MSC THESIS INTEGRATED PRODUCT DESIGN
DELFT UNIVERSITY OF TECHNOLOGY

DESIGNING PERSONALIZED SUPPORT FOR FAMILIES OF CARDIOVASCULAR DISEASE PATIENTS

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Designing personalized support for families of cardiovascular disease patients

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Acknowledgements

Dear reader,

This report presents my master thesis: *Designing personalized support for families of cardiovascular disease patients*. With this thesis I conclude the master's program in Integrated Product Design at the faculty of Industrial Design Engineering at TU Delft.

Throughout my education at the faculty, I have gained multiple skills that enabled me to take on this project. With this project I got the chance to show and further develop myself as a designer while contributing to a healthier society.

I would like to thank my supervisory team, whose guidance, support, and enthusiasm have been very helpful through this project. Additionally, your collective proposal to take extra time for refining my work has given me the chance to give this project what it deserves, in my opinion.

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Finally, I am thanking my family and friends who were there every step of the way. Your interest, questions, input, and faith helped me in this journey.

Despite the challenges in this project, I would do it again in a heartbeat.

Enjoy reading my thesis!

Sander Eversdijk

Executive summary

This project focuses on the often-overlooked role and requirements of family members who care for patients with cardiovascular diseases (CVD), particularly those recovering from myocardial infarction (MI) or having open-heart surgery (OHS). While cardiac rehabilitation (CR) programs are beneficial in improving patient outcomes and lowering risk factors, they are often centered around patients. However, family members play an important role in maintaining lifestyle changes and supporting rehabilitation at home, despite receiving minimal to no support.

The project proposes the Family Box, a personalized, digitally enabled support system based on the Leids Universitair Medisch Centrum's (LUMC) modular "Box," as a solution to this issue. The Family Box provides personalized support relevant to a wide range of family members. The research uses literature reviews, focus group data, qualitative interviews, and surveys, all of which are based on the human-centered design methodology ("Hear, Create, Deliver"). In addition to recognizing possibilities to empower family members through personalized support, this approach highlights important problems, including managing caregiver burden, understanding medical information, balancing household tasks, and addressing emotional needs.

The project states that personalization is important because a one-to-all solution can not meet every family member's diverse needs and preferences. Through the development of a framework for personalization, a personalization strategy is designed for the Family Box. By considering a set of four personas (Protector, Adaptor, Talker, & Observer) based on dimensions like involvement, care approach, and emotional coping strategies, the system can personalize educational modules, goal-setting tools, and progress-tracking features. Using data from wearable devices and other health measurements, family members can receive meaningful updates, reassurance about the patient's condition, and relevant lifestyle advice without becoming overwhelmed.

Early findings suggest that a Family Box can improve family member well-being, foster better collaboration between family and patient, and ultimately improve adherence to rehabilitation guidelines. Furthermore, by creating a scalable, modular system, the design can scale beyond MI and OHS to other care paths and eventually to preventive applications. However, ethical risks, such as protecting user privacy and preventing over-reliance on constant monitoring, must be carefully managed.

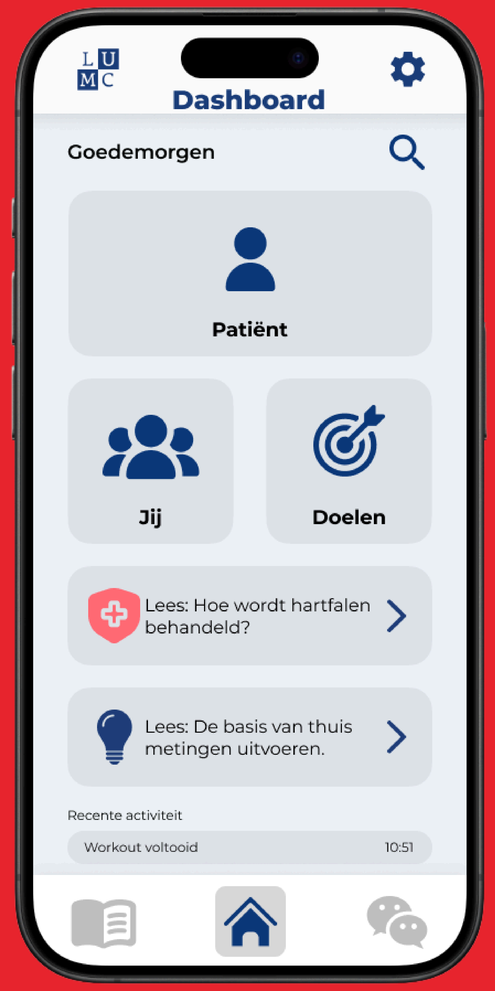
In conclusion, this project shows how personalized support can improve the involvement of family members in CR, leading to the improved well-being of both family members and patients. For further development, the project provides a roadmap for developing such a platform and highlights areas for further research, including the refining of data-driven personalization and larger-scale implementation studies. Additionally, the framework for personalization is discussed for application in other projects, using this project as a case study.

Protector

Adaptor

Talker

Observer



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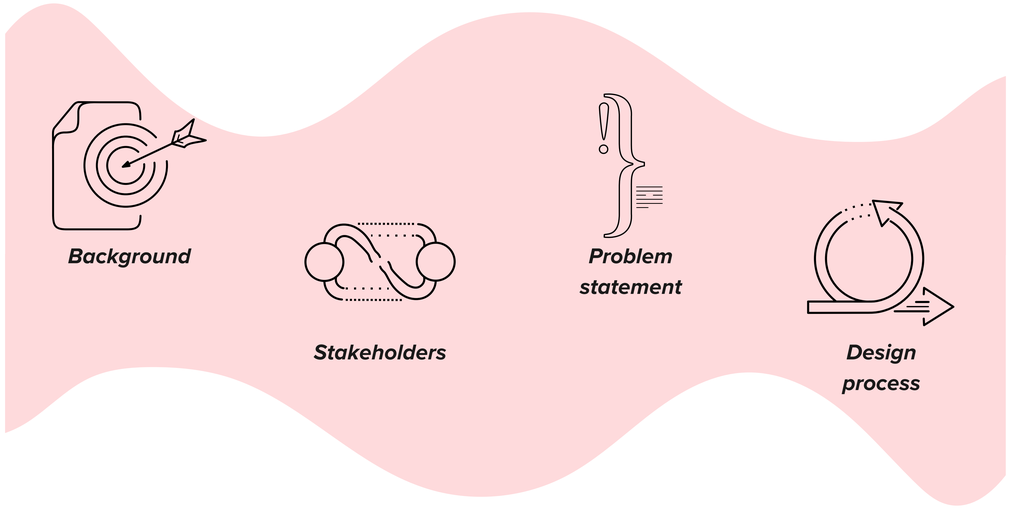
Introduction

In this phase, the background and context of the Family Box will be discussed. First, it explores the pressure that is growing through the perspectives of patients, families, and stakeholders. Followed by a dissection of the problem statement through the scope, aspects, and solution space. Finally, the design process and outcomes of the project will conclude the phase.



Background

Around 1.7 million people in the Netherlands live with a cardiovascular disease, which is close to ten percent of the population (Hartstichting, 2025). A decrease in cases is seen in the past decades, but an increase was found from 2020 till 2022, worrying the 'Hartstichting' (2023). At the same time, CVD is fourth in disease burden in the Netherlands in 2022 (Hart & Vaatcijfers, 2024; Volksgezondheid en Zorg, n.d.). Disease burden is expressed in lost years of life and years lived with health problems, and weighted by the severity of the health problems (Volksgezondheid en Zorg, n.d.). Every year, new people are diagnosed as chronically ill. As a result, the number of years that people can expect to live with a chronic illness is decreasing, while the overall life expectancy is increasing, see Figure 1 (CBS, 2024).

Figure 1: Life expectancy trends (CBS, 2024).

There can be multiple causes of CVD. They are called risk factors, which can be split into non-modifiable and modifiable risk factors (NHS, 2024). Managing them can be done through medication or via lifestyle change. Cardiac rehabilitation (CR) is implemented to provide support after patients leave the hospital. During CR patients learn how to manage risk factors, helping them make a lifestyle change (American Heart Association, 2024). CR programs show positive effects on adults (Fleg et al., 2013; Heran et al., 2011). Despite the benefits, not even 40% of heart patients participate in CR programs in the Netherlands (Harteraad, 2019).

The development of digital tools and remote monitoring options has the potential of increasing participation & access and improving outcomes for participants (Beatty et al., 2023). In 2015, Leids Universitair Medisch Centrum (LUMC) started trials with the BOX, an e-health solution that provides patients with wearables and measurement tools (see Figure 2) to take measurements at home (Jacobs, 2016). This selection of devices allows the Box to adapt to different care paths by including only the relevant devices for that care path or patient. Thus, what started as one type of the Box for post-cardiac event patients has now evolved into a modular setup containing 16 different types of Boxes for care paths like heart failure, pre-operation, and ablation. However, currently the Box is only aimed at patients. This project will look at the possibility of supporting the family members of patients as well.

CVD patients are sent home after receiving treatment in the hospital. After a period of usually two to three months (Basalt, n.d.), patients will start CR and slowly transition back to independent living. As patients need to rebuild their strength and trust in their body, they often rely on family for various types of support, like caregiving, helping with treatment adherence, and stimulating lifestyle changes (Kärner et al., 2004).

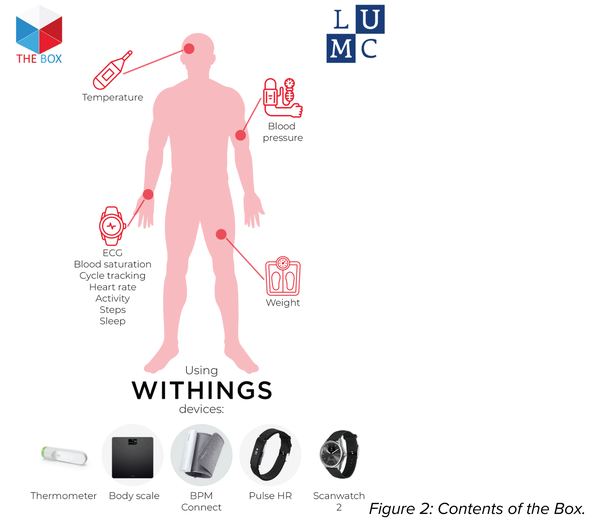


Figure 2: Contents of the Box.

Most of the actions and decisions concerning chronic illness management are made in the home of the patient, and as a result, families have a strong influence on the patient's journey and outcome (Whitehead et al., 2017). However, family members are often overlooked in the currently available care, as is also the case at LUMC (LUMC, 2024). Just as the patient, family members experience a lot during the care journey. During the care journey, family members deal with negative emotions and feel ill-informed (Fleury & Moore, 1999).

Research shows that family members perform many different caregiving tasks, ranging from communicating with healthcare professionals (HPs) to administering medication (Matthys et al., 2022). Just as their tasks can differ, family members are heterogeneous in characteristics and needs when compared to each other (Young et al., 2020). This variety in tasks and heterogeneity of family caregivers show why a one-size-fits-all solution is probably not effective. Some may need support for treatment adherence, while others require emotional support.

Without personalizing, support may misalign with the real needs of the family member, leading to wasted energy, disengagement, frustration, or more stress. Through involvement of family, patient outcomes can improve when the support is relevant to the patient's situation (Deek et al., 2016). By personalizing the support, family members could be better prepared to support the patient in a way that is effective and sustainable (NASEM, 2016; Young et al., 2020).

Improving the health and well-being of family members & patients.

CVDs are a big health issue in the Netherlands. Although CR is effective for recovery and long-term patient outcomes, participation rates remain low. Currently, digital solutions like the Box make it possible to monitor patients and offer support. However, family members are not taken into account by available care, despite the fact that they play an important role in the patient's recovery at home. This presents a challenge for healthcare because most everyday decisions about chronic illness management are made at home around or with family, but current care solutions do not support families. The impact of family members can be significant, but current solutions do not provide structured support for families.

This graduation project explores how family can be supported and involved during the care journey. It is critical to acknowledge that completely supporting the family member is challenging, as family dynamics, individual preferences of the patient, and limits of healthcare all influence what is possible. However, by finding ways to provide structured and personalized support to family members, it is possible to increase adherence, lower chances of readmission, and create sustainable lifestyle changes. With these effects, the proposal aims to improve the health and well-being of both family members and patients.

Improving the health and well-being of family members and CVD patients

Stakeholders

To improve the health and well-being of both family members and patients, researching the needs and challenges of family members is necessary. Therefore, the following parties are involved: TU Delft, LUMC, and Ancora Health. These stakeholders help guide towards an end result that is desirable, feasible, and viable. As a result of this collaboration, a framework for personalization of the support for family members will be proposed.

TU Delft

This project will serve as the conclusion of the master Integrated Product Design at the Faculty of Industrial Design Engineering at TU Delft. The faculty has two research themes that this project aligns with: Artificial Intelligence (AI) and Health (TU Delft, n.d.). The goal of this project is to recognize opportunities of AI and apply them to the big challenges in healthcare concerning the health management of chronic conditions.

LUMC Hart Long Centrum [Heart Lung Centre]

In collaboration with LUMC, this project aims to further develop the Box. LUMC has three focus points: data-driven healthcare & AI, regenerative medicine, and population health. This project builds on using data to further improve the care, combining it with AI, and exploring the transition from health to disease in society (LUMC, n.d.). The 'Hart Long Centrum [Heart Lung Centre]' aims to provide high-level and innovative care (Hart Long Centrum, n.d.). An example of this is the Box, enabling patients to monitor themselves through various trackers and measurement devices.

Ancora Health

Ancora Health aims to help people improve their health through care programs (Ancora Health, 2024). Together with LUMC, Ancora Health will build the Health Box, the new and improved platform for patients that will be the next iteration of the LUMC Care app.

Next steps for the Box

Health Box

This platform, currently in development at Ancora Health, will support patients in their care journey by introducing personalized support and bringing to life new features (e.g., chats, reading). Main functions will include monitoring of vitals, lifestyle recommendations, and educational elements.

Family Box

The Family Box will be a simultaneous next step for LUMC to start including family more in the care journey of the patient. The focus of the hospital is mostly the patient (Gilliss, 1991), while family members are also burdened with extra tasks and learning how to deal with the situation, among other things (Matthys et al., 2022; Young et al., 2020). Around 80 percent of heart disease cases are a result of an unhealthy lifestyle, and family members play a crucial role in lifestyle improvement (LUMC, 2024).

The Family Box will share features with the Health Box, like monitoring of vitals, lifestyle recommendations, and educational elements, see Figure 3. Therefore, emphasis will be placed on features or aspects that distinguish how the family will be supported in comparison to the patient, with features like monitoring of the patient, collaborating on lifestyle improvement or choices, and other support mostly relevant to the family member.

Figure 3: Main features of the Family Box.

Problem statement

Family members play an important role in the care journey of patients (NASEM, 2016) and can have a positive influence on patient outcomes and lifestyle change. However, they are rarely effectively involved or supported by the healthcare system (Gilliss, 1991). As a result, they are dealing with their own unique challenges and roles during the care journey. These challenges and roles can vary a lot, resulting in a range of unique experiences (Bhat et al., 2023; Kärner et al., 2004; Whitehead et al., 2017). To tackle this problem, personalization has been identified to increase both effective family involvement and lifestyle adherence. Thus, providing an opportunity to improve the health and well-being of both family members and patients.

Therefore, the question asked by the LUMC Hart Long Centrum is how families can be supported in a personalized manner to help them with the various challenges they encounter. To answer this question, this graduation project explores what types of support are needed, how personalized support can be offered, how the interaction between patient & family should look, and how AI can be used to make personalized interventions in the health domain.

Scope

The scope of this project focuses on the familial context of the patient, building on the ‘care for everyone’ goal of the Hart- en Vaatagenda (Hartstichting, 2024b). Family members can range from partners to informal caretakers to children. For this project, the emphasis is placed on adult family members, leaving child family members out of scope.

The care journey of MI and OHS patients is very similar from the moment of discharge. However, a key difference needs to be acknowledged. Typically, MI patients experience a sudden intake after suffering an MI, but the care journey of OHS patients also contains a period of time before their intake and discharge. Nevertheless, exceptions exist, as some MI patients may also have a longer trajectory, and some OHS patients may face sudden interventions. The pre-intake phase, when present, offers opportunities for providing support. However, the Box is given to patients at the moment of discharge or sent to their home at this point in time. Therefore, this project will focus on the opportunities for support where the Box is involved. Insights that are relevant to phases outside of the scope will still be shared when applicable.

Solution space

Building upon the current system of the Box, a product service system (PSS) will be proposed to solve the problem. This product service system will be proposed together with a roadmap showing short-term to long-term implementation steps. As the Family Box will be made available to families of any type of patient and care path, modularity will be kept in mind in the proposal.

Problem statement

Therefore, this graduation project aims to answer the following question:

How can we provide personalized support to families of patients recovering from MI or OHS, using interventions that address the unique challenges they face during the recovery process?

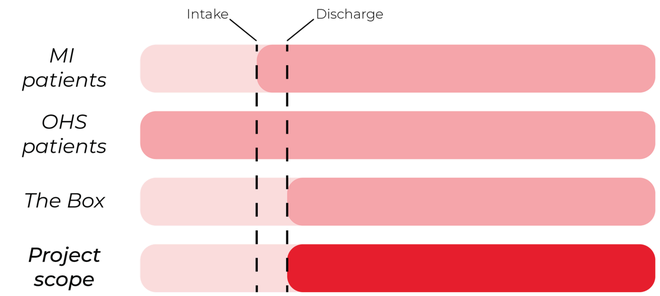


Figure 4: Scope of project

Design process

In this project, the human-centered design (HCD) method is used as the project is focused on health and well-being. HCD is an iterative design approach that prioritizes the discovery of human needs to develop products or services that meet those needs (Melles et al., 2020). The HCD approach is valuable because it prioritizes empathy and a deep understanding of the users, in this context, the families of patients. As a result, it ensures that solutions are not only functional but also meaningful and designed for the context of their users.

The process follows stages from the HCD toolkit, shown in the framework (Hear, Create, Deliver) (IDEO et al., n.d.), which guides the understanding and response to the needs of families. Using this process, a framework for personalized support will be designed together with a roadmap containing needed steps for implementation.

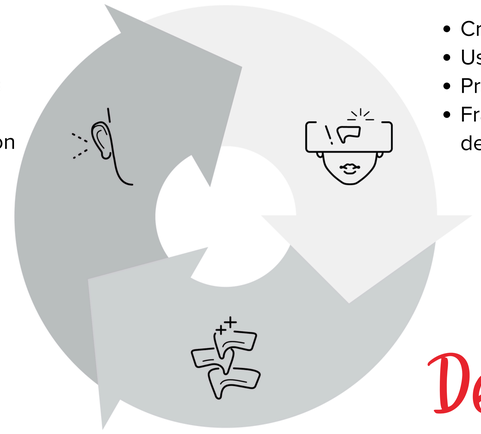
The process moves through phases of observing, synthesizing, ideating, and prototyping to keep the design solution aligned with desirability, feasibility, and viability. While moving through the different stages, iterations are made that result in jumps between stages, resulting in an iterative development rather than a linear process. First, the lens of desirability is used to later find overlap with the feasibility and viability lenses. This approach combines insights with practical applications, aiming to create a design that meets the needs of all stakeholders and fits within the context of LUMC.

Building the process upon the HCD principles, it brings together the human experience and systematic, clinical, and technological aspects of healthcare. The process will be divided into the following sections:

- **Hear:** Insights are gathered to understand the context. Through methods like reviewing literature, interviews, and focus group analysis, an understanding is built of the various aspects of the project, as well as the needs, behaviors, and challenges among families.
- **Create:** Using the insights from the stage before, directions and ideas are explored for potential solutions, both for further understanding the context and translating insights into a way of personalization. This stage concerns analyzing themes, identifying opportunities, ideation, prototyping, and testing early concepts.
- **Deliver:** This final stage is about iterating on the chosen direction and further development. Aiming to create a desirable, feasible, and viable solution with a roadmap showing needed steps across multiple horizons.

Hear

- Problem reframing
- Literature review
- Identifying key themes and needs
- Defining personalization



Create

- Creating personas
- User research
- Prototyping
- Framework for personaliztion design

Deliver

- Platform design
- Roadmap

Methodology

In order to develop a personalized support system for family members of patients recovering from MI or OHS, a mixed-methods approach was used, combining both qualitative and quantitative data collection methods.

Data gathering

- **Literature review:** Examined existing literature on family caregiving, CVD patient support, personalization in healthcare, behavioral change, and digital interventions.
- **Transcripts of focus groups:** Examined existing transcripts of qualitative data from focus groups with family members that provided care to patients recovering from MI or OHS.
- **Interviews with experts:** Conducted interviews with healthcare professionals, researchers, and industry experts, concentrating on feasibility, implementation, and best practices for support design.
- **Interviews with family members:** Conducted interviews with family members that have direct experience with MI or OHS patients, discovering their needs and preferences for information presentation, validating needs in the care journey, and checking recognition within the personas.
- **Questionnaire:** Distributed online via LinkedIn and patient platforms, reaching both experienced family members and people imagining themselves in a caregiving scenario, discovering their needs and preferences for information presentation, validating needs in the care journey, and checking recognition within the personas.

Data analysis

- **Contextmapping:** Identification of different situations, needs, and types of family members by statement card analysis to serve as a basis for a care journey map and development of personas.
- **Personas method (Lost Lemon & Muzus, 2018):** Enriched the personas through filling different phrases, building upon the found characteristics from the contextmapping method.

Envisioned outcomes

How can we provide personalized support to families of patients recovering from MI or OHS, using interventions that address the unique challenges they face during the recovery process?

To deepen the understanding of the problem and develop a solution to the problem stated above, the Family Box project will result in two outcomes. The first outcome will provide a solution to this specific problem statement, while the second outcome will show how others could design personalized support for healthcare challenges.

1. Family Box platform design

A product service system (PSS) will be shown, focusing on the implementation of the designed personalization strategy for supporting family members. It will illustrate how a structure of personalized content and features can be implemented and how the interaction between family members and patients can take place.

The personalization strategy will be defined across several aspects of personalization, explaining different needs, goals, and support strategies among family users.

As described earlier, the Box has a modular setup. This will have to be taken into account for the structure of the Family Box, as it is an addition to the Box. Therefore, content & features will be distinguished as consistent elements available to all families, personalized elements that depend on the integrated personalization process, and modular elements that are adapted to a care path. To conclude, a roadmap will be presented to guide and explain the next steps to further develop and implement the Family Box.

2. Framework for personalized support

Based on this project, a framework will be presented that discusses systematically **how** personalization can be designed for the context of the healthcare system. It will discuss key aspects of personalization that are needed to design a complete personalization strategy, like what personal characteristics are addressed, to whom it is personalized, and what is personalized.

Conclusion

Family members play a critical role in the care journey of MI and OHS patients. However, their needs and challenges are very diverse (Young et al., 2020) and often overlooked in healthcare systems (LUMC, 2024). During the care journey, they struggle with maintaining their own health and well-being (Fleury & Moore, 1999). These struggles can vary as family members can take various forms, ranging from partners to parents (Young et al., 2020).

This gap of support for family members acts as an opportunity to design relevant and structured support through personalization. By implementing personalization in the Family Box, it is possible to increase effective family involvement, reduce caregiver burden, improve patient outcomes, and improve lifestyle change adherence. This ensures that family members are recognized and provided with the tools and knowledge to manage the health and well-being of both themselves and the patient.

To design personalized support, the next chapter will explore the context of the problem further to better understand what layers of problems can be identified and how different opportunities within the context can connect to achieve the goal of this project: improving the health and well-being of both family members and patients. That exploration will elaborate the understanding of **why** personalization is needed and steer the next steps of the project.

Goal of graduation project:

Improving the health and well-being of family members and patients

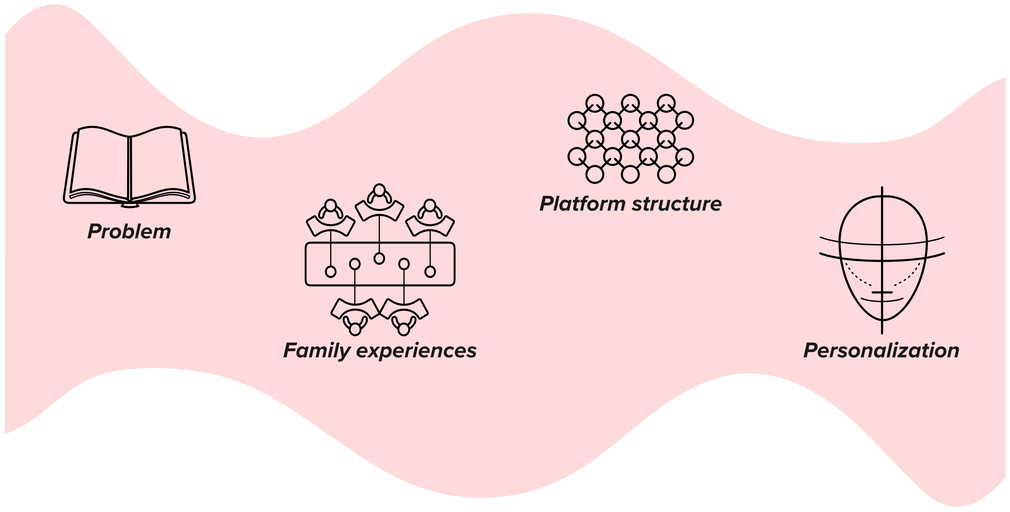
Problem statement

How to personalize support for families of patients recovering from MI or OHS, using interventions that address the unique challenges families face during the recovery process?

Hear

This phase is about understanding the problem and solution space, focusing on discovering insights and broader context. It involves the collection of information from various sources, such as literature, focus group data, and contextual mapping. Through this process, this phase identifies the specific challenges and needs that define the problem, creating a base for developing solutions that address the needs of families of patients recovering from MI or OHS.

*First, **why** personalization is needed and how personalization could be implemented will be addressed by exploring the problem from the patient's and family member's perspective. Secondly, family members' experiences will be analyzed to understand **what**, **where**, & **when** support is needed. Thirdly, the structure of the Family Box will be discussed to understand in what structure personalization can be implemented. Lastly, frameworks for personalization will be discussed to determine how personalization can be designed to make it a strategy.*



1.1 Problem

In order to design effective support for family members of MI & OHS patients, the problem is explored through various aspects. First, the human needs are explored through both the patient's and family member's perspective. In addition, challenges during the care journey will be identified. Secondly, the value of current support together with potential ways of support is explored within the healthcare system. Finally, based on these insights, the problem statement is refined by structuring the findings into fundamental problems and opportunities, and their expected effects, connecting them to the overall goal of the project.

Literature

Patient's perspective

To understand **why** support for family is needed, the patient's side of the context is explored. First, CR is discussed to understand the context of MI and OHS patients and what activities they do as part of their recovery. Secondly, patient-centered care is discussed to understand what the role of the patient is in the current care system.

Cardiac rehabilitation

There is no single cause of CVD, but multiple things can increase the risk of getting it. These are called risk factors and are separated into non-modifiable and modifiable risk factors (see Figure 5).

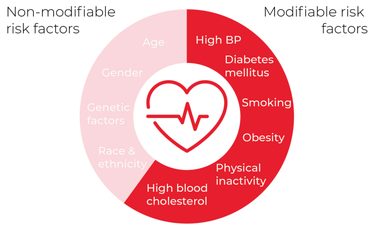


Figure 5: Risk factors CVD (NHS, 2024).

After a few weeks at home, CR starts at Basalt, the rehabilitation partner of LUMC. This CR program lasts 2-3 months, depending on the situation and development of the patient (Basalt, n.d.). During CR, patients receive exercise counseling, stress counseling, and education on living with a healthy heart (Dalal et al., 2015). As patients spend the majority of their CR period at home, most lifestyle changes must be implemented without direct supervision of healthcare professionals. Patients are expected to apply this knowledge and understanding at home when they buy groceries, plan their days, or are cooking their meals. These CR activities have a positive impact on patient outcomes, like improved heart rate recovery, reduced depression, decreased BMI, and enhanced quality of life (Fleg et al., 2013; Heran et al., 2011). Despite the clear benefits, adherence to CVD health management is globally low (Kotseva et al., 2019). To illustrate, in the Netherlands, under 40% of CVD patients participate in CR programs (Harteraad, 2019).

CR sessions are usually held with the patient only, meaning that it is then up to the patient to understand and communicate knowledge further within the family. However, sometimes information is shared during a session that triggers a reaction leading to information being missed or misunderstood (Lown et al., 2009). At home, this can result in the patient not being able to recall information or doubting if they heard or understood correctly what was shared. However, after completing CR, the process does not end as patients should maintain lifestyle changes to manage the risk factors described earlier. This is proven to be difficult, as within two years after discharge, most effects of CR are lost (Janssen et al., 2013).

Patient-centered care

This concept of care aims to provide care that takes into account the patient's preferences, needs, and values (O'Hare, 2018). This is a shift from traditional care that focused on the treatment of diseases and organ systems. PCC sees patients as active participants in the care journey and takes the patient along in the decision-making process. The effects of PCC show an increase in patient satisfaction, empowerment, and treatment adherence (Grover et al., 2021).

However, the adoption of PCC practices has its challenges. First of all, considering the context of the patient means taking more time, which is difficult with the limited time available during medical visits (Boggiano et al., 2017; O'Hare, 2018). Secondly, during conversations, disagreements are exposed, for example, on willingness to change behavior, which is difficult to discuss but worthwhile at the same time (Boggiano et al., 2017).

Family member's perspective

To understand **why** support should and **how** support could be offered to a family member, the family member's side is explored. Therefore, it is important to explore their needs, types, and involvement in the care journey.

Family dynamics

Families can fall into different categories, with family members being the partner living together with the patient, a child caring remotely for his mother that lives alone, or a sister living together with her brother. All scenarios have their own needs, challenges, and involvement of family (Houwen et al., 2024). Depending on the scenario, family members need to take up new household roles, monitor the patient remotely, or communicate on behalf of the patient with the hospital (Bhat et al., 2023; Whitehead et al., 2017) (see Figure 6). Moreover, while doing a variety of tasks, they have to maintain the original relationship with the patient aside from the caregiver dynamic (Kim et al., 2020; Whitehead et al., 2017). This balance shows the double side of caregiving. How these roles and needs change over time will be explored in **1.2 Family experiences**.

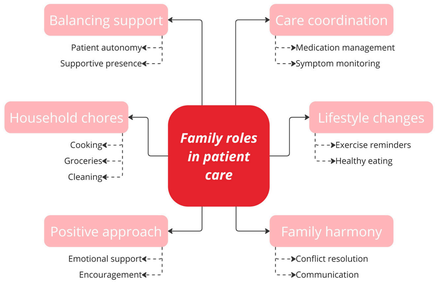


Figure 6: Various family roles in patient care (Bhat et al., 2023; Kärner et al., 2004; Whitehead et al., 2017).

Young et al. (2020) identified four factors that explain why experiences and challenges can vary across family members: caregiving context, caregiving characteristics, the person receiving care, and the caregiver (see Figure 7). These four factors demonstrate the complexity of profiling a family member providing care.

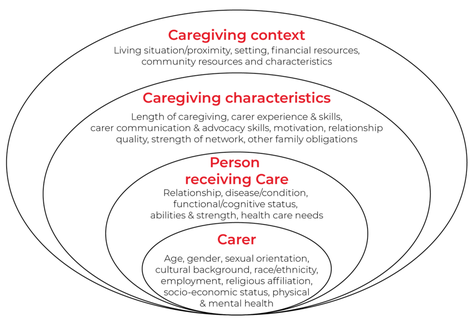


Figure 7: Heterogeneity of caregivers (Young et al., 2020).

The diverse combinations of tasks and profiles of family members illustrate how unique experiences can be and why one-size-fits-all support will most likely be ineffective.

To address the heterogeneity of family members, personalized support is needed (Deek et al., 2016; NASEM, 2016; Young et al., 2020), and multiple studies show proof that personalization can be effective in healthcare (Kocaballi et al., 2019)

Family involvement in CR

Family members are overlooked in the current care system (Gilliss, 1991; LUMC, 2024). During the care journey, family members can experience stress from balancing the responsibility of care over the patient and managing daily tasks (Fleury & Moore, 1999; Tuomisto et al., 2018). This impacts their health, which further impacts their ability to care (UNICEF, 2020).

Furthermore, the presence of family members and support in CR has also been identified as important and having positive effects on coping and relationships between family and patient (Kärner et al., 2004; Whitehead et al., 2017). As noted before, family members are usually not present at the sessions, possibly resulting in lost information that could help both them and the patient in the care journey.

Combining these two effects of low family involvement presents an opportunity to further involve the family while also addressing needs that are currently left unattended. To increase the chance of family involvement and lifestyle adherence, personalized support can be offered.

Healthcare system

To understand **how** support could be offered, different aspects of the healthcare system are explored. First, lifestyle is analyzed and the influences of behavioral science have on it. Second, the value of current solutions is discussed, followed by exploring the potential of digital tools. Finally, artificial intelligence's potential and limitations are discussed.

Focus on lifestyle

In 2022, the Integraal Zorgakkoord (IZA) was made, focusing on health instead of disease (Rijksoverheid, 2024). The direction of the Box to focus on lifestyle fits with the focus on healthy living and, in the future, on prevention. The focus makes sense since around 80% of CVDs are the result of an unhealthy lifestyle (LUMC, 2024), and lifestyle changes have shown to be difficult to maintain (Houwen et al., 2024; Murray et al., 2013; Robson et al., 2022).

The 'Leefstijlroer' (see Figure 8) has been designed to support the conversation between medical professionals and patients (Vereniging Arts en Leefstijl, n.d.), but also serves as a strong foundation for the next iteration of the Box and Family Box. Aside from that, through personalization, the care will also be adapted to fit the situation of both families and patients, linking to another goal of the IZA.

Figure 8: Leefstijlroer (Vereniging Arts en Leefstijl, n.d.).

The Box

The Box is an e-health solution from LUMC and active in the Netherlands. Patients receive the Box at discharge from the hospital and go home with it. Inside the Box are various monitoring devices, as shown in Figure 9. Patients are instructed on how many times to take measurements (varying from everyday to once a week) so that both LUMC and the patient can monitor their health (Jacobs, 2016).

By varying the contents of the Box, it is adapted to multiple care paths. Hence, the Family Box should have modular capabilities to match this adaptability.

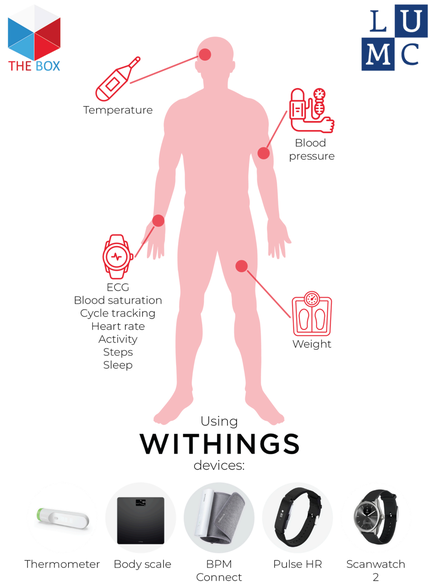


Figure 9: Contents of the Box.

Digital health solutions

Digital solutions are showing potential in increasing the reach of cardiac rehabilitation beyond traditional in-person sessions (Beatty et al., 2023). The use of digital technologies can bring clinical care right into the homes of families by offering remote access to resources, education, and monitoring tools.

For example, Corrie Health is a digital platform that combines an app, smartwatch, and blood pressure monitor (Marvel et al., 2021). As these components are similar to the current Box setup, this example is discussed to estimate the feasibility of how the Family Box can support. In the app, participants of the study from Marvel et al. (2021) could:

- Manage medications,
- Monitor vitals,
- Learn about risk factors for CVD and lifestyle modification through educational articles
- Schedule and track follow-up appointments
- Connect with their care team
- Store health information

A platform like Corrie shows that the use of digital health interventions around health management is feasible. It could also be effective for patient activation and lowering 30-day readmissions (Marvel et al., 2021). Aside from current feasible solutions, the American Heart Association has identified multiple future directions with digital technology in CR (see Figure 10).

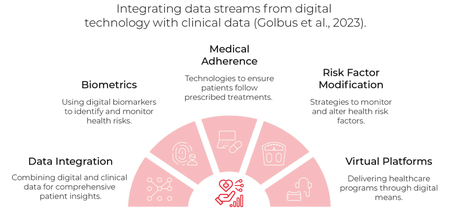


Figure 10: Future directions for digital health solutions (Golbus et al., 2023).

With the currently available technologies for digital monitoring and their capabilities, there is a lot of potential for digital health solutions.

AI in design & healthcare

In the past years, generative AI (GenAI) has quickly expanded its possibilities in various sectors, including healthcare. It offers opportunities for personalizing healthcare. GenAI tools can simulate realistic user interactions and adjust responses based on user input, making testing of functionalities easy in the early design phase. However, there are still challenges that must be addressed to responsibly and effectively implement GenAI in healthcare solutions.

In the context of this project, AI can be integrated in multiple ways, like an AI-powered conversational agent (CA) to handle one-on-one conversations with families of patients. Research has shown that AI-based CAs can enhance trust and therapeutic alliance to stimulate adherence (Anisha et al., 2024). In this study, they identify uses & benefits for AI-based CAs and challenges & limitations (see Figure 11). Other capabilities of current AI models include text generation and image analysis, which could add value to educational, monitoring, or other elements of the Family Box.

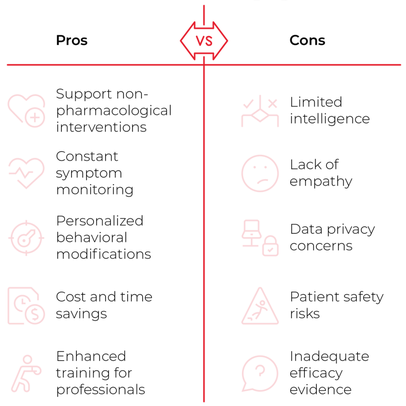


Figure 11: CAs in managing NCDs (Anisha et al., 2024).

Despite the potential, implementing AI in healthcare comes with big ethical, functional, and technical challenges. PWC (2023) has identified four broad risks for all organizations in regards to the use of AI: data risks, model and bias risks, prompt or input risks, and user risks (see Figure 12).

Figure 12: Risks for the use of AI (PWC, 2023).

In addition to those four risks, Roemmich et al. studied Emotion AI, a part of GenAI that adapts to users emotional cues. In their study, they emphasize how Emotion AI often fails to handle the nuance of situations in mental health care and potentially worsens the outcomes of users (Roemmich et al., 2024). Therefore, it is important to keep this and the earlier mentioned risks in mind and take a cautious approach in designing with AI.

The insights gained from the literature research are used in the next section to draw conclusions and develop a better understanding of the problem and how opportunities can connect to this project's goal.

Problem analysis

Based on the literature research, this section will draw conclusions to identify the fundamental problems and opportunities of this project. First, it will discuss the fundamental issues that shape the context, supported by their underlying problems. Secondly, opportunities are discussed, along with their expected effects. Thirdly, it explains how these effects can contribute to the project's goal of improving the health and well-being of family members and patients. Finally, the opportunities and expected effects are used to further develop the problem statement.

These steps are again taken in consideration of the patient's and family member's perspectives, which are then combined in the opportunities sub-section. Below is the given problem statement. After the problem is analyzed, a new problem statement will be formed to guide the next activities of the project.

How can we provide personalized support to families of patients recovering from MI or OHS, using interventions that address the unique challenges families face during the recovery process?

Fundamental problems

By analyzing the fundamental problems and their underlying issues, an understanding is developed for **why** support should be offered to family members.

Patients

The fundamental problem from the patient's perspective is the globally low adherence to the CVD health management process (Kotseva et al., 2019). It is shown in the participation rate for CR programs in the Netherlands, which is under 40% (Harteraad, 2019). In addition, lifestyle changes are difficult to maintain (Murray et al., 2013; Robson et al., 2022; Houwen et al., 2024). With around 80% of CVDs being a result of an unhealthy lifestyle (LUMC, 2024).

Family members

For family members, the fundamental problem is that they are overlooked by the current care system (Gilliss, 1991; LUMC, 2024). Despite research showing that they struggle with their own health and well-being while caring for a loved one (Fleury & Moore, 1999). The health of a family member plays an important role in their ability to care (UNICEF, 2020). During the care journey, all family members have their own experiences and challenges, depending on the care path, family member, patient, and their interaction (Young et al., 2020).

These challenges can vary a lot, like maintaining harmony in the family, balancing support & autonomy, and adhering to treatment (Kim et al., 2020). The need to change in roles and adapt to different situations can be an emotional burden and stressful for family members (Kärner et al., 2004; Tuomisto et al., 2018; Whitehead et al., 2017).

Opportunities

By analyzing the opportunities of the current context and its future, it becomes clear **how** support could be offered to family members.

Patients

Using the patient's perspective, a couple of opportunities can be identified: the effectiveness of CR, the possibilities of digital tools, and the role of the Box. First of all, CR has clear positive effects on patient outcomes (Fleg et al., 2013; Heran et al., 2011). Secondly, the availability of digital tools can increase CR participation and access, thus improving patient outcomes (Beatty et al., 2023). Thirdly, the Box generates data on the patient that is used for remote patient monitoring (Jacobs, 2016).

Family members

From the family member's perspective, two opportunities present themselves. First, support can be offered to family members through digital tools to help with their challenges and meet their needs (Houwen et al., 2024; NASEM, 2016). Secondly, research states that personalization can be applied to increase the chance of effective family involvement and adherence to lifestyle changes (Deek et al., 2016; NASEM, 2016; Young et al., 2020). Furthermore, current care programs often lack a personalized approach for both families and patients. According to Kocaballi et al., multiple studies are showing proof that personalization in healthcare is effective (2019).

These digital and personalized approaches also create opportunities for modularity to improve scalability. By including modularity in the Family Box, it is possible to scale to other care paths beyond MI and OHS in the future. By offering personalized tools and resources, family members could become empowered, gaining confidence and competence in their caregiving responsibilities.

The Box generates data on the patients in the form of measurements showing the health of the patient. Therefore, LUMC knows at which times and at what frequency patients take measurements. This can be used to personalize interventions, and by leveraging the data points, it could allow for timely, personalized notifications and support resources for family members. This shift from reactive to proactive care could empower healthcare providers to address family needs proactively.

Interaction between family member & patient

The interaction shows interesting opportunities that can be leveraged to improve the health and well-being of both. Support from family can improve patient adherence to lifestyle changes, including dietary modifications, physical activity, self-esteem, and stress management (Kärner et al., 2004). As well as a positive impact on the CR outcome ofthe patient and their lifestyle change (LUMC, 2024; Whitehead et al., 2017).

By integrating family-focused elements, it is possible to aid family members with tools and knowledge to better support the patient and manage their own health & wellbeing. Such integration could further empower family members by increasing their competence to care. Therefore, this is an opportunity by combining formal cardiac care and family involvement for structured family involvement that could stimulate positive behaviors to improve patients' health & wellbeing outcomes as well as support the family member.

Desired effects

First of all, adherence to lifestyle changes and prevention of readmission can be achieved by combining the data of the Box with the potential of digital tools. Secondly, family members can become empowered and effectively involved by personalizing and offering them support, which positively impacts the CR outcome and lifestyle change of the patient. By combining these effects, it is possible to achieve sustainable lifestyle change for both family members and patients. Therefore, improving the health & wellbeing of the family members and patients.

Conclusion

In conclusion, the challenges for family members of patients recovering from MI or OHS are diverse and often overlooked in the care journey from (pre)hospital to life at home. Despite families having a positive impact on patients' CR outcomes and lifestyle changes (Kärner et al., 2004; LUMC, 2024; Whitehead et al., 2017). However, due to a lack of involvement and personalized support, gaps in their ability to support are identified. Furthermore, with the rise of data and digital health solutions, possibilities for modular, scalable, and personalized interventions are in sight, but they are rarely aimed at family members. With a better understanding of the complex context, it is clear **why** personalized support should be offered.

However, the content & structure of **how** the support should be designed remain to be explored further. Therefore, the two opportunities concerning personalization and empowerment are included in the refined problem statement:

How can we provide personalized support to families of patients during the care journey of MI or OHS to empower family members in managing health and well-being individually and for the patient?

Impact on next steps

To address this problem statement, the next steps will include exploring **how** personalization and empowerment can be implemented by exploring their concepts and possible strategies.

Family Box: a modular opportunity for personalized support

The Box has a modular setup so that it can be used for various care paths. This flexibility enables the healthcare professional to adapt it to different patient needs. Thus, ensuring that the monitoring tools align with the treatment and recovery process of that patient. For family involvement, it is important to also include modularity to include elements that fit both the patient's situation and the role, and needs of the family member in the care journey.

As noted earlier, the Family Box will be introduced for the MI and OHS care paths, but later also to the pre-operation and other care paths. Therefore, it is important that the Family Box is structured in a way that is adaptable to different care paths. Accordingly, a structure consisting of consistent, personalized, and modular elements is needed.

- Defining and using **consistent** elements provides a basis that can evolve further but does not need changes per care path. Therefore, reducing the effort of scaling.
- Defining and using **personalized** elements allows the specification of elements based on the context or the user of the Family Box.
- Defining and using **modular** elements ensures that elements are specified for a care path. Resulting in support that is specific or needed in certain care paths. In this project, modular elements will be set up for the MI and OHS care paths.

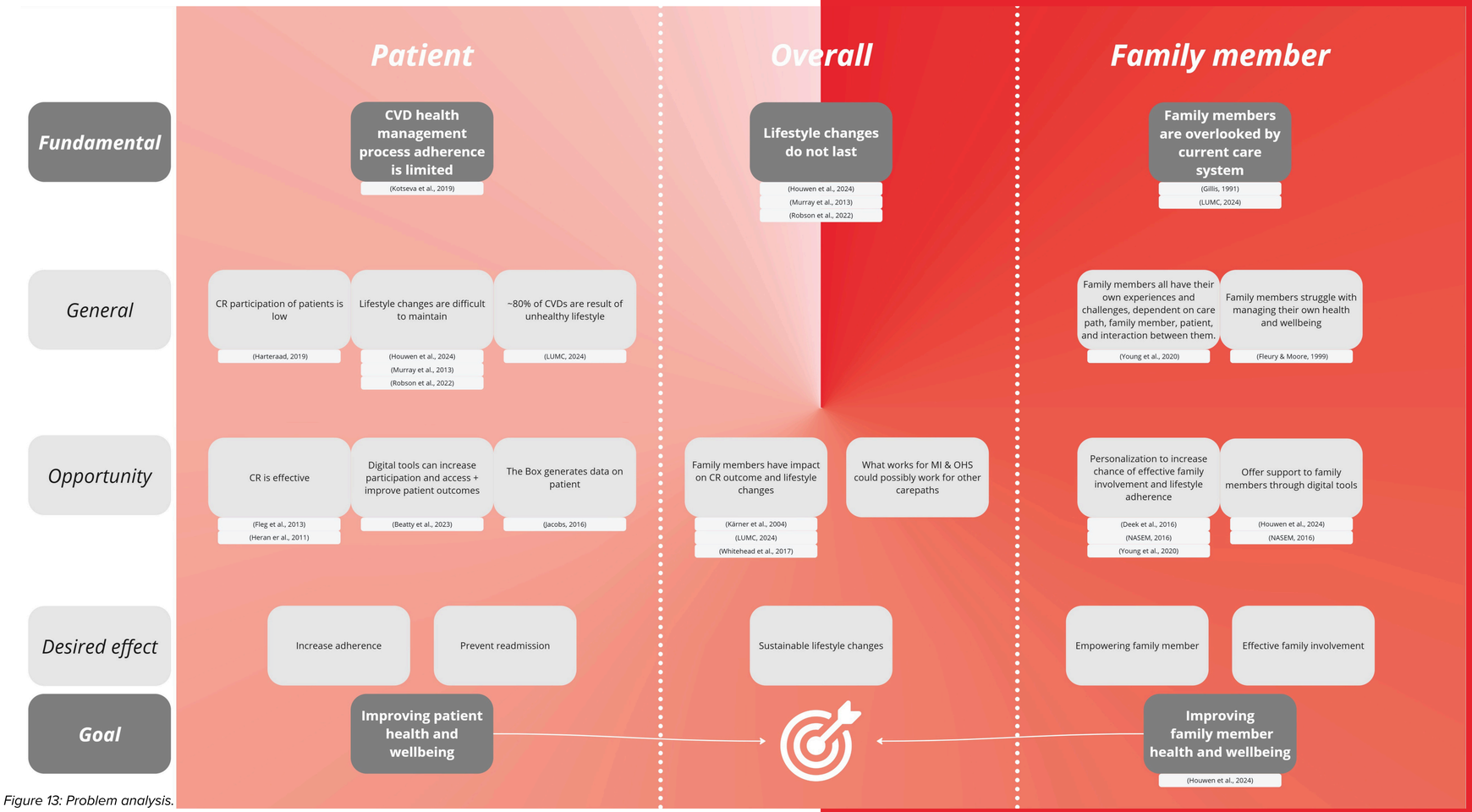


Figure 13: Problem analysis.

Refined problem statement

How can we provide personalized support to families of patients during the care journey of MI or OHS to empower family members in managing health and wellbeing individually and for the patient?

Personalization

Empowerment

1.2 Family experiences

*The previous section showed that family members play a crucial role in the care journey of MI and OHS patients but are not yet supported by the healthcare system. It is clear that the experiences, roles, and challenges of family members are very diverse. As a result, personalized support is a necessary approach to effectively meet their needs. However, while the need for personalization has been established, it is still unclear **when**, **where**, and **what** kind of support is needed for family members during the different phases of the care journey.*

To address this, this section will explore family member experiences elaborately through the contextmapping method (Sanders & Stappers, 2012). This process will provide insights into the real experiences of family members, uncovering their challenges, emotions, and behaviors over time. By understanding how their needs evolve, this section will lay the foundation for designing meaningful and relevant support strategies for the Family Box.

By exploring real experiences, this section will ensure that the designed support is grounded in the real needs of family members rather than assumptions. The findings will contribute to structuring personalized support and defining the personalization strategy, making sure that the Family Box fits with both the complexity and diversity of family member experiences.

Focus group data

A PhD candidate organized focus group sessions to gain insights into the needs, challenges, and experiences of cardiac patients and their family members who used the Box in the past. The goal of the sessions was to better understand the care and support during the care journey for both partners and patients of MI and OHS care paths, considering both the healthcare system's role and the interactions between partner and patient.

Reaching family caregivers of CVD patients can be challenging. However, the available transcripts of conversations with the target group can provide valuable insights for the project. Transcripts of the sessions with family members present were used to further understand the complexity of the various family experiences in their journeys at LUMC. At what time an experience/event took place had to be identified based on the transcript and topic of conversation. Identifying when an experience or event took place is important to develop an understanding of the evolving needs during the care journey. This will allow for more relevant support and enable the design of support that is aligned with the needs at different moments in the care journey.

Key moments and needs

To offer personalized support that empowers family members of patients, it is important to understand **when**, **what**, and **where** support is needed. Therefore, the focus group data is analyzed.

First, the focus group data was used to gain insights into themes and needs that arise over time in their journey of supporting the patient. The focus group participants consisted of patients and family members of OHS or MI cases. A session was held with four participants and the researcher, resulting in four transcripts containing the discussions with family members. Family member attendance differed per transcript, varying from one to four family members being present.

In total, the discussions of eleven family member participants were used for the next steps. Their relationships with the patient varied. Seven of them were the partner of the patient, two of them were a child of the patient, and two were a parent to the patient. Their ages varied from 20 to 85, with more participants being in the age groups above 45 (eight out of eleven).

These insights can be individual to the family member or about the interaction between patient and family. Data for these insights was extracted based on the following three questions:

1. What are the key moments in the care journey from a family member's perspective?
2. What needs can be identified over time?
3. What type of family members can be identified for personalization?

The first two questions aim at identifying the evolving struggles and opportunities that are experienced by family members throughout the care journey. This is important because the journey is comprised of different activities, which result in different needs being present at different stages of the care journey. By focusing on these changing needs, provided support will fit with the real context of the user.

Building on this, the third question will aim at personalizing the support based on unique family dynamics. Not all families support or interact with the patient the same. Recognizing these differences will help design more effective, personalized interventions. Personalization is important because it guarantees that the designed support is not just relevant to the stage of the care journey but also is aligned with the different ways in which families navigate the care journey.

The third question is used to lay a basis for personalizing the support and interventions to different family dynamics. Not all families support or interact with the patient in the same way. By identifying different types of family involvement, more effective and personalized solutions can be developed.

Together, the questions focus on **content** (struggles & opportunities) and **structure** (types of families) required to design a personalized and modular support system that adapts to the changing needs of family members over time. By presenting the results in a journey map, patterns in challenges and support needs at different stages of the care journey become visible. This helps identify **what** and **where** support is needed in combination with **when** it is needed, ensuring that the support is most relevant.

Contextmapping

The process of extracting data followed the contextmapping approach of Sanders & Stappers (2012). This user-centered design method helps develop a deeper understanding of the user experience by guiding the designer through structured reflection and interpretation. In this case, statement cards were used for interpretation and pattern finding in the qualitative data from the focus group sessions. The cards enabled the extraction of quotes, interpreting them, and categorizing them. By keeping the original quotes attached to the interpretations, this method ensures that user experiences, obvious or subtle, were made explicit. In this project, the selection was guided by the three questions stated earlier on the previous page. The process involved:

1. **Preliminary research:** Relevant literature was explored to better understand the topic.
   a. Challenges (Bhat et al., 2023; Fleury & Moore, 1999; Schulman-Green et al., 2020; Whitehead et al., 2017).
   b. Support (Jackson et al., 2015; Kärner et al., 2004; Tuomisto et al., 2018)
2. **Highlighting quotes:** Relevant statements were identified based on their connection to the research questions.
3. **Interpretation:** Each quote was interpreted to understand its deeper meaning in relation to caregiving experiences.
4. **Categorization:** Quotes were categorized based on their fit with emerging themes.

As a result, each card consists of a quote, an interpretation, and, if needed, a source to specify if it was said by a patient instead of family (see Figure 14). In total, 252 statement cards were extracted from the focus group data. These cards were used twice, once as input for theme identification to answer questions **1** & **2**, and once for identification of states, roles, feelings, and care styles to answer question **3** (see **2.1 Persona development**).

Theme identification

After sorting 252 cards, an overview of 43 themes was created. Both deductive and inductive reasoning were used to gain a well-rounded understanding of the family experiences. Deductively, analysis was done in relation to theories and frameworks from literature on family support in healthcare to categorize and interpret specific needs (see step 1 of the contextmapping process for specified literature). The literature is grouped in Challenges & Support, but cards were not grouped in one of these categories, as themes are more richly described when both are present.

Simultaneously, inductive reasoning was used by observing patterns and themes that emerged directly from the statement cards themselves, thus allowing new insights and unexpected needs to shape the understanding and development of themes. Themes varied in size from one statement card to twelve statement cards.

The themes were then used to create a journey map of the family over time. From the transcripts, it is not clear whether something is exactly two weeks or three months after discharge. Therefore, the journey is separated into phases, distinguishing four different phases at home (see Figure 15). The phases are not specified in specific timeframes to allow flexibility because phases will last longer or shorter for different families.

Considering the focus group sessions were held with MI and OHS family members and patients, a 'Before operation' phase was also created (shown by the dotted border in Figure 16); this phase is only relevant for the OHS care path since an MI patient enters the hospital in need of emergency care. From the phase "Operation / intake" and onward both care paths are relevant.

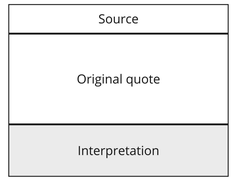


Figure 14: Statement card template.

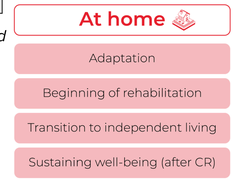


Figure 15: Four phases of care journey spent at home.

Care journey map

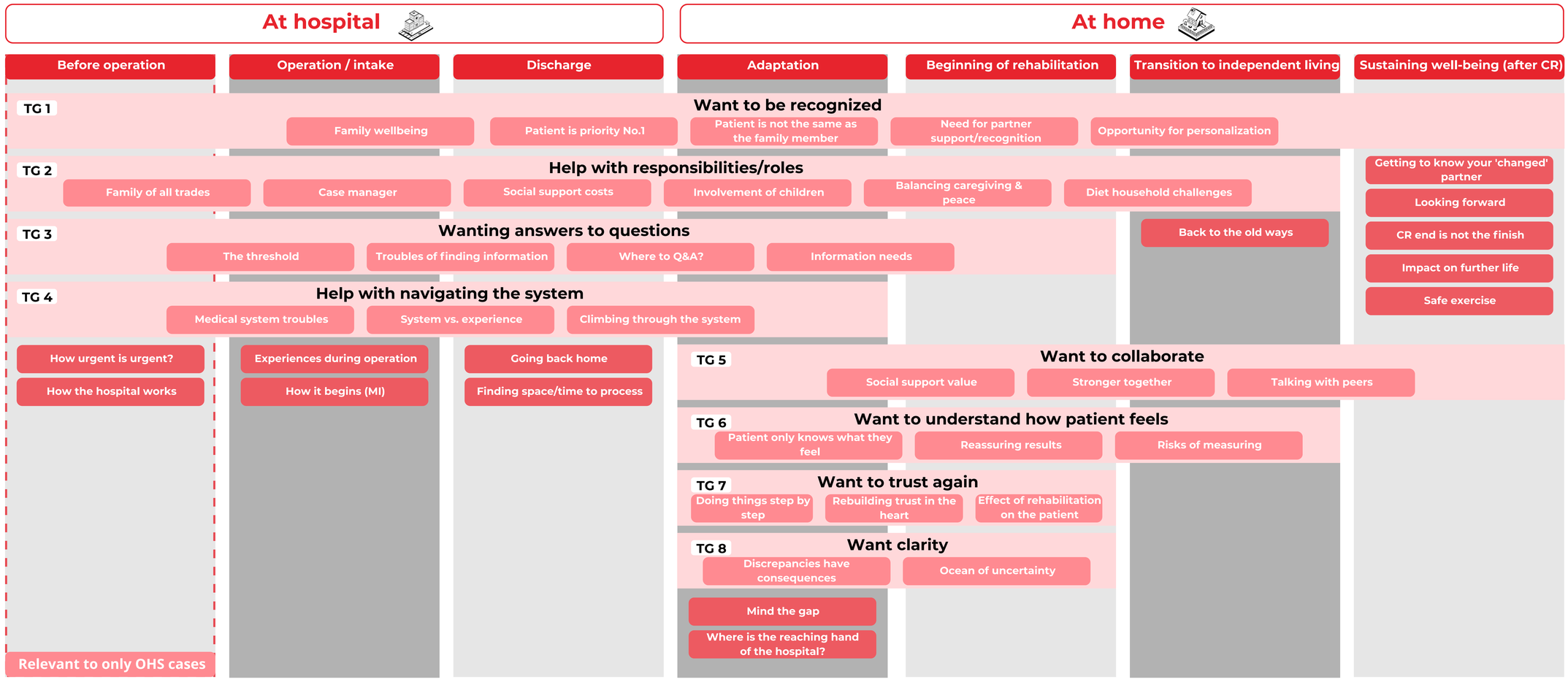


Figure 16: Care journey map.

In the journey map (see Figure 16), themes were first identified based on recurring patterns in the cards. Themes (dark pink rectangles) that shared similarities regarding needs were grouped to better show the overarching needs. These theme groups (TGs) (light pink rectangles) were then mapped onto the relevant phases of the care journey, ensuring that they aligned with specific moments where they were most relevant. Themes that are shown within TGs are present at the different phases that are covered by the TG (light pink rectangle). A legend for the journey map can be seen in Figure 17. All themes, including their statement cards, can be found in Appendix A.

Some themes were distinct and did not fit within TGs. These were placed individually within the right phase of the journey to ensure they remained correctly placed (soft red rectangles). This process led to a journey map that shows TGs and unique experiences across different phases of the care journey. Thus, showing **when**, **where**, and **what** support is needed, the following TGs emerged:

- **TG 1:** Want to be recognized
- **TG 2:** Help with responsibilities/roles
- **TG 3:** Wanting answers to questions
- **TG 4:** Help with navigating the system
- **TG 5:** Want to collaborate
- **TG 6:** Want to understand how patient feels
- **TG 7:** Want to trust again
- **TG 8:** Want clarity

All theme groups will be discussed and explained separately on the next page. Quotes from the focus group data will be shared to make them more tangible.

Figure 17: Legend of care journey map.

TG 1: Want to be recognized

Before operation | Operation / intake | Discharge | Adaptation | Beginning of rehabilitation | Transition to independent living | Sustaining well-being (after CR)

Grouped themes: *Family well-being, Patient is priority No. 1, Patient is not family and vice versa, Need for partner support/recognition, Opportunity for personalization.*

Family members shared that their well-being is under pressure as caring for someone has its limits, and they express having difficulty with doing their own things. Family members make the patient their number one priority. Just as the hospital is mainly focused on the patient, as a result, the family member is not taken into account. With the priority and focus on the patient, family members can experience feelings of loneliness and overwhelm in the care journey. Their experiences can differ completely from the patient's. In some cases, the family member is scared while the patient is not.

In this theme group, a clear opportunity for personalization is shown, with experiences regarding differences in diets, dealing with their emotions, getting standard advice from experts, or not liking activities personally. Overall, family members want to be recognized by both the hospital and the patient.

Relevant quotes:

- *Ik zeg allemaal leuk en aardig die tips, ik zeg maar ik ben er ook, hè.*
- *Maar hij is heel nuchter en ik ben heel emotioneel. Wat dat betreft zitten we helemaal niet op een lijn.*
- *Als er iets weg moet, dan meld je dat. Dat er echt alle rust bij hem is. Hij had toch al genoeg aan zichzelf. Dus dan neem je dat eigenlijk uit de handen.*
- *Anders is het jammer. Of ik mensen boos gemaakt heb. Je kiest toch even voor de gezondheid van de partner.*
- *En dus dat je je niet gewaardeerd voelt, zeg maar. Dat had ik dan wel eens. Zo van jezus, Je moet eens kijken wat ik allemaal voor je doe. Het gaat altijd om de patiënten, niet om de naasten.*

TG 2: Help with responsibilities/roles

Before operation | Operation / intake | Discharge | Adaptation | Beginning of rehabilitation | Transition to independent living

Grouped themes: *Family of all trades, Case manager, Social support costs, Involvement of children, Balancing caregiving & peace, Diet household challenges.*

While caring for someone with CVD, the caregiver takes on various roles like informing others, managing expectations, providing care, caring for young children, and cooking. At the same time, they can be juggling their regular responsibilities from work or personal life. They mention help and visits from friends and family being both helpful and energy-consuming, as it needs to be planned in regard to the rest of the patient.

While dealing with these various roles and responsibilities, one of the emphasized challenges is balancing caregiving and peace. For example, some family members explained having to deal with the stubbornness of the patient or preventing the patient from going over the limit on a good day with the result of the next day being a bad one. By balancing all these responsibilities and/or roles, family members often experience feelings of overwhelm, as if everything is happening at once.

Relevant quotes:

- *Je moet een soort expert worden in het zorgsysteem.*
- *Het nieuw uitvinden van de balans en rolverhouding. Van, hé, je, enerzijds wil je gewoon doorgaan met hoe het altijd was. Maar anders gaat het op bepaalde dingen niet meer.*
- *Je weet niet dat dat jouw rol is. Dat ontstaat een beetje. Zijn er mensen die gaan je bellen of die gaan je niet bellen die waren benieuwd.*
- *Ik hoor ook wel van mensen dat je echt een soort, een fulltime baan ernaast krijgt, om voor iemand anders te zorgen. Dat is dat best ingrijpend ook, kan het zijn. Maar ook voor je partnerrelaties samen.*
- *Hij weet dat hij het niet mag. Maar volgens mij doet ie het gewoon. Dat vond ik lastig, ja, dat vond ik ook. Daar krijg je je strijd om. Dat is het, je bent in staat om elkaar te helpen. Maar goed, je ziet ook dat ze dingen willen, want ze willen zich geen patiënt meer voelen.*

TG 3: Wanting answers to questions

Before operation | Operation / intake | Discharge | Adaptation | Beginning of rehabilitation

Grouped themes: *The threshold, Troubles of finding information, Where to Q&A?, Information needs.*

Caregiving for someone with CVD means having knowledge on many different aspects of a healthy life, from healthy foods to exercise. Family members feel it is their responsibility to the patient to be prepared with the right knowledge. However, family members express struggles with finding information from trusted sources or simply do not know where to find information. They can call the hospital, but they experience a threshold to call, as it is difficult to determine when it is urgent enough to reach out to the hospital. As a result, they doubt themselves and/or blame the system. Altogether, family members want to know where and how to find information at all times.

Relevant quotes:

- *Of ik heb gewoon een praktisch dingetje, ik zeg nou, ja, we lopen nu hier tegenaan, ik zie het nergens... Help me. Help me even.*
- *Je zit ook in een soort dilemma van ja, ik ga ook niet voor elke poep en een scheet bellen, want ja, ze hebben daar druk.*
- *Dus met een hoop dingen, of in ieder geval daar denk je op dat moment niet aan. Dan kom je thuis en denk je, oh ja. Aan wie gaan we dat eens vragen?*
- *Maar een telefoonnummer in staat dat je te bellen of kijk hier op de site of weet ik het wat. Ja, zo van kijk op de site, en als je het niet kan vinden, bel*

TG 4: Help with navigating the system

Before operation | Operation / intake | Discharge | Adaptation

Grouped themes: *Medical system troubles, System vs. experience, Climbing through the system.*

The medical system is complex and hard to understand from the family member's perspective. It is unclear to family members how systems and data are connected, and it contains repetitive steps, making the system feel inefficient.

A critical difference between the hospital and the family member is their perspective. For example, appointments at the hospital. In order to join an appointment, family members need to clear their schedule or make sure someone is with their child. In some cases, when they show up at the hospital, there is no appointment or it has been moved due to a sudden intake of a heart attack patient. For the hospital, this is daily business, as they plan appointments in advance but have to shift when more urgent cases (like a heart attack) show up. However, family members shift their schedules and responsibilities to make sure they can support the patient at the appointment. These experiences can result in a lot of frustration on the side of family members, while this is the way the healthcare system works, and it will most likely not change. By informing family members about possible events due to protocols like prioritizing cases based on urgency, more understanding can be created from the family member, resulting in less frustration and friction.

Relevant quotes:

- *Maar dat maakt dat je elke keer je verhaal opnieuw aan het vertellen. Of de situatie opnieuw aan het vertellen bent. Wat moet dat, moet. Maar dat kan effectiever.*
- *Want die krijg je ineens weer niet, omdat we ook niet goed in getikt is van... Nee, en dan denk je van, hey, maar die is bijna op. Dus daar raakt je soort van in de stress van.*
- *Ik had alles met werk geregeld, vind ik niet erg, doe ik, weet je wel. Voor ons kind moest oppas geregeld, je regelt van alles, hè. Dus dat is helemaal niet erg, dat doe je gewoon. Dan kom je daar, vervolgens meld je je en krijg je eigenlijk van: huh, afspraak?*
- *Je bundelt al je vragen. Daar regel je van alles. Helemaal niet erg, doe je gewoon. En dan wordt daar zo makkelijk mee omgegaan. Dan denk je, maar wacht even, weet je waar je hebben we het hier nou over. Dat voelt wel frustrerend*

TG 5: Want to collaborate

Adaptation | Beginning of rehabilitation | Transition to independent living | Sustaining well-being (after CR)

Grouped themes: *Social support value, Stronger together, Talking with peers.*

The value of social support is recognized in helping with everyday stuff or with giving the caring family member time to rest. Help from friends, family, and work is seen as a relief by the family member, lessening the burden of caregiving. Family members also explain that dealing with the journey together with the patient, by attending appointments together or exercising together, is very important to them. One reason is that otherwise they hardly do anything together, and the other reason is that they feel like getting healthy or being sick together. Talking about their experiences with peers, friends, colleagues, or professionals is also very valuable to them. While they share their experiences, they often realize they are not alone. With these three themes together, it becomes clear that most family members want to collaborate with others, whether they are friends or professionals.

Relevant quotes:

- *Iedereen zegt dat ik, oh ja, dat is wat voor je kan doen. Ja, dat moet je zeggen. Nou ja, ik zeg het ook. Ik zeg ook, ik ga ook serieus wat aan je vragen.*
- *Gewoon samen weer kijken om het plekje te geven. En weer verder te komen. Dus vooral een korte lijntje is nog met een ziekenhuis. Dat zou wel fijn zijn.*
- *...ook af en toe iets doen. Wat jij niet leuk vindt, maar je vrouw wel. Anders doe je samen niks meer.*
- *Zij let volgens mij ook wel meer op mij. Even wat meer nog dan, nog meer dan daarvoor. Dan heb je het gevoel dat je met zijn tweeën je beter wordt of ziek bent of... Dat vind ik wel fijn.*
- *Nou, dit... Dat je ervaringen deelt. Nu heb ik ook niet het gevoel. Je hoort het, alles komt er uit. Nu heb ik ook niet het gevoel dat wij alleen zijn.*

TG 6: Want to understand how the patient feels

Adaptation | Beginning of rehabilitation | Transition to independent living

Grouped themes: *Patient only knows what they feel, Reassuring results, Risks of measuring.*

The patient feels how their body reacts to everything and can estimate how the recovery and journey are going. The family, however, cannot, but they want to know what the patient feels so that they can anticipate or help when needed. The Box plays a big role in this because they can see it objectively in the taken measurements, and this might reassure the family members. The feeling of being monitored also gives them a certain reassurance, with no news being equal to good news. However, the trackers also have the risk of triggering over-monitoring/over-protective behavior from the patient or the family member, as some quotes describe. Overall, the Box can provide an objective view of the patient's wellbeing, which can have a reassuring effect, but with the risk of overmonitoring or overprotective behavior.

Relevant quotes:

- *Maar daar wil je toch ook een beetje meer bij betrokken zijn, voorbereiden... ...weten wat er gebeurt, weten wat ze nog gaan doen.*
- *Gaf ons wel alle vertrouwen, die Box. Gewoon die waardes ziet. Maar ook dat je kon zien of het goed is of niet. Maar ook het idee dat je gemonitord werd.*
- *Ja, het kan aan de ene kant geruststelling zijn. Maar aan de andere kant kan het ook weer stress geven. Het gaat twee kanten op dus vooral heel veel praktische en informatieve ziekbehoeftes,*
- *Maar voor hen, dat realiseer ik me nu zo, natuurlijk de houdvast van, hey, gaat het goed met hem? Zitten we op de goede weg? Gebeuren er geen gekke dingen, zie ik dan voldoende, he? Dus het is wel graag dat de partners vaak... En nog meer mee bezig zijn met de controle. Ja, Wij voelen dat ook niet (hoe het gaat)*

TG 7: Want to trust again

Adaptation | Beginning of rehabilitation

Grouped themes: *Doing things step by step, Rebuilding trust in the heart, Effect of rehabilitation on the patient.*

During the care journey, both patient and family need to rediscover where the limits are of the patient's body. Changing to salt-less cooking can be a quick change, but other changes, such as increasing physical load, require the family member to rebuild trust in the body of the patient to complete the physical therapy. Due to such changes, family members often find it difficult to leave the patient alone and are continuously monitoring the patient when separated. Nevertheless, family members have to rebuild confidence in the body's capabilities to live independently again. There were no trust issues shared regarding adherence to lifestyle changes.

Relevant quotes:

- *Hij ging het ook wel heel snel de afstand groter maken. Maar hij was helemaal niet bang. Ik wel. Ja, die angst zit er goed in.*
- *Maar dat went ook heel snel. Geen zout eten, ja daar merk je niet zo veel vaak. In het begin is het even van... Nee, er zijn heleboel dingen wat je standaard doet zou maar zeggen. Ik maak het zo met anderen, ik doe er andere kruiden op.*
- *Ik app je steeds tussendoor. Zodat we dan een nummer afgelopen waren van, gaat het? En dan krijgen we een duimpje terug. De hele tijd. En je gaat gestrest weg. Ja, dat is allemaal een spanning voor de naaste.*

TG 8: Want clarity

Adaptation | Beginning of rehabilitation

Grouped themes: *Discrepancies have consequences, Ocean of uncertainty.*

Family members sometimes hear different stories or instructions when interacting with hospital staff (doctors or nurses), local healthcare providers (GP) and others (e.g. neighbourhood nurse). These discrepancies lead to a lot of doubt in received instructions, as family members no longer know what is true and what is not. As a result, family members have to deal with a lot of uncertainty, which they have to learn how to deal with in their own opinion. Essentially, they want to check things, but do not know how to verify information to be reliable.

Relevant quotes:

- *En dan kreeg ze de wijkverpleegkundige die kwam, een verpleegkundige uit het ziekenhuis die belde, en een arts die belde. En alle drie hadden ze weer wat anders. Wie moet je geloven?*
- *Kijk, sommige dingen kom je zelf ook wel uit. Dus het is niet zo dat je helemaal hopeloos bent. Maar ja, als je zeker in het begin is, is er een hele hoop, dat je denkt, ja. Wat moet je mee? Ja, dat voelt gewoon heel spannend.*
- *Maar wat je zegt aan het begin. Je valt in zo diep gat dat je denkt van, ja, waar doe je goed aan? Inderdaad, mag die alles wel weer? Want je stent moet zich natuurlijk echt zetten, zeg maar. Ja, je staat een beetje in het luchtledige, zeg maar. Doe maar wat we denken dat goed is. Hoop dingen weet je niet.*

User research

To ensure that the Family Box addresses the actual needs of family members, it is important to understand how they experience the care journey and what kind of support would be most relevant to them. While the focus group data provided insights into challenges by family caregivers, this study aims to elaborate on those insights by gathering direct data from family members with experience on specific aspects for the Family Box's design.

The goals of these activities were to:

1. Identify which challenges were perceived more difficult per experience
2. Explore preferences regarding information sharing

The first activity, builds upon the family experiences that were analyzed in the focus group data. Insights from this activity will inform the personalization strategy of the Family Box, as some challenges might be experienced as more difficult by family members while others might not. Therefore, helping inform which challenges to focus on to provide the most relevant and valuable support for family members.

The second activity builds upon **TG 6:** *Understanding how the patient feels*. In this TG, the importance of monitoring is emphasized from the perspective of the family member. The data from the measurements can have a reassuring effect, but also bring the risk of overmonitoring or overprotective behavior. To design balanced and personalized monitoring features, it is important to understand how family members prefer to receive and interact with patient health data. Without knowing these preferences, there is a risk of providing inappropriate data, which could overwhelm or negatively influence family members' well-being.

Therefore, this activity helps answer the question: *"What preferences do family members have regarding the receiving of shared health data from the patient, and how do they vary across their experiences?"* Answering this question is essential because it provides insights into the preferences of family members in regards to the sharing of health data.

By gathering quantitative insights through a survey and qualitative data through interviews, this research aids in designing the Family Box so that it is both relevant to real-world needs and personalized to their preferences. These insights directly inform the understanding of needs and challenges that will aid the future feature design, data sharing, and personalization strategies. Therefore, helping to create a solution that empowers family members through personalized support.

A survey was sent out to understand which family caregiving needs are considered most challenging, allowing prioritization of these needs in the Family Box design. Understanding the differences in how challenging specific needs are helps understand if some needs are relevant to all family members, while other challenges might differ a lot across different family members. If the latter is the case, this could inform the personalization strategy for the Family Box. Additionally, the survey explored preferences about data sharing to ensure that the Family Box provides relevant and valuable health data, adapted to the preferences and expectations of family members. The survey can be found in Appendix B. It was filled in by both experienced family members (with experience with caregiving for a patient recovering from MI and OHS) and by individuals imagining themselves in a caregiving role.

Interviews were also conducted with three experienced family members, covering the same topics as the survey. The interview guide for the interviews can be found in Appendix C. First, participants were asked about how they supported the patient during the care journey to recall their experience. Afterwards, they had to rate a range of challenges from not difficult to very difficult. This range of challenges was based on the identified challenges from the focus group data and challenges that were described in literature (NASEM, 2016; Young et al., 2020). Using these questions, it was possible to identify which challenges were perceived as more or less difficult by a family member.

This section outlines the findings from user research that describe the difficulty of different challenges and their role in shaping the design of the Family Box. Insights on the perceived difficulty of challenges will aid in the design of the personalization strategy by understanding if challenges are consistent or varied across different family members. Moreover, if challenges are ranked not difficult consistently, they can be seen as adequately supported, thus not needing an emphasis in the design of the Family Box. However, the opposite will result in a needed emphasis on specific challenges.

Secondly, it will describe the preferences for data sharing. Family experiences from the focus group data showed that family members like to know certain data about the patient while preferring to not know other data. To build a better understanding of which data is preferred to have and not have available to them, they are asked to rate different types of data. Similar to the challenges, consistent preferences will help put emphasis on specific types of data, while variation in preferences will indicate personalization is needed in this aspect.

Participant demographics

Survey demographics

Variable	N	Percentage of sample
All participants	7	100
Gender		
Male	2	29
Female	5	71
Age		
25-34	2	29
35-44	1	14
45-54	1	14
55-64	2	29
65+	1	14
Education background		
HAVO, VWO, MBO2-4	2	29
Bachelor (HBO/WO)	3	43
Master (HBO/WO)	2	29
Relationship with patient		
Child of patient	4	57
Parent of patient	2	29
Not specified	1	14

Interview demographics

Variable	N	Percentage of sample
All participants	3	100
Gender		
Male	1	33
Female	2	67
Age		
Under 25	1	33
25-34	1	33
55-64	1	33
Education background		
HAVO, VWO, MBO2-4	1	33
Bachelor (HBO/WO)	1	33
Master (HBO/WO)	1	33
Relationship with patient		
Partner	2	67
Child of patient	1	33
Patient's heart disease		
MI	3	100

Difficulty of different needs

Survey

Participants were asked to rate different challenges on difficulty ranging from not difficult to very difficult (green to red in Figure 18). The challenges originate from the focus group data and literature (NASEM, 2016; Young et al., 2020), see Figure 19. They varied from emotional support to informing others to logistic support. The ratings were translated to scores from 1 to 5 to produce a ranking of the most difficult challenges, see Figure 20.

Challenges
C1: Internal emotions
C2: Emotional support
C3: Medical information
C4: Understanding medical system
C5: Understanding the disease
C6: Logistic support
C7: Financial responsibilities
C8: Balance of care and personal life
C9: Informing others

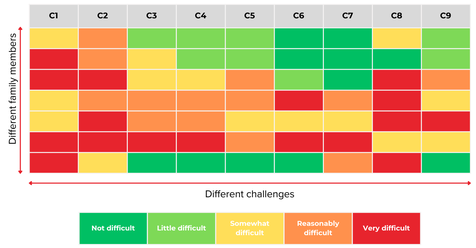


Figure 18: Challenges rated on difficulty.

Figure 18 shows rows of participants clearly indicating no experience is the same. Not a single challenge was rated the same by everyone, with multiple challenges showing all five possible scores. However, when looking at the average scores (see Figure 20), challenges related to emotions, both from the patient or the family member, are scored highly in comparison to other challenges. Balancing caregiving with personal life was also scored highly, with a score of 3.86 being close to reasonably difficult. Challenges regarding understanding and informing were ranked at the somewhat difficult score. While the financial and logistical aspects have the lowest

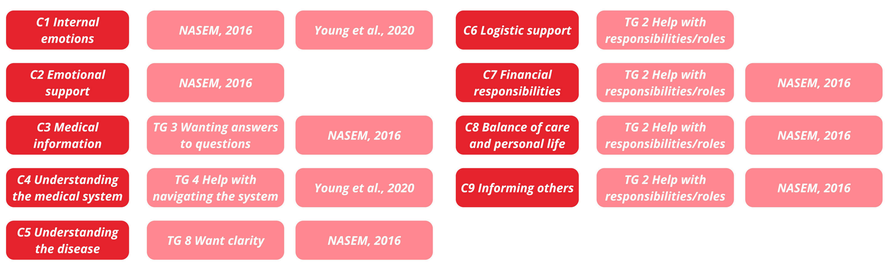


Figure 19: Challenges origin.

scores, indicating that most participants experienced less difficulty with them.

Ranking	Challenge	Score
1	Emotionally supporting the patient	4.29
2	Dealing with internal emotions	4.14
3	Balance with personal life	3.86
4	Understanding medical information	3.14
5	Understanding the medical system	3.0
6	Understanding the disease & Informing others	2.86
8	Financial aspects of care	2.71
9	Logistical support	2.57

Figure 20: Challenges, average scores.

As a result, emphasis can be placed on the development of support for emotional needs, followed by creating a better understanding of the medical system and disease. Finally, financial and logistical challenges could be less focused on at the beginning as they might appear less frequent.

Interviews

Interviews with family members also covered the challenges they experienced. During the conversation, various challenges were discussed, like physical challenges for both patient and family member, daily chores, and also emotional challenges like being scared or concerned. All interviewed family members had different challenges as their most difficult challenge. The challenges were also discussed across the different phases of the care journey to get a better understanding of how their experiences changed over time, see Figure 21.

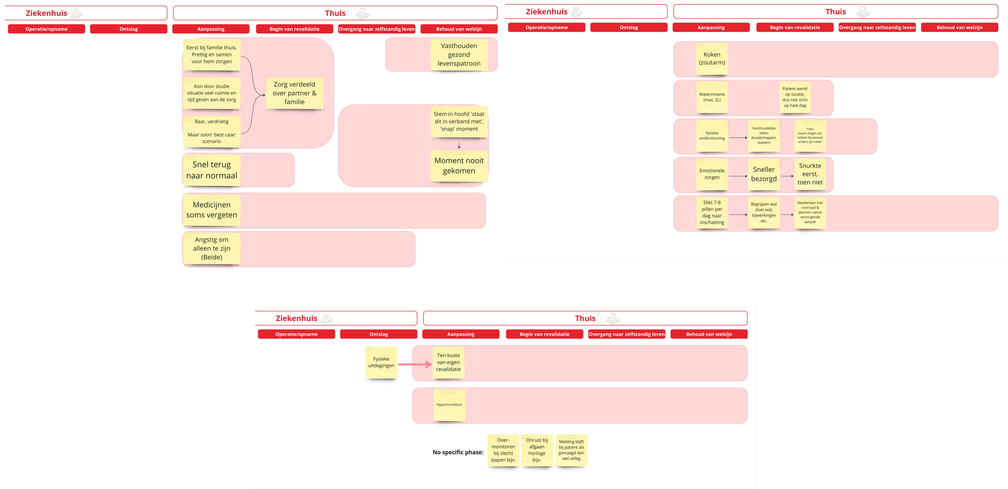


Figure 21: Interview themes across phases.

One had the most difficulty with balancing their own well-being combined with the care for their partner (**C8**: Balance of care and personal life), as this person was still rehabilitating as well. This participant also mentioned that the patient shows signs of hypochondriasis, meaning that the patient is worried about having a serious illness (**C5**: Understanding the disease). How to deal with this was not clear to them and also not explained by healthcare professionals (**C2**: Emotional support). Another participant found dealing with concern and responsibility the most difficult (**C1**: Internal emotions), as he was the child of the patient, and he felt responsible for the well-being of his parent. The third participant, mentioned having difficulty with understanding the patient's specific situation, phases, and milestones (**C5**: Understanding the disease). These were challenges that stayed throughout the phases, as they never found a clear cause why an MI happened.

Again, from the interviews, it appears that each family member has their own experience with their own unique challenges. Furthermore, emphasizing why a personalized approach is important and valuable to family members providing care to MI or OHS patients.

Shared information preferences

Survey

Participants of the survey were asked to rank a selection of ten physical data points. This selection of ten physical data points was made based on the data that the Box gathers on the patient and the data that is relevant in relation to the Leefstijlroer aspects, see Figure 22.

Figure 22: Physical datapoints origin.

The data points were ranked on a 5-point scale, with 1 being not important and 5 being very important (green to red in Figure 23). They were also given the option to select not applicable (shown in grey) if they found a data point not relevant to the patient or simply did not want to see information on it. Figure 24 shows the ranking of physical data points that family members would like to get the data from or not. The data points varied from heart rate to stress level. Most important were blood pressure (3.71), physical movement (3.29), and stress level (3.14). Considered least important were food log (2.43), smoking (1.86), and alcohol (1.71).

Preferences
P1: Heart rate
P2: Blood pressure
P3: Steps
P4: Weight
P5: Food log
P6: Movement
P7: Smoking
P8: Alcohol
P9: Sleep quality
P10: Stress

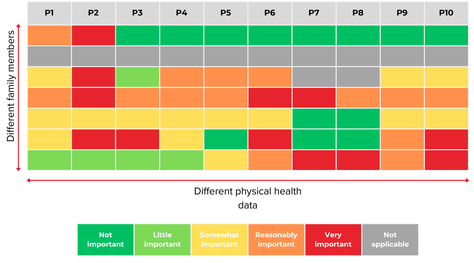


Figure 23: Preferences rated on importance.

Ranking	Physical data point	Average score
1	Blood pressure	3.71
2	Physical movement	3.29
3	Stress level	3.14
4	Heart rate & Sleep quality	2.86
6	Steps & Weight	2.57
8	Food logs	2.43
9	Smoking	1.86
10	Alcohol	1.71

Figure 24: Preferences average scores.

The same ratings were filled in for datapoints that were less objective and more in relation to the care journey of the patient, for example, progress in rehabilitation and mediation updates (see Figure 25). These six data points were selected because they reflect aspects identified as relevant in the family caregiving journey (e.g., the emotional side and understanding disease progression). Interestingly, these almost all scored higher than any physical data point, with blood pressure being the exception (see Figure 26). Most important were emotional state (4.57) and progression in rehabilitation (4.29). The least important of these data points was self-set goals (3.29), but still higher than most physical data points.

Preferences health information
PH1: Medical information updates
PH2: Progression in CR
PH3: Lifestyle recommendations
PH4: Future appointments
PH5: Emotional state
PH6: Self-set goals

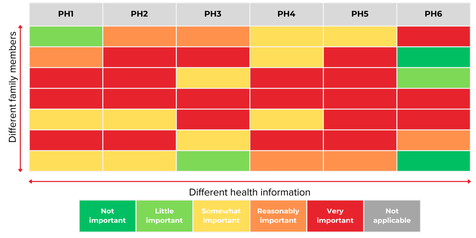


Figure 25: Preferences for health information rated on importance.

Ranking	Broader health datapoint	Score
1	Emotional state	4.57
2	Progress in rehabilitation	4.29
3	Appointments + procedures	4.0
4	Medication updates & Lifestyle + recommendations	3.86
6	Self-set goals	3.29

Figure 26: Preferences for health information average scores.

From the results, it becomes clear that the overall preferences for shared data show stronger preferences for data points that are in relation to the care journey of the patient rather than objective data points. One participant even preferred not to get any physical data and only receive the care journey-related data.

Interviews

Shared data preferences among the interviewed family members also showed varying preferences, with some wanting all physical data while another wanted just a few, as these felt controlling. Two of them also mentioned that they wanted a lot of information in the beginning but would prefer to have less data when more time has passed.

Insights from Focus group data & User research

Findings from the focus group data and the user research were translated to a list of insights, followed by their relevance to the need for personalization.

Findings from the focus group data and the user research were translated to a list of insights, followed by their relevance to the need for personalization.

- **General needs (TG 1 & User research):** These concern the basic needs of family support, including the need for proactive support from the hospital and personalized care solutions. Families are looking for a relationship with the hospital where they feel supported and included.
- **Information (TG 3 + 4 + 8 & User research):** Information is essential for families to feel confident and capable in their support roles. This includes access to FAQs, clear & aligned instructions, and guidance on safe exercise. The need for information is strong in the beginning of the care journey and decreases over time as they slowly become experts in caregiving. For example, a clear understanding of hospital procedures and expectations helps families better navigate the healthcare system. However, information needs vary strongly for different family members.
- **Multiple responsibilities (TG 2 + 5 & User research)**: Families of recovering patients often deal with multiple responsibilities, including managing appointments and tracking instructions (see Figure 27). This topic emphasizes the need for tools that help families organize these tasks, along with support for managing social and household responsibilities during the journey. Balancing these responsibilities with daily life is a big burden on the family member.

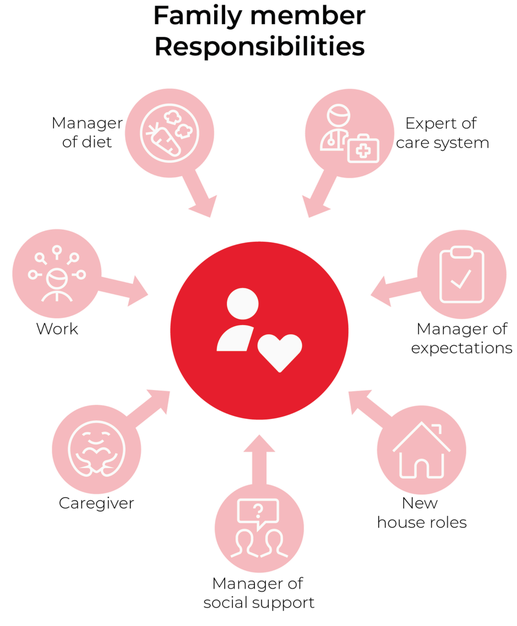


Figure 27: Multiple responsibilities of family members.

- **Emotional needs (TG 1 + 7 & User research):** Emotional support is very important for families as they cope with the stress and emotional burden of caregiving. Providing emotional support resources can help families process their experiences, reduce feelings of overwhelm, and support their mental health.
- **Interaction family & patient (TG 5 + 6 & User research):** Family support relies on the quality of interaction between patient and family members. Families need insights into the patient's recovery progress to adjust their support as needed and build trust in the patient's recovery capabilities, helping them regain confidence in their health and body.

Relevance of themes

From the focus group data and user research, the need for personalization is clear. These insights highlight the diverse experiences, roles, problems, and needs of family members, emphasizing that a one-size-fits-all solution will not be sufficient. Key insights that argue why personalization is needed include:

- **TG 1:** Want to be recognized
  - Family members feel overlooked and a focus on the patient
  - Differences in individual preferences, such as diets and activities.
  - Family members want acknowledgement of their contributions to the patient's care journey
- **TG 2:** Help with responsibilities/roles
  - Family members take on various roles, depending on the family dynamics
  - Individual circumstances and the different dynamics between family and patient
- **TG 6:** Want to understand how the patient feels
  - Objective insights can address different family needs
  - Need to personalized to avoid over-monitoring or anxiety
- **User research:**
  - Every family member experiences caregiving differently
  - No single challenge is universally the most difficult

Supporting a loved one in their care journey of CVD can bring various challenges, emphasizing the need for personalization in family support. Family members are frequently overlooked and express a need to be recognized not only for their contributions but also for the challenges and needs of their situation. The struggle of juggling different roles, personal and professional, and understanding the patient's needs highlights the need for solutions fit to their specific situations.

For example, family members need practical tools to take care of things and process their experiences. The range of individual preferences, such as diets or preferred activities, are examples of why a general solution will not be optimal. With tools like the Box providing objective insights into patient health, which can be reassuring, it also introduces the risk of overmonitoring for some.

With a personalized solution that addresses the different needs, it is possible to create a system that empowers families. This would not only improve patient-family interactions but also improve the caregiving experience by making families feel recognized, capable, and supported during the care journey. Thus, personalization is not a preference but an essential component for effective support for families.

1.3 Platform structure

*The findings of the family experiences show that family members encounter different challenges, perceive challenges differently in terms of difficulty, and vary in preferences for shared health data. Thus, highlighting the need for a structured way to present and access information and support. With these findings in mind, it is important to understand **how** the current platform (LUMC Care) and future platform (Health Box) can inform the development of the Family Box. By analyzing their structures and functionalities, aspects can be selected or adjusted for the Family Box.*

LUMC Care

This is currently available to patients that use The Box and is designed to help patients monitor their health from home while reducing the workload for healthcare professionals. The app allows patients to take their own measurements, such as blood pressure, oxygen levels, and weight, using digital devices provided by The Box. The data is recorded in the electronic patient file, removing the need for manual entry by healthcare professionals. Through this platform, patients become more independent, and doctors can monitor the patient's condition remotely (Innovatic, n.d.).

Structure & functionality

The current version of the patient platform has an onboarding component, shows measurements, shows how to do measurements, and allows the patient to choose a focus based on the 'LeefstijlroerI' (Vereniging Arts en Leefstijl, n.d.). The 'LeefstijlroerI' is a tool that helps healthcare professionals discuss lifestyle changes for a healthy lifestyle. It is based on a rudder to illustrate the patient being in charge of the changes. Those features give a good foundation, but that is where the functionality ends. However, the look and feel of the platform is preferred to be used in the Family Box as well.

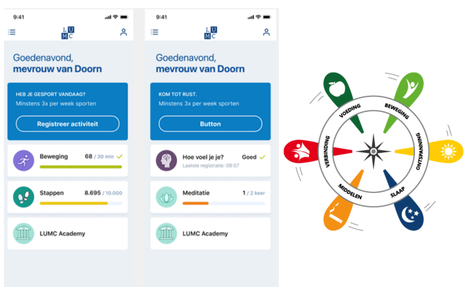


Figure 28: LUMC Care app & Leefstijlroer.

Health Box

This platform is still in development in a collaboration between LUMC and Ancora Health. The Health Box will introduce new features to the patient. It is designed to improve remote healthcare and introduce personalized support for the patient. As a result, it will provide patients with structured health tracking, personalized care plans, and proactive interventions from home.

Structure & functionality

Expanding on the current features of the LUMC Care platform, it will combine lifestyle coaching, goal-setting, and interactive health tools. By doing this, patients can take a more active role in their health management, while healthcare professionals can still monitor progress and intervene when needed from a distance. The integration of telemedicine will also allow patients to connect with specialists remotely, thus reducing the threshold to contact expert care. A couple of the developed features include a diary, chatting with a lifestyle coach, setting goals, and interacting with recommended elements. These features are very valuable to support the patient and can also be valuable to a family member.

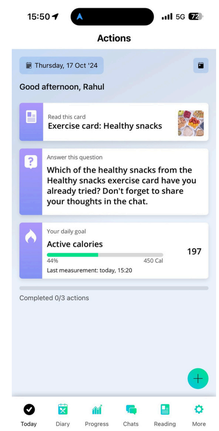


Figure 29: Health Box app & features.

Combining strengths

The structure of the Family Box is designed by combining elements from LUMC Care, the 'Leefstijlroer,' and the Health Box. These decisions are based on the needs and preferences of family members identified in **1.2 Family experiences**.

Why use the look and feel of LUMC Care?

The LUMC Care platform is currently in use for patient monitoring and has been developed to align with the needs of individuals with different levels of education and health skills (Innovatic, n.d.). By adopting a similar look and feel, the Family Box ensures a consistent experience for family members that may already be familiar with LUMC Care. This can also improve trust, as the platform keeps the professional and recognizable identity associated with LUMC.

Why use the 'Leefstijlroer' to structure health aspects?

The 'Leefstijlroer' provides a structured approach to lifestyle and health management by covering key aspects such as nutrition, movement, relaxation, sleep, substances, and connection. Through this model, a structure is created balancing the health and well-being of both patients and family members within the Family Box.

Why integrate functionalities of the Health Box?

The Health Box offers new features such as goal setting, a personal diary, lifestyle coaching, and personalized recommendations. These functionalities can align with the need for personalization and engagement as identified in the research. By incorporating these functionalities, the Family Box can provide family members with relevant tools to manage their own health, set goals, and receive guidance, making it more than just a monitoring solution.

Family Box structure

The platform will have a homepage called the dashboard where the following features will be displayed:

- **Patient:** showing health of the patient through progress of different health aspects (based on 'Leefstijlroer'), medication information (e.g., types, instructions), and appointments.
- **You:** showing the health of the family member through the progress of different health aspects (based on 'Leefstijlroer': Nutrition, Movement, Relaxation, Sleep, Substances, & Connection).
- **Goals:** allowing the family member to set personal goals and see the goals of the patient.
- **Knowledge:** providing information or tools on various health aspects, aspects of caregiving, and behavior change.
- **Chat:** helping the family member to get answers to questions.

Figure 30: Family Box structure.

Features as consistent elements

These main features will provide a consistent basis of elements that can be used for MI and OHS cases but possibly also for other care paths in the future. Figure 31 shows the main features highlighted in dark blue. Each main feature supports the found needs from the care journey, shown as TGs:

- **Patient**
  - Supports TG 6 & TG 7 by showing information on how the patient is doing
  - Supports TG 8 by showing information on instructions and health metrics.
- **You**
  - Supports TG 1 by giving the family member a space to look at their own well-being.
- **Goals**
  - Supports TG 5 by giving the family member a space to set goals for themselves and in collaboration with the patient
  - Supports TG 6 by showing details on how the patient is doing with their goals
- **Knowledge**
  - Supports TG 2 by providing tools to support the different responsibilities and roles of the family member
  - Supports TG 3 by providing answers to questions
  - Supports TG 4 by providing tools and knowledge on how things work and how to navigate them
  - Supports TG 8 by providing clear information on questions
- **Chat**
  - Supports TG 3 by answering questions
  - Supports TG 4 by answering questions

TG 1: Want to be recognized

TG 2: Help with responsibilities/roles

TG 3: Wanting answers to questions

TG 4: Help with navigating the system

TG 5: Want to collaborate

TG 6: Want to understand how the patient feels

TG 7: Want to trust again

TG 8: Want clarity

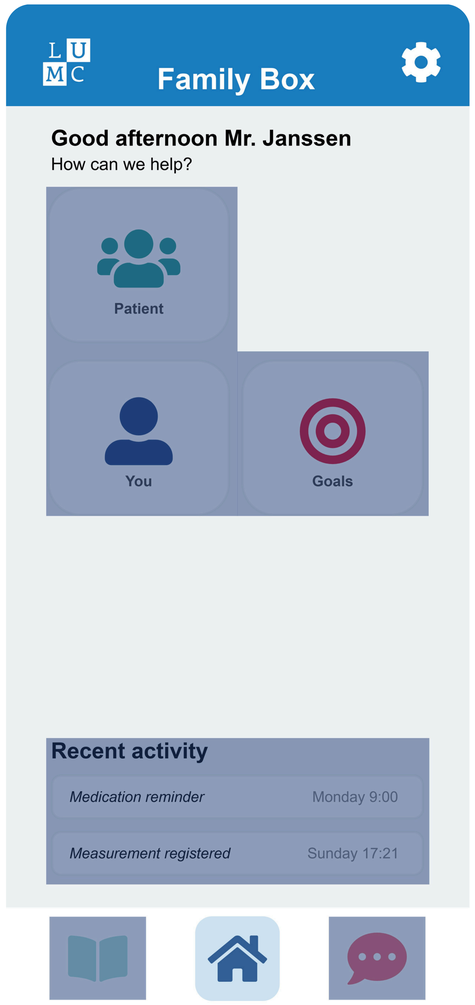


Figure 31: Consistent elements in the framework

1.4 Personalization

__Why__ personalization is needed is clear. The next step is to further understand __how__ personalization can be defined and applied in this context. Defining personalization and exploring different forms of it are important to ensure that it is effective and feasible. This will help __how__ personalization can be implemented into the system in a form that is in line with the needs of family members. Therefore, this section will define personalization, distinguish forms of it, and analyze strategy levels that can be applied for the Family Box.

Defining personalization

Personalization has many different definitions in different contexts. Therefore, a clear definition is essential to understand how personalized support can be offered to families. In the English language, personalization, customization, and tailoring share similarities in meaning but have some important differences, especially in the case of implementation. For this project, the following definition of personalization is used:

> "A process that changes the functionality, interface, information access, and content, or distinctiveness of a system to increase its personal relevance to an individual or category of individuals." (Blom, 2000)

This definition explains how personalization addresses the needs of individuals or groups instead of seeing the target group as one whole and everyone having the same needs. However, just a definition is not enough to design a personalized support system for family members. Therefore, frameworks for personalization are explored.

According to the classification framework of Fan & Poole (2006), more dimensions need to be specified to define how personalization is implemented. For instance, this definition of personalization is broad and does not specify **what**, **to whom**, and **who** does the personalization.

The framework of Fan & Poole (2006) consists of the following dimensions:

1. What is personalized (content, user interface, channel/information access, functionality)
2. To whom is personalized (categorical or individuated)
3. Who does the personalization (user or system)

FitzGerald et al. (2017) also developed a framework for personalization. Their framework is focused on the design of learning to enable effective implementation. Their framework uses six dimensions, sharing similarities with Fan & Poole's framework, but also adding a useful dimension on the personal characteristics of the learner.

The framework of FitzGerald et al. (2017) consists of the following dimensions:

1. What is being personalized (resources & content)
2. The type of learning where personalization occurs (formal, non-formal, informal)
3. What personal characteristics of the learner may be addressed (demographic, prior knowledge, self-assessed knowledge, demonstrated interests, preferred mode of learning, level of learner)
4. Who/what is doing the personalization (learner, teacher, peer, computer)
5. How personalization is carried out (name recognition, self-described personalization, segmented personalization, cognitive-based personalization, whole-person personalization, organization of resources)
6. The impact/beneficiaries of the personalization (learners, teachers, trainers, schools, government, commercial entities)

Combined framework

For this project, a combination of these two frameworks will be used. Fan & Poole's (2006) framework helps answer the right questions, such as what is personalized, to whom, and who does the personalization, resulting in a structured approach for personalizing digital systems. The framework of FitzGerald et al. (2017) elaborates the approach by highlighting the recipient's characteristics as a dimension for personalization. This will allow for more relevant personalization based on demographics, past knowledge, interests, and learning preferences.

However, while FitzGerald et al. (2017) focus on the recipient, it does this in the context of learning. Therefore, this dimension will be adapted to fit the context of personalizing support for family members. As a result, needs can also fit in this category, as these can be used to make family members feel recognized, capable, and supported. Additionally, FitzGerald et al. (2017) use a dimension for the type of learning that is less relevant in this context, resulting in its exclusion.

By combining these frameworks and refining the characteristics dimension, a more complete framework is established (see Figure 32), one that structures and aligns personalization with the context of the project. This combined framework will be used to develop the personalization strategy for the Family Box.

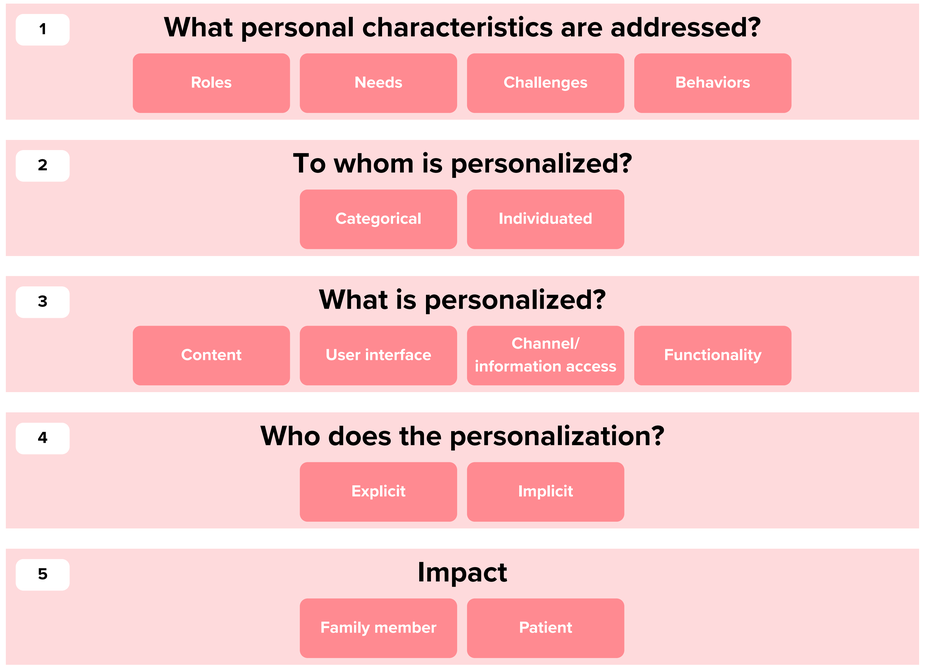


Figure 32: Combined framework for personalization.

1. What personal characteristics are addressed

In the original framework of FitzGerald et al. (2017), characteristics can vary from demographic data to preferred mode of learning. As these aspects are focused on educational tool development, an adaptation is needed.

As has been noted, Deek et al. (2016) established family involvement can enhance patient outcomes when support provided to family members is tailored to their specific situation. Therefore, this dimension will use the insights gained from **1.2 Family experiences** to build the personalization strategy, divided into roles, needs, challenges, and behaviors.

By designing personalization based on these characteristics of family members, the system can provide relevant and meaningful support, helping them navigate their role more effectively while ensuring that their own well-being is taken into account.

Data of The Box

Additionally, the Box will also generate data from the measurement devices that the patient uses. This data can also be used to inform the family member, but is characterizing the patient's situation rather than the family member's. Therefore, it is important to acknowledge but not include in this dimension of the framework, as it does not influence the personalization for the family member.

2. To whom is personalized

Personalization can be designed to target different types of users depending on their characteristics. Fan & Poole (2006) identify two approaches for personalization:

- **Categorical personalization:** this approach puts users into predefined groups based on shared characteristics. These categories allow for structured personalization, ensuring that individuals with similar needs receive relevant support.
  - These categories can be achieved through segmentation, personas, or microsegmentation (Kaiser, 2023).
- **Individuated personalization:** this approach focuses on the characteristics of an individual. It offers the highest degree of personalization, requiring dynamic adjustments based on user interactions.
  - This can be achieved through human interaction (user and dynamic adjustments done by humans) or with GenAI (Kaiser, 2023).

However, within categorical personalization, multiple levels of implementation can be identified. For example, Fan & Poole (2006) argue that individuated personalization can be done through elaborate categorical analysis. Therefore, this dimension is better defined when using different levels that address the volumes it targets. For example, in the beginning this can be done through four different groups, which is later increased to ten and so on, eventually ending up at individuated personalization. To distinguish these levels, the following terms will be used: one to all, one to many, one to some, one to few, and one to one (Kaiser, 2023). These terms better describe the different levels within this dimension (see Figure 33). Each level has its own benefits and challenges in regards to feasibility and effectiveness. In general, the higher the level of personalization, the more system resources are needed (Fan & Poole, 2006).

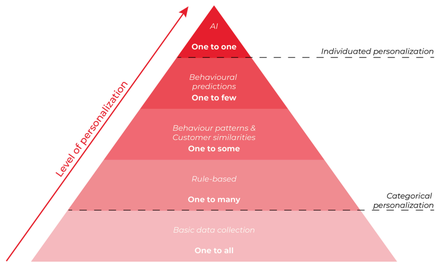


Figure 33: Levels of personalization (Fan & Poole, 2006; Kaiser, 2023).

Impact on Family Box

Individuated personalization would be ideal to implement, but achieving this through human interaction is resource-intensive and difficult to scale. GenAI has interesting possibilities to achieve this high level of personalization, but it brings its own risks that require a careful and calculated approach. As addressed earlier, GenAI has its risks with data, models and bias, prompts or inputs, users, and nuance. Consequently, it brings up concerns about the current feasibility for integration in sensitive parts of the solution under the name of LUMC and within the sensitive context of health and care. PWC has a framework for managing these risks (2023), but for short-term implementation of personalization, other levels will be better suited.

Given these considerations, categorical personalization is the best fit for the current scope and context of the project. Within this approach, personas provide an effective method for structuring personalization, as it offers a balance between feasibility, scalability, and relevance to the diverse family experiences that were identified in **1.2 Family experiences**.

The decision to use personas is based on the collected data on family experiences, which shows a variety in caregiving roles, needs, and challenges. Rather than applying segmentation, personas enable a more nuanced understanding of the user and thus a more human-centered approach, ensuring that family members receive support that is relevant to their specific needs and challenges. By using personas, a structured basis can be established for personalization while allowing for future iterations that could refine the personas or introduce GenAI tools. Depending on how elaborate the personas will be and in what quantity, this means the personalization level could range from the “one to many” to the “one to some” level.

To not fully close the door on GenAI and its wide range of opportunities, a careful exploration for possible methods of integration will be undertaken. This will focus on how AI can be used to improve different features of the app, like education, goals, and guidance.

3. What is personalized

Personalization can be applied to several parts of a system, impacting how users interact with content, access information, and use features. To understand **what** can be personalized for the Family Box, four categories of this dimension are explored: content, user interface, channel/information access, and functionality.

Content

This category refers to information that is provided to family members. Information and resources can be personalized based on their needs, roles, challenges, and/or types of involvement. For example, personalized education modules, recommendations for lifestyle changes, or reminders based on caregiving responsibilities. To what extent this is feasible is yet to be explored later in **2.1 Persona development** and during prototyping activities.

User interface

This category refers to how information is displayed and interacted with by family members. This can be personalized to fit the preferences of family members and their behavior. For example, through personalizing dashboards, changing layouts, or visual elements that help family members quickly find relevant information without being overwhelmed. What preferences family members have in regards to UI will be explored during prototyping activities.

Channel/information access

This category refers to the medium through which information is delivered to family members. Family members may have varying preferences for receiving and interacting with information. Some may benefit from real-time notifications, while others prefer email summaries or in-app updates. By using multiple communication channels, flexibility is improved to accommodate varied preferences. The question is if this is within the scope or doable for this project.

Functionality

This category refers to the tools and features available to family members. The Family Box could adapt tools and features to align with the needs of family members. For example, tools for monitoring, lifestyle changes, or planning the care journey.

Impact on Family Box

By personalizing across these four categories, family members can be empowered, resulting in better health and well-being for both family members and patients. Further defining and exploring **how** and **what** will be personalized in these categories will be explored further in **2.3 What is personalized**.

4. Who does the personalization

Personalization can be applied in different ways, depending on whether the user actively changes their experience or whether the system changes it automatically. Fan & Poole (2006) describe this difference as explicit (user-driven) and implicit (system-driven):

- **Explicit:** The process of personalization performed by the individual user. For example, choosing which category of news a reader would like to receive most from their news app.
- **Implicit:** The process of personalization performed by the system. For example, recommending a news article based on articles that were read in the past from the same author.

Impact on Family Box

Explicit personalization can be applied to let family members set preferences and/or allow them control over some aspects of the Family Box. This gives family members the power to further personalize their support themselves. **Implicit** personalization can be used to adjust support, recommendations, or content presentation based on the personalization level. This reduces feelings of overwhelm while still offering relevant support to family members.

By using both applications, it creates a personalization strategy that is adaptable to different family members while balancing ease of use and providing choices for the family member.

5. Impact

By implementing a structured personalization approach, the Family Box can enhance support for family members while making sure that their needs are taken into consideration in the care journey of the patient. By aiming for categorical personalization, feasibility and effectiveness are balanced. Through the combination of **explicit** and **implicit** personalization, the strategy can allow users to take control and, at the same time, lower the cognitive load placed on them.

By addressing personalization across these five dimensions, a complete personalization strategy can be designed. These five dimensions will help guide the following phase of Create, where the personalization strategy will be further developed. First, “What personal characteristics will be addressed” & “To whom is personalized” will be discussed together in **2.1 Persona development,** as these will lay the basis for the implementation of the other dimensions. Secondly, “What will be personalized” will be discussed in **2.3 What is personalized**. Thirdly, the fourth dimension (Who does the personalization) will be discussed in **2.4 Who does the personalization**.

The last dimension that discusses the impact of the personalization strategy will be discussed in the Deliver phase after presenting the final design in **3.2 Impact**.

1.5 Conclusion of Hear

The problem analysis at the beginning of this phase showed clearly **why** family members of MI and OHS patients need personalized support. The first chapter identified key challenges and opportunities, looking at the problem from the patient's, family member's, and health system's perspectives. It revealed that while patients benefit from the support of family members, the family members often lack support to maintain their ability to do so. The analysis of family dynamics showed that caregiving responsibilities vary a lot, showing why flexibility is important for the support strategy. Furthermore, the role of digital health solutions and AI was examined, showing opportunities to provide care beyond the hospital setting. Overall, these findings emphasized that a one-size-fits-all solution would be ineffective, thus explaining **why** personalized support is needed.

Building on this, the second chapter explored real family experiences to identify **when**, **where**, and **what** kind of support is needed. With the contextmapping method, themes and needs were established across different phases of the care journey. The analysis showed that emotional, practical, and informational needs change over time and are not universal across family members. Therefore, explaining **why** personalized support is needed.

In order to translate the insights into a structured solution, the third chapter analyzed existing platform structures to identify relevant elements for the Family Box. Through the inclusion of components from these platforms, the Family Box can offer a structured and flexible experience. The included components focus on health monitoring, goal-setting, and knowledge building. Additionally, the Leefstijlroer model will guide the structuring of health-related aspects, providing a universal structure for both patient and family member well-being. As a result, this structure enables the Family Box to be both familiar and scalable.

Finally, the fourth chapter demonstrated a personalization framework that will guide the design of personalized support from the Family Box. The framework combines elements from Fan & Poole (2006) and FitzGerald et al. (2017), resulting in five dimensions for personalization:

1. What personal characteristics are addressed?
2. To whom is it personalized?
3. What is personalized?
4. Who does the personalization?
5. Impact

Regarding what is feasible, a categorical level of personalization using personas was chosen, balancing scalability and relevance. This personalization framework will form the basis for a flexible personalization strategy that can be refined over time.

After analyzing and collecting these insights, the project will proceed to the Create phase. There, the focus will go from arguing why personalization is needed and how it could be implemented to conceptualizing the personalization strategy. The next phase will develop and test personas and features, ensuring that the Family Box effectively supports the diverse needs, challenges, and roles of family members while staying feasible to develop.

Create

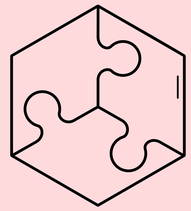
The previous phase explored the experiences of family members in the care journey, highlighting their diverse needs, challenges, and roles. By analyzing focus group data and user research, key themes, preferences, and behaviors were identified, showing that a one-size-fits-all approach would be ineffective. Additionally, a framework for personalization was developed that will guide the next steps for developing a personalization strategy. Altogether, the insights and framework form the foundation for the Create phase.

In this phase, the insights from the previous phase are used to design a structured personalization strategy for the Family Box. First, personas will be developed to align the personalization strategy with the different needs, challenges, and roles of family members. Then empowerment methods will be established to help family members gain confidence and ability in managing both their own health and well-being and the patient's. Thirdly, various aspects of what can be personalized will be explored to determine what should be personalized and what is feasible. Finally, who controls the personalization is examined to balance explicit and implicit personalization, resulting in a balance between flexibility and usability for the Family Box.

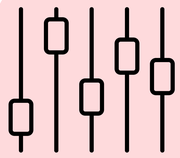
Together, these activities ensure that the personalization strategy is practical, relevant, and scalable, forming the basis for the Deliver phase, where the strategy will be illustrated together with steps for implementation and further development.

Persona development

Empowerment methods



What can be personalized



Control of personalization

2.1 Persona development

*The previous chapter (**1.4 Personalization**) established that categorical personalization is the most suitable approach for the current setting of the Family Box. This level of personalization will allow family members to receive relevant support based on shared characteristics. To implement this approach effectively, a persona-based personalization method will be created.*

To create personas that accurately reflect the actual experiences of family members, this section uses the focus group data to understand dimension 1 of personalization: 'What personal characteristics are addressed?' The focus group data provides insights into the different ways family members engage in caregiving but also shows their needs, challenges, and roles. These insights will then inform the personas, allowing for family members experience-based personas that will further influence the design of personalized support.

What personal characteristics will be addressed?

It is important to identify what can be addressed to personalize support for family members (FitzGerald et al., 2017). In order to answer this question, the statement cards that were generated in the process of contextmapping (Sanders & Stappers, 2012) were used. These statement cards were used to answer the third question for contextmapping, introduced in **1.2 Family experiences**: "What type of family members can be identified for personalization?" The goal was to find statement cards that describe the family members, their relationship with the patient, characteristics of their caregiving, and their context (Young et al., 2020). These factors were renamed as states, roles, feelings, and care styles. The process involved three steps. Each step will be explained, and an overview of steps is visible in Figure 34 on the next page.

First, the statement cards were reviewed and sorted. The statement cards were generated in relation to the three questions of **1.2 Family Experiences**. However, this section focuses on the third question only. Therefore, all 252 statement cards were assessed on whether or not they described a state, role, feeling, or care style. Those that did not fit one of these categories were set aside as not relevant. A total of 69 statement cards was excluded for this reason.

Secondly, the remaining 183 statement cards were categorized into two sets: 'States & Roles' and 'Feelings & Care styles'. The set 'States & Roles' contained 75 cards that reflect the different phases and roles that family members take on during the care journey. Family members are not static in their roles. They change from different roles and responsibilities constantly, depending on factors such as the patient's condition, their own well-being, and other circumstances. Capturing 'States' personas can reflect how caregiving changes over time. By identifying 'Roles' the personas can illustrate how family members approach and act in the care journey.

The other set, 'Feelings & Care styles' consisted of 108 cards and focused on the emotions and caregiving styles of the family member. Family members deal with a wide range of emotions, varying from concern and stress to confidence and detachment. This affects their level of involvement, how they provide support, and their needs for support. 'Feelings' help understand how family members experience the care journey emotionally. By identifying 'Care styles,' a deeper understanding of the interaction with both the patient and the system is created.

Thirdly, based on what each card described, groups were made, placing cards describing similar subjects together. This resulted in 14 'States & Roles' groups (e.g., communicator, social animal) and 25 'Feelings & Care styles' groups (e.g., adaptability, in search of control). The 39 created groups are visible in Figure 35 on the next page.

Now that it is clear what personal characteristics of family members can be addressed, the next step will be to design to whom it is personalized.

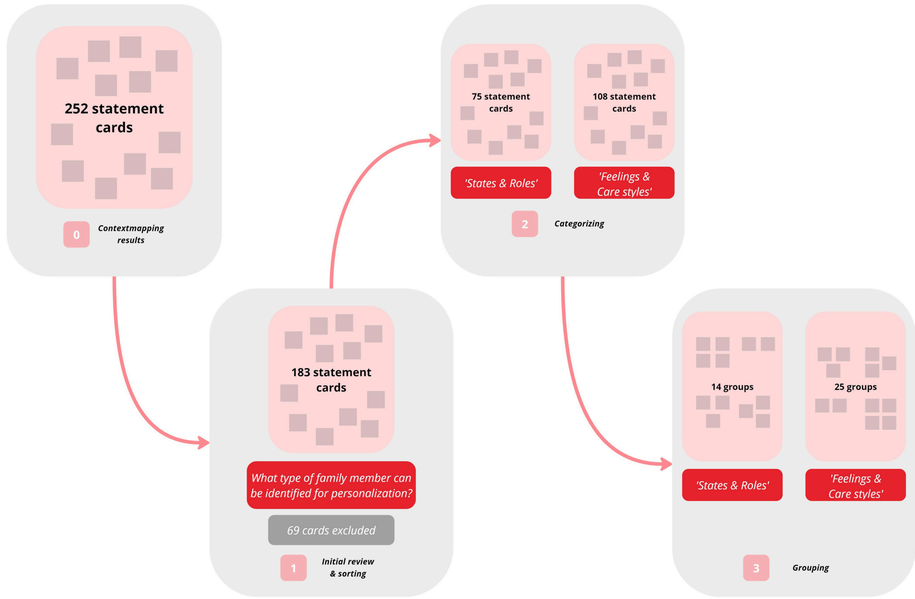


Figure 34: Process of identification of 'States, Roles, Feelings, & Care styles'.

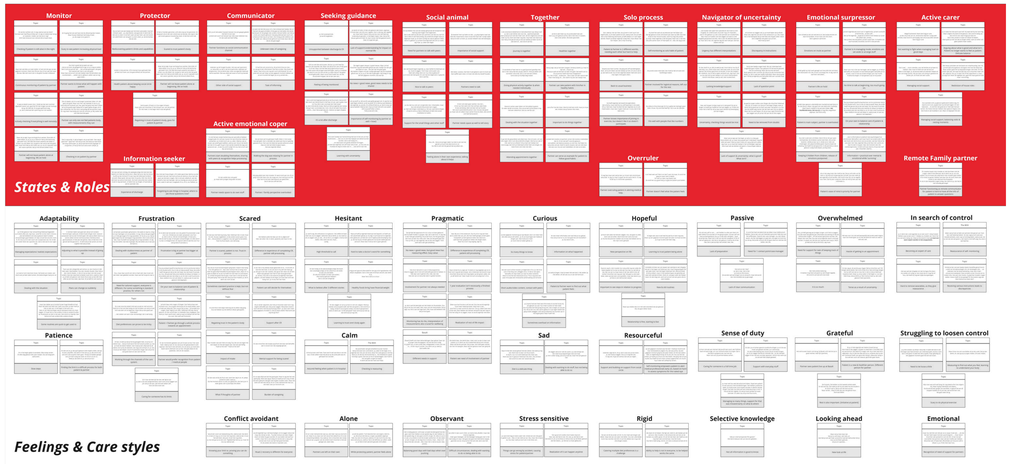


Figure 35: Identified 'States, Roles, Feelings & Care styles'.

To whom will be personalized?

As established earlier, the Family Box will use categorical personalization to support family members. However, the level of personalization still needs to be determined. For short-term implementation, individuated personalization is not feasible, but the question is what levels of categorical personalization are. The higher the level of personalization, the more system resources will be needed, which could delay short-term implementation.

Use & development of dimensions

The previous step identified a wide range of ‘States, Roles, Feelings, & Care styles’. The next step is to structure them in a way that enables categorical personalization. To achieve this, dimensions were introduced as a way to structure these differences in characteristics among family members. These dimensions show opposing characteristics that define the behaviors and experiences of family members, helping to categorize family members into distinct personas based on their dominant characteristics.

At this stage of the Family Box only the extremes of a dimension will be defined, but by using dimensions, future refinements are possible. In the future, this could mean increasing the level of personalization by accommodating the support to match family members that fall somewhere between the extremes. The following steps were taken to define these dimensions that will form the basis for the next steps of developing the personas (see Figure 36):

1. The ‘States & Roles’ that shared similar characteristics or themes were grouped together to form a category (e.g., active carer & overruler).
2. The categories were further elaborated with ‘Feelings & Care styles” groups as descriptive elements.
3. These elaborated categories were organized in a way that they would represent extremes of a spectrum (e.g., solo versus together).
4. States, roles, feelings, and care styles that did not describe or fit a type of family were left out of the categories. These will serve as general guidelines for understanding users.
5. These sets were simplified to four dimensions showing ranges that can be used to classify types of families. Letters are given to each extreme of a dimension to help classification.

Combination of dimensions and personas

A common state of family members is ‘Information seeker,’, a role that describes that they look for information during the care journey but might benefit from support that addresses this common state. Support for this state can be implemented through simple navigation and categorization of information. Another aspect is ‘Selective knowledge.’, underscoring the importance of allowing family members to choose what they want and do not want to see or learn about. At last, general emotional reactions of family that should be anticipated are feelings like frustration and the emotional toll the journey takes on the family member.

Dimensions

As a result of the process described earlier, four dimensions were created. They show opposing characteristics relevant to the family member and the care journey. They help categorize family members based on behavioral and relational differences, ensuring that personalization captures crucial differences in their experiences. The first two dimensions define the interaction between family members and patients, highlighting how they are involved in decision-making and daily care. While dimensions 3 and 4 define how the family member behaves, including how they approach caregiving and deal with their emotions.

Dimension 1: Distance (Remote [R] vs. Inhouse caregiver [H])

This dimension describes the different scenarios family members and patients are in. With some family members, like partners living in-house with the patient or a child of the patient living remotely. Both scenarios bring their own complications, e.g., remote caregivers sometimes have to communicate on behalf of the patient with experts with them not being physically present to double-check questions. On the other side, in-house caregivers can experience difficulty with having a space that is not influenced by the patient’s situation.

Dimension 2: Involvedness (Solo [S] vs. Together [T])

Among family members and patients, some do everything together, while other patients prefer to stay autonomous by keeping information close to the vest. On the ‘Solo’ side of involvement, the patient may value independence and control over the situation. Family members can experience feelings of loneliness or being scared. Especially when challenges emerge for the patient that are difficult to handle by themselves. Family members on this side may feel excluded or uncertain about how to provide support.

On the ‘Together’ side, family members and patients show adaptability and are pragmatic and grateful as they keep looking for solutions with the help of each other. This dynamic can create a strong support system. However, it may also lead to potential challenges, such as the family member becoming over-involved, which could result in overprotective behavior or challenges regarding boundaries. At the same time, the patient might become dependent, putting extra burden on the family member.

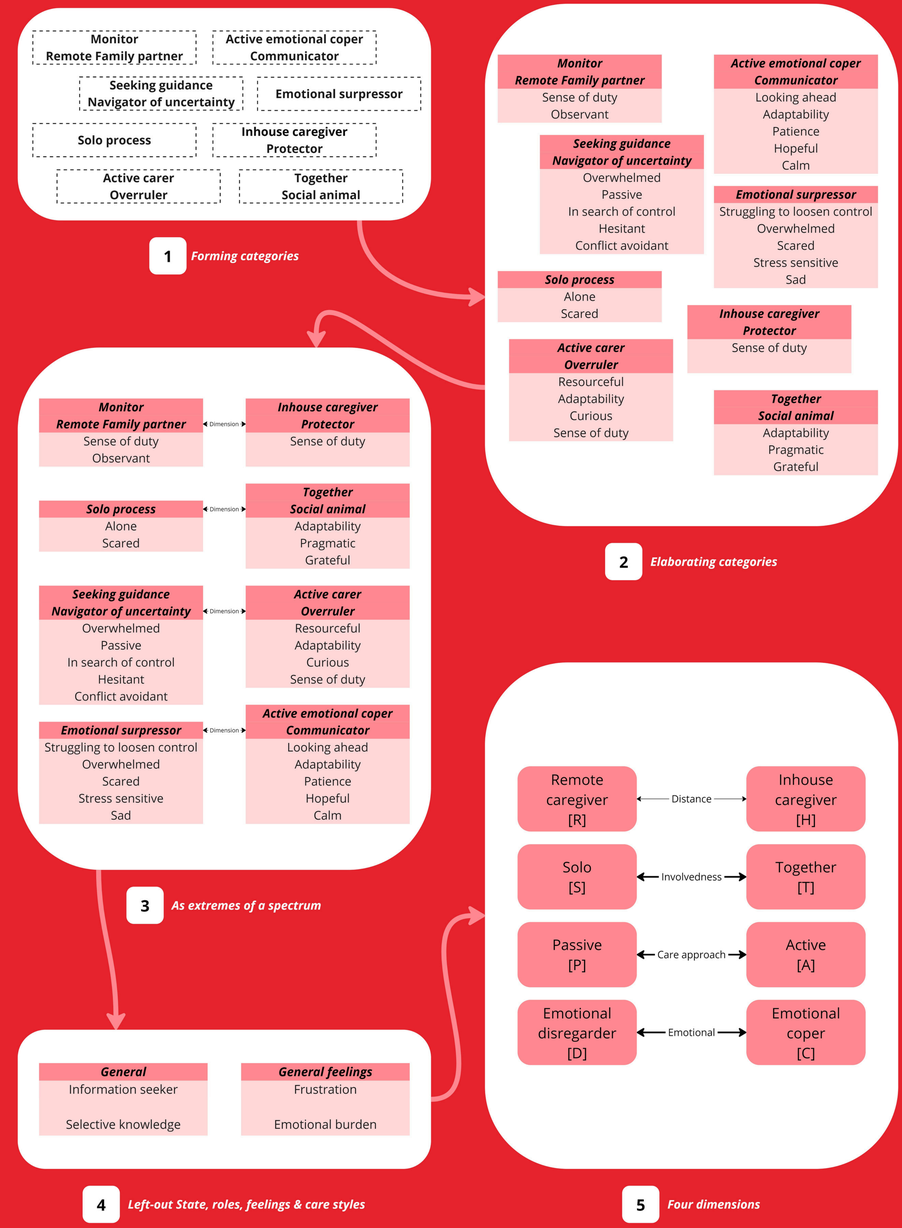


Figure 36: Dimensions development process

Dimension 3: Care approach (Passive [P] vs. Active [A])

This dimension shows the different ways in which family members approach caregiving. Family members on the passive side tend to take a step back or need a push with clear instructions to support. This behavior can be a result of being conflict avoidant or hesitant. On the opposite side are active family members. They take initiative by seeking information and taking care of things. They often come across as curious and resourceful. However, their support can sometimes overstep or overwhelm the patient. As a result, balancing adequate support and avoiding overwhelming is something to consider.

Dimension 4: Emotional (Disregarder [D] vs. Coper [C])

Family members deal differently with the emotional side of the caregiving experience. Some disregard their emotions and may find it difficult to deal with the patient's emotional state by avoiding feelings or focusing on their tasks. This can create distance or misunderstandings between the family member and patient. However, other family members actively cope with their emotions, finding ways to process despite their challenges. Copers often prioritize patience, looking ahead, and calmness.

First iteration of personas

Being inspired by the Myers-Briggs Type Indicator (MBTI) (The Myers-Briggs Company, n.d.), these four dimensions could be used to create personalized experiences. MBTI is used to sort people into different sixteen personality types, as each dimension gives a person one letter. The result of this test is a four-letter code, like ENTP.

Using a similar structure with the identified dimensions, personalization could be realized for families. For example, every letter code unlocks a certain set of modules and/or features, resulting in eight different packages. By scoring the family member on these four dimensions, they end up with a combination of four letters. As shown in Figure 37, this family member is scored as RTPD, meaning that they get modules and/or features that are relevant to the Remote caregiver, Together, Passive, and Emotional disregarder sides of the dimensions.

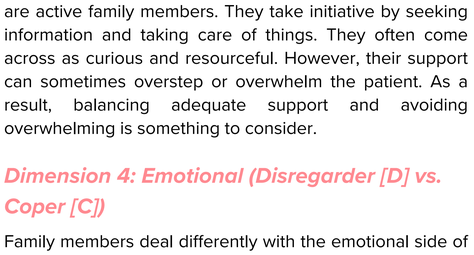


Figure 37: Example scoring.

By having four dimensions with two options each, this structure provides sixteen combinations while having only eight packages (see Figure 38). The sixteen possible combinations, inspired by MBTI (The Myers-Briggs Company, n.d.), offer a high-level personalized approach by identifying sixteen different family members and personalizing the support to them.

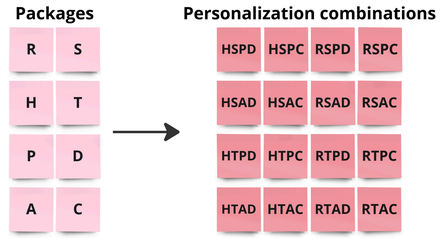


Figure 38: Sixteen possible combinations.

Feasibility guidelines

As Ancora Health is developing the Health Box, it is important to explore if the high level of personalization is feasible for the short-term implementation of personalization in the Family Box. This is relevant as the Family Box will likely be built on the same system. To set guidelines for this, an intervention developer from Ancora Health and a postdoctoral researcher on inclusive and tailored eHealth interventions were approached.

For the development of a platform providing personalized features, a large number of personas is difficult to implement. For example, personalizing text in modules would mean having X number of versions of a module in the system, with X being equal to the number of personas. Instead, an amount of around four personas was suggested by both to keep development and implementation feasible. In the long term, a different structure or implementation of Large Language Models (LLMs) could support the use of more personas. The personas can include socio-economic and biomedical data, helping to identify relevant support preferences and behavior patterns.

Further development of personas can consider specific modules (knowledge articles or tools), for example, to address family support needs in communication or conflict management. These modules can be optionally selected or recommended based on user input. Additionally, flexibility is part of the design to enable patients to choose modules that fit their needs & situation.

GenAI was introduced to the intervention developer as a potential method to dynamically tailor content to the family member. It is unclear how familiar the developer was with the capabilities of GenAI. However, priority was given to a manageable structure with customizable elements to develop a solution that is feasible and efficient. By focusing on a basis of flexible personas and adaptive modules, the Family Box can support diverse family members while maintaining a practical and scalable approach to personalization.

Feasible level of personalization

As described in the previous section, feasibility concerns arose during discussions with a developer at Ancora Health. The implementation and maintenance of sixteen unique combinations within the system would make the development more complex and increase the difficulty for scaling. Due to these limitations, a different approach was explored.

Instead of relying on sixteen combinations, a set of four personas was designed. This set is still based on the four dimensions but does not represent every possible combination. The set shows the four types of family members that were most distinct in the focus group data.

The choice for these four personas was guided by the patterns in the focus group data. By identifying which extremes of the dimensions were most frequently aligned with family members, four personas were created. These personas ensure that key differences across the dimensions are reflected while keeping the model feasible for implementation.

The goal is to design personas that are relevant to a majority of family members, meaning that most can recognize aspects of themselves in a persona. This balance between representation and feasibility will ensure that personalization remains effective without making the system difficult to realize. At this stage, the accuracy of the personas remains an assumption. However, this direction provides a feasible and scalable way to implement a method of personalization.

The four personas were given a name, a short description, and some possible support strategies (see Figure 39).

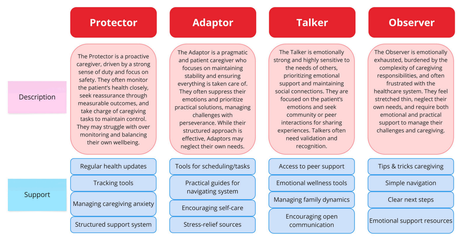


Figure 39: First iteration of four persona set.

Second iteration of personas

To evaluate the first set of four personas, the postdoctoral researcher was approached again. During the conversation with him, the focus was on the evaluation and development of personas. Mainly on achieving balance between specificity and practicality. He underlined the value of dimensions and characteristics (such as levels of activity and autonomy), and support needs as parts of the personas. This conversation provided the following insights to iterate further on the personas:

- **Distance dimension relevance:** This dimension does not allow for a better understanding of a persona, as all personas can be in-house or remote. Therefore, this dimension will not be used for defining the personas.
- **Blending of dimensions and personas:** The dimensions should be used to more precisely define the personas, creating a frame of reference to each other.

Combination of dimensions and personas

After removing the 'Distance' dimension, the remaining three dimensions, 'Involvedness,', 'Care approach,', and 'Emotional,' were used to iterate on the definition of the four personas. In order to make the link more clear between the dimensions and the personas, a scoring chart of the dimensions was added to each persona.

The method of Lost Lemon & Muzus (2018) (see Appendix D) was used to enrich the description of the personas. This method uses short phrases like 'They are,', 'These are barriers to them,', and 'This tempts them.' Using these phrases, the personas are more clearly defined and relatable.

The personas were further enriched through:

- **Drives:** Each persona was assigned a main drive, helping to clarify their main needs and decision-making tendencies.
- **Quotes:** Quotes from the statement cards were included to add real examples for each persona, making them more tangible.

This set of personas serves as a tool for designing support based on caregiving styles and needs of family members. At the end of the next section, each persona will be explained in detail, showing how they align with different family member types and behaviors.

Impact on Family Box

The use of personas ensures that family members receive support that is relevant to their role and needs. This personalization can be reflected in both the content they interact with and how the app functions for them.

One way this is achieved is through dynamic elements. This prioritizes the recommendation of modules and features that are most relevant to a persona. All created

modules and features should be available to a family member. This will prevent the absence of relevant support when assumptions within strategy prohibit family members from finding information they deem relevant. For example, modules related to overprotective behavior will be recommended to the personas that these modules are relevant to.

Additionally, the app can adapt to different engagement types, adjusting how information is presented to match the family member's needs. Some users may prefer simplified health data, while others may prefer detailed insights. By personalizing the data presentation, the app can ensure that family members receive information in a way that is both useful and in line with their preferences. This is in line with the 'Selective knowledge' characteristic that was identified as a general characteristic earlier.

Third iteration of personas

To further iterate the personas to best match real-life scenarios, discussions were held with a cardiologist and a medical psychologist, providing the following insights:

- **Overall fit:** The cardiologist estimated that 80–90% of the family members he deals with at the hospital would likely fit within the personas, showing how close the set is to real-world cases.
- **Recognition of personas:** The medical psychologist found the personas relatable, with the Protector and Talker being the most recognizable.
- **Overlap concerns:** The medical psychologist noted overlap between personas and suggested changing the Adaptor to the 'ideal' caregiver by changing the score on the emotional dimension, so it is better distinguishable from the Protector.
- **Emotional dimension refinement:** The emotional dimension is in line with coping strategies. The medical psychologist suggested scoring the emotional dimension on emotion-focused coping and problem-focused coping (Folkman, 2013).

Emotional dimension refinement

The emotional dimension is in line with coping strategies problem-focused coping and emotion-focused coping these strategies are used by people to deal with stressful situations. Problem-focused coping fits people that prioritize managing the problem that is the source of distress rather than acknowledging their emotional responses. Their activities include seeking information, looking for solutions, or seeking advice. This approach can lead to emotional fatigue. Emotion-focused coping is when people focus on their emotional responses, usually when the problem is difficult to solve. They seek social support, think about the positive side, or use humour to process their situation. This may result in avoiding moments when problem-solving is crucial (Folkman, 2013).

To strengthen the framework of the personas, the dimension will use these terms for scoring the emotional aspects of the family member. As a result, 'Emotional disregarding' becomes problem-focused coping, 'Emotional coping' becomes emotion-focused coping, and the dimension is reframed as a coping strategy.

Using these insights, the personas of the second iteration were further defined with the addition of needs from the family journey, descriptions were changed to behaviors, changes were made to the Adaptor, and the emotional dimension was refined.

In the next section, each persona will be introduced separately, consisting of:

- **Dimension scoring**
- **Drive**
- **Description**
- **Characteristics**
- **Behaviors**
- **Relevant needs from care journey**
- **Quotes**
- **Potential support strategies**

Persona set

Protector

Adaptor

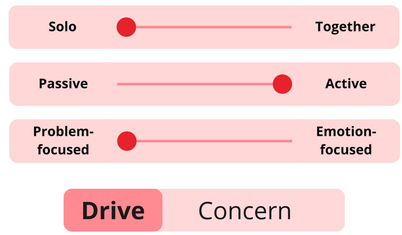
Talker

Observer

Protector

Dimension scoring

- **Solo:** They take full responsibility for the patient's well-being, often managing care independently rather than relying on the help of others. They prefer to do things by themselves. As they like control, they want to oversee everything.
- **Active:** They are proactive, taking initiative in providing care to the patient. They continuously monitor the patient's health, intervene when necessary, and seek out resources or information to ensure the patient is well cared for.
- **Problem-focused coping:** They tend to suppress their own emotions, prioritizing the practical aspects of caregiving and the health of the patient. With feelings set aside to provide the best care, they view emotional expressions as potential distractions from their responsibilities.



Description

The Protector is a proactive caregiver, driven by a strong sense of duty and focus on safety. They often monitor the patient's health closely, seek reassurance through measurable outcomes, and take charge of caregiving tasks to maintain control. They may struggle with overmonitoring and balancing their own well-being.

Characteristics

- Overprotective/cautious
- Responsible
- Controlling

Behavior

- Prioritizing patients over themselves
- Searching reassurance & control
- Monitoring health & behaviour of patient

Relevant needs from care journey

- **TG 6**: Want to understand how patient feels
- **TG 7**: Want to trust again

Potential support strategies

- Providing health updates
- Supporting management of caregiving anxiety
- Creating awareness of emotions
- Creating awareness of patients' autonomy

"Het belangrijkste is dat hij zich niet druk hoeft te maken. Dan kan hij rusten."

"Je wilt de patient toch ergens beschermen, denk ik. Ja, die wil je niet met jouw zorgen opzadelen zeg maar."

"We moeten voor elkaar zorgen, maar soms ben je daar alleen in."

Adaptor

Dimension scoring

- **Together:** They prefer collaborating and a shared approach with the patient and other family members. Working alongside others is comfortable for them, adapting their support to fit the process and needs of the patient.
- **Active:** They are quick to adapt to the situation, actively stepping in to help when needed. They are engaged in their care approach and take initiative.
- **Emotion-focused coping:** They often deal with their emotions, focusing on being flexible and adaptable to support the patient. Priority is given to seeking social support and seeing the positive sides of things.

Description

The Adaptor is a pragmatic and patient caregiver who focuses on maintaining stability and ensuring everything is taken care of. They often suppress their emotions and prioritize practical solutions, managing challenges with perseverance. While their structured approach is effective, Adaptors may neglect their own needs.

Characteristics

- Open
- Pragmatic & organized
- Cooperative

Behavior

- Everything needs to be taken care of
- Managing with perseverance
- Seeking & using help of others

Relevant needs from care journey

- **TG 2**: Help with responsibilities/roles
- **TG 5**: Want to collaborate
- **TG 8**: Want clarity

Potential support strategies

- Support in scheduling/management of tasks
- Practical guides for caregiving/navigating the system
- Encouraging self-care
- Stimulating stress-relief

"Je moet realistisch zijn, soms moet je dingen aanpassen naar wat wel lukt."

"Als je weet dat het lang gaat duren, dan pas je je leven aan op een manier die werkt."

"Er zijn veel veranderingen, je hebt gewoon geen andere keuze dan aanpassen."

Talker

Dimension scoring

- **Together:** They are communicative and prefer a collaborative approach, involving the patient and sharing insights, updates, and concerns. They thrive in collaboration, relying on open communication with patients, their social circle, and healthcare professionals.
- **Passive:** They contribute to caregiving needs using a communicative approach rather than actions. They take a conversational and supportive role, relying on others to take up hands-on caregiving while they provide emotional support.
- **Emotion-focused Coping:** They are open to discussing and processing their emotions, managing their feelings by talking with others like family or colleagues. This may lead to avoiding or struggling with moments when problem-solving is necessary, as they might feel less confident with hands-on caregiving.

Description

The Talker is emotionally strong and highly sensitive to the needs of others, prioritizing emotional support and maintaining social connections. They are focused on the patient's emotions and seek community or peer interactions for sharing experiences. Talkers often need validation and recognition.

Characteristics

- Sensitive to emotional needs
- Big on sharing
- Hesitant

Behavior

- Sharing experiences with others
- Seeking validation & recognition of needs
- Supporting emotionally

Relevant needs from care journey

- **TG 1**: Want to be recognized
- **TG 4**: Help with navigating the system
- **TG 6**: Want to understand how patient feels

Potential support strategies

- Providing ways of connecting/sharing
- Empowering through educational content
- Developing hands-on caregiving skills

"Ik heb geleerd, ik moet mijn waffel open doen en niet alles bij mezelf houden."

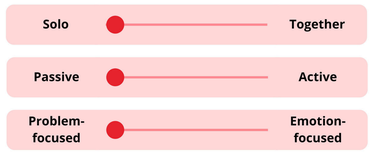
"Ik wil mijn zorgen kunnen delen dat helpt enorm."

"Het is belangrijk om samen dingen te delen, dat helpt."

Observer

Dimension scoring

- **Solo:** They prefer to or are forced to maintain a distance from the patient. This can be due to distance or the wishes of the patient to be autonomous. In some cases they respect the patient's autonomy, while in other cases the family member might force the patient to manage by themselves. They avoid direct interference and tend to observe rather than get involved closely.
- **Passive:** They take a hands-off approach, as they provide support from a distance and only step in when there is no other option. They are less to not involved in day-to-day caregiving, often watching from the sidelines while the patient cares for themselves.
- **Problem-focused coping:** They are prone to suppressing or ignoring their emotions, choosing not to deal with the emotional side of caregiving. They focus on maintaining a calm and detached perspective, often avoiding open emotional expression.



Drive Understanding

Description

The Observer prefers or is forced to stay in the background, respecting the patient's autonomy, resulting in low direct involvement in caregiving. They take a passive role, intervening only when necessary. They want to understand the patient's condition, but without engaging with the patient.

Characteristics

- Emotionally tired
- Frustrated
- Curious

Behavior

- Respects autonomy of patient
- Supports from a distance
- Observes patient

Relevant needs from care journey

- **TG 3**: Wanting answers to questions
- **TG 6**: Want to understand how patient feels

Potential support strategies

- Informing on patient
- Stimulating support without interfering
- Preparing for moments when interference is needed

"Soms observeer ik gewoon en neem ik alles in me op, zonder te veel te zeggen."

"Je leeft in je eigen wereld, je ziet dingen maar kunt niet altijd helpen."

"Ik kijk toe en laat hem dingen op zijn manier doen, dat werkt vaak het beste."

Recognition of personas

To ensure that the Family Box uses personas that represent actual family members, it is important to check if family members with experience recognize themselves within the set of personas. Therefore, user research was conducted to assess the applicability of the four personas. This was done with the same participants as described in **1.2 Family experiences**. The data was gathered through a survey and interviews.

Survey

Participants were asked to rate their level of identification with a persona, ranging from not to very closely (red to dark green in Figure 40). The responses show that a large number of participants identified with multiple personas. Only one participant identified very clearly with one persona, while others were more spread out across the set. One case also shows no clear difference in identification between the personas.

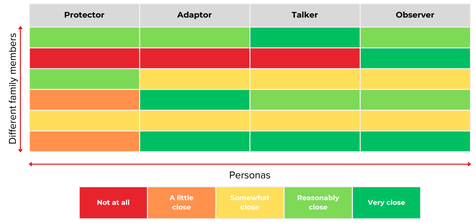


Figure 40: Recognition of personas survey results.

The results show that people have difficulty identifying in just one persona. Reasons for this could be that the descriptions have overlap, participants were not forced to choose one or two but were asked to rate identification with all of them, or that the personas are not distinct enough.

Interviews

From the interviews, participants identified differently across three personas :

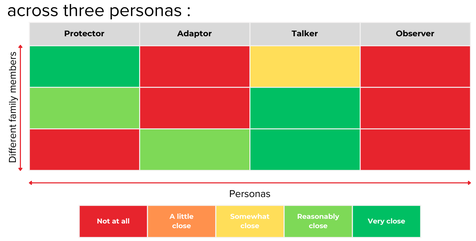


Figure 41: Recognition of personas interview results.

Important to mention is that participants in the interviews were asked if they recognized themselves within one persona and later if they recognized themselves in other personas as well. This framing probably resulted in more focused outcomes in comparison to the survey results.

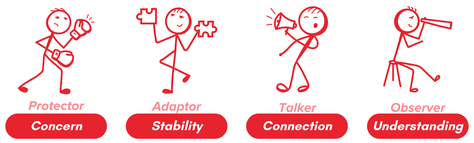
Participants mentioned aspects of personas that felt most relevant to them:

- **Protector:** Protecting patient & patient's wellbeing; Creating a safe environment.
- **Adaptor:** Keeping structure.
- **Talker:** Open communication; Strong connection with patient; Collaboration is key; Maintaining a transparent relationship.

A possible way of dealing with the scenario of identifying with multiple personas is to offer more flexible support. A rigid match might not fit with the complexity and variety of caregiving experiences because many participants recognized aspects of themselves in multiple personas. Shifting between personas should be considered, as some aspects might present themselves stronger in different phases.

Conclusion

The foundation for the personalization strategy is now set with the developed set of four personas. Through the analysis of the insights from the **1.2 Family experiences**, three dimensions were created that classify family members into personas based on their involvement, approach, and coping behavior. As a result of these dimensions and through multiple iterations, the following four personas were developed:



The set of personas has been validated through healthcare professionals and user research. From the professional side, they seemed to represent family members quite well, but from user research, it became clear that family members identify with multiple personas rather than a single one. This might suggest that the fit of a persona can be fluid and change over time, highlighting the importance of flexibility in the personalization strategy.

To ensure feasibility, the number of personas was limited to four, balancing accuracy and implementation difficulty. A higher level of personalization is still possible in the future, as the current structure provides room for increasing the number of personas through combinations of the dimensions and/or classifying neutral points in the dimensions as options.

Personalization alone is not enough to support family members effectively. Therefore, the next step for the personalization strategy will focus on how a family member can be empowered. By aligning empowerment strategies with personalization, the Family Box can offer families personalized support that helps them manage the well-being and health of themselves and the patient.

2.2 Empowerment

*The previous sections have demonstrated the need for personalized support for family members based on their diverse experiences during the care journey. In **1.1 Problem** & **1.2 Family experiences** it became clear how family members experience the care journey differently, demonstrating that a one-size-fits-all approach would not be effective. Those differences in experience were used in **2.1 Persona development** to create a set of personas, making sure that the personalization strategy uses key aspects of the care journey.*

However, personalization by itself is not enough. Family members also need to be empowered to navigate the care journey effectively. Through empowerment, they can gain control over the situation and build confidence to manage the health and well-being of themselves and the patient.

*This section will explore how empowerment can be implemented in the Family Box through four methods based on literature, family experiences, and the features of the Family Box. They will then be linked back to the identified TGs in **1.2 Family experiences** and the created personas from **2.1 Persona development**. This way, empowerment can be personalized and implemented in the Family Box.*

Empowerment of the family member

The problem to be addressed by the Family Box is the following:

How can we provide personalized support to families of patients during the care journey of MI or OHS to empower family members in managing health and wellbeing individually and for the patient?

To address this, the Family Box will personalize features with the aim of empowering family members throughout the care journey. The features can focus on individual needs, family needs, or both.

Definitions and instruments of empowerment vary a lot in cases of patient empowerment (Mora et al., 2021). However, family-centered empowerment can improve the health literacy and self-efficacy of caregivers, leading to better quality of caregiving (Jafari et al., 2020). Therefore, the definition of empowerment from WHO is used:

"Empowerment refers to the process by which people gain control over the factors and decisions that shape their lives. It is the process by which they increase their assets and attributes and build capacities to gain access, partners, networks and/or a voice, in order to gain control." (WHO, n.d.)

This definition of empowerment is used in this project because it illustrates that empowerment is a process. It is an effect of other multiple methods that lead to empowerment. For example, the family-centered empowerment model used by Jafari et al. (2020) provides three factors that influence empowerment of the family: motivational, cognitive, and personal traits. This further illustrates that empowerment is an effect of other methods.

For the Family Box, empowerment can be implemented through various features. It is not just about informing the family member about the patient but also engaging with family members through methods that help them manage the health and well-being of the patient and themselves.

Methods of empowerment

As noted earlier in **1.3 Platform structure**, the Family Box has five main features: Patient, Family member, Goals, Knowledge, and Chat. To ensure that the Family Box can support family members to manage their health and well-being, four methods of empowerment were identified: Monitoring, Guiding, Educating and Challenging. These methods are based on the features of the Family Box, the experiences and challenges identified in **1.2 Family experiences**, and literature (Deek et al., 2016; Jafari et al., 2020; Kitko et al., 2020; NASEM, 2016) (see Figure 42).

Why these four methods of empowerment?

The decision to focus on these four methods is to address the following objectives:

- Bridging the gap between identified family needs and the goal of empowerment
- Providing structured empowerment methods that align with the personalization strategy

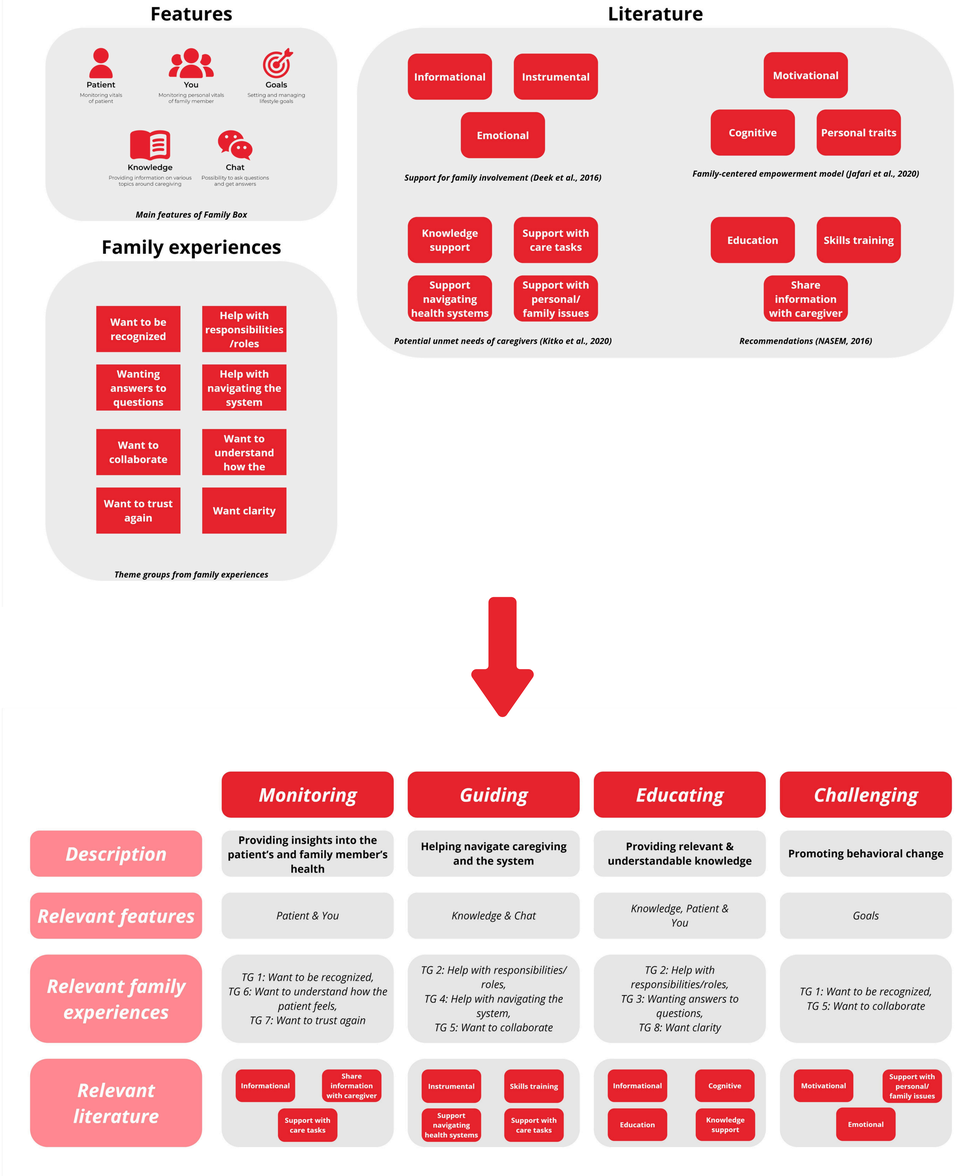


Figure 42: Methods of empowerment.

Connecting the four methods to family member needs

Findings from the focus group data and user research show that family members need a variety of support at different phases of the care journey and that not all family members engage with caregiving in the same way. These findings align with literature underscoring that empowerment is comprised of motivational, cognitive, and personal traits (Jafari et al., 2020).

- **Monitoring:** Supports family members who seek clear and structured insights into their own and the patient's health status. This addresses the need for being recognized, understanding how the patient feels, and the need to trust the patient's body again **(TG 1 + 6 + 7)** by helping them stay informed.
- **Guiding:** Helps family members navigate challenges by providing tools that support family members with their different responsibilities during the care journey. This responds to the needs related to navigating the health system and wanting to collaborate **(TG 2 + 4 + 5)**.
- **Educating:** Focuses on increasing the family member's knowledge and confidence through informational content, FAQs, and health insights. This method is based on the need for help with responsibilities, wanting answers to questions, and wanting clarity **(TG 2 + 3 + 8)**.
- **Challenging:** Aims to trigger lifestyle changes by providing reminders and goal-setting opportunities to promote self-care, caregiving, and family goals. This addresses the need of wanting to be recognized and wanting to collaborate **(TG 1 + 5)**.

Personalized empowerment through personas

Family members' needs, challenges, and roles vary and change over time. Designing features across the four empowerment methods helps offer support that stays relevant throughout the different phases of the care journey.

Each method of empowerment serves a different purpose, but altogether they affect empowerment. Family members might naturally lean towards one benefit but still benefit from others. For example, an Observer might have more direct value from Monitoring or Educating, but when they need to directly support the patient, this may change to Guiding.

By maintaining a flexible and still personalized approach, it allows the Family Box to engage with family members. This can be with tools that fit their natural tendencies while also encouraging them to develop new caregiving skills. Instead of assigning one empowerment method per persona, the Family Box should provide access to all four, anticipating the changes in needs, challenges, and roles over time.

Conclusion

The four empowerment methods serve as the link between family needs, the personas, and the goal of empowering the family member. They provide a structured approach that combines empowering and personalizing support. Therefore, by implementing these methods in the Family Box, family members are given not just information but also the guidance, motivation, and confidence they need to effectively manage the health and well-being of themselves and the patient.

2.3 What is personalized?

*The previous chapter has outlined four methods of empowerment: Monitoring, Guiding, Educating, & Challenging. To reach the goal of empowering family members, the Family Box personalizes the support to fit different needs, challenges, and roles of family members. This chapter explores **what** can be personalized and how it contributes to empowerment.*

*Using the personalization framework from **1.4 Personalization**, this chapter explores different aspects of the Family Box that can be personalized, including content, user interface, channel/information access, and functionality. AI technologies will be explored to understand their potential in improving personalization. Additionally, user research will inform how information can be structured and presented to family members.*

The goal of this chapter is to understand the possibilities and limitations of personalization in the Family Box. This will help ensure that the platform can support the family member in a relevant and effective manner. By aligning personalization with empowerment, this chapter helps structure a strategy that allows family members to get the right support for their situation.

AI capabilities

As noted earlier, in **1.1 Problem** and **1.4 Personalization**, the current capabilities of AI could be used to personalize the support for family members based on their specific needs and personas. Therefore, opportunities for AI will be explored through two types of machine learning. After identifying their capabilities and limitations, prototypes will be made to illustrate different ways of how AI could be implemented for offering personalized support. These different ways will be presented in line with the identified methods of empowerment from **2.2 Empowerment.**

Large Language Models (LLM)

LLM is a technology that is usually formed by deep neural networks and contains billions of parameters. These models train themselves on huge raw datasets, followed by a stage of fine-tuning to use the gained knowledge to generate output as desired by end-users. Input can vary from a simple question to large datasets. The output of these LLMs can be the generation of text or code to summarize, translate, or answer a question (Shen et al., 2023).

Multimodal Large Language Models (MLLM)

LLMs can analyze text as input, but MLLMs can also process other data types such as visual and audio (Han et al., 2024). The capabilities of analyzing visual or audio data bring interesting opportunities, like the identification of objects for nutrition or physical exercise purposes.

Based on this gained understanding of what is capable with AI, prototypes were made that will be presented in the following sections.

Content

As noted earlier in **1.4 Personalization**, Content refers to information and resources that are provided to family members. This content should address the needs of family members. However, to create information and resources that address the wide ranges of needs, challenges, and roles requires lots of resources. To make the process of making content more efficient, LLMs can be used.

Content creation

LLMs can be used to create content by using existing trusted resources to generate specific modules. For example, a booklet from the Hartstichting about heart failure covers various topics that can be split up into eleven modules that cover topics more specifically, like the symptoms, the causes, or living with heart failure.

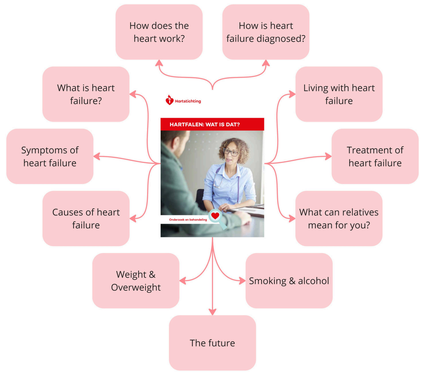


Figure 43: Creating 11 modules based on 1 booklet (e.g., "Hartfalen: Wat is dat?" (Hartstichting, 2024a)).

Content adaptation

LLMs can be used to change existing modules to fit better with the family member by adapting the reading level, translating, or rephrasing the text to address a family member or specific aspects of a family member instead of a general writing style. For example, by translating the text to French, a family member that does not speak Dutch very well can be supported without the need for external tools (see text below). As a result, making it easier for them to use the support available to them.

English

Rehabilitation after a heart condition, such as a heart attack or heart failure, often continues at home once the patient is discharged from the hospital. This home-based rehabilitation phase is critical for the patient to regain their strength and resume daily activities, but it comes with unique challenges that can make recovery difficult for many individuals.

French

La rééducation après un problème cardiaque, comme une crise cardiaque ou une insuffisance cardiaque, se poursuit souvent à domicile après la sortie de l'hôpital. Cette phase de rééducation à domicile est essentielle pour que le patient retrouve ses forces et reprenne ses activités quotidiennes, mais elle présente des défis uniques qui peuvent rendre la récupération difficile pour de nombreuses personnes.

User interface

As explained earlier in **1.4 Personalization**, this category addresses how information is displayed and interacted with by family members. Personalizing the user interface can create a user experience that feels relevant and supportive. In the context of the Family Box, user interface personalization can refer to adapting the way information is presented, navigated, or recommended based on personas. This can include variations in detail level and visual emphasis. Designing with these characteristics in mind can provide more relevant support in relation to the different characteristics of personas and family members.

To better understand the preferences of family members, user research was conducted via a survey and interviews. This is done to address the fact that family members show a 'Selective knowledge' characteristic where some family members want to know everything while others would like to know just a little bit. How this variety in preferences can be supported in the Family Box user interface is thus explored in the user research.

Preferences for information presentation

Survey & Interview results

Participants were shown five ways of presenting the heart rate of the patient, see Figure 44. They were asked to assess their preferences in two scenarios, one being when they would want to check the health of the patient quickly and one when they would want to check the health of the patient more elaborately.

Figure 44: Data presentation examples.

The methods were ranked in comparison to each other. To create a ranking, the first position was given 3 points, the second position 2 points, and the third position was given 1 point. Figure 45 shows the calculated scores.

Example	Quick (survey + interviews)	Elaborate (survey + interviews)
Graph	9 pts (9 + 0)	16 pts (8 + 8)
Colour	20 pts (12 + 8)	8 pts (8 + 0)
Numbers	15 pts (8 + 7)	9 pts (6 + 3)
Emoji	7 pts (6 + 1)	5 pts (4 + 1)
Text	5 pts (3 + 2)	6 pts (4 + 2)

Figure 45: Data presentation calculated scores.

For checking the health quickly, there are strong preferences for the use of colors (20 pts) and numbers (15 pts), while the elaborate checking shows a strong preference for the usage of graphs (16 pts). During the interview, participants elaborated on their choices, with colors having a quick interpretation effect and proposing the combination of colors and numbers to accommodate both scanning and detailed monitoring in a quick manner (see Figure 46). These preferences will be taken into account for the design of the Family Box platform.

Figure 46: Example of combined preferences.

Channel/information access

The way support is provided to family members is crucial to ensuring that it is accessible, engaging, and aligned with their preferences. Family members have different preferences when it comes to which information they would like to receive, as was established in **1.2 Family Experiences**. Additionally, based on their understanding of how they would like to see information being presented, it can also be assumed that they have different preferences regarding the reception of information and support. Some might prefer all notifications and updates to take place in the app, while others might prefer to receive email summaries or phone notifications. To account for these diverse preferences, flexibility is important, as this will help in supporting family members without adding unnecessary burden.

Personalization of information access

Personalizing **how** family members receive information will improve alignment with their needs. For example, real-time notifications could be better suited for highly involved family members that want to be updated continuously. While email summaries or less frequent updates could be preferred by family members that want to be updated but are less involved in daily caregiving tasks. Additionally, interactive elements such as a chatbot could guide family members in finding information, improving accessibility.

Feasibility

While multiple communication channels could improve engagement and accessibility, it does require more system resources. Therefore, the following challenges need to be considered when implementing or adding multiple communication channels:

- **Managing information overload:** As addressed by family members, they are selective in what they want to know and what not. Additionally, too many notifications or updates could overwhelm, which is something that the Family Box should prevent doing.
- **Privacy and security concerns:** Sensitive health information of the patient should be shared securely, ensuring that privacy is maintained and that the patient has control over what is shared and what is not.
- **Timeline of development:** As mentioned, implementing multiple communication channels requires more system resources and infrastructure, which may not be feasible for short-term timelines.

Impact on Family Box

Based on the identified challenges, the Family Box will need to balance flexibility and feasibility. As this project focuses on feasibility and allowing scalability in long-term goals, a starting point for the Family Box could be to start with general communication via in-app updates and allowing users to personalize their notification preferences. For the future, email summaries could also be explored to add as an extra communication channel and improve the flexibility of communicating with family members.

Functionality

This category will discuss various tools and features that could be made available to family members through the capabilities of both LLMs and MLLMs. These will be discussed along the four empowerment methods: Monitoring, Guiding, Educating, & Challenging.

Monitoring

The following tools and features are explored to help support family members in seeking clear and structured insights into their own and the patient's health status. As a result, addressing **TG 1**: Want to be recognized + **TG 6**: Want to understand how the patient feels + **TG 7**: Want to trust again.

Observation checklist

Generating a list of possible observations on a knowledge topic. For example, in the case of the Observer, this could allow them to respect the patient's autonomy while keeping an eye on possible signs of symptoms. This connects back to the drive of the Observer 'understanding.' This could be done with a module discussing the symptoms of heart failure, showing a list of visible signs that could be in line with certain symptoms so a family member can monitor visually as they do not feel what the patient feels.

Family Box fit: *Patient & Knowledge*

Interpretation of health data

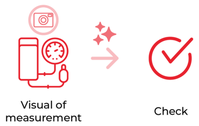
LLMs can analyze the health data of both patients and family members. Enabling the identification of trends in health data and summarizing them. This could help identify moments where better lifestyle choices can be made. For example, if a salt-heavy snack is logged frequently on Friday evening, this trend could be identified and result in the Family Box recommending a module on making salt-less snacks for a Friday night on the couch. With this feature, understanding the condition of both patients and family members becomes more interactive by identifying patterns that can help identify opportunities for lifestyle improvement.

Family Box fit: *Patient & You*

Measurement checker

Using MLLMs, it could be possible to analyze if measurement equipment is applied correctly. Using a camera, a photo or video could be taken to let the MLLM check whether or not all required steps were taken correctly in applying the device. Since there is no healthcare professional checking if the devices are used correctly, this feature could remove doubts from family members around measuring. For some methods of measurement, it might be possible to register data automatically through the camera. This could be useful for moments where the patient or family member uses devices that are not part of the setup of The Box but could add to the health data of the patient and family member.

Family Box fit: *Knowledge*



Guiding

The following tools and features are explored to help family members navigate the various challenges of caregiving. This focuses on the different responsibilities and roles by addressing **TG 2**: Help with responsibilities/roles, **TG 4**: Help with navigating the system, & **TG 5**: Want to collaborate.

Reflective question

This feature generates questions in modules or as a notification that connect an aspect of caregiving to a family member's own experience. This can stimulate self-reflection, helping family members consider their own roles, challenges, and approaches. This feature can help family members navigate their responsibilities and/or roles with more awareness. Instead of receiving information, they are triggered to think about how it applies to their situation. This could help them make informed decisions and better anticipate challenges, strengthening their ability to provide support to the patient.

Family Box fit: *Knowledge*

Module summary

A module can be summarized to show a brief overview of its content, enabling family members to quickly understand if it is relevant to them. This lowers the chances of information overload and helps family members more easily find the information they need. This feature can help the family member navigate their challenges more efficiently. Through this feature, they can scan key takeaways and quickly see if the content aligns with their current challenges.

Family Box fit: *Knowledge*

Conversation starter

This feature generates a question or statement to discuss a topic between a family member and patient. This facilitates the discussion of sensitive issues and both parties' expectations. Effective communication is essential in caregiving, as misunderstandings or concerns can cause stress and frustration for both parties. This prompt for conversation could promote collaborative caring and help family members connect with the patient.

Family Box fit: *You, Knowledge*

Step-by-step guide

Breaking down a module on a caregiving task or health-related actions into steps makes it easier for family members to apply this knowledge in real-life situations. As previously stated, caregiving may be challenging, and without clear instructions, family members may hesitate to take action due to uncertainty or fear of making mistakes. By offering clear and actionable directions, the bar for taking action is lower. Possibly making family members feel more confident and prepared. This feature allows family members to handle their responsibilities and roles with clarity, making them more manageable and effective.

Family Box fit: *Knowledge*

Nutrition tracking & scanning

Through MLLMs, it is possible to analyze photos of foods and drinks. First, this allows family members to track foods and drinks by making a photo, which then automatically adds it to the nutritional intake for the day. Secondly, they can determine if food and drinks fit a heart-healthy diet. Diet plays a huge role in recovery. By knowing and tracking what you eat and drink and knowing what is suitable, it becomes easier to make healthier choices. Having a quick way can remove uncertainty and make it easier to make informed decisions. As a result, it helps family members navigate the role of nutrition expert in a way that does not require prior knowledge. Instead of having to look up information every time, they get feedback immediately, making it easier to follow diet guidelines.

Family Box fit: *Knowledge*

Recipe generation

Another feature that could build upon the possibility of MLLMs to analyze photos is the recipe generator. Based on the photos showing the contents of the fridge or cupboards, a recipe can be suggested. Coming up with meals that fit heart-healthy diet guidelines and possibly also take into account food preferences (e.g., vegan, gluten-free, or taste preference) can be quite difficult. This tool uses available ingredients based on the analysis from the photos to suggest a meal, making it easier to make a meal that fits with the specific needs. As a result, what used to be general tips for nutrition can become personalized suggestions fit to the situation of the family member and patient. An example of this can be found here and seen in Figure 47.

Family Box fit: *Knowledge*

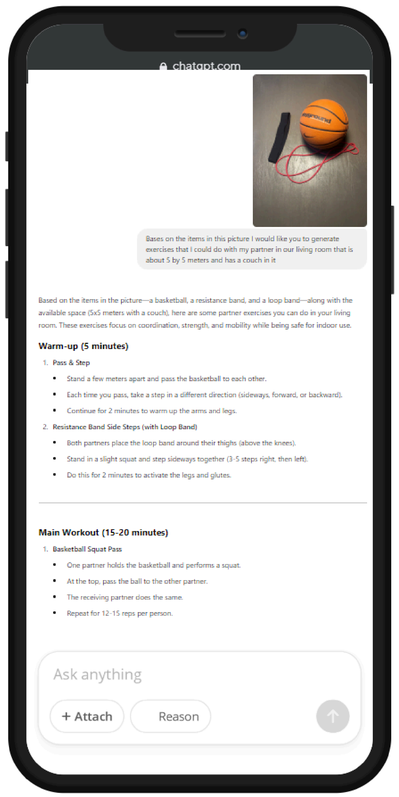


Figure 47: Example of recipe generator.

Recording appointments

As mentioned earlier, MLLMs can also process audio. This could be used to record voice memos or meetings with healthcare professionals. Remembering everything from an appointment can be difficult, as was described earlier in **1.1 Problem**. Especially with family members explaining that they live towards an appointment and want to get the most out of that short time, it is important that value is not lost. Having a way to save and revisit the discussions and shared information could clarify instructions, reduce misunderstandings, and make it harder to miss something important. As a result, it helps a family member to stay organized and lowers the responsibility of making sure everything is noted by hand or remembered.

Family Box fit: *Knowledge*

Educating

The following tools and features are explored to increase the family member's knowledge and confidence. This will address **TG 2**: Help with responsibilities/roles, **TG 3**: Wanting answers to questions, & **TG 8**: Want clarity.

Quiz questions

Based on modules in the Knowledge feature, it is possible to create quiz questions that help family members learn in a more interactive way. Instead of just reading information, they can test their understanding, which makes the content more engaging and helps them remember key details. This can be especially valuable for family members that are new to caregiving or less familiar with medical terms, as this will help build confidence in what they know. As a result of the quiz questions, family members will actively think about the information rather than just reading it. Through the questions, they can assess what they already know and what they might want to revisit.

Family Box fit: *Knowledge*

Medication scanner

Using the MLLM's capability to analyze photos, family members can scan medication. This can be used to identify the type of medication, what it does, and provide other relevant information. Knowing different prescriptions, dosages, and possible side effects can be a lot, especially when multiple medications are involved. By providing quick access to clear instructions and explanations, it helps family members feel more prepared during the care journey. As a result, learning about medication becomes more accessible and practical. Instead of searching for information or scanning long documents, family members get the right information quickly. This can reduce uncertainty and make it easier to effectively support the patient.

Family Box fit: *Patient, Knowledge*

Challenging

The following tools and features are explored to trigger lifestyle changes. Doing so will address **TG 1**: Want to be recognized & **TG 5:** Want to collaborate.

Goals or challenges

Based on the input of a family member or a module, goals and/or challenges can be suggested. This helps family members set personal targets to make lifestyle changes. Setting a goal can be motivating, but it can also be difficult to know where to start. By offering suggestions, family members can select something that feels achievable and relevant to their situation. Challenges can also introduce small, manageable steps to help them and the patient make healthier changes together. This encourages family members to take action and apply their knowledge.

Family Box fit: *Goals*

Physical exercises

This feature can suggest physical exercises based on photos of the family member's or patient's environment. Exercise plays an important role in recovery, but it is not always easy to know which moves are safe or practical to do in a certain environment. By analyzing the surroundings and recommending simple exercises using available space or items, this tool makes it easier to do physical exercise without needing extra equipment. This nudges family members to integrate movement that fits in their environment, making it easier to build and maintain a more active lifestyle, helping both the family member and the patient. An example of this can be found here and in Figure 48.

Family Box fit: *Knowledge*

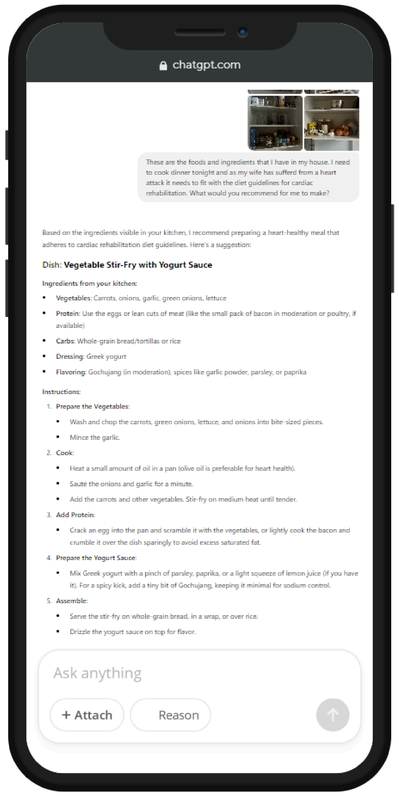


Figure 48: Example of physical exercises generator.

Fit with personas

The goal is to offer personalized support that fits with the caregiving styles and challenges of different family members. Each persona has a better fit with some features as they directly match their drive. As a result, Monitoring & Guiding features are better at supporting them in a way that seems natural to them. However, Educating & Challenging features can play an important role in expanding their skills and promoting behaviors outside of their comfort zone. By learning more about the patient's condition, becoming more familiar with taking measurements, or working on healthier habits, these features can help personas find new ways to manage the well-being of both themselves and the patient.

To determine which features best fit with a persona, the persona's drive, caregiving style, and coping strategy were used as guiding principles. For example, features that create structure and control were seen as more of a relevant fit to a persona driven by stability, while emotionally oriented features were seen as more relevant for personas that frequently engage in communication with the patient. Furthermore, features that do not directly fit according to the guiding principles were categorized as falling outside of the natural tendency of the persona. Together, these categorizations identify relevant features while also highlighting how some features might be irrelevant to a persona.

Mapping features to personas not only ensures a better alignment of their natural behavior and needs but also helps reduce overwhelm by guiding them to features that are relevant to them in the care journey. By distinguishing features that fit with a persona, it becomes easier to offer relevant support to family members when they are placed in a persona. As a result, giving them personalized support that can empower them to manage the health and well-being of both themselves and the patient.

Protector — *Drive: Concern*

The Protector is highly involved in caregiving and takes a hands-on approach to monitoring and managing the patient's health and well-being. They feel responsible for the patient and seek clear ways to track progress and minimize uncertainty. Therefore, features related to 'Monitoring' will most likely fit with their natural tendencies.

- *Features fitting best*
  - **Health data interpretation:** This helps the Protector make sense of trends in the patient's health data, supporting their concern and habit to control the situation.
  - **Module summary:** Allowing them to quickly scan relevant information without going through full modules.
  - **Measurement checker:** Providing direct insight into whether the measurement is taken correctly, helping them with their concerns regarding the accuracy of monitoring.
- *Features outside their natural tendency*
  - **Reflective questions:** Encouraging reflection, which the Protector might deprioritize in favor of practical caregiving tasks.
  - **Conversation starter:** Protectors may deem open discussions as less necessary, as they cope using a problem-focused strategy rather than an emotion-focused .

Adaptor — *Drive: Stability*

The adaptor is in search of balance between caregiving and daily life. They prefer practical and structured support that helps them stay organized and manage their responsibilities without becoming overwhelmed. Therefore, features regarding 'Guiding' will likely be more valuable to them.

- *Features fitting best*
  - **Step-by-step guide:** Helping them navigate caregiving roles with clear instructions, helping them stay organized, and reducing uncertainty.
  - **Conversation starter:** Stimulating emotional collaboration with the patient, building upon their tendency to approach the care journey together.
  - **Exercise generator:** Offering practical suggestions to include physical activity, making it easier to balance caregiving roles and daily life.
- *Features outside their natural tendency*
  - **Observation checklist:** As the Adaptor is highly involved with the patient, they may not need a list for visual cues, as they are already informed on the patient's condition.

Talker — *Drive: Connection*

The Talker is big on communication and emotional support. They feel most confident in open dialogue, sharing experiences, and ensuring that both they and the patient feel heard. Therefore, features that involve communication with the patient or others will likely be a better fit, while features that focus on hands-on caregiving will not.

- *Features fitting best*
  - **Conversation starter:** Aligning directly with their tendency to communicate and share with the patient or others.
  - **Reflective questions:** Encouraging reflection and emotional processing, which the Talker has a natural tendency for. This allows them to explore their thoughts and feelings while possible, triggering discussions with the patient and others.
  - **Goals generator:** Supporting their focus on approaching the care journey together by allowing them to set and track goals with the patient.
- *Features outside their natural tendency*
  - **Measurement checker:** Talkers focus more on the emotional aspects rather than hands-on caregiving, so they likely will not feel the need for verifying measurements.

Observer — *Drive: Understanding*

The Observer prefers to stay informed as they maintain or are forced to maintain a distance. Therefore, they value structured knowledge and tend to be more passive in hands-on caregiving while wanting a clear understanding of the patient's condition. Therefore, features that give insight into the patient's condition will likely have a good fit, while features that require active involvement in the caregiving of the patient might not be.

- *Features fitting best*
  - **Observation checklist:** Helping them to keep an eye on the patient's condition without them becoming directly involved, matching their situation of supporting from a distance.
  - **Medication scanner:** Allowing them to find out quickly without needing to ask the patient, fitting their independent involvement.
  - **Health data interpretation:** Helping them understand the patient's condition without needing to involve themselves.
- *Features outside their natural tendency*
  - **Step-by-step guide:** Observers may be less likely to take up caregiving tasks, thus reducing the relevance of structured instructions.
  - **Conversation starter:** As Observers avoid or are kept at a distance, discussions on health topics will not be likely, making this feature less relevant.

Balancing persona fit and flexibility

Each persona has their own natural tendencies, which makes some features fulfill their direct drive in the care journey, but this does not mean that they are limited to them. For example, a Talker might benefit from the Step-by-step guide feature to help them become more involved in caregiving. Similarly, an Observer might want to discuss health topics, making the Conversation starter feature more interesting.

By structuring the Family Box features around personas, the system provides a toolbox of features that are relevant to a range of different challenges and needs in the care journey. By keeping features available to all family members, they are in control of using the ones that feel most relevant to them. This way ensures that while core needs are addressed, family members can adapt and discover new ways to involve themselves in the care journey, as their roles might change over time. At the same time, features can be suggested to family members based on their personas to reduce overwhelm and provide the most relevant support.

Conclusion

The Family Box provides personalized support that adapts to different caregiving needs, but several challenges must be considered to keep it feasible and effective.

First, overpersonalization should be avoided. While personalizing support to a persona is helpful, limiting them to a set of features may prevent them from developing new caregiving skills. Personalization should help and not restrict. Thus, exploration beyond natural tendencies should be encouraged.

Secondly, privacy and security are crucial when dealing with health-related data. Family members and patients should have clear options for managing their data, knowing what is collected, shared, and why. Transparency in this could help build trust and ensure that both parties are comfortable with personalization features.

Thirdly, AI-driven personalization adds complexity to the Family Box. These technologies are able to analyze, generate, and modify content in a short amount of time. However, they should be reliable, ethical, and able to deal with nuance. A phased approach where AI output is validated before becoming automated could help deal with this challenge.

Overall, through these features and the structure, the Family Box can offer flexible and relevant support that adapts without overwhelming family members. Personalization should make the care journey easier while empowering the family member, ensuring that support adapts based on the needs of family members.

2.4 Who does the personalization?

The previous chapter explored the different aspects of what is personalized within the Family Box. These elements define what can be designed to fit the needs, challenges, and roles of family members. However, it is also important to determine who controls the adjustments. This section will explore when personalization should be explicit (user-driven) or implicit (system-driven), as explained in ***1.4 Personalization****.*

By using explicit personalization, it gives family members control, allowing them to set preferences and personalize their experience. On the other hand, implicit personalization makes automatic adjustments, reducing the effort required from the family member while still providing relevant support.

Both approaches have advantages and challenges. While explicit control offers transparency and autonomy, it also puts more responsibility on the family member. Meanwhile, implicit personalization can smoothen the experience but requires a careful approach to make sure that it fits well with the family member's situation. Therefore, this chapter will explore how these types of control can be applied in the Family Box to match strengths and opportunities appropriately.

Explicit and implicit personalization

In this chapter, the matching process will be discussed first, followed by how personalized elements from the previous chapter are controlled in the Family Box.

Matching process

In **2.1 Persona development,** a set of four personas was created. However, it remains unclear how family members can be matched with the most relevant persona. To explore how this could be done, the following steps were taken. First, this was discussed with the postdoctoral researcher to understand how this process could be done. Secondly, the timing of this process was further discussed with the medical psychologist to better understand if this fits the care paths of MI and OHS.

The matching process design consists of two parts: the way the matching is conducted and the timing. Together they inform on whether or not this process can be done explicitly or implicitly.

How can the match be made

There are three possibilities for the matching process, see Figure 49. First, the system can completely do the matching, thus implicitly personalizing the support. This could be done through questions, going through scenarios, or a chatbot, for example. The second option allows the family member to choose themselves which persona fits best with them in their opinion, thus explicitly personalizing the support. Or third, the system proposes a persona, and the family member can choose to accept or change it. This way allows for both implicit and explicit personalized support.

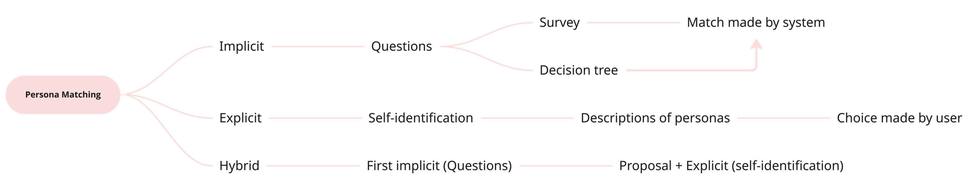


Figure 49: Matching methods.

Timing

Essentially, there are two moments of timing when the matching process could take place. First, the process could be conducted at the start during the onboarding process or later on. When done immediately, users can be matched based on information that is gathered at that moment, or they can choose their own persona. By doing this at the start, it could help the family member feel recognized and provide clarity, linking back to **TG 1**: Want to be recognized & **TG 8**: Want clarity from the identified family experiences. Secondly, it could be done later during use, meaning that data is gathered already on the family member during its use in the app, possibly helping with the identification of needs that fit with specific personas.

Additionally, a medical psychologist was approached to better understand the ability of family members of MI and OHS patients to self-identify or know what they need in regards to matching them to a persona. During the discussion, it became clear that there is a crucial difference between MI and OHS patients and their family members. The medical psychologist explained that after hearing that their relative/partner has experienced an MI or is in need of an OHS, family members typically go through a psychological shock lasting approximately 2-3 weeks. During this psychological shock, it is difficult for a person to know and consider what they want or need. As a result, it is difficult during this psychological shock to match a family member with a persona that actually is most relevant to them.

However, the timing of the psychological shock and the receival of the Family Box are different per care path. As explained earlier in **Problem statement**, the Family Box will be shared with family members at discharge. This moment of receival can align with the psychological shock, as some care paths have a shorter time period before discharge in comparison to others. For example, an MI patient could have been walking the dog in the morning before work and suddenly be in the hospital in the afternoon. As a result, the Family Box is introduced during the phase of psychological shock. However, an OHS patient has been preparing for the operation for a longer period of time. Thus, the moment the Family Box is introduced to an OHS family member is likely a moment that they are capable of assessing what persona is most relevant to them. This difference should be taken into account for the timing of the matching process in the Family Box.

Matching process for the Family Box

To determine which timing and method of matching is most suitable for the Family Box, the following steps are taken. First, the way that matching takes place is determined through considering four aspects that stem from the TGs and problem statement. Secondly, the moment of matching will be decided based on TGs and expertise from a medical psychologist.

To determine which method of matching is best suitable for the Family Box, an analysis is done based on four aspects:

- Support from hospital
  - Based on **TG 2** Help with responsibilities/roles, **TG 4** Help with navigating the system, & 'Where is the reaching hand of the hospital?'.
- Patient empowerment
  - Based on the problem statement goal.
- Collaboration
  - Based on **TG 5**: Want to collaborate.
- Cognitive load (time & easy to do)
  - Based on **TG 8**: Want clarity.

Using these aspects in combination with the Harris Profile method, the three possible matching methods were evaluated. This method helps make evaluations more explicit (Van Boeijen et al., 2014). Based on these four aspects, the following evaluation was conducted, see Figure 50.

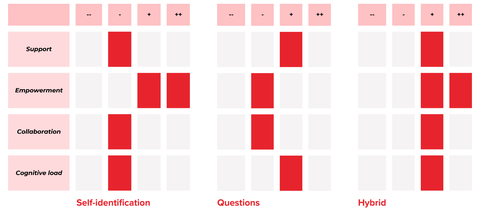


Figure 50: Harris profile evaluation.

Looking at the three matching methods, it becomes clear that the hybrid approach combines the strengths of both self-identification and questions while also improving the collaboration aspect. Using the hybrid approach allows the family members to decide themselves at all times if they want to make this process explicit or implicit. As a result, creating a balance between the two that is flexible for different family members.

Given the differences between planned and sudden hospitalizations, a possible solution could be to make the matching a modular element. Meaning that immediate matching is done for the planned care paths (like OHS), and delayed matching is used for sudden care paths (like MI). Another approach is to make the matching a consistent element, using a delay of 3 weeks before matching takes place. This creates an opportunity for family members, regardless of their care path, to process the situation before getting into the decisions about their support needs.

Considering feasibility, the latter option is better suited to implement, as this option simplifies the process and structure by making it a universal moment. However, the option to make the timing of the matching process modular could be interesting for the future to improve the relevance of the Family Box over different care paths.

Explicit vs. implicit in the Family Box

Within the five main features, various elements can be personalized explicitly and implicitly. Explicit personalized elements will be used to give the family member control over the personalization to alter it to their preferences. Therefore, making the Family Box flexible to the variety of family members within personas. Implicit personalized elements will be used to reduce overwhelm and lower the complexity of the Family Box for family members. This will be done through automated processes that are based on the persona, goals, or input of the family member.

To clarify which elements are explicit and which are implicit, the following list will show elements that are part of the five main features:

- **Us:**
  - Will be named after patient if consent is given. [Explicit]
  - Will only share data that is preferred to be shared by both family members and patients. [Explicit]
  - Will allow family members to pin health data they prefer. [Explicit]
  - Will contain textual elements that are written from the perspective of a family member reading about the patient and taking persona into account. [Implicit]
- **You:**
  - Will allow family members to pin health data they prefer. [Explicit]
  - Will contain textual elements that are written from the perspective of a family member reading about themselves. [Implicit]
- **Goals:**
  - Will allow the creation of own goals. [Explicit]
  - Will suggest goals in line with persona. [Implicit]
- **Knowledge:**
  - Will recommend knowledge and tools based on persona. [Implicit]
  - Will adapt knowledge based on persona. [Implicit]
  - Will recommend knowledge and tools based on goals. [Implicit]
  - Will recommend knowledge and tools based on the input of family members. [Implicit]
- **Chat:**
  - Will suggest chats based on persona. [Implicit]

Furthermore, content can be made available to the family member through the dashboard page. This can recommend a relevant module that helps with needs or challenges that are present with a persona. This process uses implicit personalization to help family members automatically with challenges and needs in a certain phase of the care journey.

Hotkey features

To further increase the flexibility of personalization to support different types of family members within a persona, family members can explicitly personalize a main feature on the dashboard. Instead of implicitly assigning a feature to the family member based on their persona, family members can explicitly select the feature they deem most relevant.

This feature functions as a hotkey for the family members, providing a feature that aligns with their own needs, challenges, or roles. In order to make a selection of features for the family members to choose from, features were ideated based on a persona's drive, characteristics, behaviors, and possible support strategies from **2.1 Persona development**, see Figure 51.

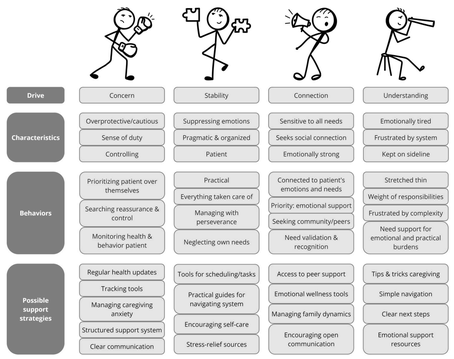


Figure 51: Personas with drives, characteristics, behaviors, and possible support strategies.

In total, fifteen unique features were developed and then reduced to eight features based on their relevance to multiple caregiving styles, impact on the care journey, and alignment with needs identified from family experiences (see Figure 52). It is important to note that these features serve as illustrative examples rather than a definitive selection. They provide a starting point for exploring how support could be personalized and can be expanded or refined in future iterations of the Family Box. The selection of these eight hotkey features will be presented shortly on the next page.

Figure 52: Eight hotkey features.

Quickview of patient's health

Many family members want to be informed about the patient's condition but prefer to know if they are okay rather than seeing detailed information. This feature helps them check at a glance without overwhelming them with too much data. This can be relevant for both highly involved family members and those at a distance.

Alerts

As family members balance multiple roles, they can be overwhelmed by these roles and their daily lives. Through this feature, family members can be quickly notified about critical moments. As a result, important events are not missed, making the care journey less stressful and more structured.

Checklist

As caregiving involves various tasks, a checklist can help family members organize their responsibilities and roles to ensure nothing gets overlooked. This feature helps both active family members that like planning and more passive family members who need reminders.

Self-care tracker

Family members often neglect their own well-being. This feature stimulates them to be aware of their own health and well-being by helping them track activities and moments of self-care. This feature builds upon the need of family members wanting to be recognized by giving them the space to work on their own well-being.

Family communication channel

Family members often act as informers for other family members or friends. At the same time, family members recognize the value that the help of others can be in lightening the caregiving burden. To address both aspects of the care journey, this feature allows them to share updates and ask for help through one channel rather than having to deal with multiple chats and calls. As a result, helping them with their role as manager of social support.

Diary

Family members need time and space to process what happens during the care journey. This diary feature offers them a space to reflect or note down their thoughts and experiences. Some family members may use it for writing down practical things, while other family members could use it for emotional reflection. This feature respects both coping strategies represented in the third dimension of the personas.

Patient journey map

Understanding at what phase the patient is in the journey can reduce uncertainty and prepare family members to help them provide support in specific phases. It helps family members anticipate challenges, track progress, and become more prepared for their roles.

Conversation starter cards

Communication is an important part of caregiving, but discussing sensitive topics can be challenging. These cards can help family members to initiate conversations about health, emotions, and expectations. While some family members may naturally engage in discussions, others may need a nudge to start them.

To ensure that family members are not limited by their persona and still have access to features that could be valuable to them, a flexible approach is taken. With this approach, family members can explicitly personalize the hotkey feature themselves to use a feature they deem most valuable or useful to them.

2.5 Conclusion of Create

Modularity in the Family Box

As mentioned earlier in **1.1 Problem**, modular elements are features, modules, or other elements that can be added, removed, or adapted to increase the relevance of the support for a specific care path. This makes them important for scalability to different care paths or even a prevention lifestyle version of the Box.

First, a visual cue will be introduced within Patient and Knowledge visible as a health aspect called ‘Zorgpad’ (English: care path). This cue will be displayed on information or tools specific to the care path of the patient. This will be added to the list of aspects based on the 'Leefstijlroer', see Figure 53. In this project, this element will focus on MI and OHS cases, but in the future, this element can be set up for other care paths.

Figure 53: Leefstijlroer (Vereniging Arts en Leefstijl, n.d.)

Secondly, a modular element will be on the dashboard (see Figure 54, shown in light green), showing recommendations based on the phase of the care journey. These recommendations will focus on the needs of family members that change over time. For example, suggesting topics relevant to the discharge phase early on and later shifting to content that supports sustaining well-being. This modularity means that the content and functionality of the Family Box recommendations can be adapted to different care paths or phases in the journey without having to redesign the Family Box. As a result, creating a system that remains flexible and is personalized while being scalable to other care paths beyond MI and OHS.

Figure 54: Modular element on dashboard.

Conclusion

At the beginning of the Create phase, the persona strategy was developed, which serves as the basis for personalization in the Family Box. Based on the family experiences, three dimensions were identified that were used to structure a set of four personas: involvement, care approach, and coping strategy. The personas were validated with experts and user research, confirming their accuracy but also highlighting a fluidity across personas. This insight emphasized the need for flexibility in the personalization strategy to adapt to this fluidity.

Personalization will help ensure that the support for family members is relevant, but the Family Box also aims to empower family members. Therefore, four methods of empowerment Monitoring, Guiding, Educating, and Challenging were introduced to connect personalization to the goal of empowerment. Each method of empowerment is connected to the features of the Family Box, the literature, and the identified needs. Together, they help family members manage the health and well-being of both themselves and the patient.

In order to implement personalization effectively, the Family Box needed a clear overview of what elements could be adapted to the family member. The third chapter explored four aspects of personalization. AI technologies were explored, showing that they can personalize support in various ways, varying from content adaptation to creating food recipes that are in line with heart-healthy diet guidelines. Additionally, user research was conducted to understand how family members prefer information to be structured and presented, ensuring that the Family Box’s interface meets the needs of family members.

The last step of the phase focused on who controls the personalization and whether it should be explicit or implicit. A combination of both was used to balance flexibility for different family members within personas while ensuring that they also benefit from automated personalization. The matching process of the personas was also discussed, resulting in the decision to delay this for three weeks to account for the psychological shock period of caregivers. Additionally, a hotkey feature was introduced that allows family members to explicitly personalize a feature that best supports their situation, further ensuring flexibility within the personas.

This phase built the basis for a structured, flexible, and feasible personalization strategy that allows the Family Box to offer support that is relevant and empowering for family members. Through the use of personas, empowerment methods, and personalized features, the Family Box can align with the diverse needs of family members without being restrictive or overwhelming.

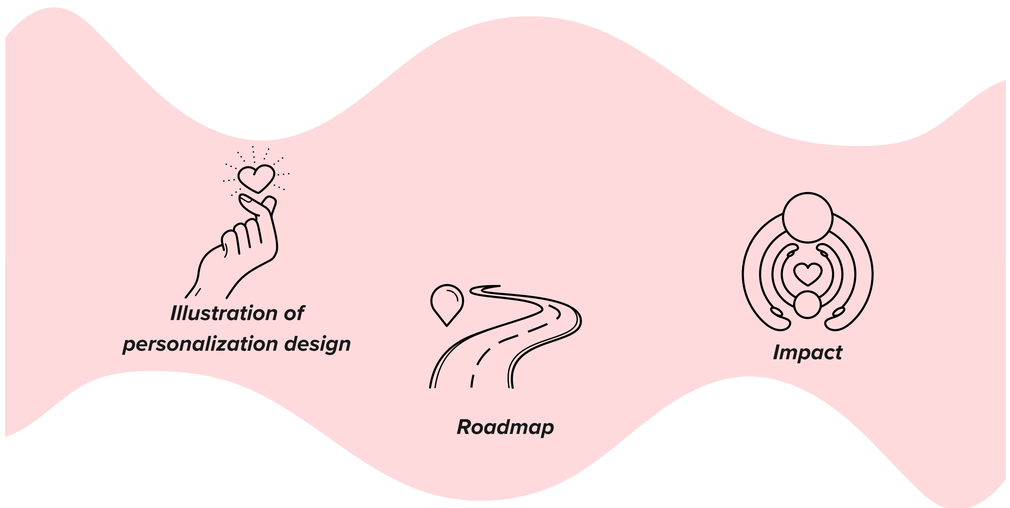
The next phase, Deliver, will focus on illustrating this strategy together with presenting a practical implementation roadmap. This roadmap will include testing the feasibility, desirability, and accuracy of the personalization strategy. Altogether, this will guide the further development of the Family Box to personalize support and empower family members to manage the health and well-being of both themselves and the patient.

Deliver

The Create phase resulted in a structured personalization strategy relevant to the diverse needs and roles of family members. By developing personas, identifying empowerment methods, exploring personalization aspects, and evaluating personalization mechanisms, a foundation was built for implementing personalized support within the Family Box.

In the Deliver phase, this strategy is illustrated through interfaces. These interfaces show how personalization can take shape within the Family Box through example scenarios, modular elements, and support tools. The design outcomes focus on feasibility and scalability, showing how the system can adapt to various care paths and family dynamics while remaining user-friendly. In addition, steps for implementation and opportunities for further development are outlined, providing a clear pathway from concept to realization.

Together, these outcomes demonstrate how the Family Box can offer meaningful, personalized support to families, contributing to improved health experiences and collaborative care in both current and future contexts.



Overview of personalization strategy

To summarize, the personalization strategy consists of the following core components:

0. Main features

Based on the current Box setup and the development of the Health Box, the Family Box will consist of five main features:

- Patient
- You
- Goals
- Knowledge
- Chat

1. Persona-based personalization

Personalization framework dimensions: *1. What personal characteristics are addressed & 2. To whom is personalized.*

Based on the family experiences in the focus group data, three dimensions were created:

- Involvement
- Care approach
- Coping strategy

These dimensions were then used to develop four personas:

- Protector
- Adaptor
- Talker
- Observer

Together, these personas serve as the foundation for personalizing the support to different challenges and needs during the care journey.

2. Empowerment methods

Empowerment is implemented through four methods: **Monitoring, Guiding, Educating, & Challenging**. These methods are integrated into the Family Box's features and directly linked to the identified needs and challenges of the personas.

3. Personalized elements

Personalization framework dimension: *3. What is personalized.*

Key elements such as **content, user interface, & functionality** have been explored for personalization. Through the use of AI technologies (e.g., LLMs and MLLMs), personalization is enhanced throughout the Family Box.

4. Balanced personalization control

Personalization framework dimension: *4. Who does the personalization.*

A combination of **explicit** (user-driven) and **implicit** (system-driven) personalization is implemented. Family members can personalize themselves to improve flexibility for differences between family members within a persona. The Family Box can personalize for family members to reduce feelings of overwhelm and receive personalized support automatically that is relevant to their persona.

5. Modularity for scalability

Modular elements are integrated into the Family Box to ensure that it can be adapted for different care paths beyond MI and OHS. This enables future scaling without redesigning the Family Box's structure.

Together, these components form a personalization strategy that is relevant, feasible, and scalable. It ensures that the Family Box offers the right support at the right time to empower family members to manage the health and well-being of both themselves and the patient. The final dimension of the personalization framework, 'Impact,' will be discussed in **3.2 Impact**.

3.1 Design illustrated

Building upon the previously identified components of the personalization framework, this chapter will present the final design for the Family Box. The design illustrates how the defined strategy can be implemented in a structured platform, ensuring that the support for family members is both relevant and adaptable to their needs. Through the implementation of consistent, personalized, and modular elements, the Family Box remains feasible and flexible.

The illustrated design makes the personalization strategy feasible by showing how family members can interact with the platform, navigate, access relevant sources, and personalize their experience. Each feature has been designed to align with the needs and behaviors identified in the user research, ensuring that family members feel recognized, supported, and empowered throughout the care journey.

*In the following sections, the main features will be discussed shortly. Followed by a scenario showing **when**, **where**, and **how** the Family Box is involved in the care journey. Finally, the personalization strategy within the design will be discussed further by covering different aspects like the onboarding process, explicit & implicit personalization, and modular elements will be discussed in detail, showing how they fit in the strategy to create a relevant and effective support system.*

Consistent main features

First, the dashboard will be presented, followed by an overview of the main features and how they connect to family member needs.

Dashboard

The dashboard will be the main page where the family member can access all main features, access settings, and search for information (see Figure 56). While some main features exist in the current Box setup (**Patient**), this design focuses on how the family member interacts with the patient data.

Although the Box includes similar features, its primary focus is on the patient. Features like **Goals**, **Knowledge**, and **Chat** are still in development but are designed with the patient in mind. The introduction of the '**You**' feature is new, offering a distinct feature that focuses on the health and well-being of the family members. While some features share similarities with the current and future features of the Box, they have been designed to ensure that they support family members effectively, leading to differences in their structure, content, and functionality.

Purpose

Give a simple overview of features, balancing simplicity and functionality.

Addressed needs

- **TG 1**: Want to be recognized
- **TG 3**: Wanting answers to questions
- **TG 6**: Want to understand how patient feels
- **TG 8**: Want clarity

The next page will shortly present the main features, followed by a page highlighting where the addressed needs are supported in the interfaces. A more elaborate explanation of the main features can be found in Appendix E.

Modular adaptability

To ensure scalability for the Family Box across different care paths, modular elements are implemented. These allow the system to adapt its content to the specific context of the patient, for example, distinguishing between family patients recovering from an MI or an OHS. While there is overlap between these care paths, there are differences in treatment, medication, and recovery.

Through the use of these modular elements, it is possible to make content more relevant to the situation of the family member and patient. For example, through the identification of important health data, care path-specific modules, and challenges.

On the dashboard, modular elements can be shown in the notification area that also shows notifications related to the **Goals** feature (see Figure 56). In other features, modular elements are labeled using the care path category icon, see Figure 55.

Purpose

Provide relevant support that matches goals of the family member or patient or the care path of the patient.

Addressed needs

- TG 1: Want to be recognized
- TG 8: Want clarity

Figure 55: Care path specific icon.

Figure 56: Dashboard, consistent features marked in pink.

Main features Family Box

Patient

Purpose

Give a structured overview of health aspects and providing information on the patient.

Addressed needs

- **TG 6**: Want to understand how the patient feels
- **TG 7**: Want to trust again
- **TG 8**: Want clarity

You

Purpose

Give a structured overview of health aspects of the family member.

Addressed needs

- **TG 1**: Want to be recognized

Goals

Purpose

Allow monitoring of goals and creating them for the family member or the patient and family member.

Addressed needs

- **TG 5**: Want to collaborate
- **TG 6**: Want to understand how the patient feels

Knowledge

Purpose

Provide relevant information and tools for a wide range of topics.

Addressed needs

- **TG 2**: Help with responsibilities/roles
- **TG 3**: Wanting answers to questions
- **TG 4**: Help with navigating the system
- **TG 8**: Want clarity

Chat

Purpose

Provide a space for family members to ask questions or express their concerns.

Addressed needs

- **TG 2**: Help with responsibilities/roles
- **TG 3**: Wanting answers to questions
- **TG 4**: Help with navigating the system

Main features elaborated

Patient

Possibility to pin aspects

First layer of health aspects

Purpose

Give a structured overview of health aspects and providing information on the patient.

Addressed needs

- **TG 6**: Want to understand how the patient feels
- **TG 7**: Want to trust again
- **TG 8**: Want clarity

Second layer of health aspect

You

First layer of health aspects

Purpose

Give a structured overview of health aspects of the family member.

Addressed needs

- **TG 1**: Want to be recognized

Recommended modules for deepening knowledge

Goals

Want to understand how the patient feels [TG 6]

Want to collaborate [TG 5]

Purpose

Allow monitoring of goals and creating them for the family member or the patient and family member.

Addressed needs

- **TG 5**: Want to collaborate
- **TG 6**: Want to understand how the patient feels

Creation of goals

Knowledge

Wanting answers to questions [TG 3]

Recommended modules/tools

Help with navigating the system [TG 4] + Want clarity [TG 8]

Purpose

Provide relevant information and tools for a wide range of topics.

Addressed needs

- **TG 2**: Help with responsibilities/roles
- **TG 3**: Wanting answers to questions
- **TG 4**: Help with navigating the system
- **TG 8**: Want clarity

Modules with a focus on family members

Chat

Help with responsibilities / roles [TG 2]

Wanting answers to questions [TG 3]

Purpose

Provide a space for family members to ask questions or express their concerns.

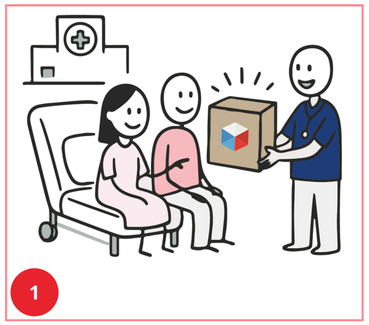
Addressed needs

- **TG 2**: Help with responsibilities/roles
- **TG 3**: Wanting answers to questions
- **TG 4**: Help with navigating the system

Check if healthcare expertise is needed

Scenario

Discharge

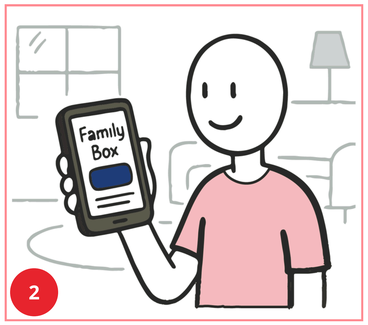


Upon hospital discharge, the patient and family receive the Box and Family Box. The Box contains monitoring devices that allow the patient to take measurements and a flyer introducing the Family Box app to the family member.

Family member

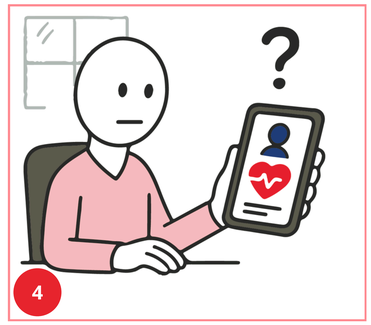
Patient

Adaptation



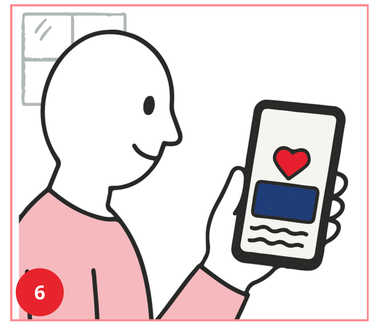
At home, the family member has downloaded the Family Box app and gets introduced to the features, content, and structure of the Family Box through an onboarding process.

As part of the onboarding process, the family member and patient discuss which types of health data they would like to share or receive. This helps set boundaries and expectations for transparency and involvement.



When the onboarding is completed, the family member can access the five main features of the Family Box (**Patient**, **You**, **Goals**, **Knowledge**, & **Chat**) in their general state (not yet personalized). This allows the family member to monitor the patient remotely to check how they are doing when they are separated.

During this phase it is also possible to create goals for themselves based on the 'Leefstijlroer' aspects. Within the **Goals** feature they can also monitor the goals of the patient and create shared goals for tackling lifestyle goals together.

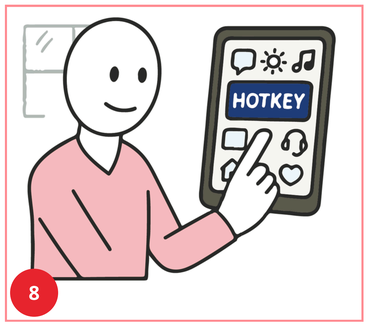


The Family Box suggests specific modules, tools, or content based on the patient's care path. Helping the family member to understand specific information, challenges, or needs of the MI care path.

Beginning of rehabilitation

After 3 weeks, the family member is guided through a matching process. This process is set up to match the family member with a persona **explicitly** or **implicitly**. This persona shapes how support is personalized to their needs, preferences, and caregiving style.

Additionally, the family member can rename the **Patient** & **You** feature to the name of the patient and their own name if preferred.



After being matched to a persona, the family member can select a hotkey feature that will be available to them from the dashboard interface. This allows the family member to **explicitly** personalize the support, letting them make the choice of which feature they find most valuable to their situation.

The Family Box will now recommend modules or tools based on the persona. Depending on the phase of the care journey, different topics or roles will be addressed. For example, in the phase 'Beginning of rehabilitation', a module will be suggested on the topic of creating a basis for heart-healthy eating.

Transition to independent living

Through the **Chat** feature, the family can get answers to questions quickly at a low threshold. For example, when a medication change occurs, the family member can check what impact this could have on the patient.

As the patient becomes more independent over time, the Family Box will offer tools or modules covering relevant topics to this phase. These phase-specific modules support the family member in their roles and responsibilities.

Sustaining well-being (after CR)

Even after CR ends, the Family Box continues to offer relevant support for the family member. Modules and tools in this phase focus on sustaining healthy routines, maintaining emotional balance, and paying attention to the relationship beyond the caregiving role.

Onboarding

As shown in the scenario on the previous page, family members will be welcomed to the Family Box platform through an onboarding process. This process introduces them to the different features and where to find specific things. The personalized support will be mentioned, but the family member will be explained that they start in a general version of the app to give them the time to process being home with the patient. After 3 weeks, they will enter the matching process, in which the Family Box uses input from the family member to determine which persona fits best to their situation.

The onboarding is also the moment where both patients and family members get to fill in their preferences for data to be shared/received. The overlap of preferences will be shared so that the privacy of the patient is maintained if preferred and the family member does not get information they do not want (see Figure 57).

The interfaces shown on this page illustrate how family members are onboarded onto the Family Box app (Figures 58 and 59). This onboarding process is designed to offer a reaching hand, provide clarity, and introduce the main features.

It begins with a welcoming screen (**1**) that explains in short the purpose of the onboarding process. Followed by the second screen (**2**) that acknowledges the family member's role. This is done to address **TG 1**: Want to be recognized and reassure family members about their value in the care journey. Additionally, it is explained that personalized support will be offered, but the family member will start in a general version.

Next, the Family Box introduces the structure based on the 'Leefstijlroer' (**3**). The structure consists of the six lifestyle aspects that are elaborated with the care path aspect to show information and tools specifically relevant to a care path.

An important part of the onboarding involves gathering the preferences for shared health data. First, the concept of shared data is explained (**4**) and how the Family Box recommends health data is most relevant to the care path of the patient. In the next interface (**5**), they are presented with three sets of health data (physical, lifestyle, and care path data). Out of these three sets they can indicate which they would like to receive. After both the patient and family member have filled in their preferences, they will be presented with the overlapping data that will be shared (**6**).

Finally, the family member lands on the general version dashboard (**7**), which becomes their main starting point in the app. From here, they can access the main features and stay updated with relevant modules or reminders. Together, this onboarding process not only introduces the Family Box's features but also addresses the needs of family members right from the start.

Purpose

Welcome and introduce the family member with the Family Box.

Addressed needs

- TG 1: Want to be recognized
- TG 4: Help with navigating the system
- TG 6: Want to understand how the patient feels
- TG 8: Want clarity

Figma prototype

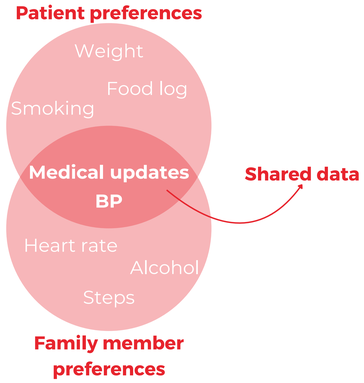


Figure 57: Shared data preferences example.

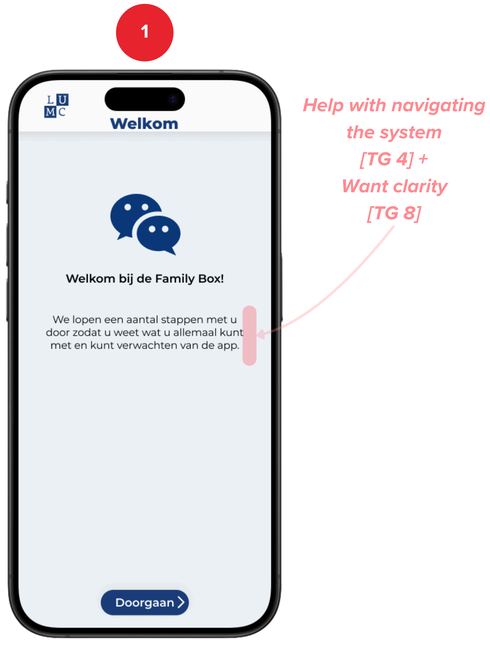


Figure 58: Onboarding first step.

Figure 59: Onboarding process interfaces.

Personalized support strategy

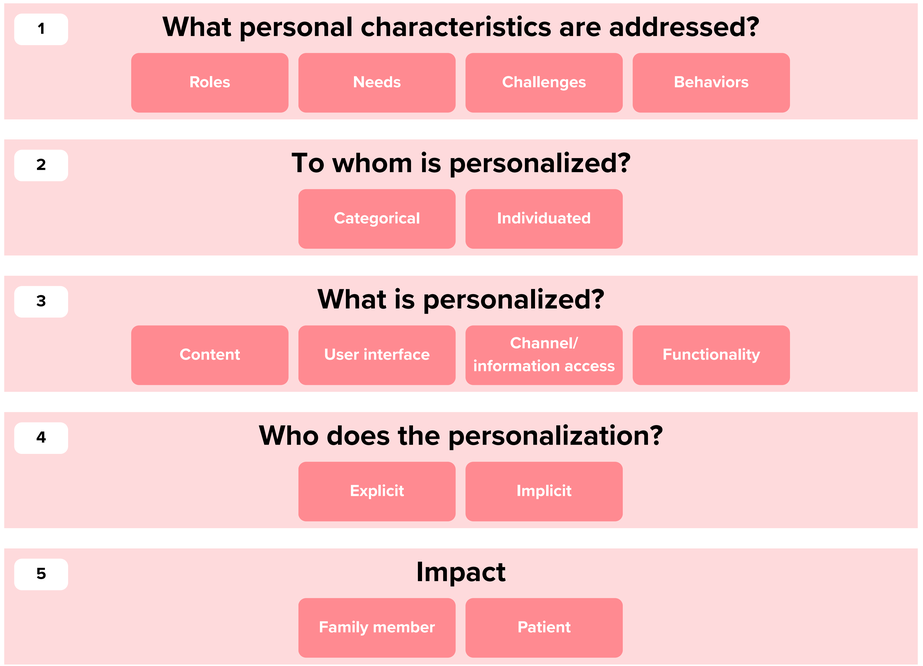


Figure 60: Personalization framework.

Using the personalization framework designed in **1.4 Personalization**, the personalized support strategy will be presented in the following pages. The dimensions of the framework will be used to explain how personalization is implemented within the Family Box.

Additionally, the empowerment methods that were identified in **2.2 Empowerment,** will be used to explain how the personalization contributes to the goal of empowering family members to manage the health and well-being of both themselves and the patient.

Figure 61: Four methods of empowerment.

Together, this framework and methods of empowerment will explain how the problem statement can be answered with this design of the Family Box.

How can we provide personalized support to families of patients during the care journey of MI or OHS to empower family members in managing health and wellbeing individually and for the patient?

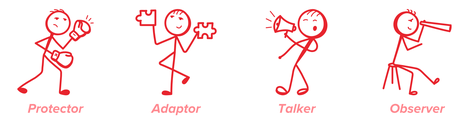
What personal characteristics are addressed?

The personalized support starts similarly to the framework by identifying *what personal characteristics are addressed*. In **2.1 Persona development,** this was done through the analysis of family experiences from focus group data. Leading to four personal characteristics to be addressed in the strategy:

- Roles
- Needs
- Challenges
- Behaviors

To whom is personalized?

Secondly, these characteristics informed the design of personas that helped set the level of personalization. As a result, strengthening the understanding of *to whom is personalized*. This led to a set of four personas and categorical personalization at a persona level.



This places the current level of personalization on the lower side of the '**one to some**' level of **categorical personalization**, as can be seen in Figure 62.

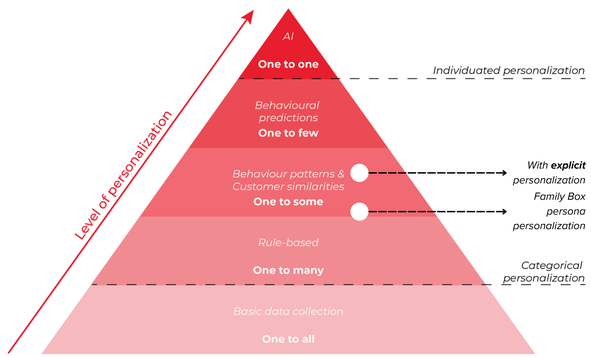


Figure 62: Level of personalization Family Box.

It is important to mention that this level of personalization is reached through the use of personas. With the help of **explicit** personalization, the strategy becomes more flexible, leading to more differences within personas, which increases the personalization level (see Figure 62).

Finally, this dimension is further elaborated with the matching process that will be explained on the next page. This process is essential to match the family member with the most relevant persona, which allows the Family Box to offer support that is most relevant to the family member's involvedness, care approach, and emotional coping strategy.

Matching process

As shown in scenario steps seven and eight, the Family Box uses a matching process in order to provide family members with support that fits their situation. This process helps the family member determine which persona fits best with their role, preferences, and needs during the care journey.

As earlier described, this process will take place after three weeks of using the general version. This period of time gives family members the opportunity to familiarize themselves with the Family Box platform and process their new caregiving situation before making choices on what they think fits them best.

The process can be done through **explicit** and **implicit** personalization (interface 2). The **explicit** (interface 5) option allows the family member to directly choose the persona that they think has the best fit based on a description or after the **implicit** process is completed. The **implicit** process (interfaces 3 & 4) guides the family member through a series of nine questions that are based on the dimensions of the personas. These questions are situationally phrased to understand what family members would do, feel, or think in a situation (see Appendix F). As a result, helping the system to place them on a side of one of the dimensions. After completing the questions, a persona will be suggested. By suggesting the persona, a family member can decide to follow the suggestion or, when preferred, pick another persona if they feel that persona fits them better.

Providing both personalization types allows the Family Box to collaborate with the family member, remain flexible to different preferences, and, if needed, reduce the feeling of overwhelm by suggesting a persona rather than the family member selecting one.

How does it work?

1. **Introduction:** The family member is welcomed to the matching process and informed about its purpose: personalizing the support to their specific situation. Additionally, they are asked for their preferences regarding using names in the Family Box for both themselves and addressing the patient.
2. **Explanation:** A short explanation will be given on the process using questions, while also explaining that the family member can choose themselves, which allows family members to skip the questions and proceed to the final selection stage.
3. **Questions:** The family member answers a set of questions that reflect their involvement, approach, and coping strategy. Currently this is done through a set of nine questions that are spread out evenly and based on the three dimensions of the personas (see Appendix F).
4. **Suggested persona:** Based on the answers to the questions in the previous step, the system will recommend a persona. This persona will be suggested with a description to allow family members to understand the persona and see if it is relevant to them.
5. **Final selection:** In this last step, the family member can accept the suggested persona or explore the other personas to decide themselves which persona is the best fit for them.

Purpose

Match family members with the correct persona. While allowing flexibility for making the choice themselves or letting the system decide.

Addressed needs

- TG 1: Want to be recognized
- TG 5: Want to collaborate
- TG 8: Want clarity

Figma prototype

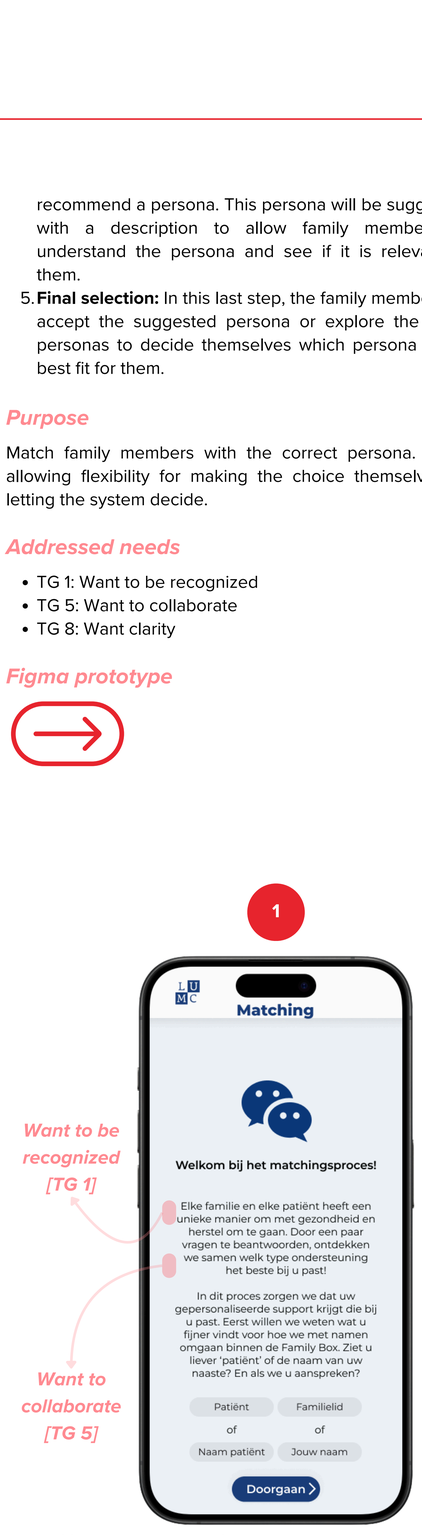
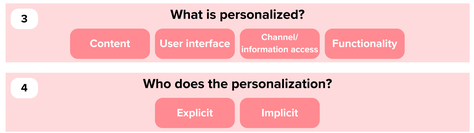


Figure 63: Matching process first step.

Figure 64: Matching process remaining steps.

What is personalized? & Who does the personalization?



The Family Box is personalized across four aspects: **Content, User Interface, Channel/Information access, and Functionality**. Altogether, they contribute to offering personalized support to family members. This dimension of *What is personalized?* is influenced by the fourth dimension *Who does the personalization?*. Therefore, these are explained together by going through the aspects **Content, User interface, & Functionality** of the third dimension and clarifying when **explicit** or **implicit** personalization is used.

Explicit personalization is used to increase the flexibility of persona. This way differences between family members within the same persona can be taken into account. **Implicit** personalization is used to lower complexity and feelings of overwhelm.

Content

Explicit personalization

During the onboarding process, family members can choose which data is shared as explained on pp. 87-88. As a result, family members can have different health data visible to them, making the support more relevant to their situation. For example, a family member might prefer to see data on smoking, while another family member is more worried/interested in data on alcohol use (see Figure 65).

Figure 65: Differences in shared data.

Next, during the matching process, family members can decide whether or not they want to use names in the Family Box to replace the mentioning of the patient and the family member. This impacts the main features, **Patient** and **You**, but also how content is written within features and modules. In the example shown in Figure 66, this results in the features being called Noor and Lucas.

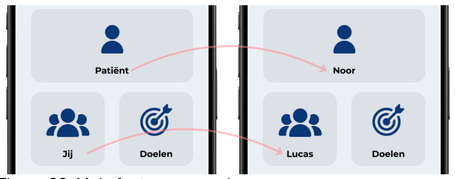


Figure 66: Main feature name changes.

Additionally, text can be adapted to make the text more personal for the family member reading the text, like 'Noors hartslag' instead of the patient's heart rate, see Figure 67.

Figure 67: Names of patient in text.

Implicit personalization

Implicit personalization is applied through the recommendation of knowledge/tools based on the persona and phase of the care journey. This can be done based on the drive of the persona in combination with the phase, resulting in multiple topics that could be relevant to a persona, see Figure 68. The topics in Figure 68 are just to illustrate what could be done, not necessarily meaning that this should be three for every phase or persona.

As described earlier in **2.4 Who does the personalization**, it is not the goal of the Family Box to restrict family members. Therefore, these recommended modules are available to every family member. However, family members that will likely find it relevant will get them recommended, while family members with less obvious relevance based on their persona can find it when searching.

	Discharge			Drive
Protector	*Monitoring tools 101*	*Emergency planning*	*Managing anxiety as a caregiver*	**Concern**
Adaptor	*Setting expectations together*	*Prepared for emergency together*	*Shared planning tips*	**Stability**
Talker	*How to keep the family informed*	*Connecting without overwhelming*	*Emotional needs from the patient*	**Connection**
Observer	*Why you are important*	*Staying informed without interfering*	*Coping with feeling helpless*	**Understanding**

Figure 68: Examples of recommended topics per persona.

These personalized modules and tools will be recommended to the family member on the dashboard in the '**Personal tip**' area (highlighted in pink in Figure 69).

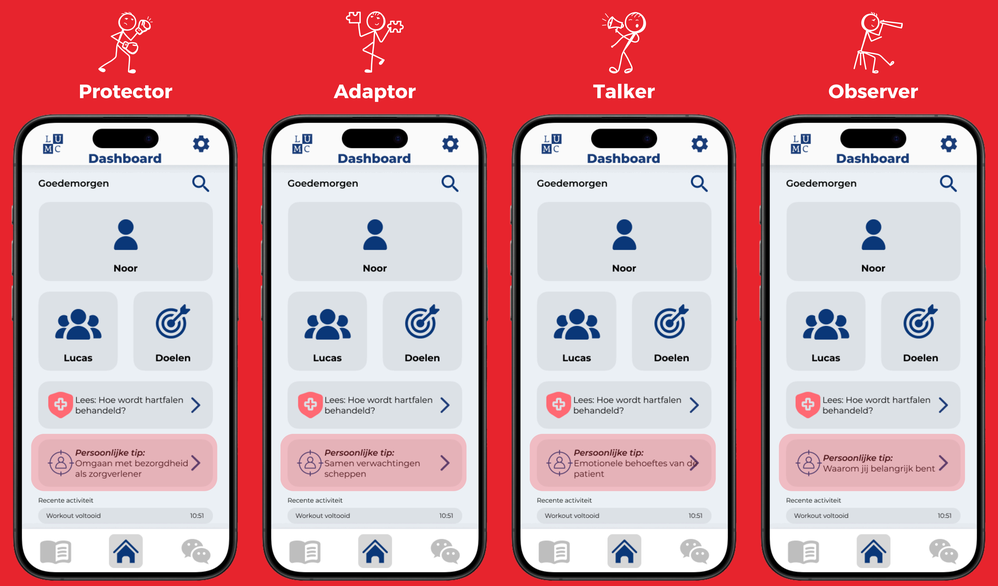


Figure 69: Personal tip area for each persona.

User interface

Explicit personalization

After the matching process is completed, family members are guided through a short and intuitive process to set their preferred hotkey feature, a shortcut to the function they find most valuable (see Figure 71).

To introduce this feature, family members first land on an explanation screen (**1**). This page explains the purpose of the hotkey: giving them quick access from the dashboard to what matters most to them personally, whether that is checking on the patient, managing tasks, or reflecting on emotions.

Next they are shown an interface (**2**) where they can choose one hotkey feature from eight available options. Each option includes a name and short description to help them understand its value.

As discussed in **2.1 Persona development**, every caregiving experience is unique, making it difficult to predict which features match which persona best. Therefore, this hotkey process is **explicitly** personalized so that the choice is made by the family member.

After selection, the dashboard is updated to include the chosen hotkey feature in a spot at the top (see Figure 70).

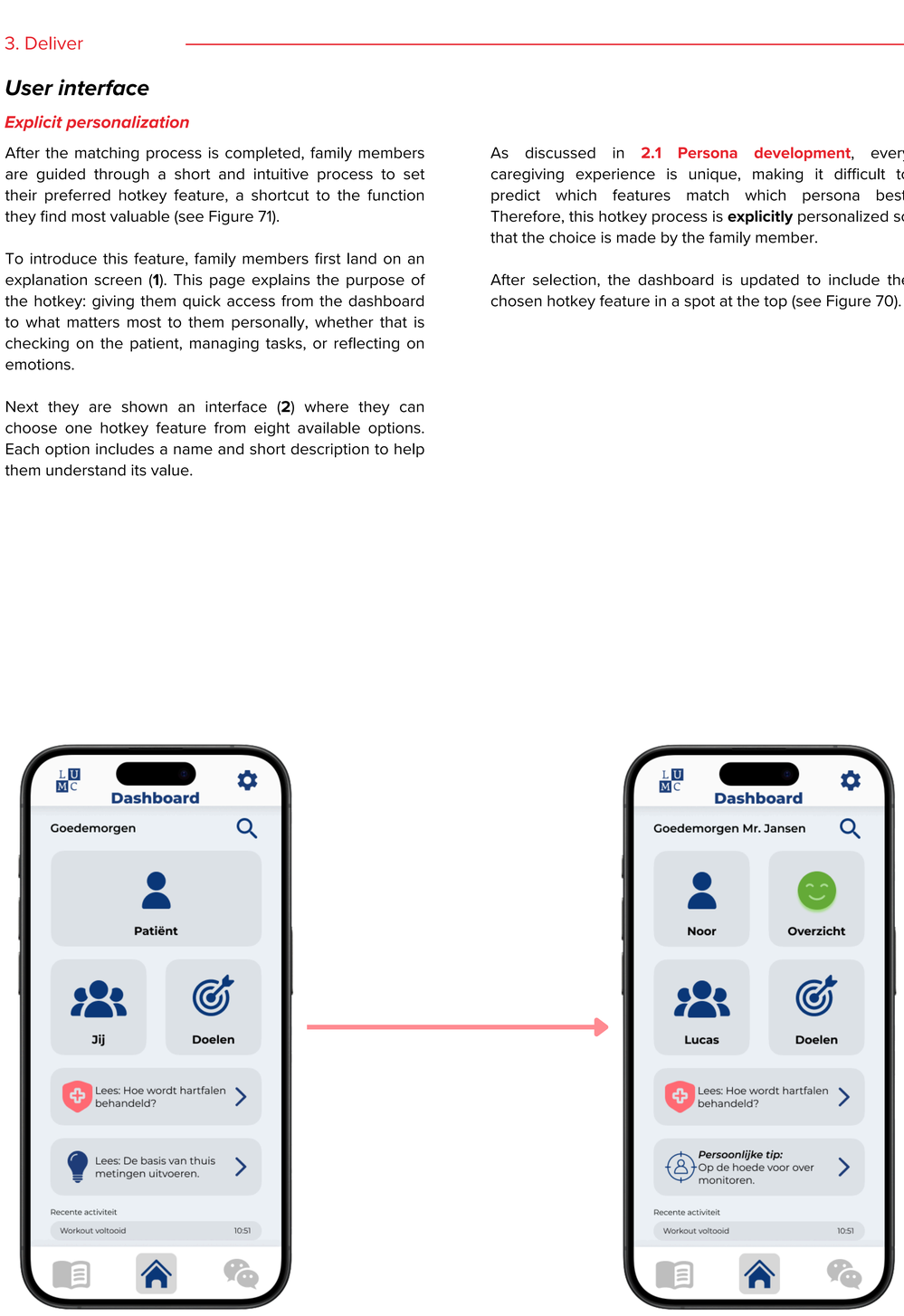


Figure 70: Dashboard update.

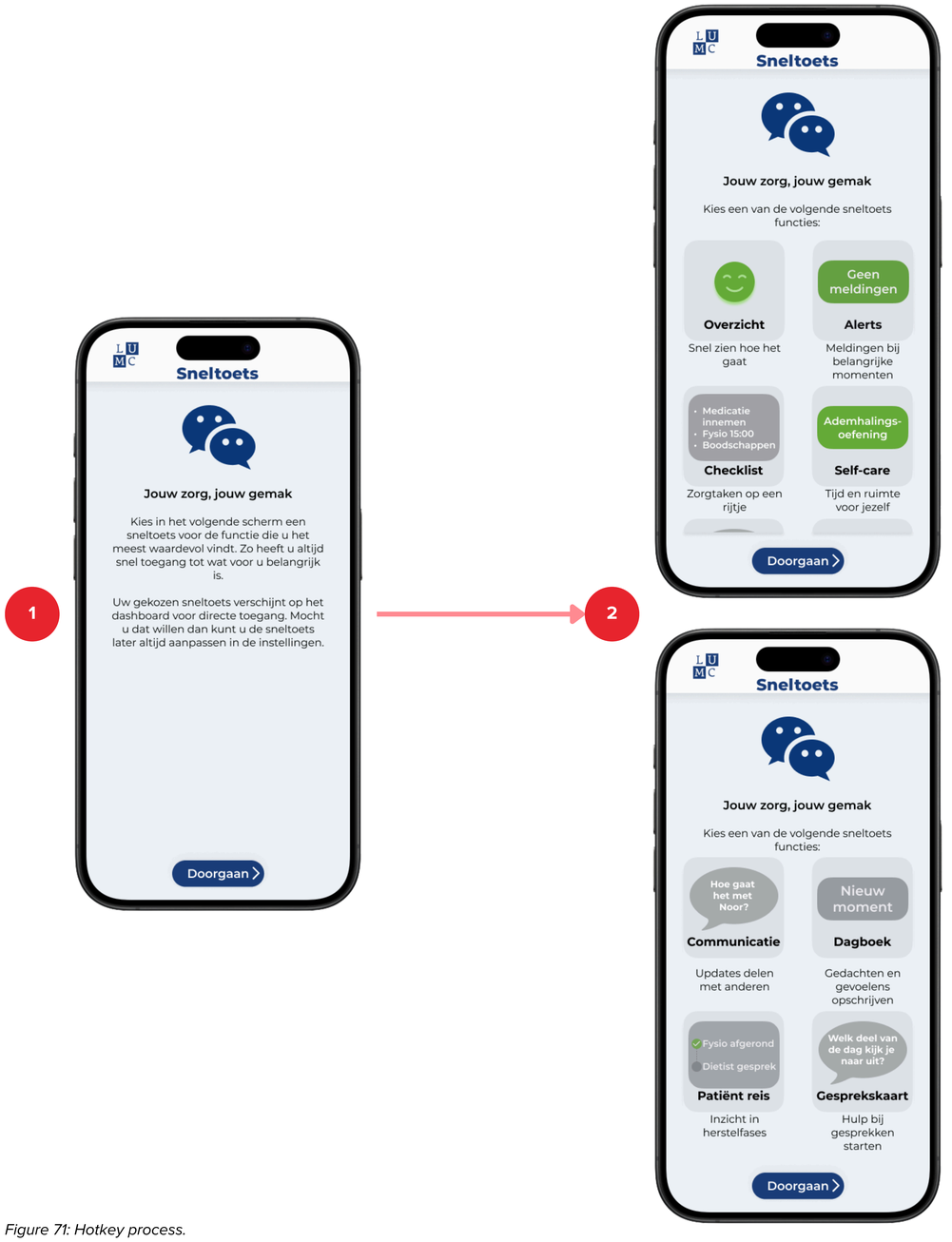


Figure 71: Hotkey process.

Functionality

Explicit personalization

An important way family members can personalize the support is in the **Goals** feature (see Figure 72). Instead of choosing from a fixed list of goals, they can create their own goals that reflect what they want to achieve in their care journey, which can be by themselves and together with the patient.

The goals are created in three steps:

1. Choose a category (**1**)
2. Define the goal (**2**)
3. Confirm the goal (**2**)

This not only gives family members control but also allows the Family Box to adapt to a wider range of caregiving needs and preferences.

Figma prototype

Now that all details of the illustrated design have been discussed, this link will show a Figma prototype of the personalized Family Box.

Figure 72: Creation of goals.

Implicit personalization

To reduce complexity and prevent feelings of overwhelm, the **Goals** and **Chat** features also use **implicit** personalization. Within these features, the system proactively suggests relevant content, such as goal ideas (see Figure 72, (**2**)) or conversation topics (see Figure 73) without requiring the user to search for or choose them manually.

These system-driven suggestions are based on factors like the current phase in the care journey or the user's matched persona. For instance, a Protector persona might receive a gentle prompt to set a self-care goal, such as "*Plan a moment for yourself this week*," reflecting their tendency to prioritize the patient over their own well-being, as described in **2.1 Persona Development**.

This subtle, behavior-informed personalization supports family members by offering guidance tailored to their caregiving style without demanding extra effort.

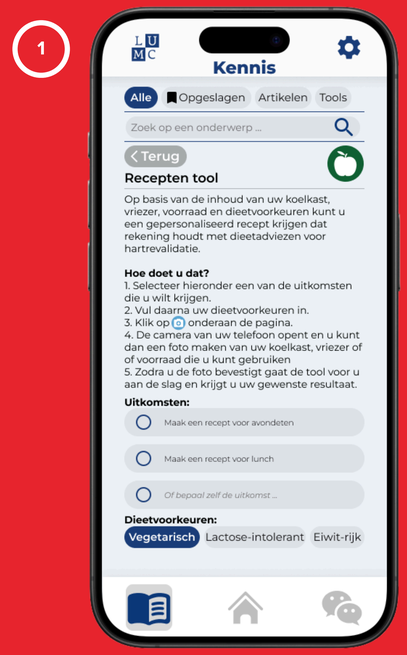
Another way **implicit** personalization is applied in the Family Box is through the use of multimodal AI models. These features allow family members to upload pictures, for example, of a meal or a physical space, which the system can then analyze to generate personalized suggestions, such as heart-healthy recipes or suitable physical exercises in line with cardiovascular guidelines.

Because the output is generated based on user-provided input, the resulting recommendations are unique to the specific situation of the family member. This creates a highly personalized experience without requiring the user to actively search or select from pre-defined options.

Two features using multimodal AI models are illustrated on the next page. One for recipe generation and the other for physical exercises.

*Figure 73: Suggested conversation topics in **Chat**.*

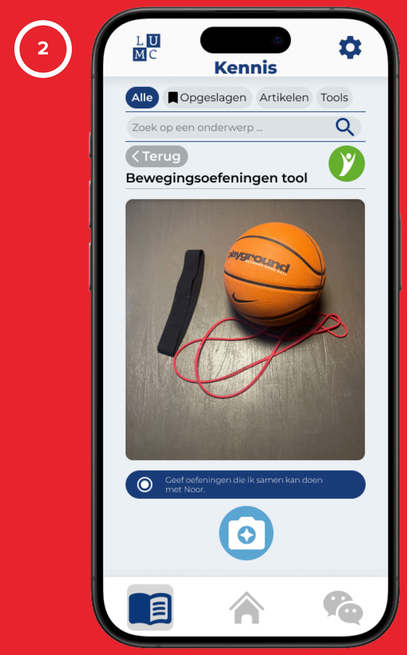
Recipe generator



Help with responsibilities /roles [TG 2]

Figure 74: Interfaces of recipe generator.

Physical exercises generator



Help with responsibilities /roles [TG 2]

Figure 75: Interfaces of physical exercise generator.

Empowerment

Monitoring

Supports family members with clear and structured insights into their own and the patient's health, helping them stay informed and build trust in the process.

Addressed needs

TG 1: Want to be recognized
TG 6: Want to understand how the patient feels
TG 7: Want to trust again

Implemented through:

Patient, You

Guiding

Provides tools that help family members navigate responsibilities and challenges throughout the care journey, offering structure in uncertain moments.

Addressed needs

TG 2: Help with responsibilities/roles
TG 4: Help with navigating the system
TG 5: Want to collaborate

Implemented through:

Knowledge & Chat

Educating

Increases knowledge and confidence by offering relevant information, health insights, and answers to common caregiving questions.

Addressed needs

TG 2: Help with responsibilities/roles
TG 3: Wanting answers to questions
TG 8: Want clarity

Implemented through:

Knowledge, Patient & You

Challenging

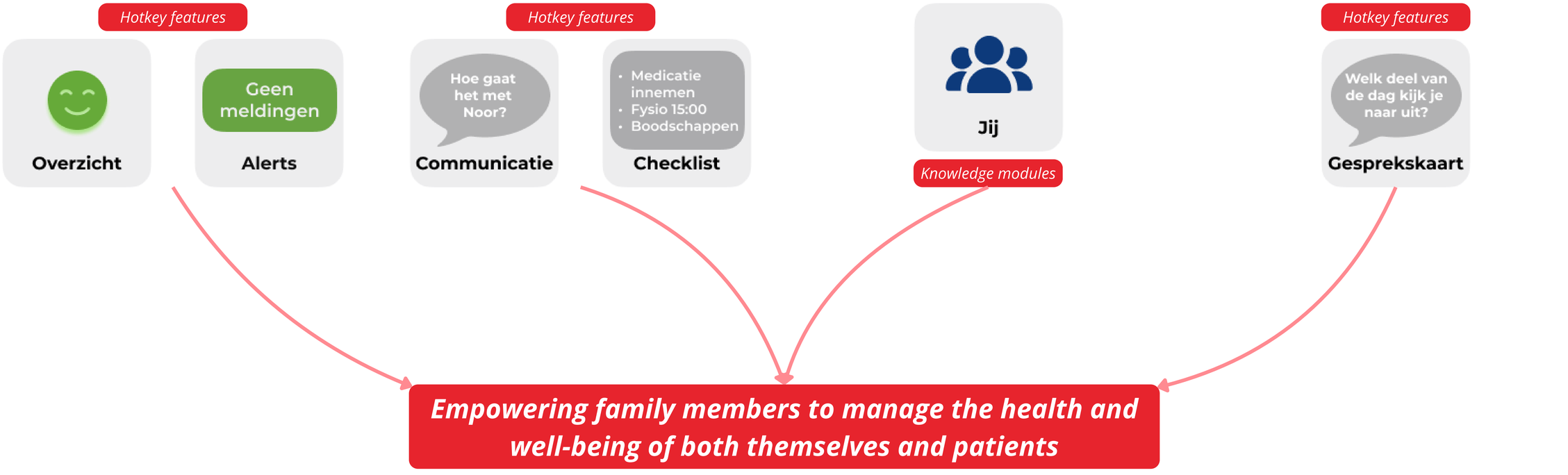
Encourages action and behavior change through reminders and goal-setting, promoting both self-care and active caregiving involvement.

Addressed needs

TG 1: Want to be recognized
TG 5: Want to collaborate

Implemented through:

Goals



Empowering family members to manage the health and well-being of both themselves and patients

3.2 Impact

*Building upon the previous dimensions of the personalization framework, this chapter focuses on the final dimension: **Impact**. While earlier sections explored **how** the Family Box personalizes and empowers, this chapter evaluates **what** that personalization achieves in terms of actual support, empowerment, and value for family members.*

*To do so, the **impact** is evaluated with family members, offering insights into **how** the Family Box is perceived in terms of relevance, usefulness, and support. These insights help determine whether the design truly supports family members in the care journey.*

Evaluation approach

The Family Box has been developed using literature, family experiences (focus group data & survey), interviews, and expert insights. Altogether it aims to improve the health and well-being of both family members and patients of the MI or OHS care paths.

To explore if the Family Box meets this goal, an evaluation was conducted to understand if the design answers the problem statement of this project:

How can we provide personalized support to families of patients during the care journey of MI or OHS to empower family members in managing health and wellbeing individually and for the patient?

The evaluation offers insights into the perceived value and relevance of the Family Box and shows whether its design results in support for family members. These insights can guide further development and refinement of the Family Box.

Participants

Interfaces were made with Figma in order to replicate the Family Box experience as closely as possible. These interfaces included the full set of key screens that illustrate the personalization strategy throughout the project. It allowed the participants to see the main features, processes, and other aspects of the Family Box, giving a clear impression of how the system would function in practice (see Appendix G).

Procedure

Throughout the evaluation, the design was presented through interface walkthroughs and visual scenarios (see Appendix G). These interfaces were used to demonstrate both **explicit** and **implicit** personalization elements, as well as how features are adapted to different care paths.

Since the goal of the evaluation was to assess perceived support, personalization, and empowerment rather than interaction usability, participants were guided through the interfaces via structured discussion. This allowed them to connect their own experiences to the features shown and evaluate how well the design would meet their needs in managing the care journey.

To guide the evaluation, a semi-structured interview format was used, focusing on key goals from the design: support, personalization, empowerment, and overall perceived impact. Questions were based on the **TGs** identified in earlier research phases, personalization, empowerment methods, and the problem statement. Therefore, participants were asked to reflect on how the design supports them in the following areas:

Support & Needs (TGs):
- To what extent does the design make you feel recognized?
- To what extent does the design help with responsibilities/roles during the care journey?
- To what extent does it help you get answers to questions?
- To what extent does it help you with navigating the health system?
- To what extent does it allow you to collaborate?
- To what extent does it help you understand what the patient needs?
- To what extent does it help you trust the patient's body?
- To what extent does it give you clarity?

Personalization:
- To what extent does this solution offer you personalized support?
- To what extent is the support relevant and useful for your situation?
- Are there aspects of caregiving where you feel this design is missing something? Personal or relevant to you?

Empowerment:
- To what extent does this design help you monitor during the care journey?
- To what extent does this design guide you during the care journey?
- To what extent does this design educate you during the care journey?
- To what extent does this design challenge you during the care journey?
- To what extent do you feel more empowered to support both yourself and the patient?

Overall impact:
- To what extent does this design help you manage the health and well-being of yourself and the patient?

This question structure allowed for flexibility while staying aligned with the personalization and empowerment goals of the Family Box. Responses were collected through guided conversation, observation, and direct quotes, providing qualitative data for assessing the impact of the design.

Limitations

Before discussing the results of the evaluation, it is important to acknowledge some limitations that may have influenced the outcomes or scope of the insights gathered.

1. *Limited to MI care path*
All three participants were family members of patients recovering from MI. As a result, the evaluation may not fully capture the needs or experiences of family members involved in the OHS care path.

2. Prior involvement of participants
The participants in this evaluation had previously contributed to interviews earlier in this project. While this continuity allowed for a deeper understanding of the context, it may have impacted their willingness to offer critical feedback. Their familiarity with the project could have led to greater empathy or support for the design, possibly limiting the expression of more critical perspectives.

3. Conceptual nature of the prototype
The evaluation was based on non-interactive interfaces, rather than on a functional system. Although participants were guided through realistic interfaces and interactions, some aspects could not be fully assessed. Therefore, the evaluation reflects anticipated perceptions rather than tested behaviors.

4. Qualitative focus and limited sample size
The evaluation followed a qualitative approach, based on structured conversations and reflection. While this provided in-depth insights, it does not offer quantifiable data or generalizable results. The limited size also might not represent the full diversity in caregiving roles, needs, and behaviors.

Evaluation results

As explained earlier, the evaluation results will be discussed per area: general support, personalization, empowerment, and overall impact.

*General support (**TGs**)*

To assess the design's effectiveness in supporting family members, participants were asked to reflect on the **TGs**. These **TGs** were developed earlier in the project and represent needs among family members involved in the care journey. Each **TG** was explored during the evaluation interviews to understand how well the design addressed it.

TG 1: Want to be recognized

Family members often feel overlooked in healthcare settings, where the focus is predominantly on the patient. Across the sessions, family members shared that the concept made them feel recognized and acknowledged. They appreciated that the design included content specifically personalized to them, rather than positioning them as secondary figures.

“Er wordt gedacht aan het familielid, zeker voor vragen of dingen die je niet snapt.”

“Helpt heel erg, doelen helpt ook voor jezelf.”

While this **TG** was well supported overall, family members suggested that recognition could go even further by including features that also acknowledge the emotional impact of caregiving.

TG 2: Help with responsibilities/roles

Participants noted that the concept provided them with clarity and structure around their caregiving responsibilities. They felt more equipped to support the patient through daily tasks and health goals. The ability to track behaviors and progress together made it easier for them to stay engaged in the care process.

“Bijvoorbeeld met koken helpt welstel, je kan niet koken is een uitdaging.”

“Visueel maken van doelen of gewoonten die gezond zijn helpt mij om mijn vader te ondersteunen.”

At the same time, some responsibilities, such as becoming an expert of care, could benefit from more specific support.

TG 3: Wanting answers to questions

A major strength of the concept is its ability to provide clear and trustworthy answers to common questions. Family members frequently mentioned that they previously had to rely on uncertain online sources or burden the patient with repeated questions. The app helped centralize relevant information and reduced that dependency.

“Ja, begin onduidelijk welk medicijn wat is, dat wil je weten... kwartier aan het googlen totdat je een beeld hebt.”

“Artikelen, vragen beantwoord krijgen, zou ik veel aan hebben. Zeker voor vragen achteraf of dingen die je niet snapt.”

Family members did not express a strong need for improvement in this area but emphasized the importance of keeping the content up-to-date and easily searchable.

TG 4: Help with navigating the system

Family members often feel lost or a lack of support when trying to find their way in the medical system. In this context, family members found the design helpful in providing structure and guidance, especially around CR, medication use, and follow-up appointments.

“Bijvoorbeeld met medicijnen, duidelijkheid daarover. Biedt een dubbele check.”

“Met voorbereiding helpt het, dingen uitvragen bij patiënt is minder nodig.”

Although the design supported this **TG** well, one area for growth is offering earlier guidance. For example, when family members often first step into their new roles and responsibilities.

TG 5: Want to collaborate

Family members appreciated the collaborative aspects of the design, particularly in setting and tracking goals together. This enabled a shared sense of purpose and mutual accountability between family members and patients.

“Doelen stellen kan allebei motiveren. Misschien zelfs sneller.”

However, a family member mentioned that while the design offers ways for practical collaboration, emotional or conversational collaboration is still largely dependent on communicating within your relationship:

“Samenwerken is vooral communicatie. Technologie vervangt moeilijk het gesprek.”

This suggests an opportunity to improve the collaborative aspect further.

TG 6: Want to understand how the patient feels

Family members expressed that the design offered valuable insights into the patient's condition but that it lacked emotional depth. While progress tracking and symptom logging could help them understand behaviors or recovery trends, participants still found it difficult to understand how the patient was truly feeling.

“Wat hij echt voelt niet. Meer praktisch & fysiek. Wat er in hem omgaat nog niet”

Family members proposed including features that support emotional awareness, such as mental health goals or a space where the patient can reflect and share how they are doing emotionally.

TG 7: Want to trust again

After a hospital intake and discharge, many family members experience a sense of fear or uncertainty when it comes to trusting the patient's physical recovery. The design's monitoring and logging features helped ease some of these concerns by offering a structured way to track progress.

“Dit is wel fijn, je kan monitoren...”

Yet family members also mentioned that data alone does not always reassure them, especially when the patient appears unwell despite ‘normal’ values.

“Daarom maak je, zeg maar ook met elk stapje dat iemand mis zet. Maak je je zorgen dat je ziet dat het niet gaat.”

Family members suggested implementing expert interpretations or contextual explanations to help bridge this gap between observations and numbers.

TG 8: Want clarity

Finally, clarity was one of the more appreciated qualities of the design. Family members described feeling more in control thanks to explanations of what was happening, what was expected of them, and when to take action.

“Uitleg over wat iets is, wanneer je je zorgen moet maken. Uitleg was is normaal.”

“Rustig in kaart, rustig lezen. Mag dat, wat moet ik doen als...”

Although this **TG** was well addressed, some family members felt the design could benefit from more visual overviews, such as graphs, timelines, or alert thresholds, to further reduce the complexity.

Personalization

One of the key parts of this design is to offer personalized support to family members. During the evaluation sessions, family members were asked to reflect on how personal, relevant, and useful the design felt in the context of their experience.

Personal relevance

Across the sessions, family members shared that the design felt closely aligned with their own experiences. The availability of personalized content, such as articles, exercises, and goals, was appreciated. The fact that the design did not generalize their experience but instead acknowledged individual differences made them feel supported and seen.

“Ik hou er sowieso al van als er gewoon iemands naam staat, dus dat het persoonlijk is en niet dat er staat de patiënt.”

“Ik vind het fijn om alles te weten, dus vooral de kennis is voor mij fijn. Prettig dat het vanuit het ziekenhuis komt, dat geeft vertrouwen.”

Family members also valued how the design supports shared goals, such as giving up smoking or improving lifestyle habits, which helps maintain motivation and makes it feel more personal and meaningful.

“Wij zijn samen gestopt met roken. Dit had echt wel kunnen helpen.”

Relevant support for caregiving tasks

The personalized features were not just about content but also about practical caregiving support. Family members mentioned how they felt the design was designed with their specific needs in mind, whether it is keeping track of medication use, accessing information, or guiding rehabilitation routines.

“Medicijn gebruik is voor ons erg relevant. Iets erin kunnen opslaan zodat je het kan checken.”

This kind of support reduces the complexity that is often experienced by family members, especially in moments of uncertainty. Additionally, the trust in the tool was strengthened by the fact that the information came from the hospital, rather than a variety of online sources.

Suggestions for improvement

While the personalization of content was well received, family members indicated that personal emotional needs were not always addressed. One family member mentioned that although the design addressed physical goals well, it lacks support for psychological or emotional challenges.

“Alles wel opzich, min het stukje geestelijk.”

Similarly, others expressed a desire for more features that would help them or the patient reflect emotionally, such as mental health tracking, mood logs, or guidance on how to deal with stress and uncertainty in the caregiving role.

This feedback shows an opportunity to expand the concept by offering personalization not only in terms of task-related support but also in how family members cope, reflect, and connect emotionally.

Another point that became clear in the evaluations was the need to balance rich, personalized content with a simple, not-overwhelming interface. While family members enjoyed having access to detailed and relevant information, too much complexity or input might risk features becoming too demanding.

Empowerment

Another key part of the design is empowering family members. This is done through the four empowerment methods: **Monitoring, Guiding, Educating,** and **Challenging**. During the evaluation sessions, family members were asked to reflect on how the design contributes to these methods.

Monitoring

Family members frequently deal with uncertainty regarding whether the patient is making sufficient progress or when something might be going wrong. The **Patient** and **You** features were seen as valuable parts that helped increase transparency in the care journey. Being able to see and follow patterns, such as exercise routines or medication intake, gives family members a sense of control and reassurance.

“Je kan nu samen delen, hij had alles, ik wist niks.”

Family members liked that they no longer had to rely entirely on verbal updates from the patient, which not only reduced the burden of constant discussing the care journey but also allowed them to intervene or support when needed.

Guiding

Family members described how the design offered helpful structure and direction, guiding them through various phases of the care journey. The idea that they did not have to ‘figure it out all alone’ was empowering in itself. The design helped family members feel more included and better prepared. Having this form of digital guidance makes it easier for them to stay engaged, even when they were not physically present at every step.

“Ik denk wel dat je daar best wel wat makkelijker jezelf mee kan begeleiden. Ook omdat je ook misschien wat zelf meer houvast hebt.

Educating

In terms of learning, family members appreciated the design's ability to provide clear and relevant information, particularly around medication, symptoms, and recovery routines. This learning aspect helps them build confidence in their own ability to support the patient's recovery.

"Medicatie vooral, wat wel en niet mag. Daar wilde ik veel over weten."

Others mentioned how the information allowed them to feel more prepared for conversations with healthcare professionals, to ask better questions, or to recognize early symptoms, thus making them actively involved in the patient's care.

Challenging

Beyond information and monitoring, the design also provides goals that could help family members start or sustain lifestyle changes, both for themselves and together with the patient. For example, one family member shared how the design could have supported the shared decision to quit smoking.

"Zou best wel helpen, werkt ook op het familielid. We zijn samen gestopt met roken. Dit had echt wel kunnen helpen."

This indicates that the design not only supports the family member in managing the health and well-being of the patient but also has the potential to positively impact the family member's own health and well-being.

Suggestions for improvement

Some family members missed emotional or thought-provoking cues, but others felt empowered in terms of providing practical support. The design now places a greater emphasis on practical support (such as tracking, learning, and planning) and less emphasis on the emotional and psychological development of family members as a result of their roles.

Empowerment may be strengthened by characteristics that promote reflection, recognize tension or worry, or direct emotional processing. A family member, for instance, stated that although they were already familiar with medical matters, they could use some advice on how to handle emotional uncertainty.

This implies that empowerment could be increased by including the confidence to feel and cope in addition to the confidence to act.

Overall impact

At the end of each evaluation session, family members were asked if the design answers the problem statement.

How can we provide personalized support to families of patients during the care journey of MI or OHS to empower family members in managing health and wellbeing individually and for the patient?

At the end of each evaluation session, family members were asked if the design answers the problem statement. The evaluation sessions demonstrated that the design had a positive and meaningful impact on the family members. It supported them not only in their role as caregivers but also in managing their own well-being.

"Heel goed, je wordt veel meer betrokken. Je komt in niemandsland."

Rather than simply observing or reacting, family members felt like active participants in the care journey. The design encouraged shared goals and mutual motivation without undermining the patient's autonomy.

"Je wilt iemand niet controleren, maar je kan elkaar wel helpen onthouden met de verschillende aspecten."

"Zelf ook meedoen en dus samen ermee bezig zijn."

The availability of knowledge reduced uncertainty and helped family members feel calmer and more in control.

"Rustig in kaart, rustig lezen. Mag dat? Wat moet ik doen als..."

Lastly, all family members expressed a strong interest in using the design in their own lives, confirming the design's relevance and desirability.

"Ik zou hem heel graag willen gebruiken. Andere gezinsleden van patiënt ook."

Scalable impact

One of the family members also mentioned how this design could be relevant for the different care paths of cancer. This indicates that the current state of the design might already translate very well to other care paths.

Opportunities for design improvement

While the evaluation sessions confirmed the overall value and relevance of the design, family members also pointed out several areas for refinement. These suggestions offer valuable input for further development of the design. Key opportunities include:

- Adding support for emotional and mental aspects of caregiving
- Enhancing features that foster collaboration and communication between family member and patients
- Providing clearer guidance when interpreting health data

The following outlines how these improvements could be implemented in future iterations of the design.

Support for emotional and mental aspects

One of the most mentioned opportunities for improving the design lies in offering more support for the emotional and mental side of caregiving. They indicated that family members not only look for tools for the practical aspects but also need support in coping with their own emotions and well-being. Caregiving can be overwhelming, yet the design lacks in supporting this aspect.

To address this, the design could include features such as emotional check-ins or guided reflections (see Figure 76). These additions would allow family members to reflect on how they are doing and feel recognized in their emotional journey and receive prompts to take care of themselves.

By implementing emotional support into the existing design, it can empower family members not only to do more but also to feel more seen and supported throughout the care journey.

Figure 76: Example of emotional check-in.

More collaboration and communication

Another important area for improvement is strengthening the concept's support for more collaboration between the family member and patient. While participants valued features like shared goal-setting and progress tracking, some noted that collaboration often remained functional rather than relational.

This suggests that while the design allows for coordination, it could do more to encourage and facilitate open dialogue between family members and patients. For example, family members sometimes struggle to bring up sensitive topics or to understand the emotional state behind a patient's behavior. Supporting these aspects of collaboration and communication could deepen their connection and increase mutual understanding.

To address this, the design could give the hotkey feature 'Conversation starter cards' a more central role on the dashboard. On the other hand, it might be more interesting to design a feature where a family member and patient can select topics or prompts that they can explore together. By providing this space in a shared screen (see Figure 77) between the Family Box and Box, it allows for open communication.

By designing for collaboration as a relationship, not just as coordination, the design can support family members and patients in building more open, trusting communication during a challenging time.

Figure 77: Example of shared interface.

Health data interpretation

While family members valued the design's ability to monitor and present health data, a few shared that they still felt uncertain about how to interpret what they were seeing, especially when data did not align with the patient's behavior. This disconnect from numbers and lived experience sometimes caused more worries than reassurance.

"Zit een verschil in data en wat je ziet met je ogen."

This insight highlights an opportunity: family members need more than just data. They want context, guidance, and meaning. When family members do not have a medical background, raw numbers can be difficult to interpret, and small changes may feel alarming without proper explanation.

To address this, the design could include context interpretations, for instance, through simple explanations or alerts that are framed with a nuance. This could be implemented through a pop-up next to a graph or data point (see Figure 78). This addition could help family members build trust in the data, reduce worry, and help them know when and how to act.

Figure 78: Example of contextual interpretation in dark grey.

3.3 Roadmap

The previous chapters presented the final design of the Family Box and how family members evaluated the design. The design illustrates what could be the Family Box, but that requires some activities in the near and far future. This chapter provides a roadmap, divided into three phases. Each phase will address specific challenges, activities, and roles of involved parties. By mapping out these steps, this chapter provides a structured approach for long-term impact, ensuring that the Family Box iterates to empower family members through a personalized approach.

Horizons overview

The roadmap is structured around three horizons, each representing a different phase in the development and scaling of the Family Box (see Figure 79).

Horizon 1 (2025) - Introduce

Strategy: Test how families interact with the Family Box and validate assumptions.

Key activities

- **Lo-fi physical tools:** Explore the value of physical tools like conversation cards to support families through a tangible product.
- **Pilot with MI & OHS families:** Testing the Family Box with a small group of families of patients. Feedback from these families can help develop features but also help develop a list of valuable modules.
- **Validation of personas:** The set of personas and questions for matching should be tested for representativeness. Based on feedback, they may be refined or extended.
- **Setup of persona-specific modules:** Modules personalized for personas allow for the one-to-many personalization level in this horizon.

Personalization

This horizon lays the basis for personalization by testing the set of personas in practice. In this horizon the personalization level is positioned at one to many using the set of personas of the design presented earlier. The pilot will help test if modules are relevant to the real world and the behavior and needs of families.

Involvement

- **LUMC:** Leads activities, medical content validation, and ethical oversight.
- **Ancora**: Develops a minimum viable product (MVP) platform of the Family Box and the first recommender system based on the personas.
- **Families:** Provide input through testing, feedback, and validation sessions.

Why these activities?

The research showed that families cope very differently with their caregiving roles. In preliminary validation attempts it became clear that there might be some refinements needed. Therefore, testing and validating are needed. Otherwise, this personalization strategy remains theoretical. As a result, this phase should ensure foundational accuracy and trustworthiness for the next phases.

Horizons	Horizon 1 (2025)	Horizon 2 (2027)	Horizon 3 (2029)	Future vision
Strategy	Introduce Testing & validating	Scale Improving & deepening	Advance Personalizing & expanding	Improving the overall care for families and patients by personalizing support to empower families in their unique experiences during the care journey. As well as stimulating healthier lifestyle choices to improve the health of families, patients, and people in the Netherlands.
Activities	Lo-fi physical tools; Pilot with MI & OHS families; Validation of personas; Setup persona-specific modules	Children Family Box; Habits category; Care path specific modules; Developing explicit & implicit personalization	Partnering with insurance providers; Design of Lifestyle Box; Multimodal AI training; Individuated personalization through AI	
Medical goal	MI & OHS care paths	Other Box care paths	Prevention: Lifestyle Box	
Personalization level	One-to-many (Personas)	One-to-many + Explicit & Implicit (Personas+)	One-to-one (AI)	
Autonomy level	Validated & supervised by healthcare professionals	Passive monitoring of platform	Autonomous support from platform	
Involved parties	LUMC: Define medical content, Involve families + patients; Ancora: Develop MVP platform, Build recommender system	LUMC: Expand to other care paths, Monitor results; Ancora: Enhance AI abilities, Improve platform scalability	LUMC: Evaluate long-term impact, Partnering up; Ancora: Develop individuated personalization	

Figure 79: Roadmap.

Horizon 2 (2027) - Scale

Strategy: Improve care path coverage and deepen personalization strategy.

Key activities

- **Children Family Box:** Addresses the inclusion of children within impacted families. This way children can also be involved in the care journey and educated on healthy lifestyle habits.
- Habits category: Through the development of a Habits category in the Family Box, it is possible to educate family members on tips and tricks regarding building and maintaining healthy habits. As a result, making it easier to make sustainable lifestyle changes.
- **Care path-specific modules:** As the medical coverage increases across multiple care paths, each care path will get specific modules. By making specific modules, the Family Box stays relevant, making scaling easier.
- **Developing explicit & implicit personalization: The** personalization level is increased through the development of explicit and implicit features as discussed in the design illustration.

Personalization

Moving from one-to-many with only personas to the level of one-to-many with personas that is more flexible through the use of **explicit** and **implicit** personalization. As a result, the Family Box becomes relevant for a wider range of family members.

Involvement

- **LUMC:** Expands to other care paths and monitors results.
- **Ancora:** Develops explicit and implicit features. Trains AI models to increase autonomy of the platform.

Why these activities?

Insights from the focus group data revealed that family roles change during the care journey. Therefore, increasing the personalization to be more flexible and dynamic is important to make the support more relevant.

Horizon 3 (2029) - Advance

Strategy: Personalize at an individuated level and expand support to before hospital intake by focusing on lifestyle.

Key activities

- **Partnering with insurance providers:** Involving insurance providers in the development of a Lifestyle Box for Dutch citizens.
- **Design of Lifestyle Box:** By developing a Lifestyle Box, it is possible to reach people before they arrive at the hospital in need of treatment, which leads to a lower inflow of patients.
- Multimodal AI training: Through the development of this technology, features like the recipe and physical exercise generator can be released to families.
- **Individuated personalization through AI:** Fully personalizing content to a one-to-one level. This needs to be done carefully in regards to the risks of AI discussed earlier in **1.1 Problem**.

Personalization

This phase moves from one-to-many to one-to-one personalization, shifting from categorical personalization to individuated. As the Family Box will be using AI for recognizing individual differences, content can be personalized to the individual. As a result, the highest level of personalization is reached, as well as the Family Box having the ability to actively adapt to the family member.

Involvement

- **LUMC:** Evaluates long-term impact and collaborates on increasing the medical coverage to before the hospital.
- **Ancora:** Develops and maintains the AI infrastructure.

Why these activities?

Every care journey has its own challenges and needs. Therefore, individuated personalization should give the most relevant support as it adapts to the individual differences. Furthermore, through the Lifestyle Box, Dutch citizens are supported before intake and after the care journey in making healthier lifestyle changes.

Recommendations

To guide the implementation and development of the Family Box, the following recommendations are proposed. These recommendations are directly linked to the roadmap horizons and based on the insights gained during this project.

Persona validation (Horizon 1)

The first horizon should include the validation of the personas and matching questions. Preliminary validation with experts and experienced family members has shown that the identification with personas might be fluid or that the set can be improved in representativeness. This should be validated with a wide range of family members to make sure if refinement is needed. Additionally, the matching questions were developed based on the dimensions of the personas but remain to be tested.

Support creation guidelines (Horizon 1-3)

To ensure the platform delivers meaningful and trustworthy support, clear guidelines should be established for the creation and curation of content. These should balance clinical reliability and personal relevance.

- **Medical validation**: All informational and behavioral guidance should be reviewed and approved by healthcare professionals or similar experts to guarantee clinical reliability and build trust.
- **Request-based content:** Family members should be able to request content they deem relevant, increasing perceived relevance. In later stages this content could be generated with the help of AI if the output is reliable.
- **Community contribution**: As family members become experts of their own experience during the care journey, the Family Box could invite them to share personal experiences, tips, or reflections. These stories could help support other family members in their care journeys.

Habits category (Horizon 2)

A category dedicated to habits should be introduced to help family members and patients build and maintain healthy habits. Modules in this category can offer tips on creating new habits, setting realistic goals, sustaining motivation, and celebrating progress. During the research phase, an overview of guidelines for the user and system of a mobile health recommender system was created, see Appendix H.

3.4 Conclusion

This conclusion evaluates the design of the Family Box according to feasibility, desirability, and viability based on human-centered design principles. It summarizes key outcomes, highlights insights obtained during the Deliver phase, and outlines the key recommendations for future development to enhance the design's effectiveness and long-term impact.

This phase presented an illustration of the personalization strategy for the Family Box. This design addresses the project's problem statement of providing personalized support to families during the care journey of MI or OHS.

Based on the developed personalization framework, a personalization strategy has been designed. Through the use of a set of four distinct personas, a categorical level of personalization is established in the short term. Using these personas, the Family Box is able to align support with the diverse and evolving needs of family members. Together with the use of explicit and implicit personalization, the support becomes more flexible and relevant. Explicit personalization allows the Family Box to adapt to the differences of family members within the same persona. At the same time, implicit personalization reduces feelings of overwhelm by offering support automatically.

Feasibility
The Family Box design identifies and demonstrates essential conditions for practical implementation. The design uses existing technology such as mobile health systems and combines this with a structure of consistent, modular, and personalized elements. Throughout the project, constraints were encountered in regards to ethics and reliability. Therefore, steps have been proposed for the development and integration of newer technologies like AI models to make sure family members receive support they can trust and have no negative impact on health outcomes.

Desirability
Evaluation sessions demonstrated that the Family Box contributed to family members feeling recognized, empowered, and actively involved in managing both their and the patient's health.

“Heel goed, je wordt veel meer betrokken. Je komt in niemandsland.”

Family members particularly appreciated the integration of medically validated content, practical caregiving guidance, and opportunities for collaboration with patients. Nevertheless, family members also identified areas for improvement. Specifically, they expressed the need for deeper emotional and psychological support and clearer guidance for interpreting health data.

“Wat hij echt voelt niet. Meer praktisch & fysiek. Wat er in hem omgaat nog niet.”

“Zit een verschil in data en wat je ziet met je ogen.”

These insights underline the importance of balancing emotional and practical aspects of caregiving.

Goal of graduation project:

Improving the health and well-being of family members and patients

Problem statement

How to personalize support for families of patients recovering from MI or OHS, using interventions that address the unique challenges families face during the recovery process?

Viability
The Family Box roadmap addresses key factors for long-term sustainability by recommending scaling to other care paths, establishing clear guidelines for content creation, and proposing continuous monitoring of results. The suggested collaboration with insurance providers to introduce a lifestyle-focused version of the Box further supports the long-term viability and scalability of the design.

Future development steps include the validation and refinement of personas, scaling to other care paths, and the creation of guidelines for creating reliable and relevant content. Moreover, introducing a dedicated Habits category is suggested to further facilitate sustainable lifestyle changes.

Overall, the Family Box shows how personalized support can empower family members during the care journey, thereby addressing both the family member's and patient's well-being. Moving forward, the proposed roadmap provides a clear path for further refinement, testing, and integration, ensuring that the Family Box continues to evolve and positively impact the health outcomes of families and patients. With this ongoing development, guided by user insights, the Family Box is positioned to provide meaningful support to the health and well-being of family members and patients.

Limitations

Data triangulation

Due to the individual nature of this graduation project, data triangulation was inherently limited. Triangulation typically involves using multiple data sources, researchers, or methodologies to validate findings (Bhandari, 2022). Conducting the project individually constrained the depth of triangulation achievable, potentially impacting the robustness of the resulting personas and design decisions.

Focus group data limitations

The focus group data used in the research was given as transcriptions. By not being present during the sessions, it could have resulted in the misinterpretation or loss of nuanced context.

Limited number of family members

The insights gathered on top of the focus group data originate from a limited sample size of interviewed family members and a limited number of respondents in the survey. Although the data was insightful and valuable, the restricted number of experienced family members may affect the generalizability of the findings. A broader sample could have potentially uncovered additional nuances in caregiving roles, emotional coping strategies, or personalization needs.

Generalizability across other care paths

The research and resulting personas were focused on families dealing with MI and OHS patients. The applicability and relevance of these personas and resulting personalization strategy choices remain uncertain. Additional research and validation would be necessary to confirm whether the personalization strategy that was developed translates effectively to other care paths and different medical contexts.

Reflect

Building on the personalization strategy that was developed and proposed in previous phases, the Reflect phase takes a step back to evaluate the overall process, results, and future of the outcomes of this project.

First, the framework for personalization will be discussed, using the Family Box as a case study. Followed by a conclusion on the outcomes of this project. Finally, this phase will end with a personal reflection on the past few months.

4.1 Framework for personalized support

This chapter presents the developed personalization framework to facilitate personalization within healthcare solutions. Although initially designed for this project, this framework can offer practical guidance on implementing personalization across various contexts and projects.

Defining personalization

As explained earlier in **1.4 Personalization**, personalization is defined as the following:

> "A process that changes the functionality, interface, information access, and content, or distinctiveness of a system to increase its personal relevance to an individual or category of individuals." (Blom, 2000)

This definition emphasizes personalizing to individual or group-specific needs to enhance relevance and effectiveness.

Framework development

The developed framework combines dimensions of two frameworks found in literature:

Fan & Poole (2006)
- What is personalized?
- To whom is personalized?
- Who does the personalization?

FitzGerald et al. (2017)
- What personal characteristics are addressed?
- Impact of the personalization

Through the combination of these frameworks, the framework visible in Figure 80 has been developed.

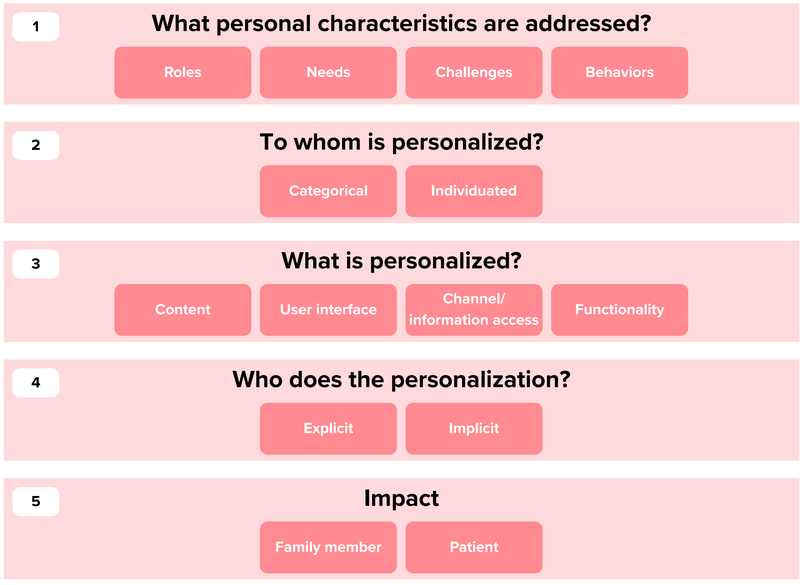


Figure 80: Framework for personalization.

Dimensions of personalization

1. What personal characteristics are addressed?

This dimension involves the identification and selection of characteristics of users to guide personalization. These characteristics form the basis for making the support relevant and meaningful. Depending on the project's goal(s), available data, and context, different types of characteristics can be considered:

- **Demographic data:** User data such as age, gender, education, and socioeconomic status.
- **Behavioral data:** User habits, engagement patterns, decision-making styles, and coping mechanisms.
- **Context-specific roles:** Roles specific to the situation, like caregiving roles, professional duties, or other context-specific roles, to directly address real-world experiences.
- **Needs and challenges:** Insights drawn from user research and feedback to address user needs, barriers, or difficulties.

Example from Family Box:
Through the analysis of focus group data, interviews, and a survey, roles, needs, challenges, and behaviors were identified.

2. To whom is personalized?

This dimension involves defining the level of personalization. This is done by defining the segmentation that is needed to make the support relevant to most users. This dimension focuses on balancing the personalization's effectiveness against the feasibility of the approach. The approaches are distinguished based on categorical and individuated personalization levels (see Figure 81).

- **One-to-all:** Broad personalization that applies universally, ensuring consistency but low specificity.
- **One-to-many:** Categorical personalization based on common characteristics, balancing specificity with scalability.
- **One-to-some:** More refined categorical personalization, allowing for detailed targeting without the complexity of individual-level customization.
- **One-to-few:** Highly specific categorical personalization, suitable for narrowly defined similar users.
- **One-to-one**: Individuated personalization, highly specific but resource-intensive.

Example from Family Box:
Personas provided a feasible approach, achieving a categorical personalization level that efficiently and effectively supports diverse family members.

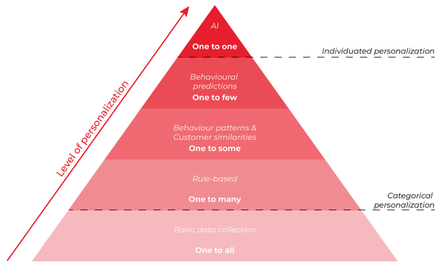


Figure 81: Levels of personalization (Fan & Poole, 2006; Kaiser 2023).

3. What is personalized?

This dimension is used to identify system components suitable for personalization, impacting user interaction and experience. By exploring the possibilities of the following four aspects, a broad range of personalization possibilities can be identified, allowing the combination of the most valuable options for the personalization strategy.

- **Content:** Personalizing information and resources ensures users receive relevant and useful content.
- **User interface:** Adapting layout, visuals, and interaction modes to align with user preferences, reducing complexity and improving usability.
- **Channel/information access:** Using preferred communication channels such as real-time notifications, emails, or apps, improving accessibility and convenience.
- **Functionality:** Personalizing system features and tools to better address specific user tasks, roles, and needs, directly improving usability and effectiveness.

Example from Family Box:
Personalized educational modules and interface elements were developed to reduce family member overwhelm and improve the usability.

4. Who does the personalization?

This dimension examines the differences between user-driven personalization and system-driven personalization.

- **Explicit personalization:** Allows users to control the personalization, improving user autonomy and increasing the flexibility of the personalization level.
- **Implicit personalization:** Automates personalization based on user behavior, design choices, or user preferences. This reduces complexity and increases relevance through dynamic changes.

Example from Family Box:
- *Explicit personalization:* The hotkey feature allows the family member to personalize their dashboard.
- *Implicit personalization:* By suggesting modules based on the family member's persona, it is possible to provide them with relevant support automatically.

5. Impact

This dimension focuses on the impact the personalization strategy should have on the user. By defining what the personalization should do for the user, it is possible to determine if the strategy serves its purpose.

Example from Family Box:
The personalized support of the Family Box should empower the family member, which should then result in supporting the health and well-being of both themselves and the patient.

Tips & concerns

Tips:
- Clearly define the goals of personalization early in the project.
- Balance the personalization level with the available resources. As a result, keeping the strategy feasible.
- Regularly validate the personalization approach with users to make sure it is desirable.
- Approach the personalization level as a process. It is possible to gradually increase the level by extending the range of versions available to users.

Concerns:
- Ensure privacy and ethical considerations are addressed when using user data.
- Avoid overly complex personalization that might overwhelm or confuse users.

Application & adaptability

The framework was used in this project and adapted to be applied across other contexts. The dimensions give a frame to work with but should not restrict if the context demands adaptations. With this framework it is possible to design a wide range of personalization approaches, ensuring effective, scalable, and user-centered solutions.

Conclusion

This personalization framework addresses key dimensions of personalization, providing reference while being flexible for different contexts. Its adaptability allows designers to create relevant, user-centered solutions, improving system effectiveness across different contexts within healthcare.

4.2 Project conclusion

This project has explored how personalized support might improve the well-being of families caring for patients with cardiovascular disease using a human-centered design approach. The design process was built around the real-life experiences of family members by integrating context mapping, in-depth interviews, literature review, and prototyping. The Family Box is designed to provide personalized support for family members of MI and OHS patients. By doing this, the project ensured that families' perspectives were heard at every stage and provided both a feasible design solution and a better understanding of the emotional journey of caregiving.

A key insight of this thesis is the complexity and heterogeneity of family member experiences. Every situation comes with its own roles, challenges, and evolving needs. Rather than taking a one-size-fits-all approach, the Family Box embraces personalization as a core principle. The design adapts to different family members and situations, informed by personas and real user input. As a result, each family can receive support that feels relevant and meaningful to them.

This personalized approach recognizes that family members are individuals with distinct roles and emotions, not just extensions of the patient's care. The Family Box helps family members feel recognized, supported, and empowered in their role by supporting their individual needs, whether those are practical or emotional. The human impact of creating with empathy and a focus on personalization is highlighted by the positive feedback received from families during evaluation. They noted how the concept aligned with their experiences and made them feel valued.

This project's implications go beyond its current context. It provides LUMC with a vision for personalized care that actively supports and involves the family unit: solutions such as the Family Box can be used in follow-up and CR programs to extend care by bridging the gap between the hospital and the patient's home.

For designers, this project provides a case study in designing personalized support in healthcare. It shows the value of involving users. Moreover, the developed personalization framework can guide new approaches to designing for other healthcare contexts where one must support diverse human needs. There is future potential to expand and adapt this concept, whether by scaling it to other care paths or exploring intelligent features (like AI-driven content personalization) to enhance its effectiveness. Such developments would further improve the relevance of personalized family support within healthcare ecosystems.

In conclusion, this project shows how design can make an impact in everyday lives. Personalizing care is not only feasible but also valuable. As a result, this design contributes to a future of healthcare where families and patients improve together.

Improving the health and well-being of family members and patients

4.3 Personal reflection

Looking back on this project, it is time to take a look at the motivation and personal ambitions I initially outlined in the project brief (see Appendix I). At the start, I wanted to contribute meaningfully by creating something that can impact people's lives in a positive way. Additionally, I wrote down the following two personal ambitions:

1. Broadening design competencies to include digital health solutions and user experience design.
2. Enhancing empathy in design

Dealing with this project required a lot of adapting and critical thinking. The main challenge I experienced with this project was balancing the broad range of relevant topics at the earlier stages. Keeping clear boundaries of what topics, activities, and steps were valuable or relevant was a theme that continued. This is something that improved during the project but remains a point of improvement for me personally as a designer. Using a more strict planning that I reflect on consistently could have helped, together with asking myself the question, ‘Why is this ... relevant?’.

Throughout the project, user research was the basis of my approach. With the focus group data and interviews, this project allowed me to empathize with family members' lived experiences. As a result, it helped make my design based on real-world needs. Additionally, integrating generative AI tools presented a layer of complexity. It challenged me to combine human-centered methodologies and advanced technologies. This challenge improved my skills in both areas, making me capable of using new technologies to improve user experience while keeping empathy and personalization.

One of my key personal learning ambitions was to broaden my design competencies, particularly with digital health solutions and user experience design. I worked on this ambition through the development and iterative prototyping of a wide range of interfaces that align with user behavior and needs.

Equally important was my ambition to enhance empathy in design. This was implemented throughout the whole process, from empathizing with the focus group data to interpreting face-to-face responses and translating them into design elements that recognize and empower family members. Moreover, through the iterations of my design, I was consistently reflecting on the user needs, allowing me to stay close to the family members’ experiences.

Reflecting critically, there are aspects I would approach differently in the future. Testing generative AI earlier could have provided more insights sooner, potentially adding refinement and making the development recommendations more elaborate. Additionally, as mentioned before, dedicating more reflection moments to the process might have improved and increased the iterations I did.

To conclude, I am satisfied with my final design and how it responds to the original project brief. It addresses the key aspects of the problem as given while aligning with the needs of family members. This project not only helped me achieve my personal ambitions but also helped me develop myself as a designer.

Looking forward to the future challenges as a designer .

Sander Eversdijk

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Appendix A:
Themes & statement cards

Theme Groups

Want to be recognized

Partner wellbeing

Patient is priority Nr. 1

Patient is not partner and vice versa

Need for partner support/recognition

Opportunity for personalization

Help with responsibilities/roles

Partner of all

Case manager

Costs of social support

Involvement of children

Balancing caregiving & peace

Diet household challenges

Wanting answers to questions

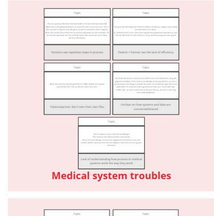
The threshold

Troubles of finding information

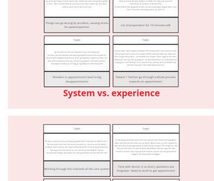
Where to Q&A?

Information needs

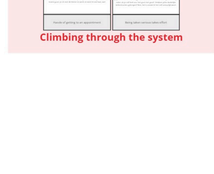
Help with navigating the system



Medical system troubles

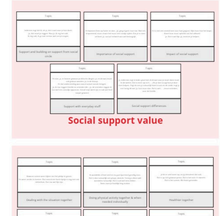


System vs. experience



Climbing through the system

Want to collaborate



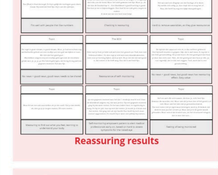
Social support value

Stronger together

Talking with peers

Want to understand how the patient feels

Patient only knows what they feel



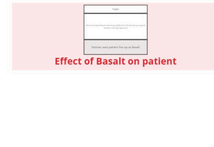
Reassuring results

Risks of measuring

Want to trust again

Doing things step by step

Rebuilding trust in the heart



Effect of Basalt on patient

Want clarity

Discrepancies have consequences

Ocean of uncertainty

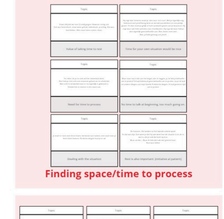
Distinct themes

How urgent is urgent?

How the hospital works

Experiences during operation

How it begins (MI)



Going back home

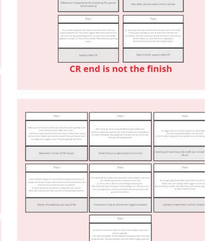
Finding space/time to process

Mind the gap

Where is the reaching hand of the hospital?

Back to the old ways

Getting to know your 'changed' partn



Looking forward

CR end is not the finish

Impact on further life

Safe exercise

Appendix B: Survey setup

Introduction
Support van families van hart- en vaatziektenpatiënten: Inzicht in uw ervaringen Dank u voor uw deelname aan deze enquête. Dit onderzoek wordt uitgevoerd door Sander Eversdijk van de TU Delft voor de afronding van de masteropleiding Integrated Product Design. Uw feedback helpt ons bij het ontwerpen van betere tools en ondersteuningssystemen voor familieleden van patiënten met hart- en vaatziekten. Deze enquête is anoniem, en alle antwoorden blijven vertrouwelijk. Het invullen duurt ongeveer 10 minuten. Dit project richt zich op de Family Box, een concept dat is ontworpen om families van hartpatiënten te ondersteunen tijdens hun herstelproces. Het is een toevoeging aan de Box: een doos met trackers, zodat patiënten hun gezondheid kunnen monitoren. De Family Box heeft als doel de samenwerking en communicatie tussen patiënten en hun dierbaren te verbeteren, en biedt gepersonaliseerde ondersteuning die is afgestemd op de unieke dynamiek van elke familie. Uw input draagt bij aan een oplossing die niet alleen het welzijn van de patiënt centraal stelt, maar ook de rol van families als actieve partners in het revalidatieproces versterkt. In deze questionnaire wordt gevraagd naar: 1) Uitdagingen tijdens het verlenen van zorg. 2) Informatievoorkeuren. 3) Voorkeuren voor de presentatie van informatie. 4) Hoe potentiële profielen op u aansluiten. Deze onderwerpen worden elk behandeld in hun eigen sectie, waar ook een open vraag zal zijn om eventuele opmerkingen of gedachtes te vermelden. Zoals bij elke online activiteit is het risico van een databreuk aanwezig. Wij doen ons best om uw antwoorden vertrouwelijk te houden. We minimaliseren de risico's door uw persoonlijk identificeerbare informatie/gegevens (PII/PIRD) geanonimiseerd en vertrouwelijk op te slaan samen met vergelijkbare gegevens bij de onderzoeker en deze mogen uitsluitend voor dit project gebruikt worden. Uw persoonlijke gegevens zullen ontoegankelijk zijn voor iedereen die niet bij dit project betrokken is. Gegevens die zijn verwerkt in resultaten, kunnen worden gepubliceerd in de eindpresentatie en het rapport van het afstudeerproject. Uw deelname aan dit onderzoek is volledig vrijwillig en u kunt op elk moment stoppen. U bent vrij om vragen over te slaan. Als u uw gegevens uit dit onderzoek wilt laten verwijderen, neem dan contact op met de onderzoeker. In geval van terugtrekken zullen alle gegevens uit dit onderzoek verwijderd worden. Voor verdere vragen, opmerkingen of zorgen kunt u contact opnemen met de onderzoeker Sander Eversdijk

Demographics
In deze sectie vragen we u om enkele basisvragen te beantwoorden die helpen om uw situatie beter te begrijpen. Deze informatie stelt ons in staat om de resultaten van dit onderzoek te analyseren en de FamilyBox beter af te stemmen op verschillende groepen gebruikers. Uw antwoorden blijven volledig anoniem.

Wat is uw leeftijd? Onder 25; 25-34 jaar oud; 35-44 jaar oud; 45-54 jaar oud; 55-64 jaar oud; 65+
Wat is uw geslacht? Man; Vrouw; Other
Wat is uw hoogst behaalde opleidingsniveau? Geen diploma; Basisonderwijs; VMBO HAVO / VWO onderbouw, MBO 1; HAVO, VWO, MBO2-4; Bachelor (HBO/WO); Master (HBO/WO); Doctor, PhD
Welke van de volgende opties beschrijft het beste uw ervaring? Ik heb ervaring met zorgverlenen aan een persoon met hart- en vaatziekten.; Ik heb ervaring met zorgverlenen aan een persoon met een andere chronische ziekte.; Ik heb geen ervaring met zorgverlenen aan een persoon met bovenstaande scenario's; Other
Wat is de relatie tot de persoon waar u voor zorgt/zorgde? Echtgenoot/Partner; Broer of zus; Kind (u bent het kind van de persoon); Ouder (u bent de ouder van de persoon); Vriend; Other

Uitdagingen tijdens zorgverlenen
Het verlenen van zorg aan een familielid met hart- en vaatziekten kan een complexe en veeleisende ervaring zijn. Deze sectie richt zich op de verschillende aspecten die mogelijk als uitdagend worden ervaren. Door uw ervaringen te delen, helpt u ons beter te begrijpen waar familieleden mee te maken hebben, zodat we ondersteuning kunnen bieden die aansluit bij uw behoeften. We vragen u om aan te geven in hoeverre u bepaalde situaties of taken als uitdagend ervaart. Er zijn geen goede of foute antwoorden – het gaat om uw persoonlijke ervaring.

Hoe uitdagend vindt/vond u de volgende aspecten van zorgverlenen? (Beoordeeld van niet uitdagend tot zeer uitdagend)
- Interne emoties (bijv. omgaan met eigen emoties)
- Emotionele support (bijv. omgaan met emoties van patiënt)
- Medische informatie behoeftes (bijv. het begrijpen van medische instructies of termen)
- Begrijpen van het medische systeem (bijv. wanneer hulp vragen aan professionals)
- Begrijpen van de ziekte (bijv. wat er gebeurt in het lichaam van de patiënt)
- Logistieke support (bijv. het vervoer naar afspraken in het ziekenhuis)
- Financiele verantwoordelij kheden (bijv. kosten van de zorg)
- Balans van zorgverlenen met persoonlijke leven (bijv. tijd voor werk, rust en andere zaken naast zorgverlenen)
- Informeren van sociale kringen (bijv. updates geven aan familie/vrienden)

Voor elk aspect dat u beoordeelde als 'redelijk' of 'zeer' uitdagend, geef alstublieft uitleg over uw ervaring daarmee:
Mist u een aspect in de lijst? Laat het alstublieft hier weten:
Als u vragen, opmerkingen of zorgen over deze sectie kwijt wilt, kunt u dat hier doen:

Informatie behoeftes
De Family Box wordt ontwikkeld om families te ondersteunen tijdens het herstelproces van patiënten met hart- en vaatziekten. Een belangrijk onderdeel hiervan is het verstrekken van relevante informatie die u helpt om de gezondheid en het herstel van uw familielid beter te begrijpen. In deze sectie vragen we naar uw informatiebehoeften met betrekking tot verschillende aspecten van de gezondheid van de patiënt. Eerst over aspecten met betrekking tot de lichamelijke gezondheid van de patiënt en daarna over andere aspecten. Uw antwoorden geven ons inzicht in welke informatie het meest waardevol is voor families, zodat de FamilyBox kan worden afgestemd op uw behoeften. Op deze manier streven we ernaar om u te voorzien van de juiste ondersteuning om uw rol als zorgverlenend familielid te versterken.

Hoe belangrijk is het voor u om informatie te ontvangen over de volgende aspecten van de lichamelijke gezondheid van de patiënt? (Beoordeeld van niet belangrijk tot zeer belangrijk, inclusief optie niet van toepassing)
- Hartslag
- Bloeddruk
- Stappen
- Gewicht
- Voeding logboek
- Lichamelijke beweging
- Roken
- Alcohol consumptie
- Bloedsuiker
- Slaap kwaliteit
- Stress level

Voor elk aspect dat u beoordeelde als 'redelijk' of 'zeer' belangrijk, geef alstublieft uitleg over uw reden daarvoor:

Hoe belangrijk is het voor u om informatie te ontvangen over de volgende aspecten van de gezondheid van de patiënt? (Beoordeeld van niet belangrijk tot zeer belangrijk, inclusief optie niet van toepassing)
- Medicatie updates (bijv. veranderingen in instructies)
- Progressie in revalidatie
- Levensstijl aanbevelingen
- Toekomstige afspraken & procedures
- Emotionele staat
- Zelf gestelde doelen

Voor elk aspect dat u beoordeelde als 'redelijk' of 'zeer' belangrijk, geef alstublieft uitleg over uw reden daarvoor:
Zijn er aspecten die u miste in 1 van de lijsten? Laat het alstublieft hier weten:
Als u vragen, opmerkingen of zorgen over deze sectie kwijt wilt kunt u dat hier doen:

Voorkeuren voor data presentatie
De FamilyBox biedt inzicht in de gezondheid en voortgang van de patiënt door middel van gegevens die eenvoudig te begrijpen en te gebruiken zijn. In deze sectie willen we graag meer te weten komen over uw voorkeuren voor hoe deze gegevens worden gepresenteerd. Denk hierbij aan de manier waarop informatie wordt weergegeven, zoals grafieken, samenvattingen of getallen. Uw input helpt ons om de presentatie van gegevens binnen de FamilyBox zo helder en bruikbaar mogelijk te maken, zodat u gemakkelijker geïnformeerd beslissingen kunt nemen en de voortgang van het herstelproces kunt volgen.

Hieronder staan voorbeelden van hoe gezondheidsdata kan worden gepresenteerd. Als u snel de gezondheidsdata van de patiënt, wilt checken welk voorbeeld heeft dan uw voorkeur? (Bovenste = meeste voorkeur; Laagste = minste voorkeur)
- Grafiek
- Kleur-codering
- Getallen
- Emoji
- Tekst

Hieronder staan voorbeelden van hoe gezondheidsdata kan worden gepresenteerd. Als u uitgebreid de gezondheidsdata van de patiënt wilt checken, welk voorbeeld heeft dan uw voorkeur? (Bovenste = meeste voorkeur; Laagste = minste voorkeur)
- Grafiek
- Kleur-codering
- Getallen
- Emoji
- Tekst

Als u vragen, opmerkingen of zorgen over deze sectie kwijt wilt kunt u dat hier doen:

Profiel herkenning
Als onderdeel van de ontwikkeling van de FamilyBox hebben we vier verschillende profielen opgesteld die gebaseerd zijn op de diverse manieren waarop familieleden omgaan met de zorg voor een patiënt met hart- en vaatziekten. Elk profiel weerspiegelt unieke kenmerken, behoeften en benaderingen van ondersteuning. In deze sectie vragen we u om te beoordelen in hoeverre u zichzelf herkent in de beschrijvingen van deze profielen. Uw feedback helpt ons

om de FamilyBox beter af te stemmen op de uiteenlopende ervaringen en behoeften van families, zodat we een ondersteuning kunnen bieden die écht aansluit bij uw situatie.

In welke mate herkent u uzelf in elk profiel?

- Profiel 1: Dit profiel vertegenwoordigt een persoon die sterk gericht is op het beschermen van de patiënt en diens welzijn. U neemt de rol van een stille kracht op u, iemand die de stress en zorgen van de patiënt probeert te minimaliseren. U voelt zich verantwoordelijk om een veilige en stabiele omgeving te creëren waarin de patiënt zich volledig kan richten op herstel.
- Profiel 2: Dit profiel beschrijft een persoon die zich richt op het behouden van stabiliteit binnen de dagelijkse routine, terwijl u flexibel inspeelt op de veranderende behoeften van de patiënt. U bent iemand die rust en structuur wil waarborgen, zowel voor uzelf als voor de patiënt, ongeacht de uitdagingen die zich voordoen.
- Profiel 3: Dit profiel beschrijft een persoon die veel waarde hecht aan open communicatie en een sterke verbinding met de patiënt. U bent iemand die gelooft dat begrip en samenwerking de sleutel zijn tot een succesvol herstelproces. U streeft ernaar om samen met de patiënt een ondersteunende en transparante relatie te onderhouden, waarin wederzijds respect en vertrouwen centraal staan.
- Profiel 4: Dit profiel beschrijft een persoon die de patiënt stimuleert om zelfstandig verantwoordelijkheid te nemen voor zijn of haar herstelproces. U neemt een ondersteunende en analytische rol aan, met een sterke focus op het begrijpen van de situatie en het bieden van gerichte inzichten wanneer dat nodig is. U vertrouwt op de autonomie van de patiënt en ziet uw rol vooral als begeleider en analist.

Beoordeeld per profiel van niet tot zeer nauw

Als u vragen, opmerkingen of zorgen over deze sectie kwijt wilt kunt u dat hier doen:

Bedankt voor uw deelname!

Hartelijk bedankt voor het invullen van deze enquête. Uw input is van grote waarde en helpt om de FamilyBox verder te ontwikkelen en beter af te stemmen op de behoeften van families van patiënten met hart- en vaatziekten. Met uw feedback kunnen we een oplossing creëren die niet alleen de patiënt ondersteunt, maar ook families sterker maakt als actieve partners in het herstelproces. Als u nog vragen, opmerkingen of aanvullende ideeën heeft, aarzel dan niet om contact met de onderzoeker Sander Eversdijk op te nemen via s.m.eversdijk@student.tudelft.nl. Nogmaals dank voor uw tijd en bijdrage!

Mocht u nu aan het einde nog vragen, opmerkingen of zorgen hebben kunt u die hier nog vermelden

Appendix C: Interview guide

Introductie

- Stel mezelf, het project en het doel van het interview voor.
- Laten zien van het consentformulier, eventueel uitleggen en ondertekenen daarvan
- Benadruk dat het gesprek gaat over het begrijpen van hun ervaringen, behoeften en voorkeuren om de Family Box te ontwikkelen en te verbeteren.
- Leg uit hoe gegevens worden verzameld, wat de risico's zijn en welke protocollen worden gevolgd.
- Benadruk dat deelname vrijwillig is en op elk moment kan worden stopgezet, waarbij alle gegevens worden verwijderd.

Deel 0: Demografische vragen

- Wat is uw leeftijd?
- Wat is uw geslacht
- Wat is uw hoogst behaalde opleidingsniveau?
- Heeft uw ervaring met zorgverlening aan een persoon met hart- en vaatziekten?
- Wat is de relatie tot de persoon waar u voor zorgt/zorgde?

Deel 1: Uitdagingen

Hoofdvraag:

1. Kunt u vertellen over uw ervaring met het ondersteunen van X (patiënt) tijdens hun zorgtraject voor hart- en vaatziekten?
   - Hoe hebben jullie elkaar ondersteund tijdens het ziekteproces? Is dat in de loop van de tijd veranderd?
   - Wat was voor u persoonlijk het meest uitdagend?
2. Beoordeel deze lijst van aspecten van niet uitdagend tot zeer uitdagend:
   - Interne emoties (bijv. omgaan met eigen emoties)
   - Emotionele support (bijv. omgaan met emoties van patiënt)
   - Medische informatie behoeftes (bijv. het begrijpen van medische instructies of termen)
   - Begrijpen van het medische systeem (bijv. wanneer hulp vragen aan professionals)
   - Begrijpen van de ziekte (bijv. wat er gebeurt in het lichaam van de patiënt)
   - Logistieke support (bijv. het vervoer naar afspraken in het ziekenhuis)
   - Financiele verantwoordelijkheden (bijv. kosten van de zorg)
   - Balans van zorgverlenen met persoonlijke leven (bijv. tijd voor werk, rust en andere zaken naast zorgverlenen)
   - Informeren van sociale kringen (bijv. updates geven aan familie/vrienden)
3. Hoe verhouden deze aspecten zich over tijd?
   - Stel we houden de volgende fases aan:
     - Voor operatie
     - Operatie/opname ziekenhuis
     - Ontslag
     - Weer thuis & wennen aan situatie
     - Revalidatie
     - Transitie naar zelfstandig leven
     - Behouden van welzijn

Vervolgvragen:

- Hoe was de verdeling van rollen tijdens het zorgtraject?
- Met welke emotionele uitdagingen bent u geconfronteerd tijdens dit proces?
- Waren er momenten waarop u zich onvoorbereid of onzeker voelde over wat te doen? Kunt u daar meer over delen?
- Zijn er logistieke moeilijkheden, zoals het beheren van afspraken of medicatie, die opvallen?

Voelt u zich voldoende ondersteund door zorgverleners? Waarom wel of niet?

Deel 2: Informatiebehoeften

Hoofdvraag:

1. Welke informatie over de gezondheid of het zorgproces van de patiënt vindt u het meest nuttig?
   - Denk hierbij aan lichamelijke gezondheidsinformatie zoals:
     - Hartslag
     - Bloeddruk
     - Stappen
     - Gewicht
     - Voeding logboek
     - Lichamelijke beweging
     - Roken
     - Alcohol consumptie
     - Bloedsuiker
     - Slaapkwaliteit
     - Stress level
   - Of andere aspecten zoals:
     - Medicatie updates (bijv. veranderingen in instructies)
     - Progressie in revalidatie
     - Levensstijl aanbevelingen
     - Toekomstige afspraken & procedures
     - Emotionele staat
     - Zelf gestelde doelen
2. Zijn er soorten informatie die u liever niet wilt weten? Waarom?

Vervolgvragen:

- Zou u meer begeleiding willen over hoe u X (patiënt) kunt ondersteunen? Zo ja, wat voor soort begeleiding?
- Zijn er momenten geweest waarop u informatie nodig had, maar deze niet had? Kunt u die momenten beschrijven?
- Zou u graag updates ontvangen over de gezondheid of voortgang van X (patiënt)? Wat voor soort updates zouden het meest nuttig zijn?

Deel 3: Presentatie van data

Hoofdvraag:

- Als er een app was om patiënt gerelateerde gezondheidsinformatie met u te delen, hoe zou u willen dat die informatie wordt gepresenteerd?

- Als u snel de gezondheid wilt checken van de patiënt, welk voorbeeld heeft dan uw voorkeur?
- Als uitgebreid de gezondheidsdata van de patiënt wilt checken, welk voorbeeld heeft dan uw voorkeur?

Vervolgvragen en verkenningen:

- Heeft u de voorkeur voor gedetailleerde cijfers, eenvoudige grafieken of intuïtievere visuals zoals kleuren en symbolen?
  - Voorbeeld: Als een grafiek de bloeddruk van X (patiënt) in de tijd weergeeft, zou u dan cijfers, trendlijnen of alleen een indicatie "normaal" vs. "niet normaal" willen zien?
- Voelt u zich comfortabel bij het interpreteren van grafieken en diagrammen? Waarom wel of niet?
- Zou het nuttig zijn om korte uitleg of tips toe te voegen bij de gegevens?
- Hoe belangrijk is emotioneel comfort bij het bekijken van gezondheidsdata? Bijvoorbeeld, zou u liever waarschuwingen in een kalmerende toon zien in plaats van urgente meldingen?

Deel 4: Validatie van persona's

Introductie van persona's:

- We hebben vier persona's gecreëerd om verschillende manieren te vertegenwoordigen waarop familieleden patiënten ondersteunen. Deze persona's zijn:
  - Profiel 1: Dit profiel vertegenwoordigt een persoon die sterk gericht is op het beschermen van de patiënt en diens welzijn. U neemt de rol van een stille kracht op u, iemand die de stress en zorgen van de patiënt probeert te minimaliseren. U voelt zich verantwoordelijk om een veilige en stabiele omgeving te creëren waarin de patiënt zich volledig kan richten op herstel.
  - Profiel 2: Dit profiel beschrijft een persoon die zich richt op het behouden van stabiliteit binnen de dagelijkse routine, terwijl u flexibel inspeelt op de veranderende behoeften van de patiënt. U bent iemand die rust en structuur wil waarborgen, zowel voor uzelf als voor de patiënt, ongeacht de uitdagingen die zich voordoen.
  - Profiel 3: Dit profiel beschrijft een persoon die veel waarde hecht aan open communicatie en een sterke verbinding met de patiënt. U bent iemand die gelooft dat begrip en samenwerking de sleutel zijn tot een succesvol herstelproces. U streeft ernaar om samen met de patiënt een ondersteunende en transparante relatie te onderhouden, waarin wederzijds respect en vertrouwen centraal staan.
  - Profiel 4: Dit profiel beschrijft een persoon die de patiënt stimuleert om zelfstandig verantwoordelijkheid te nemen voor zijn of haar herstelproces. U neemt een ondersteunende en analytische rol aan, met een sterke focus op het begrijpen van de situatie en het bieden van gerichte inzichten wanneer dat nodig is. U vertrouwt op de autonomie van de patiënt en ziet uw rol vooral als begeleider en analist.

Hoofdvragen:

- Herkent u zichzelf in een van deze beschrijvingen van hoe u X (patiënt) heeft ondersteund? Waarom?
- Voelt u zich verbonden met meer dan één persona? Op welke manieren?
- Zijn er aspecten van uw ervaring die niet passen bij deze persona's?
- In het geval dat u vanuit u bij u meest passend persona een functie op een sneltoetspositie in de app kan plaatsen, welke functie zou u dan het liefst daar willen hebben?
  - Medicatie tracker
  - Gedeelde agenda
  - Familie communicatie omgeving
  - Patiënt reis kaart
  - Snel overzicht van gezondheid
  - Checklist
  - Dagboek
  - Herstel inzichten
  - Waarschuwingen
  - Self-care tracker
  - Gesprekstarter kaarten
  - Volgende mijlpaal

Vervolgvragen:

- Welke onderdelen van deze beschrijvingen voelen het meest accuraat voor uw ervaring?
- Als u iets zou kunnen toevoegen of veranderen aan deze persona's, wat zou dat zijn?
- Denkt u dat deze persona's de verschillende manieren waarop mensen zorg geven goed weergeven? Waarom wel of niet?

Deel 5: Afronden

Hoofdvraag:

1. Als u het ideale ondersteuningssysteem voor uzelf als familielid zou kunnen ontwerpen, hoe zou dat eruitzien?

Vervolgvragen:

1. Zijn er hulpmiddelen, bronnen of veranderingen in het zorgproces die het voor u makkelijker zouden maken?
2. Heeft u advies voor andere familieleden die een soortgelijke ervaring doormaken?
3.
4. **Afsluiting**
5. Bedank hen voor hun tijd en waardevolle inzichten.
6. Vraag of ze nog laatste gedachten hebben of iets willen delen dat niet aan bod is gekomen.
7. Herhaal hoe hun input zal bijdragen aan het verbeteren van de ondersteuning van families in de zorg voor hart- en vaatziekten.
8.

Appendix D: Personas Lost Lemon & MUZUS

The four personas were further described to elaborate argumentation on their dimension scoring. This was done according to the method of Lost Lemon & Muzus (2018).

Protector

They are

Cautious, dutiful, and controlling. Protectors have a strong sense of responsibility and prefer to manage everything themselves, often focusing on the patient's safety over their own needs. The patient is their priority, possibly resulting in moments where the protector overrules the patient.

This grabs their attention

Clear guidelines on care procedures, assurance that their efforts positively influence the patient's health, or tools that help them monitor and control the caregiving process.

These are barriers for them

Concern over not doing enough, lack of reliable information, and challenges with navigating the complex healthcare system.

This tempts them

Tools for tracking and monitoring and reassurance from trusted sources like professionals.

This is their goal

To ensure that the patient is safe, unburdened, and experiences no setbacks.

This is their experience

Structured, but emotionally challenging, as they mostly suppress their feelings to focus on caregiving.

This motivates them

The patient's health and safety and the desire to do everything right.

This causes them to quit

Feeling unsupported by the healthcare system or when they experience constant complex challenges.

These are their terms

Clear, structured support and easy access to resources that provide updates and feedback.

As a result, the Protector persona was scored as follows:

- Solo: They take full responsibility for the patient's well-being, often managing care independently rather than relying on the help of others. They prefer to do things by themselves. As they like control, they want to oversee everything.
- Active: They are proactive, taking initiative in providing care to the patient. They continuously monitor the patient's health, intervene when necessary, and seek out resources or information to ensure the patient is well cared for.
- Problem-focused coping: They tend to suppress their own emotions, prioritizing the practical aspects of caregiving and the health of the patient. With feelings set aside, to provide the best care, they view emotional expressions as potential distractions from their responsibilities.

Adaptor

They are

Flexible, collaborative, and practical. Adaptors work closely with the patient and other family members, adjusting their support as situations change. They want everything taken care of while neglecting their own needs.

This grabs their attention

Practical solutions for immediate caregiving needs, adaptable schedules, and tools that simplify caregiving tasks.

These are barriers for them

Complexity in caregiving tasks, lack of communication among family or with healthcare professionals.

This tempts them

Tools or resources that simplify caregiving, allow for flexible scheduling, or promote collaboration.

This is their goal

To adapt and stay organized, ensuring the patient's needs are fully met in any way possible.

This is their experience

Often fluid and unpredictable, they are balancing caregiving with their own responsibilities, like work, while adjusting constantly to patients' needs.

This motivates them

A desire for stability in the patient's condition.

This causes them to quit

When emotional and physical demands become overwhelming.

These are their terms

Accessible and practical tools that help manage caregiving tasks in a flexible way.

As a result, the Adaptor persona was scored as follows:

- Together: They prefer collaborating and a shared approach with the patient and other family members. Working alongside others is comfortable for them, adapting their support to fit the process and needs of the patient.
- Active: They are quick to adapt to the situation, actively stepping in to help when needed. They are engaged in their care approach and take initiative.
- Emotion-focused coping: They often deal with their emotions, focusing on being flexible and adaptable to support the patient. Priority is given to seeking social support and seeing the positive sides of things.

Talker

They are

Communicative, supportive, and empathetic. Talkers rely on open dialogue with family and healthcare providers to support the patient emotionally.

This grabs their attention

A supportive community, opportunities for emotional expression, and tools that facilitate communication.

These are barriers for them

Lack of access to emotional support resources or peer communities, feeling that concerns are unheard.

This tempts them

Resources or tools that stimulate sharing and emotional processing, group sessions, and forums with other caregivers.

This is their goal

Providing emotional support and feeling connected with the patient and their social circle.

This is their experience

They feel a strong emotional bond with the patient but may feel burdened when they lack opportunities for emotional expression.

This motivates them

Connection with the patient and social circle. They have a desire to connect, share concerns, and receive validation.

This causes them to quit

When they feel isolated or when communication falls apart.

These are their terms

Resources or tools that offer connection opportunities and validate their caregiving role, as well as tools that facilitate patient and social circle communication.

As a result, the Talker persona was scored as follows:

- Together: They are communicative and prefer a collaborative approach, involving the patient and sharing insights, updates, and concerns. They thrive in collaboration, relying on open communication with patients, their social circle, and healthcare professionals.
- Passive: They contribute to caregiving needs using a communicative approach rather than actions. They take a conversational and supportive role, relying on others to take up hands-on caregiving while they provide emotional support.
- Emotion-focused coping: They are open to discussing and processing their emotions, managing their feelings by talking with others like family or colleagues.

Observer

They are

Detached, patient, and calm. They maintain distance, respecting the patient's autonomy and stepping in only when necessary.

This grabs their attention

Low-maintenance tools, minimal involvement care solutions, and resources or tools that respect the patient's independence.

These are barriers for them

Feeling pressured to intervene more than they prefer or being required to act in high-stress situations.

This tempts them

Tools for remote monitoring, non-intrusive support tools, and resources that guide caregiving without interfering with the patient.

This is their goal

To support the patient without interfering and respecting their autonomy.

This is their experience

They may feel detached, focusing on observing rather than supporting, which can create a sense of loneliness or distance.

This motivates them

The patient's independence and seeing their progress.

This causes them to quit

Overly involved expectations, or when they are expected to manage complex aspects of caregiving, like emotional or logistical aspects.

These are their terms

Resources or tools that allow them to remain in a passive role and options that support the patient's autonomy.

As a result, the Observer persona was scored as follows:

- Solo: They prefer to or are forced to maintain a distance from the patient, respecting the patient's autonomy and allowing them to manage their own health. They avoid direct interference and tend to observe rather than getting involved closely.
- Passive: They take a hands-off approach, as they provide support from a distance and only step in when there is no other option. They are less involved in day-to-day caregiving, often watching from the sideline while the patient cares for themselves.
- Problem-focused coping: They are prone to suppressing or ignoring their emotions, choosing not to deal with the emotional side of caregiving. They focus on maintaining a calm and detached perspective, often avoiding open emotional expression.

Appendix E: Elaborated main features

Patient & You

These features will show the family member the health data of the patient (**Patient**) and their own (**You**). The addition of **You** acknowledges the impact that caregiving can have on their well-being. By making their own health visible to them, family members are encouraged to be aware and stay aware of their own health and well-being. The health data is shown in a simple manner, using color coding and numbers to fit the need for checking quickly but also allowing family members that prefer details to see the facts when they glance over the health data.

Family members can pin health aspects at the top of the page so they do not have to search for the aspects they prefer to see more often.

The health aspects are presented in a layered structure, with the first layer showing the latest or current value combined with a color. The second layer is when a family member selects that health aspect, giving them the option to see the health aspect over time in three timeframes: day, week, and month. Followed by an explanation of thathealth aspect, what to look out for, and recommended modules that might be interesting. This way, someone who wants to know more can find it in an intuitive way.

Within the **Patient** pages, text will be addressed to the family member by interpreting the data and showing interesting insights or things to look out for.

In the **You** pages, text will be adapted to still address the family member, but it will address the family member directly about their own data. For example, using phrases like 'your heart rate.'.

Purpose

Give a structured overview of health aspects and providing information when preferred.

Addressed needs

Patient

- TG 6: Want to understand how the patient feels
- TG 7: Want to trust again
- TG 8: Want clarity

You

- TG 1: Want to be recognized

Figure 82: Patient & You features.

Figure 83: Patient & You detailed pages.

Goals

An important part of the Family Box is that family members and patients can work on healthier lifestyles. To support this, the **Goals** feature enables them to set personal goals, view the patient's goals, and create shared goals.

Encouraging family members to set their own health and well-being goals has multiple purposes. First, it encourages the family member to be involved in making lifestyle changes. This could also have the effect of making the patient not feel alone in this part of the care journey. Secondly, it addresses the fact that the health and well-being of the family member is important, not just for themselves but also for their ability to care. By providing the opportunity to monitor and collaborate with each other, this feature supports the making of sustainable lifestyle changes, aligning with the goal to improve the management of the health and well-being of both family members and patients.

The feature shows progress over the relevant timeframes of the goal. Family members can create new goals based on the 'Leefstijlroer' aspects by themselves or use suggested goals.

Purpose

Allow monitoring goals and creating them for the family member or the patient and family member.

Addressed needs

- TG 5: Want to collaborate
- TG 6: Want to understand how the patient feels

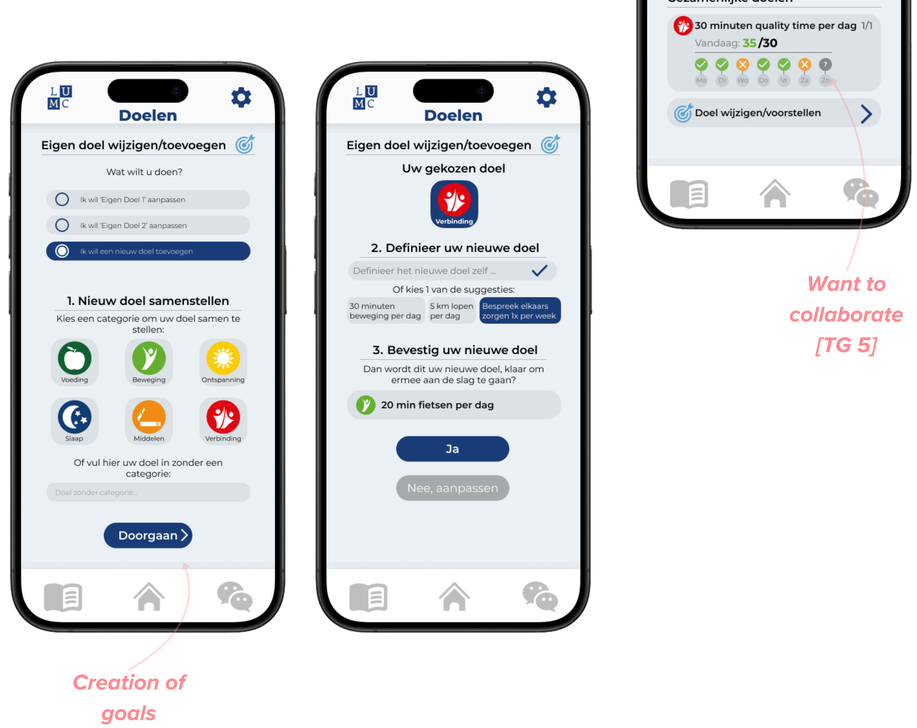


Figure 84: Goals & Knowledge features.

Knowledge

The **Knowledge** feature consists of both modules providing information or tips on relevant topics and tools that help family members deal with the various aspects of caregiving, like the multiple roles they can take on in the care journey. Modules or tools will also be recommended to family members. Based on how their needs change over time, family members will receive recommendations for relevant modules and tools. Depending on the phase of the care journey (e.g., discharge, adaptation), the modules will cover different topics or help with different responsibilities. As an example, Figure 86 shows modules that could be offered during the discharge phase. These examples are based on the **TGs** and distinct themes that were found in the analysis of the focus group data.

Within **Knowledge**, family members can filter on saved topics, modules, or tools, as well as search for a topic that they want to learn about, or they can select one of the seven categories to explore relevant topics.

Purpose

Provide relevant information and tools for a wide range of topics.

Addressed needs

- TG 2: Help with responsibilities/roles
- TG 3: Wanting answers to questions
- TG 4: Help with navigating the system
- TG 8: Want clarity

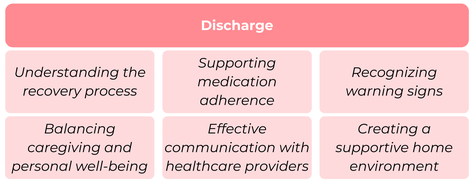


Figure 86: Examples of recommended topics in the discharge phase.

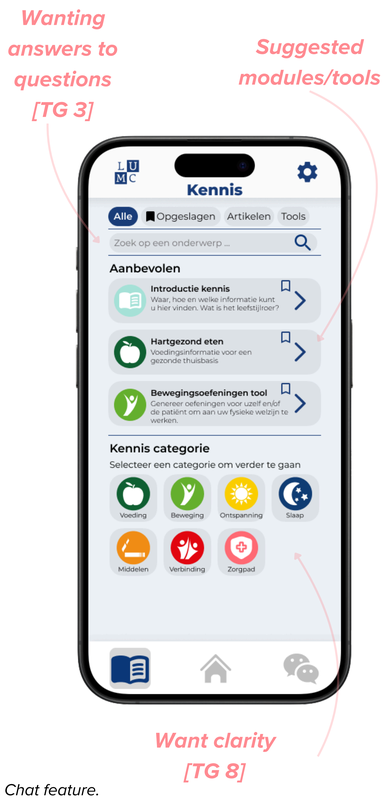


Figure 85: Chat feature.

Chat

The **Chat** feature allows family members to ask questions and receive guidance. They can use this feature to find information, gain a better understanding of caregiving-related topics, or determine whether they need to contact a healthcare professional. Depending on the nature of the question, the **Chat** feature can support them as an AI assistant for instant support, provide a space to store questions for an upcoming consultation, or offer resources to guide their next steps.

Purpose

Provide a space for family members to ask questions or express their concerns.

Addressed needs

- TG 2: Help with responsibilities/roles
- TG 3: Wanting answers to questions
- TG 4: Help with navigating the system

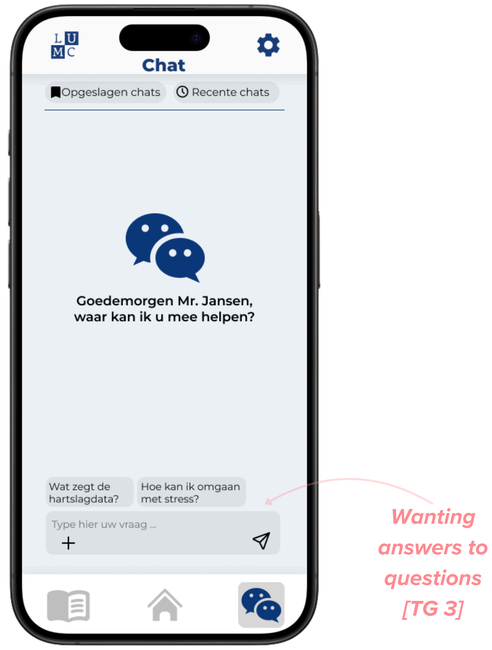


Figure 87: Chat feature.

Appendix F: Matching process questions

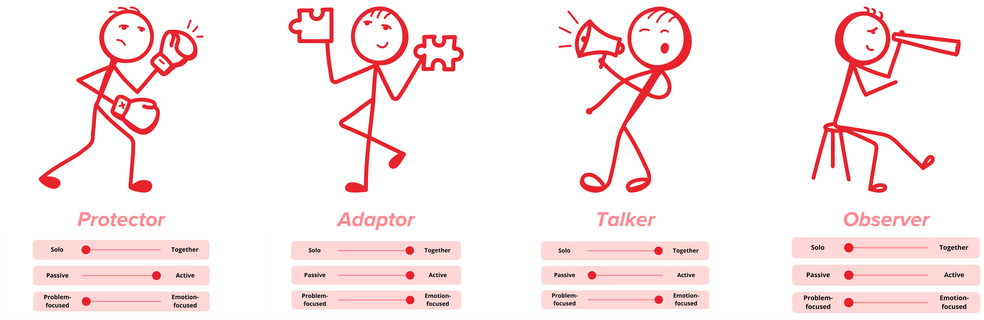
As mentioned in **3.1 Final design**, the platform includes a matching process that helps the family member get matched with one of the four personas. This is done to personalize their experience and ensure the support they receive is relevant to them.

In order to do this, the matching process uses a set of nine questions, which together assess a family member across the three dimensions that were used to design the personas:

1. **Involvedness** (Solo vs. Together): Measures how closely the family member collaborates with the patient in the care journey, whether they maintain distance or prefer to share the journey.
2. **Care approach** (Passive vs. Active): Evaluates the degree to which the family member takes initiative in caregiving tasks, ranging from hesitant or hands-off to highly proactive.
3. **Emotional coping strategy** (Problem-focused vs. Emotion-focused): Assess how the family member handles the emotional side of caregiving, whether they tend to focus on the practical aspects or prioritize the emotional processing and connection.

Each dimension is covered by three questions, totaling nine. The questions are phrased using realistic scenarios and neutral language to avoid socially desirable answers. For each question, one of the two options corresponds to one side of the dimension. This allows the platform to determine the dominant trait within each dimension for that individual.

Based on the combination of their responses, the family member is matched with one of the four personas:



Dimension 1: Involvedness

The first three questions focus on the '**Involvedness**' dimension. From the two options, the upper one represents the **Solo** side, while the lower one represents the **Together** side of this dimension.

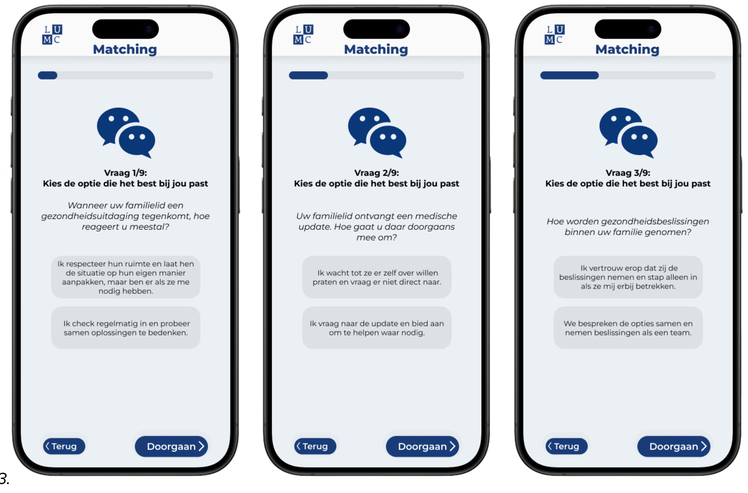


Figure 88: Matching questions 1 - 3.

Dimension 2: Care approach

Questions four, five, and six focus on the '**Care approach**' dimension. From the two options, the upper one represents the **Passive** side, while the lower one represents the **Active** side of this dimension.

Figure 89: Matching questions 4 - 6.

Dimension 3: Emotional coping

Questions seven, eight, and nine focus on the '**Emotional coping**' dimension. From the two options, the upper one represents the **Problem-focused** side, while the lower one represents the **Emotion-focused** side of this dimension.

Figure 90: Matching questions 7 - 9.

Appendix G: Evaluation sessions interfaces

The following pages show the slides used for the evaluation sessions with family members that were discussed in **3.2 Impact**.

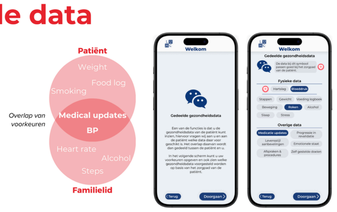
1

Introductie

2

Gedeelde data

Voorkeuren



3

Hoofd functies

4

Patiënt & Jij

5

Doelen

6

Kennis

7

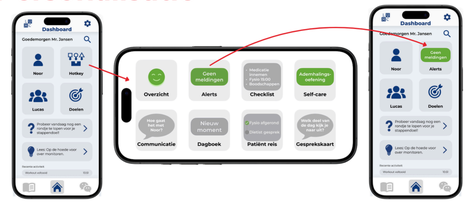
Kennis

8

Personalisatie

9

Personalisatie



10

Personalisatie

11

How to personalize support?

3. Offering implicit support

	Discharge			Drive
	Monitoring tools 101	Emergency planning	Managing anxiety as a caregiver	Concern
	Setting expectations together	Prepared for emergency together	Shared planning tips	Stability
	How to keep the family informed	Connecting without overwhelming	Emotional needs from the patient	Connection
	Why you are important	Staying informed without interfering	Coping with feeling helpless	Understanding

Offering 3 modules persona-specific relevant to a specific phase as a starting point

For example

Onboarding | Matching | **Implicit support** | Explicit support

12

How to personalize support?

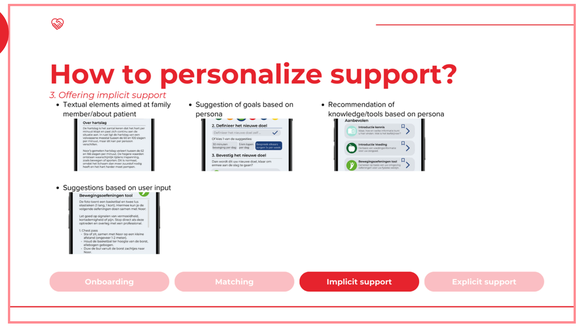
2. Match family member to persona

- Done after 3 weeks of regular use

- Explicit or implicit personalization, both are available to family member
- Suggestion match based on dimensions + interactions
- Questions based on dimensions
  - Situational questions
  - Aimed at preferences

Onboarding | **Matching** | Implicit support | Explicit support

13



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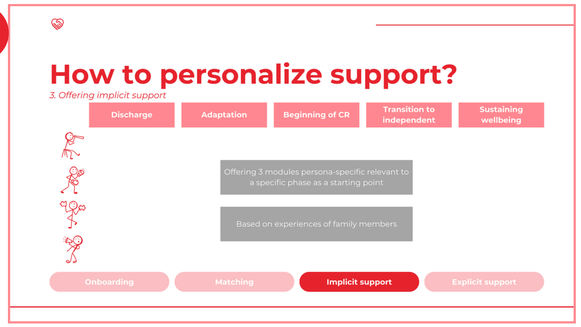

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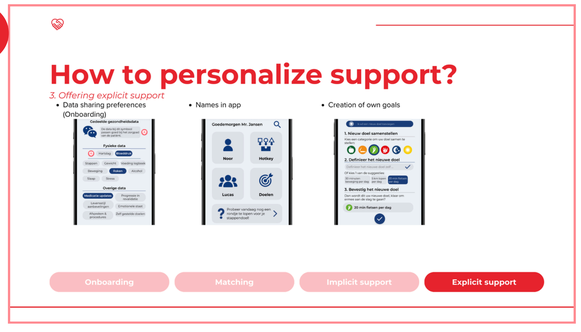

Appendix H: Guidelines mobile health recommender system

This visual framework illustrates design guidelines for personalized support based on a combination of behavior change theories and persuasive system design principles. It is based on the work of Torkamaan & Ziegler (2021), who integrated multiple models such as the health belief model, self-determination theory, and Fogg's behavior model to guide the development of health recommender systems.

The framework is divided into two domains:

- **User-side factors** (blue) (Figure 91): These include beliefs, attitudes, and social influences that shape user goals, motivation, and readiness for behavior change.
- **System-side** (purple) (Figure 92): These include content strategies, interface functions, and persuasive techniques used to tailor support to users' goals and contexts.

Together, these guidelines support the development of a system that is not only behaviorally effective but also user-centered and adaptive to emotional and practical needs. In the context of this thesis, they could inform how support for family members could be designed while being built upon behavior change theories.

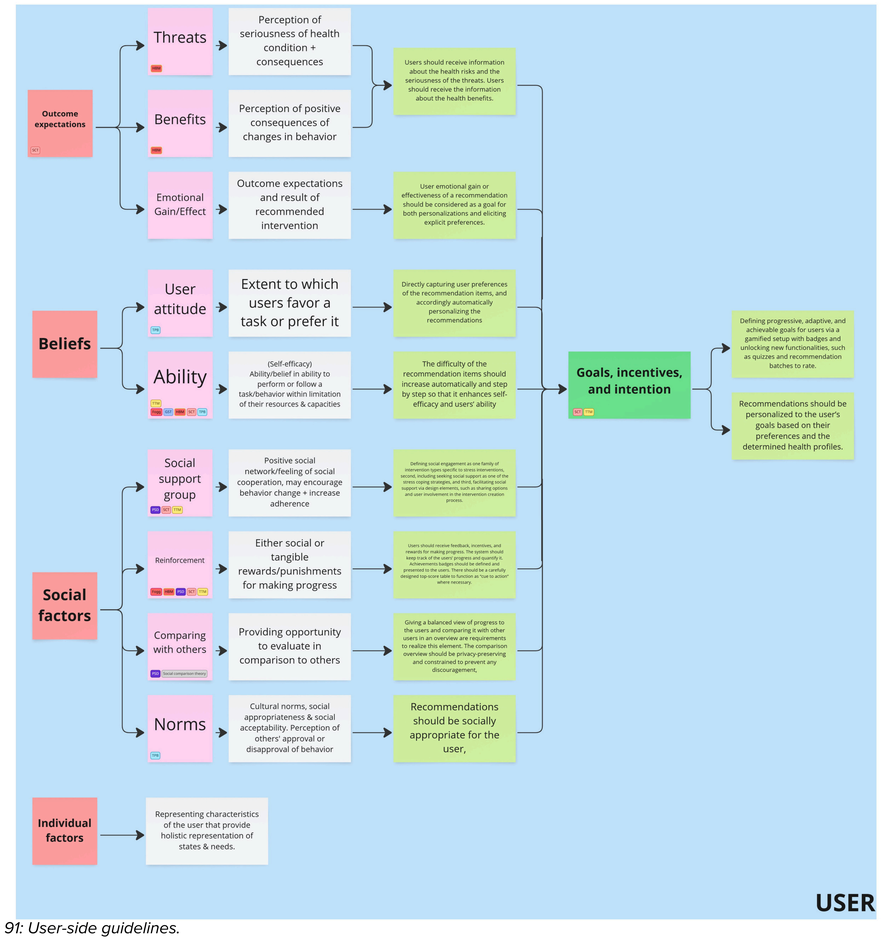

Figure 91: User-side guidelines.

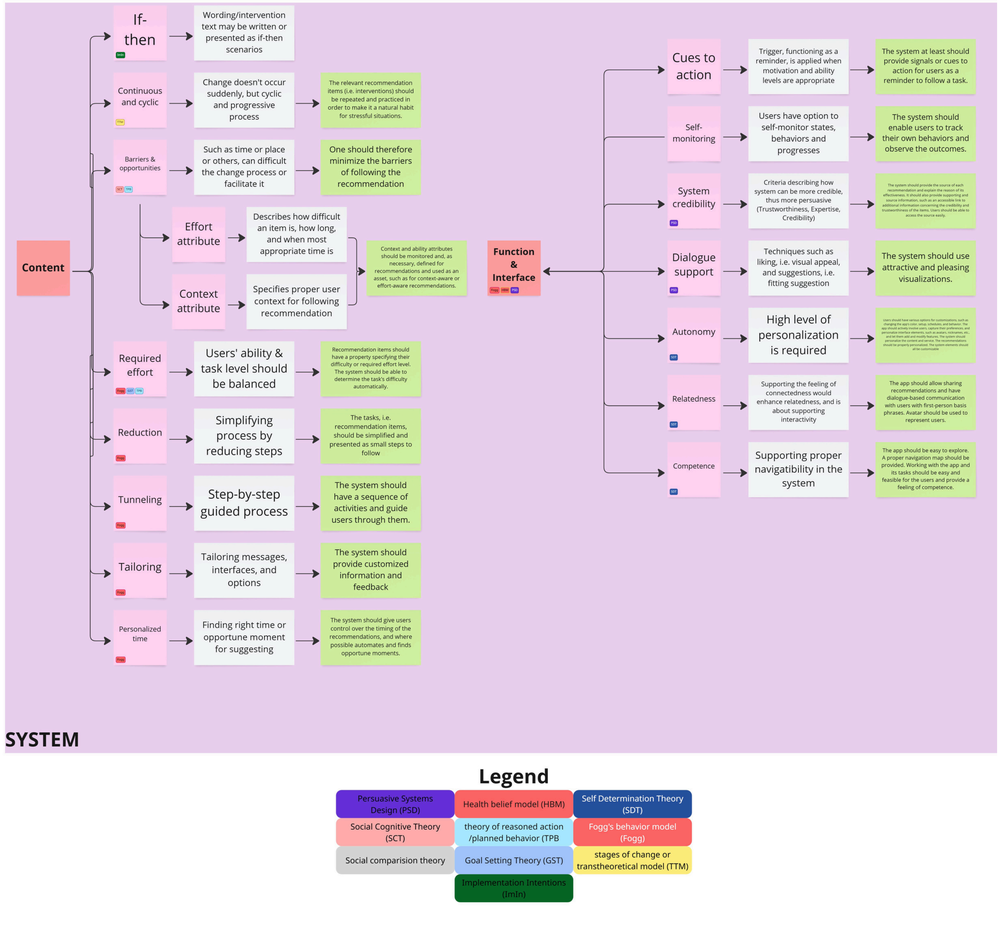

Figure 92: System-side guidelines.

Torkamaan, H., & Ziegler, J. (2021). Integrating Behavior Change and Persuasive Design Theories into an Example Mobile Health Recommender System. Adjunct Proceedings Of The 2021 ACM International Joint Conference On Pervasive And Ubiquitous Computing And Proceedings Of The 2021 ACM International Symposium On Wearable Computers, 218–225. https://doi.org/10.1145/3460418.3479330

Appendix I: Project brief

DESIGN FOR our future

TUDelft

Personal Project Brief – IDE Master Graduation Project

Name student Sander Eversdijk **Student number** 4872096

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

Project title Designing personalized support for cardiovascular disease patients and their families.

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

Introduction

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

The project takes place within the healthcare domain, with the focus being on preventive health and well-being of cardiovascular disease patients. The aim is to develop a supportive digital tool, embodied as an app, to assist patients and their familial context in managing health and well-being post-cardiac events.

Main stakeholders:
1. Cardiovascular disease patients, users of the app. Their interests concern improving their health, understanding their condition, and managing daily activities effectively.
2. Familial context (family members & caregivers), also users of the app. They seek tools to support their loved ones, while being enabled to manage their emotional and mental well-being.
3. Healthcare providers (LUMC), supplier of solution. Interested in innovation in healthcare to improve the patient care, adherence to treatment plans, and provide better health monitoring and outcomes.

Opportunities:
1. Technological advancements: With the use of generative AI, rapid prototyping and personalized user experiences can be tested.
2. Preventive Health Trends: Growing focus on preventive care creates interest of many external stakeholders.
3. Data-enabled Design: Using a data-driven approach to distuingish family needs, customize interventions, and improve user testing outcomes.

Limitations:
1. Diverse Needs: Personalizing to the variety of needs of different users requires a highly personalized approach.
2. Representative user testing: Testing with actual users might be difficult concerning ethical aspects.

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DESIGN FOR our future

TU Delft

Personal Project Brief – IDE Master Graduation Project

Problem Definition

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

I am to solve the lack of personalized support for cardiovascular disease patients for myocardial patients and their families in managing their health and well-being after cardiac events. Despite existing resources, there is a gap for the integration of physical, mental and emotional health management into one solution.

Opportunities for added value:
1. Personalized health management: Using generative AI tools, customized action plans, health insights can be created.
 > Personalization increases trust & acceptance of healthcare services (Guo et al., 2016) (Liu & Tao, 2022)
2. Holistic support: By addressing physical, mental and emotional health the app offers a holistic care solution.
3. Education of users: By implementing various knowledge resources users will develop themselves into experts on their condition, but also on building healthy habits for example.
4. Scalability/modularity: translating this proposed solution to other carepaths by keeping scalability/modularity in mind.

Assignment

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

Design a prototype to improve the health management experience for cardiovascular disease patients and families in the post-cardiac context.

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

1. Initial Research: Literature review, building upon found literature by reviewing new literature on cardiovascular disease patient care, health management, digital health solutions, behavioural change, personalization of health. Interviews & surveys, engaging with patients, families and healthcare providers to gather qualitative & quantitative data on e.g. patient journey. Contextmapping.
2. Data-enabled design (approach) + Rapid prototyping & testing: Data collection to distuingish needs of family groups.
> Development of personas and scenariosto understand diverse requirements.
> Generative AI tools to create rapid prototypes and personalized based on user input/feedback. Wireframes and mockups to visualize app's interface and UX.
3. Final design & validation: Pilot test with final prototype, followed by integration of feedback to end with final revised prototype.
> 1st outcome: Proposal Box system
> 2nd outcome: Do's & Don'ts guidelines + methodology of personalization with AI for similar healthcare cases using this as example case.

Project planning and key moments

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

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

Kick off meeting	2-9-2024
Mid-term evaluation	13-11-2024
Green light meeting	30-1-2024
Graduation ceremony	13-3-2024

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

Part of project scheduled part-time	✔
For how many project weeks	25
Number of project days per week	4

Comments:
Fridays are used for my 2nd Msc at EUR.

Motivation and personal ambitions

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

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

I wish to start this project because of my personal interests in sports which has translated to an interest in preventive health. Besides from that, I want to do a project which makes a meaningful impact which is something I can do with this project. During this project I aim to prove and develop the following competencies:

1. User-centered design
2. Data-enabled design
3. Generative AI tools
4. Interdisciplinary collaboration
5. Qualitative user research

Personal learning ambitions:
1. Broadening design competencies: to include digital health solutions and user experience design.
2. Enhancing empathy in design

TU Delft

LUMC