-switching is important, since person’s that have recently experienced a traumatic event or injury probably feel distanced from themselves. The event resulted in identity dissociation and the person is searching for how to adapt to the new situation (Center for Substance Abuse Treatment (US)., 2014). The person’s focus after a traumatic injury is usually on what they can no longer do. The focus must be shifted back towards the core of who they are as a person. Although your self-image, your capacities, beliefs and behavior can change after a traumatic event, your values will remain constant. To unravel the most valuable information about what is important to a person, it is important that the person answers from their core, and not from a medical perspective. Otherwise, a person will be biased by their current medical situation and what he regards as (no longer) possible.

Guided exercise

Although mind-switching can be facilitated through different means, a guided exercise was regarded as the most suitable for this context. The guided exercise is an interactive online workbook guided by a voice-over. It isolates the person from his environment and guides him through the process of mind-switching by means of vocal instructions and generative techniques. The guided exercise was mainly chosen over alternatives because it is suitable for the context of a rehabilitation center, since it can be easily made on a tablet in isolation. Additionally, it requires the least cognitive and physical effort from the patient. Alternative options considered, were the creation of a photo book or a moodboard, that visualises important moments in this person’s life. These options were regarded as less suitable, since it requires more effort from the patients and it is less practical in the rehabilitation environment. Also, not everyone is familiar or feels comfortable with this level of creativity, which makes it a more demanding task. Additionally, it would significantly increase the time needed to finish the ‘Life Compass’ exercise, which could reduce the willingness of patients to participate.

Generative techniques

Generative techniques allow patients to express themselves on a deeper level by creating things (Goodman et al.. 2012). Generative techniques help people to express themselves on a deeper level than possible by just asking them a question, since some feelings, desires or thoughts are hard to articulate (tacit knowledge) (Sleeswijk Visser et al., 2005). Generative techniques help a person with divergent thinking, widening their perspective while providing answers about themselves (Goodman et al., 2012). The 'Life Compass' exercise uses these techniques to get richer information from a person about what is really important to them. With these techniques, more valuable and comprehensive answers will be obtained than when the person is asked directly what is important to him during consultation.

The generative techniques used in the 'Life Compass' exercise are explained below in the description of the 'Final prototype 'Life Compass''. Inspiration was gained from assignments from other tools, (work)books and research:

- Workbook: *Acceptance and Commitment Therapy Workbook* (Kruit, 2020)
- Workbook: *Defensity College Young Talents Journal* (Defensity College, 2025)
- Article: *Shein's Career anchors* (Shein, 1996)
- Book: '*The seven habits of highly effecitve people'* (Covey, 2014)
- Online tool: Personal Values Assesment (Personal Values website, 2025)
- Article: *'10 ways to figure out what is important to you'* (Barkley, 2023)
- Book: *'An integrity Model, Existential Perspective in CLinical Work With Men From a Gender and Health Perspective' (Chapter 9)* (Lander & Nahon, 2017)

Sample of participants for concept testing

It was deliberately chosen not to test the concept with ex-trauma patients. This has to do with the fact that they are already too familiar with trauma rehabilitation and can therefore be biased. It is not the intention that during the completion of this assignment, one (unconsciously) reflects back on one's own trauma rehabilitation. That is why it was chosen to test the different prototypes with people (n=6) who have no experience with trauma rehabilitation. They were asked to imagine that they recently had a traumatic injury that changed their life drastically. By completing the 'Life Compass' exercise, their rehabilitation can be attuned as well as possible to what is really important to them. Then, the users were asked to complete the exercise in silence, with full focus. After completion, user feedback on the prototype was collected and another design iteration was made. There was also an expert consultation that resulted in a design iteration.

Table 4: Sample of participants

Test number	Test type	Number of participants	Participants characteristics	Location
1	Quick user test, one-on-one	n=2 (users)	Female (1) and male (1)	Workplace
2	Expert consultation	n=1 (Life coach and victim support worker)	Female (1)	At her office
3	Exuberant user test, one-on-one	n=3 (users)	Female (3)	Workplace
4	Final user test, one-on-one	n=2 (users)	Female (1) and male (1)	At their location

Concept iterations

The ‘Life Compass’ exercise was developed by means of participatory design. Participatory design is a collaborative approach to design, where end users and other stakeholders are directly involved in the decision-making process of product development (McIntosh et al., 2011; Robertson and Simonsen, 2012). This collaboration starts already in the early design phases. It is a way of evaluative research, where users test the prototypes of developed concepts (Sleeswijk Visser, 2004). The ‘Life Compass’ exercise made a total of 4 iterations (see Figure 22). The design evolved from the first prototype - a printed questionnaire worksheet - to the fifth and final prototype - a fully developed guided exercise (consisting of an interactive workbook with voice-over guidance). The final prototype is shown at the bottom of this chapter (see pages 79 to 85).

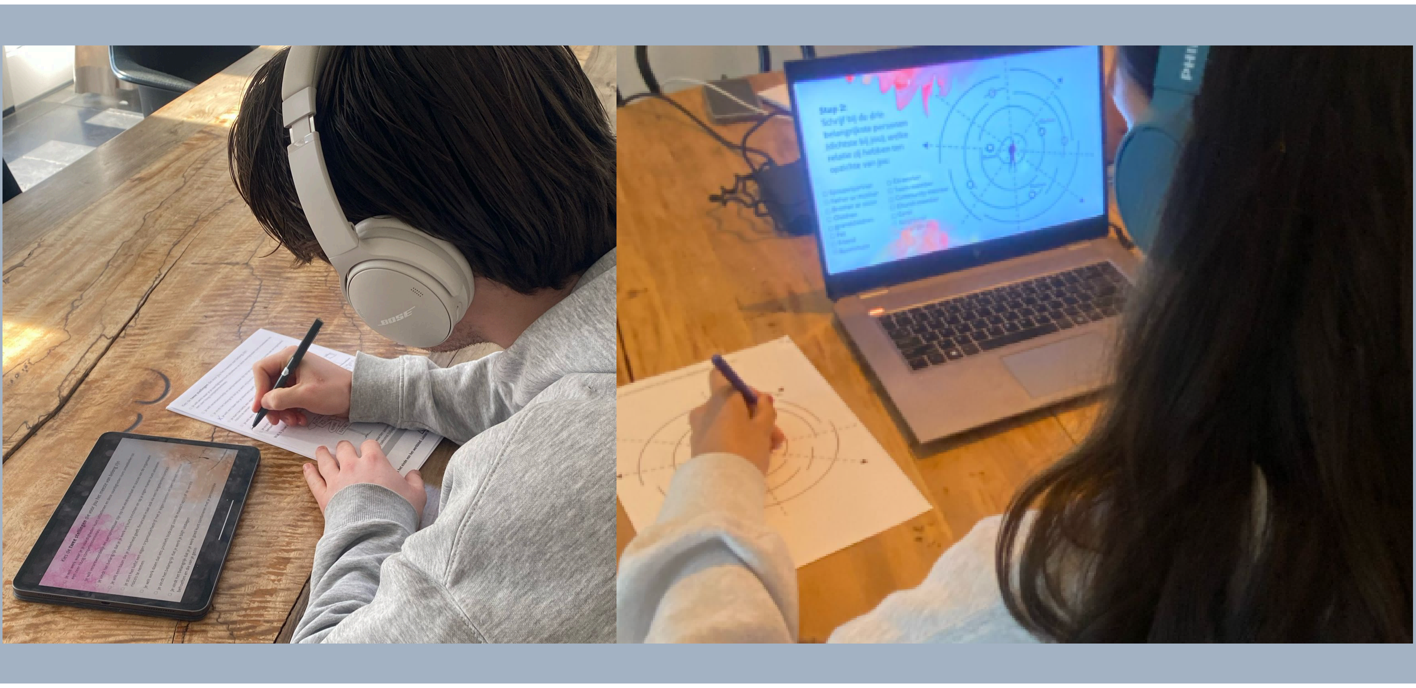


Figure 21: User tests

PROTOTYPE 1: Questionnaire

A questionnaire (technical worksheet) based on online research, online tools for eliciting values and own reasoning.

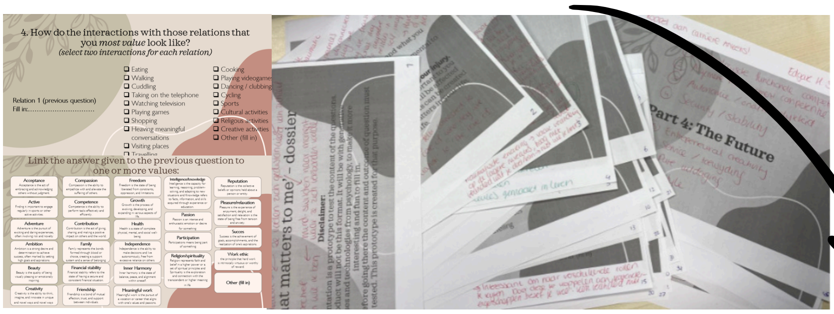
Test 1: Quick user test (n=2)

A quick user test to test the collection of questions and answer options, as well as the formulation and completeness.

Insights: (1) Questions and answer options need to be clarified or reframed, (2) Work should be included, since this is a significant part of your life, (3) Factors about the future should be included

PROTOTYPE 2: Visualization of adjusted questionnaire

A visual presentation that helps to understand the interactive mechanism of the tool (by clicking to the next slide).



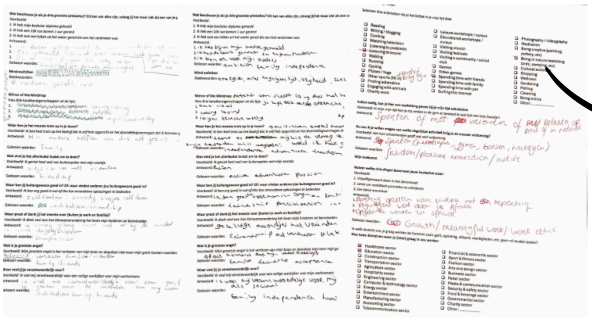
Test 2: Expert validation (n=1)

Validation with a life coach and victim support worker on the content and completeness of the question and answer options.

Insights: (1) Cannot directly ask a person that recently experienced a traumatic event about what matters most to them. Mind-switching is needed for this! (2) Reformulation of some questions, (3) add career anchors

PROTOTYPE 3: Interactive exercise of the 'Life Compass'

A visual presentation that helps to understand the interactive mechanism of the tool (by clicking to the next slide in combination with an physical answer sheet). Since the content and completeness of the questions was validated, all questions were made generative and visual.



Test 3: Exuberant user test (n=3)

An exuberant user test where users were asked to test the quided meditation text (still textual) in combination with the generative exercises. Users were asked to isolate themselves to fully focus on the mind-switching and generative exercises. The user test took around 45 minutes.

Insights: (1) sequence of some questions should be adjusted, (2) multiple examples should be provided by the open questions to make users think of a broad domain of possibilities (one example steers towards that direction)

PROTOTYPE 4: Guided audiovisualisation of the 'Life Compass' exercise

A video recording of the visual presentation with generative exercises in combination with the guided meditation (audio recording) and an answer sheet. This prototype simulates the interactive working of the tool as realistic as possible without developing the interactive tool.

Test 4: Final user test (n=2)

A final user test to test the audio recorded test of the guided meditation in combination with visual presentation of the generative exercises.

Insights: (1) herformulation of sentences, (2) visual cues on screen simultaneously with audio recording of guided meditation

FINAL PROTOTYPE 'Life Compass'

Figure 22: Test iterations 'Life Compass' exercise

First prototype: Questionnaire

The first prototype was a technical worksheet of a questionnaire, with options and example answers. The content of the questionnaire has been compiled on the basis of online research, online tools and own reasoning. During the first user test, users were asked to go through the questions and examine the formulation and framing of the questions, as well as the completeness and clearness of answer options. After the first user test the content of the questionnaire was significantly adjusted. Questions and answer options were added or reframed, as illustrated by the blue text.

Table 5: Technical worksheet questionnaire (prototype 1)

Question	Output	Options	Example
Part 1: What do you think is important?			
1. Rate the six most important areas in your life *(from most important (1) to less important (6)) (Barkley, 2023)*	Ranking options (top six)	(1) Family, (2) Friends, (3) Health and fitness, (4) Income, (5) Independence, (6) Influence and power, (7) Making use of talents, (8) Personal growth, (9) Professional growth, (10) Prestige and status, (11) Positive impact on society, (12) Security, (13) Religion, spirituality or faith, (14) Partner, (15) Stimulating and/or rewarding work, (16) Time for leisure and relaxation, (17) Wealth and savings	*1 Health and fitness 2 Family 3 Friends 4 Personal growth 5 Positive impact on society 6 Stimulating and/or rewarding work*
2. What are your most important character traits? (maximum of three)	Choose three options	(1) Active/Athletic, (2) Adventurous, (3) Ambitious, (4) Brave, (5) Caring/Loving, (5) Committed, (6) Competitive, (7) Cooperative, (8) Creative, (9) Curious, (10) Disciplined, (11) Empathic, (12) Encouraging, (13) Flexible, (14) Helpful, (15) Humoristic, (16) Integrity/Honesty, (17) Loyal/Trustworthy, (18) Patience, (19) Passionate, (20) Playful/energetic, (21) Reliable, (22) Responsible, (23) Supportive, (24) Knowledgeable, (25) other (fill in)	*1 Adventurous 2 Creative*
3. Who are the three most important relations in your life? *(from most important (1) to less important (3))*	Options ranking (top three)	(1) Partner, (2) Father/mother, (3) Brother/sister, (4) Child, (5) Grandchild, (5) Pet, (6) Friend, (7) Roommate, (8) Co-worker, (9) Team member, (10) Community member, (11) Church member, (12) Carer, (13) Neighbor, (14) Other (fill in)	*1 Mother 2 Friend 3 Team member*
4. How do the interactions with those relations that you most value look like? (select two interactions for each relation).	Options from previous selection	(1) Eating, (2) Walking, (3) Cuddling, (4) Talking on the telephone, (5) Watching television, (6) Playing games, (7) Shopping, (8) Heaving meaningful conversations, (9) Visiting places, (10) Travelling, (11) Cooking, (12) Playing videogames, (13) Dancing/Clubbing, (14) Cycling, (15) Sports, (16) Cultural activities, (17) Religious activities, (18) Creative activities, (19) Other (fill in)	*1 Mother: Traveling and cooking2 Friend: Visiting places and clubbing3 Team member: Having meaningful conversations and creative activities*
5. Describe the human interaction you value the most in more detail *(one sentence)*	Quote + aligned value(s)	X	*"Having meaningful conversations about the complexity of life with my friend"*
6. What roles do you have in life?	Options	(1) Partner, (2) Father/Mother, (3) Grandfather/Grandmother, (4) Son/Daughter, (5) Brother/Sister, (6) Godfather/Godmother, (7) Pet-owner, (8) Athlete, (9) Team-athlete, (10) Friend, (11) Volunteer, (12) Employee, (13) Boss, (14) Co-worker, (15) Company owner, (16) Artist, (17) Musician, (18) Community member, (19) Church member, (20) Confidant/Mentor, (21) Student, (22) Neighbor, (23) Traveller, (24) Other (fill in)	*Selection of multiple roles: Daughter, sister, pet-owner, athlete, employee, friend, co-worker, student, traveller*

7. What are the three most important roles to you? (From most important (1) to less important (3)) (Lander & Nahon, 2017)	Options from previous selection	Choose from the selection you made in the previous question.	*1. Friend* *2. Student* *3. Employee*
8. What are the most important character traits of the roles you have chosen? (select two character traits for each role). (Lander & Nahon, 2017)	Link top three roles from the previous question to options	(1) Active/Athletic, (2) Adventurous, (3) Ambitious, (4) Brave, (5) Caring/Loving, (5) Committed, (6) Competitive, (7) Cooperative, (8) Creative, (9) Curious, (10) Disciplined, (11) Empathic, (12) Encouraging, (13) Flexible, (14) Helpful, (15) Humoristic, (16) Integrity/Honesty, (17) Loyal/Trustworthy, (18) Patience, (19) Passionate, (20) Playful/energetic, (21) Reliable, (22) Responsible, (23) Supportive, (24) Knowledgeable, (25) other (fill in)	*1. Friend: Encouraging, Loyal* *2. Student: Responsible, Reliable* *3. Employee: Responsible, Committed*
9. Describe in one sentence how you want others to remember you? (Barkley, 2023)	Quote + aligned value(s)	X	*"I want others to remember me as a kind person that contributes to society and is always open to help the vulnerable"* *Value(s): Contribution, compassion, family, meaningful work, participation*
Part 2: What drives you			
10. Describe in one sentence what do you think or talk about the most, except your family or work? (Barkley, 2023)	Quote + aligned value(s)	X	*"I think a lot about this new innovative project at work that I am responsible for"* *Value(s): Competence, Growth, Participation, Succes, Work Ethic*
11. Describe in one sentence what you enjoy doing the most? (Barkley, 2023)	Quote + aligned value(s)	X	*"What I enjoy the most is playing outside with my son"* *Value(s): Family, Freedom, Pleasure*
12. Describe in one sentence what you are afraid of?	Quote + aligned value(s)	X	*"My biggest fear is losing my job and not being able to provide for my family"* *Value(s) Family and Financial stability*
13. Describe in one sentence what you are most proud of?	Quote + aligned value(s)	X	*"I am most proud of the company that I have founded and my dedication to it"* *Value(s): Ambition, Reputation, Succes*
14. Describe in one sentence what gives you an extraordinary amount of energy?	Quote + aligned value(s)	X	*"Being outside in the snow gives me a lot of energy"* *Value(s): Freedom, Inner harmony, Pleasure/Relaxation*

15. Describe in one sentence what you are exceptionally good at?	Quote + aligned value(s)	X	*“I am good at thinking outside-of-the-box and create innovative solutions”* *Value(s): Creativity, Competence, Growth*
16. Describe in one sentence what you feel responsible for?	Quote + aligned value(s)	X	*“As a business-owner, I feel responsible for my employees”* *Value(s): Reputation*
17. Describe three things that are on your bucket list	Fill in (3x) + aligning value(s)	X	*1. Volunteering in an animal shelter* *2. A creative cursus* *3. Skydiving* *Value(s): Contribution, creativity, adventure*
18. Describe in one sentence what your ambition for the future is?	Quote + aligned value(s)	X	*“I want to start my own company, making assistive technology for the disabled”* *Value(s): Ambition, Contribution, Passion*
Part 3: A day in your life			
19. Choose how you like to spend your free time (maximum of three)? If necessary, please specify in one sentence	Options + sentence	(1) Reading, (2) Writing/Blogging, (3) Cooking, (4) Watching television, (5) Listening to podcasts, (6) Listening to music, (7) Walking, (8) Running, (9) Cycling, (10) Pilates/Yoga, (11) Other sports (fill in), (12) Finding adrenaline, (13) Engaging with animals, (14) Charity work, (15) Leisure workshop or cursus, (16) Educational workshop or cursus, (17) Visiting church, (18) Visiting festivals, (19) Visiting a community or social club, (20) Games, (21) Video-games, (22) Spending time with friends, (23) Spending time with family, (24) Spending time with pet, (25) Photography/Videography, (26) Meditation, (27) Being creative, (28) Being in nature, (29) Cultural activities, (30) Shopping, (31) Wellness, (32) Gardening, (33) Fishing, (34) Cleaning, (35) Being online, (36) Other (fill in)	*1. Spending time with family* *2. Other sports* *3. Reading* *“In my free time you can find me a lot in the gym or playing padel with my family”*
20. Describe in one sentence what daily activities satisfy you the most?	Quote + aligned value(s)	X	*“Cleaning the house satisfies me”* *Value(s): Inner harmony*
21. Describe in one sentence what your weekly highlights are?	Quote + aligned value(s)	X	*“Sunday morning watching the soccer game of my son”* *Value(s): Family*
22. In which field would you most like to work?	Options	(1) Health Care sector, (2) Education sector, (3) Construction sector, (4) Transport sector, (5) Agriculture sector, (6) Hospitality sector, (7) Technical sector, (8) Computer and technology sector, (9) Energy sector, (10) Entertainment sector, (11) Manufacturing sector, (12) Accounting sector, (13) Telecommunication sector, (14) Financial and economic sector, (15) Sports and fitness sector, (16) Fashion sector, (17) Art and design sector, (18) Business sector, (19) Retail sector, (20) Media and communication sector, (21) Security and safety sector, (22) Food and beverages sector, (23) Government sector, (24) Charity sector, (25) Other (fill in)	*1. Hospitality sector* *2. Charity sector*

Final prototype ‘Life Compass’

The ‘Life Compass’ exercise is an interactive exercise with voice-over guidance, that can be performed on a laptop or tablet, while using headphones or earphones. By making this exercise the person’s ‘What matters to me’-dossier can be generated, that will be used to align the rehabilitation care with a person's values and goals. The exercise can be divided into six (mostly generative) parts:

Part 0: Introduction

In this introduction part the goal and value of the ‘Life compass’ exercise is explained. The voice-over explains why it is important to unravel your latent values (especially for trauma patients) and how the mind-switching and generative techniques support this. It is explained how the output dossier can be used to actively participate in the customization of their care plan.
Output: no output in the ‘what matters to me’-dossier

Part 1: My Life Map

During the first part of the exercise the person is asked about big moments in their life, such as an important decision and biggest achievements. After that the person is asked to create a personal Life Map, a visual representation of their life cycle, highlighting important moments. This generative technique helps the person find a moment in his life when he felt connected to himself, which is necessary for mind-switching. The voice-over guides the person during the process of mind-switching. For example, by saying: “Choose a moment, preferably in the past few years, when you did feel connected to yourself. Close your eyes and think back to this moment. Why did you feel connected to yourself? What went well in your life?...”
Output: output 2 and 3 in the ‘what matters to me’ dossier (see Figure 23)

Part 2: Mirror of Me Mind Map

This generative technique asks the person to visualize a big mirror in his home. He looks at himself in the center of the mirror. Now he is asked to create a mind map around him, based on the following questions: (1) what are your most important character traits, (2) what are you most proud of, (3) what do you enjoy the most, (4) what are you exceptionally good at, (5) what do you think or talk about most, (6) what are you afraid of, and (7) what do you feel responsible for. All answers given have to be linked to value(s). Answering these questions requires time and reflections.
Output: output 4 in the ‘what matters to me’ dossier (see Figure 23)

Part 3: My Relation-web

This generative technique asks the person to place his closest relations in a web around him. The closer a relation is placed to the center (to him), the more important this relation is for the person. For the three most important relations, the person is asked to define the interactions he values most with those relations.
Output: output 6 in the ‘what matters to me’ dossier (see Figure 23)

Part 4: My roles passport

This generative technique asks the person to reflect on the most important roles he fulfills in life, and to link those roles to character traits that he finds crucial for this specific role.
Output: output 5 in the ‘what matters to me’ dossier (see Figure 23)

Part 5: A day in my life

The person is asked about his most important daily, weekly and monthly activities and has to link those to values.
Output: output 8 in the ‘what matters to me’ dossier (see Figure 23)

Part 6: My Future

Finally, the person is asked to think about his future. He is asked about his bucket list wishes and ambitions (including new roles to fulfill) for the future. Additionally, the person has to choose from different work sectors and between career anchor statements.
Output: output 7, 9,10 and 11 in the 'what matters to me' dossier (see Figure 23)

Personal values: The person has to link all his answers to open questions to values. In the background his top five values are generated. The personal values can be used during consultation when considering which PROMs are the most important and to create personal goals.
Output: output 1 in the 'what matters to me' dossier (see Figure 23)

For every part a simplified visualization will be provided below. It gives an indication of the frames a person sees while making the interactive exercises and what the guiding voice-over is telling him. All frames are visualized. However, only fragments of the guiding voice-over text are shown. Those fragments were selected to give an impression of the guidance. For the full voice-over text (including the closure), see Appendix I. For the specific questions and answer options, see Appendix J.

Part 0: Introduction

Frame:

1

Welkom to your Life Compass

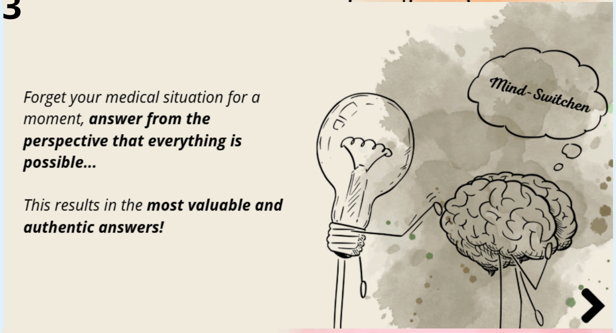
A compass that provides insight into what is really important in your life. A compass that helps you align your care pathway with what matters to you!

2

Together we search for the core of who you are

To customize your care pathway accordingly

3



*Forget your medical situation for a moment, **answer from the perspective that everything is possible...***

*This results in the **most valuable and authentic answers!***

4

Take Jonathan as example...

Part 0: Introduction

Guided exercise text essence (not the full text!)

A personal Life Compass contains information about who you are and what is important to you. While creating this compass, you will reflect on your life and consider your values. Your values are your fundamental beliefs or ideals. It is the core of what you strive for and what shapes your behavior. Values are things that you really find important in life and they give direction to your life...

You have experienced a traumatic event and this can temporarily knock the solid ground from under your feet. You may feel distanced from yourself at the moment. Know that this is normal, and this is not something to be ashamed of. A traumatic event has a major impact on your life, but it does not change who you are. The core of who you are remains unchanged, together we will go to this core....

In order to bring out the most valuable answers for your care pathway, we will answer from a different perspective. Together we will go back to a moment in your life where you were satisfied with your life and experienced security. This moment could be yesterday, but also a few years ago. From this perspective we will determine what is important to you. We will park the traumatic experience for now...

For example, Jonathan can no longer play the guitar due to his traumatic injury to his hand. However, Jonathan is encouraged to list 'playing the guitar' when asked 'what gives you a lot of energy'. Even if playing the guitar is no longer possible, it can be looked at how this hobby can be replaced in another way that gives the same satisfaction. If Jonathan never lets it be known that playing the guitar is important to him, valuable information about Jonathan's needs and wishes is missing...

Part 1: My Life Map
Frame:

1


Exercise 1:
My Life Map

2


Which 6 life areas are the most important factors in your life?
Ranking: (1) most important --> (6) less important

- ☐ Family
- ☐ Friends
- ☐ Health
- ☐ Income
- ☐ Independence
- ☐ Influence and power
- ☐ Making use of talents
- ☐ Personal development
- ☐ Professional development
- ☐ Prestige and status
- ☐ Positive influence on society
- ☐ Security
- ☐ Religion, spirituality or faith
- ☐ Partner
- ☐ Rewarding work
- ☐ Time for relaxation and leisure
- ☐ Wealth

3


What is an important choice you have made in the past 10 years? Why did you choose this outcome?

Answer:

What are your three biggest achievements?

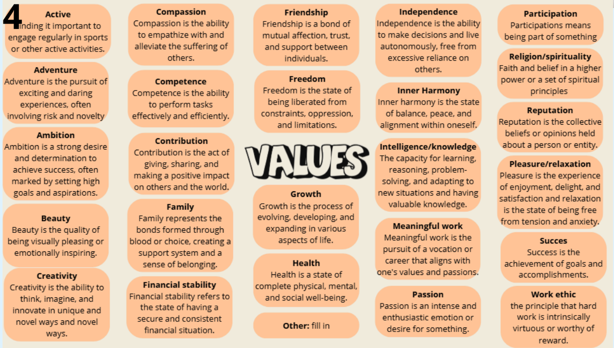
Answer:

1.

2.

3.

4


VALUES

Active
inding it important to engage regularly in sports or other active activities.

Adventure
Adventure is the pursuit of exciting and daring experiences, often involving risk and novelty

Ambition
Ambition is a strong desire and determination to achieve success, often marked by setting high goals and aspirations.

Beauty
Beauty is the quality of being visually pleasing or emotionally inspiring.

Creativity
Creativity is the ability to think, imagine, and innovate in unique and novel ways and novel ways.

Compassion
Compassion is the ability to empathize with and alleviate the suffering of others.

Competence
Competence is the ability to perform tasks effectively and efficiently.

Contribution
Contribution is the act of giving, sharing, and making a positive impact on others and the world.

Family
Family represents the bonds formed through blood or choice, creating a support system and a sense of belonging.

Financial stability
Financial stability refers to the state of having a secure and consistent financial situation.

Friendship
Friendship is a bond of mutual affection, trust, and support between individuals.

Freedom
Freedom is the state of being liberated from constraints, oppression, and limitations.

Growth
Growth is the process of evolving, developing, and expanding in various aspects of life.

Health
Health is a state of complete physical, mental, and social well-being.

Other: fill in

Independence
Independence is the ability to make decisions and live autonomously, free from excessive reliance on others.

Inner Harmony
Inner harmony is the state of balance, peace, and alignment within oneself.

Intelligence/knowledge
The capacity for learning, reasoning, problem-solving, and adapting to new situations and having valuable knowledge.

Meaningful work
Meaningful work is the pursuit of a vocation or career that aligns with one's values and passions.

Passion
Passion is an intense and enthusiastic emotion or desire for something.

Participation
Participations means being part of something

Religion/spirituality
Faith and belief in a higher power or a set of spiritual principles

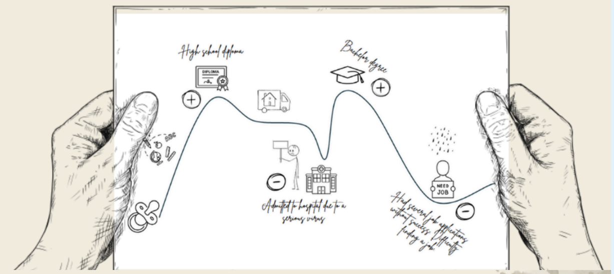
Reputation
Reputation is the collective beliefs or opinions held about a person or entity.

Pleasure/relaxation
Pleasure is the experience of enjoyment, delight, and satisfaction and relaxation is the state of being free from tension and anxiety.

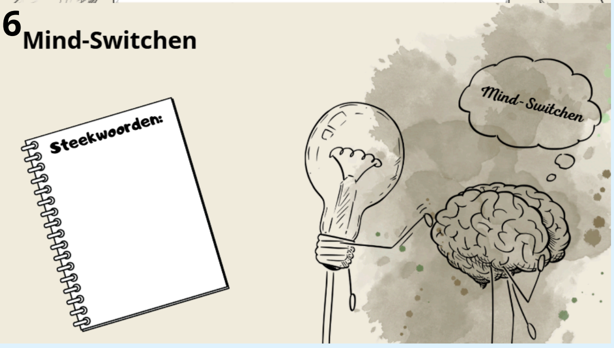
Succes
Success is the achievement of goals and accomplishments.

Work ethic
the principle that hard work is intrinsically virtuous or worthy of reward.

5 *Here an example of a Life Map...*



6 **Mind-Switchen**



Part 1: My Life Map
Guided exercise text essence (not the full text!)

We start by making your life map. First I will ask you a few loose questions to help you on your way. Then you will fill in your own life map. Of course I will help you with an example.

First of all I would like to ask you to answer the following question. Which factors do you consider most important in your life? Select 6. Number 1 is the most important, number 6 a little less important.

What is an important choice you have made in the past 10 years? And why did you choose that outcome?
Example: Three years ago I decided to look for a new job. I was not appreciated at my old job and was no longer happy there.
Example: Despite being 45 years old I decided to go to college, I felt that I have more potential that I have never used...

Once you have filled in your answers, take a good look at them and select the values that your answers relate to (maximum three values)

Let's delve deeper into your life. I want to ask you to think about the big picture in your life. I ask you to draw a Life Map. In this Life Map you give a schematic representation of your life. What big moments of choice have there been in your life? And what did you choose then (and why)? What were peaks in your life? What were valleys? You can draw your life line however you want...

As I said before, we want to imagine a moment in your life where you felt connected to yourself. Your life map helps with this. Take a good look at your map. When did you feel connected to yourself? Choose a moment, preferably in the past few years. Close your eyes and think back to this time. Why did you feel connected to yourself? What went well in your life? Maybe you were successful and satisfied with your work? Maybe you had just achieved an achievement or success?...

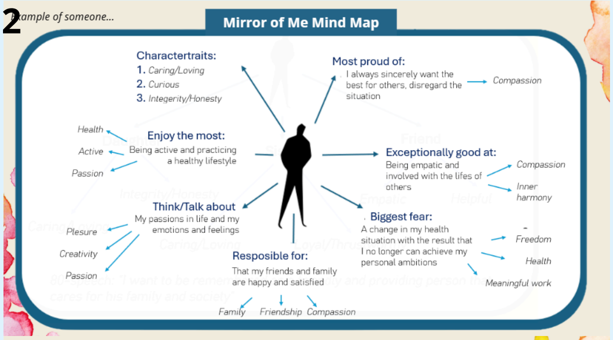
Part 2: Mirror of Me Mind Map Frame:

1

Exercise 2:

Mirror of Me Mind Map

2



Example of someone...

Mirror of Me Mind Map

Charactertraits:
1. *Caring/Loving*
2. *Curious*
3. *Integerity/Honesty*

Most proud of:
I always sincerely want the best for others, disregard the situation → *Compassion*

Enjoy the most:
Being active and practicing a healthy lifestyle → *Health*, *Active*, *Passion*

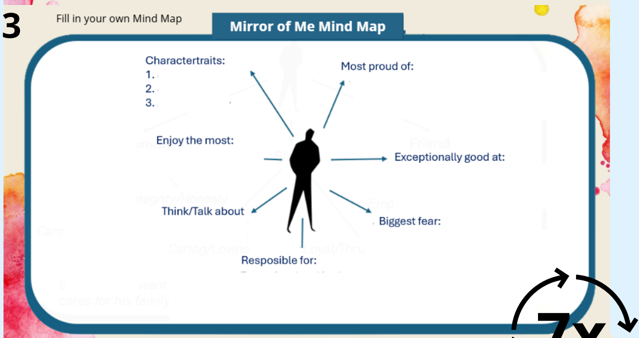
Exceptionally good at:
Being empatic and involved with the lifes of others → *Compassion*, *Inner harmony*

Think/Talk about
My passions in life and my emotions and feelings → *Plesure*, *Creativity*, *Passion*

Biggest fear:
A change in my health situation with the result that I no longer can achieve my personal ambitions → *Freedom*, *Health*, *Meaningful work*

Resposible for:
That my friends and family are happy and satisfied → *Family*, *Friendship*, *Compassion*

3



Fill in your own Mind Map

Mirror of Me Mind Map

Charactertraits:
1.
2.
3.

Most proud of:

Enjoy the most:

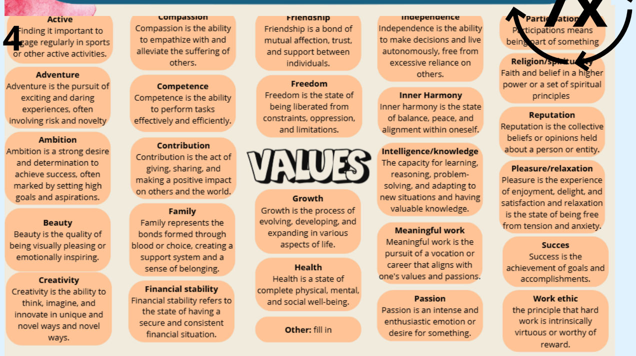
Exceptionally good at:

Think/Talk about

Biggest fear:

Resposible for:

4



VALUES

Active Finding it important to engage regularly in sports or other active activities.

Adventure Adventure is the pursuit of exciting and daring experiences, often involving risk and novelty

Ambition Ambition is a strong desire and determination to achieve success, often marked by setting high goals and aspirations.

Beauty Beauty is the quality of being visually pleasing or emotionally inspiring.

Creativity Creativity is the ability to think, imagine, and innovate in unique and novel ways and novel ways.

Compassion Compassion is the ability to empathize with and alleviate the suffering of others.

Competence Competence is the ability to perform tasks effectively and efficiently.

Contribution Contribution is the act of giving, sharing, and making a positive impact on others and the world.

Family Family represents the bonds formed through blood or choice, creating a support system and a sense of belonging.

Financial stability Financial stability refers to the state of having a secure and consistent financial situation.

Friendship Friendship is a bond of mutual affection, trust, and support between individuals.

Freedom Freedom is the state of being liberated from constraints, oppression, and limitations.

Growth Growth is the process of evolving, developing, and expanding in various aspects of life.

Health Health is a state of complete physical, mental, and social well-being.

Other: fill in

Independence Independence is the ability to make decisions and live autonomously, free from excessive reliance on others.

Inner Harmony Inner harmony is the state of balance, peace, and alignment within oneself.

Intelligence/knowledge The capacity for learning, reasoning, problem-solving, and adapting to new situations and having valuable knowledge.

Meaningful work Meaningful work is the pursuit of a vocation or career that aligns with one's values and passions.

Passion Passion is an intense and enthusiastic emotion or desire for something.

Participation Participations means being part of something

Religion/spirituality Faith and belief in a higher power or a set of spiritual principles

Reputation Reputation is the collective beliefs or opinions held about a person or entity.

Pleasure/relaxation Pleasure is the experience of enjoyment, delight, and satisfaction and relaxation is the state of being free from tension and anxiety.

Succes Success is the achievement of goals and accomplishments.

Work ethic the principle that hard work is intrinsically virtuous or worthy of reward.

Part 2: Mirror of Me Mind Map

Guided exercise text essence (not the full text!)

Imagine: There is a very large mirror hanging in your house. You can see yourself completely when you look into it. Close your eyes and imagine that you are standing in front of this mirror. You see yourself in the middle of the mirror and around you we are going to place information about you. The mirror becomes a mind map in which you as a person are central.

Here you see an example of someone who came before you. This is how your mind map should look like. There will be a number of questions that you have to answer. Note these answers in the right place in your mind map. Also link each answer to one or more values. After filling in all the questions, your mirror image mind map is finished!

Let's begin: Imagine yourself standing in front of a mirror, looking yourself straight in the eye. Who is actually standing in front of you?

#Iteration of questions with examples (see full text in appendix I)

- What are your three most important character traits?
- What are you most proud of?
- What do you enjoy the most?
- What are you exceptionally good at?
- What do you think/talk about the most?
- What are you afraid of?
- What do you feel responsible for?

Link the answers you gave to value(s)

Part 3: My relation-web

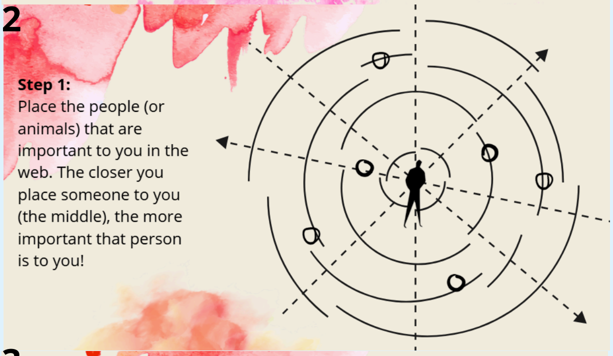
Frame:

1

Excersice 3

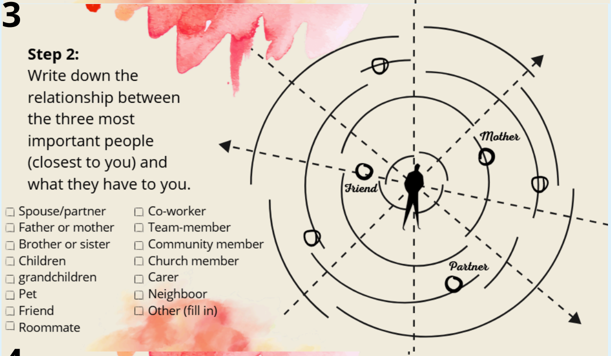
My relation-web

2



Step 1:
Place the people (or animals) that are important to you in the web. The closer you place someone to you (the middle), the more important that person is to you!

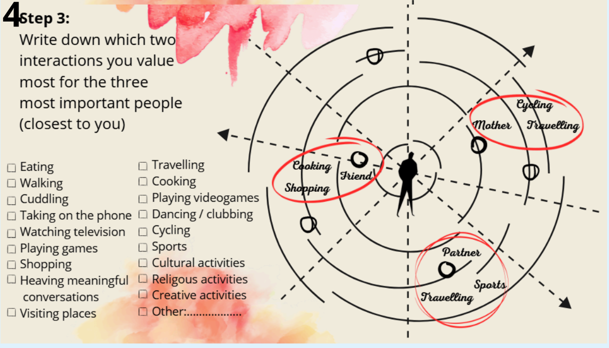
3



Step 2:
Write down the relationship between the three most important people (closest to you) and what they have to you.

☐ Spouse/partner
☐ Father or mother
☐ Brother or sister
☐ Children
☐ grandchildren
☐ Pet
☐ Friend
☐ Roommate
☐ Co-worker
☐ Team-member
☐ Community member
☐ Church member
☐ Carer
☐ Neighboor
☐ Other (fill in)

4



Step 3:
Write down which two interactions you value most for the three most important people (closest to you)

☐ Eating
☐ Walking
☐ Cuddling
☐ Taking on the phone
☐ Watching television
☐ Playing games
☐ Shopping
☐ Heaving meaningful conversations
☐ Visiting places
☐ Travelling
☐ Cooking
☐ Playing videogames
☐ Dancing / clubbing
☐ Cycling
☐ Sports
☐ Cultural activities
☐ Religous activities
☐ Creative activities
☐ Other:.................

Part 3: My relation-web

Guided exercise text essence (not the full text!)

Now we have a good idea of who you are as a person. Let's look at your social circles. Who are important in your life? How close are you to these people/animals?

Think of the people (or animals) you are often in contact with and who are important to you. Draw them in the web around you. The closer you place someone to you (so to the middle), the more important this person is to you.

Look at which three people are most important to you. You should have placed these closest to yourself – so in the middle. Note down for these three people what relationship they have to you, for example mother. Choose from the list of options.

Then, write down for these three people which interactions you value most with this person. You can choose two interactions from the menu per person and write them down for that person. For the sake of clarity, you can circle the people with interactions together.
Congratulations, your relationship web is finished!

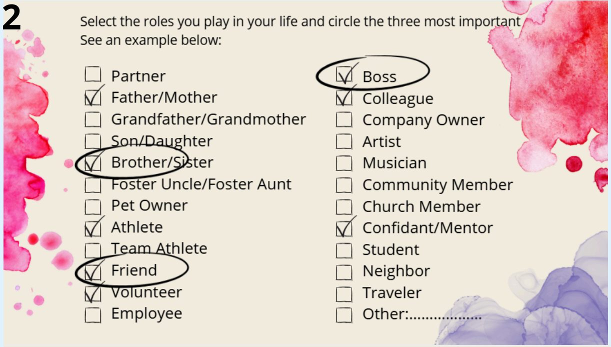
Part 4: My roles passport
Frame:

1

Exercise 4:

My roles passport

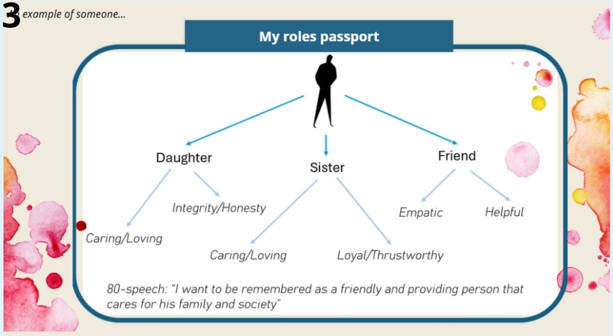
2



Select the roles you play in your life and circle the three most important
See an example below:

☐ Partner
☑ Father/Mother
☐ Grandfather/Grandmother
☐ Son/Daughter
[✓ ☑ Brother/Sister]
☐ Foster Uncle/Foster Aunt
☐ Pet Owner
☑ Athlete
☐ Team Athlete
[✓ ☑ Friend]
☑ Volunteer
☐ Employee
[✓ ☑ Boss]
☑ Colleague
☐ Company Owner
☐ Artist
☐ Musician
☐ Community Member
☐ Church Member
☑ Confidant/Mentor
☐ Student
☐ Neighbor
☐ Traveler
☐ Other:..................

3



example of someone...

My roles passport

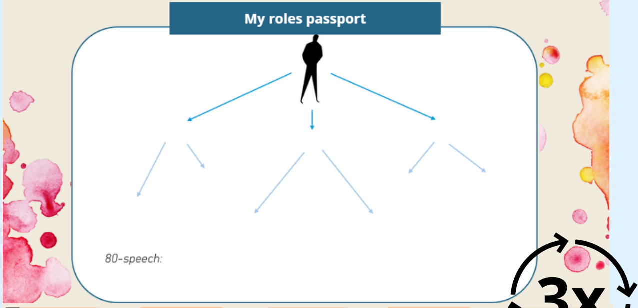
Daughter
Caring/Loving
Integrity/Honesty

Sister
Caring/Loving
Loyal/Thrustworthy

Friend
Empatic
Helpful

80-speech: "I want to be remembered as a friendly and providing person that cares for his family and society"

4

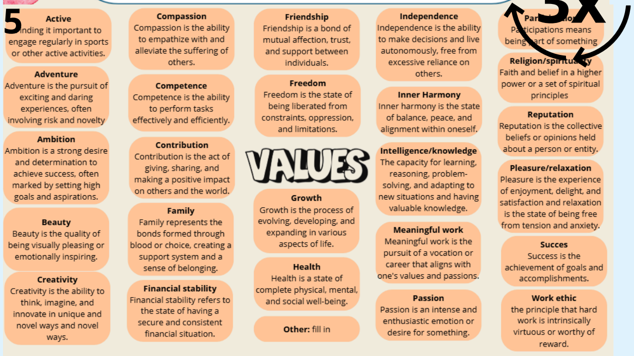


Now fill in your own role passport, by linking your three most important roles to two character traits. Then listen to the assignment about your 80-year surprise speech!

My roles passport

80-speech:

5



VALUES

3x

Active
Finding it important to engage regularly in sports or other active activities.

Adventure
Adventure is the pursuit of exciting and daring experiences, often involving risk and novelty

Ambition
Ambition is a strong desire and determination to achieve success, often marked by setting high goals and aspirations.

Beauty
Beauty is the quality of being visually pleasing or emotionally inspiring.

Creativity
Creativity is the ability to think, imagine, and innovate in unique and novel ways and novel ways.

Compassion
Compassion is the ability to empathize with and alleviate the suffering of others.

Competence
Competence is the ability to perform tasks effectively and efficiently.

Contribution
Contribution is the act of giving, sharing, and making a positive impact on others and the world.

Family
Family represents the bonds formed through blood or choice, creating a support system and a sense of belonging.

Financial stability
Financial stability refers to the state of having a secure and consistent financial situation.

Friendship
Friendship is a bond of mutual affection, trust, and support between individuals.

Freedom
Freedom is the state of being liberated from constraints, oppression, and limitations.

Growth
Growth is the process of evolving, developing, and expanding in various aspects of life.

Health
Health is a state of complete physical, mental, and social well-being.

Other: fill in

Independence
Independence is the ability to make decisions and live autonomously, free from excessive reliance on others.

Inner Harmony
Inner harmony is the state of balance, peace, and alignment within oneself.

Intelligence/knowledge
The capacity for learning, reasoning, problem-solving, and adapting to new situations and having valuable knowledge.

Meaningful work
Meaningful work is the pursuit of a vocation or career that aligns with one's values and passions.

Passion
Passion is an intense and enthusiastic emotion or desire for something.

Par[illegible]ion
Participations means being part of something

Religion/spirituality
Faith and belief in a higher power or a set of spiritual principles

Reputation
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Pleasure/relaxation
Pleasure is the experience of enjoyment, delight, and satisfaction and relaxation is the state of being free from tension and anxiety.

Succes
Success is the achievement of goals and accomplishments.

Work ethic
the principle that hard work is intrinsically virtuous or worthy of reward.

Part 4: My roles passport
Guided exercise text essence (not the full text!)

Now, let's think about which roles you have. You have roles as an individual; for example, athlete or artist. You have roles within your family; for example, father, brother or uncle. You have roles within your work; for example, HR manager, administrative employee or real estate agent. You have roles within your society; for example, board member of an association, member of a church or volunteer...

Think carefully about which roles you have and select the roles that apply to you. Now, I want to ask you to be critical. What are your three most important roles? Circle the three most important roles. With these three roles we will create your role passport.

Write your chosen roles in the role passport, and link them to the two character traits that are most important for this role. You can see an example here.

Now it is your turn! We now have a picture of who is important in your life and what roles you fulfill in your life.
I have an interesting assignment for you.
Imagine: You are almost 80 years old. A surprise party is given for you. A few people give a speech about who you were as a person during your life. How do you want people to describe you as a person?
Describe in no more than three sentences how you would like people to remember you...
Please link the answer you gave to value(s).

Part 5: A day in my life

Frame:

1

Exercise 5:

A day in my life

2

What do you like to do most in your free time? Choose three activities:

- ☐ Reading
- ☐ Writing / blogging
- ☐ Cooking
- ☐ Watching television
- ☐ Listening to podcasts
- ☐ Listening to music
- ☐ Walking
- ☐ Running
- ☐ Cycling
- ☐ Pilates / Yoga
- ☐ Other sports (fill in)
- ☐ Finding adreneline
- ☐ Engaging with animals
- ☐ Leisure workshops / cursus
- ☐ Educational workshops / cursus
- ☐ Visiting church
- ☐ Visiting festivals
- ☐ Visiting a community / group
- ☐ Games
- ☐ Video-games
- ☐ Spending time with friends
- ☐ Spending time with family
- ☐ Spending time with pet
- ☐ Surfing the internet
- ☐ Charity work
- ☐ Photography / videography
- ☐ Meditation
- ☐ Being creative (painting, pottery, etc)
- ☐ Being in nature (watching birds, camping, etc)
- ☐ Cultural activities
- ☐ Shopping
- ☐ Wellness
- ☐ Gardening
- ☐ Fishing
- ☐ Cleaning
- ☐ Being online
- ☐ Other:.....................

Explanation:

3

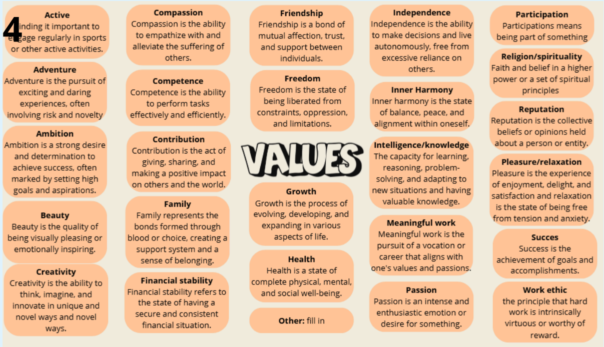
Which daily activities satisfy you the most?

Answer:

What is your weekly/monthly highlight?

Answer:

4



Active
Finding it important to engage regularly in sports or other active activities.

Adventure
Adventure is the pursuit of exciting and daring experiences, often involving risk and novelty

Ambition
Ambition is a strong desire and determination to achieve success, often marked by setting high goals and aspirations.

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Growth
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Health
Health is a state of complete physical, mental, and social well-being.

Other: fill in

Independence
Independence is the ability to make decisions and live autonomously, free from excessive reliance on others.

Inner Harmony
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Succes
Success is the achievement of goals and accomplishments.

Work ethic
the principle that hard work is intrinsically virtuous or worthy of reward.

Part 5: A day in my life

Guided exercise text essence (not the full text!)

Let's take a look at how you like to fill your days. What do you like to do and what gives you energy? Do you have any hobbies?

First, I would like to ask you to choose what you like to do most in your free time. You can choose three activities. If your answer is not there, you can add it yourself!
If necessary, you can provide an explanation of your free time activities here. For example: In my free time you can find me in the gym and I spend a lot of time with my pet!

Now I would like to ask you which daily activity gives you the most satisfaction? For example: Cleaning the house gives me a lot of satisfaction or running outside gives me a lot of satisfaction

And what is your weekly/monthly highlight? Something you look forward to every time? For example: My weekly highlight is the padel competition on Friday evening or my weekly highlight is when the grandchildren come to visit on Sunday!

Please link the answer you gave to value(s).

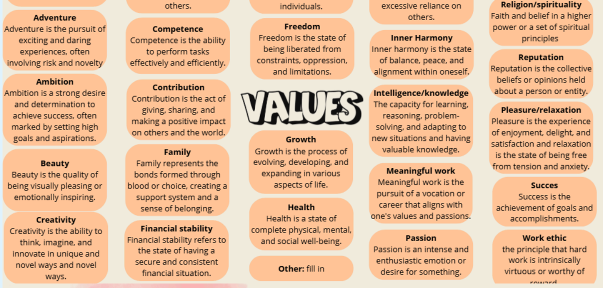
Part 6: My Future
Frame:


1

Exercise 6

My Future


2 *What three things are on your bucket list? Write them down!*

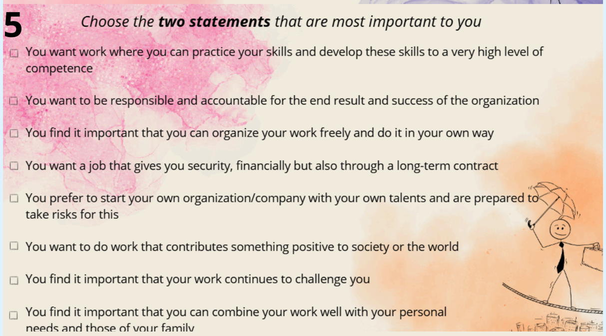

3

- **Active** Finding it important to engage regularly in sports or other active activities.
- **Adventure** Adventure is the pursuit of exciting and daring experiences, often involving risk and novelty
- **Ambition** Ambition is a strong desire and determination to achieve success, often marked by setting high goals and aspirations.
- **Beauty** Beauty is the quality of being visually pleasing or emotionally inspiring.
- **Creativity** Creativity is the ability to think, imagine, and innovate in unique and novel ways and novel ways.
- **Compassion** Compassion is the ability to empathize with and alleviate the suffering of others.
- **Competence** Competence is the ability to perform tasks effectively and efficiently.
- **Contribution** Contribution is the act of giving, sharing, and making a positive impact on others and the world.
- **Family** Family represents the bonds formed through blood or choice, creating a support system and a sense of belonging.
- **Financial stability** Financial stability refers to the state of having a secure and consistent financial situation.
- **Friendship** Friendship is a bond of mutual affection, trust, and support between individuals.
- **Freedom** Freedom is the state of being liberated from constraints, oppression, and limitations.
- **Growth** Growth is the process of evolving, developing, and expanding in various aspects of life.
- **Health** Health is a state of complete physical, mental, and social well-being.
- **Other:** fill in
- **Independence** Independence is the ability to make decisions and live autonomously, free from excessive reliance on others.
- **Inner Harmony** Inner harmony is the state of balance, peace, and alignment within oneself.
- **Intelligence/knowledge** The capacity for learning, reasoning, problem-solving, and adapting to new situations and having valuable knowledge.
- **Meaningful work** Meaningful work is the pursuit of a vocation or career that aligns with one's values and passions.
- **Passion** Passion is an intense and enthusiastic emotion or desire for something.
- **Participation** Participations means being part of something
- **Religion/spirituality** Faith and belief in a higher power or a set of spiritual principles
- **Reputation** Reputation is the collective beliefs or opinions held about a person or entity.
- **Pleasure/relaxation** Pleasure is the experience of enjoyment, delight, and satisfaction and relaxation is the state of being free from tension and anxiety.
- **Succes** Success is the achievement of goals and accomplishments.
- **Work ethic** the principle that hard work is intrinsically virtuous or worthy of reward


4

Choose two domains you would like to work in later:

☐ Healthcare Sector
☐ Education Sector
☐ Construction Sector
☐ Transport Sector
☐ Agriculture Sector
☐ Hospitality Sector
☐ Technical Sector
☐ Computer and Technology Sector
☐ Energy Sector
☐ Entertainment Sector
☐ Manufacturing Sector
☐ Accounting Sector
☐ Telecommunication Sector
☐ Financial & Economic Sector
☐ Sports & Fitness Sector
☐ Fashion Sector
☐ Art & Design Sector
☐ Business Sector
☐ Retail Sector
☐ Media & Communication Sector
☐ Security & Safety Sector
☐ Food & Beverage Sector
☐ Government Sector
☐ Charity Sector
☐ Other:....................


5

*Choose the **two statements** that are most important to you*

☐ You want work where you can practice your skills and develop these skills to a very high level of competence

☐ You want to be responsible and accountable for the end result and success of the organization

☐ You find it important that you can organize your work freely and do it in your own way

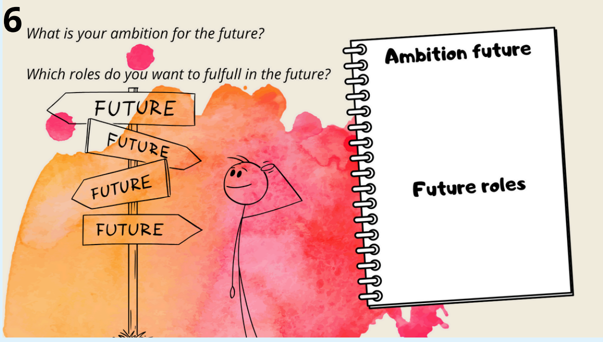
☐ You want a job that gives you security, financially but also through a long-term contract

☐ You prefer to start your own organization/company with your own talents and are prepared to take risks for this

☐ You want to do work that contributes something positive to society or the world

☐ You find it important that your work continues to challenge you

☐ You find it important that you can combine your work well with your personal needs and those of your family


6 *What is your ambition for the future?*

Which roles do you want to fulfull in the future?

Part 6: My Future
Guided exercise text essence (not the full text!)

We have already looked at the past and your current situation. Now I am curious about the future. What are activities that you would still like to do? Or goals that you want to achieve? Skills that you want to learn? Experiences that you want to gain?

What's on your bucket list? Of course, it could be anything!
Write down the three things at the top of your bucket list
Let me give you an example:

1. Volunteer at an animal shelter
2. Learn to paint realistic portraits
3. Run a half marathon

Link your bucket list activities to (maximum three) values!

In which domain would you like to work if factors such as money, education, distance, skills, etc. did not play a role?
Choose two domains in which you would like to work (later)

Now I want to ask you to read the questions below carefully. Choose the two statements that are most true for you. In this way, we determine which career anchors are important to you. By doing so, we can find out what kind of company and job you will feel comfortable with.

We have already reached the last question. Last but not least, I am curious about your ambition for the future.
This ambition is personal and can be anything: moving to another country, having children, starting your own business, becoming a volunteer, etcetera. There is no right or wrong answer, as long as you really want to achieve it. I am curious about your answer! What is your ambition for the future?
Link your ambition to (maximum of three) values...

14.4 ‘What matters to me’-dossier (1.2)

In the Figure below the ‘What matters to me’-dossier is visualised, with a description of the meaning of the different outputs. The outputs are generated by the person's input during the ‘Life Compass’ exercise, as explained before.

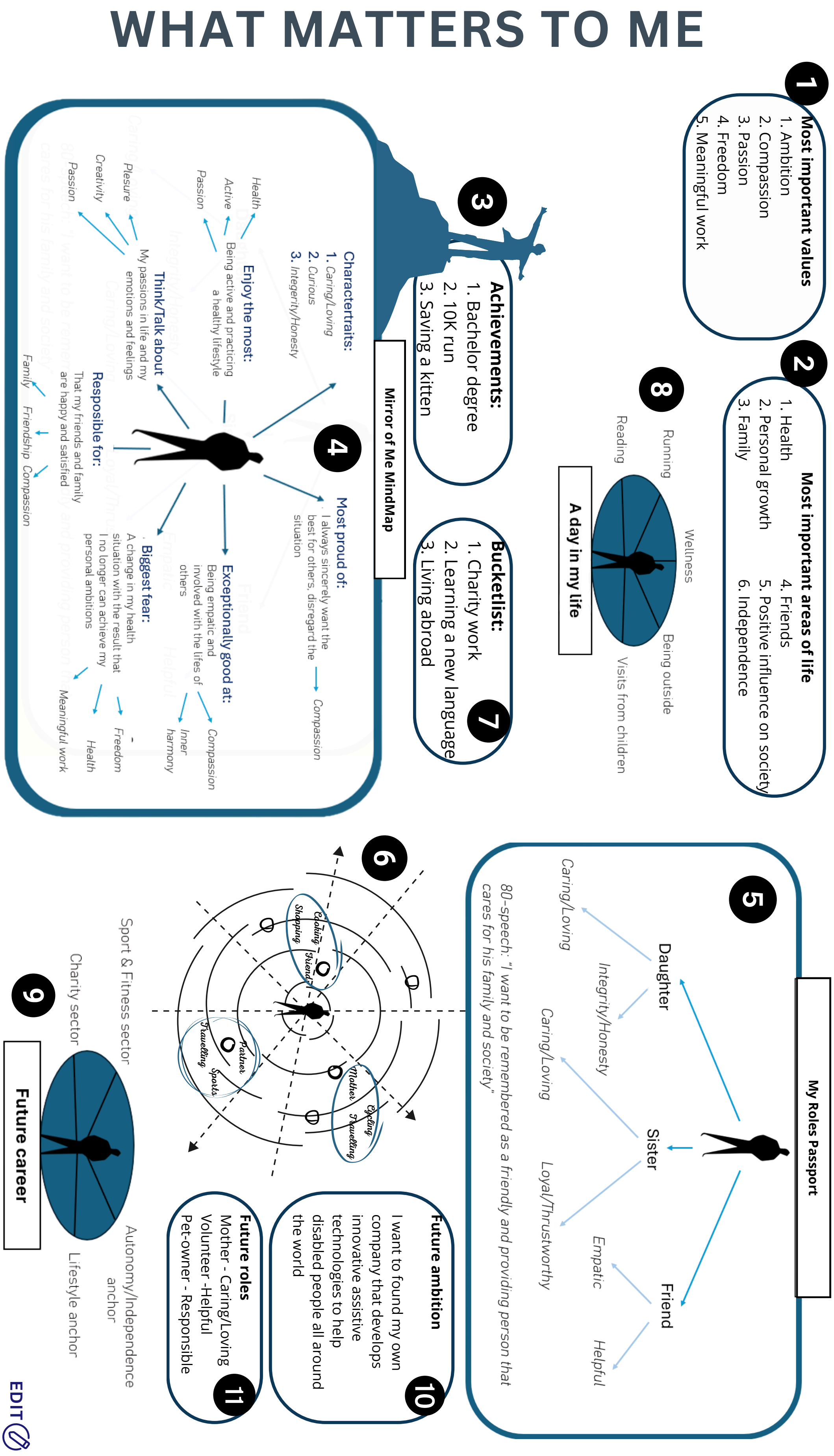


Figure 23: ‘What Matters To Me’-dossier

1. Enumeration most important values

The most important values of this person are generated, based on multiple open questions that had to be answered and linked to value(s) (total of 25 values to choose from). The tool keeps track of the score of different values and generates the top 5 values for this person. This approach is more suitable to unravel latent values instead of directly asking patients to choose their top 5 values. The personal values can be used during consultation, when considering which PROMs are the most important and to create personal goals.

2. Enumeration of most important areas of life

The person is asked to choose the 6 most important areas of their life, from a total of 18 options. This indicates what this person prioritizes in his life, health care goals should be aligned with those priorities.

3. Three greatest achievements

This outcome indicates what this person considers to be achievements. These achievements are important moments in their life and can be used as inspiration for overarching goals or future ambitions within their new situation.

4. The mirror of me mindmap: a simple and visual representation that contains a lot of relevant information about this person

Based on questions: (1) what are your most important character traits, (2) what are you most proud of, (3) what do you enjoy the most, (4) what are you exceptionally good at, (5) what do you think or talk about most, (6) what are you afraid of, and (7) what do you feel responsible for. All answers have to be linked to value(s). The answers provide detailed information about this person and touch upon subjects that would regularly not be talked about during consultation.

5. Personal roles passport

This passport contains information about the three most important roles that this person fulfills in his life. The roles are linked to character traits that this person finds crucial for this specific role in his life. Health care providers should keep those roles in mind while working towards health outcomes. Because of their roles, person's might prefer different health care outcome(s) or procedures.

6. The relation-web

The relation-web is a visual representation of the closest relations of this person, and the interactions this person values the most with those relations. The interactions provide valuable information for health care providers. Care must contribute to making these interactions possible again, so that the person's social life is also taken into account in the care pathway.

7. Enumeration bucket list wishes

The bucket list can serve as inspiration for health care providers and psycho-social workers to work towards enabling future activities.

8. Most important daily, weekly, and monthly activities

This information provides a picture of this person's regular activities. With the rehabilitation we want to make these activities possible again as far as possible. When certain activities are no longer possible, health care providers should guide the patient in finding suitable alternatives or assistive technologies.

9. The sector this person would want to work in and the career anchors that this person finds important

The traumatic injury can result in the person no longer being able to do his job. This chance is especially present with military personnel, due to the physical nature of the military profession. The file provides insight into domains in which the person would like to work. This provides direction, but also a lot of freedom for the type of work within a domain. This information can be used by the case coordinator or reintegration worker.

10. Ambition for the future

The future ambition is a starting point for formulating overarching goals. Later, subgoals can be created in collaboration with health care providers that contribute to those overarching goals.

11. Roles in the future

Roles in the future are a starting point for formulating overarching goals. Later, subgoals can be created in collaboration with health care providers that contribute to those overarching goals.

How does this support the creation of a customized care plan?

The ‘What’s important to me’-dossier can be found in the tool and can be consulted by patient and health care providers during consultation to support shared decision-making and facilitate personal goals and preference creation. Care provision can be aligned with the personal values, goals and preferences. Personal goals should be documented in the tool to link them to PROMs and to facilitate effective interdisciplinary collaboration, as explained in the next chapter. It is important to note that this dossier does not replace medical advice from professionals. However, the dossier is the starting point of the patient actively participating in the development of his/her customized care plan.

This dossier bypasses the communication and organizational barriers, explained in chapter 10. Eliciting values is no longer dependent on the communication skills of the patient or health care provider or on the organizational structure of the health care system, such as the time available for consultation. The dossier ensures that all health care providers have the same starting point of insights into what is important for this person. Additionally, the patient will not have to have the ‘what matters to me’ conversation multiple times with different health care providers. The dossier circumvents the dependency on the quality of the health care providers’ documentation and reduces the documentation burden for health care providers.

Chapter 15: Design part 2 - A tool that supports effective interdisciplinary goal-setting and links those personal goals to patient reported outcome measurements (PROMs)

In this chapter the design part that relates to the goal '*to support effective interdisciplinary goal-setting and to link those personal goals to patient reported outcome measurements (PROMs)'* is described.

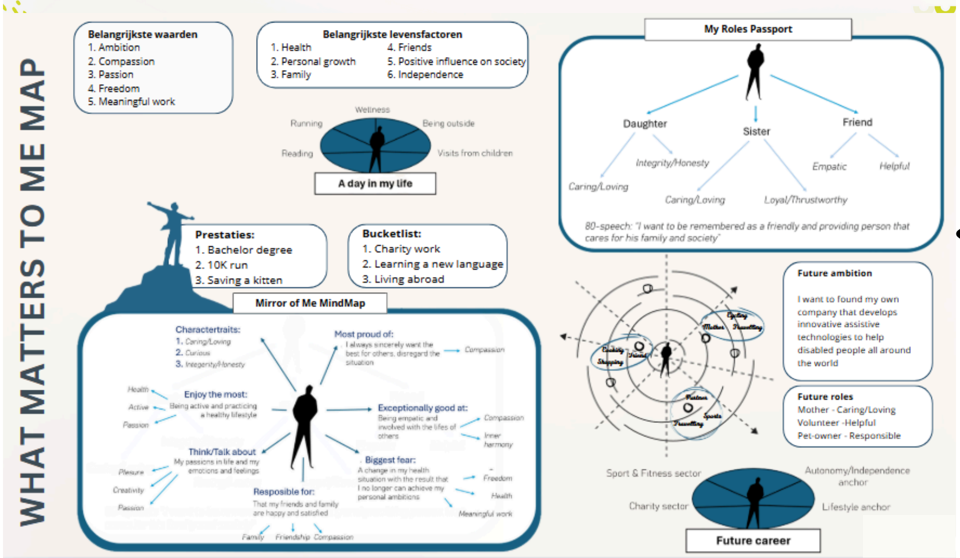
15.1 Objective design part 2

What: The second design part focuses on (1) effective interdisciplinary goal-setting by standardized documentation providing overview for the patient and all health care providers, and (2) the linking of personal goals to patient reported outcome measurements (PROMs).

Why: It was indicated during patient interviews, that the goals a patient is working towards with different health care providers are sometimes conflicting (patient interviews, see chapter 4 and 5). *"In Raboud there was a lot of miscommunication and disagreement about the care I should receive. The health care professionals had different opinions and gave me conflicting advice" (Patient interview 6).* The tool supports effective interdisciplinary care provision by standardized documentation of personal goals. The tool provides an overview of all health care providers a patient is in contact with, and the goals they work towards. This ensures that health care providers can align their care and advice. It prevents that the goals they work towards with the patient contradict. Effective interdisciplinary care provision eliminates most of the organizational barriers of PCVBHC. The personal goals documented are (where possible) linked to patient reported outcome measurements (PROMs), this combines the principles of PeCHC and VBHC. Based on the personal goals health care providers can choose care processes and structures that match or support those goals, within the constraints of limited resources. This structure is exactly what PCVBHC is trying to facilitate.

How: In this part multiple aspects can be found that contributed to the creation and standardized documentation of the customized care plan.
(1) The 'WMTM'-dossier is presented in the beginning of the customized care plan, since this information is fundamental for the creation of personal goals.
(2) The tool provides an overview of all personal goals (overarching and subgoals) a patient works on with the different health care providers. Personal goals should align with what matters to this person, and can be adjusted, created or eliminated at any time. Standardized documentation of personal goals facilitates effective interdisciplinary collaboration and avoids contradicting goals between health care providers. The subgoals are documented in relation to a health care provider, to the overarching goal it supports and to a specific PROMs (problem) area it aims to improve.
(3) This part also contains patient reported outcome measurements (PROMs) data and shows which personal goals contribute to the different PROMs areas. The PROMs used were specially selected to be suitable for the trauma care domain. Regular measurements ensure continued patient involvement and evaluation.
(4) The provider map gives an overview of all the health care providers a patient is working with.
(5) Finally, an agenda is included where a patient can see his different appointments and is reminded to regularly do a new PROMs measurement.

15.2 User navigation



Belangrijkste waarden
1. Ambition
2. Compassion
3. Passion
4. Freedom
5. Meaningful work

Belangrijkste levensfactoren
1. Health
2. Personal growth
3. Family
4. Friends
5. Positive influence on society
6. Independence

Prestaties:
1. Bachelor degree
2. 10K run
3. Saving a kitten

Bucketlist:
1. Charity work
2. Learning a new language
3. Living abroad

Charactertraits:
1. Caring/Loving
2. Curious
3. Integerity/Honesty

Most proud of: I always sincerely want the best for others, disregard the situation → Compassion

Enjoy the most: Being active and practicing a healthy lifestyle → Health, Active, Passion

Exceptionally good at: Being empatic and involved with the lifes of others → Compassion, Inner harmony

Think/Talk about My passions in life and my emotions and feelings → Pleasure, Creativity, Passion

Biggest fear: A change in my health situation with the result that I no longer can achieve my personal ambitions → Freedom, Health, Meaningful work

Resposible for: That my friends and family are happy and satisfied → Family, Friendship, Compassion

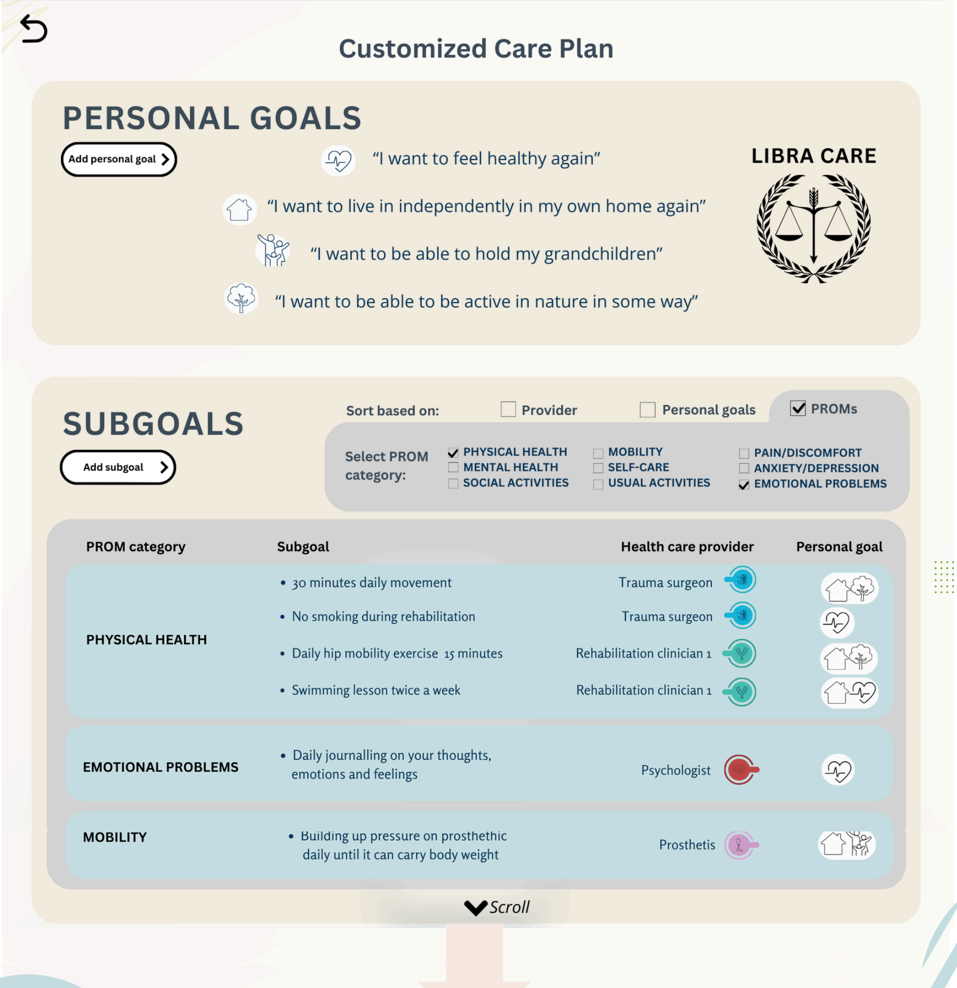
80-speech: "I want to be remembered as a friendly and providing person that cares for his family and society"

Future ambition

I want to found my own company that develops innovative assistive technologies to help disabled people all around the world

Future roles
Mother - Caring/Loving
Volunteer -Helpful
Pet-owner - Responsible

Since the elicited personal information of the patient is fundamental for the creation of personal goals, the 'WMTM'-dossier is presented in the beginning of the customized care plan.



The personal overarching- and subgoals are documented

Customized Care Plan

PERSONAL GOALS

Add personal goal ›

"I want to feel healthy again"

"I want to live in independently in my own home again"

"I want to be able to hold my grandchildren"

"I want to be able to be active in nature in some way"

All personal subgoals are documented within the tool in relation to the health care provider, PROMs and overarching goal(s).

SUBGOALS

Add subgoal ›

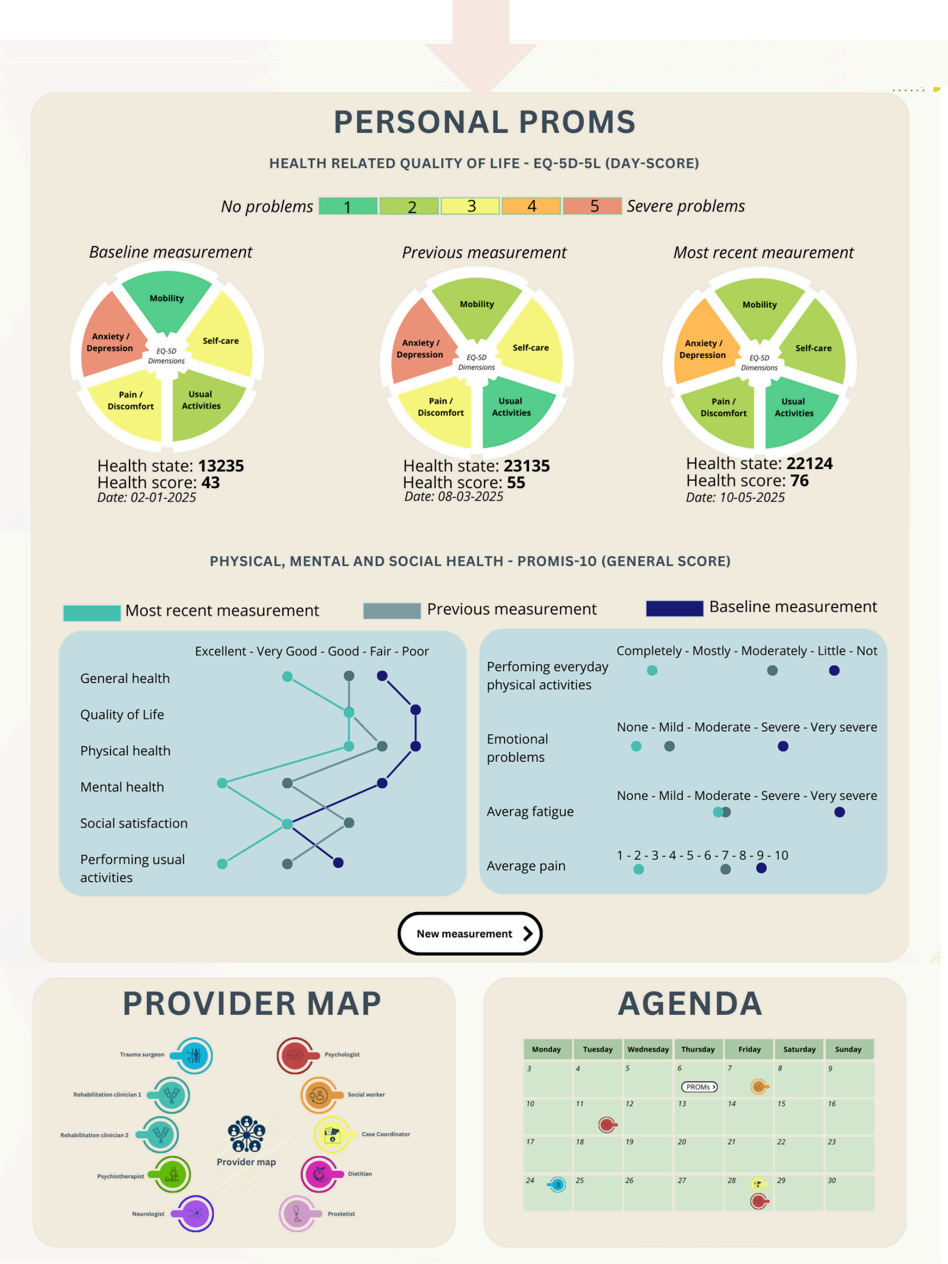
Sort based on: ☐ Provider ☐ Personal goals ☑ PROMs

Select PROM category:
☑ PHYSICAL HEALTH
☐ MENTAL HEALTH
☐ SOCIAL ACTIVITIES
☐ MOBILITY
☐ SELF-CARE
☐ USUAL ACTIVITIES
☐ PAIN/DISCOMFORT
☐ ANXIETY/DEPRESSION
☑ EMOTIONAL PROBLEMS

PROM category	Subgoal	Health care provider	Personal goal
PHYSICAL HEALTH	• 30 minutes daily movement	Trauma surgeon	🏠 🌳
	• No smoking during rehabilitation	Trauma surgeon	♡
	• Daily hip mobility exercise 15 minutes	Rehabilitation clinician 1	🏠 🌳
	• Swimming lesson twice a week	Rehabilitation clinician 1	🏠 ♡
EMOTIONAL PROBLEMS	• Daily journalling on your thoughts, emotions and feelings	Psychologist	♡
MOBILITY	• Building up pressure on prosthethic daily until it can carry body weight	Prosthetis	🏠 👪

Scroll

Continues on next page



Health state: **13235**
Health score: **43**
Date: 02-01-2025

Health state: **23135**
Health score: **55**
Date: 08-03-2025

Health state: **22124**
Health score: **76**
Date: 10-05-2025

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

Patient Reported Outcome Measures (PROMs) are tracked and the progress is visualized. The visual output of the PROMs directly shows health care providers the current state and problem areas of the patient's health (and quality of life) as well as their progress over time.

Overview of all the health care providers who are treating the patient

Overview of the scheduled appointments

Figure 24: User navigation 'Customized care plan' part of the tool
Note: arrow means that the user has to click to reach the next frame. Otherwise the user can just scroll down.

15.3 Patient Reported Outcome Measurements (PROMs) - Input

Patient-reported outcome measures (PROMs) capture a person's perception of their own health through questionnaires. They enable patients to report on their quality of life, daily functioning, symptoms, and other aspects of their health and well-being (Australian Commission On Safety And Quality in Health Care, z.d.). PROMs can be used to incorporate patients' perceptions of their health and medical condition within the care pathway (Field et al., 2019). PROMs support person-centred and value-based care by providing a way of measuring health outcomes from the patient's perspective. Within PCVBHC the personal goals of a patient are linked to PROMs, to create a customized care plan that aligns with what matters to this person (Kidanemariam, 2025).

PROMs in the Libra Care Tool

To measure PROMs, a patient is regularly (once every three months) asked by the tool to fill in the EQ-5D-5L questionnaire in combination with the PROMIS-10 questionnaire (see Figure 25 & 26). This combination of questionnaires was selected after consultation with a member of a project group, that is occupied with establishing a validated PROMs-questionnaire specially formulated for trauma care (in person discussion, February 2025). Both questionnaires are used by the project group as input for the trauma PROMs selection, and are therefore regarded as suitable for the documentation of progress in trauma rehabilitation. The EQ-5D-5L questionnaire and PROMIS-10 questionnaire were selected over other questionnaires, since they touch upon the most relevant aspects of trauma rehabilitation. The combination of both questionnaires ensures all relevant domains are covered (EQ-5D-5L focus on health status today and PROMIS-10 focuses on health status in general, also paying attention to mental health, social activities and emotional problems). This combination was regarded as the most effective and least demanding way of collecting PROMs, while compiling with the goal of showing an individual’s progress and problem areas regarding their self perceived health. Since we focus on individual care pathways, we do not include the comparison of outcomes to national standards, as is commonly done to make conclusions about populations or health services (EuroQol Research Foundation- EQ-5D-5L user guide).

During first use of the tool, the patient is asked to fill in the baseline PROMs measurements, that will be updated regularly. Within the tool the person can find an agenda, including his upcoming appointments with health care providers and the moments a new PROMs measurement is recommended (see Figure 24). Every three months the person receives a reminder to do a new PROMs measurement. This ensures that the PROMs data is updated in time, and always accurate during consultations.

PROMS QUESTIONNAIRE

Part 1: EQ-5D-5L (score today)

PLEASE RATE YOUR SITUATION TODAY!

Mobility

☐ I have no problems in walking about
☐ I have slight problems in walking about
☐ I have moderate problems in walking about
☐ I have severe problems in walking about
I am unable to walk about

☐

☐ **SELF-CARE**
☐ I have no problems washing or dressing
☐ myself
☐ I have slight problems wahing or dressing
myself
☐ I have moderate problems washing or
☐ dressing myself
☐ I have sever problems washing or dressing
☐ myself
☐ I am unable to wash or dress myself

☐ **USUAL ACTIVITIES**
I have no problems doing my usual activities
I have slight problems doing my usual activities
I have moderate problems doing my usual activities
I have severe problems doing my usual activities
I am unable to do my usual activities

PAIN/DISCOMFORT
I have no pain or discomfort
I have slight pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

ANXIETY/DEPRESSION
I am not anxious or depressed
I am slightly anxious or drepressed
I am moderate anxious or depressed
I am severly anxious or depressed
I am extremely anxious or depressed

Finally, rate your health TODAY on a scale from 0-100 (see scale on the right)
0 = worst health you can imagine
100 = best health you can imagine

Place an X on the scale to indicate your health TODAY
Write the number you marked on the scale in the box below:

SCORE:

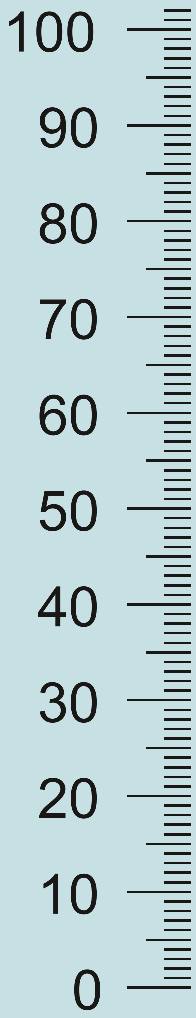
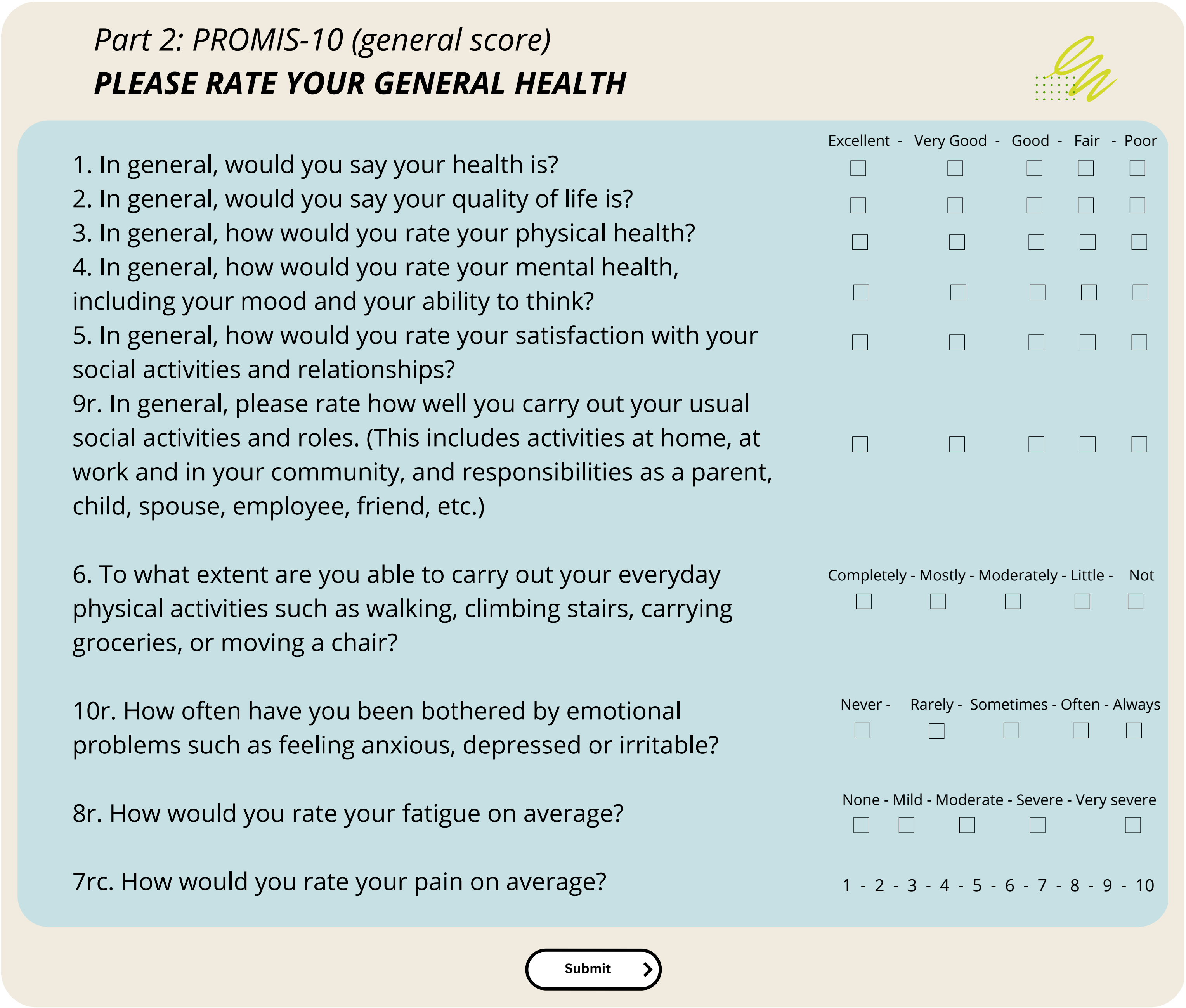


Figure 25: PROMS questionnaire (1/2) - EQ-5D-5L



Part 2: PROMIS-10 (general score)

PLEASE RATE YOUR GENERAL HEALTH

	Excellent -	Very Good -	Good -	Fair -	Poor
1. In general, would you say your health is?	☐	☐	☐	☐	☐
2. In general, would you say your quality of life is?	☐	☐	☐	☐	☐
3. In general, how would you rate your physical health?	☐	☐	☐	☐	☐
4. In general, how would you rate your mental health, including your mood and your ability to think?	☐	☐	☐	☐	☐
5. In general, how would you rate your satisfaction with your social activities and relationships?	☐	☐	☐	☐	☐
9r. In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)	☐	☐	☐	☐	☐

	Completely -	Mostly -	Moderately -	Little -	Not
6. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	☐	☐	☐	☐	☐

	Never -	Rarely -	Sometimes -	Often -	Always
10r. How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	☐	☐	☐	☐	☐

	None -	Mild -	Moderate -	Severe -	Very severe
8r. How would you rate your fatigue on average?	☐	☐	☐	☐	☐

7rc. How would you rate your pain on average? 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10

Figure 26: PROMS questionnaire (2/2) - PROMIS-10

15.4 Patient Reported Outcome Measurements (PROMs) - Output

In the figure below the output of the EQ-5D-5L questionnaire is visualized. The five different areas (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) have all been contributed a score between 1 (no problems) and 5 (severe problems), visualised by a colour code. The 'Health state' is the enumeration of the five different scores, it is a code that most health care providers are familiar with (EuroQol Research Foundation- EQ-5D-5L user guide). The 'Health Score' is the self-attributed score of the patient's health today. The frame consists of three visual measurement scores: the baseline measurement, the previous measurement and the most recent measurement. The color of the different areas directly and visually show problem areas and progress over time. The PROMs output is used during consultation.

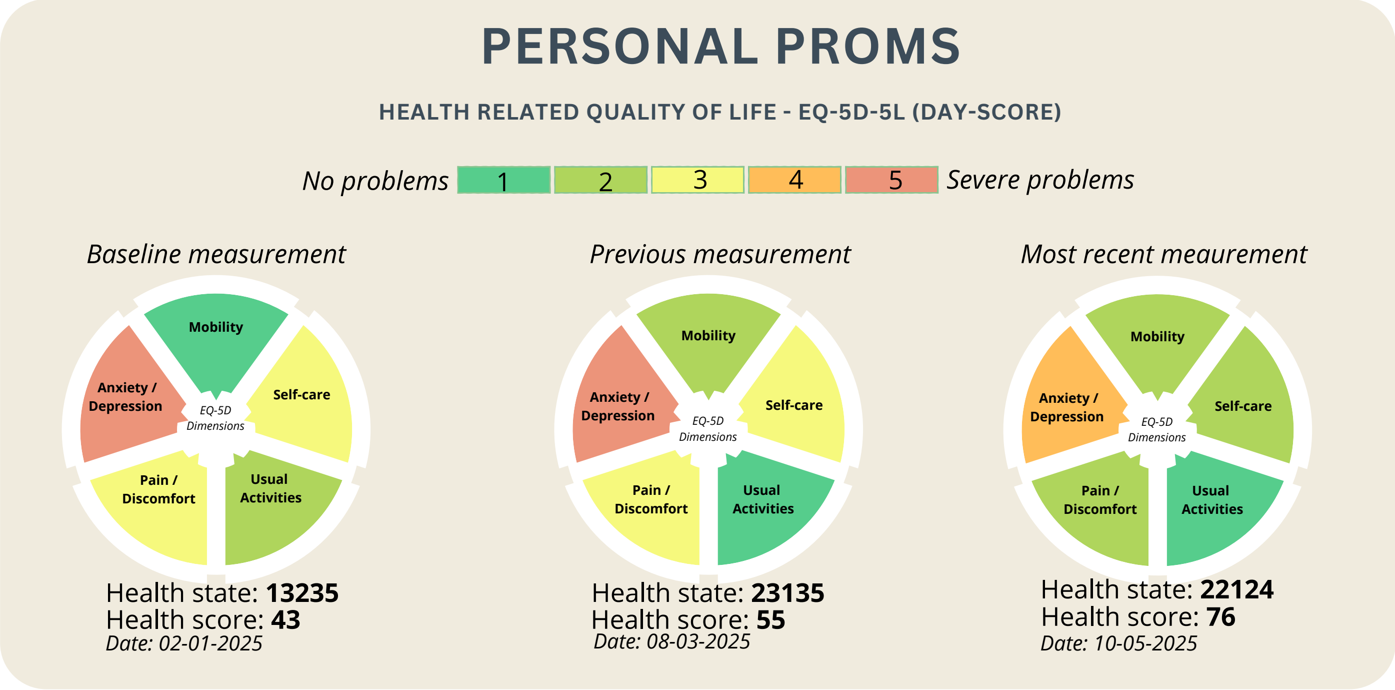


Figure 27: Visualized PROM output Q-5D-5L

In this frame the output of the PROMIS-10 questionnaire is visualised. The 10 different areas (general health, quality of life, physical health, mental health, social satisfaction, performing usual activities, performing everyday physical activities, emotional problems, average fatigue and average pain) have three different measurement scores: the baseline measurement, the previous measurement and the most recent measurement. This visual representation directly shows problem areas and progress over time. The PROMs output is used during consultation.

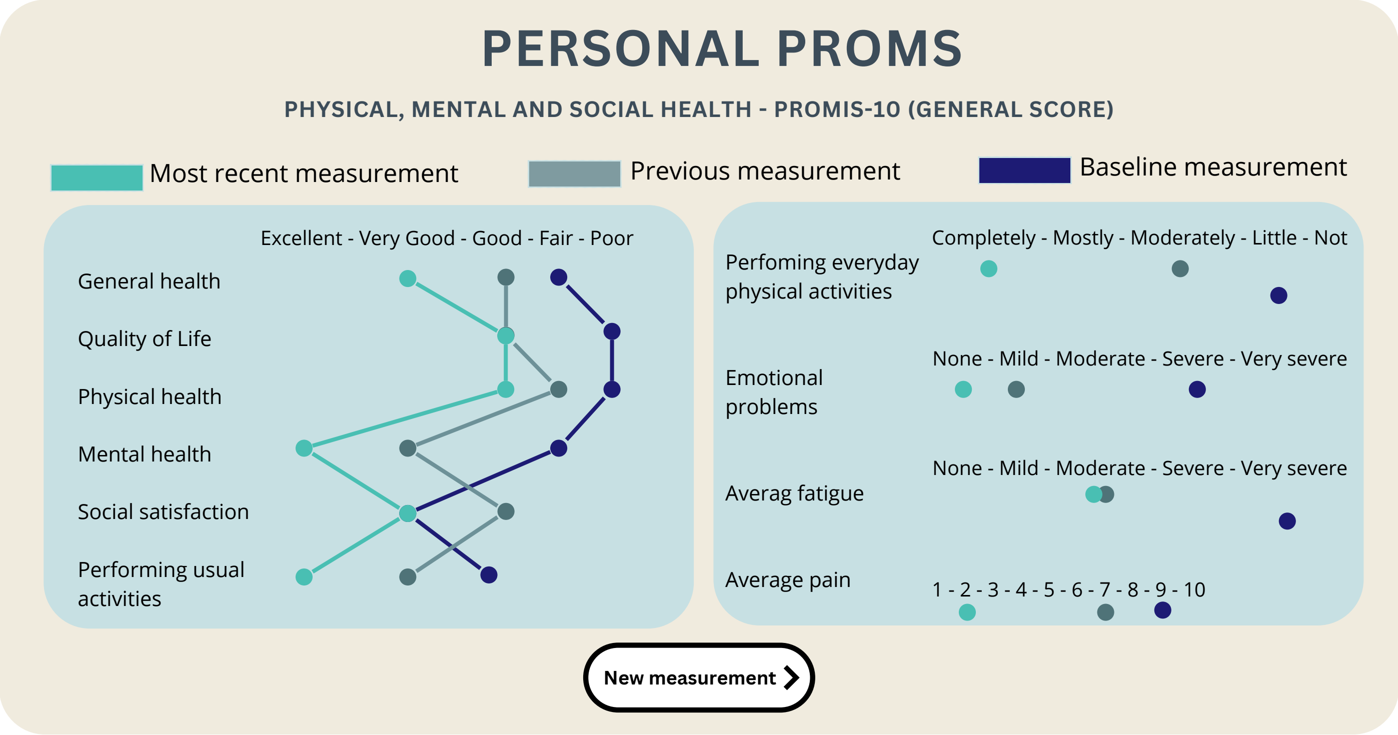


Figure 28: Visualized PROM output PROMIS-10

15.5 Personal goals

A rehabilitation patient receives care from different health care providers. Together, the patient and health care providers set personal goals they want to work towards. For goal-setting to be effective, patients must be informed about their health condition, prognosis, and the different treatment options (Srur et al., 2024). Goals should be divided into overarching goals and subgoals to make them easier to measure and evaluate. It is important to note that goal-setting and goal-evaluation is an iterative and reflective process. Goals can be redefined or adjusted if necessary, since goals can vary with life and health changes (Srur et al., 2024).

- **Overarching goals:** Overarching goals touch the broader aspects of life that matter to the patient, for example: *'I want to live in my own home for as long as possible'*
- **Subgoals:** Subgoals are more concrete and support the overarching goals. Preferably, they should be formulated in a way that is specific, measurable, actionable, realistic and time bound (SMART) (Llewellyn-Thomas & Crump, 2012). For example: *'I need to be able to get out of a chair without falling over'*

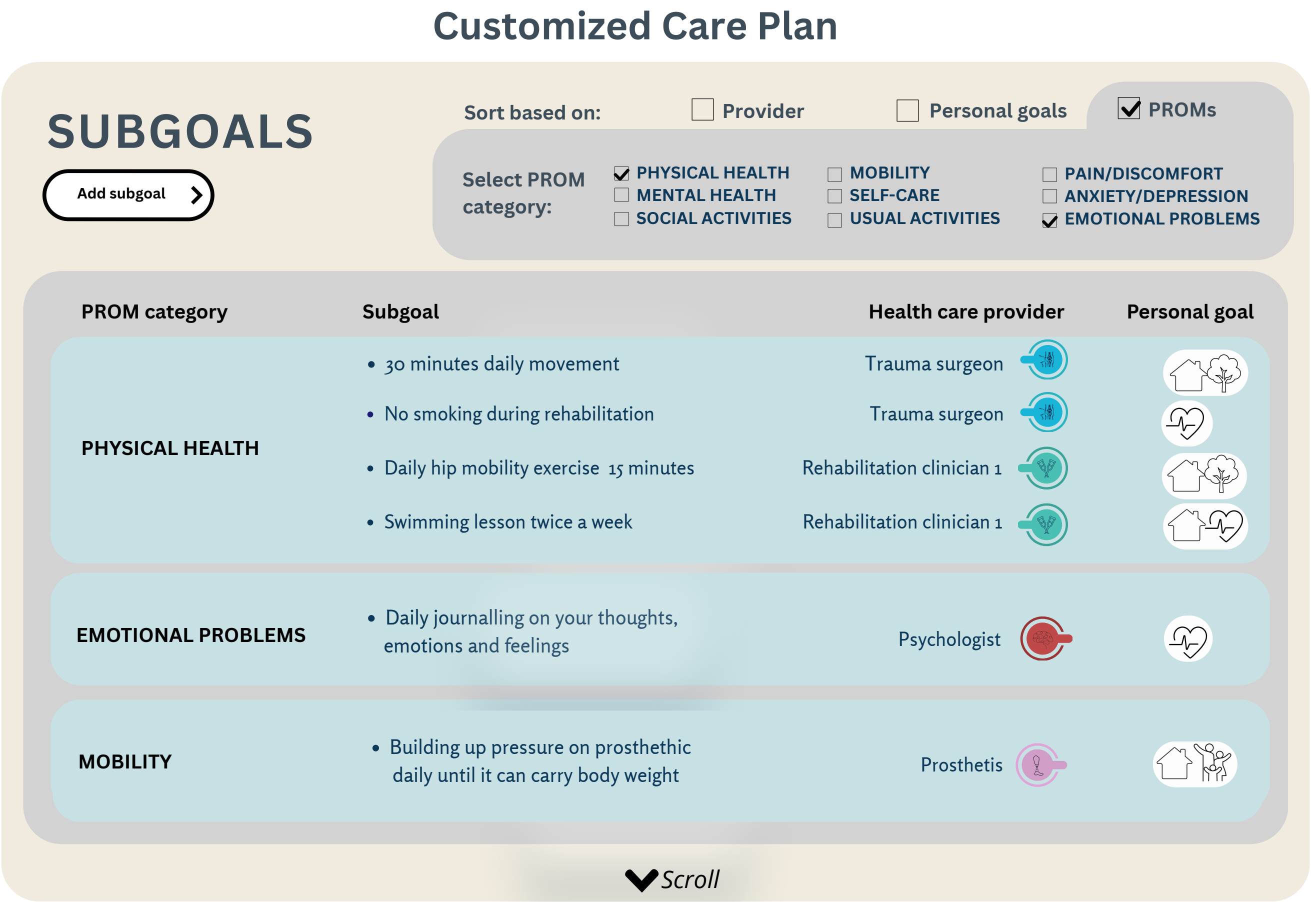
During consultation the goal-setting should be supported by the 'What matters to me'-dossier and the most recent PROMs data. The 'What matters to me'-dossier, explained in chapter 14, supports the creation of personal goals that align with what really matters to this person. Personal goals assist the development of customized care plans and support people receiving care to maintain a sense of purpose and control (Srur et al., 2024).

The visual output of the PROMs directly show the patient's current health state and problem areas, as well as their progress over time. Based on this information, personal goals can be adjusted, eliminated or new goals can be added that target a problem area. New personal goals should target the patient reported problem areas. Depending on the problem area, different health care providers can be involved in the care pathway. The tool provides an overview of all the personal goals a patient works towards with different health care providers, documented in a standardized manner. This ensures that the different health care providers can align their care and advice, and prevents the goals they work towards contradict. Standardized documentation is needed to facilitate effective interdisciplinary collaboration.

All personal goals (established during consultation) are documented within the tool, as well as the PROMs area(s) they target. This way the tool provides an overview of all the goals a patient works toward with different health care providers, as well as which PROM areas those goals support (and this is how the goals eventually contribute to the patient's quality of life).

Linking personal goals to patient reported outcome measurements (PROMs) is the fundament of PCVBHC. The tool helps both patients and health care providers to make the care pathway both person-centred and value-based, while simultaneously contributing to effective interdisciplinary collaboration. With this strategy, a customized care plan can be created with the highest value for the patient, and that is the goal of Libra Care.

Within the 'Personal goals' and 'Subgoals' sections of the tool, an overview can be found of a patient's overarching goals (based on 'What matters to me'-dossier) and subgoals (based on overarching goals and PROMs). All subgoals are documented in relation to the associated health care provider, and in relation to the overarching goal and PROMs they support (see Figure 29).



Customized Care Plan

SUBGOALS

Sort based on: ☐ Provider ☐ Personal goals ☑ PROMs

Select PROM category:

☑ PHYSICAL HEALTH	☐ MOBILITY	☐ PAIN/DISCOMFORT
☐ MENTAL HEALTH	☐ SELF-CARE	☐ ANXIETY/DEPRESSION
☐ SOCIAL ACTIVITIES	☐ USUAL ACTIVITIES	☑ EMOTIONAL PROBLEMS

PROM category	Subgoal	Health care provider	Personal goal
PHYSICAL HEALTH	• 30 minutes daily movement	Trauma surgeon	
	• No smoking during rehabilitation	Trauma surgeon	
	• Daily hip mobility exercise 15 minutes	Rehabilitation clinician 1	
	• Swimming lesson twice a week	Rehabilitation clinician 1	
EMOTIONAL PROBLEMS	• Daily journalling on your thoughts, emotions and feelings	Psychologist	
MOBILITY	• Building up pressure on prosthethic daily until it can carry body weight	Prosthetis	

Figure 29: Personal overarching- and subgoals documented within the tool. The subgoals can be sorted on provider, personal goals (overarching) they support or PROMs they are linked to.

BEFORE YOU LEAVE...

Document! Who are you working with today?

Document this consultation:

Libra Care is used during consultation between the patient and the health care provider. When the tool is closed, a pop-up will arise, stimulating the documentation of new goals (or adjusting old goals) in a standardized manner. This way, the patient and all the health care providers have an overview of all the goals a patient is working towards with different health care providers.

Figure 30: Pop-up notification

Chapter 16: Design part 3 - Coping tool that helps patients with acceptance

In this chapter the functionalities of the tool that relate to the goal '*to help patients with acceptance'* are described. This goal is a result of PCVBHC, and was suggested during patient interviews. When discussing the design of a trauma rehabilitation tool with patients, they all estimated that it would be valuable for such a tool to also focus on quality of life and the possibility to learn from the experiences and coping strategies of others.

16.1 Objective design part 3

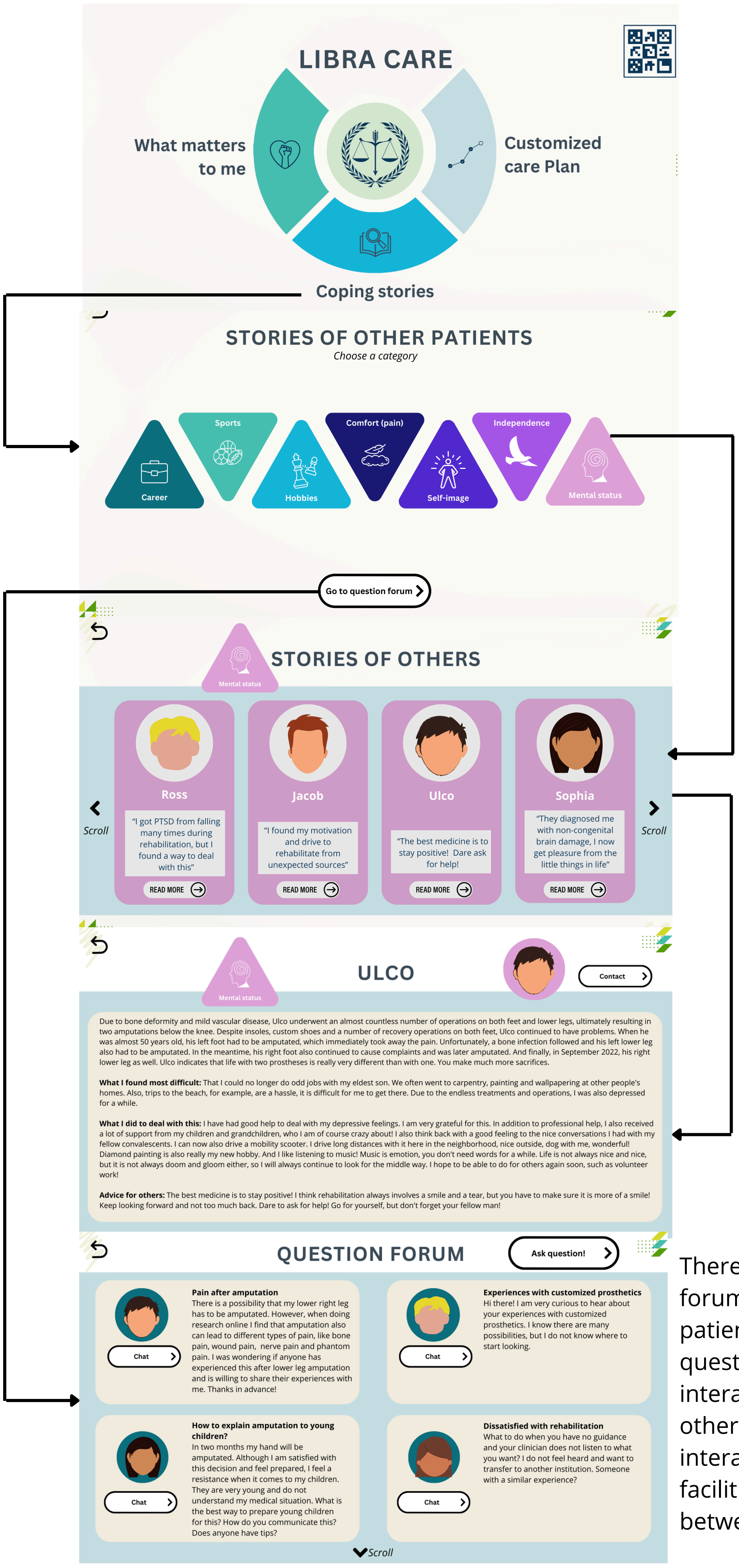
What: The third design part of the tool supports patients in coping with and accepting their new situation. This is done by letting them focus on what they can still do, instead of on what is no longer possible. They also learn about the experiences and coping strategies of other trauma patients. Finally, the tool provides the opportunity to patients to support each other.

Why: Patients inidcated that a tool should not only support the medical care pathway, but also contribute to coping and acceptance, as this also makes an essential contribution to the quality of life. In addition, learning from the experiences of others can give patients more control over their own care pathway, because they become familiar with different possibilities in terms of interventions and tools. This also prevents patients from experiencing the same mistakes in the care pathway. By becoming familiar with different possibilities, a patient can take a more active role in shared decision-making, which contributes to PCVBHC.

How: It is important to mention that both design parts 1 and 2 contribute to helping patients with acceptance. The 'Life Compass' exercise and the 'What matters to me' dossier (design part 1) help patients to realize that most things that are important to them will still be possible even in their new condition. The exercise helps the patient to elicit all aspects that are important in their life. This makes it easier for the patient to focus on the things they still can do, instead of only focusing on their losses. Personal goal-setting focuses on what is still possible for the patient (or could be possible in the future) (design part 2). Furthermore, the tool will help patients to explore the experiences and coping strategies of other patients. And therefore, it helps patients to find ways to mitigate or compensate the losses they experience. The tool will help them to realize that quality of life can be achieved in many ways, and that their losses can often be mitigated or compensated. Finally, the tool provides the opportunity to patients to support each other within an interactive forum.

During multiple patient interviews, it was stated that patients would find it valuable if they could learn from the experiences and coping strategies of other trauma patients. *"If I had the opportunity to learn from the experiences of others, I would probably have been spared a lot of suffering and would have realized more quickly that my situation was unacceptable."* (Patient 6). Patients indicated that learning from the experiences of other patients would contribute to their own experience and acceptance of their new situation. Therefore, this functionality was included in the tool. After consultation with the Military Rehabilitation Center Aardenburg, it was decided not to focus on similarities of trauma, but on coping strategies (in person, discussion, December 2024). The main reason for this, is that when you compare the experiences of patients based on medical conditions, it becomes tempting for the patient to predict their own situation based on the progress of someone else with a similar trauma. This can lead to them estimating their situation much gloomier than it actually is. But, it is even more damaging if they cling to medical success stories. Trauma is very complex and every trauma is unique, which is why rehabilitation clinicians recommend not to focus on the medical story, but on the coping strategies a patient uses to compensate for or accept losses.

16.2 User navigation



"I got PTSD from falling many times during rehabilitation, but I found a way to deal with this"

"I found my motivation and drive to rehabilitate from unexpected sources"

"The best medicine is to stay positive! Dare ask for help!

"They diagnosed me with non-congenital brain damage, I now get pleasure from the little things in life"

Due to bone deformity and mild vascular disease, Ulco underwent an almost countless number of operations on both feet and lower legs, ultimately resulting in two amputations below the knee. Despite insoles, custom shoes and a number of recovery operations on both feet, Ulco continued to have problems. When he was almost 50 years old, his left foot had to be amputated, which immediately took away the pain. Unfortunately, a bone infection followed and his left lower leg also had to be amputated. In the meantime, his right foot also continued to cause complaints and was later amputated. And finally, in September 2022, his right lower leg as well. Ulco indicates that life with two prostheses is really very different than with one. You make much more sacrifices.

What I found most difficult: That I could no longer do odd jobs with my eldest son. We often went to carpentry, painting and wallpapering at other people's homes. Also, trips to the beach, for example, are a hassle, it is difficult for me to get there. Due to the endless treatments and operations, I was also depressed for a while.

What I did to deal with this: I have had good help to deal with my depressive feelings. I am very grateful for this. In addition to professional help, I also received a lot of support from my children and grandchildren, who I am of course crazy about! I also think back with a good feeling to the nice conversations I had with my fellow convalescents. I can now also drive a mobility scooter. I drive long distances with it here in the neighborhood, nice outside, dog with me, wonderful! Diamond painting is also really my new hobby. And I like listening to music! Music is emotion, you don't need words for a while. Life is not always nice and nice, but it is not always doom and gloom either, so I will always continue to look for the middle way. I hope to be able to do for others again soon, such as volunteer work!

Advice for others: The best medicine is to stay positive! I think rehabilitation always involves a smile and a tear, but you have to make sure it is more of a smile! Keep looking forward and not too much back. Dare to ask for help! Go for yourself, but don't forget your fellow man!

Pain after amputation
There is a possibility that my lower right leg has to be amputated. However, when doing research online I find that amputation also can lead to different types of pain, like bone pain, wound pain, nerve pain and phantom pain. I was wondering if anyone has experienced this after lower leg amputation and is willing to share their experiences with me. Thanks in advance!

Experiences with customized prosthetics
Hi there! I am very curious to hear about your experiences with customized prosthetics. I know there are many possibilities, but I do not know where to start looking.

How to explain amputation to young children?
In two months my hand will be amputated. Although I am satisfied with this decision and feel prepared, I feel a resistance when it comes to my children. They are very young and do not understand my medical situation. What is the best way to prepare young children for this? How do you communicate this? Does anyone have tips?

Dissatisfied with rehabilitation
What to do when you have no guidance and your clinician does not listen to what you want? I do not feel heard and want to transfer to another institution. Someone with a similar experience?

The catogories consist of aspects in which a patient can experience a loss. By selecting one of the catogories, multiple patient stories will appear.

Within an individual patient story, multiple aspects are touched upon: (1) medical situation, (2) most difficult part of the new situation, (3) coping strategies and (4) advice for others.

There is also a forum where patients can ask questions and interact with each other. This interactive forum facilitites support between patients.

Figure 31: User navigation tool 'coping stories' part
Note: arrow means that the user has to click to reach the next frame. Otherwise the user can just scroll down.

16.3 Stories of other patients

Within the tool, stories of other trauma patients can be found. As explained earlier, it was deliberately chosen not to focus on medical situation, but on what this patient has done to accept his new situation and to compensate his losses. That is why the stories are divided into 6 categories (see Figure 32). The categories consist of aspects in which the patient can experience a loss, for example no longer being able to perform his work, sport or hobby. Or the loss of comfort, for example due to a continuous pain experience. In addition, mental problems or the decrease in independence and/or self-image can also be experienced as a great loss. These categories were drawn up by analyzing multiple patient stories (KorterMaarKrachtiger, 2025). Within a category multiple patient stories can be found and selected to read (see Figure 33).

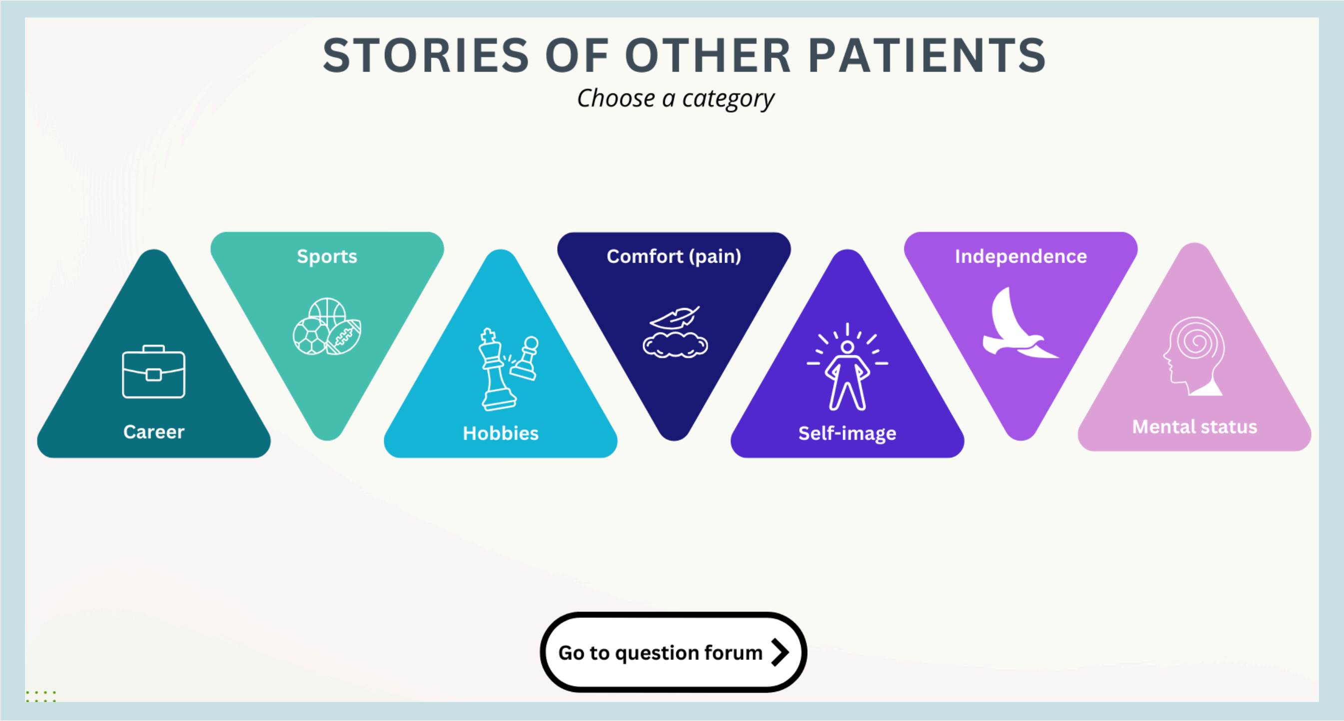
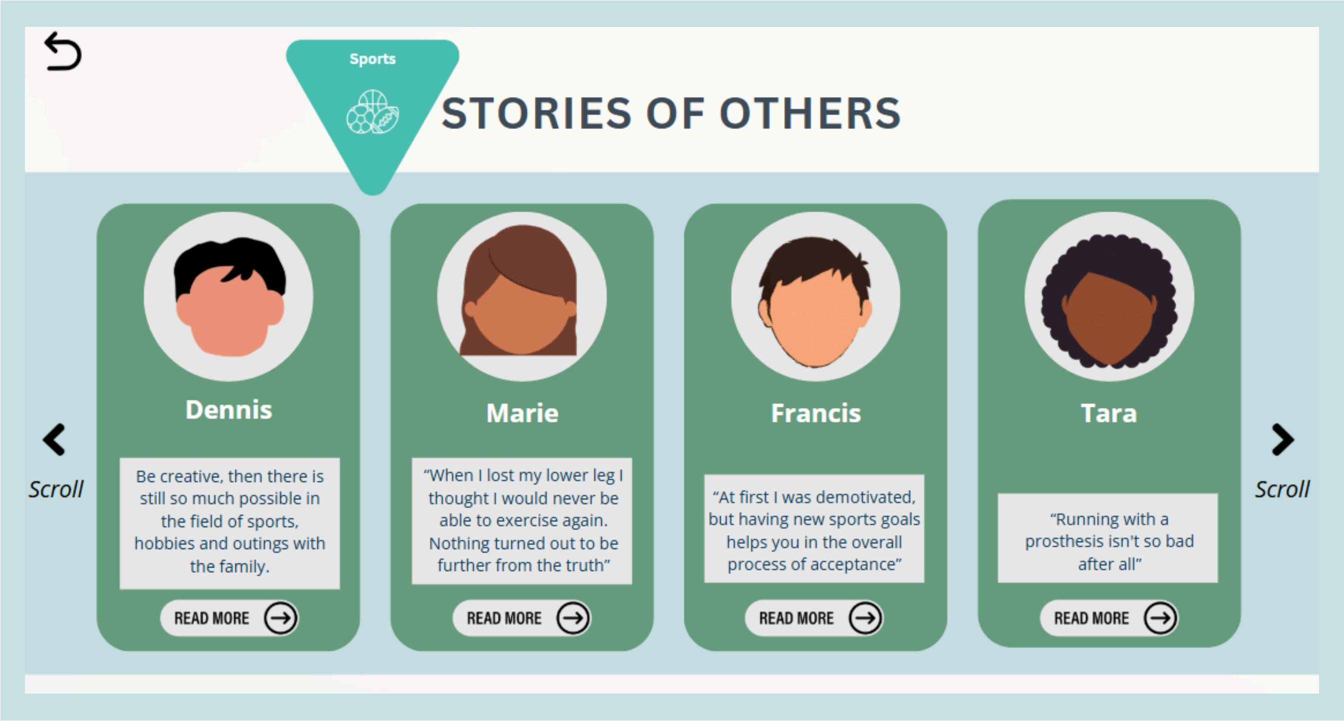


Figure 32: ‘Categories within the section ‘stories of other patients’’



Be creative, then there is still so much possible in the field of sports, hobbies and outings with the family.

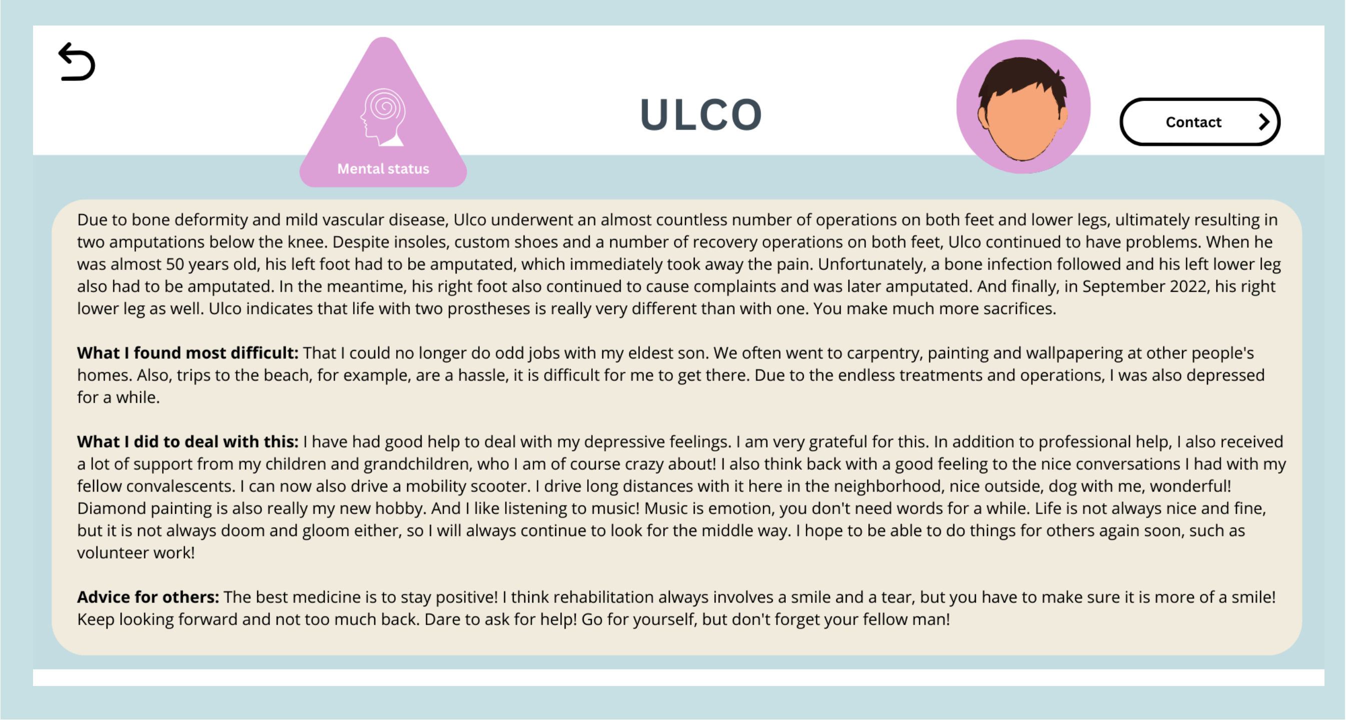
“When I lost my lower leg I thought I would never be able to exercise again. Nothing turned out to be further from the truth”

“At first I was demotivated, but having new sports goals helps you in the overall process of acceptance”

“Running with a prosthesis isn't so bad after all”

Figure 33: ‘Category sports - stories of other patients’

Within an individual patient story, multiple aspects are touched upon (see Figure 34 & 35). First, the medical situation is briefly explained. Then, the patient explains what he or she finds most difficult about his new situation. The patient explains what he or she has done to deal with this, or which coping strategies have been used. And finally, the patient gives advice to others. The stories used for the design concept of the tool are created based on the patient stories available on the website of the 'KorterMaarKrachtiger' foundation (KorterMaarKrachtiger, 2025). The original stories are modified, so only information relevant for the purpose of this project is presented. For more patient stories see Appendix K.



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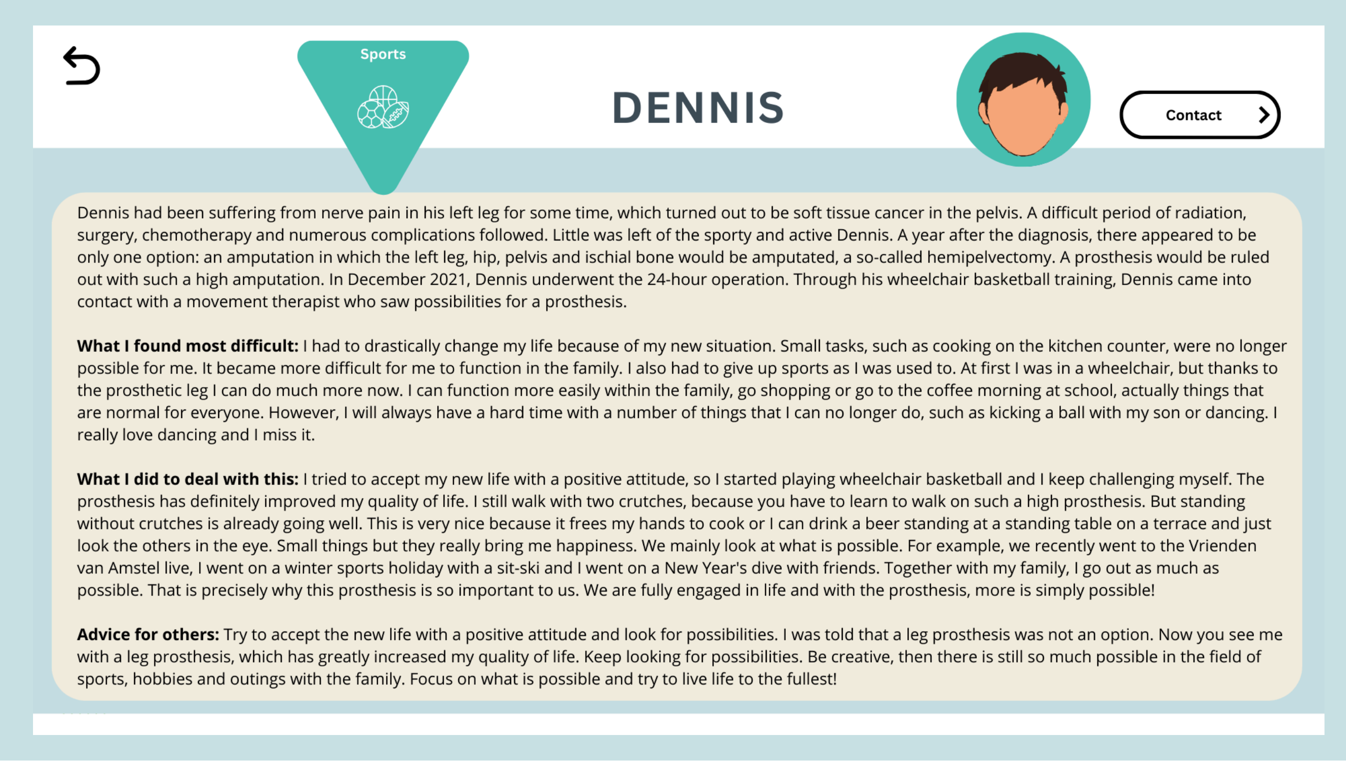
What I found most difficult: That I could no longer do odd jobs with my eldest son. We often went to carpentry, painting and wallpapering at other people's homes. Also, trips to the beach, for example, are a hassle, it is difficult for me to get there. Due to the endless treatments and operations, I was also depressed for a while.

What I did to deal with this: I have had good help to deal with my depressive feelings. I am very grateful for this. In addition to professional help, I also received a lot of support from my children and grandchildren, who I am of course crazy about! I also think back with a good feeling to the nice conversations I had with my fellow convalescents. I can now also drive a mobility scooter. I drive long distances with it here in the neighborhood, nice outside, dog with me, wonderful! Diamond painting is also really my new hobby. And I like listening to music! Music is emotion, you don't need words for a while. Life is not always nice and fine, but it is not always doom and gloom either, so I will always continue to look for the middle way. I hope to be able to do things for others again soon, such as volunteer work!

Advice for others: The best medicine is to stay positive! I think rehabilitation always involves a smile and a tear, but you have to make sure it is more of a smile! Keep looking forward and not too much back. Dare to ask for help! Go for yourself, but don't forget your fellow man!

Figure 34: Category 'mental state' story of Ulco



Dennis had been suffering from nerve pain in his left leg for some time, which turned out to be soft tissue cancer in the pelvis. A difficult period of radiation, surgery, chemotherapy and numerous complications followed. Little was left of the sporty and active Dennis. A year after the diagnosis, there appeared to be only one option: an amputation in which the left leg, hip, pelvis and ischial bone would be amputated, a so-called hemipelvectomy. A prosthesis would be ruled out with such a high amputation. In December 2021, Dennis underwent the 24-hour operation. Through his wheelchair basketball training, Dennis came into contact with a movement therapist who saw possibilities for a prosthesis.

What I found most difficult: I had to drastically change my life because of my new situation. Small tasks, such as cooking on the kitchen counter, were no longer possible for me. It became more difficult for me to function in the family. I also had to give up sports as I was used to. At first I was in a wheelchair, but thanks to the prosthetic leg I can do much more now. I can function more easily within the family, go shopping or go to the coffee morning at school, actually things that are normal for everyone. However, I will always have a hard time with a number of things that I can no longer do, such as kicking a ball with my son or dancing. I really love dancing and I miss it.

What I did to deal with this: I tried to accept my new life with a positive attitude, so I started playing wheelchair basketball and I keep challenging myself. The prosthesis has definitely improved my quality of life. I still walk with two crutches, because you have to learn to walk on such a high prosthesis. But standing without crutches is already going well. This is very nice because it frees my hands to cook or I can drink a beer standing at a standing table on a terrace and just look the others in the eye. Small things but they really bring me happiness. We mainly look at what is possible. For example, we recently went to the Vrienden van Amstel live, I went on a winter sports holiday with a sit-ski and I went on a New Year's dive with friends. Together with my family, I go out as much as possible. That is precisely why this prosthesis is so important to us. We are fully engaged in life and with the prosthesis, more is simply possible!

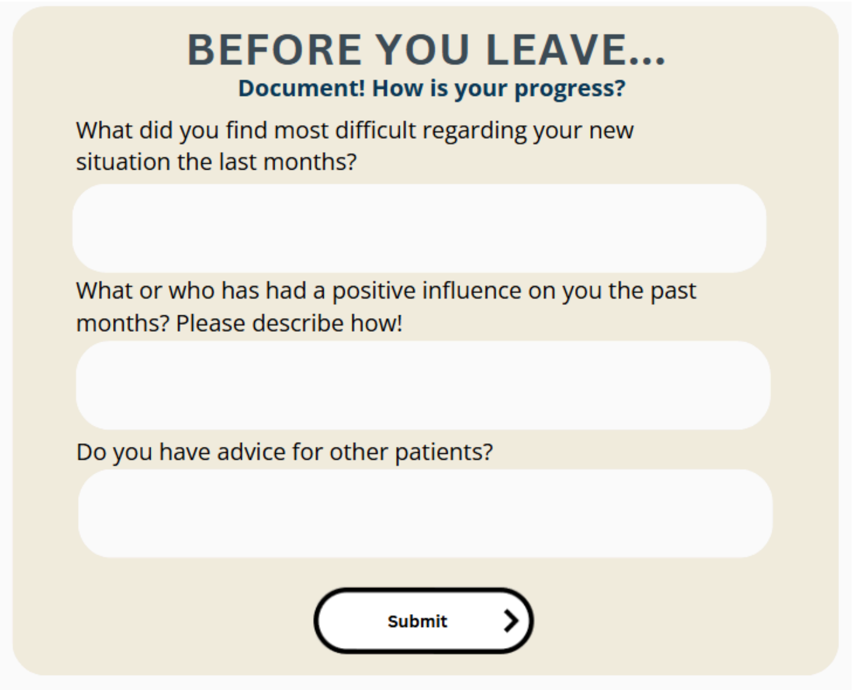
Advice for others: Try to accept the new life with a positive attitude and look for possibilities. I was told that a leg prosthesis was not an option. Now you see me with a leg prosthesis, which has greatly increased my quality of life. Keep looking for possibilities. Be creative, then there is still so much possible in the field of sports, hobbies and outings with the family. Focus on what is possible and try to live life to the fullest!

Figure 35: Category 'Sports' story of Dennis

16.4 How are new stories collected

As described before, the first stories were collected from the KorterMaarKrachtiger foundation website, and modified for this project (only relevant information was included). Libra Care will have a mechanism to collect new patient stories from patient-users over time.

Patients are regularly (once every three months) asked to do a new PROMs measurement, to measure progress over time and to identify problem areas (as explained in chapter 15). This measurement is designed to be accessible and quick to complete (total of 2-5 minutes). At the end of the measurement, the patient will be asked to answer a few open questions, about their experiences and progress. In the background, a personal experience blog is created with the provided answers.


BEFORE YOU LEAVE...

Document! How is your progress?

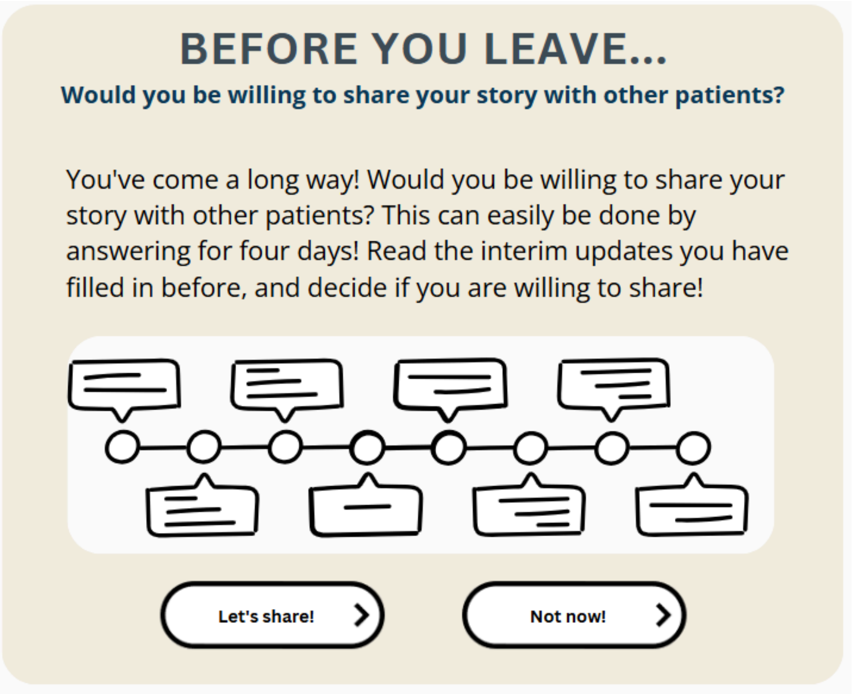
What did you find most difficult regarding your new situation the last months?

What or who has had a positive influence on you the past months? Please describe how!

Do you have advice for other patients?

Figure 36: Pop-up notification personal experience

After one year, the patient is asked if he is willing to share his/her own story on the platform. To make the writing of a story as easy as possible, a timeline is given with the given answers to the previously received open questions. The patient can then easily read back how he has assessed his process in the past, and this makes the writing of a personal story easier. The story will be written in a standardized manner, which also reduces the cognitive load of writing a story. The story is created by answering four questions: (1) shortly describe your medical situation and care process, (2) what did you find the most difficult regarding your new situation, (3) what did you do to deal with this, and (4) do you have any advice for others? The patient can decide not to share his story. In this case, the patient will be asked again after half a year.


BEFORE YOU LEAVE...

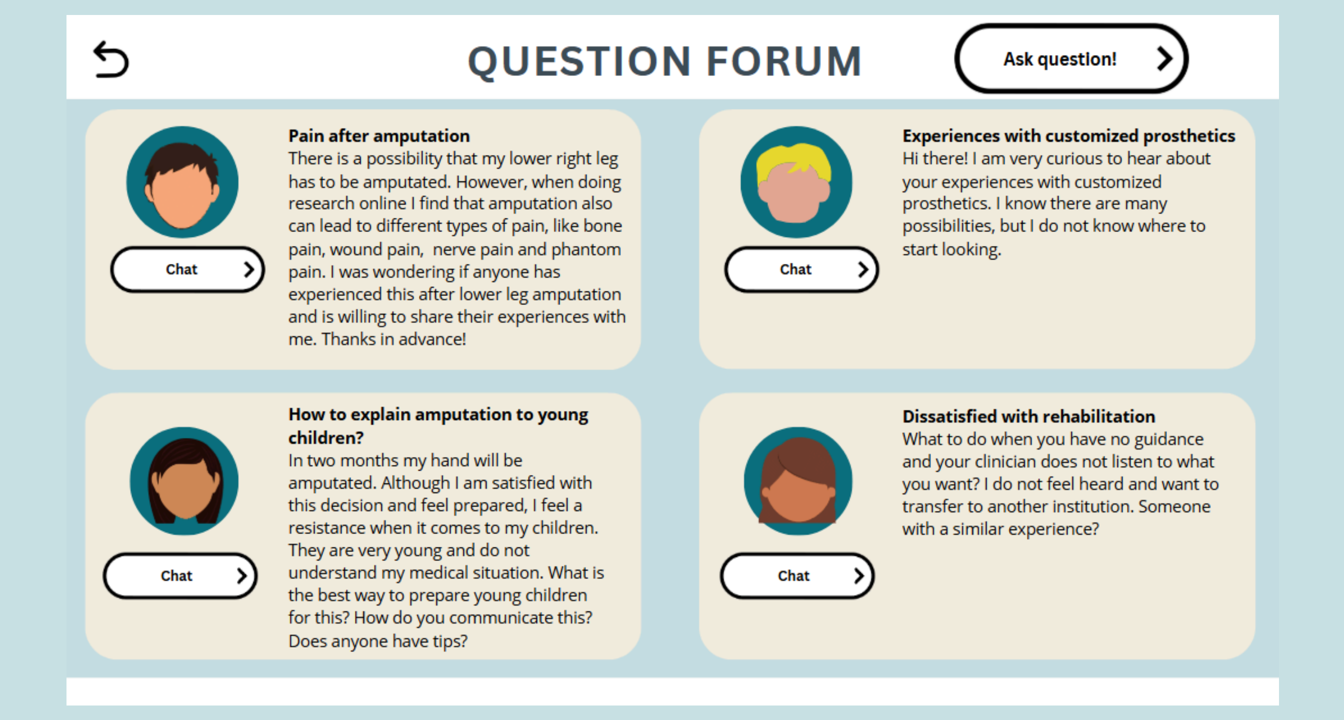
Would you be willing to share your story with other patients?

You've come a long way! Would you be willing to share your story with other patients? This can easily be done by answering for four days! Read the interim updates you have filled in before, and decide if you are willing to share!

Figure 37: Pop-up notification personal story

16.5 Interactive Forum

This part of the tool also includes an interactive forum. Patients have the possibility to ask questions or share concerns on this forum. Other patients will be notified if new threads are placed, and can decide to chat with this person to share their advice or experiences. Feeling supported and connected has been proven to support mental, physical, and emotional health, especially in times of stressful life challenges (Umberson & Montez, 2010; Yang et al., 2014). Strong social support may improve the capacity to cope with losses, since it helps to protect against the negative psychological and physiological responses to stress (Harrop et al., 2020). Online communities enable the exchange of knowledge and information. Participants can share their experiences, concerns, and emotions. It provides a safe space to express themselves and receive understanding and encouragement from others (Wu, B. 2020). Therefore, the forum contributes to the patients being able to accept their new situation.



Pain after amputation
There is a possibility that my lower right leg has to be amputated. However, when doing research online I find that amputation also can lead to different types of pain, like bone pain, wound pain, nerve pain and phantom pain. I was wondering if anyone has experienced this after lower leg amputation and is willing to share their experiences with me. Thanks in advance!

Experiences with customized prosthetics
Hi there! I am very curious to hear about your experiences with customized prosthetics. I know there are many possibilities, but I do not know where to start looking.

How to explain amputation to young children?
In two months my hand will be amputated. Although I am satisfied with this decision and feel prepared, I feel a resistance when it comes to my children. They are very young and do not understand my medical situation. What is the best way to prepare young children for this? How do you communicate this? Does anyone have tips?

Dissatisfied with rehabilitation
What to do when you have no guidance and your clinician does not listen to what you want? I do not feel heard and want to transfer to another institution. Someone with a similar experience?

Figure 38: Interactive patient forum

Chapter 17: Design conclusion

"Libra Care is an interactive tool that supports PCVBHC during trauma rehabilitation, by making patients more actively involved in the design of their customized care plan and by facilitating effective interdisciplinary goal-setting. Additionally, Libra Care helps patients with acceptance, as this makes an essential contribution to quality of life" (see Figure 39).

Libra care empowers patients to actively participate in the development of their customized care plan. Patients get a more active role in aligning care with what matters in their life, since they are the only one that can determine the value of various health outcomes. PCVBHC is achieved when the health care providers and the patient work together in balance to achieve the most person-centered and value-based outcome(s). Regular patient reported outcome measurements ensure continuous patient involvement and evaluation. Patient involvement supports individuals to maintain identity and feelings of purpose, which contribute to overall well-being (Eklund et al., 2018).

The tool that I designed uses a guided exercise in combination with generative techniques and mind-switching, to elicit latent values and the things that are important in the life of this person. The generated 'What matters to me'-dossier is the starting point for consultation with different health care providers. The information in the dossier supports expectation management, shared decision-making and personal goal-setting. It was indicated during patient interviews, that the goals a patient is working towards with different health care providers are sometimes conflicting. To overcome this, all goals a patient works towards with different health care providers are documented in relation to the overarching goal and PROMs they support. This ensures that health care providers can align their care and advice and it prevents that the goals they work towards with the patient contradict. The linking of personal goals to PROMs is fundamental for the concept of PCVBHC.

The information in the dossier can also be used by psycho-social workers to support conversations about acceptance, coping and adjusting to the new reality. The dossier helps to broaden a patient's perspective, by making them realize that most of what is important to them remains unaffected by the trauma injury. Personal goal-setting focuses on what is still possible for the patient (or could be possible in the future), providing motivation. Furthermore, the tool will help patients to explore the experiences and coping strategies of other patients, and therefore it helps patients to find ways to mitigate or compensate for the losses they experience. The tool will help them to realize that quality of life can be achieved in many ways, and that their losses can often be mitigated or compensated. Within the tool, patients can share their experiences, concerns, and emotions. Feeling supported and connected with other patients supports mental, physical and emotional health and it may improve the capacity to cope with losses.

‘WMTM’-dossier
The ‘WMTM’-dossier supports the patient in conveying what is important to him on a deeper level, including his most important values. This information is crucial to create a customized care plan that actually contributes to the quality of life of this person!

Personal PROMs
The patient can easily convey his self-perceived health by the visualized PROMs-outcomes within the Libra Care.

Patient input

Expert input

Consultation

Shared decision-making

Discuss overarching personal goals

Discuss personal subgoals

Find suitable health interventions or therapies

Health care preferences that allign with personal PROMs, values and goals

Customized Care Plan

LIBRA CARE

Standardized documentation within Libra Care
Overview for all health care providers

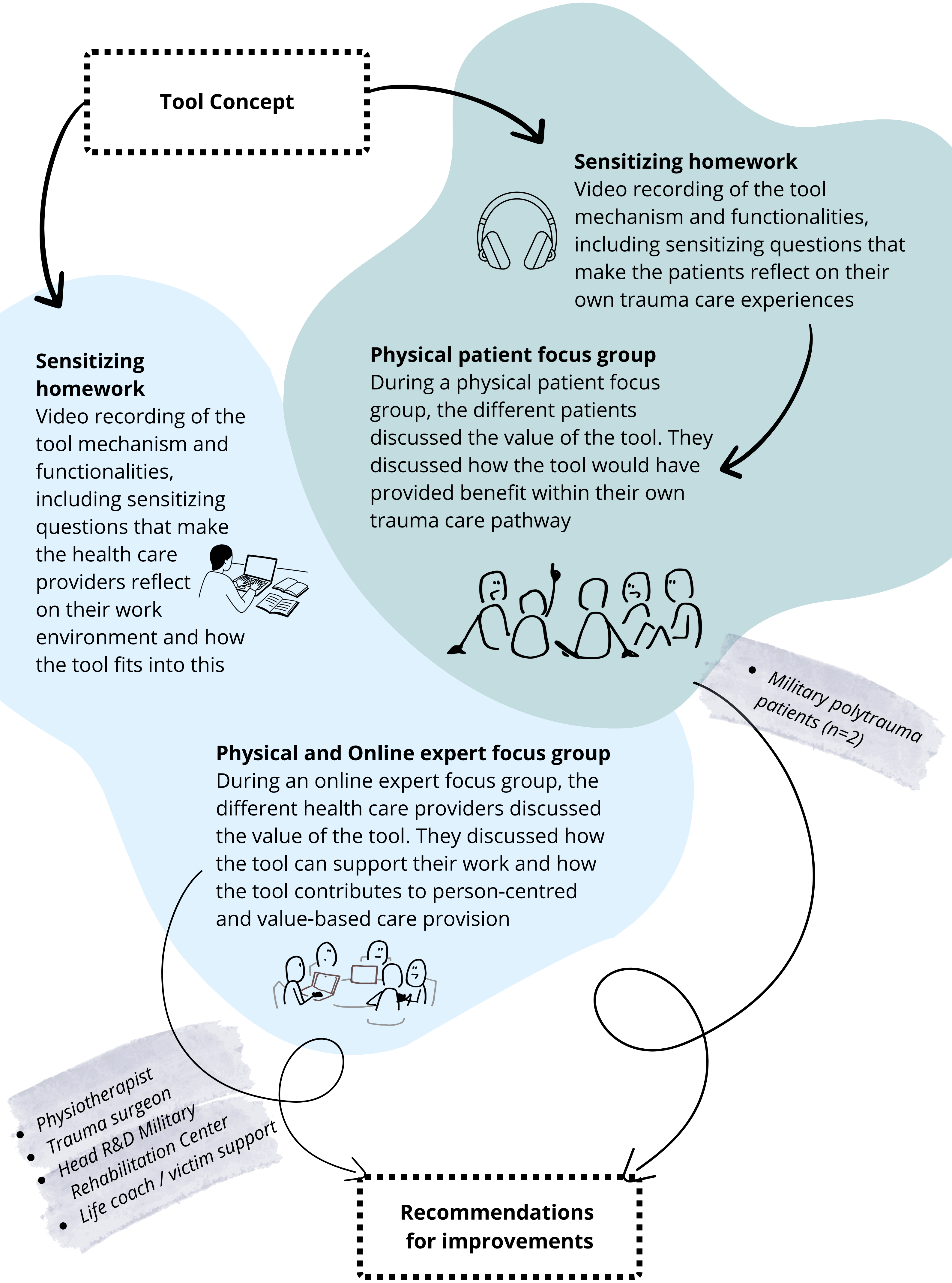
Medical knowledge
The health care provider has the medical knowledge to assess symptoms and find suitable treatment(s)

Familiarity with possibilities
The health care provider is familiar with the different health interventions and therapies that suit the medical situation of the patient

Authority to refer the patient within the health care system

Figure 39: Representation of how Libra Care can be used during consultation to supports the creation of a customized care plan

Part 4: Validating



Tool Concept

Sensitizing homework
Video recording of the tool mechanism and functionalities, including sensitizing questions that make the patients reflect on their own trauma care experiences

Physical patient focus group
During a physical patient focus group, the different patients discussed the value of the tool. They discussed how the tool would have provided benefit within their own trauma care pathway

- Military polytrauma patients (n=2)

Sensitizing homework
Video recording of the tool mechanism and functionalities, including sensitizing questions that make the health care providers reflect on their work environment and how the tool fits into this

Physical and Online expert focus group
During an online expert focus group, the different health care providers discussed the value of the tool. They discussed how the tool can support their work and how the tool contributes to person-centred and value-based care provision

- Physiotherapist
- Trauma surgeon
- Head R&D Military Rehabilitation Center
- Life coach / victim support

Recommendations for improvements

Chapter 18: Concept validating

To test the feasibility, desirability and viability of Libra Care, three focus groups were performed. One with patients, and two with health care providers. A focus group is a qualitative research method in which a group of participants is asked about their perceptions, ideas and opinions (Kitzinger, 1995). Compared to individual interviews, the group discussion in a focus group can provide interesting additional insights. This chapter discusses the most important insights.

18.1 Sensitizing homework

In order to sensitize the participants for the focus groups, homework was provided. Participants were asked to watch a video explaining the design project. This video (40 minutes) explained the most important insights from the research phase, the design objective and the final design of Libra Care.

A conscious decision was made to have the participants watch this video at home. This gave them the opportunity to watch the video and form an opinion, without being influenced by other participants or the designer. At the end of the video, sensitizing questions were asked to encourage the participants to reflect on their own (previous) trauma care trajectory and how the tool would fit into it. Participants were given several days to let the questions sink in, to reflect on the tool and to form a well-considered opinion. The sensitizing questions are listed below:

Questions for patients:
- *Is the objective of the tool clear? Are you convinced about the reasoning behind this objective?*
- *Is the mechanism of the tool explained clearly?*
- *What is your first impression of Libra Care?*
- *Would you have used Libra Care within your own trauma rehabilitation? Why (not)?*
- *Looking back at your care pathway, when could Libra Care have added value and how?*
- *Considering Libra Care, what is appealing to you? What does not appeal to you?*
- *Are there parts that you would like to change, remove or add within the tool?*
- *Think about other feedback, tips or ideas you would like to share within the focus group!*

Questions for experts:
- *Is the objective of the tool clear? Are you convinced about the reasoning behind this objective?*
- *Is the mechanism of the tool explained clearly?*
- *What is your first impression of Libra Care?*
- *Do you think the tool adds value for patients? Why (not)?*
- *Do you think the tool adds value for health care providers? Why (not)?*
- *Looking at your profession, when can Libra Care add value and how?*
- *Would you as a professional be open to use Libra Care? Why (not)?*
- *Considering Libra Care, what is appealing to you? What does not appeal to you?*
- *Are there parts that you would like to change, remove or add within the tool?*
- *Think about other feedback, tips or ideas you would like to share within the focus group!*

18.2 Patient focus group

On April 4, 2025, a physical focus group was held at the Kromhout Kazerne in Utrecht with two military polytrauma patients. During this focus group, the patients indicated that they had no considerations about the feasibility of the tool. The patients clearly confirmed the desirability of the tool. They considered the tool viable in the long term, but more research is needed into its implementation within the trauma care pathway. The most important insights are discussed below.

Insight 1: Creating awareness for the need for customized solutions and stimulating military trauma patients to be assertive in this themselves

The tool helps to create awareness within the organization (Ministry of Defense) for the situation and the future perspective of military (ex-)trauma patients. This is important because there is a need for customization. The Ministry of Defense lacks possibilities for customization for injured or disabled personnel because it is too procedurally organized. Persons within the organization make decisions based on institutional rules, without thinking carefully about what these outcomes mean for the quality of life of individuals. There is little customization and no eye for the future of these individuals. For example: injured military can no longer be military simply because they cannot pass the Defense Fitness Test. It is understandable that they can no longer return to the operational battle, but customization should ensure that these people can start working as reservists (part-time military) in a supporting role that suits their new situation. It is ungrateful to throw the military, who have made a great sacrifice, out of their field (and often way of life).

When military patients are reintegrated into the organization after trauma treatment, they are placed in a function at the level at which they entered the organization. Many injured military are men who joined the armed forces at a young age. With this system, they often end up in a function below their potential. Both participants of the focus group eventually managed to break through this system. They received customization and were eventually retrained as health care professionals. But, they emphatically indicate that this was only possible through assertiveness, having a high rank (one of the two), pressure from family members on the organization, and pressure from higher up in the organization. Unfortunately, this is not the standard procedure for every injured military.

The Ministry of Defense has an urgent need to quickly increase the number of reservists (parliamentary letter of the Minister of Defense State Secretary Gijs Tuinman, 2025). It is unthinkable that professionally trained military personnel, who have made a great sacrifice for the fatherland, are not offered customized solutions to remain appointed as reservists and to fulfill a suitable function within the organization. Libra Care contributes to this goal by raising awareness for trauma patients and the need for customized solutions. Additionally, the tool encourages patients to be assertive themselves and to continue to exert pressure. However, for patients to be stimulated to be assertive and take control, they need to be convinced that there is something to gain in it for them, and therefore the mind-switching is crucial!
‘The tool creates awareness within the entire organization, emphasizes the need for customization and encourages patients to take control of this themselves. But for them to take control, the process of mind-switching is fundamental. Patients need to be convinced that there is something to gain for them, and therefore, need to switch their focus away from the limited medical focus!’ (Focus group patient 2)

Insight 2: Quality of guidance

The tool can contribute to the quality of guidance from the organization. At this moment, this guidance is severely dependent on the assertiveness and involvement of the case coordinator assigned. The tool stimulates patients to be assertive themselves and take control of their care pathway. It also provides patients the opportunity to learn from the experiences of other patients, and if they feel the guidance of a case coordinator is not sufficient, they can reach out to other patients.

'The quality of guidance is very dependent on your assigned case coordinator. Does he act strictly by the imposed rules or is he willing to go the extra mile for your future?' (Focus group patient 1)

Insight 3: Direct psychological value for patients

The tool provides direct psychological value for patients. This is mainly due to the mind-switching and the focus on future perspective. Both patients experienced an extreme focus on what was no longer possible (medical limited focus) after their trauma incident. They indicated that the 'Life Compass' exercise, with the mind-switching, had been valuable for them to take a step back, get a helicopter view and create a new future perspective with focus on what is still possible (or what will be possible again in the future), instead of only focussing on what is no longer possible. They indicated that this would be valuable for everyone in a difficult situation, to take a step back and reflect on their lives from a value-driven perspective. Becoming conscious of the possibilities early in your care pathway is very valuable for patients.

"Mind-switching would have been very valuable to me. It could have given me a lot of peace and a future perspective. I still remember how I only experienced stress about the thought that I would never be able to study again after losing one eye. Looking back, this was an idiot thought, but I was consumed by it at that time." (Focus group patient 2)

Insight 4: Person-centredness means patients are unique individuals

The 'WMTM'-dossier provides an easy visual overview of who this patient is as a person. The broad approach of the 'WMTM'-dossier directly shows the person's uniqueness and this is valuable for the health care providers. One of the patients provided an anecdote from his own care pathway (Focus group patient 2). This conversation was during a follow-up check 6 months after shoulder surgery:

- *Patient: 'Does this mean I am able to do everything again from now on?'*
- *Practitioner: 'Yes, indeed!'*
- *Patient: 'Also an iron man?'*
- *Practitioner: 'Oh, uhm, I don't think so, let me check with the trauma surgeon'*
- *Practitioner: 'No that would be very unwise and irresponsible'*
- *Patient: 'So, I am not able to do everything again…'*

This story emphasizes the uniqueness of patients. For one patient, doing everything again means being able to walk outside, bike to work and maybe sport for an hour every day. For another patient, this could mean training intensively three times a day. Therefore, it is crucial that health care providers invest in understanding the uniqueness of each patient and not rely on assumptions or the average person's common practice. The 'WMTM'-dossier is a conversation starter that facilitates this in an easy and visual manner. It facilitates the patient in clearly conveying what is important to them. The health care provider is then better able to align the care provision with the personal values, goals and preferences of the patient.

Insight 5: Broad perspective that includes all care providers

The design of the 'WMTM'-dossier supports person-centred and value-based care, since it does not have a dominant clinical focus. Instead, it touches upon multiple aspects in the life of a patient and combines the somatic components with future components. Some aspects are more relevant for health care providers; other aspects are more interesting for the case coordinator or reintegration worker. It was indicated that the tool can be used during the whole care pathway, contributing to the viability of the tool (increasing the chance of success in the long-term). "I could still use the tool today, not necessarily medically, but it really is about providing some guidance". (Focus group patient 2)

Insight 6: Problem of the When/Who/Where implementation within the care pathway
Although both patients were clearly convinced of the desirability of the tool, there was an interesting discussion about what the best model is for successful implementation within the care pathway. There was an extensive discussion about the questions: **When, where and by whom will the tool be provided to the patient?** At this moment, even after discussion, I can not clearly state one optimal model for this. The main considerations are noted below and used for recommendations for further research and testing.

Military context
For the military context, three different options were considered:
(1) The tool could be provided to the patient by the rehabilitation center, but not every military patient will be treated in the rehabilitation center (one of the participants of the focus group was never treated there, although he had multiple follow-up surgeries and the tool would definitely have been valuable to him). Next to this, it is also hard to determine the timing of provision. Both patients indicated that they experienced a rebellious phase during their recovery. They had a 'fuck-it' mentality and performed acts that did not contribute to their recovery, for example smoking and drinking. When the tool is provided during this phase, chances of the patient actually using it will be low. Ideally, the tool is provided directly after this processing phase, when the patient is in a process of acceptance and works consciously towards a new future. This ideal moment is subjective for each patient, and therefore difficult to process in a standardized provision plan for the tool.

(2) The tool could be provided by the trauma surgeon directly after the acute phase. But, trauma surgeons have limited time and you are dependent on their willingness to do so. Therefore, it would be interesting if the tool could be provided by a standardized email after visiting the trauma surgeon. However, there were concerns about the timing of provision. Both patients had concerns that providing the tool directly after the acute phase would have been too early in the process of acceptance for the patient to actually start using it (as explained in the first option). Therefore, the chances of ignorance by the patient are estimated highest for this option.

(3) The tool could be provided by the case coordinator (the military reintegration officer). Each injured military is assigned a case coordinator who guides him along the care pathway and helps with the reintegration within the Ministry of Defense or into society. The advantage of this option is the consistency: every military patient works with a case coordinator. The disadvantage is that the quality of the guidance by case coordinators is highly dependent on the person (an insight that emerged during the patient interview and the focus group). Nevertheless, guidance by the case coordinator was considered the most viable option. The tool makes it easier for case coordinators to provide guidance and stimulates the patient to be more assertive and to take control themselves, which reduces the impact of the disadvantage. Still, the problem of timing (as explained in option 1) remains. To address this problem, recommendations are made for further research and testing in chapter 21.

Civilian context
The same problem occurs and is even more prevalent in the civilian context. Civilian patients are not guided in the same way during rehabilitation as military personnel (an insight found during the patient interviews). Civilian patients are not automatically assigned to a case coordinator. They can contact a life coach or reintegration worker, but they usually have to arrange this themselves. In addition, interdisciplinary rehabilitation care for civilians is often not geared to one specific rehabilitation center, but spread across different locations. Here too, we considered different options:

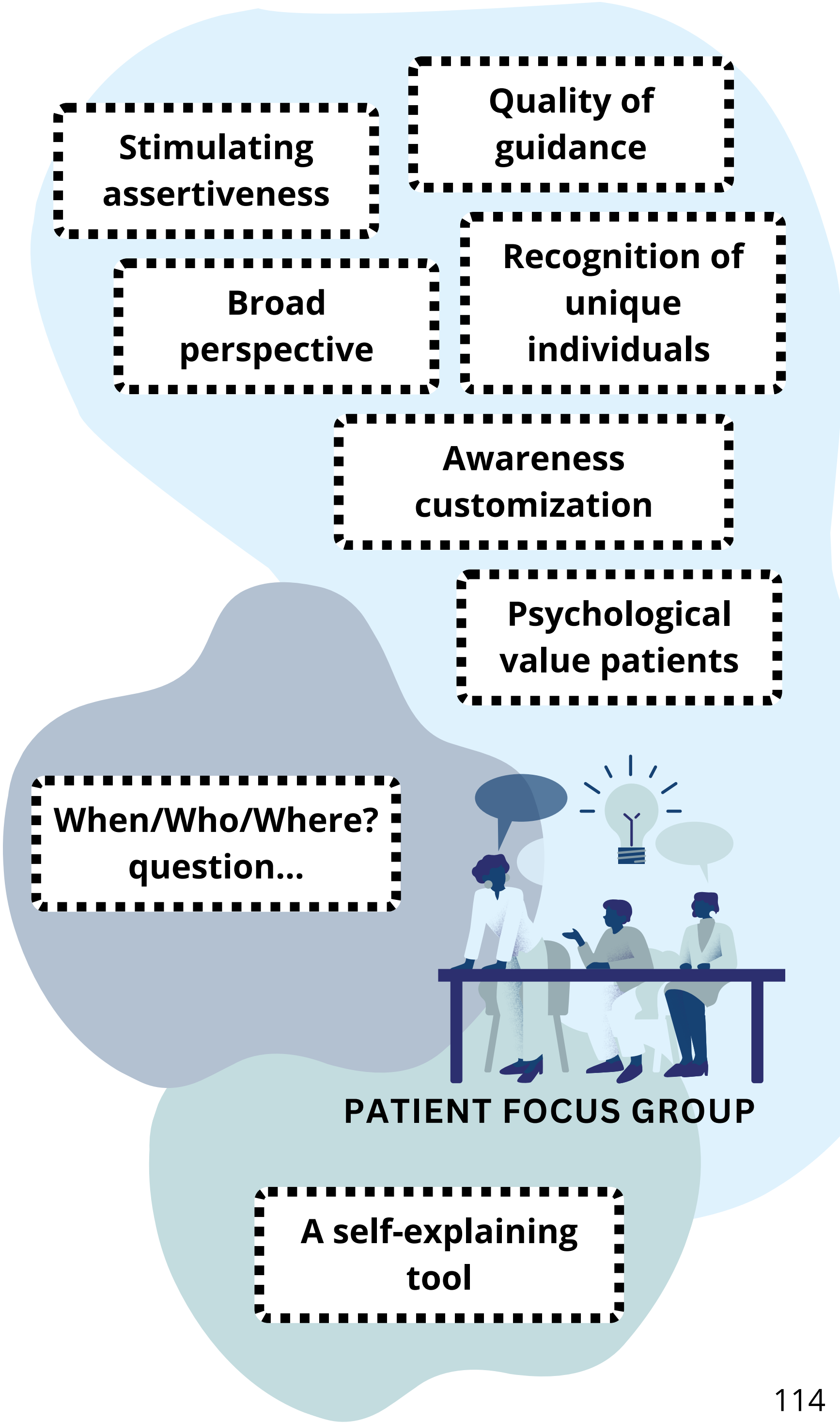
(1) The tool can be provided by a civilian rehabilitation center. This will have the same disadvantages as described above for the military context. In addition, civilian rehabilitation is not centralized like military rehabilitation, which means that the intensity and frequency of visits to the rehabilitation center can vary. It is likely that the different health care providers a civilian patient works with are spread across different organizations and locations, which makes it difficult to make arrangements about the provision of the tool. Additionally, if not all health care providers want to work with Libra Care, value is lost.

(2) The tool could be provided by the trauma surgeon immediately after the acute phase. This would have the same disadvantages as described above for the military context.

(3) The patient's general practitioner could provide the tool. This is their most regular and accessible point of contact. Most civilian trauma patients are referred to rehabilitation providers by the general practitioner. If patients are referred by other providers, the general practitioner will be notified. Therefore, the general practitioner was considered the most viable option. However, the issue of timing remains (as explained in option 1 of the military context). To address this problem, recommendations are made for further research and testing in chapter 21.

Recommendations patient focus group
To increase the usability of Libra Care, it should be self-explanatory. This makes the tool less dependent on the willingness of healthcare providers (or case coordinators) to explain the importance of using Libra Care to patients. Offering the tool can be made as easy as sending a single email to the patient. Offering the tool to patients becomes a simple task for health care providers, increasing the likelihood that they will be willing to use the tool. Libra Care itself should convince patients of the value of mind-switching and let them actively take control of their own care pathway. The patients of the focus group indicated that the example in the 'Life Compass' exercise of mind-switching (guitarist example - page 80) is very valuable to understand the importance of changing your perspective from a medical focus to a broader value-driven focus.

At this moment, the importance of mind-switching and patients actively participating in the design of their customized care pathway is explained convincingly in the introduction of the 'Life Compass' exercise (as indicated by both focus group patients). However, this should also be done in the email that introduces the patient to Libra Care. The patient should directly be convinced to use the tool and to perform the 'Life Compass' exercise. Otherwise, there is no initial incentive for the patient to perform the exercise, increasing the chances of ignorance.



18.3 Expert focus groups

A physical focus group was organized at the Kromhout Kazerne in Utrecht, with a physiotherapist and a trauma surgeon (4 April 2025). An online focus group was organized with a civilian life coach and victim support worker and the head of research and development of the Military Rehabilitation Center Aardenburg (4 April 2025). Due to working hours, a combined focus group was not feasible. However, the insights of both expert focus groups are combined and presented below. There were no concerns about the feasibility of the tool. The desirability of the tool for both patients and health care providers was confirmed. More research and testing are needed to develop suitable implementation plans for the different contexts: civilian, military and military during main task 1.

Insight 1: Desirability from different professions

The different participants indicated the value of their tool for their specific profession. There was consensus that the tool provides added value in terms of learning what matters to a patient and stimulating active patient participation. It is extremely valuable for health care providers if patients can convey clearly what is important to them, so health care providers can anticipate their care on this. They acknowledged that patients have the motivation to participate within their care pathway, but they are not familiar with how to do this properly. The participants recognized the added value and would be willing to use the tool within their profession. However, there were some concerns about responsibilities, as will be explained in the next insights.

‘As a trauma surgeon, my goal is to adjust treatment based on the life of this specific patient. Therefore, it would be valuable if patients are guided to explain themselves better. The better a patient can convey what is important in their life, the better professionals can align their treatment’. (Trauma surgeon)

Insight 2: When do you use the tool in the care pathway

The consideration of when to provide the tool to patients was a recurring dilemma that resulted in three options:

(1) One of the participants with a psycho-social background (experience with victim support) suggested that it would be best if Libra Care were offered immediately after the acute phase, as anxiety and stress occur immediately after the traumatic incident. When the tool is offered as soon as possible, patients feel guided and reassured. The patient can decide for themselves when to perform the 'Life Compass' exercise. Other participants disagreed, as patients need a processing phase and are not yet mentally ready to perform the 'Life Compass' exercise (a conclusion that also emerged during the patient focus group). Performing the exercise too early can be harmful to the patient and reduce the willingness to participate in the future.

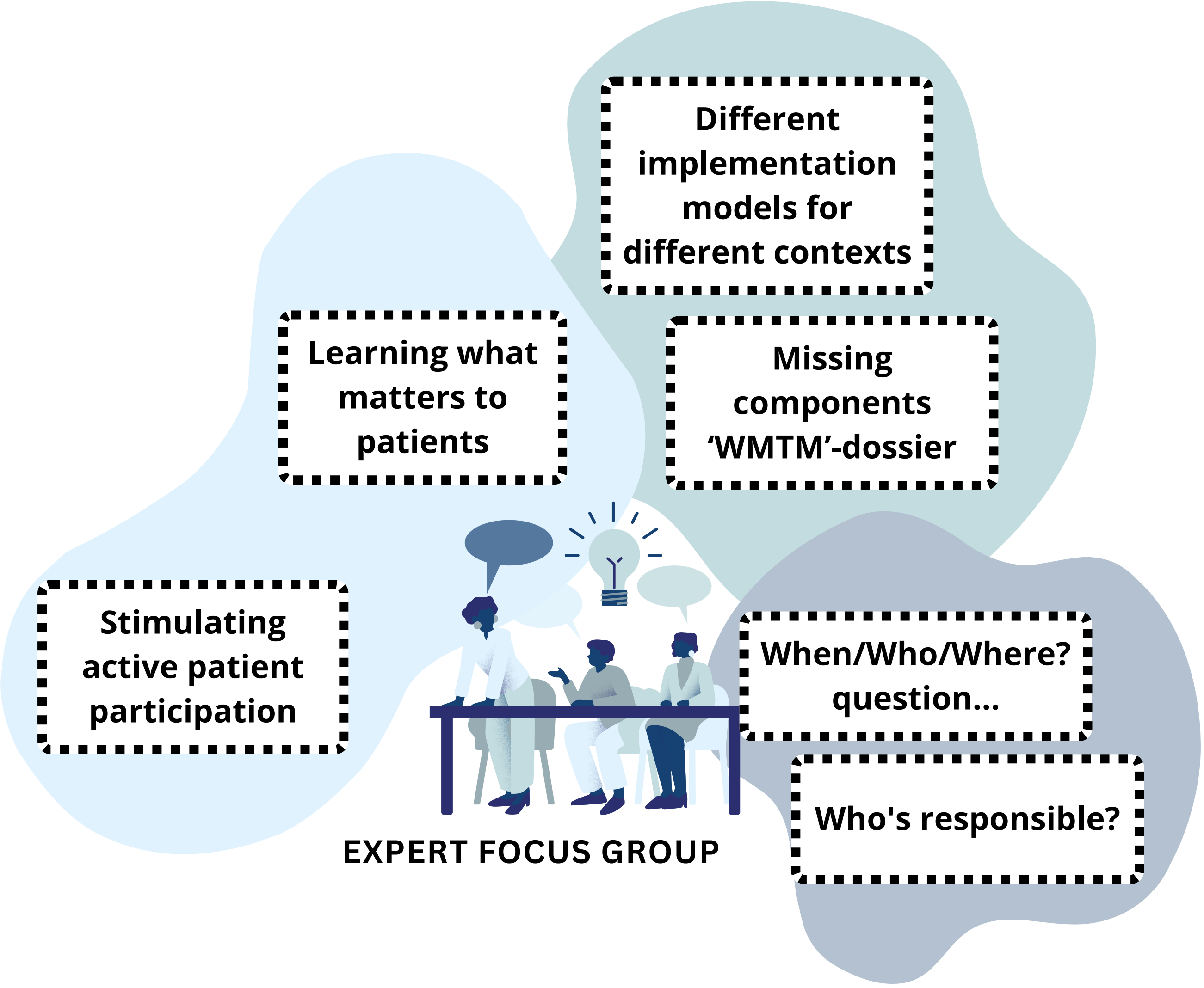
(2) Therefore, it was suggested to offer Libra Care after the processing phase. Patients are given the opportunity to process their situation and when they are ready, they are asked to do the 'Life Compass' exercise. This is the moment when they are ready to focus on their recovery and future, and therefore this is the moment when the tool actually offers value to the patient. However, this moment is subjective and therefore leads to practical limitations. Further research should be done to determine the best moment to offer the tool.

(3) During the discussion, a new option emerged. Looking to the future, we need to prepare for main task 1 (NATO involved in an armed conflict to protect its territory). This means that it is realistic to expect more military trauma patients and more pressure on healthcare capacity. Taking this into account, it could be interesting if military personnel performs the 'Life Compass' exercise before deployment. In case of a trauma injury, the ‘WMTM’-dossier can be used directly during treatment. Military personnel who are preparing for deployment are aware of the risk that they could be injured during the mission, and are therefore capable of completing the ‘Life Compass’ exercise with consideration.

Insight 3: Missing components in the ‘WMTM’-dossier
Although the ‘Life Compass’ exercise and mind-switching were evaluated as valuable, we discovered two components that are important but missing at the moment:
(1) Family is included in the exercise to some extent, but it would be valuable if it were clearly stated what the role of this person is within his family. What tasks does he fulfill within the family? What does his family expect of him?

(2) Although the exercise focuses on a future career, it does not contain current career requirements. Most (military) patients would like to return to their profession. Therefore, information about their job requirements and what is expected of them in this role should be included in the ‘WMTM’-dossier.

Insight 4: Whose responsibility?
During the focus groups, we discussed the responsibilities of different stakeholders regarding the tool. It was expressed that it is important that health care providers take it seriously when a patient takes the time to complete the ‘Life Compass’ exercise and create a ‘WMTM’-dossier. Otherwise, there is a risk that the patient does not feel heard. However, health care providers who want to change their way of working need to have some form of ownership and familiarity with the process. For the Military Rehabilitation Center, an approach could be devised where health care providers are involved at an organizational level, for example with an interdisciplinary meeting where a patient's ‘WMTM’-dossier is discussed. Unfortunately, this is not possible for civilian patients, and it is unrealistic to expect this to be possible during main task 1 (NATO patients involved in armed conflict), given the increase in the number of military patients. This discussion led to the recommendation to create different implementation models for the different contexts: (1) civilian, (2) military and (3) military during main task 1. To do this, the current working methods and responsibilities within a specific rehabilitation context should be investigated and pilots should be conducted to test different models, as explained in chapter 21.



Chapter 19: Conclusion validation

There were no concerns about feasibility. The tool consists of existing technologies and methods. Although the use of mind-switching and generative techniques is unique to this context, this does not have negative consequences for its feasibility.

All focus groups proved the desirability of the tool. Patients indicated that the tool creates awareness for customized solutions for military patients within the Ministry of Defense, also with regard to reintegration. The tool emphasizes understanding the unique characteristics of individual patients. In addition, the tool encourages patients to be assertive within their care pathway and to take control themselves. The tool offers psychological value to patients and improves the quality of guidance. Healthcare providers indicated that the tool is valuable for patients and health care providers. Health care providers benefit from active patient participation and patients who can clearly convey what is important to them. Because the tool includes both somatic and future-oriented aspects, it is useful for a wide range of health care professionals.

That said, the tool should be self-explanatory. The tool itself should be able to convince patients of the value of mind-switching and active patient participation from the start. Patients should be motivated to do the 'Life Compass' exercise. In addition, the ‘WMTM’-dossier should contain job requirements and the tasks that someone fulfills within his or her family.

In order to implement Libra Care successfully, future research should be performed into when and by whom Libra Care can best be offered to the patient. It is wise to develop different implementation models for the different contexts (civilian, military and military during main task 1). The possibilities for implementation within each context should be investigated and tested with pilots, to find the most feasible moments of providing Libra Care to the patients.

A visual of the combined insights can be found on the next page in Figure 40.

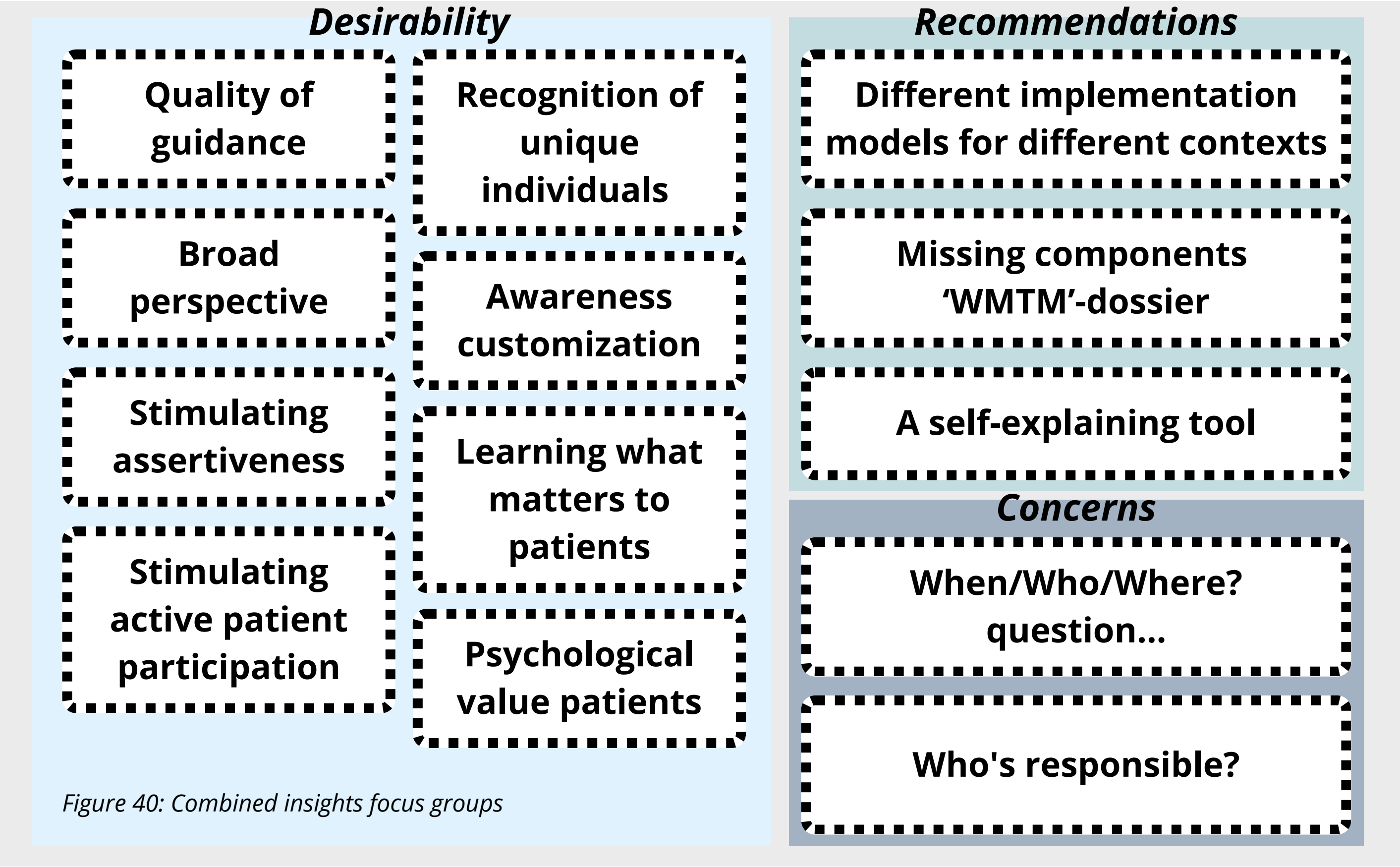
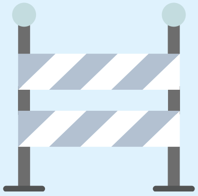


Figure 40: Combined insights focus groups

Part 5: Limitations, Recommendations and Implications

Limitations

The weaknesses of the study, based on factors that are often outside of your control as the researcher



Recommendations

A recommendation is a suggestion or proposal for something that should be done, as derived from the findings

Implications

Theoretical implications relate to how your findings connect to other theories or ideas in your field, while practical implications are related to what we can do with the results

Chapter 20: Limitations

In this chapter the limitations of this graduation project are described. Limitations refer to the weaknesses of the study.

20.1 Research phase

In general, I had difficulty finding patient participants for the generative interviews. The goal was to interview 2-5 patients for the civilian care pathways of burns and crush injury, and 2-5 patients for the military care pathways of burns and crush injury. For me, it was not feasible to find multiple military trauma patients with burns or crush injuries that had occurred during their service in the Netherlands. I think the main reason for this is that the inclusion requirements are too limiting (not many military are severely injured during service in the Netherlands, due to the strict safety regulations within the organization). Ultimately, this was not a problem since the performed interviews with patients and experts resulted in a direction change, where the focus was no longer on the care pathways of burns and crush injury. However, since I could not create military patient journeys for those specific care pathways, a truly detailed one-on-one comparison of civilian and military patient journeys was not possible. Furthermore, only one civilian patient was found for the crush injury patient journey.

20.2 Design phase

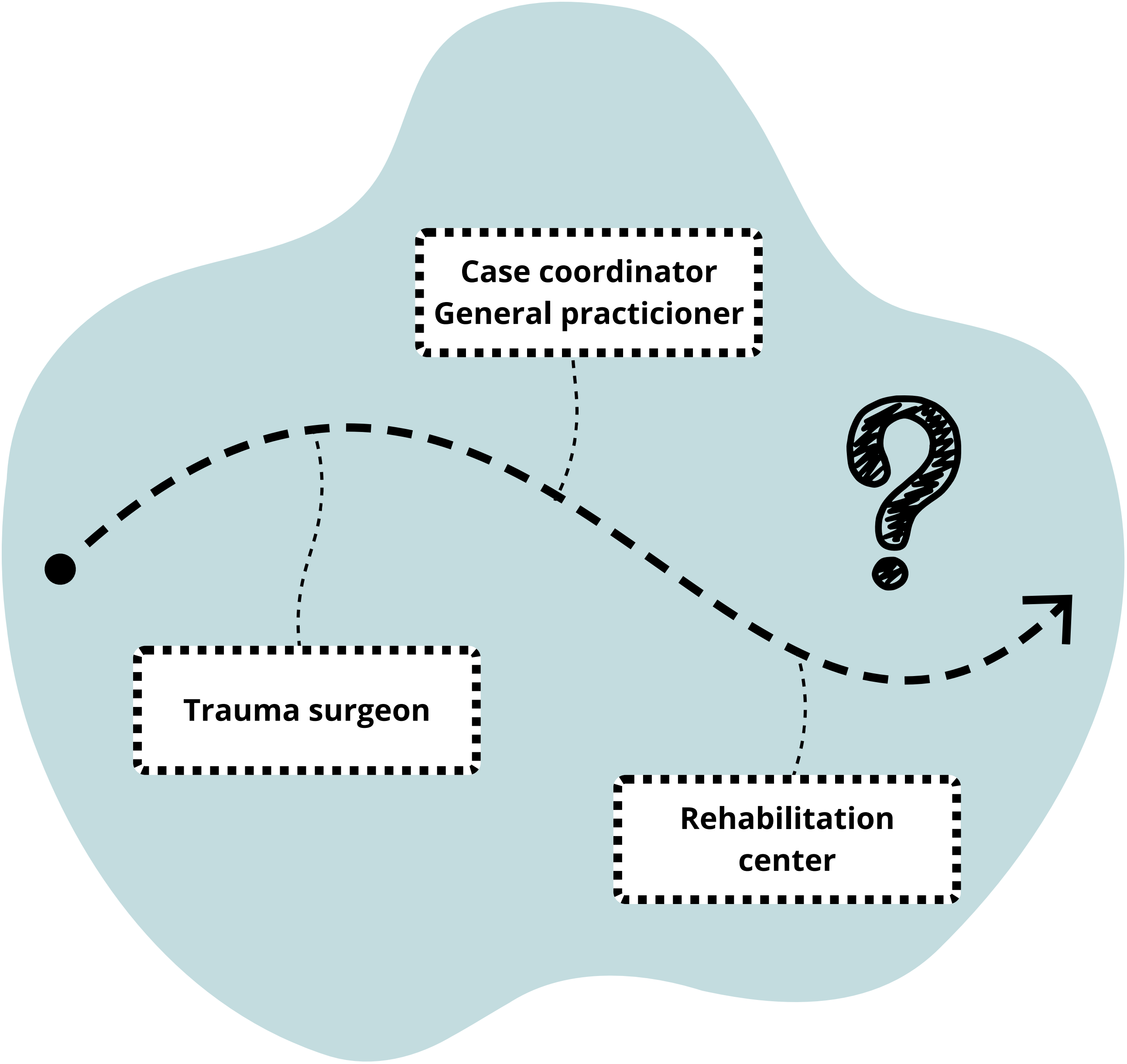
The ‘Life Compass’ exercise was converted into a high-fidelity prototype with multiple test iterations and optimizations. Participants were asked to imagine that they had recently lost their leg due to a traumatic injury, before performing the exercise. In addition, ex-trauma patients evaluated the exercise and indicated how valuable it would have been to them during rehabilitation. However, the exercise was not tested with participants who had recently suffered a traumatic injury. As a result, the effects of mind-switching could only be tested to a limited extent.

Another limitation is that the ‘Life Compass’ exercise was mainly tested with highly educated participants. This group is probably not representative for the standard composition of trauma patients. Especially when we look at military trauma patients, it is realistic to expect that we are mainly dealing with lower-educated people. The lower ranks are the military personnel who are most often seriously injured as a result of their high-risk work. This is evident from research by Hoencamp et al., which showed that 72.4% of casualties in the battle in Afghanistan were young soldiers (2014). These lower ranks require a high school diploma, but no further academic education is necessary. With additional education, it is likely that you will hold a higher rank within the organization. For the civilian context, a similar reasoning is possible for construction workers, where traumatic injuries occur relatively often (Alsharef et al., 2023).

Another limitation of Libra Care is that the tool is not yet aligned with the current systems that healthcare providers use during rehabilitation. Since the initial focus was not on rehabilitation, this component was not investigated in detail during the research phase. This resulted in insufficient time (after the direction change) to investigate the current online systems that are used within civilian and military rehabilitation. To address this, the choice was made to design Libra Care in a simple and accessible way, so that it can be used alongside the current systems without placing too many demands on health care providers.

20.3 Testing and validating

The validation of the tool was limited due to the number of participants and the background of the participants. The patient focus group consisted of two military polytrauma patients and no civilians. Although civilians were included in the research phase, I was not able to include civilian patients in the validation phase. Therefore, there is a significant chance that valuable insights are missing. The expert focus groups included the main professions, but ideally more professions would be included (e.g. psychologists or prosthetists). Three focus groups were conducted with a total of 2 participants each. A focus group is a qualitative research method in which a group of participants is asked about their perceptions, ideas and opinions. Compared to individual interviews, the group discussion of a focus group can provide interesting additional insights. However, a total of two participants is not ideal for a focus group. The aim during this project was to organize focus groups of 3-5 participants. Unfortunately, this was not feasible due to the accessibility of the participants.



Chapter 21: Recommendations

In this chapter recommendations are provided for further research and to improve Libra Care. A recommendation is a suggestion or proposal for something that should be done, as derived from the findings. The recommendations provided are aimed at the CETC. The recommendations support the successful further development of the tool and provide guidance for valuable future research.

21.1 Recommendations for improving the 'Life Compass' exercise

During the validation phase we identified two important aspects that are not (enough) present within the 'WMTM'-dossier, and therefore should be included within the 'Life Compass' exercise.

- First, an open question should be included about the patient's role within the family. At this moment, the patient indicates what his/her most important roles are and which character traits are most important to fulfill this role. However, it would be valuable if it were more specific about what the family expects from the patient. For example, doing the shopping or taking the children to school. This information is very valuable, because not being able to perform family tasks can affect self-image and dignity. Together with care providers, a patient can explore new possibilities to perform the tasks or find new tasks that give the patient meaning within family functioning.
- The patient's job requirements should also be included in the 'Life Compass' exercise. Most patients want to return to work as soon as possible. Unfortunately, many military patients are unable to perform their military jobs after trauma injury. By emphasizing the job requirements, the patient and caregivers can explore possibilities and this can form the basis for customized reintegration. The job requirements are a goal to work towards. If it is not feasible to meet all the requirements, the case coordinator can look for possibilities for an exception or look for other functions that are similar to the previous function, but with different requirements. The Military Rehabilitation Center Aardenburg already works according to this approach (occupational rehabilitation) and has indicated that it would be valuable to include this in Libra Care. Losing your job has a negative impact on your self-image (especially for military personnel, for whom being military is part of their identity).

As shown in chapter 14, a high-fidelity prototype of the 'Life Compass' exercise was created and tested. This prototype included the guiding voice-over, the final design and a realistic simulation of the interactive mechanism. However, the prototype itself was not fully interactive and could not generate output. The 'WMTM'-dossier that was delivered as output was a self-made example format. In order to further test and evaluate the 'Life Compass' exercise, it should be developed as interactive software. This interactive software should be tested for errors, before the final test is performed. The final test should be performed in the (military) rehabilitation center with trauma patients. The content of the exercise and the principle of mind-switching were already validated during this project. However, with a final test we can demonstrate the added value of the 'Life Compass' exercise compared to eliciting personal values, goals and preferences during regular consultation.

Final test set-up

For the final test, a total of 5-10 trauma patients who have recently arrived at the rehabilitation center must be selected. Preferably, this are patients who still have to have an intake consultation. After the intake consultation, the patient is asked to reflect on the quality of eliciting personal information (by means of a questionnaire). The patient is only asked afterwards, to avoid influencing this process (unconsciously) during the consultation. The patient is then asked to complete the 'Life Compass' exercise and to create a personal 'WMTM'-dossier. The patient is asked to look back on the consultation and consider whether he/she would have given different answers based on the results in the 'WMTM'-dossier. If so, the 'Life Compass' exercise and 'WMTM'-dossier offer added value, because it allows patients to express themselves more deeply. A new consultation (with the 'WMTM'-dossier) can be simulated with another health care provider to compare both experiences. After this, a qualitative interview with the patient can map out the full added value of the 'Life Compass' exercise and the 'WMTM'-dossier.

21.2 Recommendations for validating Libra Care

As explained in the limitations, the group discussions during the focus groups with patients and experts provided valuable insights, but the focus groups were limited in terms of the number of participants and their background. Therefore, I recommend the CETC to organize two new focus groups, with more participants from different backgrounds, to allow for fruitful group discussions. Ideally, military and civilian patients are combined in one focus group. In addition, an expert focus group should be organized, with more professions included, such as psychologists and prosthetists.

21.3 Recommendations for context research

The 'Map My Experience Trauma Care’ tool was developed to investigate and map the patient journeys for the trauma care pathways of burns and crush injury, for both civilians and military (focused on the context of acute trauma care and treatment in the Netherlands). This tool has proven to be very suitable for mapping patient experiences within the acute trauma care pathway and creating patient journeys, as described in chapter 4 and 5. As explained in the limitations, I could not find multiple military trauma patients with burns or crush injury, that had been sustained during their service in the Netherlands. Therefore, it was decided to interview a military polytrauma patient, who had been severely injured during their deployment. This interview provided valuable insights and created a deep understanding of the military context. However, the 'Map My Experience Trauma Care' tool was not suitable for this context. The military (NATO) care chain consists of different roles of treatment facilities, that are not well included in the tool. Because of this I could not create a military patient journey.

To further analyze the context, military trauma patients injured during their service in the Netherlands should be identified and interviewed (using the ‘Map My Experience Trauma Care' tool). Then, differences between the civilian and military patient journeys can be analyzed. In addition, the tool should be tailored to the context of military deployment, with different 'islands' for the roles of medical treatment facilities.

The ‘Map My Experience Trauma Care’ tool is developed with a focus on the acute phase, and rehabilitation is implicitly represented by the 'small islands' for after care. To answer the question when Libra Care should be provided to the patient, further research into the rehabilitation care pathway is needed. The tool can be tailored for this research by shifting the dominant focus to rehabilitation.

21.4 Recommendations for implementation research

As explained in chapter 18, there is uncertainty about the best implementation model for the different contexts (civil, military and military during main task 1). At this moment, there is insufficient validated information available to advocate a specific implementation option (from the options described in chapter 18). A new project should be dedicated to investigate and test the implementation possibilities.

During this new project, research needs to be done into the three contexts. First, the rehabilitation care pathways need to be mapped in detail. To do so, the Map My Experience Trauma Care tool can be tailored and used during generative patient and expert interviews. It is important to investigate who is involved in this care pathway and what responsibilities they have. In addition, the systems that care providers work within the care pathway need to be studied (e.g. Epic or Chipsoft), so that the tool can be aligned with those systems. Libra Care is primarily intended to support patients in expressing themselves and in self-managing their customized care plan. The input required from the health care provider (in terms of additional documentation) is limited. However, it would be optimal if the customized care plan could be aligned with the existing online systems, as this would increase the willingness and ease to implement Libra Care. To do so, additional in-depth research for the different contexts is needed.

21.5 Recommendations for implementation testing

Once the care pathways and stakeholders of the three contexts have been mapped in detail, the different options described in chapter 18 can be explored. A selected group of patients can be followed throughout the care pathways, to see whether the different implementation options of the tool would have been practical and whether the timing is suitable. Ultimately, pilots should be conducted for the different options and to measure the return on investment (how many patients perform the ‘Life Compass’ exercise and use the ‘WMTM’-dossier during the consultation, when the tool is offered at this specific timing). The advantages and limitations of each option should be studied to make an informed choice. Ultimately, an ideal implementation model can be created for the three different contexts.

For the military context, it is interesting to test the value of performing the ‘Life Compass’ exercise before deployment. Military personnel need to be convinced that it is useful for them, and be motivated to perform this exercise with dedication and focus. If it is not feasible to motivate them sufficiently, and the exercise is seen as a quick to-do task before deployment, the value is lost. However, if the ‘Life Compass’ exercise is performed with conviction and the military believes in the outcome, this model can be very fruitful. Should a military be injured during deployment, is the ‘WMTM’-dossier directly available during the acute phase. As explained in the previous chapter, the timing of the implementation is difficult because of the processing phase. Performing the ‘Life Compass’ exercise during the processing phase is not desirable and can even be harmful to the patient. With this new model we eliminate this timing problem, because the ‘Life Compass’ exercise is already performed before deployment. A pilot should be conducted with military personnel (from different divisions), who will be deployed in the near future. It should be assessed whether the exercise is carried out with conviction and whether the military personnel can be convinced of the added value for their own benefit in the future.

21.6 Recommendations for implementation guidance

Implementing Libra Care requires a shift in the current way of working of health care providers. It is wise to appoint a project team that carries out the studies and pilots described above, and also actively contributes to the implementation process. This project group can visit the various stakeholders, convey the added value of Libra Care and show how the tool is used effectively.

Ideally, I recommend to perform the pilots in the military context, as there is a budget and this context is more structurally designed than the civilian context. Implementation will therefore be easier, because it can be initiated top-down within one organization. The project team will facilitate the successful implementation of the tool, and collect data that demonstrates the added value of the tool. When the added value is demonstrated by hard data, it will be easier to convince civilian organizations to implement and use Libra Care.

Chapter 22: Implications

In this chapter the implications of the research are described. Implications refer to the consequences, effects or significance of the research findings. Implications suggest how the results of this project can be applied in practice, policy, further research or theory.

22.1 Generative techniques to elicit personal information

The method of eliciting personal information using generative techniques is interesting for the entire healthcare domain. The pressure on health care capacity is increasing. This poses a major threat to person-centered and value-driven care. When time is limited, health care providers prioritize medical tasks, which leads to a focus on the disease rather than on the person (Ekman et al., 2011). Generative techniques stimulate the patient to think more deeply about what is important to him or her (than by simply asking them). Eliciting personal information using generative techniques before the consultation results in more fruitful and efficient conversations between the patient and health care providers. Therefore, this method is promising for the entire healthcare domain and valuable far beyond trauma care. Other strategic designers could use this method to transform current healthcare practice and ensure that future healthcare remains person-centered and value-driven, even with increasing pressure on healthcare capacity. Patients eliciting what is important to them before the consultation could become a new common practice. The information obtained serves as a starting point for the conversation during the consultation. In this way, care can be efficiently and effectively aligned to what is important to the person.

22.2 Map My Experience Mapping Trauma Care tool

The ‘Map My Experience Trauma Care’ tool proved to be useful in mapping patients’ experiences, feelings, thoughts and opinions regarding their acute trauma care journey. Therefore, I encourage other researchers in acute trauma care to use the tool and adapt it if necessary. The tool helps people to express themselves in a creative way, provides structure to the interview and was experienced by patients as a fun and interesting way to share experiences. In addition, it would be interesting if other researchers could use this project as inspiration to adapt the tool to other research contexts.

22.3 Bottlenecks civilian trauma care

During the project, several bottlenecks within the civilian trauma care pathway were identified. Patient interviews were the most important source for this. It turned out that civilians often feel abandoned after acute trauma care. Furthermore, patients experience a significant difference between the quality of treatment facilities in terms of care provision, information provision, interdisciplinary collaboration, friendliness and professionalism of the staff, and the possibilities for assistive technologies. These findings point to interesting opportunities for strategic design projects within civilian trauma care. It may also be interesting to investigate whether policies can regulate the possibilities for assistive technologies between different treatment facilities, contribute to health equity.

22.4 Bottleneck military trauma care

Although the military trauma care chain has been evaluated in a more structured way, and patients receive standard guidance through the assignment of a case coordinator, an urgent need for customization in the field of reintegration within the Ministry of Defense after treatment was identified. Based on these insights, new policy can be developed that better matches the wishes of individual military (patients) and aligns with the need to increase the number of reservists.

22.5 Matching based on coping strategies

This project matches trauma patients based on experienced losses (for example, not being able to work anymore or a deterioration of your self-image) and coping strategies, instead of similarities in medical condition. This approach is unique and could be applied to many other (health) domains.

Chapter 23: Project conclusion

In conclusion, the project encountered several limitations that impacted its scope and outcomes. The research phase revealed challenges in finding military trauma patients, leading to an inability to draw up patient journeys for military trauma care pathways. This hindered the in-depth comparison of civilian and military patient journeys. The design phase faced limitations in testing the 'Life Compass' exercise with a representative sample of trauma patients, as it was mainly tested with highly educated participants. This may not reflect the standard composition of trauma patients (especially in the military context). Moreover, Libra Care lacks alignment with current healthcare systems used during rehabilitation, due to insufficient time for detailed investigation of those systems. The validation phase was also limited by the number and background of participants. Finally, it remains undecided what the best implementation models for the three different contexts are due to insufficient validated information. Overall, the project's limitations highlight the need for future dedicated research and testing.

Therefore, recommendations have been provided to further research the context, to improve the ‘Life Compass exercise’ and to validate Libra Care more elaborately. Additional, in depth research and testing regarding the implementation model for three different contexts (civilian, military and military during main task 1) is needed. Lastly, the importance of appointing a project team to actively contribute to the implementation process has been highlighted for implementation guidance.

The project has multiple interesting implications for the health domain. The generative techniques for eliciting personal information have the potential to revolutionize the common practice for consultations. The 'Map My Experience Trauma Care' tool has proven to be valuable in capturing patients' experiences and could be adapted for use in other research contexts, enhancing the creative expression of patients and providing structure to interviews. The identification of bottlenecks in both civilian and military trauma care pathways presents opportunities for strategic design projects and policy development to improve customized care provision and reintegration, addressing the unique needs of individual patients. Further exploration of how to effectively advocate for active patient participation among citizens, even before they become patients, could lead to substantial improvements in health care outcomes. The principle of matching patients based on similar losses and coping strategies can be be applied to many other (health) domains.

Overall, the research findings offer actionable insights for transforming health care practices and policies, ensuring that care remains person-centered and value-driven, despite the challenges posed by increasing healthcare demands.

Chapter 24: Personal reflection

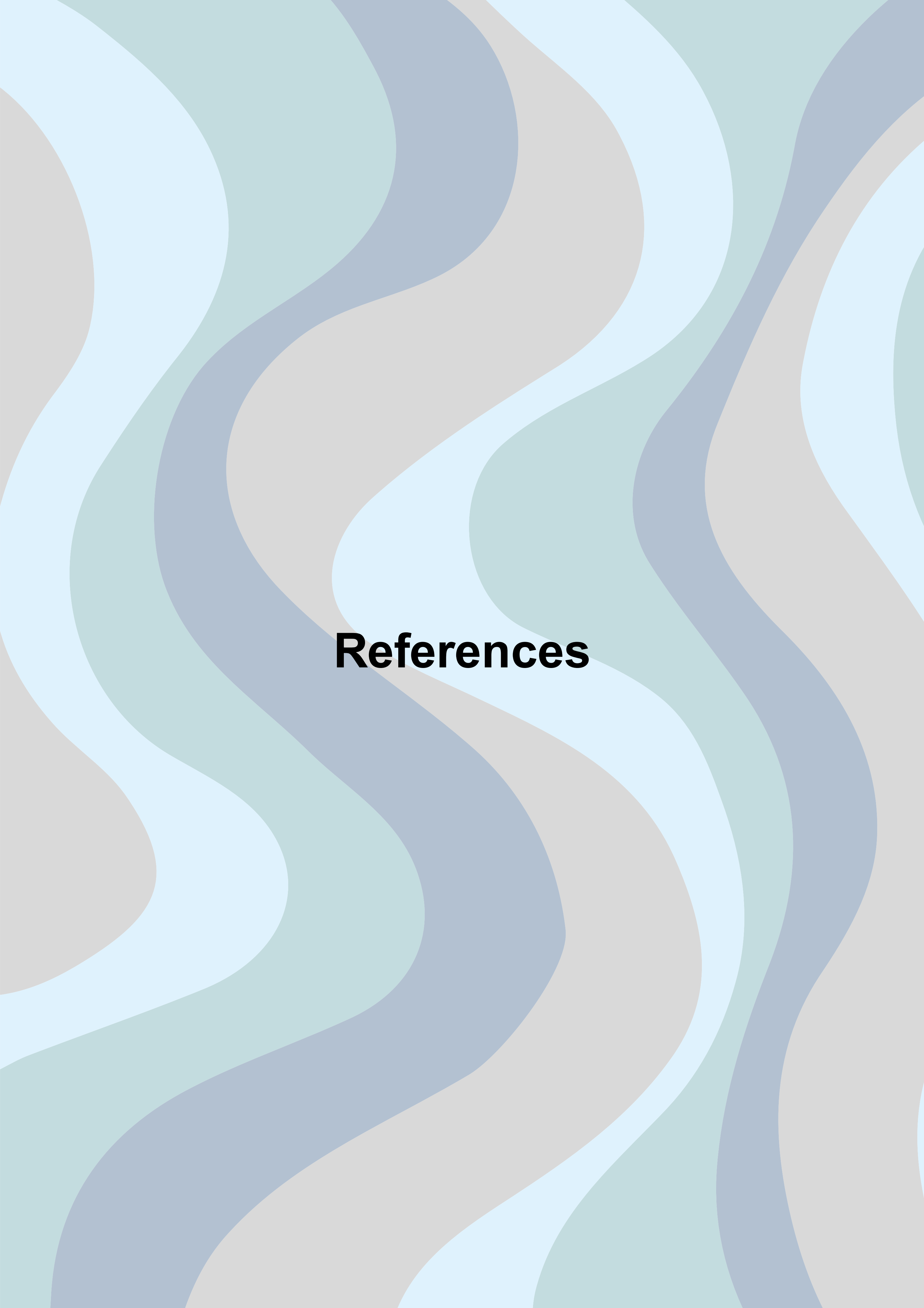
Reflecting on this graduation project, I can confidently say it has been both a fascinating and challenging journey. I chose this project because of my strong passion for combining strategic design with healthcare, as well as my interest in the military context. I aimed to deepen my understanding of how to apply my skills as a strategic designer in environments where a designerly approach is not common practice and to co-create meaningful solutions and transitions that have impact. Reflecting on this journey, I can state that I accomplished this goal.

Choosing the complex context of civilian and military trauma care, a context that I was not familiar with, was challenging. I learned the value of directly involving a wide range of stakeholders to have in depth discussions about the context. These discussions provided invaluable insights that literature alone could not have uncovered. Reflecting on the journey, I now recognize that it was those conversations that made the project both engaging and enlightening. Patients, for instance, shared their remarkable experiences, such as an attack by a suicide vehicle. I am honored that they felt comfortable sharing these stories with me, as their contributions were crucial to the success of the project.

Working alongside the CETC was a rewarding experience. They granted me the freedom to incorporate my research-based recommendations and adapt the design direction accordingly. My initial lack of expertise in trauma care kept me open-minded and receptive to all the information gathered during the research phase. By allowing the project to evolve in response to these insights, I am confident that the final design supports person-centered and value-based healthcare, ultimately benefiting both patients and health care providers.

Reflecting back, I am proud of my ability to immerse myself in an unfamiliar context to the extent that I can make valuable recommendations to increase the long-term impact of the design. The fact that Libra Care will be developed and implemented (a PhD-trajectory is established for this purpose) is rewarding for me as a strategic designer, and I see this as a big accomplishment in the beginning of my professional career. I am excited to see the further development and implementation of Libra Care and am curious to see its long-term value within civilian and military trauma care.

This project has made me realize how driven and internally motivated I become when working on projects that have a big social impact. I have also noticed how much other people like to contribute to a project that matters. This insight will guide my future career choice(s). In view of the increasing tensions in the world (which brings with it an increasing chance of military deployment), I am certainly open to delving further into military trauma care.



References

References

- Alsharef, A., Albert, A., Awolusi, I., & Jaselskis, E. (2023). Severe injuries among construction workers: Insights from OSHA's new severe injury reporting program. *Safety Science*, 163, 106126. https://doi.org/10.1016/j.ssci.2023.106126
- Atiyeh, B., Gunn, S., & Hayek, S. (2007, 31 december). *Military and Civilian Burn Injuries During Armed Conflicts*. https://pmc.ncbi.nlm.nih.gov/articles/PMC3188083/
- Australian Commission on Safety and Quality in Health Care. (z.d.). https://www.safetyandquality.gov.au/
- Australian Healthcare and Hospitals Association. (2022, March 25). *What is value-based health care?* [Video]. YouTube. https://www.youtube.com/watch?v=RpSunN_PD_w
- Ayers, J. W., Poliak, A., Dredze, M., Leas, E. C., Zhu, Z., Kelley, J. B., Faix, D. J., Goodman, A. M., Longhurst, C. A., Hogarth, M., & Smith, D. M. (2023). Comparing Physician and Artificial Intelligence Chatbot Responses to Patient Questions Posted to a Public Social Media Forum. *JAMA Internal Medicine*, *183*(6), 589. https://doi.org/10.1001/jamainternmed.2023.1838
- Barkley, S. (2023). *10 Ways to Figure Out What's Important to You*. Psych Central. https://psychcentral.com/health/10-proactive-ways-to-figure-out-whats-most-important-to-you#importance-of-priorities
- Belmont, P. J., McCriskin, B. J., Sieg, R. N., Burks, R., & Schoenfeld, A. J. (2012). Combat wounds in Iraq and Afghanistan from 2005 to 2009. *Journal Of Trauma And Acute Care Surgery*, *73*(1), 3–12. https://doi.org/10.1097/ta.0b013e318250bfb4
- Bradley, E., & Green, D. (2017). Involved, inputting or informing: "Shared" decision making in adult mental health care. *Health Expectations*, *21*(1), 192–200. https://doi.org/10.1111/hex.12601
- Brandwondenzorg Nederland. (2024). *Behandeling van brandwonden.* https://brandwondenzorg.nl/artikel/behandeling-van-brandwonden/
- Bortolin, M., & Ciottone, G. R. (2015). Urban Search and Rescue. In *Elsevier eBooks* (pp. 329–333). https://doi.org/10.1016/b978-0-323-28665-7.00052-2
- Busse, J. W., Jacobs, C. L., Swiontkowski, M. F., Bosse, M. J., & Bhandari, M. (2007). Complex Limb Salvage or Early Amputation for Severe Lower-Limb Injury: A Meta-Analysis of Observational Studies. *Journal Of Orthopaedic Trauma*, *21*(1), 70–76. https://doi.org/10.1097/bot.0b013e31802cbc43
- Cancio, L. C., Horvath, E. E., Barillo, D. J., Kopchinski, B. J., Charter, K. R., Montalvo, A. E., Buescher, T. M., Brengman, M. L., Brandt, M., & Holcomb, J. B. (2005). Burn Support for Operation Iraqi Freedom and Related Operations, 2003 to 2004. *Journal Of Burn Care & Rehabilitation*, *26*(2), 151–161. https://doi.org/10.1097/01.bcr.0000155540.31879.fb
- Canese, K., Jentsch, J., Myers, C., National Center for Biotechnology Information, National Library of Medicine, & National Institutes of Health. (z.d.). PubMed: The Bibliographic Database. In *The NCBI Handbook*. http://www.biodados.icb.ufmg.br/cromatina/NCBI_selected/PubMed_ch2d1.pdf
- Catalyst, N. (2017). What is Value-Based healthcare? *NEJM Catalyst*. https://catalyst.nejm.org/doi/full/10.1056/CAT.17.0558
- Centers for Disease Control and Prevention. (2009). *Crush Injury and Crush Syndrome* [Press-release]. https://www.acep.org/siteassets/uploads/uploaded-files/acep/clinical-and-practice-management/ems-and-disaster-preparedness/disaster-preparedness-grant-projects/blastinjury_crush_eng.pdf
- Center for Substance Abuse Treatment (US). (2014). *TIP 57: Trauma-Informed Care in Behavioral Health services* ((SMA) 14-4816). Samhsa.
- Covey, S. R. (1997). *The Seven Habits of Highly Effective People: Restoring the Character Ethic.* Macmillan Reference USA.
- Department of Defense, United States of America. Triage. In: "Emergency War Surgery NATO Handbook", part I, Types of wounds and injuries, chapter III,
- Doukas, C. W. C., Hayda, C. R. A., Frisch, H. M., Andersen, C. R. C., Mazurek, C. M. T., Ficke, C. J. R., Keeling, C. J. J., Pasquina, C. P. F., Wain, H. J., Carlini, A. R., & MacKenzie, E. J. (2013). The Military Extremity Trauma Amputation/Limb Salvage (METALS) study. *Journal Of Bone And Joint Surgery*, *95*(2), 138–145. https://doi.org/10.2106/jbjs.k.00734
- Eklund, J. H., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J., Sundler, A. J., Condén, E., & Meranius, M. S. (2018b). "Same same or different?" A review of reviews of person-centered and patient-centered care. *Patient Education And Counseling*, *102*(1), 3–11. https://doi.org/10.1016/j.pec.2018.08.029
- Elwyn, G., Frosch, D., Volandes, A. E., Edwards, A., & Montori, V. M. (2010). Investing in Deliberation: A Definition and Classification of Decision Support Interventions for People Facing Difficult Health Decisions. *Medical Decision Making*, *30*(6), 701–711. https://doi.org/10.1177/0272989x10386231
- Elwyn, G., Laitner, S., Coulter, A., Walker, E., Watson, P., & Thomson, R. (2010). Implementing shared decision making in the NHS. *BMJ*, *341*(oct14 2), c5146. https://doi.org/10.1136/bmj.c5146
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rollnick, S., Edwards, A., & Barry, M. (2012). Shared Decision Making: A Model for Clinical Practice. *Journal Of General Internal Medicine*, *27*(10), 1361–1367. https://doi.org/10.1007/s11606-012-2077-6
- Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I., Kjellgren, K., Lidén, E., Öhlén, J., Olsson, L., Rosén, H., Rydmark, M., & Sunnerhagen, K. S. (2011). Person-Centered Care — Ready for Prime Time. *European Journal Of Cardiovascular Nursing*, 10(4), 248–251. https://doi.org/10.1016/j.ejcnurse.2011.06.008
- EuroQol Research Foundation. EQ-5D-5L User Guide, 2019. Available from: https://euroqol.org/publications/user-guides.
- Ewout in kinderbrandwondencentrum. (2024, 2 oktober). RTL Nieuws & Entertainment. https://www.rtl.nl/boulevard/entertainment/artikel/5473652/kijkers-onder-indruk-aflevering-ewout
- Feuerriegel, S., Hartmann, J., Janiesch, C., & Zschech, P. (2023). Generative AI. Business & Information Systems Engineering, 66(1), 111–126. https://doi.org/10.1007/s12599-023-00834-7
- Field, J., Holmes, M. M., & Newell, D. (2019). PROMs data: can it be used to make decisions for individual patients? A narrative review: Patient Related Outcome Measures, Volume 10, 233–241. https://doi.org/10.2147/prom.s156291
- Genthon, A., & Wilcox, S. R. (2013). Crush Syndrome: A Case Report and Review of the Literature. *Journal Of Emergency Medicine*, 46(2), 313–319. https://doi.org/10.1016/j.jemermed.2013.08.052

- Gerdin, M., Wladis, A., & Von Schreeb, J. (2012). Surgical management of closed crush injury-induced compartment syndrome after earthquakes in resource-scarce settings. Journal Of Trauma And Acute Care Surgery, 73(3), 758–764. https://doi.org/10.1097/ta.0b013e3182513363
- Goodman, E., Kuiavsky, M., & Med, A. (2012) More than words. In *Elsevier eBooks (pp. 179-209)* https://doi.org/10.1016/b978-0-12-384869-7.00008-5
- Greaves, I., Porter, K., & Smith, J. (2003). Consensus Statement on the Early Management of crush Injury and Prevention of Crush Syndrome. *Journal Of The Royal Army Medical Corps*, *149*(4), 255–259. https://doi.org/10.1136/jramc-149-04-02
- Griffioen, I. P. M., Melles, M., Brands, J., Snelders, H. M. J. J., & Stiggelbout, A. (2022). Metro Mapping. A service design method to improve shared decision-making in oncology. *Journal for Human Factors*, *47*(2), 20-23.
- Handboek Brandwondenzorg. (z.d.). https://handboek.brandwondenzorg.nl/deel_0/iii-organisatie-brandwondenzorg
- Hartlief, G. (2018). Huidtransplantatie bij grote brandwond. *Nursing*, *24*(3), 34–37. https://doi.org/10.1007/s41193-018-0042-4
- Harrop, E., Scott, H., Sivell, S., Seddon, K., Fitzgibbon, J., Morgan, F., Pickett, S., Byrne, A., Nelson, A., & Longo, M. (2020). Coping and wellbeing in bereavement: two core outcomes for evaluating bereavement support in palliative care. *BMC Palliative Care*, 19(1). https://doi.org/10.1186/s12904-020-0532-4
- Het Nederlandse Rode Kruis. (2023, 14 augustus). *Brandwond - Rode Kruis Nederland*. Rode Kruis Nederland. https://www.rodekruis.nl/ehbo/ehbo-tips/brandwond/
- Hillary, W., Justin, G., Bharat, M., & Jitendra, M. (2016). *Value Based Healthcare.* Grand Valley State University, USA.
- Hoencamp, R., Huizinga, E. P., Van Dongen, T. T. C. F., Idenburg, F. J., Ramasamy, A., Leenen, L. P. H., & Hamming, J. F. (2014). Impact of Explosive Devices in Modern Armed Conflicts: In-Depth Analysis of Dutch Battle Casualties in Southern Afghanistan. *World Journal Of Surgery*, *38*(10), 2551–2557. https://doi.org/10.1007/s00268-014-2645-5
- Hoencamp, R., Idenburg, F. J., Vermetten, E., Tan, E., Plat, M., Hoencamp, E., Leenen, L. P., & Hamming, J. F. (2014). Impact of combat events on first responders: Experiences of the armed conflict in Uruzgan, Afghanistan. *Injury*, *46*(5), 863–869. https://doi.org/10.1016/j.injury.2014.12.012
- Hoencamp, R. (2015). *Task force Uruzgan, Afghanistan 2006-2010 : medical aspects and challenges* (Door Leiden University, Ministry of Defence, J. F. Hamming, L. P. H. Leenen, H. G. J. M. Vermetten, J. A. H. Bos, R. S. Breederveld, J. D. Graaf, E. Hoencamp, S. A. G. Meylaerts, I. B. Schipper, & E. C. T. H. Tan). https://www.trauma.nl/wp-content/uploads/2023/05/Proefschrift_Medical_Aspects_Challenges_0.pdf
- Hoencamp, R. (2016). Amputation: Not a failure for severe lower extremity combat injury. *Injury*, *48*(2), 371–377. https://doi.org/10.1016/j.injury.2016.12.001
- Jeevaratnam, J. A., & Pandya, A. N. (2013). One year of burns at a Role 3 Medical Treatment Facility in Afghanistan. *Journal Of The Royal Army Medical Corps*, *160*(1), 22–26. https://doi.org/10.1136/jramc-2013-000100
- Johns Hopkins Medicine. (2024). *Burns and Wounds*. https://www.hopkinsmedicine.org/health/conditions-and-diseases/burns
- Kahneman, D. (2011). *Thinking, Fast and Slow*. Penguin UK.
- Kamal, R. N., Lindsay, S. E., & Eppler, S. L. (2018). Patients should define value in health Care: a Conceptual framework. *The Journal Of Hand Surgery*, 43(11), 1030–1034. https://doi.org/10.1016/j.jhsa.2018.03.036
- Kauvar, D. S., Cancio, L. C., Wolf, S. E., Wade, C. E., & Holcomb, J. B. (2006). Comparison of Combat and Non-Combat Burns From Ongoing U.S. Military Operations. *Journal Of Surgical Research*, *132*(2), 195–200. https://doi.org/10.1016/j.jss.2006.02.043
- Kitzinger, J. (1995). Qualitative Research: Introducing focus groups. *BMJ, 311*(7000), 299-302. https://doi.org/10.1136/bmj.311.7000.299
- Kidanemariam, M. (2025, February 18). *Value-based healthcare: is it truly patient-centred?* Retrieved from https://hdl.handle.net/1887/4195449
- Krueger, C. A., Rivera, J. C., Tennent, D. J., Sheean, A. J., Stinner, D. J., & Wenke, J. C. (2015). Late amputation may not reduce complications or improve mental health in combat-related, lower extremity limb salvage patients. *Injury*, 46(8), 1527–1532. https://doi.org/10.1016/j.injury.2015.05.015
- Lander, N. R., & Nahon, D. (2017). An Integrity Model, Existential Perspective in Clinical Work With Men From a Gender and Health Perspective. In *Elsevier eBooks* (pp. 251–273). https://doi.org/10.1016/b978-0-12-803864-2.00009-2
- Langberg, E. M., Dyhr, L., & Davidsen, A. S. (2019). Development of the concept of patient-centredness – A systematic review. *Patient Education And Counseling*, *102*(7), 1228–1236. https://doi.org/10.1016/j.pec.2019.02.023
- Li, N., Wang, X., Wang, P., Fan, H., Hou, S., & Gong, Y. (2020). Emerging medical therapies in crush syndrome – progress report from basic sciences and potential future avenues. *Renal Failure*, *42*(1), 656–666. https://doi.org/10.1080/0886022x.2020.1792928
- Llewellyn-Thomas, H. A., & Crump, R. T. (2012). Decision Support for Patients. *Medical Care Research And Review*, *70*(1_suppl), 50S-79S. https://doi.org/10.1177/1077558712461182
- Long, B., Liang, S. Y., & Gottlieb, M. (2023). Crush injury and syndrome: A review for emergency clinicians. *The American Journal Of Emergency Medicine*, *69*, 180–187. https://doi.org/10.1016/j.ajem.2023.04.029
- Mandel, E. I., Bernacki, R. E., & Block, S. D. (2016). Serious illness conversations in ESRD. *Clinical Journal Of The American Society Of Nephrology*, *12*(5), 854–863. https://doi.org/10.2215/cjn.05760516
- March Protocol (2024). Ministry of Defence.OLVG *Brandwonden*. (2024, 5 juni). https://www.olvg.nl/medische-informatie/brandwonden/
- McIntosh, B., Ascough, J., Twery, M., Chew, J., Elmahdi, A., Haase, D., Harou, J., Hepting, D., Cuddy, S., Jakeman, A., Chen, S., Kassahun, A., Lautenbach, S., Matthews, K., Merritt, W., Quinn, N., Rodriguez-Roda, I., Sieber, S., Stavenga, M., . . . Voinov, A. (2011). Environmental decision support systems (EDSS) development – Challenges and best practices. *Environmental Modelling & Software*, *26*(12), 1389–1402. https://doi.org/10.1016/j.envsoft.2011.09.009

- Metro Mapping. (z.d.) *Metro Mapping - De zorg verbeteren met Metro Mapping.* https://metromapping.org/en
- Michaeli, B. G. D. (1979). Medicine on the Battlefield: A Review. *Journal Of The Royal Society Of Medicine*, *72*(5), 370–373. https://doi.org/10.1177/014107687907200512
- Miles, M., Francis, K., CHapman., & Taylor, B. (2013). Hermeneutic phenomenology: A methodology of choice for midwives. *International Journal Of Nursing Practice, 19*(4), 409-414. https://doi.org/10.1111/ijn.12082
- Ministerie van Defensie. (2024, 25 juni). *Over het Militair Revalidatie Centrum Aardenburg*. Revalidatiecentrum | Defensie.nl. https://www.defensie.nl/onderwerpen/revalidatiecentrum/over-het-mrc
- Ministry of Defence (2024). *E-learning doctrine ZHKH for military personnel.*
- MRC Aardenburg. (2022, 18 oktober). *Militair Revalidatie Centrum Aardenburg | Revalideren bij het MRC* [Video]. YouTube. https://www.youtube.com/watch?v=fUk0Ib3eRpU
- National Health Council. (z.d.). *Patient Experience Mapping Toolbox*. https://nationalhealthcouncil.org/wp-content/uploads/2024/03/PEMT-Interviewer-Training-Guide-V1-final.pdf
- Nederlandse Brandwonden Stichting. (2016, 5 oktober). *Een "Virtual" kijkje in een brandwondencentrum* [Video]. YouTube. https://www.youtube.com/watch?v=KBQS1aWoAdw
- Nederlandse Brandwonden Stichting. (2018, 28 december). *HEFTIG BEZOEK AAN HET BRANDWONDENCENTRUM | mijn dossier* [Video]. YouTube. https://www.youtube.com/watch?v=xzZC2_xabho
- Owens, B. D., Kragh, J. F., Wenke, J. C., Macaitis, J., Wade, C. E., & Holcomb, J. B. (2008). Combat Wounds in Operation Iraqi Freedom and Operation Enduring Freedom. *Journal Of Trauma And Acute Care Surgery*, *64*(2), 295–299. https://doi.org/10.1097/ta.0b013e318163b875
- PCVBHC Project Team*, Allvin, T., Bos, W., Bruins, B., Collins, A., Davey, J., Dedeu, T., Hamson, A., Loehrer, S., McCabe, C., Navarro, M., Saunders, C., Sehmi, K., Spieker, N., Stein, A., Tunis, S., Vaz Carneiro, A., Wainer, Z., Wilkinson, J., Stiggelbout, A. (z.d.). *Person-Centred Value-Based health care*. https://sprink.co.uk/files/2022_07_04_PCVBHC_Report.pdf
- Personal values website (2025). *Personal values assessment. https://personalvalu.es/*
- Porter, M. E., & Tiesberg, E. O. (2006). *Redefining Health care: creating value-based competition on results: Vol. Porter ME, Michael Porter EOT, Teisberg EO.* Harvard Business School Press.
- PubMed. (z.d.). PubMed. https://pubmed.ncbi.nlm.nih.gov/about/
- Rijnmond. (2016, 30 april). *Compilatie 7 Minuten - Brandwondencentrum* [Video]. YouTube. https://www.youtube.com/watch?v=gJKyhuHkh2w
- Robertson, T., & Simonsen, J. (2012). Challenges and Opportunities in Contemporary Participatory Design. *Design Issues*, 28(3), 3–9. https://doi.org/10.1162/desi_a_00157
- Sackett, D. L. (1997). Evidence-based medicine. *Seminars in Perinatology*, 21(1), 3–5. https://doi.org/10.1016/s0146-0005(97)80013-4
- Sanders E. B.-N. (2000). Generative tools for codesigning. In Scrivener S. A. R., Linden J. B., Woodcock A. (Eds.), *Collaborative design* (pp, 3–12). Springer-Verlag. https://doi.org/10.1007/978-1-4471-0779-8_1
- Scott, D. J., Arthurs, Z. M., Stannard, A., Monroe, H. M., Clouse, W. D., & Rasmussen, T. E. (2013). Patient-based outcomes and quality of life after salvageable wartime extremity vascular injury. *Journal Of Vascular Surgery*, 59(1), 173-179.e1. https://doi.org/10.1016/j.jvs.2013.07.103
- Sever, M. S., Vanholder, R., & Lameire, N. (2006). Management of Crush-Related Injuries after Disasters. *New England Journal Of Medicine*, 354(10), 1052–1063. https://doi.org/10.1056/nejmra054329
- Shawen, S. B., Keeling, J. J., Branstetter, J., Kirk, K. L., & Ficke, J. R. (2010b). The Mangled Foot and Leg: Salvage Versus Amputation. *Foot And Ankle Clinics*, 15(1), 63–75. https://doi.org/10.1016/j.fcl.2009.11.005
- Schein, E.H., Jr. & MIT Sloan School of Management (1996). *Career Anchors Revisited: Implications for Career Development in the 21st Century*. https://factorhumano.wordpress.com/wp-content/uploads/2007/05/career-anchors-revisited-by-edgar-h-Schein.pdf
- Simonse, L., Albayrak, A., & Starre, S. (2019). Patient journey method for integrated service design. *Design For Health*, 3(1), 82–97. https://doi.org/10.1080/24735132.2019.1582741
- Sleeswijk Visse, F. S., Stappers, P. J., Van Der Lugt, R., & Sanders, E. B. (2005). Contextmapping: experiences from practice. *CoDesign, 1(2),* 119-149. https://doi.org/10.1080/15710880500135987
- Smith, J., & Greaves, I. (2003). Crush Injury and Crush Syndrome: A Review. *Journal Of Trauma And Acute Care Surgery*, *54*(5), S226–S230. https://doi.org/10.1097/01.ta.0000047203.00084.94
- Srur, A., Kelley, T., Bos, W., Edwards, A., Jakab, I., Joseph-Williams, N., Kidanemariam, M., Lander, C., Lehman, R., McCaffery, K., Montori, V., Redding, D., Rogan, E., Sanderson, J., Slade, S., South, K., Tinetti, M., Weel, A., Allvin, T., . . . Stiggelbout, A. M. (2024b). Enabling people accessing care and their clinicians to collaborate in a shared goal-setting and decision making process to align care to personal values, goals and preferences. In *Person-Centred Value-Based Health Care* [GLOBAL POLICY]. Sprink Ltd. https://sprink.co.uk/files/PCVBHC_Report_2.pdf
- Strauss, M. B., & Garcia-Covarrubias, L. (2008). Crush injuries. In *Elsevier eBooks* (pp. 427–449). https://doi.org/10.1016/b978-1-4160-3406-3.50025-1
- Strong Medicine. (2016, 10 november). *An Introduction to Evidence Based Medicine* [Video]. YouTube. https://www.youtube.com/watch?v=P-G2veeYC1Q
- Strong Medicine. (2023, 18 juli). *Can AI outperform Stanford Medical Students? (My own research!)* [Video]. YouTube. https://www.youtube.com/watch?v=eB4gxT2ciTM
- Take5media Linlin. (2022, 10 november). *Opvang brandwonden patiënten Beverwijk'22* [Video]. YouTube. https://www.youtube.com/watch?v=NcBslKhry24
- Team Blitzllama. (2024, 28 januari). *Generative research: Everything you need to know (2024).* https://www.blitzllama.com/blog/generative-research

- Teisberg, E., Wallace, S., & O'Hara, S. (2019). Defining and Implementing Value-Based Health Care: A Strategic Framework. *Academic Medicine*, 95(5), 682–685. https://doi.org/10.1097/acm.0000000000003122
- Tekin, L., Safaz, Ý., Göktepe, A. S., & Yazýcýođlu, K. (2009). Comparison of Quality of Life and Functionality in Patients with Traumatic Unilateral below Knee Amputation and Salvage Surgery. *Prosthetics And Orthotics International*, 33(1), 17–24. https://doi.org/10.1080/03093640802482542
- Umberson, D., & Montez, J. K. (2010). Social Relationships and Health: A Flashpoint for Health Policy. *Journal of Health and Social Behavior*, 51(1_suppl), S54–S66. https://doi.org/10.1177/0022146510383501
- Usuda, D., Shimozawa, S., Takami, H., Kako, Y., Sakamoto, T., Shimazaki, J., Inoue, J., Nakayama, S., Koido, Y., & Oba, J. (2023). Crush syndrome: a review for prehospital providers and emergency clinicians. *Journal Of Translational Medicine*, 21(1). https://doi.org/10.1186/s12967-023-04416-9
- Van Dongen, T. T., Huizinga, E. P., De Kruijff, L. G., Van Der Krans, A. C., Hoogendoorn, J. M., Leenen, L. P., & Bortolin, M., & Ciottone, G. R. (2015). Urban Search and Rescue. In *Elsevier eBooks* (pp. 329–333). https://doi.org/10.1016/b978-0-323-28665-7.00052-2
- White, J. (2020). PubMed 2.0. *Medical Reference Services Quarterly*, 39(4), 382–387. https://doi.org/10.1080/02763869.2020.1826228
- WHO EMT Secretariat. (2016). Management of limb injuries during disasters and conflicts. https://extranet.who.int/emt/sites/default/files/_A%20Field%20Guide.pdf.
- World Health Organization: WHO. (2023, 13 oktober). *Burns*. https://www.who.int/news-room/fact-sheets/detail/burns
- Wu, B. (2020). Social isolation and loneliness among older adults in the context of COVID-19: a global challenge. Global health research and policy, 5(1), 27.
- Yang, Y., Schorpp, K. M., & Harris, K. M. (2014). Social support, social strain and inflammation: Evidence from a national longitudinal study of U.S. adults. *Social Science & Medicine*, 107, 124–135. https://doi.org/10.1016/j.socscimed.2014.02.013
- Yayik, A. K. (2023). Crush syndrome patient care in intensive care unit. *Cerrahpasa Medical Journal*. https://doi.org/10.5152/cjm.2023.23057
- Yazici, R. (2023). A Comprehensive Review for Refreshing the Crush Syndrome Knowledge After the Devastating Earthquake in Türkiye. *Comprehensive Medicine*. https://doi.org/10.14744/cm.2023.03511
- Zhang, P., & Boulos, M. N. K. (2023). Generative AI in Medicine and Healthcare: Promises, Opportunities and Challenges. *Future Internet*, 15(9), 286. https://doi.org/10.3390/fi15090286
- Zhang, X., Bai, X., & Zhou, Q. (2014). First-aid treatments of crush injuries after earthquake: 2 special cases. *The American Journal Of Emergency Medicine,* 32(7), 817.e3-817.e4. https://doi.org/10.10*16/j.ajem.2013.12.062*

Appendix

Appendix A: Approved project brief

TUDelft

DESIGN FOR our future

IDE Master Graduation Project

Project team, procedural checks and Personal Project Brief

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

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

STUDENT DATA & MASTER PROGRAMME

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

Family name: Broos 7435

Initials: L

Given name: Lynn

Student number: 4726316

IDE master(s): IPD ☐ DfI ☐ SPD ☑

2nd non-IDE master:

Individual programme *(date of approval)*:

Medisign ☑

HPM ☐

APPROVAL OF BOARD OF EXAMINERS IDE on SUPERVISORY TEAM -> to be checked and filled in by IDE's Board of Examiners

Does the composition of the Supervisory Team comply with regulations?

YES	★	Supervisory Team approved
NO		Supervisory Team not approved

Comments:

Based on study progress, students is ...

★	ALLOWED to start the graduation project
	NOT allowed to start the graduation project

Comments:

Sign for approval (BoEx)

[redacted] Digitally signed by [redacted]
Date: 2024.10.23 10:44:43 +02'00'

Name [redacted]

Date 23 Oct 2024

Signature

Project title Increasing the maximum survivability of military and civil trauma patients

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

Introduction

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

The Civil-Military Centre of Expertise for Trauma Care (CETC) is established on 24 january 2024, as a collaboration between the Dutch ministry of Defence and the University of Medical Centre Utrecht, to jointly and otherwise contibute to improving complex acute care. Their mission is to achieve zero avoidable mortality and minimise disability after injury for both military personnel and civillians. The Centre conducts multiple projects that contribute to this mission.

This graduation project will focus on mapping the military and civilian trauma care chain (patient journey) so that it becomes clear which and where care and knowledge questions exist in the trauma care chain. The project focusses on two specific physical trauma's: burns and crush injury. Based on this, appropriate research questions for scientific research and innovations can be formulated and education and/or training to optimize the trauma care chain can be developed. Additionally, an interactive tool will be designed to generate customized care paths for polytrauma patients. One of the main goals of the tool is to give more opportunity for shared decision-making within the care path.

The main stakeholders are the CETC, trauma specialists, trauma patients, the Ministery of Defence, and the patients family.

Limitations of the domain are the availability of patients and experts that have experienced the specific trauma care paths of focus. Fortunately, the CETC has a broad network and can facilitate the contact with specialist and medical centers.

Problem Definition

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

Assignment: (1) Investigate the patient journeys of trauma care for burns and crush injury for both military and civilians and (2) create an interactive design tool that enables shared decision making for polytrauma patients.

The assignment contributes to the goal of increasing the maximum survivability of trauma care patients. By identifying the knowledge gaps new research can be started that is important for the domain of trauma care. The optimalisation focusses on patient decision-making and contributes to a shift towards value-based healthcare. The interactive tool is a mean to enable shared decision-making for polytrauma patients. The tool will be based on the principles of the MetroMapping method and will generated customized care paths where the patients have the room to create preferences for certain options/treatments (comparable to cancer care)

Assignment

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

(1) Investigate the patient journeys of trauma care for burns and crush injury for both military and civilians and (2) create an interactive design tool that enables shared decision making for polytrauma patients.

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

How?
1. Mapping the military and civilian trauma care chain (patient journey) for burns and crush injury (by conducting interviews for the 4 care paths (1) military burns, (2) civilian burns, (3) military crush injury and (4) civilian crush injury. Observations (at least one for burns and one for crush injury treatment) and interviews (2-5 for each care path - including trauma care specialists) will be performed.
--> find insights into the civilian, military, and 'civil-military connectedd' care questions and knowledge gaps
--> find opportunities for optimalisation (focus on shared decision-making)
2. Design an interactive tool for polytrauma patients that generates a customized care path based on given input (based on the Principles of MetroMapping) Enables shared decision-making and value-based healthcare.
--> input can be given by patient, experts, family, other stakeholders
--> process is based on shared decision-making
--> output is a customized care path generated by the tool based on the give input

Project planning and key moments

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

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

Kick off meeting 7 Oct 2024
Mid-term evaluation 13 jan 2025
Green light meeting 1 apr 2025
Graduation ceremony 12 May 2025

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

Part of project scheduled part-time	✓
For how many project weeks	27
Number of project days per week	4,0

Comments:
Regularly 4 days, sometimes 3 days a week due to activities and exercises as a working student at the Ministry of Defence (see worked-out schedude) Total=100days

Personal learning abitions:

- Due to personal interest I want to learn about the medical care of military. What are the differences with the civillian care paths?
- Qualitative research & thematic analysis: During my study I performed quantitative research, but did not really practice with qualitative research (so making an interview guide, conducting interview, transcribing, coding the data, etc).
- I want to get an in-depth understanding of the MetroMapping tool and methodology (and comparable tools). This tool will be used as inspiration for the design phase
- The development of a design tool. During my study I have never developed a design tool, and for this project it will be a deliverable. Therefore, I will do in-dept study into different design tool and investigate what aspects are suitable for the information about trauma care I collect.

Appendix B: Patient recruitment flyers

ONDERZOEKSPROJECT CIVIELE & MILITAIRE TRAUMA ZORG

Meld je aan!

Voor een onderzoeksproject naar de civiele en militaire traumazorg van polytrauma patiënten ben ik opzoek naar patiënten en medische experts.

Graag zou ik in gesprek gaan met patiënten die ervaringen hebben met:

- civiele trauma zorgtraject brandwonden
- militaire trauma zorgtraject brandwonden
- civiele trauma zorgtraject verbrijzeling
- militaire trauma zorgtraject verbrijzeling

Graag zou ik in gesprek gaan met medische experts die ervaring hebben met:

- Trauma zorg voor militairen (role 1 - role 4 MTF)
- Specialisatie brandwonden
- Specialisatie verbrijzeling
- Medewerkers brandwondencentrum
- Medewerkers trauma zorg ziekenhuis

TU Delft

Civil-Military Centre of Expertise for Trauma Care – The Netherlands
Ministry of Defence
UMC Utrecht

Ministry of Defence

GOED OM TE WETEN

JOUW ERVARING

In het gesprek wordt gevraagd naar uw ervaringen met het zorgtraject. Hoe heb je de verschillende stappen ervaren die je als patiënt moest doorlopen? Hoe was de begeleiding? Hoeveel input heb je gehad in het proces? Wat zijn de belangrijkste verbeterpunten?
Medische experts vertellen de ervaringen met het zorgtraject vanuit hun expertise.

HET DOEL

Met de gegevens verzameld uit meerdere interviews (met militairen en burgers) zullen we de zorgpaden analyseren en aanbevelingen doen voor verbeteringen. Wij willen de patiënt meer betrekken bij de besluitvorming. Daarom zal er een tool ontworpen worden dat gedeelde besluitvorming binnen de traumazorg mogelijk maakt en stimuleert. Deze tool draagt bij aan waarde gedreven gezondheidszorg.

HET INTERVIEW

Het interview werkt met een ethisch toestemmingsformulier om de deelnemers te beschermen. Het interview duurt ongeveer 45 minuten. Deelnemers zijn op elk moment vrij om vragen over te slaan of het interview te beëindigen als zij zich niet comfortabel voelen. Locatie van het interview is bespreekbaar.

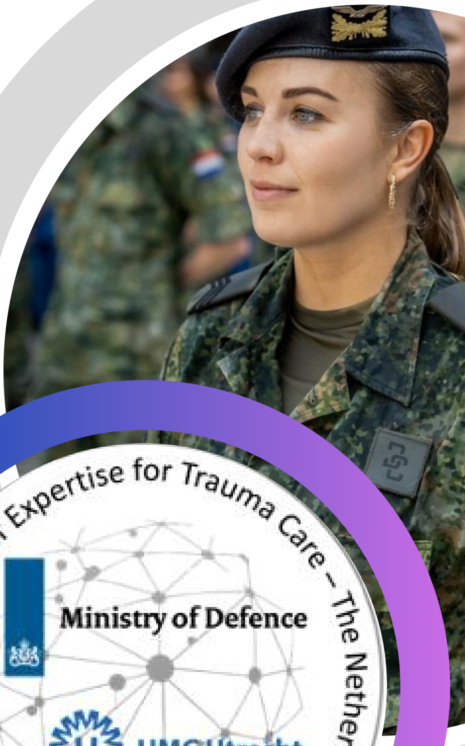
JOUW PRIVACY

Het interview zal worden afgenomen met een masterstudent Strategic Product Design & Medisign van de TU Delft (Faculteit Industrieel Ontwerpen). Het interview wordt **niet** op video opgenomen en alle data wordt anoniem opgeslagen. De gegevens zijn nooit terug te herleiden naar de deelnemers.

EEN TOOL OM

WAARDE GEDREVEN TRAUMA REVALIDATIE

MOGELIJK TE MAKEN, OOK TIJDENS HOOFDTAAK 1!



Mijn naam is Lynn Broos en ik ben militair werkstudent bij Defensity College. Daarnaast ben ik master student Strategic Product Design aan de TU Delft (met een medische specialisatie). Voor mijn afstudeerproject ontwikkel ik **een tool die waardegedreven trauma zorg (revalidatie)** ondersteunt, voor zowel militairen als civiele patiënten. Dit doe ik in opdracht van het Civil-Military Centre of Expertise for Trauma Care (CETC).

Wat doet de tool?

- Helpt patiënten hun **persoonlijke waarden, doelen en voorkeuren** naar voren te brengen. Wat is het belangrijkst in het leven van deze specifieke persoon?
- Helpt patiënten en artsen met verwachtingsmanagement, het stellen van **persoonlijke doelen** binnen het zorgtraject en het evalueren van deze doelen
- Helpt patiënten met **coping en acceptatie** (door te relativeren en door de patiënt te laten beseffen dat kwaliteit van leven op meerdere manieren kan worden bereikt en dat hun verliezen vaak kunnen worden verzacht of gecompenseerd).

UW BIJDRAGE

Graag wil ik met u in gesprek gaan om het concept van deze tool te bespreken. Waarom is dit belangrijk? Door de tool te ontwikkelen in nauwe samenwerking met patiënten en professionals, zorgen we ervoor dat de tool ook echt iets bijdraagt aan het zorgtraject.

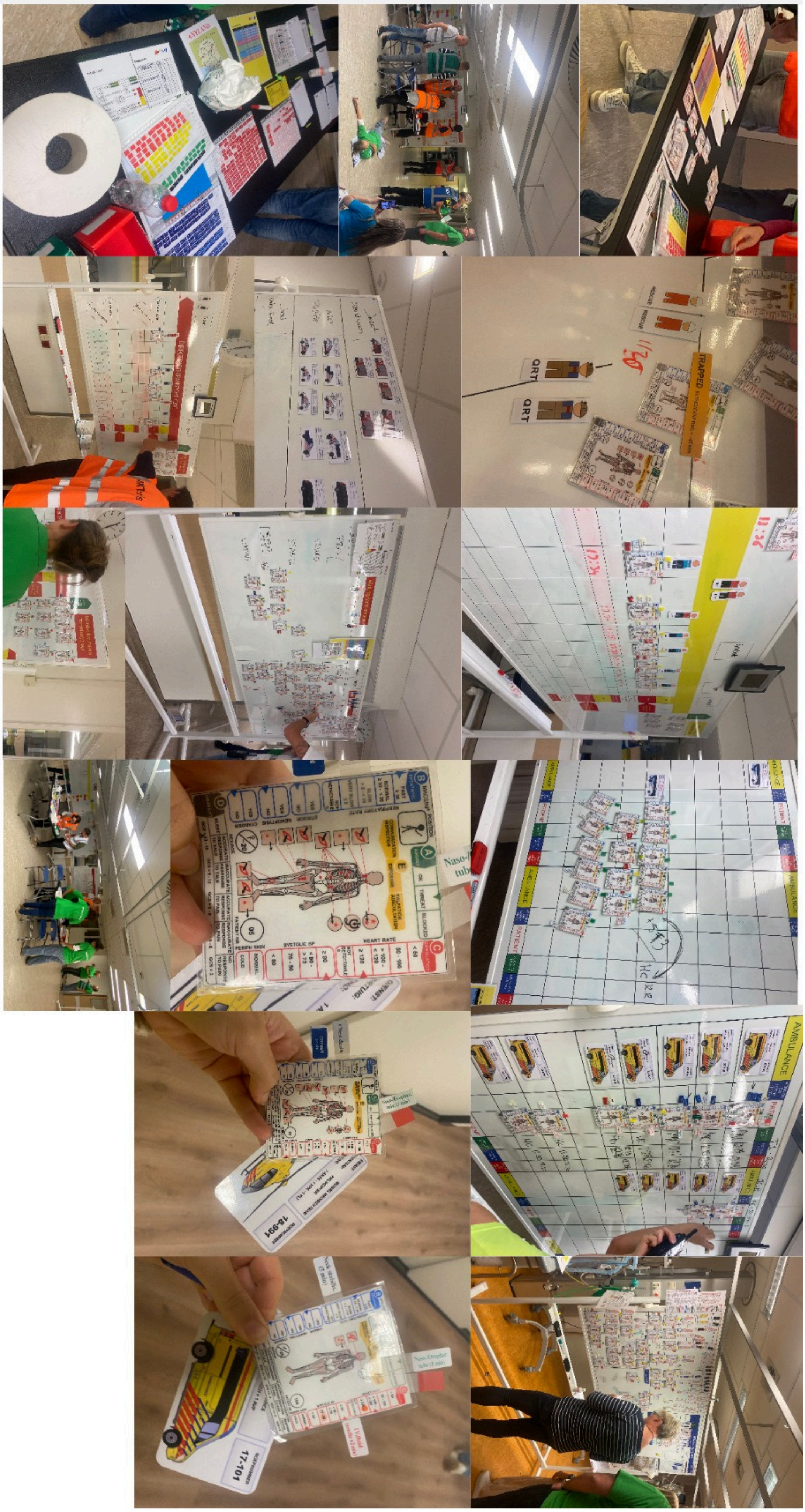
Ik ben benieuwd naar uw traumazorg & revalidatie ervaring en wil met u bespreken hoe een dergelijke tool u had kunnen ondersteunen in dit traject. Aan de hand van uw input kan ik de tool verder door ontwikkelen.

Daarnaast ben ik benieuwd hoe u zich heeft aangepast aan uw nieuwe situatie. Tijdens meerdere interviews met patiënten kwam naar voren dat zij graag hadden geleerd van de verhalen van lotgenoten. In de tool wil ik verhalen over coping & acceptatie (anoniem) gaan verwerken. Vandaar dat ik benieuwd ben naar uw specifieke ervaring hiermee. Mocht u dit niet willen delen (en alleen feedback geven op de tool algemeen) dan is dit geen probleem!

We kunnen een interview online inplannen of ik kan naar uw locatie komen. **Uw antwoorden blijven volledig anoniem en dit onderzoek heeft ethische goedkeuring.**

Door deel te nemen draagt u bij aan het verbeteren van trauma zorg voor zowel militairen als civiele patiënten!

Appendix C: Observations - Medical Response to Major Incident training



Appendix C: Observations - Annual exercise Calamiteiten hospital

Appendix D: Map My Experience Trauma Care tool

The National Health Council (NHC) developed a Patient Experience Mapping Tool (PEMT) to help researchers capture patient experience data more holistically and in a standardized manner across chronic diseases (National Health Council, z.d.). The tool helps the researcher to collect patient experience data including the impact of the disease/condition/therapy/investigation and the patient preferences with respect to different treatment options. The tool includes three phases: live before diagnosis, getting a diagnosis, and living with a diagnosis. The tool helps the collection of valuable information during each phase, for example: information gathering, symptoms, examination, diagnosis, treatment, emotional health, follow-up care, etc. The collection of patient experience data can be used to create shared decision-making tools that contribute to patient-centred and value based health care.

The Patient Experience Mapping Tool (PEMT) is developed especially for patients with chronic diseases. However, the tool can be tailored for specific health conditions. For this graduation project, the tool is tailored to make it suitable for acute trauma care patients. This new tool is named the Map My Experience Trauma Care Tool (MMETC). The adjusted tool includes the following phases: moment of accident, first aid and transportation, examination, treatment and surgeries, after care at hospital, and after care at home. Similarly, the MMETC uses textual and visual cues to capture patient experience data. All cues, as well as the life factors, are assessed and adjusted in terms of importance for the study about trauma care. Additionally, an interview guide that is tailored in combination with the new MMETC is developed.

The Map My Experience Tool is a tool to help guide discussions with patients about their experiences. The tool makes sure no important insights about a patient’s care journey are missed. The tool chronologically walks through the different stages (islands) of trauma care: the moment of the accident, first aid & transportation, examination, treatment & surgeries, after care in the trauma center, and after care at home. The brown islands indicate that the patient is treated within a trauma care center. The tool uses textual and visual cues to capture patient experience data. Also, important life factors are evaluated in every stage. The interviewer should encourage the patients to draw and write on the map, to make the interview generative. The purpose of the map is to guide the discussion, but at any time the interviewer may deviate from the approach. The map is used in combination with an interview guide.

Legenda:
(1) red mark cross = incident, (2) clock tower = time span, (3) humans = social interaction, (4) trees = emotions and feelings, (5) healthcare cross = interaction with healthcare professionals, (6) stethoscope = physical examination, (7) bandages = treatments, (8) information icon = information provision, (9) question mark = uncertainty, (10) mountain = difficulties, (11) surgery equipment = surgery, (12) gondola = follow-up treatments, and (13) house = end of care.

Life factors:
(1) family and support, (2) patient input, (3) healthcare insurance, (4) finances, (5) (mental) health, (6) medical knowledge, and (7) work.

CETC

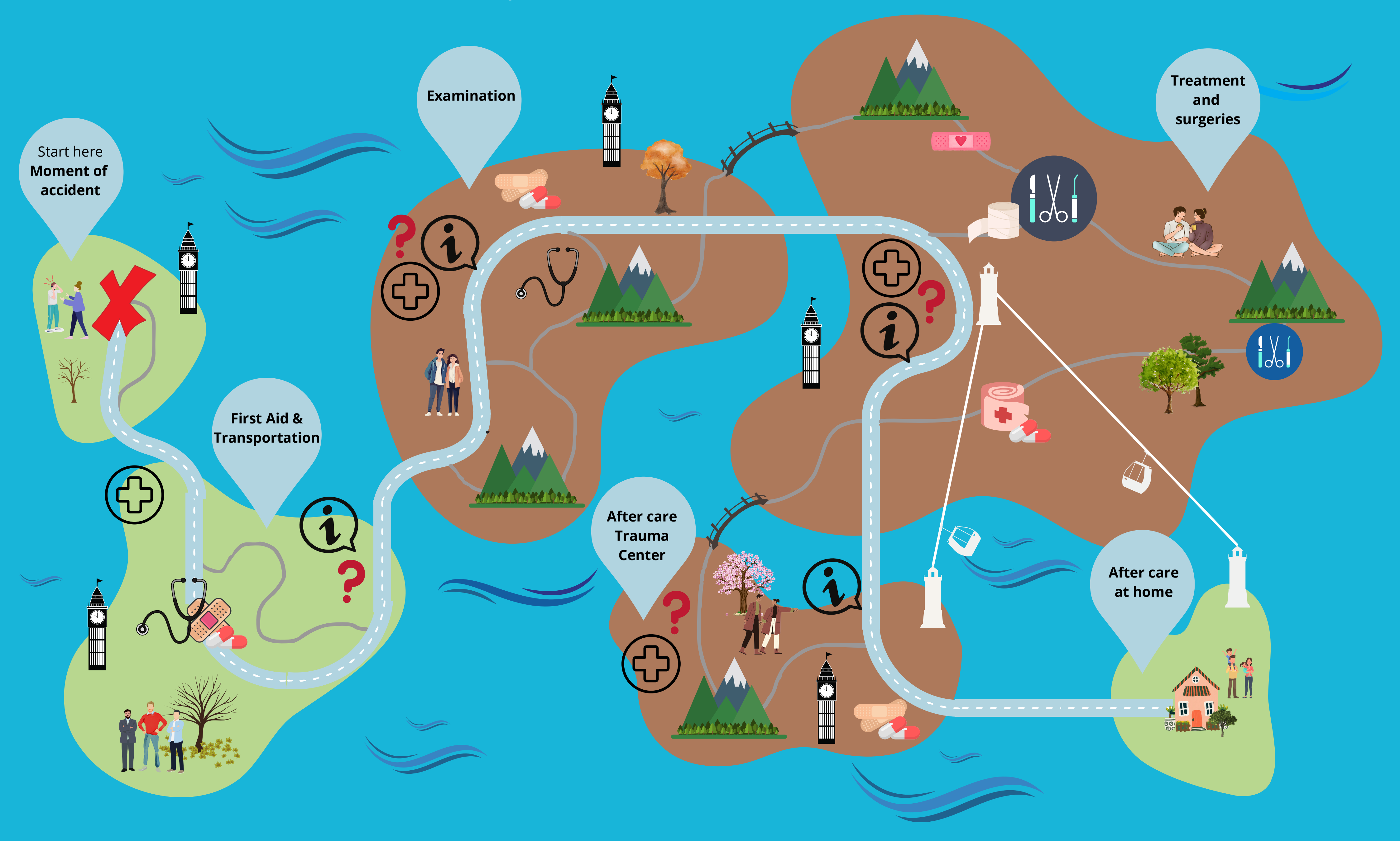
Map My Experience Trauma Care

Every patient has different experiences with their health. This map can be used as guide to think about your own experiences with trauma care. The map starts with the trauma accident, through your examination and treatment, to when you leave the trauma care centre.

Life Factors

As you go along, think about how other ‘life factors’ have played a role in your experience, such as:

- Family & Support
- Patient Input
- Healthcare insurance
- Finances
- (Mental) Health
- Medical Knowledge
- Work



Appendix E: Patient interview guide

Hello, my name is Lynn Broos. Thank you for speaking with me today. I am conducting this interview for the Centere of Expertise for Trauma Care (CETC). The study I conduct is for my graduation project at the TU Delft. This interview will take about 45 minutes to complete. During this interview there are no right or wrong answers, since we are interested in experiential aspects which are very subjective.

The purpose of this interview is to learn about your experience with trauma care for burns/crush injury, from the moment of the accident towards the moment you left the trauma care center. We will use a patient experience mapping tool to guide this interview and collect valuable data. With the data collected from multiple interviews (with military and civilians) I will analyze the care pathways and make recommendations for improvements. I want to enable patients to be more involved during decision-making. Therefore, a tool will be created that enables shared-decision making within trauma care, resulting in more value-based healthcare. Do you have any questions about the goal of the study or interview?

To get started, we will go through the privacy disclosures and I'll get your consent to participate. Then, I'll ask some general questions about you. After that, I will introduce the "Map My Experience Trauma Care" tool that will help guide the interview. Lastly, I'll be asking you a wide range of questions about the trauma care you received. We are interested in your thoughts and opinions. There are no right or wrong answers. You do not have to answer any questions that make you feel uncomfortable. Just tell me when there is a question you prefer to not answer and I will skip to the next question. I can use any materials you create during the interview, so feel free to use the tools and sketch or write on them. Do you have any questions about the interview or the storage of data?

In addition to the audio recording, I will also make some notes during the interview.

Let's have a look at the informed consent form. Let's start the audio recording.

Start recording

This is participant [ID] and today's date is [date]. Could you please confirm once more for me that you agree to be recorded?

Show Map My Experience Tool for Trauma Care

This is called the "Map My Experience Trauma Car" tool. It's a tool to help guide discussions with patients about their experiences to make sure we don't forget to talk about important parts of a patient's journey. Keep in mind, the purpose of the map is just to help guide our discussion. We will note the things that you have experienced and be sure to focus on those during our conversation. As we go through these items, if you have a question or if something does not make sense, please let me know and I can elaborate more to be sure it is clear. Let's begin on the left side of the map with a general overview. As you can see, the map has multiple islands for different phases of the care pathway. I will now be taking a closer look at symbols and icons on each island.

Discuss the meaning of different islands, life factors and cues. Is there something that you do not understand?

We will walk through this visual together, and we will make sure to capture all relevant information. At any time you are free to sketch or make notes on the map, you are even encouraged to do so. At the end of this journey the map should visualize your specific care journey! During this journey, I will continuously ask how the life factors influenced your experience in a certain phase. Since we are talking about serious physical trauma that has happened, I understand it can be hard to share this information. Please share only what you feel comfortable sharing and let me know if you need a break.

During the interview, I will fill in a template that maps your personal journey. At the end we will take some time to discuss this together and make some final adjustments. Do you have any questions before we continue?

Moment of accident

So let's start at the left end of the visual. This care journey starts at the moment of the accident that caused the physical trauma, burns/crush injury in your case.

- Can you explain how the accident happened? What do you remember of it? Please share only what you feel comfortable sharing.
- What did you feel physically?
- What did you feel emotionally? **Can you sketch your emotions on the map with a smiley and a rating (0-10)?**
- **Can you describe the different steps that happened during this phase, from the moment of the accident to the moment emergency services arrived?**
- Were there bystanders and what was their role?
- When did the accident happen? How long did it take before you received care?
- When the accident happened did you directly understand the severity of your injury?
- Were there difficulties in receiving the care needed? Could you mention them?
- What is the main thing that you remember as pleasant during this phase? Could you explain why?
- What is the main thing that you remember as unpleasant during this phase? Could you describe why?
- What was the influence of the different life factors on this phase?

First Aid and Transportation

- **Can you describe the different steps that happened during this phase, from the moment emergency services arrived until the moment you arrived at the trauma care center?**
- What was your first interaction with healthcare professionals? How did you experience this?
- How did you experience first aid provided?
- Were there bystanders involved in this process?
- To what degree did the healthcare professionals inform you about what was happening? Did you understand the situation?
- To what degree were you uncertain/insecure about what was happening?
- Was your family involved or notified? Could you tell me more about this? What would you have desired?
- How were you transported to the trauma care facility? How did you experience this?
- What was the timespan from the moment healthcare specialists arrived to the moment you entered the trauma care center?
- Do you remember what your emotions were? **Can you sketch your emotions on the map with a smiley and a rating (0-10)?**
- Did you know what was happening? Would you have desired it otherwise?
- Were there difficulties during first aid and/or transportation? Could you explain?
- What is the main thing that you remember as pleasant during this phase? Could you explain?
- What is the main thing that you remember as unpleasant during this phase? Could you explain?
- What was the influence of the different life factors on this phase?

Examination (at trauma care facility)

- How did you experience the transfer from emergency services to the trauma center?
- **Can you describe the different steps that happened during this phase, from the moment you arrived at the trauma care center until the moment you received your treatment plan?**
- How did you experience the interaction with the different healthcare professionals?
- How did you experience the examination? Were there difficulties?
- How long did the examination take?
- How did you experience the provision of information by healthcare professionals?
- How long did it take before the doctor provided a treatment plan?
- Were there different treatment options provided? To what extent could you decide what treatment to follow? Were there difficulties while discussing and/or choosing treatments?
- Was your family involved? If yes, what was their role? Would you have wished it otherwise?
- What were your emotions during the examination? **Can you sketch your emotions on the map with a smiley and a rating (0-10)?**
- What were your emotions while receiving the treatment plan? **Can you sketch your emotions on the map with a smiley and a rating (0-10)?**
- What is the main thing that you remember as pleasant during this phase? Could you explain?
- What is the main thing that you remember as unpleasant during this phase? Could you explain?
- What was the influence of the different life factors on this phase?

Treatment and surgery

- **What did your treatment journey look like? Can you describe the different steps that happened during this phase, the moment you received your treatment plan until you received all treatments/surgeries? Were there any difficulties?**
- How long did the different steps of your treatment take? And who were involved?
- How did you experience the provision of information during this phase? To what degree did you know what was going to happen? Would you have wished it otherwise?
- Do you remember the physical pain and inconveniences during the different steps?
- Do you remember your emotions during the different steps? **Can you sketch your emotions on the map with a smiley and a rating (0-10)?**
- Did you need additional surgery or treatment that was initially not in your treatment plan?
- What kind of medication did you receive? Did you have any bad experiences regarding this?
- How did you experience the interaction with different healthcare professionals?
- What was the role and involvement of your family in this phase? Would you have wished it otherwise
- What is the main thing that you remember as pleasant during this phase? Could you explain?
- What is the main thing that you remember as unpleasant during this phase? Could you explain?
- What was the influence of the different life factors on this phase?
- **After care at trauma center**
- **What did the after care at the trauma center look like? Describe the different steps.**
- Did you feel well-informed about the after care you received? To what degree did you know what was going to happen? Would you have wished it otherwise?
- What was the time span of the after care at the trauma care center?
- How did you experience the interaction with healthcare professionals?
- What was the role of your family during this phase?
- Do you remember the degree of physical pain and inconveniences during this phase?
- Do you remember your emotions during this phase? **Can you sketch your emotions on the map with a smiley and a rating (0-10)?**
- Was there the need for follow-up treatment of surgery during this phase?
- What is the main thing that you remember as pleasant during this phase?
- What is the main thing that you remember as unpleasant during this phase?
- What was the influence of the different life factors on this phase?

Additional questions

- How did you feel when leaving the trauma care center? Can you sketch your emotions on the map with a smiley and a rating (0-10)?
- After going back home, did you have to visit the trauma care center again for follow-up treatments or check-ins?
- When looking at the whole journey, what were the main pain points?
- What were moments of light during this journey?

1. If you could change something yourself, what would it be?

At this point we discussed everything I had planned. Thank you for your openness, this is very valuable for my research.

Are there additional points you want to adress or do you have any questions for me? If you have any questions later on, feel free to send me an email.

To remind you one last time, all data will be processed anonymous and your privacy will be protected.

After performing all interviews, I will analyze the data and construct patient journeys. Would you be open to validate the patient journey? This means that you will have a look at it and give feedback or suggestions for improvements. You can do this at home.

Thanks for your participation!

Appendix F: Burn patient maps

Burn patient #1

Appendix F: Burn patient maps

Burn patient #2

CETC

Map My Experience Trauma Care

Every patient has different experiences with their health. This map can be used as guide to think about your own experiences with trauma care. The map starts with the trauma accident, through your examination and treatment, to when you leave the trauma care centre.

Life Factors

As you go along, think about how other 'life factors' have played a role in your experience, such as:

#2 Burns

Start here Moment of accident

Vrijdagavond

Vrijdagavond Thee over schoot (en schaafsheek) laten vallen in huis vriendin

18 min in dadde ander douche gaat [illegible] vriendin

→ Stil niet [illegible] vriendin → moeder gebeld (arts)

→ Snel naar ziekenhuis

→ Hingen vellen af → Besef dit is niet goed!

Na koelen de ergste pijn al weg kon niet meer echt lopen

In dauchetag ze dit

First Aid & Transportation

Fransiscus

Fransiscus Ziekenhuis

UBER + vriendin

X 'dags ziekenhuis 30 min later op SEH

Trage voorrang ze zagen de ernst

* Voorrang

In kamertje brandwunde meten

35 min gewacht, zelf mensen gehaald in dadde

Ander verpleegkundige [illegible] Nu moeten [illegible] → ander dauche gedaan → Afgesproken [illegible] met verpleegkundige [illegible] wij niet [illegible] Personeel wist niet echt wat te doen

→ Bellen Maasstad Idee dat ze niet echt wisten wat te doen

70 min wachten, gedacht was idee dat ze [illegible] bellen als deo schoonmaak [illegible] schoonmaak opnieuw

ze [illegible] gebeld

2e keer [illegible] afleiding zoeken bij vriendin

[illegible]

21:30

uitslag moeten naar Maasstad

Informatie voorziening goed.

Der rangerende vellen dacht ik dit is niet goed

Verpleegkundige wonden verbonden [illegible] Maasstad [illegible] voor plein [illegible] verbranden de wonden

Paul 00:30 naar huis

X Geen goede zorg slecht behandeld werd niet echt naar haar omgekeken

X naar moment met foto's opnieuw

→ geen diagnose

Examination

Zorg goed geregeld Expertise brandwonden

Met vader naar Maasstad

10:50 afspraak

labtekeningen voor infecties

2 verpleegkundige die haar opvingen Verbonden geopend + vellen verbruiken

Hele lieve vrouwen die [illegible] deden

→ Niet laten infecteren!

→ Littekens

→ 2-3 weken voordat het dicht is.

→ 20 min wachten op arts

+ co-assistent Dode vel weghalen + verbinden teruggekomen 3 dagen later. Leuk dat ze haast had maar wel geruststellen 'veel ergste gevallen'

* Professioneel veel expertise bij iedereen in Maasstad

* Geruststellen

'only way is up'

Allen terug dus tel ontsteek

After care Trauma Center

Nieuwe verpleegkundige

met vader

Idee dat het goed ging

weer [illegible]

Beveiligd Nog 1x verzorgd en Voorschoonmaak zei er goed uit nu dangelijks Goed verzorgd kraft [illegible] gehaald

1,5 uur totaal Maasstad

Verpleegkundige Vel weghalen

opnieuw verbonden door verpleegkundige Nu op een andere maar betere manier. Uitleg over hoe zelf te doen + opschrijven in stappen + Alle verband en zalfjes meegegeven

(weer andere informatie dan Franciscus)

Treatment and surgeries

Foto gehuurd van al het water in! van ik scheren! kosten erop halen aul

→ Heel ingebroed antwoord

→ door app hoeft ze niet meer opnieuw langs!

Niet in de zon! Pas in [illegible] als het dicht is

mocht meteen naar huis

Zelf nog 2 weken verbanden aanbrengen totdat de wonden dicht waren. App waarmee afbeelding van stellen sinds de wond dicht is olie [illegible] soepel te houden

Na u dagen Halloweenfeest gingen de verbanden weg 5 zeer heftig kon ook door zelf bewegen Nu weer in studentenhuis Beetje schuiven

Thuis om de dag verbinden zo veel mogelijk met rust laten

Om de dag helemaal verschonen. Niet douchen met open wonden

Verschonen moeilijk, lastig om te doen zoekende wel goede uitleg

After care at home

Na 7 dagen op check

Emotie curves

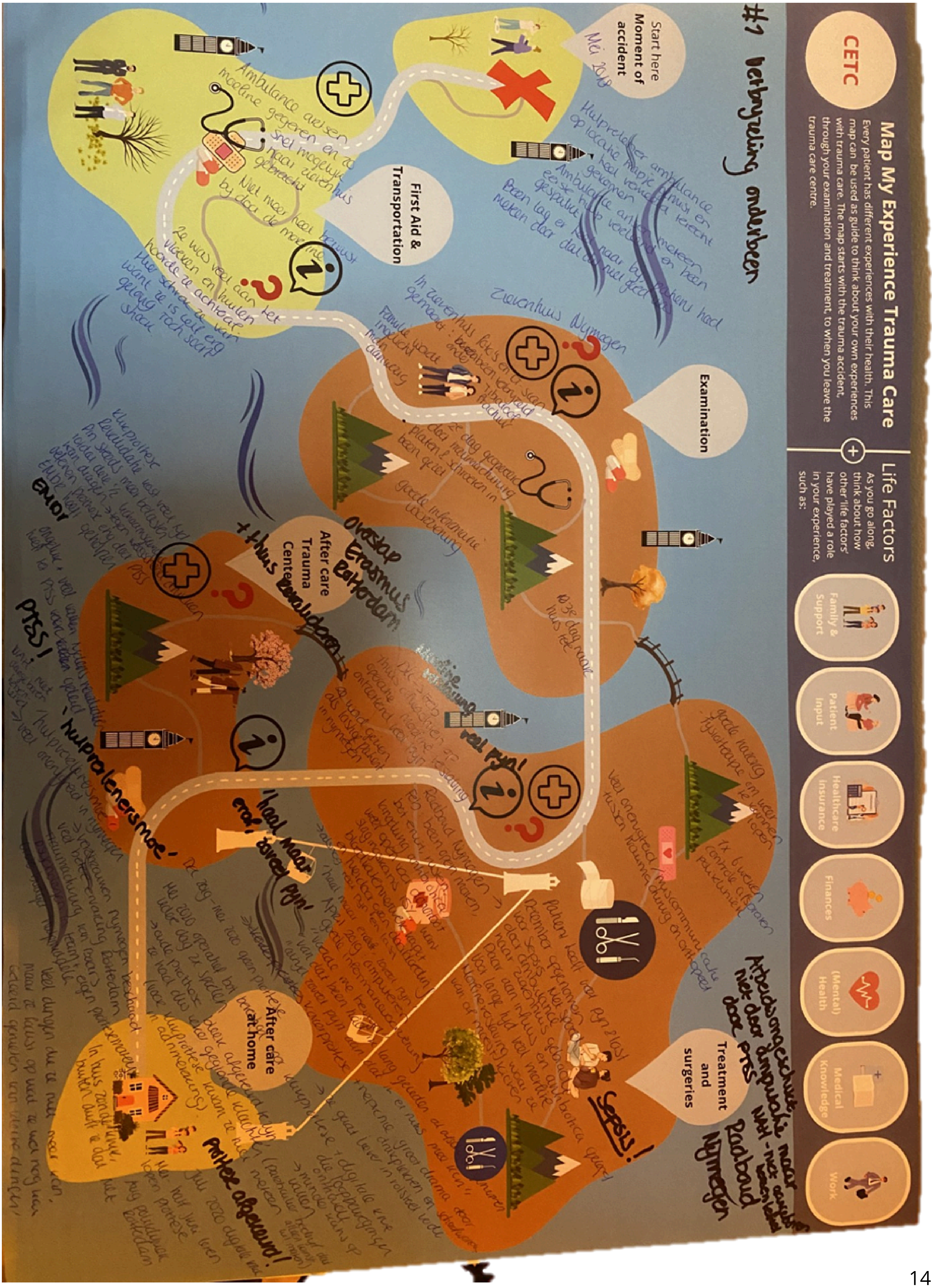
eerste dagen zag het er heel heftig uit door verbranden + pijnlijk + niet lopen afhankelijk van anders (2 dagen)

'Beter Dichtbij'

* App: snelle communicatie

Appendix G: Crush injury patient map

Crush injury patient #1



Appendix H: Expert consultations

Interview Guide (+ informed consent) → The consultations with experts were open discussions. However, I created an interview guide to make sure I wouldn't forget any important questions.

Hello, my name is Lynn Broos. Thank you for speaking with me today. I am conducting this interview for the Centre of Expertise for Trauma Care. This study is part of my graduation project from the TU Delft. This interview will take about 45 minutes to complete.

The purpose of this interview is to learn more about the trauma care pathways of burns/crush injury, from the moment of the accident towards the moment patients leave the trauma care center. During the interview we will evaluate a systematic overview of the care pathway and I will ask some additional questions to gain a deeper understanding of the carepathway, the patient experience and the interplay between patient and healthcare professionals. Do you have any questions about the goal of the interview? Do you have any questions about the interview itself or the storage of data? Then, let's have a look at the informed consent form.

Lets start with some general questions about you and your profession.
Start recording
This is participant [ID] and he is a medical specialist for burns/crush injury. Today’s date is [date]. Could you please confirm once more for me that you agree to be recorded?

1. To start off, could you please tell me a little about yourself?
2. How often do you work with burns/crush injury patients?

Great, thank you. Next, I am going to show you the system map of the care pathway that I created based on literature research.

Show System Map

1. First I want to ask you to take a look at the system map and give feedback. Do your recognize the steps visualized?
2. Are important steps missing? Or should steps be rearranged? Take your time to study the map!
3. Now we have aggreed on the content of the system map I want to elaborate it further. It was hard to get insight in the timespan of the different steps. I suggest we go over the map, and you give an indication of the time frame of each step. (How long are patients in each step, how long is examination/treatment/recovery, how long are patient generally in the trauma center, how lang are waiting times between steps, etc?)
4. How often are different treatments/surgeries/follow-up treatments required? Give an estimation.
5. Do you work in interdisciplinary teams? Who are involved? How is the dynamic? How often are there meetings and what is discussed? Does the patient have contact with multiple people of the team? Similarly, or just one by one?
6. The next thing I want to discuss is the patient experience during different procedures. What are known to be the most unpleasant experiences? What is done to minimize the pain/discomfort? (To compare if medical experts actually know what the pain points of patients are, does what they say match with the actual experiences of patients)
7. Then, I want to discuss the intensity of contact with healthcare professionals? How regularly do patient and medical expert see each other? How long are those contact moments? What is generally discussed?
8. And the intensity of contact with nurses? How regularly do patient and nurse see each other? How long are those contact moments? What happens during contact?
9. Then I want to ask about patient involvement and shared-decision making. To what extend are patients able to provide their own input and is there room for shared-decision making? (to compare if patients and experts have the same perspective on this)
10. What is the role of family during the care pathway? Can family be present in every step? Is family involved in decision making?
11. Do you see opportunities to increase the degree of patient/family input and/or shared-decision making?
12. (For medical specialists that work with military) What do you think is the main difference in the care journeys of military and civillians?
13. What do you think of a tool that supports active patient involvement during trauma care (comparable to Metro Mapping for oncology)?

This is the end of the interview. Thanks for you participation, your insights were very helpful for this study.
Are there things you think that we did not discuss, but you think are important to mention? Do you have any questions for me? Then finaly, I want to ask if you are open to evaluate the created patient journeys later on in this study. This will be a short online meeting were I show the created patient journeys (created based on all performed research, observations, and patient- and medical specialist interviews) and ask for feedback.

Appendix I: Guided voice-over text ‘Life Compass’ exercise

Here, the voice-over text of the guided exercise can be found. Frames refer to the frames in chapter 14.

Part 0: Introduction
Frame 1:
Thank you for wanting to test this prototype. A short disclaimer: the tool will eventually become an interactive platform. So imagine that you are using this tool on an iPad, for example. You will have to type or select answers while using this tool. Because the tool is not yet interactive, you will take the test today with a worksheet. Listen to the voice-over and when you have to fill in an answer on the worksheet, the voice-over will ask you to pause the video. After you have filled in your answer, you can continue with the video, you will then automatically end up at the next question. The video and voice-over are always leading, so do not work ahead on the worksheet. Are you ready? Let's get started! Good luck.

A personal Life Compass contains information about who you are and what is important to you. While creating this compass, you will reflect on your life and consider your values. Your values are your fundamental beliefs or ideals. It is the core of what you strive for and what shapes your behavior. Values are things that you find really important in life and they give direction to your life.

It is always good to pause and reflect. In addition, the results will support you in your care process. With the help of this Life Compass, we can ensure that the care you receive is in line with what is really important in your life. This compass is developed on the basis of a number of assignments. YYou can take as long as you want to complete the exercise. It is important that you sit down quietly and take your time. I advise you to do the assignments without breaks. It is best to use headphones, so that you are closed off from your immediate environment. As soon as you are ready, we can start!

Frame 2:
Over the next 45 minutes, I will guide you in reflecting on your life and what is important to you. It is essential that you think carefully about your answers, because the answers you give will improve the quality of your personal care process.

You have experienced a traumatic event and this can temporarily knock the solid ground from under your feet. You may feel distanced from yourself at the moment. Know that this is normal, and this is not something to be ashamed of. A traumatic event has a major impact on your life, but it does not change who you are. The core of who you are remains unchanged, together we will go to this core. It is possible that you can no longer do everything you used to be able to do because of the traumatic event. With the outcomes of this exercise, you (together with health care professionals) can look for ways to organize your life differently, while still experiencing the same satisfaction.

The Life Compass is not a substitute for the medical advice of health care professionals. The compass serves as a conversation starter and a guide that ensures that the goals and plans you make with your health care professionals match what is important to you. In addition, this compass can also be used within psychosocial care and outside the medical context. It gives you a little more grip and direction in your new situation.

Frame 3:
In order to bring out the most valuable answers for your care pathway, we will answer from a different perspective. Together we will go back to a moment in your life where you were satisfied with your life and experienced security. This moment could be yesterday, but also a few years ago. From this perspective we will determine what is important to you. We will park the traumatic event for now. Forget your new situation and limitations, answer from the perspective that everything is possible. These perhaps too ambitious answers reveal your underlying needs and wishes and are therefore very valuable for your personal care pathway.

Frame 4:
For example, Jonathan can no longer play the guitar due to his traumatic injury to his hand. However, Jonathan is encouraged to list ‘playing the guitar’ when asked ‘what gives you a lot of energy’. Even if playing the guitar is no longer possible, we can look at how this hobby can be replaced in another way that gives the same satisfaction. If Jonathan never lets us know that playing the guitar is important to him, valuable information about Jonathan’s needs and wishes is missing from the care pathway. We will go through a series of short exercises. Try to focus and take your time!

Part 1: My Life Map
Frame 1:
We start by creating your life map. First, I will ask you a few individual questions to help you get started. Then you will fill in your own life map. Of course I will help you with an example.

Frame 2:
First, I would like to ask you to answer the following question. Which factors do you find most important in your life? Select 6. Number 1 is the most important, number 6 is less important.
#Pause the video and fill in your ranking on the answer sheet

Frame 3:
What is an important choice you have made in the past 10 years? And why did you choose that outcome?
Example: Three years ago I decided to look for a new job. I was not appreciated at my old job and was no longer happy there.
Example: Despite the fact that I am already 45 years old, I decided to go to college, I felt that I have more potential that I have never used.
#Pause the video and fill in your choice on the answer sheet

What do you consider your top three achievements? This could be anything, as long as you consider it one of your greatest achievements! Example: 1. I got my bachelor's degree, 2. I ran a 10K in under 1 hour and 3. I once rescued a drowning kitten
#Pause the video and fill in your ranking on the answer sheet

Frame 4:
Once you have filled in your answers, take a good look at it and select the values that your answers relate to (maximum of three values)
#Pause the video and choose the values that fit your achievements

Frame 5:
Let's delve deeper into your life. I want to ask you to think about the big picture in your life. I ask you to draw a Life Map. In this Life Map you give a schematic representation of your life. What big moments of choice have there been in your life? And what did you choose then (and why)? What were peaks in your life? What were valleys? You can draw your life line however you want: with peaks, valleys, curves, obstacles, loops, or whatever you find appropriate. With pluses and minuses you can indicate highs and lows. Feel free to draw text or symbols along the line to clarify your life line. Nothing is too crazy, this is the drawing of your life! I will show you an example;
Now it is your turn. Draw your life map in the drawing box on the answer sheet. Draw, write, visualize everything that is relevant to you. This map will help you with the rest of the assignments!
#Pause the video and make your life map on the answer sheet
The Life Map helps you to reflect on your life and making this map stimulates your creativity. At a glance it becomes clear when you had to make big choices, when things were going well for you and when things were not going so well for you. These are the moments that have been important in shaping you as a person. Take another good look at your Life Map, are you satisfied? Your life map will help you answer the following questions.

Frame 6:
As I said before, we want to imagine a moment in your life where you felt connected to yourself. Your life map helps with this. Take a good look at your map. When did you feel connected to yourself? Choose a moment, preferably in the past few years.
Close your eyes and think back to this time. Why did you feel connected to yourself? What went well in your life? Maybe you were successful and satisfied with your work? Maybe you had just achieved an achievement or success? Maybe you were extra happy with your family or a good work-life balance? Maybe you felt certain about what you want in life? It could be anything. Reflect back on this time and write down a number of keywords about this moment and why you felt connected to yourself then.
#Pause the video and write down your keywords
Try to answer the following questions from this perspective. Let's switch away from your current situation and move to this familiar moment in your life. This perspective will bring out the most valuable answers and in this way we can personalize your care pathway based on what really matters in your life!

Part 2: Mirror of Me Mind Map
Frame 1:
Let's continue with the next assignment. There is a very large mirror hanging in your house. You can see yourself completely when you look into it. Close your eyes and imagine that you are standing in front of this mirror. You see yourself in the middle of the mirror and we are going to put information about you around you. The mirror becomes a mind map in which you as a person are central.

Frame 2:
Here you see an example of someone who came before you. This is what your mind map should look like. There will be a number of questions that you have to answer. Note these answers in the right place in your mind map. Also link each answer to one or more values, which you can choose from the overview in the appendix. After filling in all the questions, your mirror mind map is finished!

Frame 3 & 4 (7 times iteration)
Let's get started: Imagine you're standing in front of a mirror and looking yourself straight in the eye. Who is actually standing in front of you? What are the three most important character traits of the person you see in the mirror? Place your three most important character traits in the mind map.
#Pause the video and place your most important character traits in the mirror
You can use your life map as inspiration for the following questions!

What are you most proud of in your life? Example: I am very proud of the company I founded myself and the perseverance I have shown for this. Example: I am most proud of my son who has just started nursery school. Link your answer to values!
#Pause the video, write your answer and link it to values (maximum of three)

What do you enjoy doing the most? Example: I really enjoy playing outside with my son. Example: I enjoy online gaming the most! Link your answer to values!
#Pause the video, write your answer and link it to values (maximum of three)

What are you exceptionally good at? Or: what do others think you are exceptionally good at? Example: I am very good at coming up with innovative out-of-the-box solutions. Example: I am incredibly empathetic and always immediately understand the feelings of others. Link your answer to values!
#Pause the video, write your answer and link it to values (maximum of three)

What do you talk or think about the most (outside of your work and family)? Example: I think a lot about how climate change will affect my children's lives. Link your answer to values! Example: I am busy with my personal development and talk and think mainly about my personal goals.
#Pause the video, write your answer and link it to values (maximum of three)

What is your greatest fear? Example: My greatest fear is losing my job and not being able to provide for my family. Example: My greatest fear is becoming chronically ill and not being able to do the things I love. Link your answer to values!
#Pause the video, write your answer and link it to values (maximum of three)

What do you feel responsible for? Example: I feel responsible for a safe working environment for my employees. Example: For the happiness and opportunities of my children. Link your answer to values!
#Pause the video, write your answer and link it to values (maximum of three)

Part 3: My relation-web

Frame 1:

Now we have a good idea of who you are as a person. Let's now look at your social circles. Who are important in your life? How close do you have contact with these people/animals?

Frame 2:

Think of the people (or animals) with whom you often have contact and who are important to you. Draw them in the web around you. The closer you place someone to you (so in the middle), the more important this person is to you.

Frame 3:

Look at which three people are the most important to you. If all goes well, you have placed these closest to yourself - so in the middle. Note down for these three people what relationship they have with you, for example mother. Choose from the list of options.

#Pause the video and write down the relationships

Frame 4:

Then note down for these three people which interactions you value most with this person. You can choose two interactions from the menu per person and note them down with that person. For the sake of clarity, you can circle the people with interactions together.

#Pause the video and write down the interactions. Congratulations, your relationship web is finished! In a glance, more will become clear about your important relationships.

Part 4: My roles passport

Frame 1:

Now let's take a moment to consider which roles you have. You have roles as an individual; for example, athlete or artist. You have roles within your family; for example, father, brother or uncle. You have roles within your work; for example, personnel manager, administrative employee or real estate agent. You have roles within your society; for example, board member of an association, member of a church or volunteer.

Frame 2:

Think carefully about which roles and select which roles apply to you. If you find it difficult, mentally run through your week and see from which roles you perform your daily tasks and activities. Feel free to add a role if one of your roles is not on the list!

#Pause the video and select your roles

Now I want to ask you to be critical. What are your three most important roles? Circle the three most important roles. With these three roles we will fill in your role passport.

#Pause the video and circle the three most important roles

Frame 3:

Write the roles in the role passport and link them to the two character traits that are most important for this role. You can see an example here. You can choose the character traits from the list.

#Pause the video and fill in the role passport.

Frame 4:

We now have an idea of who is important in your life and what roles you fulfill in your life. Now I have an interesting assignment for you. Imagine: You are almost 80 years old. A surprise party is being thrown for you. A few people give a speech about who you were as a person. How do you want people to describe you as a person? Describe in a maximum of three sentences how you would like people to remember you: Example: I want to be remembered as a kind and generous person who takes good care of his family and is committed to society. Example: I want to be remembered as an intelligent person with a lot of knowledge who made a major breakthrough in science.

#Pause the video and answer the 80-speech question

Link your answer to value(s) (maximum of three) (frame 5).

Part 5: A day in my life

Frame 1:

Let's take a look at how you like to fill your days. What do you like to do and what gives you energy? Do you have any hobbies?

Frame 2:

First, I would like to ask you to choose what you like to do most in your free time. You can choose three activities. If your answer is not there, you can add it yourself! If necessary, you can provide an explanation of your free time activities here. Example: In my free time you can find me in the gym and I spend a lot of time with my pet!

#Pause the video and choose your three activities

Frame 3:

Now, I would like to ask you which daily activity gives you the most satisfaction? Example: Cleaning the house gives me a lot of satisfaction. Example: Running outside gives me a lot of satisfaction.

#Pause the video and answer on the answer sheet

And what is your weekly/monthly highlight? Something you look forward to every time? Example: My weekly highlight is the padel competition on Friday evening! Example: My weekly highlight is when the grandkids come to visit on Sunday!

#Pause the video and answer on the answer sheet

Please link the given answers to value(s) (frame 4)

Part 6: My Future

Frame 1:

We have already looked at the past and your current situation. Now I am curious about the future. What are activities that you would still like to do? Or goals that you want to achieve? Skills that you want to learn? Experiences that you want to gain?

Frame 2:

What is on your bucket list? This can of course be anything! Note down which three things are at the top of your bucket list. Example: 1. Volunteering at the animal shelter, 2. Learning to paint realistic portraits and 3. A half marathon. Link your bucket list activities to (maximum three) values!

#Pause the video and answer on the answer sheet

Frame 3:

In which domain would you like to work if factors such as money, education, distance, skills, etcetera, did not play a role? Choose two domains that you would like to work in.

#Pause the video and select two domains on the answer sheet

Frame 4:

Now I would like to ask you to read the questions below carefully. Choose the two statements that are most true for you. In this way, we determine which career anchors are important to you. By doing this, we can find out what kind of company and job you will feel comfortable with.

#Pause the video and select two statements on the answer sheet

Frame 5:

We have already reached the last question. Finally, I am curious about your ambition for the future. This ambition is personal and can be anything: moving to another country, having children, starting your own company, becoming a volunteer, etcetera. There is no right or wrong answer, as long as you want to achieve it. I am curious about your answer! What is your ambition for the future? Example: I want to start my own company in assistive technology for disabled people. Link your ambition to (maximum three) values. #Pause the video and write your ambition on the answer sheet.

Did you link your answer to values? Congratulations! You have now completed the assignments. Let's finish together!

Part: Closure

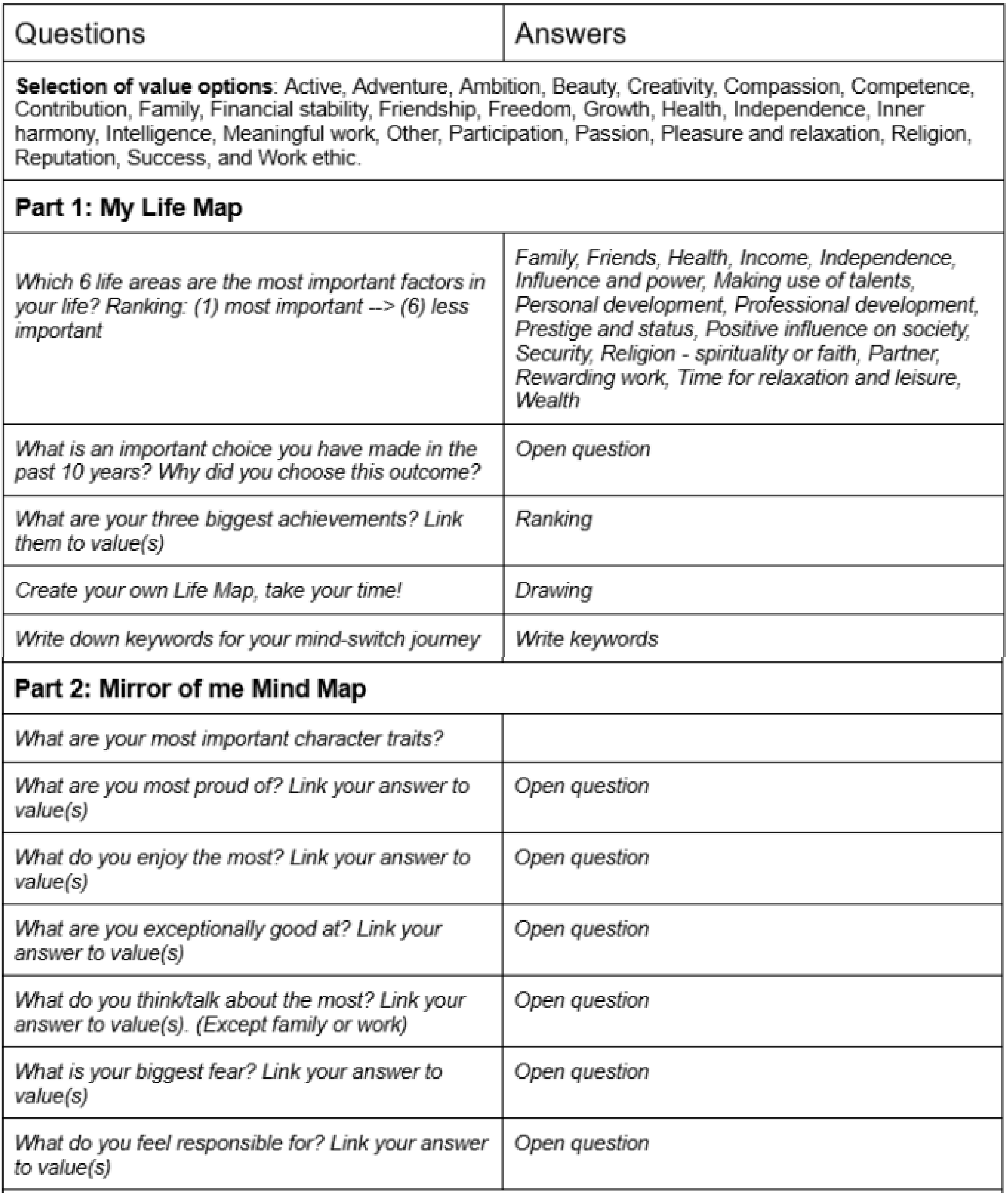
Thank you for your answers. I enjoyed working with you. A personal ‘What matters to me’-dossier is developed based on your answers. You will find the answers you gave in this exercise. You will also find your most important values, which were determined based on your answers.

This ‘WMTM’-dossier is your anchor for the future. It helps you to personalize your care process and make it value-driven. The dossier helps you and the care professionals to set goals based on what is really important in your life.

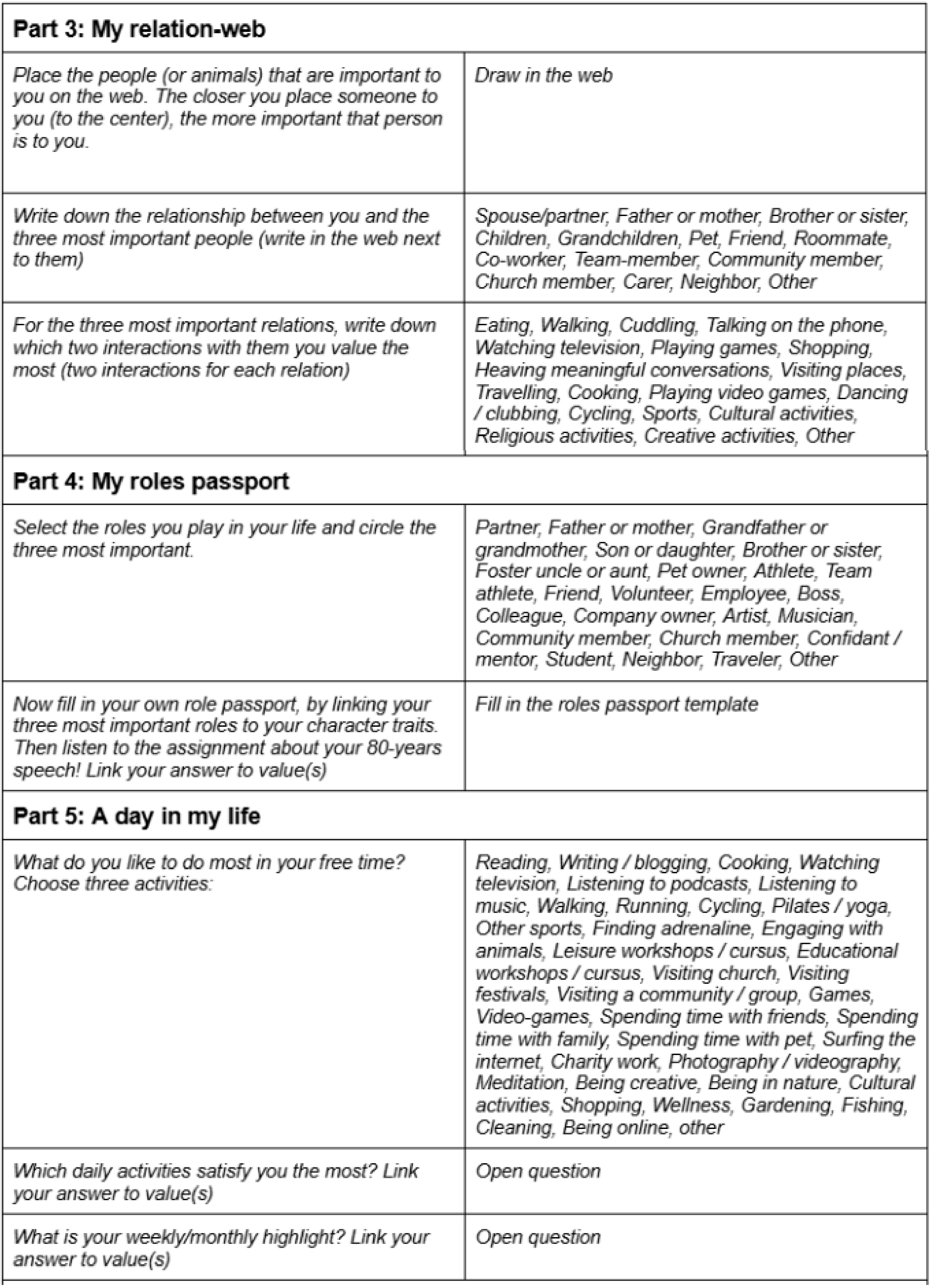
A traumatic event has a major impact on your life, but it does not change who you are. You may feel distanced from yourself for a while, but who you are at your core has not changed. Together we went to that core, and we recorded it as best we could in your personal dossier. It is possible that you can no longer do everything you used to be able to do because of the traumatic event. Supported by this ‘WMTM’-dossier, we can look for ways to organize your life differently, while still experiencing the same satisfaction. An important final note before we get to your dossier: this dossier is not a replacement for medical advice from your doctors or other health care professionals. This dossier helps you to work with them, to find medical interventions and other solutions that align with your life goals. In this way, we ensure that your care pathway aligns with what is important to you. In short, we make your care pathway more person-centred and values-driven.

Appendix J: ‘Life Compass’ exercise questions and answer options

Questions asked during the ‘Life Compass’ exercise that generate the ‘WMTM-’dossier.



Questions	Answers
Selection of value options: Active, Adventure, Ambition, Beauty, Creativity, Compassion, Competence, Contribution, Family, Financial stability, Friendship, Freedom, Growth, Health, Independence, Inner harmony, Intelligence, Meaningful work, Other, Participation, Passion, Pleasure and relaxation, Religion, Reputation, Success, and Work ethic.	
Part 1: My Life Map	
Which 6 life areas are the most important factors in your life? Ranking: (1) most important --> (6) less important	*Family, Friends, Health, Income, Independence, Influence and power, Making use of talents, Personal development, Professional development, Prestige and status, Positive influence on society, Security, Religion - spirituality or faith, Partner, Rewarding work, Time for relaxation and leisure, Wealth*
What is an important choice you have made in the past 10 years? Why did you choose this outcome?	*Open question*
What are your three biggest achievements? Link them to value(s)	*Ranking*
Create your own Life Map, take your time!	*Drawing*
Write down keywords for your mind-switch journey	*Write keywords*
Part 2: Mirror of me Mind Map	
What are your most important character traits?	
What are you most proud of? Link your answer to value(s)	*Open question*
What do you enjoy the most? Link your answer to value(s)	*Open question*
What are you exceptionally good at? Link your answer to value(s)	*Open question*
What do you think/talk about the most? Link your answer to value(s). (Except family or work)	*Open question*
What is your biggest fear? Link your answer to value(s)	*Open question*
What do you feel responsible for? Link your answer to value(s)	*Open question*



Part 3: My relation-web	
Place the people (or animals) that are important to you on the web. The closer you place someone to you (to the center), the more important that person is to you.	*Draw in the web*
Write down the relationship between you and the three most important people (write in the web next to them)	*Spouse/partner, Father or mother, Brother or sister, Children, Grandchildren, Pet, Friend, Roommate, Co-worker, Team-member, Community member, Church member, Carer, Neighbor, Other*
For the three most important relations, write down which two interactions with them you value the most (two interactions for each relation)	*Eating, Walking, Cuddling, Talking on the phone, Watching television, Playing games, Shopping, Heaving meaningful conversations, Visiting places, Travelling, Cooking, Playing video games, Dancing / clubbing, Cycling, Sports, Cultural activities, Religious activities, Creative activities, Other*
Part 4: My roles passport	
Select the roles you play in your life and circle the three most important.	*Partner, Father or mother, Grandfather or grandmother, Son or daughter, Brother or sister, Foster uncle or aunt, Pet owner, Athlete, Team athlete, Friend, Volunteer, Employee, Boss, Colleague, Company owner, Artist, Musician, Community member, Church member, Confidant / mentor, Student, Neighbor, Traveler, Other*
Now fill in your own role passport, by linking your three most important roles to your character traits. Then listen to the assignment about your 80-years speech! Link your answer to value(s)	*Fill in the roles passport template*
Part 5: A day in my life	
What do you like to do most in your free time? Choose three activities:	*Reading, Writing / blogging, Cooking, Watching television, Listening to podcasts, Listening to music, Walking, Running, Cycling, Pilates / yoga, Other sports, Finding adrenaline, Engaging with animals, Leisure workshops / cursus, Educational workshops / cursus, Visiting church, Visiting festivals, Visiting a community / group, Games, Video-games, Spending time with friends, Spending time with family, Spending time with pet, Surfing the internet, Charity work, Photography / videography, Meditation, Being creative, Being in nature, Cultural activities, Shopping, Wellness, Gardening, Fishing, Cleaning, Being online, other*
Which daily activities satisfy you the most? Link your answer to value(s)	*Open question*
What is your weekly/monthly highlight? Link your answer to value(s)	*Open question*

Part 6: My future	
Which three things are on your bucket list? Write them down and link them to value(s)	*Write down bucket list*
Choose two domains you would like to work in later	*Healthcare sector, Education sector, Construction sector, Transport sector, Agriculture sector, Hospitality sector, Technical sector, Computer and technology sector, Energy sector, Entertainment sector, Manufacturing sector, Accounting sector, Telecommunication sector, Financial and economic sector, Sports and Fitness sector, Fashion sector, Art and design sector, Business sector, Retail sector, Media and communication sector, Security and safety sector, Food and beverage sector, Government sector, Charity sector, Other*
Choose the two career anchors that are most important to you	*(1) You want work where you can practice your skills and develop these skills to a very high level of competence (Technical/functional competence TF)* *(2) You want to be responsible and accountable for the end result and success of the organization (General Management Competence AM)* *(3) You find it important that you can organize your work freely and do it in your own way (AutonomyIndependence AO)* *(4) You want a job that gives you security, financially but also through a long-term contract (Security/stability SS)* *(5) You prefer to start your own organization/company with your own talents and are prepared to take risk for this (Entrepreneurial Creativity OC)* *(6) You want to do work that contributes something positive to society or the world (Service/dedication DV)* *(7) You find it important that you work continues to challenge you (Pure Challenge ZU)* *(8) You find it important that you can combine your work well with your personal needs and those of your family (Lifestyle LS)*
What is your ambition for the future? Which roles do you want to fulfill in the future? Link your answer to value(s)	*Write down ambitions and future roles*

Appendix K: Patient coping stories

Patient stories were collected from the website of the KorterMaarKrachtiger foundation (KorterMaarKrachtiger, 2025).

Career

MARLEEN

Contact

At the age of twenty-seven, Marleen was diagnosed with a malignant tumor between the head and the socket of her hip. She underwent a hemipelvectomy.

What I found most difficult: An amputation is hard, it is not comparable to anything. There are still moments when I want to throw my crutches across the room because I am terribly upset about it. 'Just quickly' is simply not possible anymore and you have to take that into account. You have to think a lot more: is the floor not slippery, am I standing firmly, if I do this now can I still do that later... It all takes a lot more time and energy. I don't think 100% acceptance is possible, but that is not so bad. I was afraid that I would no longer be able to do my job properly, but nothing could be further from the truth

What I did to deal with this: My situation was sad and difficult, but it also saved my life. That became my starting point and that mindset has brought me far. It is what it is and I am at peace with that. During my rehabilitation I tried out different sports together with other rehabilitation patients, swimming, just doing things again, that was really fantastic. I thought it would be good to stay active afterwards and rowing is a great rehabilitation sport. It has an even load on your body and is also not super prone to injuries, so I picked it up. I did need an orthosis on the seat to keep from falling over in the boat. I soon came into contact with other adapted athletes and then things went quickly: three years after my amputation I went to the World Championships in Munich with a coxed four. When I was in the hospital after my rehabilitation, the Paralympic Games were broadcast, this inspired me and three years later I actually participated, a great victory over myself! Fantastic to experience the atmosphere at such an event! In addition, I get a lot of energy from my job in the political world and I like to contribute to creating something beautiful. In addition, I am now a member of the 'Activation team for political office holders with a disability'. We try to remove barriers by inspiring people with coaching and practical tips, among other things. In addition, we encourage political parties to pay attention to people with a disability in their programs.

Advice for others: Make use of the instrument makers we have in the Netherlands, what heroes they are! It's so nice how they always think along about how something can be made possible. I also think that we should be more open to each other about what we need. It is important to look at where your opportunities lie and what you really want, and then consider how you can achieve that. You do need the right people to support you, because it is a difficult process, an amputation. Find the right people who can inspire you! Because you can still make a career, after all, I succeeded! Find a mission for yourself that you can work on!

Comfort (pain)

IWAN

Contact

In 2013, Iwan got his arm caught between the rollers of a printing press due to an error in the cleaning protocol. A long period of suffering followed. The bone turned out to be shattered and Iwan was treated in various clinics to try to save his hand. He was in a lot of pain and took an irresponsibly high dose of painkillers. Until finally – eight years later – an amputation freed him from 24-hour pain.

What I found most difficult: I have no idea how I managed to cope. I took an irresponsible amount of painkillers, but I kept having that terrible pain. It felt like I was holding my hand in a pan of boiling water 24 hours a day. I also always felt like I had to justify myself. You think: it must be my fault, the doctors will know. I became very unhappy and depressed because of the whole situation. Your circle also became smaller and smaller, I lay on the couch all day and only picked up the children from school. I lived completely in my own cocoon, was only concerned with myself. I was also angry and frustrated about everything that had happened.

What I did to deal with this: Through the occupational therapist, I ended up at a training center specifically for people with pain. They literally pulled me out of the shit there. I was guided by a behavioral coach and a psychologist and was finally able to say everything that was on my mind. I learned to listen to my body better and to act accordingly. I started to take matters into my own hands and a process of self-reflection began. I am incredibly grateful to them. I also came into contact with someone who had experienced the same thing, which gave us both a lot of recognition and that was so nice after all those years of struggle! At one point I decided that I wanted an amputation, which ultimately turned out to be the best solution. When the surgeon approved the amputation, I hugged my wife while crying, these were the first tears of joy in eight years. This operation literally saved my life. I have regained so much freedom, and not only in movement but also in thinking. The children didn't recognize me anymore when I was dancing in the kitchen a few weeks later: 'Dad, you're crazy!'

Advice for others: It helps to get in touch with people who have gone through a similar situation. You can learn a lot from them and get support from them. Don't give up, keep looking for possibilities. I started reading a lot about pain and psychology and what you can do to become mentally stronger. That helped me too. I learned that it is important to keep talking. If you bottle up your feelings, they will come out in another way. I started to see what is really important in life and I got a lot of power from it!

Career

GEORGE

Contact

George lost his left arm in a car accident in 2015. A years-long process of adaptation followed, with the goal of becoming as ‘unlimited’ as possible. A goal that has now been approached quite closely through osseointegration and a bone-anchored prosthesis.

What I found most difficult: My biggest fear immediately was that I would no longer be able to do my job. As a craftsman, I actually needed two hands. I am a forestry consultant and that involves a lot of physical work, such as measuring the diameters of trees with large measuring instruments. Unfortunately, there was no other option, and my arm was amputated anyway. I then focused on work too quickly and did not take the time to process the accident mentally. That is a step that you cannot skip, because then it will come back like a boomerang. Talking helped then. But missing an arm is also a kind of grieving process and that simply takes time. The nurse also talked me into having phantom pain - a kind of toothache to the third power - by often emphasizing that I would have this.

What I did to deal with this: My goal was to get back to work as soon as possible. A tool was developed for me that allowed me to use my measuring equipment and continue doing my job. That was really nice, because of course it's about your income as a self-employed person. I participated in a study by Prof. Corry van der Sluis. She did research into a treatment for phantom pain with virtual and augmented reality, where your brain is fooled, as it were, by seeing the missing arm move on a screen. That has helped me a lot. I can still feel the nerves, but now I know how to prevent cramping, which means I have less trouble.

Advice for others: You have to continue with the content of life. The entire prosthesis process is actually a constant evolution of your possibilities, because there is always something that can be improved! All instrument makers and practitioners are very dedicated to make it a success. After trying many prostheses, I now have a prosthesis that I can wear every day for twelve to fourteen hours without any problems. I can also do my work as well as before, so my goal has been achieved! In addition, I have benefited greatly from contact with fellow sufferers. Seeing how others do it helps enormously to improve your own insight. You tend to stay in your own 'tunnel', while a broader view actually increases your insight. I myself now also enjoy helping others with new ideas that they can continue with!