TALLINN UNIVERSITY OF TECHNOLOGY
SCHOOL OF ENGINEERING
Department of Mechanical and Industrial Engineering

ESTONIAN ACADEMY OF ARTS
Department of Design

MSc. Design & Technology Futures

Design for Patient-centered Heart Transplant Care Journey. Multidisciplinary Support Networks for Patient Empowerment.

Disain patsiendikeskse südametransplantatsiooni teekonna suunas. Mitmetasandilised tugivõrgustikud patsiendi võimestamiseks.

MASTER THESIS

Author

Regina Tagger

204664MADM

Supervisors

Martin Pärn, TalTech & EKA

Riin Kullaste, PERH

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THESIS TASK

Student: Regina Tagger, 204664MADM
Study programme: Design & Technology Futures, MADM10/18 (code and title)
main speciality:
Supervisor(s): Martin Pärn, (+372) 5138791, Head of the Study Programme, TalTech
Riin Kullaste, (+372) 5140972, Senior Doctor, PERH

Thesis topic:

Design for Patient-centred Heart Transplant Care Journey. Multidisciplinary Support Networks for Patient Empowerment.

Disain patsiendikeskse südametransplantatsiooni teekonna suunas. Mitmetasandilised tugivõrgustikud patsiendi võimestamiseks.

Thesis main objectives:

1. Understand and map the current experience of heart transplantation
2. Practice co-design methods for creating design concept
3. Discuss on the topic of service design as an opportunity for the Estonian healthcare sector

Thesis tasks and time schedule:

No	Task description	Deadline
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2.	Participatory research	15.04.2022
3.	Concept design finalisation	05.05.2022
4.	Thesis finalisation	16.05.2022

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Student: Regina Tagger .... "......."...............................20….a

Supervisors: Martin Pärn .... "......."......................20….a
Riin Kullaste .... "......."......................20….a

Head of study programme: Martin Pärn .... "......."......................20…..a

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Abstract

Hospitals are service-based organisations, offering services to people in different roles – patients, visitors, employees are few groups who are directly related to the services. Services for people can only be designed together with the ones involved in order to make them relevant and valuable.

This thesis is focusing on the heart transplant patients and co-designing better services for them, with them. The thesis implements co-design practices, looks through the ecosystem view of the connected actors, and follows the Design Thinking Process, circling back to empathy as a key. With the support of the methodology, implementing a social- and service design view into the hospital environment, a design concept is developed.

Based on the main themes of the concept – transparency, accessibility, community, need for a specialised support network, and creating patient empowerment, a design proposal is generated to improve the heart transplant patient journey. Design proposal Teel is a multidisciplinary support network for the heart transplant patients, designed together with the patients, and their needs in mind. Teel aims to empower heart transplant patients from diagnosis to post-care. Teel includes digital space as well as a physical one to offer holistic, multidisciplinary care.

The thesis work can be modified and scaled towards various diagnoses. Implementing service design in the hospital's future is a crucial factor in balancing the workload of medical professionals, and offering quality, inclusive and transparent holistic care for the patients as well as others in contact with the hospital. Hospitals have to build together with the patients – the experts of the experiences to offer care and dialogue.

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List of Terminology

- **PERH -** North Estonia Medical Centre (Põhja Eesti Regionaalhaigla)
- **TAI (eetikakomitee)** - National Health Institute (Ethics Commitee) (Tervise Arengu Instituudi Eetikakomitee)
- **NCDs** - Non-communicable (chronic) diseases
- **ER** - emergency room (hospital)
- **ICU** - intensive care unit (hospital)
- **LVAD** - Ventricular assist device

All the illustrations of the thesis are made by the author, if not stated otherwise.

1. Introduction

"Heart transplantation is the replacement of a failing, unwell heart with a new, healthier heart from a suitable donor" - (Donald M Botta, Jr, MD and Mancini, MD, PhD, MMM, 2022). Heart transplantation is a procedure practised as a last opportunity for the cure - when all the other options are unsuitable or failed. Transplanting a human heart to another human is a complex process and requires pre-and post-care. The bigger goal of heart transplantation is to increase the life quality of the patient. Before receiving a donor's heart, the patient is usually severely unwell, therefore, the new heart can help to increase the lifespan of the patient and better the physical abilities in the longer term. In addition, it is described as the societal- and cost-effective and sustainable option for treatment (Vanholder et al., 2021), as after receiving a new organ, the patient requires less hospitalised care and can continue their life in the home environment.

The initial research topic was proposed by PERH (North Estonia Medical Centre). The hospital's first goal with this master thesis topic proposal was to document and map the patient journey within the transplantation category. Soon after accepting the topic as a personal master thesis topic, a meeting with the hospital representatives was held. No patient journey mapping until this point was conducted for transplantation patients in Estonia, and the information that doctors or facilities had was very facility-focused — narrowed to their specialty. From the hospital side, the goal was to create one, unified map to see what the patient goes through and what are his/her issues throughout the process. The hospital representatives described medical services as well structured, offering quality medical care, but the support systems that patients are needing for such a long-term treatment process are missing at this point.

At first, the research was covering all the transplant patients, as the journey seemed similar throughout different organs, but soon after, together with PERH, the decision was made to move forward with the heart transplant patients. The reason for this choice was the fact that PERH is monitoring and actively offering their services to people with heart transplants, therefore they have the leading experience in Estonia about heart transplantation and the available patient contacts. This research accesses patients in the different phases in their cure: waiting list, and after transplantation care.

This research focuses on the heart transplantation patient journey through social design and service design interventions. By implementing not only a patient-centered approach but more of a together-with-the-patient one, this thesis aims to first empathise with the problem owners and therefore use co-design with patients to build a proposal that is relevant and could be developed further into a coherent service. The approach of the

Service Ecosystem Design helps to understand the complexity of the systems, from the patient view and also from the hospital as an organisation. By including stakeholders and remembering to observe not only the patient but the closer and further connections which are playing a role. The journey of the thesis is following the Design Thinking process, moving back and forth between the process. The theory is not followed strictly but comes in helping to constantly return to the empathise phase to keep the problem owners in focus.

As a designer, I see the vast value in implementing the co-design approach and service design methods in developing health care services. Patients are the experts in their experiences like doctors are experts of their in their craft, others can only assume how the individual is communicating with the service. Being hospitalised several times at the age of 14 with a serious condition, after getting better, one of my missions was to once improve the hospital experience for the next ones who are spending their time there. And this mission has never really left me. The research work gives me the possibility to do that, from another angle but hopeful to give some food for the thought to other departments and the healthcare in on a larger scale here in Estonia. To be said - the level of medical treatment is advanced but there is so much more to the healthcare experience pre-and after treatment than the surgery. The experience starts usually starts weeks or months before reaching the hospital building and ends way later than the e-health platform Digilugu states.

The research is conducted in Estonia, based on PERH, who provided the contacts of the patients, who, due to the confidentiality agreements, would be close to impossible to be found without any hospital-side help. In addition, few external individuals, who are not connected to PERH, are included in the research as being connected to the heart transplantation either professionally or personally.

2. Methodology

Methodology firstly explains the concepts of design approaches that are in focus for the thesis. Secondly, the models used and qualitative methods for research are described and argumented. After the brief introduction to the design methodology, the hypothesis and problem question are presented.

2.1 Theoretical frameworks in focus

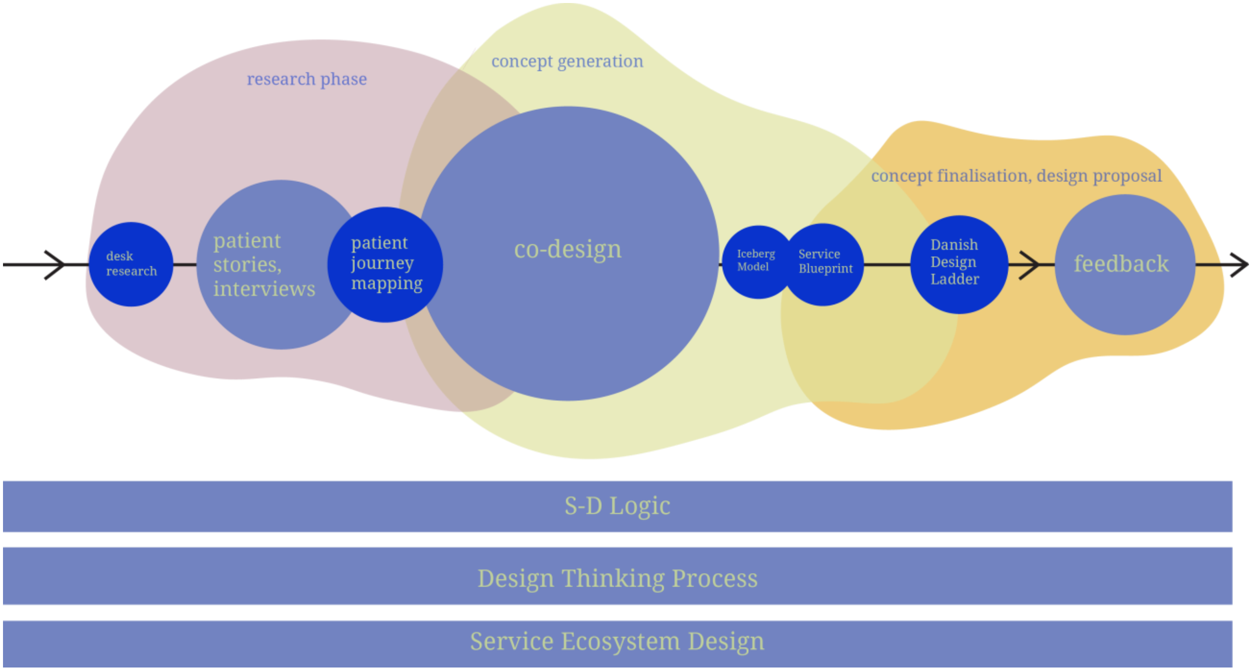


Figure 1. Theories and methodologies used during the thesis were created by the author.

Chosen theories and methods for the thesis are central to supporting the co-design aspect and practices. Figure 1 shows the methods used in circles. The theories on which the thesis is based on throughout, are illustrated as the bottom lines.

Service Ecosystem Design

Britannica describes the term ecosystem as "the complex of living organisms, their physical environment, and all their interrelationships in a particular unit of space" (ecosystem | Definition, Components, Examples, Structure, & Facts, 2022). The organisms and also institutions, places, and services can not stand alone in the current world, other stakeholders are needed for various things and people to function. This is a starting point for the current research paper.

To tackle first seen as a complex problem, the viewpoint can not be one-sided. To create a meaningful proposal, observing and learning different viewpoints of the situation is crucial. Service Design Ecosystem takes into consideration not only the stakeholders involved but also the cultural norms, beliefs, and institutional arrangements and sees connections within and between the stakeholders, values, norms, and regulations. Seeing institutional arrangement as design materials does not negate the traditional understanding that emphasizes physical artefacts and interactions as materials but rather expands the understanding of these materials and their independencies in service ecosystems. (Vink et al.,2021)

As an example from the healthcare field, it states that health is not something that can be delivered by an individual actor but health is co-created by patients, family members, healthcare workers, and wide networks of other connections (Vink et al., 2021)

Besides providing a more whole and holistic understanding of values and their co-creation, the service ecosystems view also deals with how the stakeholders themselves can be a part of co-the creation of the values and views.

The service design process values a feedback loop of reflexivity and reformation, which are intended to be practiced throughout the process of this research paper.

Service ecosystem design is not a model used in a certain part of the current thesis work, it will be a set of glasses through which the whole paper is looked through. The practice will be present throughout the learning, researching, and designing processes of the thesis.

The following models and theories described below are related to the service design ecosystem, in different states and ways, helping to understand the system and therefore designing the proposals.

Design Thinking Process

The Design Thinking Process is used as an action framework to create innovative solutions and stay on track with the process (What is Design Thinking?, n.d.). It consists of five steps of Empathize, Define, Ideate, Prototype, and Test (figure 2). The framework starts with an empathise phase. The important function to note here is the fact that the process is not linear, the movement back and forth between the stages is normal, expected, and encouraged. On the topic of current research, going back to the empathise phase and carrying the insights and learnings is the key to designing for others (added into the figure in colour pink).

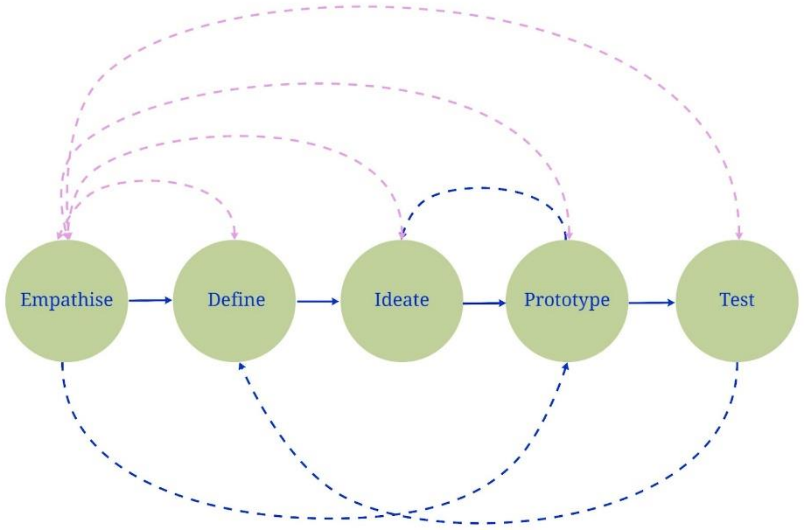


Figure 2. Original figure by the Interaction Design Foundation, modified by the author

Social Structures and Mental Models - the Iceberg framework

Social structures are shaping the way we perceive and think about the world and cultivate opinions. The model of Social Structures as Service Design Materials, which is also called an Iceberg Model, is researched in depth by Josina Vink (figure 3). The model provides the research an understanding of how visible and invisible social structures shape our ways and habits. The model consists of two parts. The upper part focuses on visible social characteristics which we can notice, observe, and easily pinpoint are activities, symbols, relations, and artefacts which people interact with.
The larger, often unseen part below the water consists of three bigger pillars - regulative, normative, and cultural-cognitive. The regulative part consists of spoken and written laws and rules, lawful behaviour, and governance-shaped interactions. A normative pillar is a category with the norm and value-laden visuals, objects meeting conventions, appropriate behaviour, and morally shaped interaction. Last but not least comes the cultural cognitive part with its identity conveying attire, objects possessing cultural meanings, meaningful behaviours, and identity shaped interactions. All these aspects are difficult to control or change but these are more often the things that change the way how the world is perceived and experienced by an individual. Having a wider overview on the topic, than staying "above the water", might be a danger without implementing the Iceberg Model and keeping it in mind, as we often are not trained to see the bigger part of our beliefs below the water.

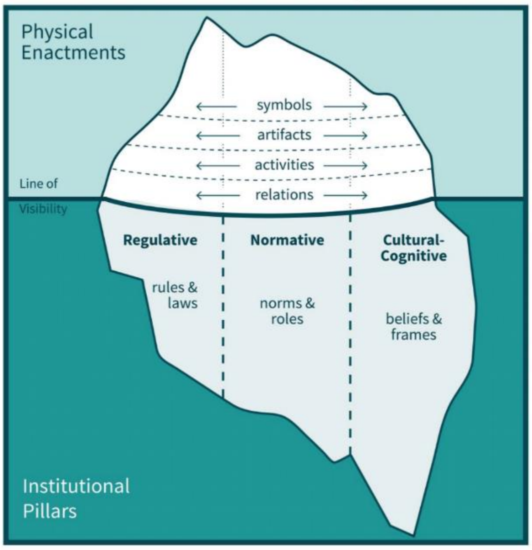


Figure 3, Iceberg (Vink and Koskela-Huotari, n.d.)

Mental models work similarly to social structures and are described at length by Josina Vink, Bo Edvardsson, Katarina Wetter-Edman, and Bård Tronvoll in the publication for Service Design Management. The authors state through the example of a doctor, with the mental model of medical education, societal norms, and institutionalized aspects they may act on the model of "doctor knows the best", but if they would implement service design practices they may shift their mental model to " the patient is an expert of their own experience", which in the end helps both sides to have more successful communication and also work results (Vink, Edvardsson, Wetter-Edman and Tronvoll, 2019).

Empirical Research

The work of the thesis is using empirical research, meaning the research is based on verified evidence. Empirical research consists of the following larger building blocks such as observation, induction, deduction, testing, and evaluation. It is used to make traditional research more authentic, using observations and experimental data. As the topic is set to work along and together with individuals from different social structures, empirical research methods such as observations, interviews, and cross-sectional methods are used to help to understand different sides of the situation.

Service-Dominant Logic

Service-Dominant Logic (S-D logic further in the next, Vargo and Lush, 2004, 2006) is an opposing structure to Goods-Dominant Logic (G-D logic). One is service-based and focuses on value creation from each side of the service, while the other logic is product-based, creating a physical need for an item. The most important point for the current research to take along is the general zooming out which is characteristic of S-D logic to have a holistic, dynamic, and realistic perspective of value among a wider range of actors, created through value exchange. The central part of S-D logic is value co-creation. Co-creation within institutions and organisational structures is discussed and elaborated on the theme of rethinking the institutions and co-creation possibilities in and beyond these frameworks. Working with S-D logic, value can not be created alone - value can only be created by co-actions.

Scandinavian Approaches to Participatory Design

Another valuable theory for the thesis research is Scandinavian Approaches to Participatory Design. “Participatory design thus entails collaborative partnerships and co-construction of knowledge in analysis and co-construction of changes in social practices” (Gregory, 2003). The theory focuses on three principles which are the following: deep commitments to democracy and democratisation; discussions of values in design and imagined futures; and how conflict and contradictions are regarded as resources in design. For this master thesis, all three principles are topical, yet the middle one is fundamental. Values in design and imagined futures are in some ways similar to S-D logic ones of co-creating values and value creation in design, working with trust and mutual learning to maintain or create relationships within communities.

Danish Design Ladder

The paper by Björklund et al. (Björklund, Hannukainen, and Manninen, 2018) describes how to measure the impact of design and design thinking in organizations at different maturity levels by using the Danish Design Ladder. The levels of the ladder increase as the maturity of design increases. Initially, the ladder was a four-stage one, now being upgraded and two more levels are added as service design in organisations is slowly but surely developing. The added two steps are designed as a community and organisation transformation and the last step being design as a national competitive strategy. The steps are one of the few ways to measure how design works and is used at the organisational level. In 2013, British Design Council published a framework (Design for Public Good, 2013) for the public sector, which the hospital is, with the references for the original Danish Design Ladder. Both versions and discussions are considered for innovation and recommendations. Later, in the analysis of the paper, Estonian healthcare and PERH will be discussed to see where they are in the process and where they could lay instead.

Patient journey mapping

Patient journey mapping is used to understand and visualise the touchpoints, actors, and interactions throughout the patient's movement throughout the journey. Mapping the journey is key to creating an understanding of the problematic points and what are the causes of these highlighted issues. Patient journey mapping helps to see both smaller pain points as well as it lays out the bigger system which gives an opportunity allows making across-journey changes. The patient journey in this thesis is one of the key methods helping to move forward towards the solution space with the chosen problematic aspects to propose solutions to (Maher, 2021).

Service Design Blueprint

Service blueprint mapping (Gibbons, 2017) is based on customer journey mapping, going more in-depth with it, expanding the first feelings and customer experience with interactions that the customer is having in both physical and digital scope. The result is a graph that presents the flow of actions that the user can see, being above the line of visibility, and the actions that happen in the background, below the line of visibility. All the actions can be performed by individuals or other entities such as artificial intelligence, organizations, departments, and institutions.

The structure is somewhat similar to the Iceberg Model of Social Structures, reminding us to keep the note also on the hidden information and notice the aspects further from the first look.

2.2 On-field research methods

The methodology overall can be considered spontaneous in one way but still structured. The analysis made is more qualitative as there are not many individuals being heart transplant patients. Also, the amount of service staff is not expected to be big. One of the key points in human-centered design is inclusivity in engaging individuals in most of the steps in the research and design process. The main methods for the qualitative info gathering are qualitative semi-structured interviews, observations, and workshops – all of which are held including the hospital and patient side. The gathered information will be translated into illustrative maps and conclusions which therefore are used to work further on the design proposal. In the design, process co-design will be implemented, which is taking place in a thematic workshop where the participants can affect the direction of the design with their ideas and thoughts.

During the research process, the main data is gathered from the personnel and first of all – the patients themselves.

The qualitative data presented is anonymous, the interviews are numbered and the workshop materials do not have names on the work due to confidentiality agreements between PERH, TAI, TalTech, and the author.

2.2.1 The on-field qualitative research

The choice of the individuals participating in the research was happening primarily on the precondition of individuals being directly connected to the transplantation process. To include the individual in the research they have to have the status of one of the following:

- The heart transplantation patient – before the active transplantation process, active treatment, or aftercare
- The close individual to a transplantation patient (either family or a close friend)
- Health care worker who is connected to the transplantation process
- An individual who has other connection to a heart transplantation patient - experience advisor, psychologist, etc.

The first goal was to map today’s transplantation patient journey, beginning of the condition and feelings about it, transplantation decision to healing, rehabilitation treatment, and learning to live with the new organ. The value created in the first stage of the research was based on creating an understanding of different stakeholders’ viewpoints and engagement in the journey through the service design ecosystem view. The patient experience here is crucial, being important for the health care service providers and personnel to create better holistic service components.

The mapping and analysis of the field research is forming the first part of the thesis work. The second part is a design process, where the development of the existing system was studied in the following categories:

- Ecosystem design suggesting possible strategical changes to the current service ecosystem, which would benefit the process.
- Service or a group of service modules that would help the collaboration between the hospital facilities, personnel, and the patient as well as people on the patient’s side in one way or another. Services could be both physical and digital, such as counselling or web apps.
- A product design proposing possible products that are helping to solve tricky or weak links discovered on the patient’s journey.

To achieve the desired development, the following qualitative methods to gather data and perform co-design were implemented:

Qualitative semi-structured interviews

The interviews, preferably conducted physically, and face-to-face to have more flow in the conversation but also conduct an observation (especially if done in the hospital environment). Also, video-calling tools were used as the heart transplant patients understandably keep their physical contacts small due to the weak immune system and ongoing pandemic situation. The interview structure was set and confirmed by the TAI Ethics Committee. As the interviews are semi-structured, the main themes are discussed but the questions can be altered and the interviewee can add and expand the topics, therefore potentially giving helpful information from various previously unnoticed aspects.

Observations

Due to the ongoing covid-19 pandemic situation, the access to various hospital services connected to heart transplant patients is decreased. The observations are still a nevertheless valuable source of information, even when the number of observation possibilities is reduced. Meaningful observing allows noticing information that is not spoken or shown through other forms of communication. The environment and a situation in it give an insight further from the actions and words of a person. Observations help notice the patterns of how people feel about certain things, interact with the environment around them, and how artefacts are placed, perceived, and used.

Co-design workshop

To facilitate a human-centered social design project, an active participant collaboration is needed in every phase from initial research to validation and feedback. Co-design workshop is one way to achieve active collaboration in creatively. When prepared right, the workshop format results in rich outcomes for the research as well as positive new insights and learnings for the participant.

The workshop format was used for concept format generation and ideation with the patients. The input for the workshop was gathered with them previously and therefore the workshop could be built based on that to understand certain habits and preferences of the patients deeper.

2.3 Research question and framing the topic

Firstly, the problem space of the thesis topic was defined as the hospital was unaware of the different stages of the patient journey during their time in treatment. Therefore, two players were presented - the hospital, who needs information, and the patient, who has the information needed. If the structure were solved in this way, we would only be talking about the tip of the iceberg, with a narrow scope of information and mental models, which, in the end, would result in a mediocre outcome which would not touch the deeper roots and causes nor help to design a full-service ecosystem.

Now, reframing the problem by taking into consideration the hospital-system view understanding the issues through active listening and co-creation, together with implementing the practices and theories, there is an opportunity to view the hospital and patient not only as two players but the extended service ecosystem, with different actors and the web of interactions between different stakeholders. When acting strategically, yet with curiosity and flexibility, there is a potential to create better environment, not only by the author of the thesis but rather created and tested together with those who live in the environment where changes are innovated and implemented.

The final research question for this thesis is following:

How might we improve heart transplant patients' journey by using co-design and service design methods? Design for patient-centered heart transplant care journey through social design ecosystem practices.

2.4 Hypothesis

Hypotheses for the following thesis research work are created based on the given topic and the current hospital services. These assumptions will be analysed in the Conclusion of the research (page 82) to understand if the hypothesis were relevant. Before conducting in-depth research on the industry and its processes, the research states the following hypotheses:

The hypothesis for the thesis project is that medical institution as PERH does not have a unified holistic understanding of the patient journey for the heart

transplantation patients, therefore the whole process is fragmented and missing strong links in health support for the patients.

Heart transplant patients’ preparation journey, assuming that active treatment and rehabilitation process can be significantly improved when including patients in the decision-making process by involving them in co-designing for the support service.

2.5 Research process and schedule

The collaboration with PERH began in early October 2021. The limitations of implementing methodologies and the wider choice of co-designing methods were held back due to the postponed decision of TAI Ethics Committee. The decision of the acceptance of the current research paper was made on the 9th of February 2022, the application was filed originally by the 1st of December 2021. By December the desk research was planned to be completed and the co-design process started but it was prolonged unexpectedly. Between these two months from December to February, the input for the thesis was allowed only to be gathered via public sources such as published articles, literature video material, and else, accessible to everyone. This is definitely a good starting point but as there is not much information in the context of Estonia, much of the information online is not valid due to the differences between regions when it comes to organ transplantation. Only after February, the qualitative data from both PERH-side and the patient contacts could be accessed. This left limited time to gather the first-hand data and work with co-designing methods. Even though the time was cut short, the work implements qualitative methods which are led by empathy, open-end, and visual outlet.

For the qualitative research, five out of seven patients on the PERH heart transplant patient list were participating in the research. Three out of four medical specialists were included in the research (contacts from PERH, externally one other medical professional from Tartu University Hospital were contacted). Two external individuals are included in the work being part of the patient ecosystem.

2.6 Chapter overview

Chapter 3 introduces organ transplantation and heart transplantation, internationally and at the Estonian level. The problem owners of the research are mapped for further work.

Chapter 4 presents the participatory research in a form of semi-structured interviews with the problem owners. The repetitive points from the talks are brought out.

Chapter 5 introduces existing practices of service design in the medical field and analyses the services and products available for Estonian heart transplant patients.

Chapter 6 maps the patient journey based on the previous research, suggests possible improvement areas on the journey and chooses the focus of the concept generation.

Chapter 7 introduces a co-creation workshop on the design concept with the heart transplant patients. The goals and actions of the design concept are mapped, based on the main themes.

Chapter 8 gives an overview of the design proposal Teel. The chapter introduces the concept and the functionalities. The system view is given through Service Blueprint. The patient journey from chapter 6 is analysed by including Teel activities and seeing the effects. Example user stories are added to understand the different potential users and their roles.

Chapter 9 gathers feedback for development and opens up on data privacy as one of the future focus of Teel.

Chapter 10 gives an organisation advice on implementing design activities in PERH on a larger scale.

Chapter 11 concludes the work, elaborates on the process, and presents the author’s notes.

Chapter 12 gives a summary of the thesis.

3.0 Background Research

The following chapter moves toward the case topic, giving an introduction to organ transplantation. The aim is to offer insight into the topical landscape. Firstly, transplantation as a form of medical care is described in the context of the European Union and the recommendations given by the referred materials. Afterwards, the brief history and current state of heart transplantation in Estonia are described to understand the context of the situation locally. Based on local and international information, problem owners are mapped on whom the thesis is focused, are mapped.

3.1 Organ transplantation

Non-communicable (chronic) diseases have become a more urgent health concern during the last decades. They are a heavy load for healthcare, also impacting the economy, quality of life of the individuals and their close ones, employment capabilities, and social life. Although NCDs can be mostly treated by lifestyle changes and/or medicaments, a major number of people affected by chronic illnesses develop a severe organ failure of a certain sort. To maintain a healthy population, countries are firstly taking measures to prevent NCDs and their aggressive progression, when the chronic illnesses have progressed to an end-state organ failure, providing transplants within the legal frameworks is the primary option.

Organ transplantation can be considered to have an immense effect on a patient's survival, quality of life, and societal cost (Vanholder et al., 2021). The European region has been leading developments and innovations within the transplantation field, yet there are differences within the EU countries when it comes to organ transplantation competency, meaning there is room for improvements to be made.

Heart transplantation is a complex operation that requires long-term preliminary work before the actual transplantation operation. After the heart transplantation, patients stay in care basically until the end of their lifetime. The recovery process is slow and the daily requirement to take different antirejection medications in addition to other medications will be part of the routine.

Choosing the recipient for the new heart is also a carefully considered process. The opportunity for a new heart is presented to only those who do not have any other forms of treatment available, meaning the treatment is not fitting, is not helping, or can not be executed.

European Union is the leading region when it comes to organ transplantations in terms of new methods and the numbers of patients who got help by new organs. In 2019, more than 34 000 organ transplantations were performed in the EU, 85% of which were kidney (21,235) and liver (7,900) transplants. Cardiothoracic transplantation numbers were 13% with 2,269 hearts and 2,136 lungs transplanted, whereas pancreas (2%), small bowel, and multi-visceral transplants represented a small fraction (Vanholder et al., 2021).

In Europe, there are few organisations that are uniting countries to develop an organ network. For Central Europe, the organisation for this is Eurotransplant, an NGO that manages the organs within the hospitals internationally. Before 2015, the few heart transplantations which were conducted for Estonian patients were organised independently and in other countries. Since 2017, Estonia is a member of a Scandinavian transplant network called Scandiatransplant. More about the connection between Scandiatransplant and Estonia will be discussed under the topic of Heart transplantation in Estonia (page 27). Scandiatransplant covers the total population of 28.6 million people from which about 2000 patients receive new organs yearly. It is a network between Norway, Denmark, Sweden, Finland, Iceland, and Estonia.

In European Union, the law defines ethical principles that state the anonymity between the organ donor and receiver. In the United States, for example, it’s the opposite. The receiver can get in touch with the organ donor family and it is common to do so as a form of honouring the passed donor. In Europe, the recipient will not know where their organ comes from, nor the name of the donor, the hospital, or the country. This information is confidential and only known to the medical staff who is transporting the organ and regional organ exchange network (for example Scandiatransplant). The reason for that is to reduce the potential mental difficulties and grief which can be connected to identified individual donors.

In the publication for organ donation and transplantation, is stated the following: In the EU, there is an urgent need for reliable registry data assessing not only the number of transplants but also the long-term medical and social outcomes among recipients and living donors. Access to such data could help shape clinical practice and future research.

(Thematic Network on Improving Organ Donation and Transplantation in the EU 2019, 2019) alongside many innovative and collaborative ways how to create more holistic and educational experiences for both the hospital medical staff and patients.

For the most vital organs, transplantation is the only life-saving therapy. Thematic Network on Improving Organ Donation and Transplantation in the EU – Joint Statement, 2019 has put together a list of factors that are barriers to the transplantation decision and further procedures. From this list it can be seen, that the requirements for both the patient, healthcare professional, and also from the system's side have to match various challenging factors for the transplantation to be successful.

Non-medical barriers to transplantation (Vanholder et al., 2021)

Barriers at the patient level

- Attitude, role perception, motivation
- Distrust of healthcare professionals
- Lack of knowledge
- Fears and concerns
    - Fear of rejection or graft failure
    - Fear of surgery
    - Fear of medication or adverse effects
    - Previous negative experiences (self or others)
    - Fear for the living donor's health
- Sociocultural background
- Religious reasons that oppose transplantation
- Unsuitable living circumstances
- Costs
- Shortcomings in patient efforts or investments
- Reluctance to ask potential living donors
- Lack of social support
- Lack of adherence or hygiene

Barriers at the level of the healthcare professional

- Attitude, role perception, motivation
- Lack of knowledge and expertise

- Fears and concerns
- Difficulty in selecting patients
- Lack of communication skills

Barriers at the level of the healthcare system

- Financial barriers
- Lack of support staff
- Competition with other treatment modalities
- Patient doing well on other treatment modalities

International organ Exchange

In order for smaller countries to also have possibilities for finding right the organs and executing the procedures at the highest level, it is common within the European Union to have clusters of countries that have developed united networks for organ exchange. In Europe, several organisations have been established, such as Eurotransplant, South Alliance for Transplantation, and Scandiatransplant. These networks have been crucial in keeping the quality of transplantation procedures and also developing the transplantation for the future. Being part of a certain network of organ exchange is opening also the availability to a much bigger number of possibly suitable organs than just one country's organ donor network.

Estonia is part of Scandiatransplant, a network that unites Sweden, Norway, Denmark, Iceland, Finland, and Estonia. Scandiatransplant also has a working group for Latvia and Lithuania, without the countries being part of the network itself. The network was founded in 1969 and currently covers a population of about 28.9 million inhabitants. The activities facilitated by Scandiatransplant include updated common waiting lists and follow-up registry, organise organ allocation for kidney, liver, heart, lung, pancreas, pancreatic islet, liver cell, composite graft, intestinal and multivisceral transplantation to the member hospitals, and offering a network of hospitals for research and development. Scandiatransplant is also making sure that all the member countries follow ethical rules and regulations during the transplantation process.

Complimentary to international European organ exchange networks, in 2012, FOEDUS-EOEO was created to make sure that the available urgent organs that cannot be matched within the national or international systems can be available across the European Union if needed. This platform is beneficial to recipients who have a small choice of suitable donors, for example, children and adolescents.

Factors in focus, influenced by the transplantation process

Transplantation is changing the patient’s life, there is no doubt about that. The patient has to live by certain rules before the transplantation and also unknown routines and lifestyles after the organ transplantation operation. To create a full understanding of the transplantation a wide range of factors has to be taken into consideration. Here the main block of issues are highlighted and considered more influential for the current paper. The factors described below are concluded and analysed from the articles of Organ donation and transplantation: a multi-stakeholder call to action (Vanholder et al., 2021) and Thematic Network on Improving Organ Donation and Transplantation in the EU 2019 (Thematic Network on Improving Organ Donation and Transplantation in the EU – Joint Statement, 2019)

Social re-integration

When the patient is going through the transplantation process, pre- during- and after the transplantation, there are limited options for employment, yet the risk of unemployment can be still resulted in dealing with chronic illness. The constant hospitalizations have a negative impact on the economy, also affecting social quality and stress levels. The hospital visits and mind-space of transplantation waiting time and recovery are taking their own time, often feeling the patients with a difficulty reintegrating into the activities of the community.

Quality of life

Heart transplantation is a long process. The daily life of patients includes many hospital visits and different daily routines which becomes a new normal. Patients have first-hand experience of the seriousness of the organ failure with complications, poor mobility, depression, shortness of breath, infertility, and more. The list of prescribed drugs is long and will affect the patient’s everyday diet until the end of their life. The situation is also a challenge for the family and close ones of the patient. They are often the first caregivers and the ones to help out with daily activities. The close ones are also often those who listen the struggles that the patient is going through which can be a heavy topic to deal with but at the same time crucial to share.

Economic impact

Transplantation is more often than not the most cost-effective way of treatment for the people who need it. It is still an expensive procedure and as it is a long–term treatment, the numbers are heavy for the funds, but not as heavy as other alternatives, if there are even any. Most of the treatment is funded by the National Health Care in Estonia, but there are still bills the patient has to be responsible for. As the patient can not always be active on the job market and the focus on the health is not only the patient’s concern but often also the caregivers such as families, the economic impact is felt not only in the healthcare system but more to the patient and patient’s family.

Although the factors in focus are worrisome, some countries are front movers in transplant patient health in these categories mentioned above. The example brought out there is Spain, who has put attention to the coordination of the donor processes and support processes. The crucial support processes that Spain has begun innovating and other regions such as the UK, France, Northern Italy, and Croatia have adapted, are the attention to the critical care communities, provision of guidance, and continuous professional training. The countries that have implemented measures to tackle the issues with the attention on care communities and education have increased transplantation rates, which is a positive aspect, allowing more inclusivity and equality in the decision-making of organ transplantation. (Vanholder et al., 2021)

3.1 Heart transplantation in Estonia

In Estonia, the area of organ transplantation is below average, in comparison to European countries both in organ donation and organ transplantation activities. The reasons for this could be starting from the education, awareness, and easiness to fill in the donation forms to the fact that due to the size of Estonia, the organ market is limited. For the limited availability, there has been a widescale development since Estonia joined Scandiatransplant in 2017. Cardiologist Pentti Põder has stated that joining Scandiatransplant was more complex for Estonia than joining NATO (Eesti Arstide Päevad 2021).

The medical care for heart transplant patients was established in 2015. The transplantation operation for Estonian patients takes place in the University Hospital of Helsinki, pre and aftercare will take place both in Helsinki and Estonia. For the whole process to be successful, the periods of before, during, and after the transplantation are crucial. Since 2015, 14 heart transplantations have been conducted for Estonian patients, 11 of the patients are still living, one of them has lived with a donor heart for 16 years already. Currently, there are 6 patients on the waiting list for a new heart, 4 patients are receiving aftercare and one patient is a potential candidate to be on the waiting list for the heart transplantation (2021 information from PERH).

Even though the improvements during the last 5-10 years have been noticeable in Estonia, there are also some possible gaps noted. The medical services are described as high quality, yet when talking with Dr. Riin Kullaste during the first interview brief, she noted that there is no patient mapping or systematic analysis done from the patient side of the view. The medical data stays in the databases of the hospital, however no social data is recorded in any step of the transplantation process.

3.2 Problem owners

The direct problem owners who are in the focus of this research paper are people who are heart transplant patients and candidates, the family of heart transplant patients/candidates, and the hospital staff who are involved with heart transplant patients (mainly the cardiology unit). The additional local problem owner in Estonia is an NGO Siirdatud Süda, which unites all the heart transplant patients in Estonia, offers information and some support (more about the NGO activities on page 40).

The more distant problem owners, in this case, are involved organisations and institutions such as Scandiatransplant, pharmacies, and other hospital units. They are distantly affected by the well-being and processes of heart transplant patients from the non-medical side but are not directly affected by the social well-being and awareness of the patient and their patient journey.

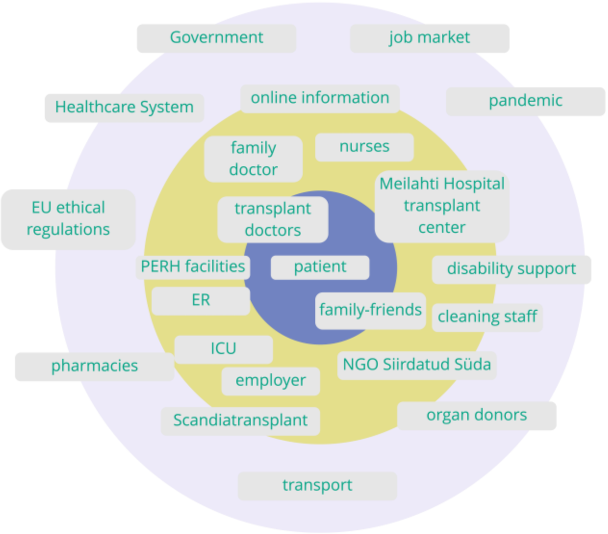


Figure 4. Stakeholder Map by the author

3.3 Concluding the desk research

The wait for the TAI approval prolonged the planned research unexpectedly. During the waiting time, the desk research was analysed from the theoretical side and the literature recommended from the hospital side was reviewed. The UN health reports and yearly European reports helped to understand the scope of the procedures.

When the approval from TAI was signed, the supervisor from the North Estonia Medical Center side could use the access to the patient lists for handing me the patient list of heart transplant patients treated in the hospital and also the contacts to the personnel.

The analyses of the desk research informed the following qualitative research process. The desk research provided understanding and introduction to the topic, including the current work which has been done or is in process in the other regions of the European Union. The non-medical barriers and factors in focus were taken into consideration while moving forward with the work. Nevertheless, it is important to note that these are not assumptions to go into the qualitative research with, as the barriers are possibly not the case in further research. The desk research has given an overview of the European Union context, which Estonia can fit into but is not expected to do so.

4. Participatory Research

The participatory research started with structured talks with the medical specialists, the patients, and the close ones of the patient to understand their situations. The medical professional interviews include questions about the processes and how they see the current state of heart transplantation healthcare and the future. The patient and loved one interviews include their personal story with their highs and lows. Main repeating outcomes from the interviews are concluded and elaborated further.

Meeting the heart transplantation first-hand. Interviews with the patients and hospital personnel and the close individuals to the patients

Semi-structured qualitative interviews are used as the main form of qualitative data collection. As there are fairly few heart transplant patients and hospital staff connected to them, the interviews are semi-structured, giving the interviewee the possibility to always speak more and open up about various subjects. The structure of the interviews is prepared beforehand and accepted by TAI (appendix 1). Also, an agreement document about the data collection and the purpose of the project has been sent out to the interviewed patients beforehand for them to read through and understand how and why the medical information is collected (appendix 2). All the interviews are presented anonymously, to protect the personal and medical data of the individual.

4.1 Interviews with the patients

Three patient interviews were conducted. Two of the patients were already living with the organ heart and one was still on the waiting list for a new heart. All of them were set up via video call sessions. All the interviews lasted between 40 minutes and 1 hour. The questions were divided into individual experience questions and overall questions about the future of heart transplantation. The personal questions included a story of their heart transplant experience, the positive, upbringing moments and the negative downhills, where they get emotional support when they need it and how can one support a heart transplant patient. The overall subject questions were about how they see the heart transplantation going further in the next 10 years and what they would like to make better for the next patients, going through the experience.

The stories of the three patients were very different from each other - in terms of their journey towards the heart transplant, how long they waited on the waiting list for the new organ, and their recovery and life after the transplantation procedure.

1

Patient 1 has been on the waiting list for a new heart now a little over a year (as of May 2022). They have been living with heart failure since birth, therefore the constant check-ups and health forecasting were not anything surprising for them, having the first heart-related surgery at 11, involving mitral valve application. Additional surgeries were done at ages of 14 and 15 when the bioprostheses were operated. During this surgery, patient 1 suffered a stroke, with after-effects of motorics. Patient 1 celebrated their 16th birthday in a wheelchair. First signs of needing a new heart began a couple of years ago, when the patient led a remarkably active life, both career and study-wise but could do less and less, at the same time arrhythmias were becoming much more frequent. During 2020 the patient got a heart stimulator. Since 2021, the patient started to get Levosimendan infusion once every ten days as this is the only way for the 1 to stay alive. Patient 1 has also had other complications, for example not being able to eat solid foods for the foreseeable future due to the heart being bigger and distracting the usual functions of the esophagus. The waiting time has not been the easiest and there are no current updates on when the patient could get a chance for transplantation since the procedures are stopped due to the pandemic. Despite the current situation the patient manages to stay realistic and hopeful mentioning that nobody life would have to be easy. When asking where does patient 1 get support when feeling low, the patient mentioned that now the 1 is in contact with close ones and they give the patient support but there have been times when 1 was not feeling a need, or will to seek communication with anyone and decided to keep more on their own. Recently they have been seeing a psychologist, who in their words, helps a lot. Now the patient feels more comfortable opening up to their close ones as well

When asking about what could be better for the future patients starting this journey, patient 1 mentioned practical information, without a second thought. Practical information about the transplantation visits to Helsinki, about the family accommodation, the expenses of travels, the more detailed information of what to look forward to after transplantation. Such matters may cause stress for patients and their families, and it would be helpful to have all the practical questions clarified at an early stage.

2

Patient 2 had a very different medical journey. Being an active young person with little kids, they enjoyed sports, and did not have co-morbidities. While staying home with a child, patient 2 started to feel more tired. First, the patient thought it is just normal tiredness of being a parent of young children. As the problem continued, the general practitioner was contacted and blood tests were taken. The results were nothing too alarming - a bit low on vitamin D and iron, which can be counted as a common issue for Estonians. Their well-being worsened gradually within a short time until 2 could not walk up the stairs. Patient 2 felt this was not common exhaustion and decided to visit ER. The patient 2 was hospitalised and quickly diagnosed with inflammation in the heart which was at this point already severe. The patient mentioned that they somehow even knew that they could not go home during this day. The experience and feelings were so intense that the patient mentioned that they could not stop crying, therefore the doctors had to put the patient to sleep for several days for the heart to heal - crying would slow the healing. Patient 2 does not have memories from the following days spent in PERH ICU. The external blood circulation helped them to stay somewhat stable. The patient was so weak that they do not remember much. Soon after, the staff from PERH decided to transport the patient to Helsinki to continue waiting for the heart there as it would have been too risky to travel during the later stages of the condition. The patient received a donor heart a month after arriving to Helsinki.

Patient 2 got a new heart in the autumn of 2020. After the transplantation procedure it was clear that patient 2 had lost motoric abilities from the legs but they are still hopeful to learn to walk again in the future. The transplantation experience was considerably quick but still very hard for the patient and the family. In Estonia, at first, the family could not get any information, or the information they were provided was overly dramatic (with a message to the family of their family member already losing their life). With the change in intensive care units, the information flow improved in Estonia and the family received more adequate up-to-date information. The patient mentioned the journey being emotionally heavy for them as the family could not join patient 2 either in Tallinn hospital or in Helsinki. Patient 2 mentioned that in Helsinki a psychologist was offered but 2 refused due to not feeling comfortable of sharing feelings in a foreign language. Estonian hospitals offer pastoral care services which help with emotional trauma but the patient felt unsure as they were not with a religious background themself and did not feel comfortable with this category of help. When asked where did the patient and the family find information about heart transplantation, the patient mentioned that they purposely did not search for any information online due to the reason of possible additional panic and unclear negative messages from the internet search.

The patient has now a positive outlook on life and also finds ways to help others in the journey. The patient is certified experience advisor (kogemusnõustaja) to be there for other heart transplant patients and the ones who are still on the waiting list. Patient 2 is also active in communication with the heart transplant community where they meet up a couple of times a year.

3

Patient 3 story also starts with no signs of other illnesses, and no complaints in the previous medical journey. In a way, it was somewhat similar to patient 2 story - being an active individual, doing sports and physical work, yet suddenly starting to feel weak and out of breath. For patient 3, the decreasing curve was faster – they felt tired the day before and on the next day they called an ambulance and were signed to the ER. The heart failure was obvious but initially patient 3 declined the offer to be put on the waiting list for a new heart. After living with an LVAD (left ventricular assist device), which gave patient 3 an electric stimulation each time the heart experienced arrhythmia for a year, the patient decided to be put on the waiting list. Initially the electric simulations became so frequent that the patient experienced them daily and could not even go outside during the winter without experiencing a small electric shock. During this time patient 3 still did not have enough power to work or do regular daily activities.

As the shocks became very frequent and the life quality decreased, patient 3 decided to agree on admission to the waiting list. The waiting list for the current patient was very short - 3 waited only a couple of days before they got a call from the PERH telling them to get ready for the transfer to Helsinki. The operation and intense recovery period was also the shortest and smoothest it has been for any heart transplant patient. After a couple of weeks, the patient was admitted to home care.

Emotionally the patient mentioned that the heart transplant journey itself was not difficult for them as they did not have any time to process it after agreeing on the waiting list spot. Patient 3 mentioned that if had they had a longer waiting time, they would might have had declined or been more hesitant. Their initial hesitation was caused by the possibilty of being disabled after the transplantation and thus not being able to take care of their family. The aftercare rehabilitation also went without any major complications.

The patient described themself as an introvert who likes to process their emotions on their own, therefore they did not feel like they needed any psychological help. They admitted that there were hard moments of course but they tried to not show them in front of the family - they stayed strong and calm for their close ones.

4.2 Patient close-one interview

The interviews with the friends and family of patients were expected to be the shortest ones but were one of the longest talks instead. During the interview with patient close-one, the journey questions were not asked, the focus was rather put on the ways they were there to help the patient, what were the highs and lows of the experience, and how they see it to be better in the future.

The close 1 was a close relative of the patient, living together with them and taking care of them daily. The patient is still on the waiting list for new a heart. From the conversation it came quickly out that the close 1 needed someone to listen them, to share their experiences and thoughts. The most important things the person mentioned were the lack of knowledge on how to be the best help for the patient while taking care of themselves as well as lack of close communication within the same background people as the close 1 is - the family and friends of the patient who could share their experiences and learn from each other. Most of the talk was about the close 1 feeling the need for support. They expressed it by talking about the daily difficulties and the fact of not knowing how to act when the patient feels down and the feeling of being alone with the problems. The person was still hopeful that the heart will be found soon, this is the goal and fact that keeps them alive, literally.

4.3 Hospital staff interviews

The interviews in the hospital were conducted with highly skilled medical professionals who are the first contact to the heart transplant patient. Two professionals are the primary contact and lead for heart transplantation in Estonia.

1

Hospital staff 1 was the first interview for the purpose of this research paper. The main focus of the interview was all the technical (medical) parts of the journey, so that the author would understand the terms and alternatives of the heart transplant as well as the heart transplantation procedure itself. The hospital staff 1 described what (usually) happens with the patient before getting admitted to the waiting list, and what the patient needs to do to even be considered for the waiting list. The main components are included in the initial patient journey map (appendix 4).

Besides the medical, hospital staff 1 highlighted the importance of social support. Social support is often offered by family or close ones, who are dedicated to being there for the patient on their journey. Support network can also be a critical factor in even getting elected to the waiting list of the new organ (Ladin et al., 2019). As there are no psychologists mandatorily connected to the transplantation program, it is important that patient can share their thoughts and feelings with someone they can trust.

When asking about where the patients get information about the procedure (if they have preparation time for it) staff 1 mentioned a booklet in Finnish, which describes the heart transplantation as a whole and what to expect before and after the procedure. The booklet also includes hands-on recommendations on daily life after the transplantation.

The service design examples in the health care sector were introduced to the interviewee as a part of the interview. The staff 1 saw potential in using service design and co-design as methods to tackle health care issues, yet they mentioned the lack of time. The process and neither the outcome should not put an extra burden on the health care personnel since they are occupied with their daily tasks, even more now than ever before since the covid-19 pandemic situation is still a relevant topic. They care about the patient's overall well-being a lot, but just do not have time to focus on this, as medical care is priority.

2

Interview with hospital staff 2 was conducted with more focus on side activities and the overall improvements and weak points of the transplantation journey as the researcher already had an overview of the medical journey of the heart transplantation.

The role of the hospital staff 2 is to meet them at the beginning of the journey and go through the whole process with the patient, therefore seeing most of the stages of the medical journey. The staff 2 recognises, that the patient might go through a lot but also admits that there is not much that the medical staff can do with it, therefore the thing in their power is to only give a green light of transplantation only to the patients who are mentally strong and prepared in the examination. If a patient is hesitating or overly emotional, they are not a good candidate for the new heart, mentions hospital staff 2. A problem that the medical professional mentions is people not caring for their health. This is related to the cardiac patients but also is considered an overall issue. The patients do not have an interest in their medical history or condition, also they do not know about the medicine they are taking if being asked which is crucial in the opinion of staff 2. Patients are hoping that the doctors know everything and the they are just being served, which is the case if the patient is not able to be informed or take care of themself (for example while being in ICU). But when the patients are taking care of themselves at home and not being able to keep up with the daily doses of medicine or healthy routines, it is impossible to help the person. The patient has to show dedication also for financial reasons - the healthcare system is investing major amounts of resources in treating heart transplant patients. Regarding the question of how transplantation treatment would or could look like in the next decades in Estonia, the staff 2 is not overly optimistic - they mention that almost nothing has changed for the better during the last 10 years so there is no real hope that it would get better during the next decade. The mindset of the patients seems to be one of the most important topics for staff 2, which could be much more prepared and dedicated.

3

Hospital staff 3 was interviewed during the later stage of the research process when the patient journey was already close to being clarified. During the same time, around the ideation phase, also an external hospital professional was interviewed, who is working very closely with the transplantation patients in another hospital. These two interviews were focused on the topic of what would the hospital professionals change in the system and what are the current strengths and weaknesses. Staff 3 is working closely with the patients who are having LVADs, but they are also often the patient's who are heart transplant candidates and LVADs are implemented as an option for the waiting time of the new organ. The lack of disability funding at the governmental level was the highlighted topic of the conversation. The treatment and drugs are costly, yet the healthcare system only covers some, leaving a very small amount of money for the patient to live a healthy, quality life. Another bigger topic was communication. The lack of patient networks and therefore a major workload for the hospital staff to be the network for the patient, struggling with the health problem and not knowing anyone to share the same issues with. Staff 3 does their best to be there to support the patients, not only with medical practices but to also as a person of trust. They mention that they can be the person for them because there are not that many patients but if the number would be a little bigger, they would not have the energy and power to do it, unfortunately.

The external hospital staff was contacted to get an understanding of the patient care under the same system, yet in a different place. They mentioned the same - that they are very close to the patients, going through the journey but the patients need a regulated system with a supportive structure starting from other specialists (such as nutritionists, physiotherapists, and psychologists) included in the treatment program. They also seconded the opinion on the active community but were very aware of the activities of NGO Siirdatud Süda, which is actively arranging meet-ups for transplanted patients a couple of times per year.

4.4 Conclusion of the interviews

Speaking with different problem owners from different positions, there were certain topics were brought out and highlighted throughout the talks. The main points to conclude the interviews were:

- The lack of psychological help,
- The importance of mental support and also other support services such as physiological and nutritional help,
- Everyone’s journey in transplantation is different so there is no one certain path,
- Individual (and also overall public) health should be taken more seriously and individuals should grow a mentality of responsibility towards their health situation.

Before the interviews, the preparation in terms of knowledge of the patient journey for transplantation was sourced from the initial desk research. The reality of patient journeys, especially when talking about heart transplant patients, is widely different. There are no two identical patient journeys. The patients interviewed had different symptoms, intensities of the situation, and also different periods of time spent on the waiting list. The only phases which were similar were the actual procedure time in Helsinki and the aftercare and rehabilitation which were similar in activities. Therefore it was understood that visualising the patient journey will be a bit of a struggle since the pre-surgery activities are different for each patient.

Despite the learnings about the actual journey of the patients, the categories of topics mentioned above followed through each discussion with patients and staff. The leading heart transplant staff mentioned that strong social support is considered one of the criteria to be chosen for the waiting list for a heart transplant. The reason for this is practical - if the patient does not have anyone close to them helping out during the rehabilitation period, there will be almost no option to return home for treatment, making the patient stay under the care of the hospital for much longer. Another, sometimes even more relevant reason for having close family and friends is the mental toll that the rollercoaster journey will take from the patient. Even the mentally strong patients admitted that they “stayed strong for the family”. The ones’ who naturally would like to share their feelings, the family and friends are often the ones with whom the ups and downs are shared. As it is a heavy topic, the close ones become almost like support systems or therapists themselves.

There is no mandatory or even optional possibility of professional psychological help in the transplant program in Estonia. From the hospital side, the lack of psychological help is mentioned but due to the lack of resources, not discussed further.
The interviews with the medical professionals included interesting discussions on the healthcare as a mentality, not necessarily connected to the heart transplant patients but also relating to this group of people. The message that stood out was that individuals need to care about their health on daily basis and need to be more responsible for their health and how they are doing. The root of the problem could be in the free healthcare - if individuals would see the cost of healthcare, they might care about it more. Healthcare is currently widely available all over Estonia and also very high-quality treatment is offered, with a short waiting time. This has become a normality and level of expectancy in the nation, which is, of course good, but makes people less aware of their health conditions and responsibility because they subconsciously know that the healthcare system will be there when needed. This relates to choosing who will be accepted to the waiting list for the new organ. The individual who is selected needs to take care also on their own as they can not forget any drugs, they need to take them in the right amounts and at the right time, know what to eat, and so on. A person who does not know what drugs and what amounts they are taking daily or do not carry their treatment scheme (raviskeem in Estonian) with them, is not selected for the further steps of the transplantation process. Therefore the dedication has to come from the patient’s side first, and the hospitals need to see that.

5. Existing Services and Products. Co-design in the Medical Field

The following chapter introduces the cases, where co-design and service design practices are used in the healthcare sector. In addition, the support content which is available for heart transplant patients in Estonia and where the patients could get help now is introduced. Even though the thesis works with heart transplantation in focus, the content for patients from PERH is brought out, showing the hospital’s efforts in communication with patients and health-curious individuals.

5.1 Co-designing in healthcare

Co-design and human-centered service design are rather new concepts; co-creation from the 1960s, human-centered service design from around the 1990s (Gioia, 2015), even newer terms in the international medical field and even more unknown to the medical field in Estonia. The book Health Design Thinking, published in 2020, is in the author's (of the thesis) knowledge the first extensive workbook for applying design thinking and co-design practices in healthcare. The growing importance of including patients and stakeholders in the processes from the start are becoming much more visible also in the PERH context. The study program of Design & Technology Futures has been collaborating with the hospital in previous years for semester projects. The collaboration has produced design solutions for complex problems, showing how inclusive mindset and practices can make a positive change in patients' well-being and personnel's load of work tasks.

"Design can not solve every healthcare problem. However, human-centered thinking has the power to start chipping away at the entrenched patterns within the medical community and in society at large that perpetuate health inequity. Change is difficult in a hospital, where mistakes are costly and can seriously damage human lives. Not every proposal is implemented and not every intervention succeeds. Change requires the space and the courage to test new ideas" - (Ku and Lupton, 2020).

- **Practices of Service Design in healthcare systems by design agencies**

Several agencies are focused on changing the healthcare for better through using social design, co-design, and service design practices. In this paper, the work of Experio Lab, Center for Connected Care, and Panton - Medical Metroline are highlighted as great examples.

The agencies are solving strategic design problems within a very wide range of healthcare topics, from pregnancy to strokes. Projects relevant to the current research are focusing on value co-creation and patient journey mapping. There are no projects found on the transplant topic in focus but the strategies used are similar in some aspects throughout the topics.

A good example of this would be the Dutch organisation Panton, where a team of designers and researchers co-design different social design interventions for the medical field together with the patients. Service ecosystem and its mapping, storytelling, and implementation are successfully done in the healthcare system of Norway and led by Josina Vink, a process in which she and the team are focused on invisible social structures and connections and co-creating by disrupting, creating, reshaping the structures and possibilities.

Last but not least, the two other agencies are brought out, who specialise in implementing design practices in healthcare systems. Experio Lab in Sweden has been active in the innovative healthcare service field since 2013, being one of the pioneers in this topic and implementing the theories and methods described further below. Center for Connected Care operates in Norway, also implementing the experiments and theory into practice as well as being very active in publishing publications and innovation tools.

5.2 existing support elements in Estonia

- **Written guide for the patient living with the transplanted heart - 2016**

The only support material for patients per- and post-heart transplant in Estonian, the paper (2016) is based on the introductions written for the heart transplant patients by Helsinki University Hospital, transplanted and customised in some parts by Annika Elmet, Märt Elmet, and Kadri Kõivumägi. The support material guides the reader through the main steps of the process of waiting for the new heart and also describes recovering and living with the new heart. It describes the different threats, medications, and daily life in simple language and advises on hygiene and physical activity.

- **NGO Siirdatud Süda**

NGO Siirdatud Süda was founded in 2019 by the first Estonian who received a donor heart. The NGO was founded to bring together people who have had a heart transplant or are going through the process. Their first presence was a private Facebook Messenger group called Liidetud Südamed. Now the NGO has a website which has a short description of the heart transplantation process and an introduction to their gatherings of couple times per year. They also introduce the people who are more involved with the organisation. Having a conversation with the founder of Siirdatud Süda was special because the founder Kristin Sims was the first Estonian who received a donor heart. She explained the feelings of being the first and being alone with the condition in Estonia, therefore having even more extreme experience than the following patients. When asked what are the main problem points for the patients in her opinion, she mentioned keeping new health routines, plus starting with new (positive) things. There is a need for more in-depth aftercare in terms of physiotherapy. Currently, the NGO only works with the group of people who have already received new hearts but she also mentioned a wish to include LVAD patients and the ones who are on the waiting list.

- **Experience advisor**

An experience advisor is an individual who helps people going through certain life-changing events and traumas by supporting them with their own experience in the same or similar field. The advisor does not have to have a medical education but they have through a training program for the needed certification. In Estonia, an organisation called Kogemusnõustajate Koda is facilitating different experiences and works as an informative organ and database. Since autumn of 2021, Estonia has one new experience advisor on the topic of heart transplantation and the journey of getting a heart transplant. The advisor is a heart transplant patient themselves and the individual is here to help other patients to go through the experience and answer possible questions.

5.3 Existing mobile apps for heart transplantation patients

Doing the field research on available mobile apps, the choice at first seems rather wide. Taking a closer look, the apps are mostly focused on kidney and liver transplants and can not be customised for other organs. There are apps for medication reminders which can be customised to various organs, also for heart transplants. The apps with a focus on educational, community-centered, and/or social content are non-existent for the heart transplant community in Estonia. The apps which were found focused on the audience in the USA and Indonesia but as the treatment scheme and the whole journey is different throughout the continents, these apps were not taken as considerable options for the Estonian market.

The digital applications highlighted are AlloCare, which is customisable to your organ and asks specific questions to set up the account. There is an available resource page with can be considered not really relevant as all the resources are mixed and it also displays resources about other organs. AlloCare gives notifications to the home screen which act as “fun facts” or inspirational content.

A smart application with a different function brought out is Omronconnect. It connects straight to its own brand health devices and sends health information to the app via Bluetooth, making it easy to track the health metrics. The app is only accessible with Omron devices.

5.4 Existing for-patients additional support by PERH

PERH as an organisation has existing services for patients and visitors in order to give additional education and gain trust. Over the years, PERH has done various collaboration projects with universities to understand patients and innovate the environments. These projects usually do not last over half a year but there are activities that PERH is doing for the patients and the public.

PERH is publishes an (almost) monthly podcast which covers topics across departments to open up the topic and cover it in a casual form. The conversations in podcasts are led usually by the medical professionals, less often by the patients.

On the PERH webpage, the visual stories of departments are there to show professionality and gain the trust of the public, plus existing and future patients. The unit-introduction videos show technology, competencies, and people who work in these units.

PERH also has a seasonal magazine which can be described as a rather light read to also be readable by the people who are not specialized in medicine and have an average vocabulary. The magazine has also the value of creating transparency for the whole organisation and sharing stories from across units.

From the last year of 2021, PERH has launched a project called Patsiendikool - Patient School. The format for this at first was an online presentation by the specialist Since the autumn of 2021 it has developed into a recorded panel discussion format. The discussion is facilitated by the specialist and the panel includes patients and medical practitioners in the specific field. The project was rewarded with The Study Activity of the Year 2021 - Tallinn. Patsiendikool published a panel discussion about organ transplantation on the 14th of April 2022. The panel was facilitated by Riin Kullaste and the guests were kidney transplant recipients, heart transplant recipient, two leading specialists, and an individual who was not familiar with the organ transplantation to ask common questions about registering to be an organ donor.

The three activities by PERH mentioned above are all easily accessible from PERH front page with a click of a button which is positive since the access to patient and public information is made easy.

PERH has a sub-website called Südamekeskus - Heart Center - with a focus on cardiac diseases. The website explains common diseases and introduces cardiology specialists. The website also includes small sections for the patient close ones with overall information on support and recommendation for seeing a psychologist if there is a need.

6. Design Process. Research Analysis & Design Concept

The first part of the research outcome is presented in a form of a patient journey mapping as it is one of the desired outcomes by PERH when proposing the thesis topic for research. The purpose of mapping the patient journey not only in written medium but also visually, is to express and highlight important information for audiences in need. If a patient journey were to stay on the level of a written paper, it would lack the ability to create and see connections as well as points for improvement. The visual presentation gives a possibility to see the journey as a whole and also zoom in on different focuses.

The patient journey is created by listening to the stories of transplant patients as well as medical professionals. Before mapping the patient journey, no clear proposals for improvements are made at this to get the most comprehensive understanding of the current patient journey.

6.1 Mapping the patient journey. Comprehensive understanding of the experience

The patient journey (appendix 4) is created on the base of interviews with the hospital personnel and the patient stories. The medical journey is based mainly on the information from the hospital and the patient stories.

For the heart transplantation journey, there is a classical timeline of activities that the patient goes through and what is described as the transplantation. Yet, talking with the individuals who have gone through the experience, it quickly became clear that every experience is different in many levels, starting from the symptoms and pre-transplantation care and ending with the life with the new organ and the aftercare period. The only phase that is almost identical throughout the patients is the transplantation surgery in Helsinki. The complications and organ rejections are still a possibility to happen but overall the procedure and what the patient goes through are similar.

From the hospital side, there are more similarities to keep in mind and consider as it came out from the interviews - yes, there are urgent care patients who are not regular but the transplantation is not a regular procedure, so it already is an irregular procedure which still has touchpoints on every phase.

In order to tell a story of a patient throughout the patient journey, the story is told through a persona - implementing touchpoints from different patient stories and creating a comprehensive journey which the person is starting to step through. The persona has also possibilities on the way, illustrating still the “common” options which might be the cases, different crossroads which change the journey due to unforeseen circumstances.

The map presents a journey with pinpoints, what the patient is going through, their feelings, thoughts, touchpoints where the patient is in contact with the hospital due to its transplantation case, and last but not least, the channels through which the touchpoint connections are present. The map is categories from first left to right with the green outlined boxes, representing different stages of the transplantation journey - Serious Symptoms, Diagnosis, Waiting List, Transplantation, and Life with Transplant. Each of the boxes includes levels of characteristics in it. From up to the bottom on the left, the characteristics are described. Actions are physical moments what the patient goes through during the part of the journey. Touchpoints note the ways how the patient connects to the hospital. Channels are the ways used by the patient to help them on their health journey at that specific time. The line with the green pinpoints follows the mental state of the patient - the low and high curves illustrate where the patient might feel low and what experiences are uplifting for them, also noting the actions which are happening throughout. Feelings are patient’s feelings on the parts of the journey and Thoughts are representing the state of mind, and what is the patient thinking.

6.2 Possible Improvements

The map in appendix 5 shows the patient journey map after the analysis together with the reflection from the interviews taking into consideration also the patient family/friends interviews, which are less illustrated on the patient journey map, as the patient’s viewpoint is the center of the map. The red boxes added to the map show the areas where the improvements can be made in terms of the current research project. There are quite some areas highlighted but in these terms, there will be the following especially pointed out:

- Feeling alone with their worries - would like to know how others with similar experiences are managing their journeys
- Struggling with the self-confidence
- “Am I even asking the right questions?” Not knowing what is important to know

- Struggles with communicating the journey to the family - from one side needing support from them but from the other side the family is also clearly needing mental reassurance and support
- A lot of new information to take in for both the patient and their family. A lot of experimenting because there is not much information on handling the daily tasks and conversations
- The financial disability support is very low and managing a way around it is a struggle to make it on their own

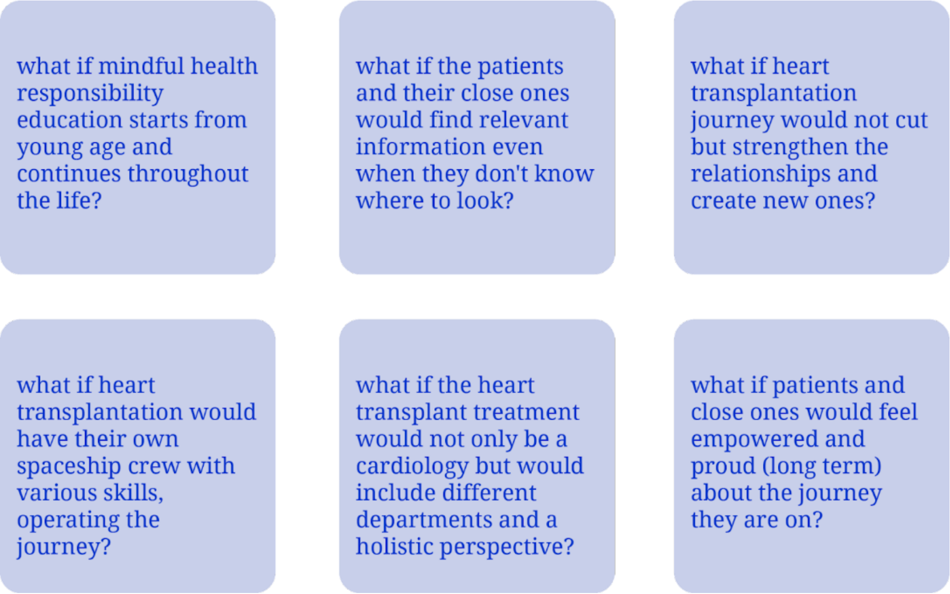
The input from the patient's family and friends is added to the journey in some aspects where it touches the patient but it would need almost a whole new journey of what the patient loved one is going through during the process. As it is strongly taken into consideration in further analysis and their input is added in the bullet points, the full patient family journey will be explained as further work on the reflection and next steps section.

6.3 Concept generation

The concept generation takes forward the analysis from the previous blocks of the research and moves forward in order to propose a positive change in the system through design practices. During the beginning stages of concept generation, no physical form of design outcome is preferred or thought of, in order to still leave space for new ideas and end formats of the outcome.

6.3.1 What if? An exercise

In order to map the possibilities and focus on opportunities, asking "what if?" question is a helpful brainstorming exercise to start with. The "what if?" -s are based on the previous research, interviews, and mapped patient journey to take the previously highlighted problem points and wonder solutions through asking questions. (Wasowski, 2017)



what if mindful health responsibility education starts from young age and continues throughout the life?

what if the patients and their close ones would find relevant information even when they don't know where to look?

what if heart transplantation journey would not cut but strengthen the relationships and create new ones?

what if heart transplantation would have their own spaceship crew with various skills, operating the journey?

what if the heart transplant treatment would not only be a cardiology but would include different departments and a holistic perspective?

what if patients and close ones would feel empowered and proud (long term) about the journey they are on?

Figure 5. „What if?" exercise by the author

The six mapped brain triggers can be categorised into three blocks: health education and perception, focus on the patient and focus on the patient's loved one.

- **Focus on systematic, educational change on how overall health is perceived by the medical system. Developing better health culture.**

From this category of the brain triggers the key takeaways are the patient education which could be interactive and motivating and personal. Phrasing one health care professional " in-depth knowledge about organ transplantation will decrease false understanding, unjustified expectations, and fears". The education around organ transplantation is important first and foremost to the patients themselves in order to understand the processes and navigate their life along the process. The knowledge and education are also crucial to the family and friends of the patient as they are also going through the journey but on their own ways, handling the issues related to the mental support and caretaker role.

Currently, the educational part of heart transplantation is on the shoulders of the medical professionals to take care of. When asking the medical professionals about how and where do the patients get the information if they want to know more, the cardiologists and nurses say that they are explaining the procedure and if there are any more questions, the patients can call and ask if there is something they doubt about. In the hospital's opinion, there is not an unbearable workload (yet) due to patient phone calls and information requests as there are not that many patients who need the guidance on transplantation and LVADs. There were no complaints from the hospital side, yet the hospital staff said that they feel that the patients would need more educational support, not only on medical questions but rather in daily, social and mental categories.

Putting a focus on the public health from the perspective of social, cultural, and current health system side is a topic for discussion but will not be dealt with primary focus later as the thesis will focus on the heart transplant patients, which therefore as problem owners would need primary attention, even though the public health awareness and education topic is discussed with the health professionals and is found somewhat worrying.

- **Focus on patient and their support network**

Patient and their supportive systems are the main problem owners in the focus of the thesis. The supportive system, in this case, is identified as where do the patients currently get support and where they could get support on their journey in the future. The supportive systems currently in place for the patients are the medical support of the healthcare system. Currently, the health care providers also act as mental support due to the need and for no mental health professionals included in the program. The other supportive system available now for the patients (who are selected for the transplant) is the family and friends of the patient.

For the patient's supportive systems focus, the importance of additional design solutions is relevant. The current concepts what would support patients for giving them the space for education, free conversations, and asking the right questions through the aspect of interaction and gamification. The space/platform for the ability to find the answers to the questions even not known to ask for, feel connected, yet not overwhelmed.

The importance is also making it clear that the concept is not supporting the patient to find the medical information from questionable sources and move towards alternative solutions. Medical knowledge and practices always come first and are strongly advised to be followed by the patient. The supportive systems would offer additional non-medical help for the patient and the non-medical help is only recommended to be tried out if it does not clash with the approved medical journey of the patient.

- **Focus on the patient's loved one and their support**

From the contact with the close people to the patient, the main outcome was that they opened up on the topic of supporting a heart transplant patient even more than the patients interviewed about their experiences. One interview with the close contact of a transplant patient expressed themselves as they are in urgent need for a knowledge of how to take the best mental care for the patient, how to answer to situations, and where to share their experiences of being a caregiver.

At first, the idea to create a concept was based on only creating the proposal for the patient but as the information from the close ones was a major turn in the direction, the option to create a proposal for the close ones being the main center of the final design was becoming an option.

The chosen concept creation areas are supported by the two following models:

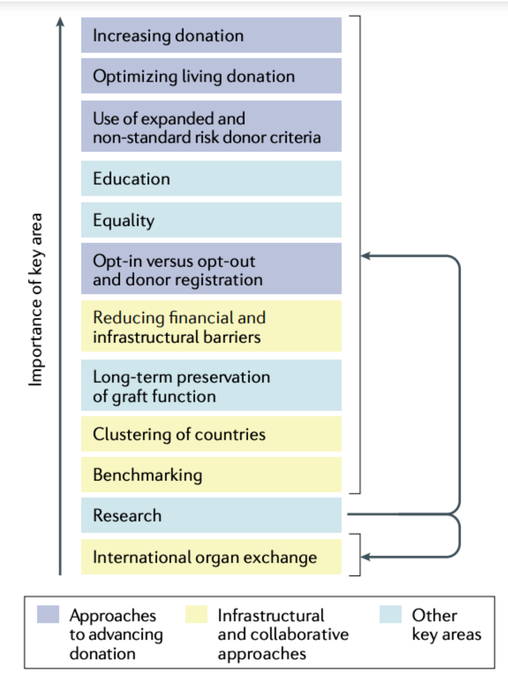


Figure 6. Key areas for promoting transplantation. (Vanholder, 2021)

The graph (figure 6) highlighting key areas for promoting and improving transplantation in Europe, education is especially important and a theme throughout the current research paper. The article elaborates both on public education/awareness, patient education, and improving the communication skills of health care specialists. The reduction of infrastructural and financial barriers is also brought out in terms of the thesis, yet this topic is opened in the reflection and further recommendations part.

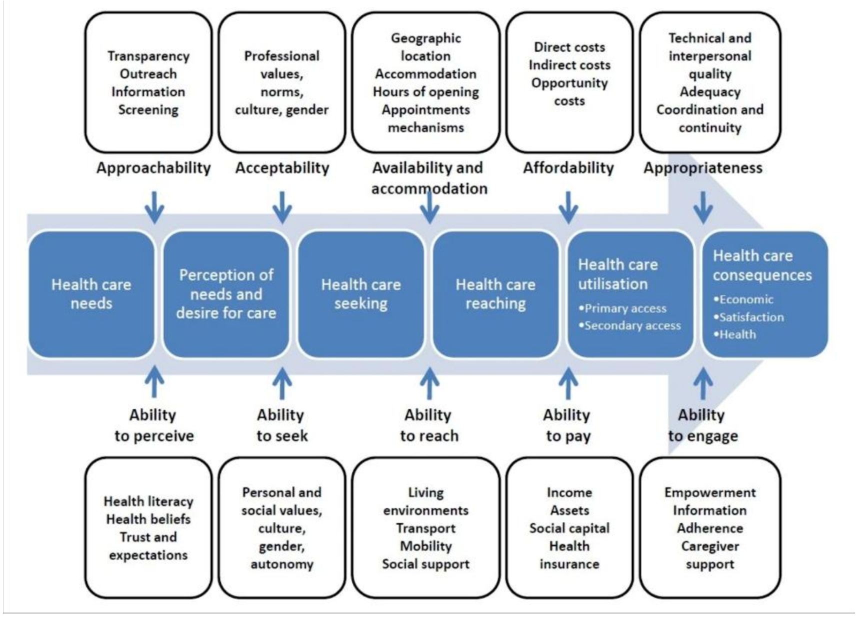


Figure 7. Conceptual framework of Access to health care. (Levesque, Harris and Russell, 2013)

Figure 7 above shows how access is captured by the supply-side (top row) and corresponding demand-side (bottom row) to create patient-centered health care. From this model, the proposal of this research paper will change things for better in the categories of Approachability and Appropriateness. By improving the heart transplant journey from the Approachability category, the focus would be on the awareness and mentioned health literacy. This would therefore also include the future transplant patients so that even before their journey they are aware of their health and wellbeing. This would include overall national, and social health education.

The block with the most potential for innovation is Approriatness which results in an ability to engage for the patient. Caregiver support is also mentioned under this category. It would result in awareness and empowerment by the patient, the caregiver, and the medical professionals. As a short, conclusive analysis the possibility to present the most novel change with the current case study is laying in the last block of supply and demand. The demand has been proved by the patients, caregivers, and medical professionals, therefore the proposal will supply technical and interpersonal quality, adequacy, coordination and continuity.

6.4 The choice of focus on the concept creation

Considering the previous three categories thoroughly and finding new potential in the third category of innovation for the patient loved ones, the design proposals for the thesis are working forward with the **patient and their supportive systems**. The first category of the possible structural improvements in the systematic side of the treatment, education, and health awareness are further discussed in the further recommendations part of the research paper.

The thought process of focusing on the patient for the design proposal was in the end rather logical - improving the patient’s wellbeing also improves the daily life of the family and friends of the patient. The structural and educational changes are the most promising in terms of the scale but is impossible for the scope of the thesis to implement and test as the investments are considerably large. Nevertheless, recommendations are made and can be acquainted in the further recommendations part.

6.5 The patient needs to be addressed

The interviews showed that the patient’s needs were a bit different depending on their journey but some overall similarities and points started to repeat. Following needs are a combined list of current needs of a patient - what they are needing now at the current point of their journey, as well as the needs that they faced during the earlier stages of the journey, which back then were not met by a successful solution.

- Need for stability of motivation in their treatment
    - From the analysis of the interviews and patient journey mapping, the lack of consistent motivation affects the patients. It is clear that the patient’s will to get a new organ and be the best self is a high priority for them, but after going through (sometimes) long wait of many years and long recovery processes, it is also clear that the motivation to stay healthy and keep on going is fragile and can be forgotten when the topics of worry, instability and unknowingness are present.

- Need for a sense of belonging, knowing they are not alone
    - Knowing that they are not the only ones who are going through this journey and there are other patients who have been through this and are healthy and thriving. As the information about other patients’ stories is confidential in the hospital, there is not much that the patient’s get to know from this side. Going through this process of treatment and recovery alone and not knowing anyone personally who has been through this can increase the feeling of uncertainty. Someone who has had a similar experience and diagnosis, who can be easily and informally contacted, is

    an important part of keeping up hope and having a longer goal in mind for the patient themselves.

- Need for access to up-to-date relevant information not only about the medical side of the transplantation journey but also about the support services and financial aid.
    - The medical questions are asked and answered by the patient’s doctor (raviarst in Estonian), who is aware of their journey, their treatment scheme as well as their current condition. The doctor is available for the patient at all times by the phone and can of course answer the medical questions professionally but there is a functioning information gap between the patient and the available support services. The patient either has to find the information themselves or ask a doctor who therefore starts to look for the information.

- Need for possible active communication within the other transplant patients
    - The current communication between the transplant patients goes through the NGO Siirdatud Südamed. The group currently unites only the patients who already have received a donor heart. The communication exchange happens couple of times per year, arranging physical meetings, they also have a closed Facebook messenger group which, as understood, is not active as a social platform.

- Need for professional support in the fields of nutrition, psychology, physiology, and finances.
    - There is no current unified network of specialists working with the patients from different areas of important health categories.

7. Co-creating Concepts

The insights from literature research, and qualitative interviews, supported by the methodology can be put into practice in concept creation. The following chapter describes the concept creation in co-creation practices. Main insights from the workshop with heart transplant patients are used as a base for generating themes for the concept. The goals and referred actions are described to frame the ideation and clarify the priorities of the concept.

Co-creation is crucial when working with an issue the author has not experienced themselves. The patient-centric mindset was developed during the interview phase, listening and empathising with the patient. When it comes to the solution space and concept creation, empathising and being informed by the issues is not enough. Nobody can know the different sides of the problems as well as useful opportunities better than the ones who are facing them daily.

7.1 Co-creation workshop

The co-creating workshop with the patients takes the project process from patient-centered to created-with-the-patients. Here, the value of co-creation is also an aspect to be put into practice, highlighting the S-D logic theory. The workshop is set up to answer the question **"how might the co-designed heart transplant patient support network look like?"**

The purpose of facilitating a workshop with the heart transplant patients is thinking together what are the formats or spaces they would use for the support on their transplant journey and what activities in what spaces they are currently doing and what they would use if there would be an opportunity to do so. The workshop's main exercise ideated ideas on the support network environments. Examples from physical private space, physical public space, and digital spaces were presented and built on.

Due to the patient's health and safety, the workshop was held online in n Zoom using Miro platform for work. The introduction to Miro was given before the workshop with one simple exercise to try out. Below is presented a brief conclusion of the workshop. The full outcome and exercises of the workshop are added in the appendix.

The tasks which patients were discussing were set up in a layering system, in a way that a previous task sets a topic for the next one, building up the knowledge and system, starting from the easiest and going more in detail and more in-depth. The goal of the workshop was to create their own perfect support system/network from their personal worries which have been unanswered. In a workshop a discussion opened up the subjects and brought up new themes or issues. As a conclusion, there were differences but when it comes to building a space for the support to be held and in which form it could be with certain functionalities, the patient's agreed on many. It became clear that the proposal of support for a patient on their transplantation journey can not be functioning only in one space or format, but rather in a combination of some.

During the workshop, the notes were gathered on what patients' said. The keywords were gathered under the categories of activities, environment, external factors, and the additional characteristics of support (figure 8). After the exercises, all the post-its were discussed together. The workshop participants all agreed on the written conclusion notes from the exercises and every patient's opinion and voice was heard. All the workshop materials are visible in appendix 6.

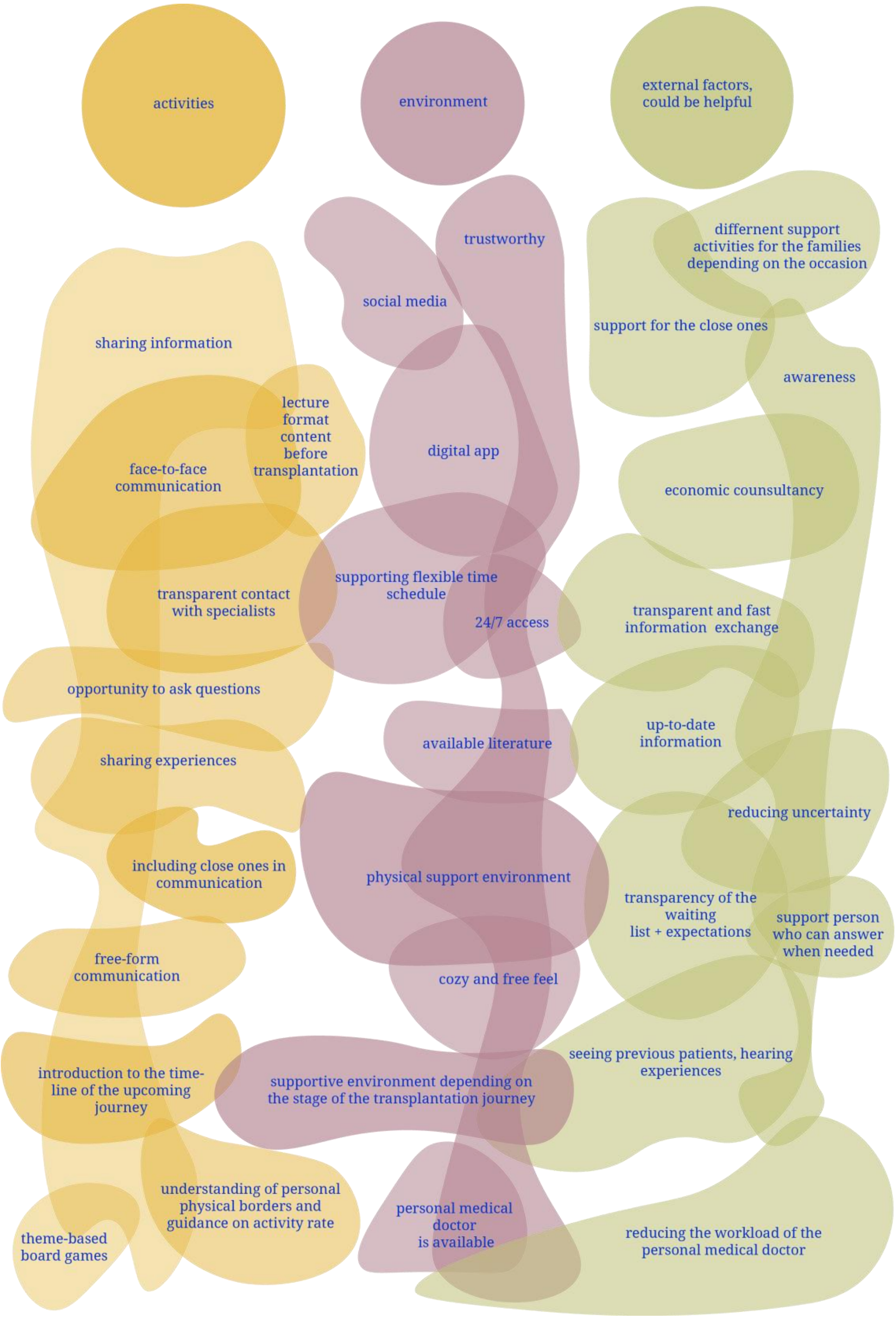


Figure 8. Conclusion from the patient co-creation workshop, by the author.

The concept elaboration was mostly done by the heart transplant patients during the workshop. Before the workshop, the expected outcome was for the design concept to lay on either one or the other format but it became clear that the support is needed in both physical and digital spaces combined to design meaningful solutions for the patients. As a conclusion from the workshop, a concept was created/outlined.

7.2 Themes

The workshop brought out the main themes the solution needs to reflect on. In order to do the selection, the Iceberg Framework was filled in to clarify the conclusions from the patients and the interviews with medical professionals and loved ones, of which social structures need to be kept and enhanced, and which ones should be challenged. The main themes of the concept are also selected by the author's possible ability to create solutions for them, therefore some of the repeated problems are further discussed in the recommendations part as they are something the author can propose but not solve in their abilities.

- Individual approach

  Each patient's journey is different and should be emphasised this way. Each of them needs to be able to get support for their needs on their specific part of the patient journey they are currently on.
- The importance of human connection, communication and two-sided-contact

  Face-to-face communication is crucial for the patients and the information exchange. The patients prefer to meet physically with the specialists and also each other if it's possible. The space for informal patient-to-patient meetings and more formal lecture-format specialist meetings are welcomed.
- Transparency and accessibility of information for both the patient and their loved ones

  The information and awareness of the current, plus the following steps are much needed to decrease the negative consequences of not knowing. The information can be communicated via both physical spaces as well as digital spaces. In addition to the information for the patient, also the selected information should be available for close contact for the patients, digitally or through a physical meeting/lecture format with specialists.
- Previous stories and community of patients

The community should be possible to access but not be pressured as some individuals are more extroverted than others. The importance of hearing and seeing previous patients’ stories and journeys are crucial, in the opinion of the patients themselves, creating the feeling of optimism in the process and the fact that this journey is manageable. Being the inspiration for each other.

- Network of a range of specialists

  Currently missing is the network of specialists from fields such as nutrition, psychology, physiology as well as other support specialists if needed concluded to be very important for the new heart recipients and the ones on the waiting list in order to keep on track with the best health.

- The support being accessible both from home as well as from the public place or hospital

  There is no one-size-fits-all in the current solution space. As each patient has a different journey and is on a different stage of the transplantation journey, the patients also have preferations when it comes to how they would like to access the information, feeling safe and welcomed and their needs met.

7.3 Patient Empowerment

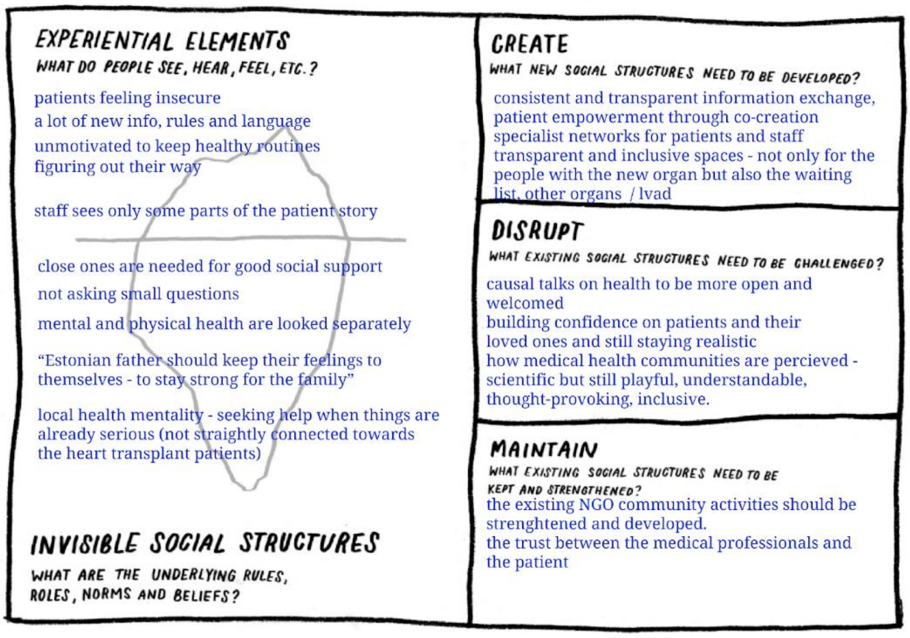
Patient empowerment is described as “a process that helps patients gain control over their lives, increasing their capacity to act on issues that they themselves define as important; a process through which patients individually and collectively are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and take action to meet those needs” - (Adapted from European Union Network on Patient Safety & Quality of Care, PaSQ, 2012). Patient empowerment has been around as a term for ten years now but there is only some improvement in the public healthcare sector.

An EMPATHIE study (Toolkit for Patient Organisations on Patient Empowerment, 2017) in 2014 created a model for patient empowerment, which identifies three key areas - education, self-management, and shared decision treatment making (appendix 7). Educational focus relies on health literacy and transparent information exchange. Self-management includes skills, behaviours, psychological support, and technical skills. Shared decision-making involve relationships between the actors, both professional and personal, decision aids, and attitudes.

In the heart transplantation case, the patients are empowered maybe even more than in some other categories as the shared decision making is present in the relationship between the medical professional and the patient. This might be a natural case due to the fact of the patient having one trusted doctor throughout the journey who they can call for questions at any time. Nevertheless, there is still room for improvement, especially with the focus on education and self-management. Through empowered patients, the whole healthcare system will profit – the patient's who are health literate and who are given resources, abilities and platforms to be involved in their treatment will result in lower costs and investment of time for the healthcare system, in the long run, lowering the burden on the caregivers as well.

7.4 What to keep, what to create and what to disrupt? The Iceberg framework

After the workshop, with the data gathered an Iceberg Framework was filled (figure 9) in order to understand the main themes that came out from co-design activities and discussions. The framework itself shows the underlying social structures well, such as the bigger health mentality, how Estonians tend to perceive health topics and the fact that even though the patient is responsible for their health, the support networks are highly important. From the blocks of create, disrupt and maintain the statements are taken further to build the concept and follow the points which are planned to be kept, created new, or disrupted.



EXPERIENTIAL ELEMENTS
WHAT DO PEOPLE SEE, HEAR, FEEL, ETC.?

patients feeling insecure
a lot of new info, rules and language
unmotivated to keep healthy routines
figuring out their way

staff sees only some parts of the patient story

close ones are needed for good social support

not asking small questions

mental and physical health are looked separately

"Estonian father should keep their feelings to themselves - to stay strong for the family"

local health mentality - seeking help when things are already serious (not straightly connected towards the heart transplant patients)

INVISIBLE SOCIAL STRUCTURES
WHAT ARE THE UNDERLYING RULES, ROLES, NORMS AND BELIEFS?

CREATE
WHAT NEW SOCIAL STRUCTURES NEED TO BE DEVELOPED?

consistent and transparent information exchange,
patient empowerment through co-creation
specialist networks for patients and staff
transparent and inclusive spaces - not only for the people with the new organ but also the waiting list, other organs / lvad

DISRUPT
WHAT EXISTING SOCIAL STRUCTURES NEED TO BE CHALLENGED?

causal talks on health to be more open and welcomed
building confidence on patients and their loved ones and still staying realistic
how medical health communities are percieved - scientific but still playful, understandable, thought-provoking, inclusive.

MAINTAIN
WHAT EXISTING SOCIAL STRUCTURES NEED TO BE KEPT AND STRENGTHENED?

the existing NGO community activities should be strenghtened and developed.
the trust between the medical professionals and the patient

Figure 9. The Iceberg Framework worksheet. Originally by Josina Vink, modified by the author.

7.5 The Concept

The spaces for the concept to be grown were introduced briefly before the co-design workshop, as these environments were the basis of the workshop. Previously there were three categories of spaces, yet now, after mapping out the themes of the concept and having insightful feedback from the workshop, the spaces to move forward with did change a bit.

The two bigger categories of spaces are the physical public space and the digital space. The individual space was still considered an important environment for the patients to solve their needs at home environments but solutions for these needs can be found through functionalities of the two formats, plus additional across-the-spaces functions.

The main goals for both spaces are described, adding specific actions on how to reach the goals.

The common physical space

Goals:

1. To have a place for the transplant patients to gather and always feel welcomed
2. To gain a community of previous patients, upcoming new patients, and their stories. Giving the patients an opportunity to share their story and learn from others.
3. To offer a possibility for the patients to be up-to-date with the literature, news, scientific innovations, and community news in a social, interactive way.
4. The loved ones of the patient would feel included and welcomed during the events and lectures to feel part of the journey and also meet others.
5. To be able to ask questions from a support person face-to-face, however small the question is.

Actions:

1. Creating a space within the walking distance of the hospital (also can be in the hospital building). The space is equipped with educational materials to educate yourself and informational materials to also take home with you. It can be also booked for the common events but at other times the space is open during the day and can be accessed by the transplant patients, hospital staff, and the patient’s loved ones. There is also a contact person, available during the opening times who is trained by the hospital and can answer common questions of the patients/close ones. If the contact person is not aware of the answer needed,

she/he has the capabilities on the spot to find out more information or forward the question.

2. The space acts as a meeting place for the patients, either curated by events or curated by the patients themselves. Seeing other transplantees and being able to have an environment for meeting, gaining new information and inspiration. The physical meeting spot can work in two ways - regular educational meet-up events organised by the hospital and also a possibility for the patients to create their own event or just a meet-up.
3. The room is equipped with up-to-date reading materials, some of them can be also taken home. The reading materials also include overall health materials, not only heart transplant-related. Plus, the room can be used as an exhibition space, there are interactive games to take part in, which are health-related. If someone has something they would like to exhibit and it is connected to the transplantation, their journey, and health, they are welcomed to do so.
4. The space is meant firstly for the patients and to build their community and wellbeing, yet the loved ones of the patients are welcomed as well as they are playing important role in the patient's life. For them, the events with the patients at the beginning of the journey are held in the physical space in order to build trust and connection. Later, they are welcomed to be part of the common events and contribute, if they feel like it.
5. Face-to-face communication when needed in the space and creating a trusting, professional bond through it. No wrong or too small questions.

Digital Space

Goals:

1. The possibility to access information, contacts, and community wherever they are located.
2. Having all the heart transplant resource information in one place - communication options with the other patients and the specialist network, sharing options with the users of the platform, and also the possibility to ask questions, archive them or share them with people chosen.
3. Helping to keep the healthy routines on track and find help from support services if needed.
4. Supporting the patient on their specific part of their journey, taking into consideration their individual journey and needs.

Actions:

1. The digital support offers all the available information, firstly filtered to the patient's current state of the journey but they can also easily access information on other parts. The platform has contact information for the network of health care professionals in order to contact them with some questions or appointments. Community feature connects the transplant patients - they can exchange messages, share goals, news, and else.
2. With functions being in one place, the same goes for the information. The platform can also be accessed by the personal doctor. They see the information which the patient wishes to share with the doctor and the same goes for the doctor-to-patient communication.
3. The patients saw the need for the information change in digital space the most at the beginning of the transplant journey when the information is new and it is important to track various metrics.
4. Even though the beginning phases of the journey when the healthy routines and health tracking is the most relevant, the following phases and recovery can also profit from the information available at their point of the journey.

Across the journey functions

Goals:

1. Specialist support network is available for answering questions and meetings if necessary.
2. The importance of previous experience stories is highlighted to feel the will to continue with the healthy routines and be in it for the long run.
3. Including the patient's family in some activities, giving them options to choose from, depending on the family dynamics and the current stage of the journey.
4. To create patient empowerment throughout the journey, from the beginning of the diagnosis to the living with a donor heart.

Actions:

1. The network can be accessed through both digital and physical (through the specialist being on spot) spaces therefore giving the patient option to either contact through digital support or go physically to the space and ask from the specialist there.
2. The experience stories were mentioned as one of the most important and influential motivating aspects which the patients are currently missing out on.

Stories can be told physically or also through the digital platform storytelling, through both mediums the uprising questions can be answered and the conversation started.

3. Patient's family is included in the information space through common activities. In the physical space, this can mean introductory meetings at the beginning of the transplantation process, keeping them informed and included in the talks as well as during later stages including them in some meetings or bringing them into the physical space for uniting games, workshops or lectures with their friends, kids or family. For the digital space, the functions stay mainly for the patient to use but can be introduced to the patient's loved ones by the patient.
4. Patient empowerment through individualisation of the digital space and the possibility of active participation on both platforms allows them to be as active in the journey as they choose to, yet have always been included and have resources if they feel like being part of it.

7.6 Conclusion of the concept generation

Figure 10. Design concept functions, by the author.

The design concept is concluded in figure 10, where the digital space, physical space, and the across-the-concept factors are mapped. These functions give a base for creating a design proposal. The reasoning behind the choices of creating for both digital and physical came from the patients through their stories and workshop exercises. The patients value the accessibility and community from various locations, yet they prioritise face-to-face connections and meetings highly.

The concept would work also on the separate two levels – the patient can also only choose to use the physical or only the online space, there lay still benefits in using one or the other. Now, the design around the themes of connectivity, accessibility, individual approach, specialist network, adding on the actions of the concept and focusing on patient empowerment, the design proposal can be ideated.

8. Design Proposal Teel

The 8th chapter describes the design proposal of the thesis. The described goals and actions to achieve the goals from the previous chapter are implemented into a design proposal. The proposal is described from both the functions and layout through visual prototypes, user stories, and system-side, with a help of Service Blueprint mapping. The following design proposal will be implemented on the previously mapped patient journey, to see whether and how the proposal can solve the highlighted problem points. Following the co-creation of the design proposal and its development, feedbacks are gathered from the patients and the hospital in order for them to give their opinions for further development.

8.1 Teel

The name Teel translates as "on the way" or "on the journey" (from Estonian). The name communicates the meaning of being on the way, which is perceived as a positive term and is usually used for being on the way towards something better. Teel also symbolises the importance of the journey and progresses, actions and feelings during the journey - there is no completion or finish line, the journey is the concept to build and grow. In addition, each way and journey are different and move their own paths.

Teel is a multidisciplinary patient support system, consisting of physical and digital touchpoints, aiming to increase patient empowerment through education, community, individual approach, and specialist network.

Teel is a tool to include in the daily life of a patient, diagnosed with a heart condition which results in needing a new heart. The support platform gives them chance to have a community feel and belonging, yet still embracing each individual and their different journey, needs, and interests.

Teel Support consists of a Teel Space and Teel Digital.

The system's mapping (appendix 8) is showing both environments and the characteristics of them.

8.2 Teel Space

The aim of the space would be to give heart transplant patients and specialists a framework which would at first be facilitated by the hospital and/or external service provider but the activities and content of the space would be set up in a way that it can developed (ideally) into partly patient-run space, where the events, talks, and gatherings are organised by the active participants in the community. A big part of the space and its program continues to be curated by the hospital - the educational medical side of the transplantation, the meetings, and the popularisation of organ transplantation activities.

Teel Space is a physical open indoor environment located in the area of the hospital and can be accessed during the Teel Space opening times, proposedly at least 4-hours daily.

The space is used by the patients, doctors, nurses, and also the patient’s loved ones. Teel Space includes educational resources such as literature, educational cardiology, and transplantation heart games, and writing exercises. The Space also works like an interactive exhibition which the patients can think along and add their knowledge to the space, therefore develop the layers of journeys and inclusivity of heart transplantation in Estonia.

The Space is decorated in a way that it can be easily transformed from a casual exhibition space into an educational classroom style where smaller gatherings and events can be held. In this way, the space can support different scenarios of use according to the current needs.

The Teel can be described as a growing ground for the heart transplantation community - the environment is available and the community has an opportunity to also add their part, be part of the planning of the room as well as organise the events they see valuable. The end goal would be that the transplantation community is engaged enough to run the content of the Teel Space. Nevertheless, it is not expected from them, the room is always there and there is no requirement to engage.

The main activities that the room supports are:

- **Introductory meetings preparing the mindset for heart transplantation**

  Patients can meet face-to-face with the personnel, in addition to the regular medical meetings. The purpose is to give an overview of the process at the beginning of the journey, where the patient's loved ones can also join, feel involved, and informed. Educational meetings or lectures can be also held with other specialists or guest lecturers such as nutritionists, physiologists and more.

Figure 11. Teel Space concept illustration by the author

- **Heart transplantation community gatherings**

  The community of individuals living with a new heart can be considered already active and meeting each other a couple of times per year. The space could be an environment for them to share experiences and meet frequently, and arrange monthly meetings. The heart transplant patients also feel that the patients on the waiting list for a new heart could be included in the community (which they are not) and future. Also the patients with LVAD can easily be welcomed and be a part of the circle as some of them will be transplant patients in the future, and if not, they have somewhat similar experiences which they can connect on.

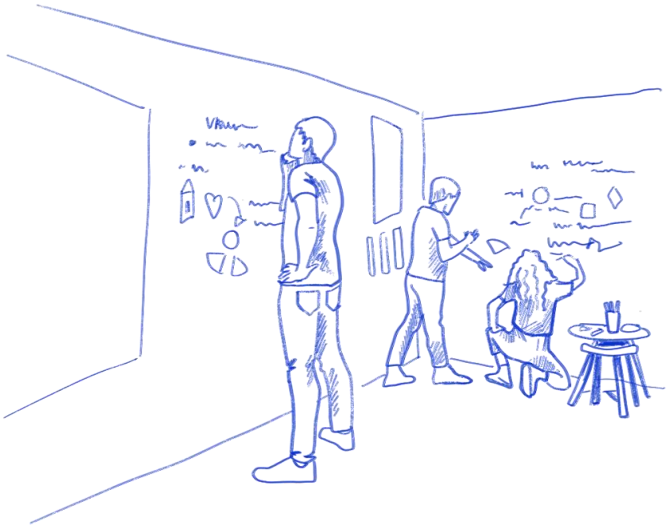


Figure 12. Teel Space concept illustration by the author.

- Casual meet-ups with the other patients and/or hospital staff

  The space welcomes patients also when there is no particular event planned. It gives patients and also hospital staff the possibility to stop by before their regular visits or to meet each other in the Teel Space. Teel also always welcomes individuals who prefer to visit the space alone and take their time to observe and learn by themselves.

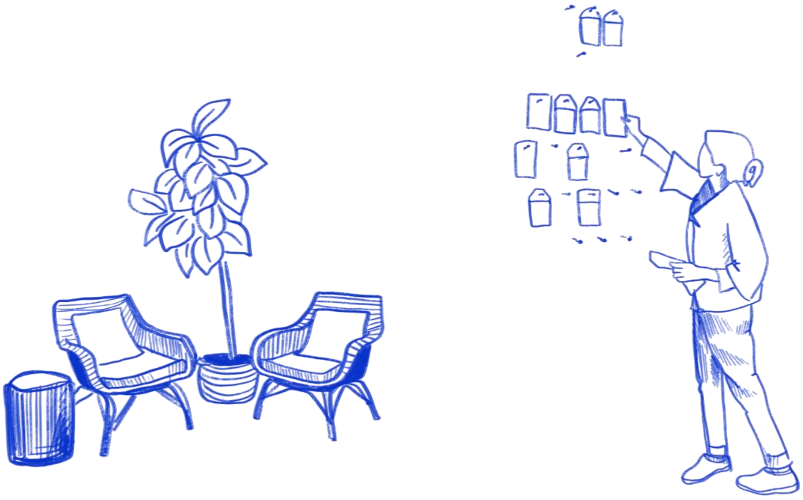


Figure 13. Teel Space concept illustration by the author.

- When Teel Space is open, there is also a support person in order to give any help or introduction needed, and answer questions about heart transplantation. Face-to-face contact and the ability to ask various questions are crucial for the patients. Therefore the option is given to have a discussion with the trained professional. If the professional does not know the answer, they have straight access to the extended specialist network who can help with answering and get back to the patient.

Teel Space Home Delivery

If a patient is not willing to use digital platforms and, due to their immune health, is unable to visit the physical space, the resource materials can be brought home to them. This requires the Teel Space support person to collect resources, advised by the patient’s doctor. Having important resources conveniently delivered to their doorstep helps the patient on their transplantation journey to feel more connected and aware, even when not using digital devices having to stay home for the period of time.

At certain times, the room can also be open for all the visitors who are curious to see and learn more about heart transplantation. The room can act as an introducing interactive space where the public can learn about heart transplantation and get more aware of the topic.

In the future, the room can be also rented out for other transplant patients in order to grow the community and grow into an organ transplantation resource center.

8.3 Teel Digital

Teel Digital is a digital platform which allows patients to track their individual journey, set small goals to sustain their motivation, and connect with other patients from their home environment. The platform also includes possibility to connect with the specialist network in order to ask questions and get additional information, especially for the individual needs. The same goes for transplantation resources – which are available to read and research on the platform.

Even though Teel Digital is mainly a patient platform, the digital space is also introduced in a medical doctor/professional mode as they are also a key user of the platform. Following, some prototype interfaces are presented and the functionalities are explained by both the patient and the medical doctor/professional view.

The concept of Teel Digital

Almost all the functionalities of the online space are customizable — topics the patient wants the digital space to include and prioritise. The digital platform is built from blocks, making it easy to customize and move around when setting up the account for the patient. Blocks include categories of digital platform features, which the individual can prioritise. The same goes for the professional view - the doctor can customize their home page for their needs from the blocks of choice. This creates opportunity for the professional view to be used by not only the personal doctor of the patient but also the Teel Space support person, nurse, or psychologist if needed.

From the concept colours below (figure 14), variations from pastel pinks and violets to darker tones can be created, making it easy to find a combo or a colour of choice. The colour card is overall rather light, pastel with a vibrant tone of marine. The colours were chosen to fit the digital platform's, and also the project's goal - to create an environment where sharing and asking are welcomed, creativity and community is encouraged, yet motivation and inspiration, as well as clear information and resources, are present. The colour code is warm and welcoming, while being professional in combination.

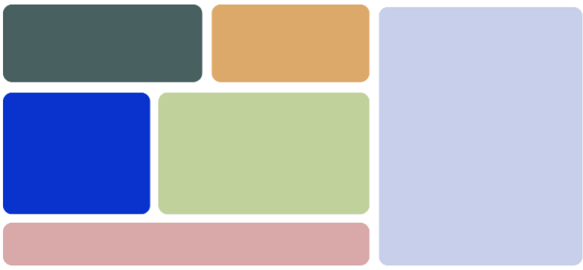


Figure 14. Colour code, by the author.

Interfaces of Teel Digital

To have a thorough understanding of the interfaces and features, both patient and the professional view is described through example profiles of users - Oliver, who is a heart transplant patient and Elo, who is a medical doctor of Oliver.

Patient view

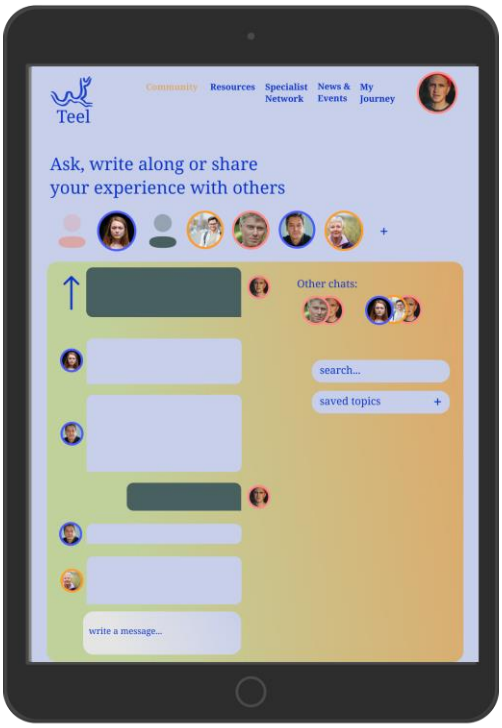
Patient Home page

Figure 15. Digital mockup of Teel, by the author.

Oliver has been using Teel Space for about two years, since the beginning of the transplantation journey. He likes to track his journey and uses the space mainly for easy tracking of goals. Seeing the movement of his progress is important for him, otherwise, as he says - he gets lost in small things. On the home page, the biggest space is taken by the journey block, where he sees a visual of his journey and can easily take a call to action to make a new entry. The second biggest block is goals, which shows what goals has he recently accomplished and which ones are currently ongoing, including also a call-to-action starting a new goal.

Asking questions is the smaller block but easily accessible, where it’s possible to ask a new question from either the doctor or specialist network and also access the previous questions asked.

Community



Ask, write along or share your experience with others

Figure 16. Digital mockup of Teel, by the author.

Community allows the patients to get inspired by each other and get in touch. This offers the feeling of not being alone in this rather rare diagnosis. It also presents the view of everyone having a different journey, which normalises the differences and creates inclusivity, while validating the uniqueness of everone's own journey.

Members of the Community have different coloured circles around their profiles so they can be recognised by their current statues of the journey – LVAD, waiting list, post-transplant, pre-LVAD. This allows patients to see who is at the same stage of their transplantation journey as well as if the questions rise, the answers from experienced individuals are easily shown, who have gone through the process.

Community sparks conversations between the patients. There is a possibility to write to a person individually or to all of the group. As for now, the communication happens in the Facebook group but this could be converted over to Teel Digital, sparking more conversation topics and continuing the conversations over questions, goals, or journeys which are features of Teel Digital. If the user base widens, the community conversation function would need a moderator in order to answer the medical part of the questions.

My journey

The patient journey section is a place where the patient can create and keep track of their journey - their daily moments as well as health metrics. The patient can add health metrics either manually or sync Teel with the already existing health tracking app or device. This function might not be used by everyone, especially the tech-savvy individuals, but it can help to keep the metrics in the same place with resources and other Estonian-based heart transplantation information.

Health Metrics

Sync health metrics from your applications or add manually

Every story is different. Create your own.

add photo, goals, video, notes or audio to your story

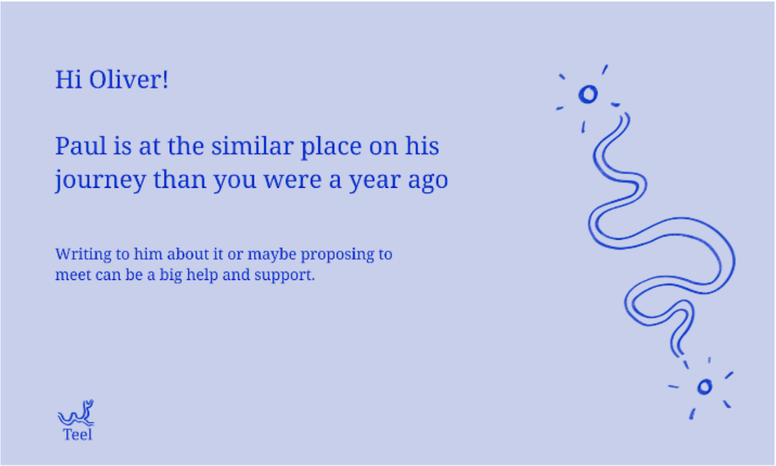
Which colour describes you currently?

Figure 17. Digital mockup of Teel, by the author.

The buildable journey function is for the patient themselves to document their experiences. The various media can be added to the journey in order to enrich the experience. They can either view the journey from start to finish or finish to start. When the new moment is added, it automatically saves the journey with the recent date but it can be changed. Changes can be made in the journey, data added in-between and deleted if liked.

The colour expression works with the patient choosing a colour which describes them at the moment. They can interpret the colours how they like and add their own. The function lets the patient see visual patterns of mood and also has a moment to think how would they describe the feeling.

The smart system can recognise the patterns and similar experiences on the patient's journey, which can connect patients with similar experiences. The system works so that if a patient who is going through the experience now, has a similar expression of it as a patient who has had the experience before, gets a notification to get in touch. The notification comes to the patient who was already gone through the experience and it advises to get in contact. The acceptance of this feature is asked previously from the users. This way no pressure of seeking for help is put on the patient who is experiencing the new. No info about exact experience details are shared and the acceptance of this feature is asked previously from the users. The example is shown below.



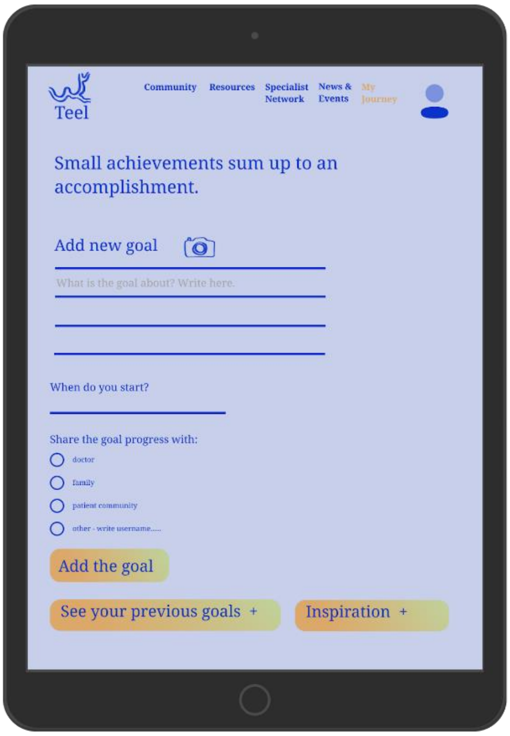
Hi Oliver!

Paul is at the similar place on his journey than you were a year ago

Writing to him about it or maybe proposing to meet can be a big help and support.

Figure 18. Notification of Teel, by the author.

Goals



Small achievements sum up to an accomplishment.

Add new goal

What is the goal about? Write here.

When do you start?

Share the goal progress with:

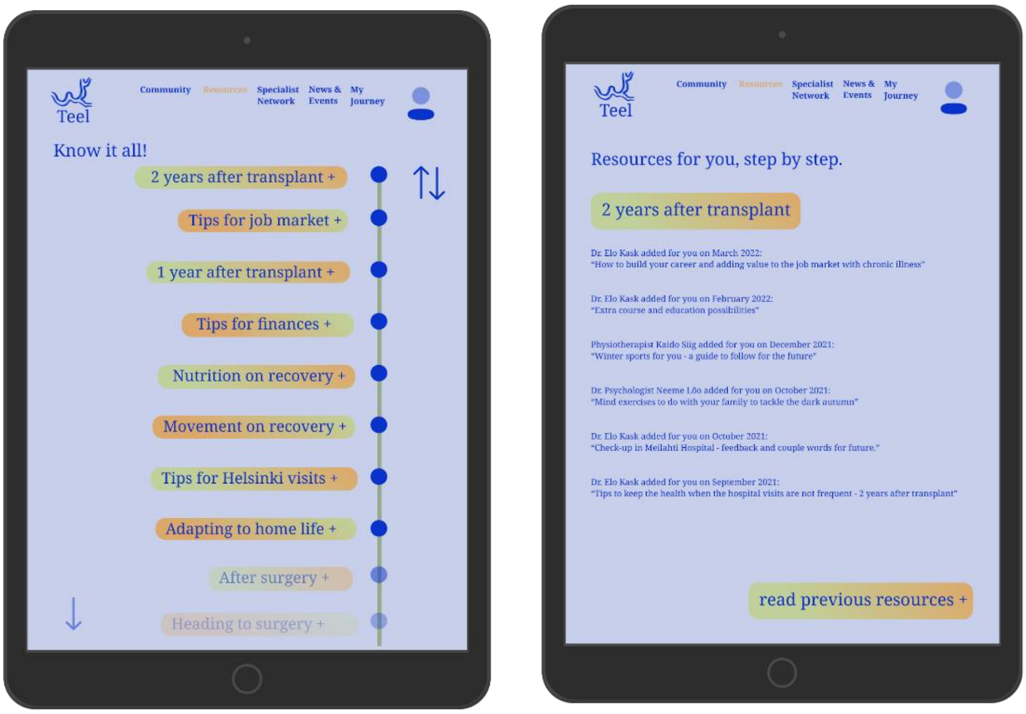
○ doctor
○ family
○ patient community
○ other - write username......

When the patient is adding a goal, a window opens for him where they can more precisely describe the goal, set the starting time, and choose who to share the goal. Sharing creates accountability but the patient can always keep it to just themselves.

Figure 19. Digital mockup of Teel, by the author.

Resources

Resources and information about the journey is prepared for each patient individually, according to their journey differences. Most of the information is the same, however there might be some news or articles which are only valid for one or two individuals. There are two ways how the resources page can be displayed depending on if the patient wants to get the full information accessible for them all together, and added on later in the categories, or get information gradually, as they go on the journey. Two previews are presented.



Resources for you, step by step.

Dr. Elo Kask added for you on March 2022:
"How to build your career and adding value to the job market with chronic illness"

Dr. Elo Kask added for you on February 2022:
"Extra course and education possibilities"

Physiotherapist Kaido Siig added for you on December 2021:
"Winter sports for you - a guide to follow for the future"

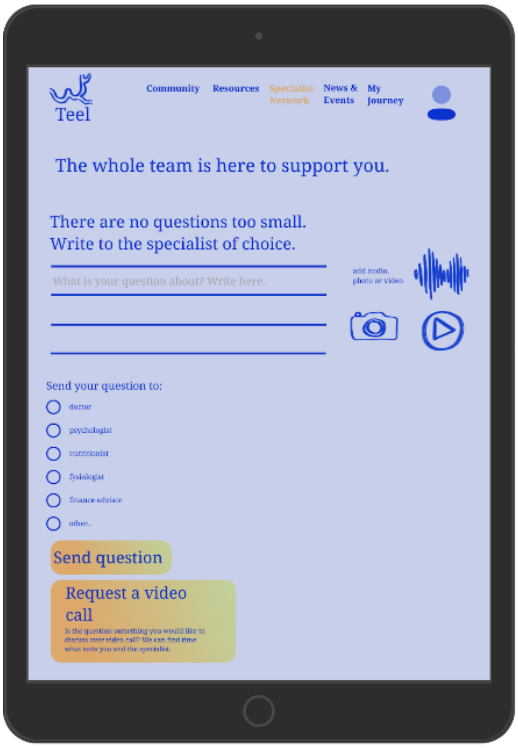
Dr. Psychologist Neeme Lõo added for you on October 2021:
"Mind exercises to do with your family to tackle the dark autumn"

Dr. Elo Kask added for you on October 2021:
"Check-up in Meilahti Hospital - feedback and couple words for future."

Dr. Elo Kask added for you on September 2021:
"Tips to keep the health when the hospital visits are not frequent - 2 years after transplant"

Figure 20 & 21. Digital mockups of Teel, by the author.

Specialist network



The whole team is here to support you.

There are no questions too small.
Write to the specialist of choice.

What is your question about? Write here.

Send your question to:
○ doctor
○ psychologist
○ nutritionist
○ fysiologist
○ finance advisor
○ other..

Is the question something you would like to discuss over video call? We can find time what suits you and the specialist.

Being able to ask for help from a wide range of specialist who can answer their questions and worries have been shown to have special interest from the patients. The patient can ask questions via the written form and easily chose one or many specialists to send the question to. If the written form is not suitable for the question, the patient can shortly describe the topic and request a video meeting with the specialist. This way the personal connection can be achieved even from the home environment. In order for the question to be as precise as possible, the patient can add media alongside the written question, such as an audio file, photo, or video.

Figure 22. Digital mockup of Teel, by the author.

The answering time depends on the question asked and who is the question towards to. It is recommended to use this feature when asking smaller questions about daily habits, recommendations, and wonders. If there is an urgent problem then a call to the personal doctor is recommended as the first choice (as it is currently).

Doctor's Home page

hi,
Elo!

you have 2 new questions from patients

1 event held today - "Introduction meeting for Paul Murakas" @ Teel Space

2 questions

Maria Mänd : I have been movin...

Oliver Aab : Yesterday I ate und...

Figure 23. Digital mockup of Teel, by the author.

In the current example (figure 23), Elo has chosen the patient questions to be on the front page, where she can open and answer them. Next is resource block which she herself can use for reference to look up or more importantly, to add new references to the database and forward them to the patient's site.

The biggest block on the front page is a specialist network, where the most popular contacts are presented right away. The full list opens with a call-to-action for more.

Patient journeys for the medical professional

Figure 24. Digital mockup of Teel, by the author.

On the patient's page, all information that the patient has decided to share with the doctor is visible to the doctor. The contact with the patient is also shown. This allows the doctor to easily access the information the patients have sent, and they can also give feedback or get in contact via the platform or phone.

Sharing content outside of the Teel Digital

Teel Digital allows for the patient to share content also outside of the platform. The key receivers here are the patient close ones. They do not have the app user view customized for their persona but the communication of the sharing feature goes through email. If a patient wishes to share a goal, journey or a question with the loved one, they have to provide the email address and the content will be sent to the loved one. As the patient and the loved one are close contacts, the loved one can give feedback and react to the shared content via other chosen communication platforms which they use in-between themselves.

Hi Kris!

Oliver wants to share updates on a goal!

Oliver has accomplished his monthly goal to walk at least 20 minutes every day.

These milestones are valuable so celebrate and congratulate him!

Teel

Figure 25. Digital notification of Teel, by the author

8.4 How the concept works within the actors - Service Design Blueprint

The service design blueprint presents all the system of the service. The schematic presentation depicts what the patient is seeing, how they are acting, and also the actions that are happening backstage in order to deliver the experience for the patient. The service blueprint (appendix 9) follows through the main points of the patient actions and how it is reflected on the medical personnel side, the physical space, and the digital space (technology). These are supported by the actions in the background. This map shows how and if the full service would be and answers to the actions of the patient.

8.5 User stories

There are different ways how individuals are connected to Teel and how the concept is perceived. Teel is told by four user stories – two patients, patient’s loved one, and a medical doctor. (figure 26-30).

Oliver , 35

A patient with a recent but urgent heart condition. Needing a l-vad and later a transplantation.

Has a family, works as a chef, enjoys sports

The medical condition came to Oliver by a big surprise. He felt very confused and could not explain how would this happen to him - a sporty, healthy man.
After diagnosis, Oliver has a meeting with his doctor Elo and in the meeting he also gets to know about Teel.

He agrees to use the support network platforms right away since he feels a bit lost thinks that every help recommended by the hospital is useful. He chooses to customise his Teel Digital home view so that he stays motivated and sees how far he has come.
He is also introduced briefly to Teel Space, where he meets the facilitator and looks around. It’s a bit overwhelming first but the introduction with the medical professional is a good start.

Later this evening, he explores the Teel Digital at home and tries out different features. He also talks about it to her family and finds it uniting to also explore the digital platform together with his partner. Soon they find it easier to also speak about his condition with their kids since they know more about it themselves and can express themself.

As he don’t yet know anyone with similar health problem, the Community feature is something Oliver enjoys more than he first thought.

At first, he just followed the conversations and read the shared questions. He feels very inspired by seeing others’ stories as he knows he’s not only one and there is a possibility to get better.
As his journey developed, he started sharing his own and asked some questions regarding to the soon upcoming transplantation.

When it was clear, that he is a candidate for new heart, he had his family were invited to the Teel Space for explaining through the transplantation in depth and answering any questions which might rise.

Until the transplantation he continues to track his journey in Teel Digital, he feels prepared for the upcoming surgery and knows what might be ahead of him. As a previously working adult, he also knows his rights on financial support and has gotten advice on dealing with them.

He has become an active member or the Community at Teel Digital, also offering help and his experiences with the new possible transplantees with l-vad’s.

When the immune system allows, while visiting PERH, he regularly stops by the Teel Space, he is curious about it and sees some other people casually there as well. Oliver decides to take part of an event there once, where he meets some already known patients from Teel Digital and some new faces as well.

He likes the meeting and comes out with his idea about the next topic being nutrition what he could lead in a workshop format with a specialist in nutrition.

Uses both Teel Digital and Teel Space

Hele, 65

Heart transplant patient. Has had transplant for 5 years now.

Loves physical moving, cooking, spending quality time with family and friends.

Hele has been connected to PERH for almost ten years now, with her heart conditions. During this time, she has seen many patients and staff. Earlier, when there were just few heart transplant patients, she did not know them much. She met one patient by a happy accident and they became good friends.
When her doctor introduced Teel to her, she was hesitant, specially becuase of the digital platform. Hele does not use any digital smart technology devices as she chooses not to. She has an mobile phone with buttons and that’s enough, she mentions. Also, for the transplant support she is not willing to learn how to use tech.

Despite the statement that Teel Digital is not for her, she is very curious about the Teel Space as she values physical connection and talks when the immune system allows. She likes the space right away on the first introduction meeting and stays there for longer to have a chat with the facilitator.

After couple of days, she goes back to Teel Space to stay for longer with her friend and read the materials. She doesn’t trust digital devices but tries out couple of interactive gadgets which positively surprised her.

As she is an active lady, she joins every time when Teel Space holds events or talks for transplant patients. Hele has gotten new and updated insights about the heart transplantation as a whole. Also, now she knows most of the patients, which makes her happy as she loves to exchange thoughts in trusted community.

As face-to-face communication is the most important to her and she values the feedback of medical professionals highly, she goes to Teel Space to ask questions and discuss topics about her health condition if she feels that there are some things left uncertain or unclear. She feels cared for, if the facilitaor doesn’t know all the answers but calls her back as soon as she can help Hele.

Uses Teel Space

Elo, 47

Cardiology doctor, works with heart transplant patients both pre- and post transplantation.

Elo's journey with Teel starts from developing it together with the team. She saw a need for support network and Teel became the solution.

Now, she's mostly using both the Teel Digital and Teel Space in order to communicate with the patients and help with the resource library.

Elo has customised her Teel Digital front page in a way that the important - resources, patient communication and specialist network are right there, visible to her and she can easily see updates or reach connections if needed.

She likes when patients share their thoughts, questions goals or parts of the journey with her, she tries her best to give professional feedback and encourage to continue with healthy habits.

With Teel Space, Elo has been a help for gathering reading, listening and watching material for the visitors to explore about heart transplantation. Also, she's doing her part on putting together a resources to take home from Teel Space, usually a booklet or a notebook. T

When a new patient is diagnosed with heart condition which needs a long cure, such as LVAD (and later heart transplant) or heart transplant, Elo introduces Teel to them, explaining the support opportunities and possibility to connect with others as well as track the journey. If the patient, like Oliver agrees, Elo shows the Teel Digital and helps Oliver to set it up, shows the customising options and goes through the possibilities of the Teel Digital. Later she visits Teel Space with Oliver, introduces the facilitator and what can be Teel Space used for - it's events, gatherings and just a stop by.

Elo is involved in some events in Teel Space. She loves to organise workshops also for the families of the heart transplant patients, yet this does not happen often.

Elo admires the specialist network who they managed to gather in order to be there for the patients. Patients themselves are also making Elo more happy than worried nowadays since they are getting more support in different fields of their life, starting from career and finances to healthy routines and nutrition.

Uses both Teel Digital and Teel Space

Merit, 35

Partner of Oliver. They also have a daugther Lea

Enjoys spending time with their family. Works as a veterinary and loves the work she does.

Merit and Lea support Oliver on her health journey for heart transplantation. The news about decreasing health levels came as as sock to Merit, since her partner and their family has all been healthy throughout their lives. When Oliver fell ill, Merit took time off from work in order to be there and support Oliver. After some time, she returned to work but still felt the need to support Oliver, not really knowing how.

Oliver told Merit about Teel, which she liked at first sight as it sounded like a support for Oliver which she had been trying her best to give to him. She had a look on the site herself and found some good articles on the public page of the Resources.
She notices that Oliver uses the platform quite a lot, which makes her happy. When the transplantation waiting list decision is made, the family is invited to the Teel Space for a meeting about what to expect and meet the doctors. They also take Lea with them who also knows a bit already since they know now how to communicate the topic.

Oliver shares quite a lot with Merit and they speak openly about how they both feel. If Oliver seems insecure or worries about something, Merit encourages to use the Specialist Network help in order to tackle the problems.

Merit, Lea and Oliver visit the Teel Space from time to time all together. Lea loves the interactive games there. Thanks to meetings and workshops where the families can join as well, Merit has met couple people who are in the similar role as she, therefore they can share their experiences and are also in touch in everyday life.

Uses both Teel Digital and Teel Space

Figures 26-30. Design concept user stories, by the author.

8.6 How the concept works on the previously mapped patient journey? What changes?

Earlier, during the research part of the topic, the patient journey of a heart transplant journey was mapped and problem points were highlighted with red. The same patient journey map is used to evaluate the proposed solution system.

Mapping the patient journey during the beginning stages of the research process, the problematic points, the lack of social and specialist support in various fields, insecurity, struggles with being alone with the worries, and also feeling lost in new information are now looked through the concept of Teel. The problems existed before and are now solved through Teel, are presented visually in an updated (appendix 11) highlighted with bright green colour. Under the rows of Feelings and Thoughts, some of which have been modified from red to orange, or staying in the colour red are the topics that the concept can not solve completely. The topics which are staying unsolved include the overall mentality towards health in Estonian society and the amount of support needed from family, friends and the caregivers on their daily tasks. The reach of the current research would need extensive widening of the topic and a different focus point in order to deal with the named issues in depth. The research is not solving every single problem that the patient has but it shows visually where the problems still exist which hopefully gives an impulse to solve these existing red blocks in the future.

Nevertheless, Teel concept can help with the previous problems, regarding the transparent information within community and doctors, the motivation and inspiration and also the specialist network can help with staying on track with the resources and help needed from various areas.

The Touchpoints and Channels section illustrates how Teel is present throughout the journey when the diagnosis is stated, giving it a new form of communication, creating new opportunities for innovation, and being there to help with both pre-and post-transplant without overwhelming neither patient and the hospital side of the platform.

8.7. Benefits for the stakeholders

The benefits lay on all the main problem owners and stakeholders. In this case, the patient, the medical specialist, the close one of the patient and PERH are the key stakeholders. The design proposal, if implemented will change the system towards patient-empowered healthcare.

The patients will have a sense of community and belonging, a feeling that they are supported by the specialist network and other members of the community. The patient has a possibility to choose to either be an active member of the concept or take an observer role. In both cases, they can benefit from the concept and get answers to their questions that might arise.

The close ones of the patient will have a smaller load, being a caregiver for the patient as the specialist network is available to offer support consultations and work professionally with the patient on the specific topic of need. The competence of starting conversations around transplantation and being health literate are also benefits for the close ones as a result of being included in design proposal activities.

The medical specialists have a better overview of the patient's journey and the security that the patient will get needed help with the support of the specialist network. Design proposal reduces their workload of answering common questions for each patient separately and also looking for specific additional help for each patient manually. Now, with the set network of specialists, the medical specialist can easily find contact to a category which needs extra attention.

PERH has an opportunity to create better services on the basis of the proposed design concepts, based on the patient activities and experiences.

9. Discussion. Further Steps for Development

In terms of available patient-centric research work on the field of organ transplantation in Estonia, there is still a long way to go, but there is a hope that the topic will be more upfront and further researches touching this field will follow.

The research project would benefit from more co-design activities in order to propose a more in-depth solution. The active co-design with the medical professionals as well as medical professionals and patients together would bring more insights to the table. It might not change the proposal concept but would highly likely give additional functionalities. Despite the fact, including as many viewpoints as possible considering the time aspect and ongoing pandemic situation, the proposal can be innovated further from the basis of the current research paper.

The design proposal and research is done on heart transplantation patients were conducted with the goal to in the future to expand the proposal further on other organ transplants, who PERH is also facilitating and offering care for.

9.1 Feedback

Feedback has a high importance in the master thesis as a tool to not only present the final outcome but rather present the proposal and have an open discussion on how the individuals involved in the feedback session feel about the concept and if they would use it or do they miss something in the concept. This way the feedback is also an input to the co-design process. Feedback rounds were done with five specialists from PERH, both from cardiology and innovation units, and two patients – one who is living with a donor heart and one in the waiting list in order to have different viewpoints to the concept and see the possible fit.

The design proposal was met with a warm welcome in PERH. In addition to the design concept, the journey findings and steps towards the end were also presented. The discussion led towards the future developments, stating that it would have potential to grow, since the heart transplant category is a group to test the idea on and take it further towards the wider users in cardiology unit. They saw the value in the idea, expressing that their work would be easier in terms of channels to send the patient available resources, and also the specialist support network. It was also discussed that the patients have their own platform and can ask questions from themselves, the platform must have a medical moderator so that the advice given would still stay in the category of science-based medicine practices.

Presenting the thesis proposal to the patient with a donor heart had also welcoming feedback. The patient did not give any more advice on what would they would like to see more from the concept. They were positive about using both Teel Space and Teel Digital.

The patient who is currently waiting for the new heart was also positive about the concept overall. The feedback discussion afterwards was interesting and lead to the different scenarios on how patients would use the proposal. Some of the features from discussion are added in the concept proposal, for example the statuses in the Community feature statuses (heart transplant, waiting list…) and Teel Space Home Delivery addition.

The open discussions on the feedback of the research and concept were valuable to put the priorities in the right place once again and place things into perspective.

9.2 Design proposal development

The design proposal of Teel is a concept which would benefit from developing to a phase where it could be given to user testing to see what functions are used and how. Before user testing could be implemented, the digital platform interfaces need more thorough design and function considerations. Also, the physical space would need to be designed with the possible exterior architects who would again, work alongside with the patients, their needs, wishes, and actions.

The specific next step will be the development of the digital platform and testing it on future users. This requires time and possibly an external service provider for help to put the functions to work in the testing format.

9.3 Scalability of the design proposal

One of the key values are set in the development of the design proposal, and also when creating the proposal. Currently, the proposal is designed on the basis of the patients connected to heart transplantation. This results in a small number of patients, making it a concept for the niche audience.

Even though the concept is created for the patients of the heart transplantation, it is designed in a way that the same idea with different content can be implemented for wider diagnosis.

A Similar idea can be taken also towards the patients with heart failure. Currently, there are around 20 000 patients in various conditions, diagnosed with some sort of heart failure (information from the cardiology unit of PERH).

Another option of category where the proposal could potentially develop without any major changes besides the content is including other organ recipients into the concept. It can be assumed that other transplantation patients, for example, kidney recipients, lung recipients, and liver recipients would benefit from the concept. This direction would scale the concept from ten potential users to around a couple hundred potential users.

If the number of patients were to grow, the Community and patient-to-patient communication would need some type of moderation to control the factual content of messages with medical content.

9.4 Data and privacy

Data and privacy are one of the central backstage figures of the Service Design Blueprint and also a crucial aspect of the design solution to keep in mind as the patient information, adding the health information is confidential to the third party.

Currently, the Teel Digital is set up for the patient together with their doctor and later the patient can log in independently using e-ID services such as mobile-ID, smart-ID or ID-card. Therefore the patient-user view and the Community view are not visible to anyone else besides the user and the other users of the platform. The patients have a complete choice, whether they would like to share their information with the community or not and they have the choice over each separate activity. For example, if a patient agrees that other patient is notified if the patient is going through a similar experience so that they could get in touch, the patient's have a choice of allowing it but also have a free choice of not doing so.

For the future work, the data privacy settings should be discussed and worked onwards with the specialists in this field. The topic is something that can not be taken lightly and any personal health information can not be leaked from the Teel Space system.

10. Organisational Ecosystem Change Towards Implementing Design Activities in PERH

Highlighted points on the patient journey were a lead for the concept direction. Looking at it again, more than one of these can be improved by the Teel solution. But some will continue to be troublesome points. From one side, these issues rely on the public health mentality of illness being a weakness, therefore avoiding it as long as possible. The brief discussion with the medical professional in the interviews opened up the topic of health culture and it received some validation while mapping the user journey, based on the patient stories. This is possibly another interesting thesis topic to cover for the next researchers.

Although the qualitative research is mainly based on the activities of PERH, its specialists, and patients, analysing the landscape of heart transplantation in Estonia, being such a small region and has two completely separate places for care (one in Tartu, one in Tallinn), the research sees potential in close communication between the hospitals - between its specialists and patients. The circle of people is small, therefore the connections are easy to establish. Discussing this with one medical professional related to heart transplant patients in Tartu, they were very curious about the practices in PERH. Additionally, the specialist from Tartu did not understand why the two departments are not in contact and that they would like to have a closer relationship, believing that both parties would benefit from it.

The other possible innovation which can increase the well-being of the patients, personnel, and the experience of the patient journey is implementing parts of service design and design thinking in the processes of the hospital environment. Understandably, medicine should not be experimental or questioned but the environment, support services, and the mentality of co-creation can be implemented into the hospital system and result in a positive impact.

Patients are the experts of their health, they have the first-hand experience in healthcare, this means that the expert voices should have a very important place around the table when discussing the next changes in structures and care. We can never predict correctly what it’s like to be hospitalised and what the patients need when attached to the wires if we don’t fully give a say to the ones who have been going through it daily and let them be a crucial part of designing new environments, products or services.

For PERH to measure their activities of inclusive design actions, the topic is looked at through the Danish Design Ladder. Danish Design Ladder is a tool used to evaluate and describe how organisations use design in their practices. It was invented back in 2001 by the Danish Design Center and had a wider introduction to the public in 2003. The original framework has four stages of design implementation, but in 2013 British Design Council together with, Danish Design Centre, Aalto University, and Design Wales published a design ladder for the public sector (figure 31), including three steps of the ladder.

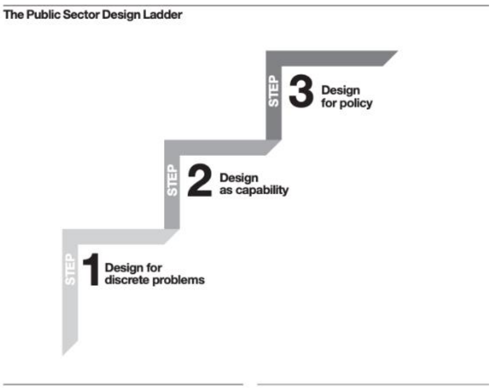


Figure 31. The Public Sector Danish Design Ladder. Author: British Design Council, Danish Design Centre, Aalto University, Design Wales

In step one, design activities are project-based and outsourced. The design thought projects are researched and done by others, tackling the issues and implementing them on a small scale. PERH systemic design activities are more or less similar to the description of the first step of the ladder - the service design innovation projects are welcomed but often outsourced, yet during the recent years the organisation has shown effort and they are doing patient-centric activities within PERH.

In stage two the employees do not only work together with the designers but can independently use design thinking and techniques to face small problems and opportunities where external help is not needed. The organisation uses design inside the organisation, the employees use practices to see the world through the customer's (patient, loved one, visitor…) view. PERH has an opportunity to move towards stage two and analysing the organisation, they are making small steps towards it as they have an innovation department that is leading the external collaborations and bringing the external people in if needed. With the current research design proposal for Teel, the patient-centric collaboration and co-creation aspects with the hospital can be facilitated in Teel Space. The design methods to effectively listen to patients, thoughtfully observe, and co-create solutions with the problem owners and stakeholders of the topic should be systematically introduced to the future hospital system of PERH.

Stage three is about bringing design thinking into policymaking and using designers to facilitate it. This allows to break down silo structures and work across structures and departments. Strongly believing in service design value creation, the leaders and policymakers be an example for others. Most of the public sector services in Estonia currently have a long way to go to reach the third step of the ladder. For PERH, the potential is there, although there is a lot of work to do be done on the structural level of organisational service design implementation.

By explaining the importance of including design thinking views and service design methods into a medical organisation it does not mean that the focus from the medical service has not been faced. It means the opposite. The care focus of the hospital is expected to increase. By knowing in-depth what the patient, visitor, taxi driver, colleague, receptionist, or others need, their worries, routines, and actions, PERH can be a better hospital for everyone. PERH offers high-quality medical services, which is an important part of the hospital and care experience. But it’s just one part. Aspiring to be better every day should never end, and this gives opportunities for innovation and changes how we view the patient role, the components of healthcare services, and the importance of PERH in it.

11. Conclusion and Reflection

The conclusion is a reflection on the hypothesis and problem question, elaborating on whether the thesis work answered the question stated at starting the research. Later, the author’s reflection on the thesis process is presented and further learning thoughts for the future are noted.

11.1 Conclusion

Heart transplantation is a life-saving treatment for patients with different care histories and heart issues, being the last option of care and increasing the patient’s life quality notably. The medical treatment and innovations within the transplantation are advanced but the patient journey based on the patients of PERH is unknown to the organisation. The research journey started with the first hypothesis about the topic of PERH not having a unified patient journey, therefore the whole process is fragmented and strong links between structural units are missing. After conducting the research, the outcome shows that this guess was partly correct, but there are factors that are unified not fragmented. The cardiology department’s internal processes are seen as unified and transparent, although the patient journey has not been mapped for the heart transplant patients before, the medical specialists know their patients and care about them as well as work towards quality care and working systems. The unified patient journey can also be seen more as an overview of the patients’ journeys. Mapping the unified patient journey was crucial to understanding the problem and also delivering the visual version for the transplantation specialists from the hospital side.

The fragmentation happens in the information flow and awareness between the hospitals in Tartu and Tallinn, as well as in the communication possibilities of pre-and post-transplant patients. The organised structural links are missing from the multidisciplinary specialist network side.

The second hypothesis focused on the betterment of the patient journey experience can be achieved by including patients in the decision-making process, using co-design methods. The design proposal was significantly developed, including the patients through the co-designing. Moving from the patient-centered mindset to collective designing with the patients as well as other stakeholders involved in the greater system, gives direct input for PERH to understand the care as a service in the bigger context and on the basis of this, designing what can be done for creating a better care experience.

The thesis research deals with the question of how might we improve the heart transplant patient’s journey. We might do it together. There is a reason why the problem question included “we”. These complex issues can not be solved by only one stakeholder. Through selected methodology, active listening, and visualising the complex problems there is a possibility for problem-solving and also innovation. To solve some of the highlighted problems of the patients, the concept of Teel is proposed.

Teel is a multidisciplinary patient support platform, consisting of physical and digital touchpoints, aiming to increase patient empowerment through education, community, individual approach, and specialist network. In the further stages of the research and thesis work, there lies a possibility to implement the proposals also to other organ transplantation categories if suited.

11.2 Reflection. Notes to self

The journey of the thesis process had its ups and downs. Questions regarding patient confidentiality and medicine-related ethics were something that I had not dealt with previously. Filling in several precise admission documents about the research was a learning curve. It seemed that the methods of the co-design were also quite bizarre for the TAI ethics committee, as the project admission took two months, leaving me with a rather short time window to approach the individuals. The additional questions from the ethics side, asking about the co-design and why certain methods and visuals are used, show the need to do similar projects even more in order for it to become the standard. Clearly, there is no doubt that the patient and personnel information is a topic that has to be dealt with care and confidentiality but there is a possibility to do so while implementing design practices.

I am proud of how the process and thesis came together in the end, although had I had more time for the design proposal part, more testing and development of prototypes would have benefited the quality of the thesis as a whole.

The most important thing I learned from the thesis process is that there is great potential in implementing co-design and service design methodologies in the medical healthcare field and it is possible to also successfully take it into practice. It was fascinating to dive into one medical condition in-depth, learning about it from the experts – the patients, the medical personnel and the close connections of the patient. The human connection and participatory research were without a doubt the most rewarding part of the process.

12. Summary

Heart transplantation is a complex process, not only the transplantation surgery itself but also the pre- and aftercare for the patients. It involves keeping health at certain levels, strict routine of drugs, check-ups and new structure of life in social, physical and financial terms. The individuals selected to be the candidates for a donor heart have to prove they are the right choice by showing the will to keep the routines on track. Even if the patients are carefully selected and prove to be the most motivated individuals who can keep the donor heart healthy for years to come, the patients have their ups and downs regardless of how perfect match they are.

Listening the stories of patients, medical professionals and close ones, the topics, where support is lacking, came out quite clearly. A need for support, both patient-to-patient shared experience and specialist support from range of topics from psychology to nutrition is relevant. Adding the resource information exchange as relevant in-depth materials are often not available in Estonian, a concept for a solution was co-created with the patients based on the needs which were clarified by the patient journey on basis of the previous interviews and stories.

A concept was developed on the aim of creating a perfect support network for the patients, together with the patients. Patient empowerment is a theme which follows the process onward. The design proposal aims to be a platform for the patients to feel empowered through education which involved health literacy, through social support and support provided by specialists. The concept helps patients to prepare for the transplantation and also have a recovery with support, transparency and clarity needed for the process.

The design proposal Teel is created as a multidisciplinary support network for patients on their pre- or post-transplantation journey. Teel concepts shares its functions both on physical room and digital platform. Teel Digital is meant as a individual resource platform. The resources are specifically for the patient; questions can be asked from the specialist network, and the heart transplant community works as a discussion-sharing function in-between the patients. Teel Space is a common environment where patients can meet face-to-face with other patients or medical professionals. Teel Space facilitates educational workshops, events and talks around transplantation but also works as a space to meet, or come alone to discover. The environment includes common resources. Individual questions can be asked from the facilitator, a trained specialist in Teel Space.

Similar touchpoints enhancing the growth of patient empowerment can also be possible needs for wider diagnosis and units. Currently, the concept is designed with heart transplant patients in focus and including also the possible heart transplant patients, for example patients with LVAD. From the feedback round, the concept seemed to be fit to be useful for bigger group of patients with heart failure. Another option for scaling up is to use same build on other transplantation categories.

The thesis work researched and analysed the patient needs and offers better care possibility as a design solution for the current and future patients in PERH. Including patients in the process of designing new or existing services leads the way towards inclusive, not only patient- but human-centered medical care experience.

12.1 Eestikeelne kokkuvõte

Haiglad on teenusepõhised organisatsioonid, pakkudes teenuseid erinevates rollides olevatele inimestele – patsiendid, külastajad ja personal on mõned grupid, mis on otseselt seotud haigla teenustega. Väärtust pakkuvaid ja ajakohaseid teenuseid saab luua vaid koos asjaosalistega, kaasates neid erinevates teenuse arenguettappides.

Magistritöö keskendub südametransplantatsioonipatsientidele ning antud patsientidega seotud teenuste parendamisele läbi koos-loome. Magistritöö kasutab koos-disaini meetodeid, vaadates teemat läbi ökosüsteemivaate ning kaasates erinevaid seotud osapooli. Disainmõtlemise protsessi jälgides keskendub töö protsess empaatiale. Kasutades sotsiaalset teenusedisaini tervishoiukeskkonnas.

Põhilised fookusteemad disainiettepanekus on läbipaistvus, kättesaadavus, kogukond, erinevate erialaspetsialistide tugi. Selle nimistu võib kokku võtta teemaga patsiendi võimestamine. Nendest teemades läbi patsientidega koos disainimise on loodud disainipakkumine, parendamaks südametransplantatsiooni patsienditeekonda

Disainilahendus Teel on mitmetasandiline tugivõrgustik südametransplantatsiooni-patsientidele, disainitud koos patsientidega ning patsiendivajadusi arvestades.Teel on abiks patsientidele alates diagnoosist kuni taasutmiseni ning ka tulevikus. Teel on loodud nii füüsilise kui ka digitaalse keskkonnana, pakkudes tervikliku ning kaasavat tuge.

Magistritöö lahendus on loodud viisil, et disainipakkumise arendust saaks edasi laiendada erinevatel viisidel, nii kardioloogiateemadel kui ka teistele organitransplantatsiooni tugiteenustena. Teenusedisaini kasutamine tervishoiu ja haigla tulevikus on oluline osa tasakaalustamaks meditsiinilise personali töökoormust ja pakkumaks kaasavat, läbipaisvat ja tervikliku teenust patsientidele ning ka osapooltele, kes on kontaktis haiglaga. Tervishoiuasutused peavad kasvama koostöös patsientidega – ekspertidega, kellel on arusaam läbitud kogemustest.

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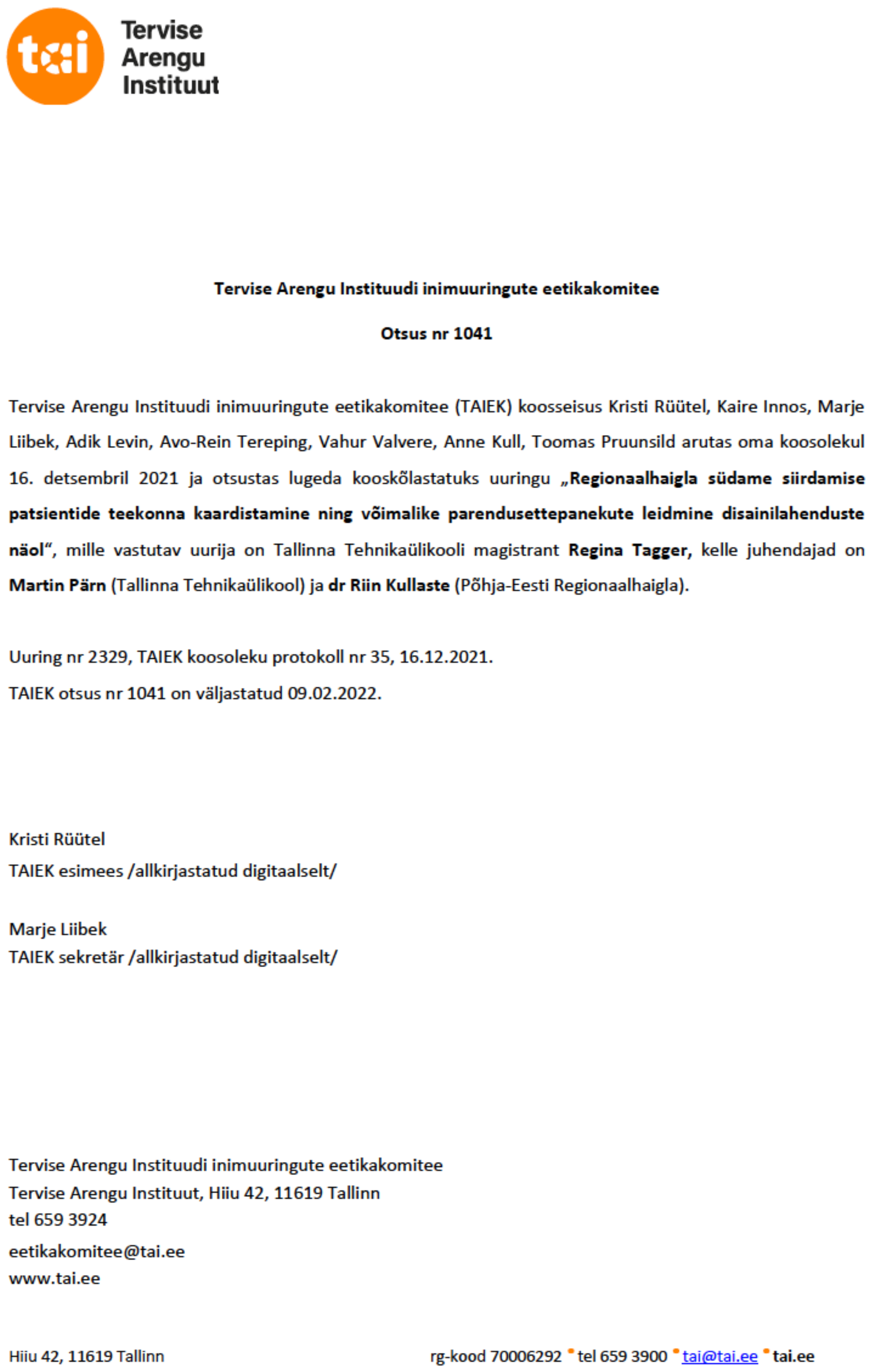
15. Appendix

1. TAI Ethics Committee Decision for the research (In Estonian). TAI



Tervise
Arengu
Instituut

Tervise Arengu Instituudi inimuuringute eetikakomitee

Otsus nr 1041

Tervise Arengu Instituudi inimuuringute eetikakomitee (TAIEK) koosseisus Kristi Rüütel, Kaire Innos, Marje Liibek, Adik Levin, Avo-Rein Tereping, Vahur Valvere, Anne Kull, Toomas Pruunsild arutas oma koosolekul 16. detsembril 2021 ja otsustas lugeda kooskõlastatuks uuringu **„Regionaalhaigla südame siirdamise patsientide teekonna kaardistamine ning võimalike parendusettepanekute leidmine disainilahenduste näol“**, mille vastutav uurija on Tallinna Tehnikaülikooli magistrant **Regina Tagger,** kelle juhendajad on **Martin Pärn** (Tallinna Tehnikaülikool) ja **dr Riin Kullaste** (Põhja-Eesti Regionaalhaigla).

Uuring nr 2329, TAIEK koosoleku protokoll nr 35, 16.12.2021.
TAIEK otsus nr 1041 on väljastatud 09.02.2022.

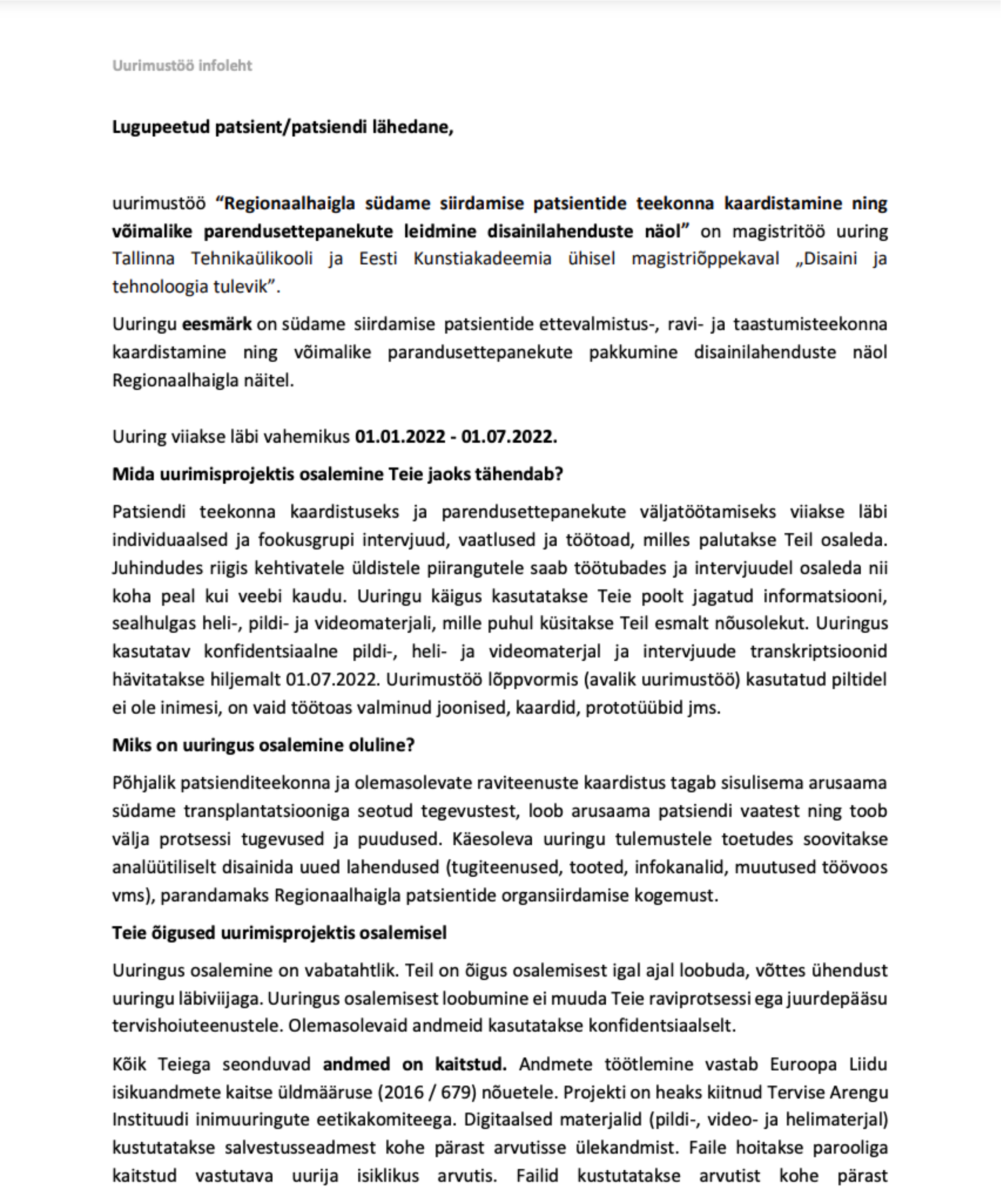
Kristi Rüütel
TAIEK esimees /allkirjastatud digitaalselt/

Marje Liibek
TAIEK sekretär /allkirjastatud digitaalselt/

Tervise Arengu Instituudi inimuuringute eetikakomitee
Tervise Arengu Instituut, Hiiu 42, 11619 Tallinn
tel 659 3924
eetikakomitee@tai.ee
www.tai.ee

Hiiu 42, 11619 Tallinn rg-kood 70006292 • tel 659 3900 • tai@tai.ee • **tai.ee**

2. Patient / close one agreement form for qualitative research. By the author. (In Estonian)



Uurimustöö infoleht

Lugupeetud patsient/patsiendi lähedane,

uurimustöö **"Regionaalhaigla südame siirdamise patsientide teekonna kaardistamine ning võimalike parendusettepanekute leidmine disainilahenduste näol"** on magistritöö uuring Tallinna Tehnikaülikooli ja Eesti Kunstiakadeemia ühisel magistriõppekaval „Disaini ja tehnoloogia tulevik".

Uuringu **eesmärk** on südame siirdamise patsientide ettevalmistus-, ravi- ja taastumisteekonna kaardistamine ning võimalike parendusettepanekute pakkumine disainilahenduste näol Regionaalhaigla näitel.

Uuring viiakse läbi vahemikus **01.01.2022 - 01.07.2022.**

Mida uurimisprojektis osalemine Teie jaoks tähendab?

Patsiendi teekonna kaardistuseks ja parendusettepanekute väljatöötamiseks viiakse läbi individuaalsed ja fookusgrupi intervjuud, vaatlused ja töötoad, milles palutakse Teil osaleda. Juhindudes riigis kehtivatele üldistele piirangutele saab töötubades ja intervjuudel osaleda nii koha peal kui veebi kaudu. Uuringu käigus kasutatakse Teie poolt jagatud informatsiooni, sealhulgas heli-, pildi- ja videomaterjali, mille puhul küsitakse Teil esmalt nõusolekut. Uuringus kasutatav konfidentsiaalne pildi-, heli- ja videomaterjal ja intervjuude transkriptsioonid hävitatakse hiljemalt 01.07.2022. Uurimustöö lõppvormis (avalik uurimustöö) kasutatud piltidel ei ole inimesi, on vaid töötoas valminud joonised, kaardid, prototüübid jms.

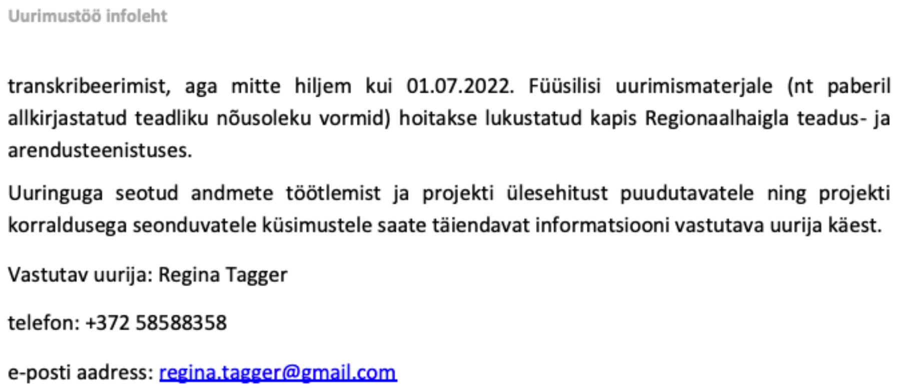
Miks on uuringus osalemine oluline?

Põhjalik patsienditeekonna ja olemasolevate raviteenuste kaardistus tagab sisulisema arusaama südame transplantatsiooniga seotud tegevustest, loob arusaama patsiendi vaatest ning toob välja protsessi tugevused ja puudused. Käesoleva uuringu tulemustele toetudes soovitakse analüütiliselt disainida uued lahendused (tugiteenused, tooted, infokanalid, muutused töövoos vms), parandamaks Regionaalhaigla patsientide organsiirdamise kogemust.

Teie õigused uurimisprojektis osalemisel

Uuringus osalemine on vabatahtlik. Teil on õigus osalemisest igal ajal loobuda, võttes ühendust uuringu läbiviijaga. Uuringus osalemisest loobumine ei muuda Teie raviprotsessi ega juurdepääsu tervishoiuteenustele. Olemasolevaid andmeid kasutatakse konfidentsiaalselt.

Kõik Teiega seonduvad **andmed on kaitstud.** Andmete töötlemine vastab Euroopa Liidu isikuandmete kaitse üldmääruse (2016 / 679) nõuetele. Projekti on heaks kiitnud Tervise Arengu Instituudi inimuuringute eetikakomiteega. Digitaalsed materjalid (pildi-, video- ja helimaterjal) kustutatakse salvestusseadmest kohe pärast arvutisse ülekandmist. Faile hoitakse parooliga kaitstud vastutava uurija isiklikus arvutis. Failid kustutatakse arvutist kohe pärast



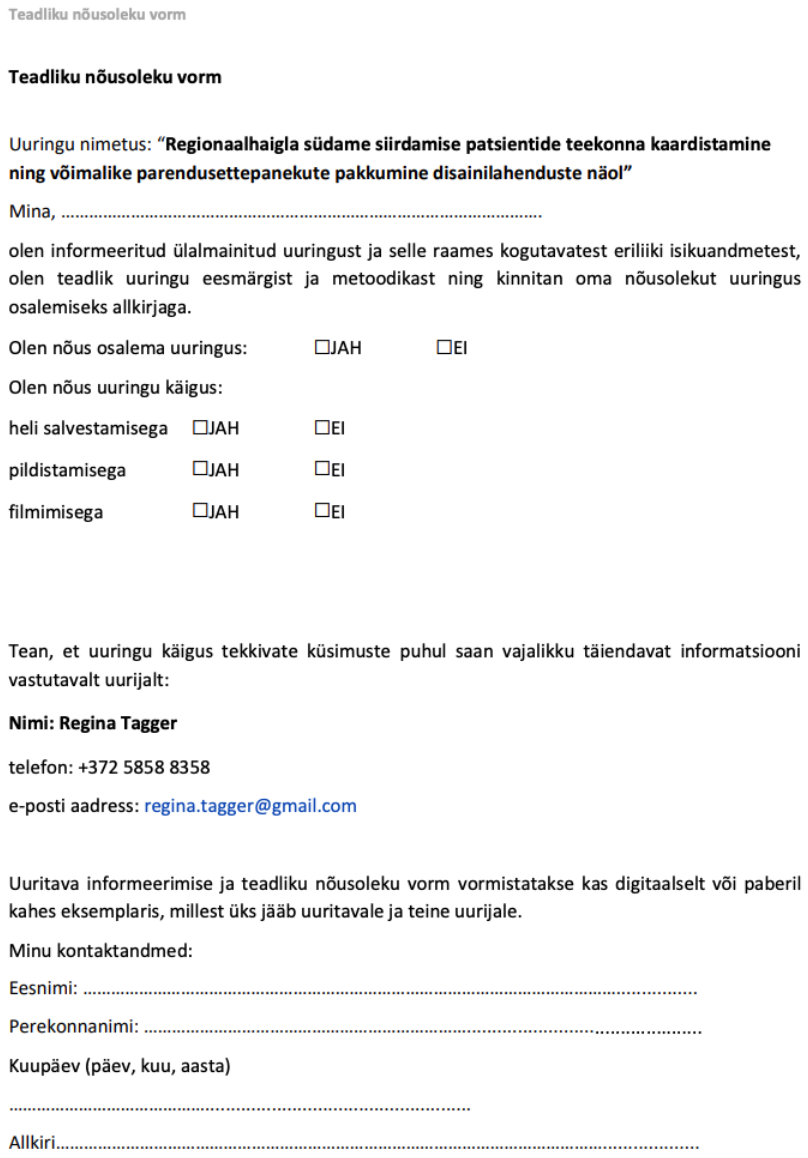
transkribeerimist, aga mitte hiljem kui 01.07.2022. Füüsilisi uurimismaterjale (nt paberil allkirjastatud teadliku nõusoleku vormid) hoitakse lukustatud kapis Regionaalhaigla teadus- ja arendusteenistuses.

Uuringuga seotud andmete töötlemist ja projekti ülesehitust puudutavatele ning projekti korraldusega seonduvatele küsimustele saate täiendavat informatsiooni vastutava uurija käest.

Vastutav uurija: Regina Tagger

telefon: +372 58588358

e-posti aadress: regina.tagger@gmail.com



Teadliku nõusoleku vorm

Uuringu nimetus: “**Regionaalhaigla südame siirdamise patsientide teekonna kaardistamine ning võimalike parendusettepanekute pakkumine disainilahenduste näol**”

Mina, ………………………………………………………………………………………

olen informeeritud ülalmainitud uuringust ja selle raames kogutavatest eriliiki isikuandmetest, olen teadlik uuringu eesmärgist ja metoodikast ning kinnitan oma nõusolekut uuringus osalemiseks allkirjaga.

Olen nõus osalema uuringus: ☐JAH ☐EI

Olen nõus uuringu käigus:

heli salvestamisega	☐JAH	☐EI
pildistamisega	☐JAH	☐EI
filmimisega	☐JAH	☐EI

Tean, et uuringu käigus tekkivate küsimuste puhul saan vajalikku täiendavat informatsiooni vastutavalt uurijalt:

Nimi: Regina Tagger

telefon: +372 5858 8358

e-posti aadress: regina.tagger@gmail.com

Uuritava informeerimise ja teadliku nõusoleku vorm vormistatakse kas digitaalselt või paberil kahes eksemplaris, millest üks jääb uuritavale ja teine uurijale.

Minu kontaktandmed:

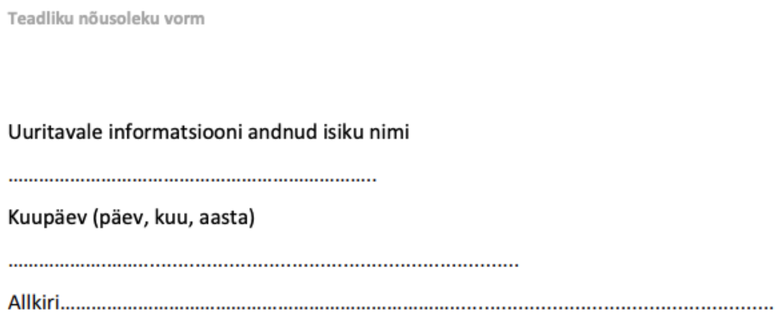
Eesnimi: ……………………………………………………………………………………………………

Perekonnanimi: ………………………………………………………………………………………………

Kuupäev (päev, kuu, aasta)

…………………………………………………………………………………

Allkiri………………………………………………………………………………………………………



Teadliku nõusoleku vorm

Uuritavale informatsiooni andnud isiku nimi

………………………………………………………………

Kuupäev (päev, kuu, aasta)

………………………………………………………………………………

Allkiri……

3. Structure for the interviews (In Estonian). By the author, approved by TAI

Patsiendi intervjuu kavand:

- Sissejuhatus, projekti laiem selgitus. Patsiendi enda küsimustele vastamine vestlusvormis.
- Palun rääkige oma südamesiirdamisteekonnast. Kuidas teile kogu protsess alguse sai? Kuidas te ennast tundsite? Mis juhtus järgmisena?
- Kuidas hindate siirdamiskogemust üldiselt? Mida teekond teile andnud / õpetanud?
- Kas te oskate välja tuua kogemusi, mis olid kas väga positiivsed või väga negatiivsed - väga rõõmsaks tegevad hetked ja ka mustemad langused. Mis tegi antud kogemused just selliseks? Kuidas te sellega toime tulite? Kas te oskate hetkel tagasi vaadates öelda, mis oleks teinud …. Kogemuse (veel) paremaks?
- Kust otsite ja leiate te kõige rohkem tuge oma raviteekonnal? Mis viisidel saab olla toeks uut organit vajavale inimesele?
- Kuidas saaks organi siirdamisteekond saaks teile kergem olla?
- Milline võiks olla organi siirdamine kümne aasta pärast?

Patsiendi lähedase intervjuu kavand:

- Sissejuhatus, projekti laiem kirjeldus, intervjueeritava tekkinud küsimustele vastamine ning selgitus, miks nende antud info on oluline antud uurimuses.
- Milline on teie seos organi siirdamise teekonnaga?
- Kuidas te ennast tundsite?
- Mis oli teie kogemuses positiivset ja negatiivset? Kuidas te sellega toime tulite?
- Mida teeksite järgmine kord teistmoodi kui peaksite uuesti toeks olema lähedasele, kellele siirdatakse uus organ?

- Kuidas saaks teie nähtud / kogetud siirdamisteekonda lähedase vaatest parandada? Mis on hetkel raviteekonnal väga hästi? Mis vajaks veel arendamist?

- Kuidas võiks näha välja organi siirdamine kümne aasta pärast?

Personali intervjuu kavand:

- Sissejuhatus, projekti laiem selgitus. Kui personalil peaks olema küsimusi, siis teemade üle arutlemine.

- Kuidas olete teie seotud südametransplantatsiooniga? Mis faasis teie patsiente näete?

- Kas olete ka kursis, mis toimub patsientidega edasi / mis on toimunud enne?

- Kuidas võrdlete eesti hetkeolukorda transplantatsioonivallas võrreldes teiste riikidega?

- Mis on meie südametransplantatsiooni ravi tugevused ja nõrkused?

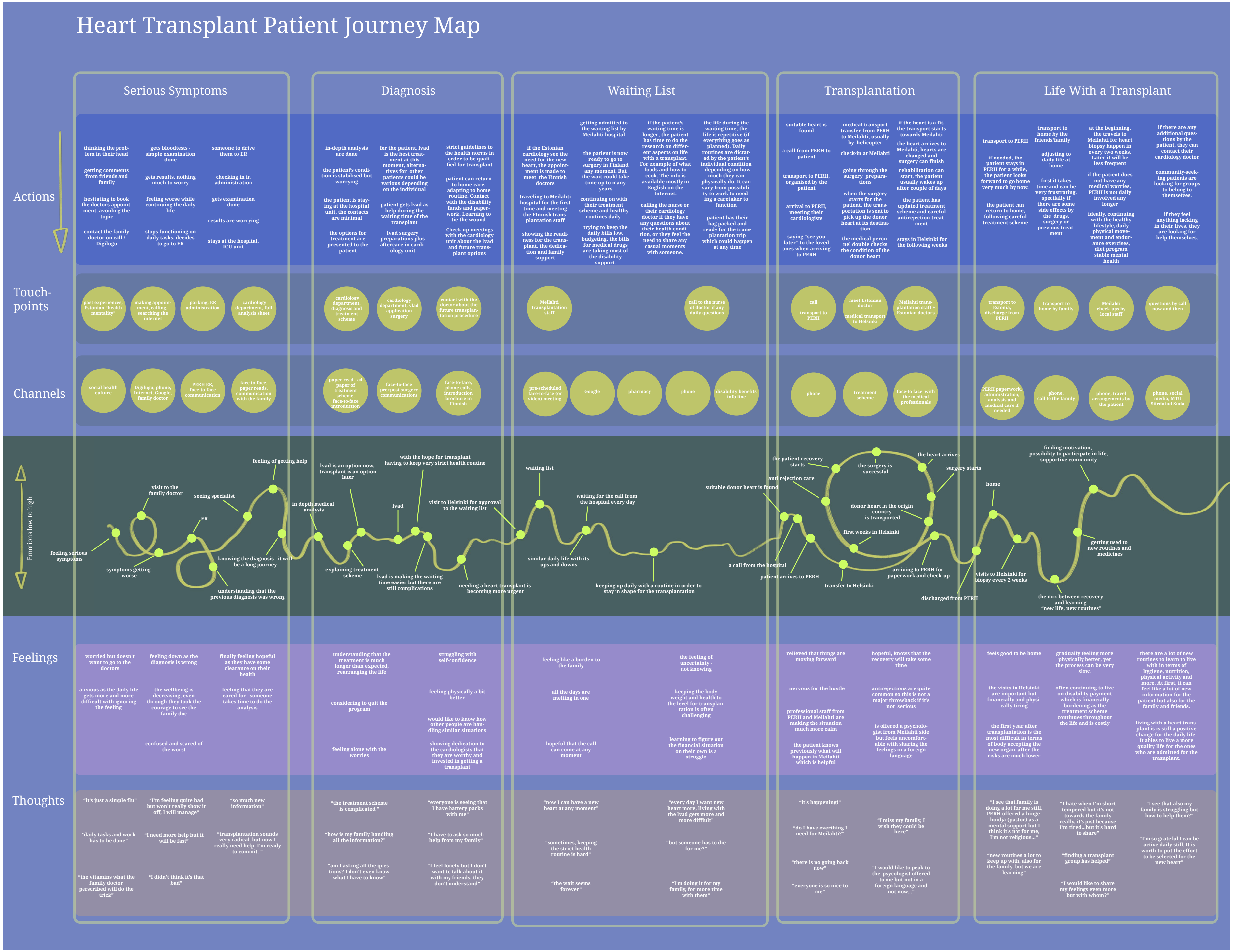
- Mis oleks teie arvates transplantatsiooniprotsessil abiks haiglale, mis patsiendile?

- (Millest on tekkinud need nõrkused?)

- Kuidas võiks välja näha organisiirdamine kümne aasta pärast?

- Euroopas ning ka Põhja-Ameerikas kasutatakse üha laiemalt teenusedisaini ning sotsiaalse disaini protsesse, et parandada meditsiiniteenuseid (tutvustus, mis on sotsiaalne, mis on teenusedisain) . See koosneb just patsientidega koos töötamisest läbi erinevate koos-disainimeetodite, näiteks töötoad ja arutelud, mille järel suudetakse mõista paremini erinevaid osapooli ning pakkuda lahedusi läbi teenuste, toodete, süsteemide loomise või muutmise. Kas olete ise mingil viisil sellise lähenemisega kokku puutunud? Kuidas te sellisesse lähenemisse suhtute, ning mida tuleks disaini ja tervishoidu ühendamisel meeles pidada?

4. Heart transplant patient journey map. By the author.



Heart Transplant Patient Journey Map

	Serious Symptoms	Diagnosis	Waiting List	Transplantation	Life With a Transplant
Actions	thinking the problem in their head getting comments from friends and family hesitating to book the doctors appointment, avoiding the topic contact the family doctor on call / Digilugu gets bloodtests - simple examination done gets results, nothing much to worry feeling worse while continuing the daily life stops functioning on daily tasks, decides to go to ER someone to drive them to ER checking in in administration gets examination done results are worrying stays at the hospital, ICU unit	in-depth analysis are done the patient’s condition is stabilised but worrying the patient is staying at the hospital unit, the contacts are minimal the options for treatment are presented to the patient for the patient, lvad is the best treatment at this moment, alternatives for other patients could be various depending on the individual patient gets lvad as help during the waiting time of the transplant lvad surgery preparations plus aftercare in cardiology unit strict guidelines to the health norms in order to be qualified for transplant patient can return to home care, adapting to home routine. Contact with the disability funds and paperwork. Learning to tie the wound Check-up meetings with the cardiology unit about the lvad and future transplant options	if the Estonian cardiology see the need for the new heart, the appointment is made to meet the Finnish doctors traveling to Meilahti hospital for the first time and meeting the FInnish transplantation staff showing the readiness for the transplant, the dedication and family support getting admitted to the waiting list by Meilahti hospital the patient is now ready to go to surgery in Finland any moment. But the wait could take time up to many years continuing on with their treatment scheme and healthy routines daily. trying to keep the daily bills low, budgeting, the bills for medical drugs are taking most of the disability support. if the patient’s waiting time is longer, the patient has time to do the research on different aspects on life with a transplant. For example of what foods and how to cook. The info is available mostly in English on the Internet. calling the nurse or their cardiology doctor if they have any questions about their health condition, or they feel the need to share any casual moments with someone. the life during the waiting time, the life is repetitive (if everything goes as planned). Daily routines are dictated by the patient’s individual condition - depending on how much they can physically do. It can vary from possibility to work to needing a caretaker to function patient has their bag packed and ready for the transplantation trip which could happen at any time	suitable heart is found a call from PERH to patient transport to PERH, organised by the patient arrival to PERH, meeting their cardiologists saying “see you later” to the loved ones when arriving to PERH medical transport transfer from PERH to Meilahti, usually by helicopter check-in at Meilahti going through the surgery preparations when the surgery starts for the patient, the transportation is sent to pick up the donor heart at its destination the medical peronnel double checks the condition of the donor heart if the heart is a fit, the transport starts towards Meilahti the heart arrives to Meilahti, hearts are changed and surgery can finish rehabilitation can start, the patient usually wakes up after couple of days the patient has updated treatment scheme and careful antirejection treatment stays in Helsinki for the following weeks	transport to PERH if needed, the patient stays in PERH for a while, the patient looks forward to go home very much by now. the patient can return to home, following careful treatment scheme transport to home by the friends/family adjusting to daily life at home first it takes time and can be very frustrating, specilally if there are some side effects by the drugs, surgery or previous treatment at the beginning, the travels to Meilahti for heart biopsy happen in every two weeks. Later it will be less frequent if the patient does not have any medical worries, PERH is not daily involved any longer ideally, continuing with the healthy lifestyle, daily physical movement and endurance exercises, diet program stable mental health if there are any additional questions by the patient, they can contact their cardiology doctor community-seeking patients are looking for groups to belong to themselves. if they feel anything lacking in their lives, they are looking for help themselves.
Touch-points	past experiences, Estonian “health mentality” making appointment, calling,- searching the internet parking, ER administration cardiology department, full analysis sheet	cardiology department, diagnosis and treatment scheme cardiology department, vlad application surgery contact with the doctor about the future transplantation procedure	Meilahti transplantation staff call to the nurse of doctor if any daily questions	call transport to PERH meet Estonian doctor medical transport to Helsinki Meilahti transplantation staff + Estonian doctors	transport to Estonia, discharge from PERH transport to home by family Meilahti check-ups by local staff questions by call now and then
Channels	social health culture Digilugu, phone, Internet, Google, family doctor PERH ER, face-to-face communication face-to-face, paper reads, communication with the family	paper read - a4 paper of treatment scheme, face-to-face introduction face-to-face pre+post surgery communications face-to-face, phone calls, introduction brochure in Finnish	pre-scheduled face-to-face (or video) meeting. Google pharmacy phone disability benefits info line	phone treatment scheme face-to face with the medical professionals	PERH paperwork, administration, analysis and medical care if needed phone, call to the family phone, travel arrangements by the patient phone, social media, MTÜ Siirdatud Süda
Feelings	worried but doesn’t want to go to the doctors anxious as the daily life gets more and more difficult with ignoring the feeling feeling down as the diagnosis is wrong the wellbeing is decreasing, even through they took the courage to see the family doc confused and scared of the worst finally feeling hopeful as they have some clearance on their health feeling that they are cared for - someone takes time to do the analysis	understanding that the treatment is much longer than expected, rearranging the life considering to quit the program feeling alone with the worries struggling with self-confidence feeling physically a bit better would like to know how other people are handling similar situations showing dedication to the cardiologists that they are worthy and invested in getting a transplant	feeling like a burden to the family all the days are melting in one hopeful that the call can come at any moment the feeling of uncertainty - not knowing keeping the body weight and health to the level for transplantation is often challenging learning to figure out the financial situation on their own is a struggle	relieved that things are moving forward nervous for the hustle professional staff from PERH and Meilahti are making the situation much more calm the patient knows previously what will happen in Meilahti which is helpful hopeful, knows that the recovery will take some time antirejections are quite common so this is not a major throwback if it’s not serious is offered a psychologist from Meilahti side but feels uncomfortable with sharing the feelings in a foreign language	feels good to be home the visits in Helsinki are important but financially and physically tiring the first year after transplantation is the most difficult in terms of body accepting the new organ, after the risks are much lower gradually feeling more physically better, yet the process can be very slow. often continuing to live on disability payment which is financially burdening as the treatment scheme continues throughout the life and is costly there are a lot of new routines to learn to live with in terms of hygiene, nutrition, physical activity and more. At first, it can feel like a lot of new information for the patient but also for the family and friends. living with a heart transplant is is still a positive change for the daily life. It ables to live a more quality life for the ones who are admitted for the trasnplant.
Thoughts	“it’s just a simple flu” “daily tasks and work has to be done” “the vitamins what the family doctor perscribed will do the trick” “I’m feeling quite bad but won’t really show it off, I will manage” “I need more help but it will be fast” “I didn’t think it’s that bad” “so much new information” “transplantation sounds very radical, but now I really need help. I’m ready to commit. ”	“the treatment scheme is complicated ” “how is my family handling all the information?” “am I asking all the questions? I don’t even know what I have to know” “everyone is seeing that I have battery packs with me” “I have to ask so much help from my family” “I feel lonely but I don’t want to talk about it with my friends, they don’t understand”	“now I can have a new heart at any moment” “sometimes, keeping the strict health routine is hard” “the wait seems forever” “every day I want new heart more, living with the lvad gets more and more diffiult” “but someone has to die for me?” “I’m doing it for my family, for more time with them”	“it’s happening!” “do I have everthing I need for Meilahti?” “there is no going back now” “everyone is so nice to me” “I miss my family, I wish they could be here” “I would like to peak to the psycologist offered to me but not in a foreign language and not now...”	“I see that family is doing a lot for me still, PERH offered a hingehoidja (pastor) as a mental support but I think it’s not for me, I’m not religious...” “new routines a lot to keep up with, also for the family, but we are learning” “I hate when I’m short tempered but it’s not towards the family really, it’s just because I’m tired...but it’s hard to share” “finding a transplant group has helped” “I would like to share my feelings even more but with whom?” “I see that also my family is struggling but how to help them?” “I’m so grateful I can be active daily still. It is worth to put the effort to be selected for the new heart”

5. Heart transplant patient journey map with highlighted problem points.
By the author.

	Serious Symptoms	Diagnosis	Waiting List	Transplantation	Life With a Transplant
Actions	thinking the problem in their head getting comments from friends and family hesitating to book the doctors appointment, avoiding the topic contact the family doctor on call / Digilugu gets bloodtests - simple examination done gets results, nothing much to worry feeling worse while continuing the daily life stops functioning on daily tasks, decides to go to ER someone to drive them to ER checking in in administration gets examination done results are worrying stays at the hospital, ICU unit	in-depth analysis are done the patient’s condition is stabilised but worrying the patient is staying at the hospital unit, the contacts are minimal the options for treatment are presented to the patient for the patient, lvad is the best treatment at this moment, alternatives for other patients could be various depending on the individual patient gets lvad as help during the waiting time of the transplant lvad surgery preparations plus aftercare in cardiology unit strict guidelines to the health norms in order to be qualified for transplant patient can return to home care, adapting to home routine. Contact with the disability funds and paperwork. Learning to tie the wound Check-up meetings with the cardiology unit about the lvad and future transplant options	if the Estonian cardiology see the need for the new heart, the appointment is made to meet the Finnish doctors traveling to Meilahti hospital for the first time and meeting the FInnish transplantation staff showing the readiness for the transplant, the dedication and family support getting admitted to the waiting list by Meilahti hospital the patient is now ready to go to surgery in Finland any moment. But the wait could take time up to many years continuing on with their treatment scheme and healthy routines daily. trying to keep the daily bills low, budgeting, the bills for medical drugs are taking most of the disability support. if the patient’s waiting time is longer, the patient has time to do the research on different aspects on life with a transplant. For example of what foods and how to cook. The info is available mostly in English on the Internet. calling the nurse or their cardiology doctor if they have any questions about their health condition, or they feel the need to share any casual moments with someone. the life during the waiting time, the life is repetitive (if everything goes as planned). Daily routines are dictated by the patient’s individual condition - depending on how much they can physically do. It can vary from possibility to work to needing a caretaker to function patient has their bag packed and ready for the transplantation trip which could happen at any time	suitable heart is found a call from PERH to patient transport to PERH, organised by the patient arrival to PERH, meeting their cardiologists saying “see you later” to the loved ones when arriving to PERH medical transport transfer from PERH to Meilahti, usually by helicopter check-in at Meilahti going through the surgery preparations when the surgery starts for the patient, the transportation is sent to pick up the donor heart at its destination the medical peronnel double checks the condition of the donor heart if the heart is a fit, the transport starts towards Meilahti the heart arrives to Meilahti, hearts are changed and surgery can finish rehabilitation can start, the patient usually wakes up after couple of days the patient has updated treatment scheme and careful antirejection treatment stays in Helsinki for the following weeks	transport to PERH if needed, the patient stays in PERH for a while, the patient looks forward to go home very much by now. the patient can return to home, following careful treatment scheme transport to home by the friends/family adjusting to daily life at home first it takes time and can be very frustrating, specilally if there are some side effects by the drugs, surgery or previous treatment at the beginning, the travels to Meilahti for heart biopsy happen in every two weeks. Later it will be less frequent if the patient does not have any medical worries, PERH is not daily involved any longer ideally, continuing with the healthy lifestyle, daily physical movement and endurance exercises, diet program stable mental health if there are any additional questions by the patient, they can contact their cardiology doctor community-seeking patients are looking for groups to belong to themselves. if they feel anything lacking in their lives, they are looking for help themselves.
Touchpoints	past experiences, Estonian “health mentality” making appointment, calling,- searching the internet parking, ER administration cardiology department, full analysis sheet	cardiology department, diagnosis and treatment scheme cardiology department, vlad application surgery contact with the doctor about the future transplantation procedure	Meilahti transplantation staff call to the nurse of doctor if any daily questions	call transport to PERH meet Estonian doctor medical transport to Helsinki Meilahti transplantation staff + Estonian doctors	transport to Estonia, discharge from PERH transport to home by family Meilahti check-ups by local staff questions by call now and then
Channels	social health culture Digilugu, phone, Internet, Google, family doctor PERH ER, face-to-face communication face-to-face, paper reads, communication with the family	paper read - a4 paper of treatment scheme, face-to-face introduction face-to-face pre+post surgery communications face-to-face, phone calls, introduction brochure in Finnish	pre-scheduled face-to-face (or video) meeting. Google pharmacy phone disability benefits info line	phone treatment scheme face-to face with the medical professionals	PERH paperwork, administration, analysis and medical care if needed phone, call to the family phone, travel arrangements by the patient phone, social media, MTÜ Siirdatud Süda
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6. Workshop materials (in Estonian). Structure and facilitation by the author, input by the participants.

3.Töötuba

0

Hea töötoa kaaslane!

Tere!

5 mins

Kuhu olen mina oma tööga jõudnud?

- teekond on kaardistatud
- ideede suunad on olemas
- tahan aga teiega koos nende teemade üle mõtiskleda

visiooniks on luua tugivõrgustik südametransplantatsiooni ootavatele kui ka uue südamega elavatele inimestele.

mida teeb tugivõrgustik?

- vähendab hirme
- annab vajalikku infot, mis on Eestile kohane, uudiseid,
- levinumad küsimused leiavad vastused
- kontaktid tugiteenustele - füsio, psühho, toitumise teemad
- annab motivatsiooni
- loob kuuluvustunde
- eeskujud, tervisliku ja võimaliku eluviisi osas - inspiratsioon
- võimalus aktiivselt suhelda, võimalus olla jälgija rollis

miks?

- ei pea üksi teekonda läbima - võrgustik annab tunde, et sa oled oluline ning sinuga tegelevad erinevate alade spetsialistid
- kui patsiendil on parem, siis on kergem ka tema lähedastel ning haigla personalil
- aitab hoida motivatsiooni ning positiivset teekonda
- uut südant ootavad inimesed saavad positiivset tuge - nähes päris inimesi teekonda läbimas ning õnnestumas

1

Jäämurdja

5 minutit

Kirjuta 1-2 positiivset kogemust viimase kuu aja jooksul. Millega need seonduvad?

- treeningud on edenenud
- hakkasin tööl käima
- elurõõm, kui see on olemas, siis ongi kõik hästi
- Mu kaal pole langenud. Rohkem oleks vaja juurde.
- Sain endale gastrostoomi. Nüüd saan manustada rohkem toiteained ööpäeva jooksul.
- hakkan covidist terveks saama

2

Harjutus

Loome enda ideaalse südame-transplantatsiooni tugipaketi

probleemid millele ootaksid tuge oma raviteekonnal?

- tuge sama teekonna läbinud inimestelt. oluline on näha, et nad saavad hästi hakkama
- ka enne siirdamist oleks hea küsida küsimusi, et mis saama hakkab
- Turvalisele teekonnale siirdamiseelselt ja postsiirdamisel.
- Kommunikatsioon ka teistega, kes on seda sama läbikogenud.
- enne - keegi inimene, kes on teekonna läbi teinud, kellega saab hirmudest ja ootamatutest rääkida
- hakkasin ise netist otsima
- praegu - füsioteraapia - kui palju? kas? füüsiline pool

mis on 3 mure mis jäävad täna vastamata?

- olen siiani kõigile oma küsimustele vastused saanud
- Kui kaua saab olema ooteaeg siirdamiseni.
- Kaua ma suudan ilma siirdamiseta toime tulla.
- Kas tuleks eelnevalt panna kõrvale reharahad (?)
- hirmutab veidi finantsiline pool. uus töövõime määramine. mille alusel nad valivad - teadmatus

mis viisil eelistad, et jõuaks abi sinuni?

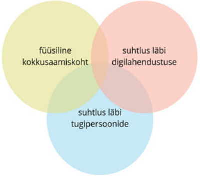
- läbi siirdatute
- raviarst, sotsiaalmeedia, kirjandus
- Näost näkku otsene suhtlus hoiab abiandja ja abivajaja infovaru kindlamaks.
- raviarst, dr Põder. saab kõik vastused
- kontaktsuhtlus - näost näkku, telefoni teel. saan lisada enda küsimusi kui tekib mingi mõte

3

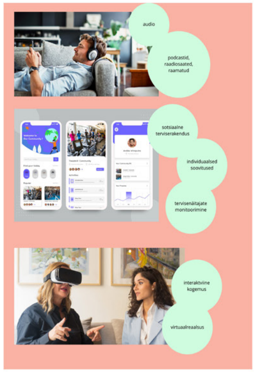
Harjutus

Tugivõrgustik

Mis tundeid tekitavad need vormid? mis teenuseid nendes formaatides kasutate? milliseid kasutaksite kui need oleksid kättesaadavad?



kirjuta siia ..



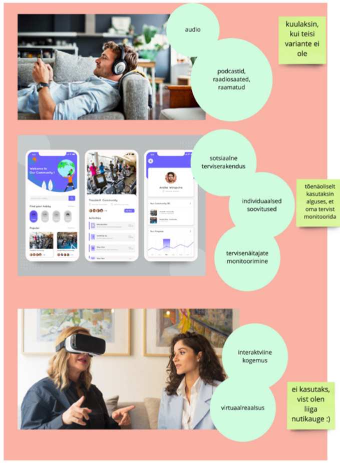
kirjuta siia ..

kasutan ja mulle sobib

hea just kasutada siirdatutega kokku saamiseks, et jagada mõtteid ja tundeid

mulle mitte nii sobilik variant aga kui kuskilt mujalt infot ei saa, siis kasutaksin seda

kasutaksin enne siirdamist, kui tervis lubab



kuulaksin, kui teisi variante ei ole

tõenäoliselt kasutaksin alguses, et oma tervist monitoorida

ei kasutaks, vist olen liiga nutikauge :)

kasutan juba praegu, sest avatud ja aus suhtlemine loob kerge ja läbipaistva õhkkonna

võimalik, et vajalik. ise puudust sel momendil ei tunne

mulle kõige sobivam variant

kirjuta siia ..

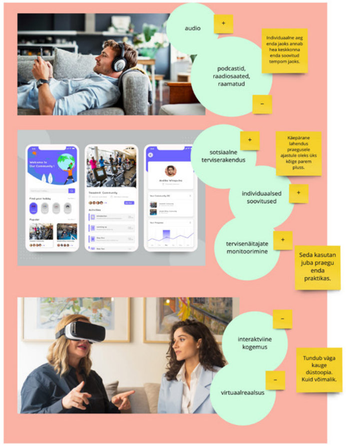
Ma tunneksin mugavalt rääkides enda teekonnast.

Samuti teiste jagatud lood annavad kolmanda osapoole, mida arvestada.

Endale antud aeg annab paremini seedida pakutud materjaliga.

Hea viis, kuidas enda pereliikmeid kaasata.

Ning informeerida enda lähedasi, kui endale tundub see protsess liiga keeruline.



Individuaalne aeg enda jaoks annab hea keskkonna enda soovitud tempom jaoks.

Käepärane lahendus praegusele ajastule oleks üks kõige parem pluss.

Seda kasutan juba praegu enda praktikas.

Tundub väga kauge düstoopia. Kuid võimalik.

Oleneb täiesti inimest ning suhtetest perekonnas.

Ei keeldu lisadest, mis võiksid aidata teekonna puhul ja suhete hoidmisel.

Esmatähtis isik, kelle kontakte on vaja igal siirdataval

vabas vormis grupivestlus

kogemuste, emotsioonide, mõtete jagamine sarnase kogemusega grupis

kirjuta siia ..

inimestega füüsiliselt rääkida

koos

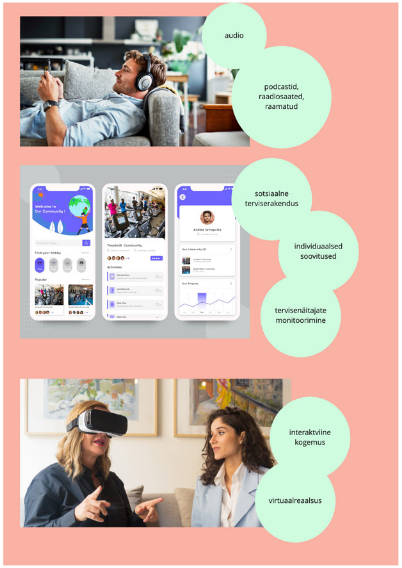
individuaalne süvenemine

sulle kasulikud infomaterjalid

spetsialist rääkimas

kuulamine + kaasa mõtlemine + arutelu

loenguvorm



audio

podcastid, raadiosaated, raamatud

sotsiaalne terviserakendus

individuaalsed soovitused

tervisenäitajate monitoorimine

interaktviine kogemus

virtuaalreaalsus

ühine aeg perega

murede-rõõmude jagamine läbi koos tegemise

lauamänge ei mängi

ühiste hobide leidmine perega. jalgpalli koos vaatamine ja analüüsimine

igakuine teemakarp, sulle kujundatud

sisaldab infot, mida vajad just selles hetkes oma terviseteekonnal

+abivahendeid, et arendada ja parandada tervislike rutiine kodustes tingimustes

professionaalne spetsialistidest koosnev võrgustik

küsimustele vastamine, nõu ja jõu

vabas vormis grupivestlus

kogemuste, emotsioonide, mõtete jagamine sarnase kogemusega grupis

kirjuta siia ..

näost-näkku kohtimised

võiks olla kaasatud spetsialistid kellega nõu küsida

julgeda küsida vastata

vaba hubane keskkond

individuaalne süvenemine

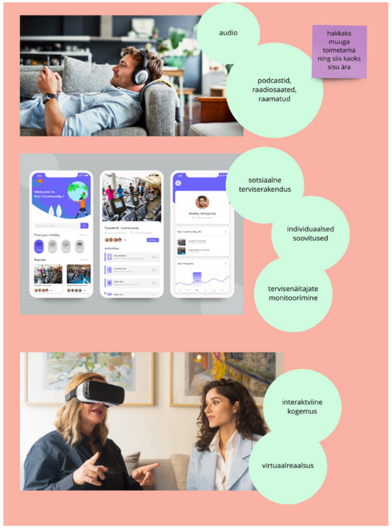
uuriksin kui oleks arsti külastus PERHis

sulle kasulikud infomaterjalid

spetsialist rääkimas

kuulamine + kaasa mõtlemine + arutelu

loenguvorm



audio

hakkaks muuga toimetama ning siis kaoks sisu ära

podcastid, raadiosaated, raamatud

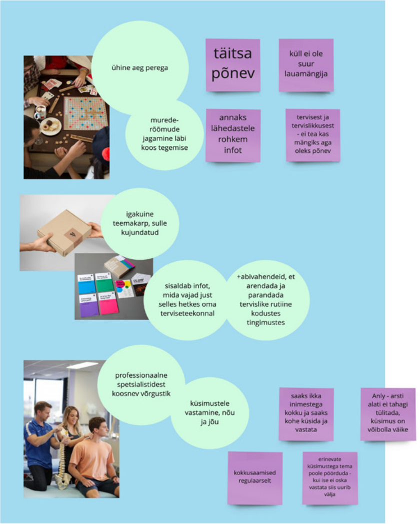
sotsiaalne terviserakendus

individuaalsed soovitused

tervisenäitajate monitoorimine

interaktviine kogemus

virtuaalreaalsus



ühine aeg perega

täitsa põnev

küll ei ole suur lauamängija

murede-rõõmude jagamine läbi koos tegemise

annaks lähedastele rohkem infot

tervisest ja tervislikkusest - ei tea kas mängiks aga oleks põnev

igakuine teemakarp, sulle kujundatud

sisaldab infot, mida vajad just selles hetkes oma terviseteekonnal

+abivahendeid, et arendada ja parandada tervislike rutiine kodustes tingimustes

professionaalne spetsialistidest koosnev võrgustik

küsimustele vastamine, nõu ja jõu

saaks ikka inimestega kokku ja saaks kohe küsida ja vastata

Anly - arsti alati ei tahagi tülitada, küsimus on võibolla väike

kokkusaamised regulaarselt

erinevate küsimustega tema poole pöörduda - kui ise ei oska vastata siis uurib välja

4

Viimased mõtted, lisades eelmisele harjutusele

Arutelu

Kuidas oleks sinu igapäev sellisel viisil saadud abist muutunud,

kui viimase kuu aja jooksul oleks sinu valitud viisil sinu murele teenus olemas olnud?

Ja see ongi tänaseks kõik! 🎉

Aitäh!

tegevused:

info jagamine

info jagamine vajalike tegevuste jaoks, mis võivad ees oodata (nt, raha kõrvale panemiseks)

kogemuste jagamine

lisaküsimuste esitamise võimalus

vabas vormis vestlused

lauamängud

lähedaste kaasamine info jagamise faasis (loengu vormis näiteks)

spetsialistide, ootajate, kogenute kokkutoomine

füüsiline kontakt

eesoleva ajajoone tutvustus

füüsiliste piiride tajumine (mis on need piirid, millega peaks arvestama)

näost-näkku suhtlus

arusaamine füüsiliste tegevuste mõjust kehale

loengud enne siirdamist

vahetu kontakt spetsialistidega

päris-inimestega rääkimine

teemakohase lauamängu mängimine lähedastega

ootaja kokku viimine kellegagi, kes on teekonna läbinud (ettekujutus tunnetest)

keskkond:

sotsiaal meedia

avalikud grupid

kirjandus

digitaalne rakendus esialgse toena

toetav keskkond vastavalt sellele, kui kaugel siirdamise teekonnal asutakse

ülevaatlik digitaalne rakendus

füüsilise toetava keskkonna olemasolu

usaldusväärsus

raviarsti kättesaadavus

kinnised grupid

toetavad keskonnad vastavalt vajadusele

toetab paindlikku ajakasutust

24/7 ligipääs spetsialistidele (toitumisnõustaja, füsio, jne)

hubane ja vaba õhkkond

välised faktorid:

tugi lähedastele

suurem teadlikkus töövõimetuse määramise protsessist

toetuste läbipaistvus

kiired vastused

majanduslik tugi

majanduslik nõustamine

ajakohane informatsioon

vahetu infovahetus

abiks võiks olla:

patsientide eelneva kogemuse nägemine

suhtlemine kellegagi, kes olnud samas olukorras

ootejärjekorra läbipaistvus

otsetee spetsialistidele

tugiisik, kes uurib vajadusel vastused välja

enne siirdamist tekkivate hirmude maandamine

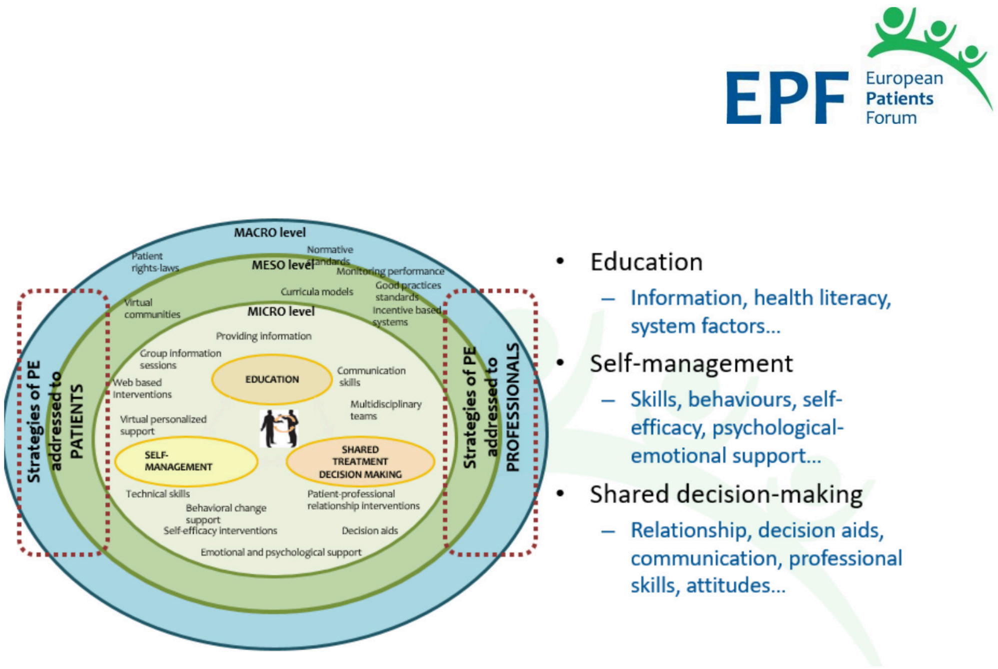
teadmatuse vähendamine

ootejärjekorra pikkuse võimalikud mõjud ja tagajärjed

erinevad toetavad tegevused erinevatele perekondadele (huvidest, lähedusest jm lähtuvalt)

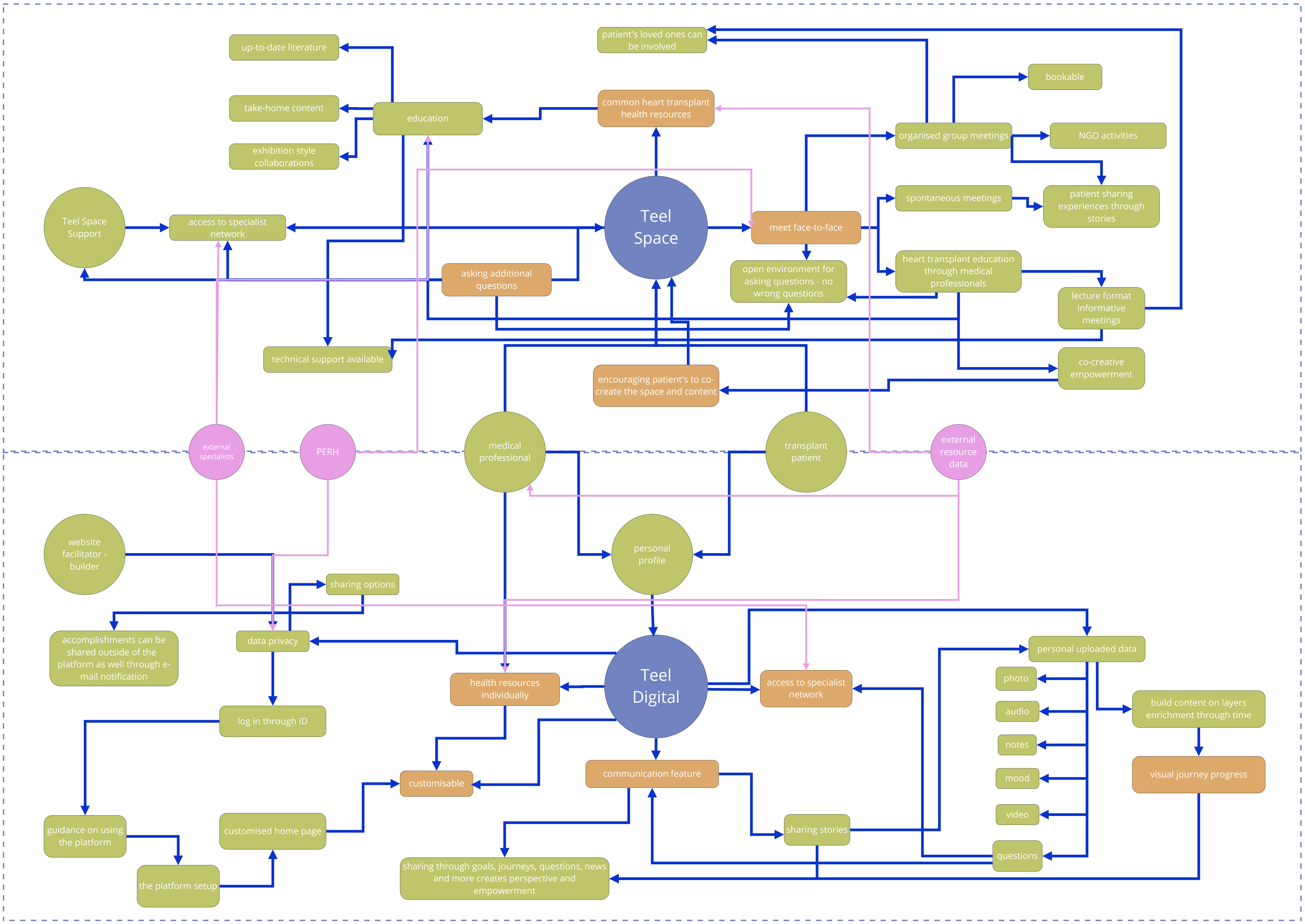
arsti koormuse vähendamine

7. Empathie Study. Author: European Patients Forum (Toolkit for Patients Organisations on Patient Empowerment, 2017)

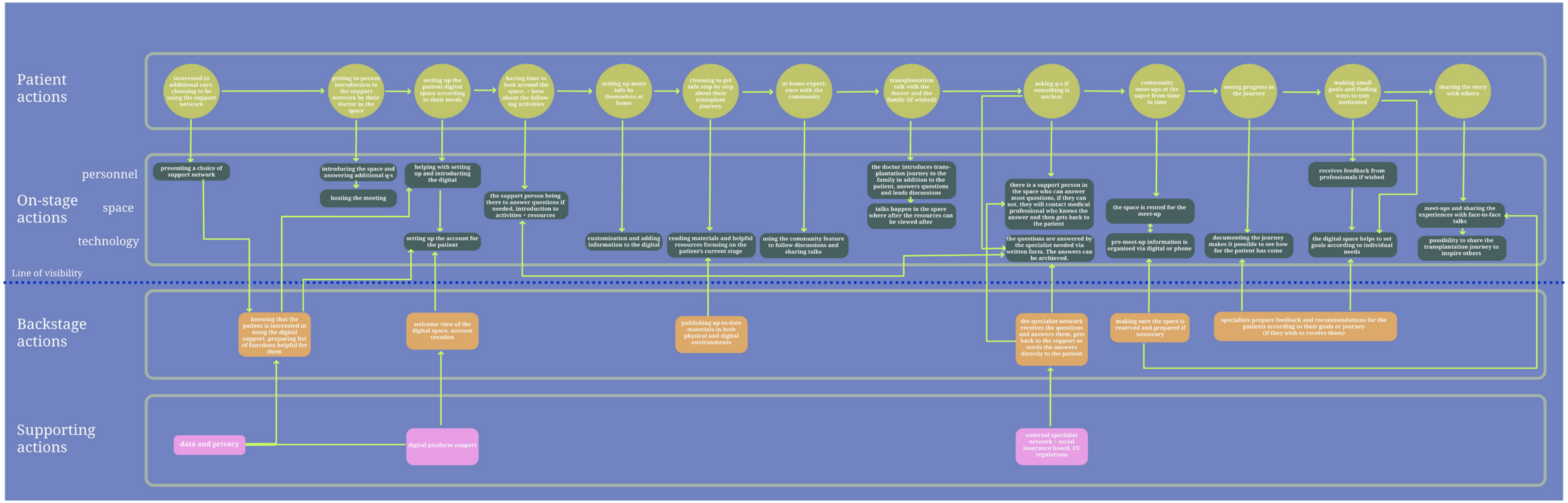


- Education
  - – Information, health literacy, system factors…
- Self-management
  - – Skills, behaviours, self-efficacy, psychological-emotional support…
- Shared decision-making
  - – Relationship, decision aids, communication, professional skills, attitudes…

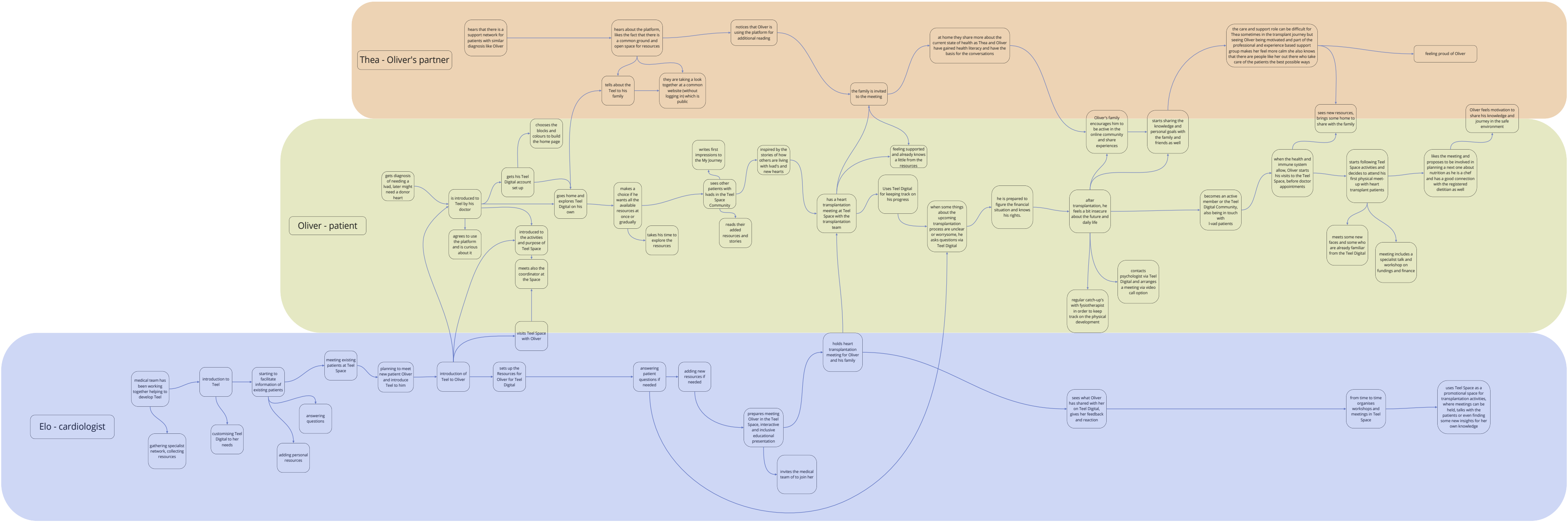
8. Systems Map of Teel. By the author.



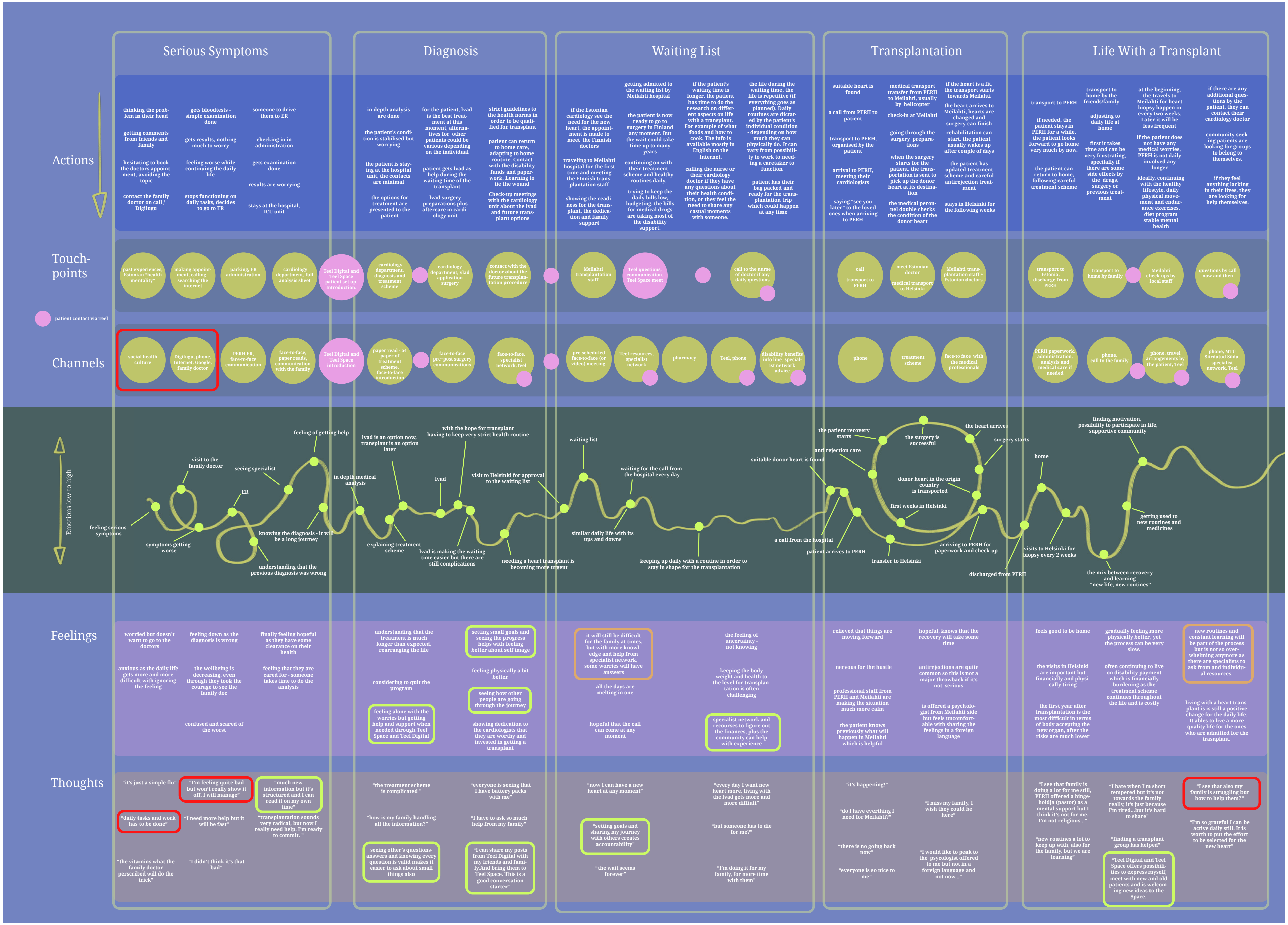
9. Service Blueprint Map of Teel. By the author



10. User journey example of Teel. By the author.



11. Improved patient journey with Teel. By the author.



● patient contact via Teel

	Serious Symptoms	Diagnosis	Waiting List	Transplantation	Life With a Transplant
Actions	thinking the problem in their head getting comments from friends and family hesitating to book the doctors appointment, avoiding the topic contact the family doctor on call / Digilugu gets bloodtests - simple examination done gets results, nothing much to worry feeling worse while continuing the daily life stops functioning on daily tasks, decides to go to ER someone to drive them to ER checking in in administration gets examination done results are worrying stays at the hospital, ICU unit	in-depth analysis are done the patient’s condition is stabilised but worrying the patient is staying at the hospital unit, the contacts are minimal the options for treatment are presented to the patient for the patient, lvad is the best treatment at this moment, alternatives for other patients could be various depending on the individual patient gets lvad as help during the waiting time of the transplant lvad surgery preparations plus aftercare in cardiology unit strict guidelines to the health norms in order to be qualified for transplant patient can return to home care, adapting to home routine. Contact with the disability funds and paperwork. Learning to tie the wound Check-up meetings with the cardiology unit about the lvad and future transplant options	if the Estonian cardiology see the need for the new heart, the appointment is made to meet the Finnish doctors traveling to Meilahti hospital for the first time and meeting the FInnish transplantation staff showing the readiness for the transplant, the dedication and family support getting admitted to the waiting list by Meilahti hospital the patient is now ready to go to surgery in Finland any moment. But the wait could take time up to many years continuing on with their treatment scheme and healthy routines daily. trying to keep the daily bills low, budgeting, the bills for medical drugs are taking most of the disability support. if the patient’s waiting time is longer, the patient has time to do the research on different aspects on life with a transplant. For example of what foods and how to cook. The info is available mostly in English on the Internet. calling the nurse or their cardiology doctor if they have any questions about their health condition, or they feel the need to share any casual moments with someone. the life during the waiting time, the life is repetitive (if everything goes as planned). Daily routines are dictated by the patient’s individual condition - depending on how much they can physically do. It can vary from possibility to work to needing a caretaker to function patient has their bag packed and ready for the transplantation trip which could happen at any time	suitable heart is found a call from PERH to patient transport to PERH, organised by the patient arrival to PERH, meeting their cardiologists saying “see you later” to the loved ones when arriving to PERH medical transport transfer from PERH to Meilahti, usually by helicopter check-in at Meilahti going through the surgery preparations when the surgery starts for the patient, the transportation is sent to pick up the donor heart at its destination the medical peronnel double checks the condition of the donor heart if the heart is a fit, the transport starts towards Meilahti the heart arrives to Meilahti, hearts are changed and surgery can finish rehabilitation can start, the patient usually wakes up after couple of days the patient has updated treatment scheme and careful antirejection treatment stays in Helsinki for the following weeks	transport to PERH if needed, the patient stays in PERH for a while, the patient looks forward to go home very much by now. the patient can return to home, following careful treatment scheme transport to home by the friends/family adjusting to daily life at home first it takes time and can be very frustrating, specially if there are some side effects by the drugs, surgery or previous treatment at the beginning, the travels to Meilahti for heart biopsy happen in every two weeks. Later it will be less frequent if the patient does not have any medical worries, PERH is not daily involved any longer ideally, continuing with the healthy lifestyle, daily physical movement and endurance exercises, diet program stable mental health if there are any additional questions by the patient, they can contact their cardiology doctor community-seeking patients are looking for groups to belong to themselves. if they feel anything lacking in their lives, they are looking for help themselves.
Touchpoints	past experiences, Estonian “health mentality” making appointment, calling,-searching the internet parking, ER administration cardiology department, full analysis sheet Teel Digital and Teel Space patient set up. Introduction.	cardiology department, diagnosis and treatment scheme ● cardiology department, vlad application surgery contact with the doctor about the future transplantation procedure ●	Meilahti transplantation staff Teel questions, communication. Teel Space meet ● call to the nurse of doctor if any daily questions ●	call transport to PERH meet Estonian doctor medical transport to Helsinki Meilahti transplantation staff + Estonian doctors	transport to Estonia, discharge from PERH transport to home by family ● Meilahti check-ups by local staff questions by call now and then ●
Channels	social health culture Digilugu, phone, Internet, Google, family doctor PERH ER, face-to-face communication face-to-face, paper reads, communication with the family Teel Digital and Teel Space introduction	paper read - a4 paper of treatment scheme, face-to-face introduction ● face-to-face pre+post surgery communications face-to-face, specialist network,Teel ● ●	pre-scheduled face-to-face (or video) meeting. Teel resources, specialist network ● pharmacy Teel, phone ● disability benefits info line, specialist network advice ●	phone treatment scheme face-to face with the medical professionals	PERH paperwork, administration, analysis and medical care if needed phone, call to the family ● phone, travel arrangements by the patient, Teel ● phone, MTÜ Siirdatud Süda, specialist network, Teel ●
Feelings	worried but doesn’t want to go to the doctors anxious as the daily life gets more and more difficult with ignoring the feeling feeling down as the diagnosis is wrong the wellbeing is decreasing, even through they took the courage to see the family doc confused and scared of the worst finally feeling hopeful as they have some clearance on their health feeling that they are cared for - someone takes time to do the analysis	understanding that the treatment is much longer than expected, rearranging the life considering to quit the program feeling alone with the worries but getting help and support when needed through Teel Space and Teel Digital setting small goals and seeing the progress helps with feeling better about self image feeling physically a bit better seeing how other people are going through the journey showing dedication to the cardiologists that they are worthy and invested in getting a transplant	it will still be difficult for the family at times, but with more knowledge and help from specialist network, some worries will have answers all the days are melting in one hopeful that the call can come at any moment the feeling of uncertainty - not knowing keeping the body weight and health to the level for transplantation is often challenging specialist network and recourses to figure out the finances, plus the community can help with experience	relieved that things are moving forward nervous for the hustle professional staff from PERH and Meilahti are making the situation much more calm the patient knows previously what will happen in Meilahti which is helpful hopeful, knows that the recovery will take some time antirejections are quite common so this is not a major throwback if it’s not serious is offered a psychologist from Meilahti side but feels uncomfortable with sharing the feelings in a foreign language	feels good to be home the visits in Helsinki are important but financially and physically tiring the first year after transplantation is the most difficult in terms of body accepting the new organ, after the risks are much lower gradually feeling more physically better, yet the process can be very slow. often continuing to live on disability payment which is financially burdening as the treatment scheme continues throughout the life and is costly new routines and constant learning will be part of the process but is not so overwhelming anymore as there are specialists to ask from and individual resources. living with a heart transplant is is still a positive change for the daily life. It ables to live a more quality life for the ones who are admitted for the trasnplant.
Thoughts	“it’s just a simple flu” “daily tasks and work has to be done” “the vitamins what the family doctor perscribed will do the trick” “I’m feeling quite bad but won’t really show it off, I will manage” “I need more help but it will be fast” “I didn’t think it’s that bad” “much new information but it’s structured and I can read it on my own time” “transplantation sounds very radical, but now I really need help. I’m ready to commit. ”	“the treatment scheme is complicated ” “how is my family handling all the information?” seeing other’s questions-answers and knowing every question is valid makes it easier to ask about small things also “everyone is seeing that I have battery packs with me” “I have to ask so much help from my family” “I can share my posts from Teel Digital with my friends and family.And bring them to Teel Space. This is a good conversation starter”	“now I can have a new heart at any moment” “setting goals and sharing my journey with others creates accountability” “the wait seems forever” “every day I want new heart more, living with the lvad gets more and more diffiult” “but someone has to die for me?” “I’m doing it for my family, for more time with them”	“it’s happening!” “do I have everthing I need for Meilahti?” “there is no going back now” “everyone is so nice to me” “I miss my family, I wish they could be here” “I would like to peak to the psycologist offered to me but not in a foreign language and not now...”	“I see that family is doing a lot for me still, PERH offered a hinge-hoidja (pastor) as a mental support but I think it’s not for me, I’m not religious...” “new routines a lot to keep up with, also for the family, but we are learning” “I hate when I’m short tempered but it’s not towards the family really, it’s just because I’m tired...but it’s hard to share” “finding a transplant group has helped” “Teel Digital and Teel Space offers possibilities to express myself, meet with new and old patients and is welcoming new ideas to the Space. “I see that also my family is struggling but how to help them?” “I’m so grateful I can be active daily still. It is worth to put the effort to be selected for the new heart”