LEVERAGING DATA STRATEGIES FOR SHARED WELLBEING

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Leveraging Data Strategies for Shared Wellbeing

Family centered care for MI patients: Strategy for enhancing adherence to lifestyle modifications through remote patient management services.

Graduation Thesis

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Executive Summary

Graduation Thesis

The main goal of this thesis is to define a remote patient management (RPM) strategy to effectively involve patients' families into e-health services, and promote the adoption and long-term adherence to lifestyle modifications of entire families. By exploring the potential of family-centered care ideology for healthcare delivery, this thesis paves a way to include family members of myocardial infarction(MI) patients as co-recipients of formal care. To accomplish the objective, various activities were undertaken, such as researching factors that influence healthcare paradigms, exploring effective strategies to promote healthy behavior, and investigating the role of family members in shaping a patient's health trajectory.

Through desk research and interviews with key-informants of cardiovascular and home based care, valuable insights were uncovered revealing the diverse roles family members can assume throughout a patient's health journey. These roles were found to be dynamic and dependent on various factors including personal preferences and the stage in the health trajectory, highlighting the need for personalized healthcare approaches that cater to the unique preferences and dynamics of each family.

Uncovering a research gap of the representation of these roles, a new perspective recognizing the perpetual influential capacity of family members was adopted to further explore individuals preferences to be involved in the patients healthcare and to influence the health behaviour of the patient. By adopting this approach, family members are encouraged to prioritize their own health while simultaneously providing support to patients in maintaining positive lifestyle behaviors essential for sustaining cardiovascular health.

Based on the insights gained from a qualitative study highlighting the differences in family contexts and subsequent preferences in health-oriented involvement, a service vision was formulated to demonstrate a family-centered healthcare delivery through a modular approach. The vision emphasizes the importance of data-driven insights to inform tailored interventions for sustainable lifestyle adherence. By harnessing comprehensive data, healthcare providers can gain valuable information about patients and family members, enabling them to tailor interventions and offer support structures to meet their specific needs.

To move closer to this service vision, it is proposed to follow a data-enabled design process that can simultaneously address human, technological and organizational considerations and thereby empower designers to iterate and expand the service ecosystem.

To conclude, this thesis creates an opportunity for engaging stakeholders and ensuring that the envisioned care approach aligns with the interconnected healthcare landscape, driving the system towards a more inclusive and comprehensive care future.

Acknowledegment

To my supervisors,
Maaike, to have had the opportunity to divulge in so many fruitful discussions with you has inspired me not only for this thesis but beyond its boundaries. This thesis wouldn't have been possible without your ever-ready solutions for every obstacle I encountered.

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To my friends, both near and far,
Sharing the ups and downs of this academic pursuit always laced with humor and supplemented with food, created an environment for work and play that I couldn't have dreamt possible. And to those who stayed with me through countless calls, thank you for your continuous belief in my abilities despite my own wavering faith.

And finally my deepest gratitude to my family, and above all, to my mother.
Your boundless love and unwavering support are the very reasons I can whole-heartedly chase my personal and professional ambitions.

- Ragini Karki

"The Family Is A Link To Our Past, And A Bridge To Our Future"

- Alex Haley

Abbreviations

CVD - Cardiovascular Disease

DBCI- Digital Behaviour Change Intervention

EHR - Electronic Patient Record

HCP- Health Care Professional

MPR- Medical Patient Record

MI - Myocardial Infarction

LUMC - Leiden University Medical Center (LUMC)

PFFC- Patient and Family Centered Care

PSS - Product Service System

RPM - Remote Patient Management/ Monitoring

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1 Introduction

This first chapter guides you through the landscape where this thesis project is situated.

Briefly navigating the developments that moved the healthcare system into adopting remote patient management services, this chapter discusses the potential of extending this service from solely focusing on an individual towards a more inclusive patient and family centered service.

Consequently this chapter establishes the grounds for the main research question of this thesis.

The chapter concludes by illustrating the approach for answering the research question. It guides the activities conducted through the duration of this project and also serves as the structural foundation of this report.

1.1 THE BACKGROUND

Digital Health & The LUMC

Today's world is being permeated with digital processes and the healthcare industry is no exception. 'Digital health' serves as an umbrella term that encompasses the use of 'technology and data to inform medical practice and improve health' (Smits et al., 2022). This includes advancements such as the efficient exchange of information through Electronic Health Records (EHR) and the increased accessibility to care through tele-health services. With the projected increase in care demands, the pursuit of efficiency and accessibility are now a necessity to tackle inevitable staffing shortages, resource availability as well as the financial pressures burdening the healthcare system (Gupta Strategists , 2021). Such advancements contribute to a growing body of evidence that highlights the potential of digital health (Meier et al., 2013).

Advancements in consumer technology have contributed towards increasing the involvement of individuals in managing their own health. The self-monitoring cultural phenomenon, Quantified Self, was the result of the widespread use of smartphone applications and wearable mobile sensors. It enables people to monitor various physiological states and behaviour such as sleep, food intake, exercise, blood sugar, mood etc. These developments garner substantial interest from medical and public health professionals, who recognize the promise of such technology as a key to advancing participatory and personalized healthcare (Sharon, 2017). When patients are empowered to participate in management of their health, they are more likely to adhere to treatment plans and adopt healthier lifestyles (Krist et al., 2017). Additionally, personalized healthcare tailors interventions and treatments to individual patient needs, optimizing their outcomes and reducing unnecessary medical expenses and resource utilization will enhance the feasibility and sustainability of healthcare delivery(Alonso et al., 2019).

Actualizing the potential of these developments and striving to improve healthcare delivery and experience, the Leiden University Medical Centre (LUMC) initiated 'The Box' projects (Treskes et al., 2022). This practice merges the convenience of self-monitoring with the surety of medical healthcare practices across an array of diseases.

Cardiovascular Diseases & The MI Box

Cardiovascular Diseases (CVDs) are the primary cause of mortality and morbidity in Europe, impacting nearly 49 million individuals throughout the European Union (Timmis et al., 2020). Although better treatment and management have led to a decline in mortality rates, it has resulted in an increase in the number of individuals living with the disease is

estimated to cost the European Union economy 210€ billion a year (Timmis et al., 2020). This syndrome brings with it a range of consequences, including but not limited to dyspnea and fatigue symptoms, arrhythmias, psychological impacts and financial burden. In order for individuals to cope with the adjustments brought about by the illness and its complex treatment regimen, it becomes crucial for them to embrace new behaviors and make lifestyle improvements, including learning how to self-monitor for managing their health at home (Bente et al., 2021).

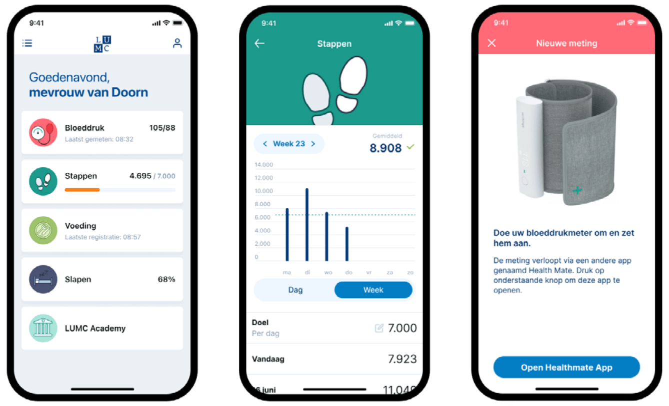
Acknowledging the role of remote monitoring in supporting CVD self-management, LUMC offers a disease specific 'Myocardial Infarction (MI) Box' for patients who have suffered from an MI, commonly known as a heart attack. The MI Box comprises a smartwatch, smart scale, blood pressure monitor, and two apps, all provided by Withings. The devices are connected to the Withings Health Mate app (Figure 2). The data collected through this app is linked to the LUMC Care app (Figure 1), allowing them to monitor symptoms, receive information and establish contact with a care professional when needed .

Both apps are connected to a dedicated LUMC patient account to ensure data sharing with the Medical Patient Record (MPR). Health professionals of the LUMC can track this data and identify the necessity for an intervention.

(a)

(b)

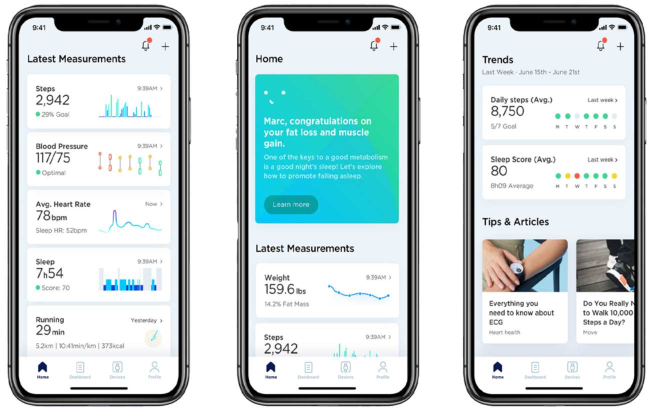
(c)



Doe uw bloeddrukmeter om en zet hem aan.

De meting verloopt via een andere app genaamd Health Mate. Druk op onderstaande knop om deze app te openen.

Fig 1: The LUMC Care App



Marc, congratulations on your fat loss and muscle gain.

One of the keys to a good metabolism is a good night's sleep! Let's explore how to promote falling asleep.

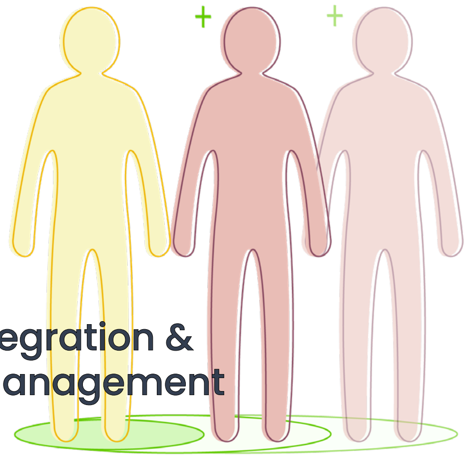
Fig 2: (a) Blood Pressure Monitor , (b) Smart Watch and (c)Smart Scale connected via the WIthings App

Lifestyle Changes & The Social Context

In the past, genetics were considered to be the primary factor affecting cardiovascular health. But studies show that, nearly 50% of CVD risk is linked to modifiable lifestyle activities such as diet, inactivity, and smoking (Rippe, 2019 ; Akinosun et al., 2021). Even after an MI event occurs, the risk for a re-infarction remains, making the maintenance of positive health behavior, from a lifestyle perspective, an absolute necessity for health improvement. Healthcare providers advise implementing secondary prevention measures to avoid the recurrence of cardiovascular events. As modifiable risk factors can be actively influenced, the typical approach for secondary prevention involves a combination of two treatments: pharmacotherapy and lifestyle adjustments. However, many individuals are unable to sufficiently modify their health behaviour even after cardiac rehabilitation care center support and are resultantly highly susceptible to a risk of re-infarction (Akinosun et al., 2021).

There are different reasons why people may not follow health advice, like not having enough information or feeling unsure about their abilities. But to adopt healthy behaviour, it is also important to have the right conditions in place. This includes factors like the way our surrounding is structured and how we interact with others (WHO, 2018). In practical terms, the health of patients can be influenced by the environment they share at home. For example, if there is healthy food and exercise equipment easily available, it can encourage everyone to stay healthy. On the other hand, if the family members are not supportive of healthy eating, it may put the patient at a greater health risk. Therefore for managing health at home, the family is well placed to influence such conditions, making them significant contributors to the patients health status (Rippe, 2019).

Despite this understanding, most behaviour interventions focus on individual factors such as abilities and motivation without or with much lesser consideration of social and environmental factors. (Christou & Christodoulou Fella, 2023). Research shows that interventions that incorporate social constructs and perceived benefits are effective in managing risk factors over an extended period (Akinosun et al., 2021). Therefore, taking the social context into account and involving family members in patient health management can be beneficial in creating an environment conducive to promoting and sustaining healthier habits for patients.



Family Integration & Remote Management

Patient and Family-centred Care (PFCC) is an approach to healthcare that recognizes the importance of family in the care and wellbeing of the patient. It involves the patient, their family members, and healthcare providers working together as a team to make decisions that meet their collective needs and preferences (Kokorelias et al., 2019). This approach may lead to better health outcomes, increased patient satisfaction, and reduced healthcare costs (Goldfarb et al., 2022).

Witnessing a significant shift from traditional care settings to the homes of patients, presents novel challenges for their families experiencing an increase in their responsibilities. This calls for innovative solutions to address the evolving needs and complexities of care giving. Remote Patient Management (RPM) emerges as a potential solution. RPM leverages technology to remotely monitor patients' health conditions and enables healthcare providers to deliver personalized care and interventions directly at home. Additionally offering education material and tele-health consultations, RPM also empowers patients to actively participate in the management of their own health (Rakers et al., 2023).

It is common practice for care providers to engage with family members of patients, and rely on their support to aid the patient in managing health behaviours, adhering to medication, and monitoring symptoms at home (Bidwell et al., 2015). However, in most situations family members do not have official access to remote patient services. By integrating PFCC principles with RPM, collaboration between patients, families, and healthcare providers can be strengthened. Development of RPM strategies that for a new paradigm of healthcare delivery facilitated via remote patient management platforms would establish a patient-centric, family-inclusive, and technology-driven approach to healthcare which could eventually lead to better outcomes, enhanced patient satisfaction, and cost-effective care.

1.2 THE PROJECT

As previously noted, the family of the patient can significantly impact their adherence and uptake of lifestyle changes. Modifiable risk factors are often linked to the collective lifestyle of the family, making it crucial to consider the collective needs of a family when developing and designing effective e-health services. This approach can serve as secondary prevention for the patient, preventing re-hospitalization, and also as primary prevention for the patient's family.

Shifting the focus of this e-health service from an patient centric to a family-oriented approach seeks to build upon existing evidence of the value of family integration in care management. This approach has the potential to promote wellbeing-oriented practices among the family, ultimately leading to better health outcomes.

To realise this potential, the following research question serves as the core of this study:

Through which Remote Patient Management (RPM) strategies can we effectively involve patients' families into e-health services, and promote the adoption and long-term adherence to lifestyle modifications of entire families?

This thesis expands upon the research conducted by Ir. Julian Houwen - 'Experiencing a Myocardial Infarction Together' (Houwen, 2021) , which focused on long-term preventive lifestyle change through positive dyadic communication and support to influence patients' and partners' illness perception. In this thesis, the scope of involvement extends beyond the partner to include any family member that the patient wishes to include in their care. Additionally, it explores the role of family members in shaping the social context of the patient, which can significantly impact the patient's health outcomes. By broadening the perspective on family involvement, this thesis aims to gain a comprehensive understanding of how family dynamics and support systems contribute to patient well-being and health management.

In the end a vision for a product service system (PSS) will serve as an illustration of a proposed strategy that answers the research question. A requisite for the solution direction is that it should build on the 'eHealth technology foundation' of the already existing The Box innovation.

Identifying the implications of the shift towards home-based care on family life and, this thesis aims to pave the way for a collaborative approach to healthcare delivery. By understanding how patients and their families manage health at home, the thesis aims to create a strategy for the development of remote patient management in a way that it that embraces and empowers families as essential partners in care. It addresses the challenge faced by patients and families in health engagement as means to contribute towards the broader goals of Predictive, Personalized , Preventive & Participatory (4P) medicine applied within the healthcare system.

Lastly, the integration of e-health with PFCC also corroborates techno-moral implications (Swierstra, 2015). For example, it raises concerns around health data privacy and sharing within the family, or the potential for technology to aggravate health anxiety. For responsible innovation, confronting this challenge with a human-centred design approach seeks to anticipate the impact of such a service on the values of patients and their families, to either mitigate or create accountability for such impacts.

1.3 A DESIGN APPROACH

The strength of the strategic design approach lies in its ability to serve as a confluence of perspectives from human, technology, and business domains, creating a solution that can withstand scrutiny from viewpoints of desirability, viability, and feasibility. To scope the intended contribution of the project and to define the research and design activities to be conducted, integration of multiple fields of study (Figure- 3) were identified to be crucial in effectively generating knowledge for the development of the e-health service as well as its contributing fields (Pannunzio, Kleinsmann, & Snelders, 2019).

Recognizing human-centeredness as a core mindset and practice in design, this study aligns with its focus on the needs of its users to generate meaningful innovation that can deliver value to intended stakeholders, as well as to address the organizational or systemic necessities required to implement the solution (Van Der Bijl-Brouwer & Dorst, 2017).

Given its methodological implications this study approached 'values' through a practice-based hermeneutic lens, which views values as lived realities that are dynamic and interactive (Boenink & Kudina, 2020).

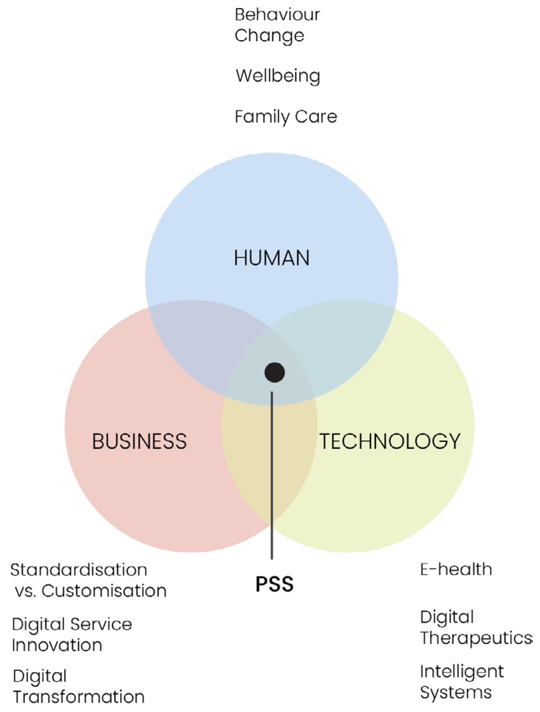


Fig 3: Convergence of Knowledge from Multiple Disciplines

This design approach, started with an initial brief that outlines the project's scope and objectives. This brief served as an introduction to inform design process understand the areas that need to be addressed.

A contextual inquiry was conducted to gain a deep understanding of the problem space. This involved a broad understanding of the healthcare system and then more specific immersion into the context of MI patients and their families.

Based on the insights from the contextual inquiry, a design opportunity was identified. It served as a new frame to continue the rest of the design process.

The value inquiry phase, explored the needs, beliefs, and priorities of the patients and families. Their perspective was used to inform the design vision ensuring it is meaningful to them.

Product-Service System (PSS) vision was developed to represent the user needs and the solution space.

Final recommendations are highlighted, based on the potential of the PSS while highlighting the barriers for implementation.

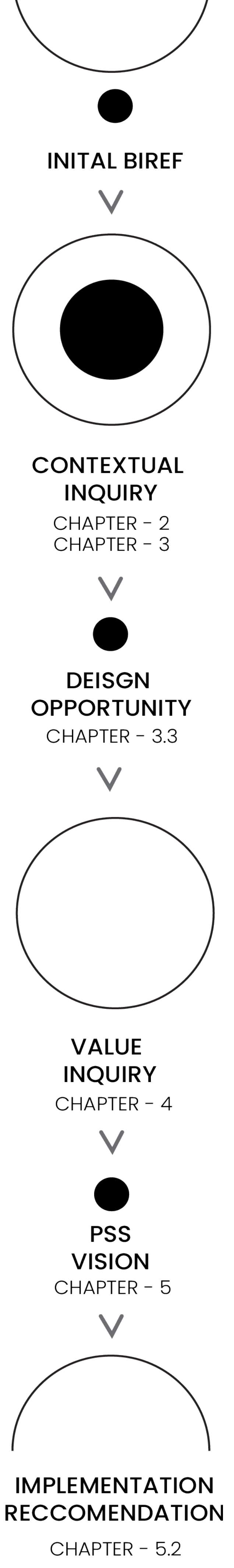


Fig 4 Thesis Approach

2

Patient and Family Centered Care

To include the family members of patients as co-recipients of formal care, would usher healthcare delivery into a new paradigm of patient *and family* centered care. This chapter explores the factors that are influencing the current health paradigm and demonstrates how the guiding principles of this project align with the broader goals of healthcare transformation that are currently accepted.

Furthermore, development and implementation of a wellbeing oriented service relies on identifying strategies that have been effective in promoting healthy behaviour. The next section of this chapter investigates commonly studied factors that influence health trajectories and the existing measures of health.

The collective findings from this literature study inform the need for an exploratory approach to family oriented healthcare delivery, paving the way for a strategy that embraces families as essential partners for health improvement.

What are the transformational forces acting on the current healthcare system that pave the way for patient and family centered care?

AIM

To support the development and adoption of a PFFC RPM strategy, the objective of this chapter is to interpret trends in the healthcare environment that inform the transformation of the current system into one that involves family as an integral part of cardiac healthcare delivery.

METHODOLOGY

A creative scanning of the current healthcare context followed by trend extraction was conducted to understand their potential impact in the future and to reveal opportunities and aid decision making (Simonse, 2018). After reading various articles and white papers on multiple online platforms, the frequently discussed ideologies driving healthcare innovation were identified. These were studied in greater detail through articles published in various academic databases, such as PubMed, Journal of Medical Internet Research, Google Scholar etc. to understand how they could influence the transformation of the current healthcare system. By adopting a PFFC perspective, these papers were analysed to draw relevant conclusions on how the objectives of this project align with the broader healthcare goals.

> *The exponential growth of Value-Based Care is not without an associated burden of home-based care.*

A transformational perspective for health care system is to maximise the value for patients per care expense. This entails improving the quality of care, while reducing the costs of care delivery. The focus on cost efficiency, strategizes maintaining good health over paying for poor health management (Porter, 2009). One interpreted practice-based objective of this ideology is to prevent hospitalizations by closely managing patients in outpatient settings, where cost and resource demands can be significantly lowered (Abrams et al., 2018). In numerous such instances, healthcare providers rely on the support and help of family members, who act as informal caregivers, to monitor the patient's health and aid in managing medications and symptoms at home (Bidwell et al., 2015). While intensive outpatient management enhances access to primary care and better management of chronic disease, rapid discharges may also leave patients and their families feeling unsure and under-prepared to manage the disease at home.

To maintain the advantages of out-patient management and avoid overwhelming families with the burden of home-based care, it is crucial for the healthcare system to acknowledge the capabilities of patients' families and provide them with the necessary support to care for the patients.

> *Preventive care is being limited to active patients within the care system.*

eHealth has moved from an acute-care orientation to prevention and disease management, from an individual focus to a population focus (Dansky et al., 2006). Similarly, to ensure that the healthcare system remains sustainable and manageable, a family-oriented preventive approach in CVD management can serve as a stepping stone towards a population based approach.

As lifestyle activities play a critical role as major risk factor for CVDs, family members of the patient, who may share similar lifestyles, could also be susceptible to the risk of experiencing an MI (Taylor et al., 2023). While secondary prevention is recommended for MI patients, there is no preventive recommendations being prescribed to the family members. To align with this preventive and population oriented approach, it becomes pertinent to involve family members, assess their risk for cardiovascular diseases and offer suitable recommendations that would serve as primary prevention measures for the family (Christou & Christodoulou Fella, 2023) and secondary prevention for the patient.

> *Family engagement can shape and improve patient experience.*

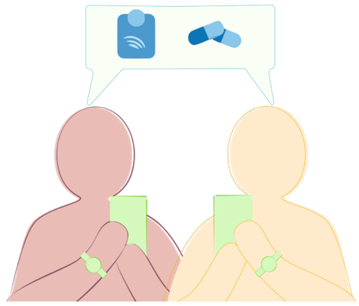
The growing emphasis on enhancing healthcare quality has led to a heightened interest in studying patients' experiences, encompassing their needs, expectations, and satisfaction with care and related services throughout the care continuum, including treatment adherence and recovery (Viitanen et al., 2022). In the extended care trajectory of individuals with CVDs, involves transitions (in some cases, multiple transitions) from hospitalization to home-based health management. Family members play a vital role during this journey (explained further in Chapter 3.2) and are eager to contribute significantly to the patient's recovery. Patients also frequently desire the presence of their family members. This could be for emotional support or more practical help with medical instructions and recommendations, as patients can feel inhibited by health-related anxiety or the effects of medication or medical procedures (Azoulay et al., 2002). The involvement of family members is therefore widely endorsed as a more effective approach in enhancing outcomes for both patients and their families, surpassing the results achieved by focusing solely on the patient (Goldfarb et al., 2022) (Azoulay et al., 2002).In many cases, patients and their families also make health decisions together. Considering family opinions ensures that shared decision-making principles are upheld, fostering a collaborative approach to care (Butterworth & Campbell, 2014).

It is important to consider that while there is societal acceptance of family involvement in care, some patients may prefer more individuality in their health management (Eliacin et al., 2015). Patients hold a central role in their own care, and their inputs are crucial in determining their level of comfort. Similarly, family members may have personal reasons for not wanting to be actively involved in the patient's health. Taking their opinions into account can prevent unnecessary stress or conflict. Transitioning from patient engagement to patient and family engagement necessitates considering the preferences of both, patients and family members.

> *Digital interventions open up opportunities to remotely engage families in health.*

The terms Digital Health, e-health, m-health, and tele-health are often used interchangeably due to the absence of standardized definitions (Burrell et al., 2022). Nonetheless, they all denote the utilization of a range of technologies to support healthcare utilization or delivery. These include various internet technologies, such as informational websites & interactive health communication applications etc. Newer technologies, such as virtual reality, home automation (Domotics) & robotics often coupled with sensor technology, are employed in domains such as rehabilitation & recovery, to support home-based (or geographically independent) care delivery (Van Gemert-Pijnen et al., 2011). Digital care is being mobilised to support what is now popularized as the 5M's of e-health, which encompasses - Measurement (e-diagnose), Monitoring (observation), Mentoring (nudging), Motivation (support), and Management of data (automated integration, adaptation and utilisation of different data) (Van Gemert-Pijnen et al., 2011). Ongoing research and advancements in e-health applications using these features have resulted in the expansion of technology to facilitate remote delivery of interventions aimed at preventing, managing, or treating medical conditions (Smits et al., 2022). These interventions are commonly known as digital therapeutics (Digital Therapeutics , 2023).

This has also opened an avenue of digital services for family members. These services encompass various functionalities, ranging from psycho educational programs to stress & care management programs with the intention of improving access to healthcare assistance and information. However, the utilization of such services is notably limited and has been linked to the disproportionate emphasis on family members' caregiving responsibilities rather than their own health (Bidenko & Bohnet-Joschko, 2022). Furthermore, even though caregiver apps are tailored to specific diseases, they typically lack an understanding of the complexities involved in diverse patient-caregiver relationships from a broader caregiver perspective e.g., Parent-Child, Partner-Spouse or Siblings, etc. (Bidenko & Bohnet-Joschko, 2022).



Looking at it from a human-centered viewpoint, this could also arise from token gestures or inadequate user engagement during the development phases, leading to a disconnect between the anticipated value and the actual outcomes (van Gemert-Pijnen, et al., 2011).

At large, digital services have been recognized for their positive impact on healthcare delivery, including increased efficiency, improved health outcomes, and reduced costs (Asbjornsen, et al., 2019). Moreover, these services have been shown to enhance patients' sense of safety and confidence (Viitanen, et al., 2022). By effectively utilizing digital tools to engage family members, similar benefits can be extended to both family members and the healthcare system. Unfortunately, the implementation and delivery of such services from the healthcare providers is frequently impeded by a multitude of factors, including insufficient reports of evidence-based outcomes (Ruyobeza et al., 2022).

> ***What factors contribute to cardiovascular health, and how effective are interventions in improving it?***

AIM

The preceding section emphasizes the potential of utilizing e-health technology to involve family members leveraging ehealth technology to enhance health outcomes and experience. However the development of such a service for improving cardiovascular health requires a complex behavioral intervention (Christou & Christodoulou Fella, 2023) as it encompasses maintaining several lifestyle habits, such as following a particular diet, participating in regular physical activity, and monitoring one's health.

Therefore to inform RPM development in a way that is effective in promotion and adherence for collective lifestyle behaviours, the objective of this section is to reveal effective strategies used in improving cardiovascular health. The relevance of commonly used outcome measures in evaluating the impact of interventions on cardiovascular health outcomes is also assessed.

METHODOLOGY

A literature review was conducted by searching various academic databases, including PubMed, Journal of Medical Internet Research, and Google Scholar. The initial search strategy was devised using the PICO framework, a widely-used approach in clinical research (Riva et al., n.d.) (see Appendix A). To expand the scope of the literature search, a snowball search method was employed after analyzing the initial findings. All the relevant articles were imported into Zotero, a reference management software used for source organization and tracking.

RESULTS

The study revealed a number of factors that could influence an individuals health as well their adherence to lifestyle recommendations, particularly in the context of cardiovascular health. Several key findings emerged from the analysis of relevant literature.

Similar to CVD risk factors, determinants of health encompass a range of factors that can affect an individual's health trajectory. Behavioral factors, such as diet, exercise, and other lifestyle choices, play a significant role in shaping current and future health outcomes. While these behaviors are modifiable and can be influenced by personal choices, other determinants like age and gender are non-modifiable yet influential factors in patient self-care and health outcomes (McLean, 2020; Bidwell et al., 2015). The study highlighted the association between socioeconomic factors, such as household income and education level with hospital readmissions.

For individuals living with chronic illnesses and supported by family members, studies revealed that strong relationship quality and social support are vital components of care. The assistance and support received from spouses, siblings, children, or other family members have also been recognized as beneficial in promoting daily adherence to recommended behaviors (Bidwell et al., 2015).

Furthermore, the type of recommendation, such as adherence to prescribed medicine or maintaining a healthy diet, may be subject to different reasons for non-compliance. Some patients may place a stronger belief in medical therapy over adopting healthy lifestyle practices and disease management (Krack et al., 2018).

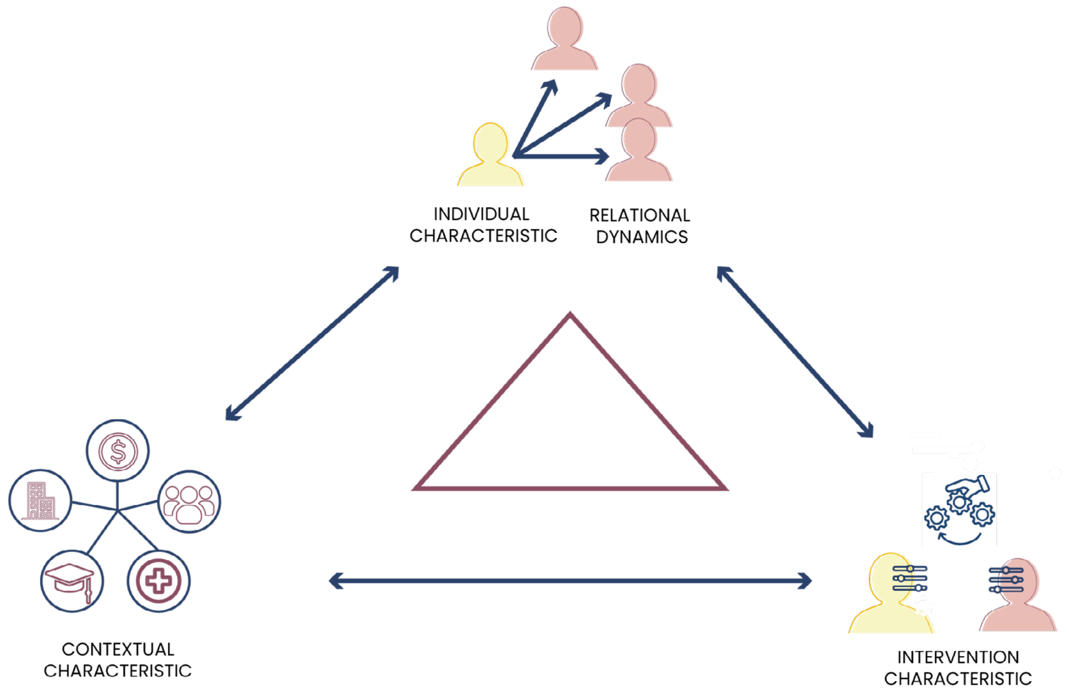


Fig 5 Moderating factors of the CVD experience and its response (Bidwell et al., 2015).

Among the various interventions, eHealth interventions with psycho education, peer support forums, and personalized information and support have shown promise in positively impacting caregivers' outcomes.

The most common outcomes measured for caregivers were depression, caregiver burden, anxiety, stress, and self-efficacy, while less focus was placed on positive aspects such as satisfaction, fulfillment, and relationship bonding (Sin et al., 2018; Bui et al., 2022). The study observed that while self-reported measures, such as satisfaction and self-efficacy, can provide insights into adherence or non-adherence to lifestyle recommendations, objective measures like clinical effectivity are instrumental in achieving consensus.

There remains a need for agreement on which domains and instruments should be prioritized for measuring intervention effectiveness (Krack et al., 2018) as the data available in the current state, does not allow effectively comparing the results across the different studies that have been carried out.

CHAPTER DISCUSSION

Numerous advancements in the healthcare system have indicated that leveraging digital tools to engage family members can bring benefits to both patients, families as well as healthcare providers. As a result, adopting a Patient-Focused Family-Centered (PFFC) strategy becomes relevant for the development of an e-health service.

While family-focused care interventions show promise in enhancing the health and well-being of individuals and families, there remains a need to assess their clinical and cost-effectiveness. Presently, due to the variation in methods of evaluation, results of different strategies lack comparability presenting the lack data to identify a desirable or effective strategy for integrating family members into an RPM service from a lifestyle perspective. This gap hinders the understanding of the scope and associated responsibilities when engaging with such a service, which is crucial for both patients and family members to make informed choices and ensure their healthcare experience aligns with their expectations.

An important insight to have emerged from research is the significance of understanding the context, as it plays a crucial role in identifying patient and family needs and determining effective interventions to support lifestyle recommendations. A context based approach cam also helps tailor the recommendations to suit the unique needs of each family (Smits et al., 2022; Christou & Christodoulou Fella, 2023; McLean, 2020).

However, understanding the complexity involved in the patient's and families context, reveals various factors that can influence the response to and experience of dealing with a Myocardial Infarction. Supplemented by the lack of conclusive data, it becomes challenging to prioritize which factors significantly contribute to the ultimate goal of improved health for patients and their family members.

CONCLUSION & INITIAL PROBLEM DEFINITION

For the patients and family members, the experience of a Myocardial Infarction and the response to the disease is a multi-faceted circumstance with several interdependent factors. When this understanding is overlay-ed against the data, in it's current state of availability within the healthcare system, it falls short in it's ability to conclude with a clinically 'effective' strategy to involve family members.

The current organization of data available to the healthcare system is inadequate to formalize the role of family members in the health trajectory of patients. This opens up the question for understanding the roles adopted by family members, while living with a MI patient.

Thus, while this research does not result in an evidenced goal for formalising the role of family members in a healthcare system, it highlights the potential for adopting an exploratory approach, that empathizes with a family's collective needs.

The next chapter of the report, establishes the result of a human centered design approach to define the opportunity for involving family members in the chronic health management of the patient.

3 Family Involvement in MI Patient Care

To explore the potential for RPM development, this chapter delves into contextual understanding of the experiences of patients and families, as well as their environment in which the service will be implemented.

By illustrating the involvement of family members throughout the patient's health trajectory, a diverse array of responsibilities that family members can assume is revealed. This sheds light on the dynamic nature of their perspectives and needs.

Through a thoughtful examination of these responsibilities and roles, a research gap emerges, indicating an opportunity to involve family members in influencing the health-related behaviors of patients while also fostering attention to their own health. This understanding presents a valuable opportunity to enhance overall healthcare outcomes for both patients and their families.

3.1 THE EFFECTS OF AN MI

AIM

WHO defines well-being as "*encompassing quality of life and the ability of people and societies to contribute to the world with a sense of meaning and purpose*" and has expanded the definition of health beyond simply physiological state of the body and to - *a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity* (WHO], n.d.).

The objective of this section of the research is to gain a comprehensive understanding of the effects and impact of MI on the lives of patients as well as their family members. This shall be used to gain a better understanding into the diverse needs of families, encompassing dimensions beyond mere physiological health, thus enhancing my understanding of their overall life context.

METHODOLOGY

To address the research questions, this study draws upon information from various sources. The following sources were consulted:

(1) The thesis project of Ir. Julian Houwen (Houwen, 2021) served a strong foundation for insights on the shared experience of an MI patient and their partner.

(2)Open-ended interviews (Appendix-B) were conducted with key-informants in this domain including Health Care Providers (HCP's) , some of who are also stakeholders of this project and with others who have experience with (MI) patients, patient families or those who are involved in home-based care.

Though the interviews were conducted during this phase of the thesis, the open ended nature of the interviews lead to information generation that could inform multiple elements of the research which have been synthesized in statement cards (Fig 6), journey map (Fig 8) and stakeholder map (Fig 20).

The interviewed experts include:
a. **Dr. V.R. Janssen** (project stakeholder)
(Psychologist,
LUMC, Leiden, NL)

b. **Prof. dr. Douwe Atsma** (project stakeholder)
(Cardiologist
LUMC, Leiden, NL)

c. **Sara Hondmann**
(PhD Candidate,
LUMC, Leiden, NL)

d. **Dr. Ajay Garg**
(Director, Home Based Primary Care
Department of Veterans Affairs, USA)

e. **Dr. Vinay Malhotra**
(Medical Director, Cardiology, Puget Sound Region
Pulse Heart Institute, USA)

f. **Tammi Hudspeth**
(Nurse practitioner, Remote Monitoring Cardio Mems)
Pulse Heart Institute, USA)

(3) Published qualitative studies with a focus on understanding the patient experience and family experience of Myocardial Infarction were also incorporated. Additionally, studies exploring the experience of living with a chronic disease, given the nature of an MI, were included to gain insights into time-dependent needs and challenges faced by patients and their families. The insights were then thematically segregated into statement cards using quotes available from (Golics et al., 2013; Goldfarb et al., 2022)

A thematic categorization of the effects of a MI on patients and their families.

EMOTIONAL IMPACT

"You go through sort of like fear, anger the life that you had, you'll never have back because in the back of your mind there's always that worry of "Is it going to come back?"

- Helpless
- Uncertainty (about the future)
- Hide true feelings
- Expressing & managing emotions
- Offering spiritual support

RELATIONSHIPS

" mother's illness ..[] as reason for marriage breakdown. "

- Role change to carer
- Being with the patient all the time
- More family arguments

WORK & STUDY

" I have reverted back to how it was when I was bringing up my children [...] "

- Time off work
- Balancing home and work

DAILY ACTIVITIES

" I have reverted back to how it was when I was bringing up my children [...] "

- Increased Housework
- Providing Food
- Assisting mobility
- Helping with personal hygiene (bathing and getting dressed)

PLANNING (/ TRAVEL /SOCIAL)

" if someone says 'Would you like to come?'[..] ' I'll let you know', because I know damn well that I'll probably have to let them down if I say I'm going "

- Unpredictably of the disease
- Short notice appointments
- Patient too unwell
- Travel insurance
- Food abroad
- Going places (eg. restaurants)
- Meeting people
- Lack of energy

FINANCIAL STRESS

" I just didn't have the time [to work]. There are so many appointments to go to and obviously my wife needed care, it got very difficult to carry on [with work]. "

- Time off work
- Mobility aids, clothes, transport etc
- Holiday insurance
- Private care

SLEEP

" I was living off [...] 2 or 3 hours sleep a night and this was [...] even antidepressants don't help [...] "

- Stress related sleep loss
- Wake to assist the patient
- Getting adequate rest

HEALTH BEHAVIOUR

"[..]husband likes fried chicken...[which] throws us off [patient eats with him]"

- Partnering in patients' self care
- Engaging in their own selfcare
- Staying physically active
- Eating and cooking healthy

HEALTH UTILIZATION

"they can do it better than I can. They've got the PhDs, not me"

- Decision-making-
  going to hospital for symptoms
- Perceptions of low social support
- Access to formal and informal Social support and services

CARE INVOLVEMENT

"they can do it better than I can. They've got the PhDs, not me"

- Managing medications, devices & appointments
- Information about patient's condition & managing symptoms
- Understanding HF and prognosis
- Handling unplanned hospitalizations & emergencies;
- Communication and coodination

Fig 6: Impact of MI on several dimensions of patient and family life

RESULTS & DISCUSSION

The emotional impact of an MI is widely acknowledged as a significant repercussion of living with CVD, often leading to worry and distress (Golics et al., 2013; Bente et al., 2021). Living with MI and dealing with co-morbidities of the condition can disrupt several routine functioning aspects, such as daily chores and professional life, often due to the patient's reduced physical capabilities (Kitko et al., 2020). Consequently, family members may take on increased responsibilities (Goldfarb et al., 2022), both in terms of everyday tasks and financial burdens, which can lead caregivers to witness deterioration in their own health conditions. The overall psychological, physical and social impacts may also lead to relational strain amongst members of the family (Golics et al., 2013 ; Nicholas Dionne-Odom et al., 2017). From a lifestyle standpoint, studies have highlighted that the behaviors of family members who are actively engaged in patient care can impact the patient's own behaviors (Nicholas Dionne-Odom et al., 2017).

All care professionals interviewed acknowledged this impact on patients and recognized the potential benefits of extending care d the potential benefits of providing guidance and support to family members seeking assistance. However, they expressed constraints in extending care to family members due time limitations or existing protocols (expanded further in Chapter 5.2).

CONCLUSION

Experiencing a MI can result in diverse consequences that go beyond physical implications. As evident from the previous chapter in the report, the impact on each family's life is uniquely shaped by their specific contexts. While addressing all these challenges is crucial for well-being, it is important to acknowledge that certain issues, like financial burdens or broader social implications, may not be fully addressed by a remote health management platform.

Therefore, addressing the focus of the primary research question on involving families to improve lifestyle adherence, this thesis will focus on exploring the role of families in health behavior and care involvement. Keeping in mind the interconnected nature of these impacts, it is reasonable to anticipate that implying that targeting specific areas through intervention may have ripple effects on other aspects.

3.2 UNDERSTANDING ROLES & RESPONSIBILITY

How are family members involved throughout the health trajectory of a MI patient?

AIM

As emphasized in the preceding section, (MI) frequently involves family members taking on the role of caregivers, which can also impact the health behaviour of the patient. This section aims to gain deeper insights from a user-centered perspective into how this involvement unfolds during the patient's health trajectory. By understanding this process, the goal is to gather insights that can be used to optimize the collective journey of patients and their families towards improved health.

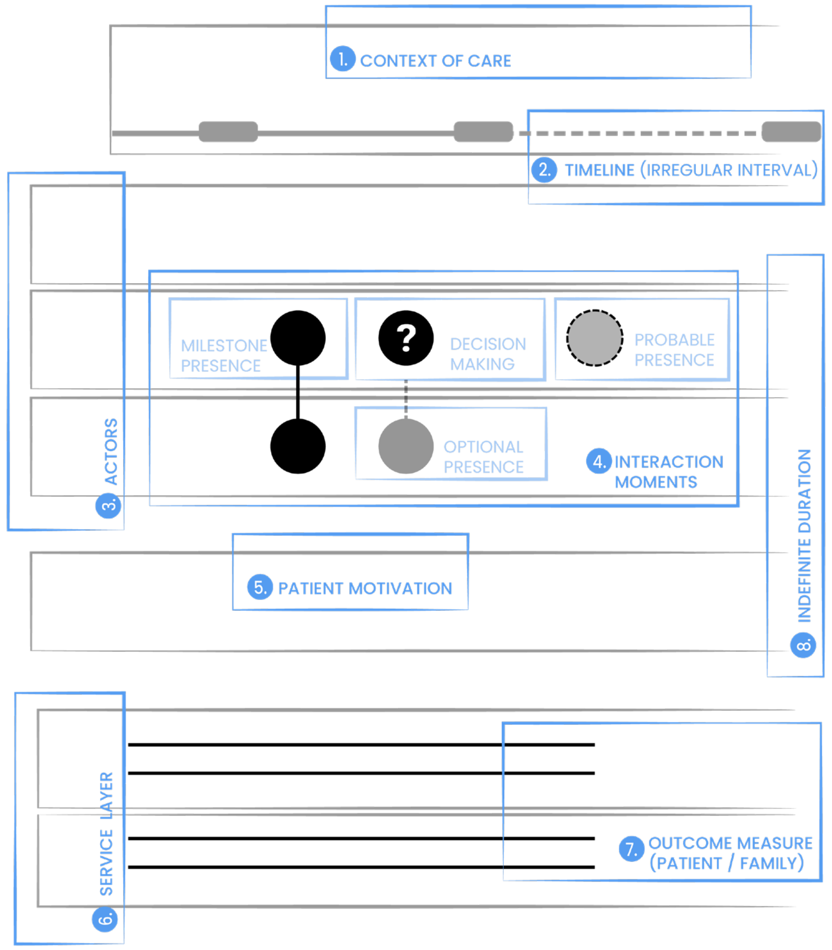


Fig 7: Journey Map with curated elements.

METHODOLOGY

For addressing this research question, a crucial step involved synthesizing insights from litreature and expert interviews, across the entire continuum of care. To achieve this, a visualization technique known as a journey map (Simonse et al., 2019) was selected. The journey map provides a diagrammatic comparison of various stakeholders and their interacting contexts throughout the MI patient's health journey (Joseph et al., 2023). Sole focus on patients journey mapping often neglects the integral role that family members play in supporting patients.

Incorporating family members' perspectives into this journey, provides a more comprehensive understanding of the family members involvement in the current care pathway, contributing to a more effective and inclusive service strategy. The inclusion of different layers in the final journey map is explained (Figure 7) below, along with the rationale behind their incorporation.

1. CONTEXT OF CARE

In this format the context layer is seen as the environment that enables interactions between the actors during a specific phase of their MI journey. This is used to specifically mark the 'milestone' phases in the health care trajectory of an MI Patient. Since the focus of this thesis is lifestyle risk oriented patients, the phases included, start from the health background before the onset of the acute event. The last phase of interaction is marked by the 12th Month of the Chronic Care period, as it is the last standard format, follow up moment by the designated care team of the LUMC.

The contexts are also divided into Hospital Based Care and Hybrid or Home Based Care, to differentiate between the environmental control over the interactions taking place within these contexts.

2. TIMELINE

The timeline is included to reflect the actual passage of time between interaction moments. Since the duration from the time of infarction and during hospital based care is much shorter compared to the chronic health period it can be visually misleading when plotted together. Therefore a timeline is included to numerically and visually clarify the irregular jumps in the intervals between two moments of interaction.

3. ACTORS

Keeping the MI patient as a central actor of this journey map, this thesis scopes the healthcare providers and family members as important actors for the developing a RPM strategy. While there are an array of actors that play a role in the healthcare trajectory of an MI patient, the selection of actors in this journey map is based on their proximity to the service interaction, when healthcare is delivered to the homes of the patients. A visualisation of this service proximity is available in Chapter 5.2 (Figure 20).

4. INTERACTION MOMENTS

The interaction moments on this journey map are used to depict the key moments in which the patient, health care provider or family member engage with each other. The distinctions in these interaction moments are made as follows-

1. **Milestone Presence:** The actor experiences this moment of interaction that refers to a significant event or stage that marks a critical point of progress or change in their medical condition, diagnosis, treatment, or overall experience during the
2. **Probable / Optional Presence:** There is a possibility for an actor to be present during this interaction, however it is not mandatory. The exact reasons for presence or absence can vary per individual case. This can range from preference, for e.g. the patient doesn't want a family member to be present or situational reasons such as the patient is not clinically required to participate in that milestone.
3. **Decision Making Moment:** Given the importance of shared decision making for a positive influence on the health care journey (Butterworth & Campbell, 2014), these planned moments are marked separately.

5. PATIENT MOTIVATION

The mapping of patient motivation on the healthcare journey is crucial as it is recognized as a significant factor influencing adherence to lifestyle modifications (Hanna et al., 2020). Through this mapping process, insight can be generated on how it interacts with other layers of the overall healthcare trajectory.

6. SERVICE LAYER

This layer marks the current offerings provided by the current 'The Box' service in combination with the Withings App, LUMC Care app and the devices included. Since this service is under constant development, the current offerings are marked in dark green and the *probable offerings are light green.

7. OUTCOME MEASURE

This layer marks the indicators of health that are being monitored to assess the progress of the patient over time. These can be patient-reported or objective measures that are useful to understand the effectiveness, quality, and experience of healthcare service and intervention (Smits et al., 2022). Again, since this service is under constant development, the current measures are marked in dark green and the *probable measures are in light green.

8. INDEFINITE DURATION

The inclusion of open-ended boxes and vanishing lines at the end of the patient journey map serves the purpose of emphasizing that the healthcare trajectory of a chronic care patient extends well beyond the one-year mark represented in the map. This visual representation aims to illustrate that the patient's progress and ongoing healthcare experiences continue for an extended period, surpassing the boundaries set by the limited duration covered within the journey map.

RESULTS

BACKGROUND

As described earlier in the report, there can be several factors that may lead up to an individual suffering from a myocardial infarction. If individuals are aware of a family history of cardiovascular disease, they are more likely to be engaged in risk mitigating activities like monitoring their health and being mindful of their diet(Ton et al., 2011). Within a family unit, the health oriented daily habits such as eating meals together, physical activity etc may or may not be interlinked depending on personal, cultural and practical considerations.

ACUTE EVENT

In the event of a heart attack, a patient may have experienced sudden chest pain, shortness of breath, sweating, and/or dizziness. It is important for the patient to receive prompt medical attention. In some cases, the patient describes to experience a 'memory blank' and waking up in the hospital. If the family member witnesses this episode, they are more likely to be anxious about the patients health.

HOSPITAL BASED ACUTE, SECONDARY & TERTIARY CARE

Upon arrival at the hospital, the patient will likely undergo a series of tests to determine the extent of the heart attack and the best course of treatment. These tests may include an electrocardiogram (ECG), blood tests, and/or a coronary angiogram. Based on the results, the patient may be treated with medication or surgery. Assisting a patient during an acute care admission can be a source of stress for family members. Usually, patients are discharged within 1-3 days of the occurrence of the event.

TRANSITION PERIOD

Patients and their family members are responsible for managing the patient's health at home from the time of discharge until they have their first contact with care providers again. This initial contact after discharge may occur either with LUMC to plan their care routine or with the staff of Basalt, who is the rehabilitation partner of LUMC. This period has been referred to as the "Dark Period" or "Black Hole" during discussions with LUMC experts.

REHABILITATION

A cardiac rehabilitation program provides guidance and support during the recovery process, but is only available up to 2 months after the acute event, due to the availability of resources. Overall, a MI patient requires comprehensive and ongoing care to manage their condition and prevent future heart attacks. With proper treatment, monitoring, and support, many patients are able to return to their normal activities and lead full and healthy lives. To enhance clarity in care plans and required follow-up, family members are offered the option to receive communication alongside the patient. Though mostly preferred, it is entirely voluntary to involve and engage them.

CHRONIC CARE MANAGEMENT

Aside from adherence to pharmacological prescriptions, chronic management also involves lifestyle changes such as diet and exercise and regular check-ups with a cardiologist. After treatment, the patient requires close monitoring and follow-up care to prevent future heart attacks and manage any existing heart conditions. This is accomplished via patients self-monitoring their key health indicators such as heart rate, oxygen levels, weight etc. This is also remotely monitored by health professionals who can then intervene when deemed necessary. This allows patients to act independently when they notice any irregularities in their health, is a crucial aspect of a patient's care process.

BEHAVIOUR CHANGE AND MOTIVATION

Positive health behaviours include eating a healthy diet; regularising physical activity; smoking cessation and reduced alcohol intake; regulating body weight, blood pressure, and blood cholesterol (F.Piepoli, 2016). Closer to the acute event patients exhibit a high level of receptiveness and greater motivation to adopt changes (Houwen, 2021). However, over time, there is a tendency to normalize the disease . This, in combination with diminishing motivation and reduced professional support, leads to a decline or abandonment of modified behaviour (Hanna et al., 2020).

REMOTE MONITORING & OUTCOME MEASURES

The Withings Health Mate app is used to collect monitored Heart Rate, Blood Pressure, ECG & Weight for the werable+ additional devices. The LUMC Care app, presents the collected data from the Withings Health Mate app in a different configuration. It also facilitates the collection of additional data, such as patient's stress levels, which is all sent to the LUMC. HCPs have their own interface within the medical patient record (MPR), where they can view data points and trends per patient and sensor.

Currently, the decision-making process is primarily carried out by the healthcare professionals themselves and is not heavily automated. When irregularities in the data are identified, the healthcare professional contacts the patient directly. If necessary, an appointment or video consultation is scheduled.

Fig 8: Patient and Family Journey for a Mycordial Infarction and Chronic Health Management

DISCUSSION

Even before the occurrence of an MI event, family members are involved in the health-oriented behaviors of a person. At times, family members may trigger discussions about health history, such as when deciding to have children, which can be important reminder for individuals at high-risk to be more mindful of their health.

During the acute event, the symptoms can be terrifying and debilitating, and whether the patient is around family during the episode can change the overall experience for the patient or family member. During or immediately after hospitalization, patients and their families often experience feelings of helplessness and heightened anxiety (Goldfarb et al., 2022). Engaging families during this phase can enhance the care experience for both patients and family members, leading to a reduction in the distress associated with hospitalization.

Upon diagnosis, family members often serve as emotional pillars, providing much-needed support and reassurance to the patient during a time of vulnerability and fear. As the recovery progresses, family members may take on the role of care coordinators, assisting in managing appointments, medications, and follow-up care, ensuring that the patient adheres to the prescribed treatment plan.

The recovery period following a (MI) is characterized by an unpredictable trajectory, where patients may experience fluctuating periods of stability and uncertainty. This recovery process for a MI patient can be lengthy and challenging, both physically and emotionally as they work towards regaining the trust in their bodies, necessitating support from healthcare professionals as well as from family.

Over time, lifestyle modifications become essential for long-term maintenance of health and prevention of future cardiac events. Family members can adopt roles as wellness coaches, engaging in activities like preparing heart-healthy meals, encouraging regular exercise, and supporting stress reduction techniques. Their involvement in these lifestyle changes can significantly impact the patient's overall well-being and health outcomes.

Through out this period, family members play a crucial role in supporting the patient through their recovery journey. While hospitals and rehabilitation centers aim to provide the best care, the reality is that continuous intensive support beyond the initial four months is not feasible due to resource limitations in terms of time and funding. As a result, a significant gap emerges between acute and rehabilitation care and long-term chronic care.

To address the gap between acute and rehabilitation care and long-term chronic care, the healthcare system places the responsibility for chronic care and lifestyle changes on the patient's social environment, often involving their partners and family members. However, there is currently no official and structured involvement of families in the healthcare trajectory, highlighting the need to develop a more comprehensive approach that incorporates the family's role in providing long-term support and promoting positive health outcomes for patients beyond the initial phases of care.

Throughout the entire duration, family members not only experience the impact of a MI on their own lives but also take on multiple responsibilities related to the health of the patient. Their roles evolve over time and depend on various factors and could entail responsibilities like coping with the initial diagnosis, adapting to lifestyle changes, and promoting medication adherence. The responsibilities of family members can range from hospital visitation to coordination of other care activities. The specific tasks of the family members as caregivers are reported to vary widely based on the individual's needs, cultural background, and the age of the affected patient (Goldfarb, et al., 2022).

Understanding the evolving roles of family members during the post-MI journey is critical for providing effective support and resources. By recognizing the different tasks and situations that family members face, healthcare providers can tailor interventions and education to meet their specific needs, empowering them to better support the patient's recovery and well-being.

Moreover, it is essential to acknowledge that the motivation and ability of family members to fulfill their supportive roles can also vary over time. External support and resources can play a vital role in bolstering family members' motivation and enhancing their ability to assist the patient effectively. By offering accessible information, counseling, and resources, healthcare providers can strengthen the family's capacity to play a supportive role in the patient's recovery journey.

CONCLUSION

The period following a myocardial infarction (MI) presents a challenging and dynamic journey for both patients and their family members. As the patient's recovery trajectory evolves, so do the roles assumed by their family members which are instrumental in providing support to the patient. These roles can range from emotional pillars during the initial diagnosis and hospitalization phase, to care coordinators in managing appointments and medications, to wellness coaches in encouraging lifestyle modifications for long-term recovery.

Understanding and acknowledging the significance of these roles have on the patient's recovery, can lead to the development of effective support structures that empower family members to actively contribute to the patient's recovery and overall well-being. By working collaboratively with healthcare providers family members become partners in the patient health, ultimately leading to improved patient outcomes, reduced burden on family members and a smoother recovery journey.

3.3 EXPLORING A A DIFFERENT PERSPECTIVE

Reflecting on the evolving roles of family members throughout the health trajectory.

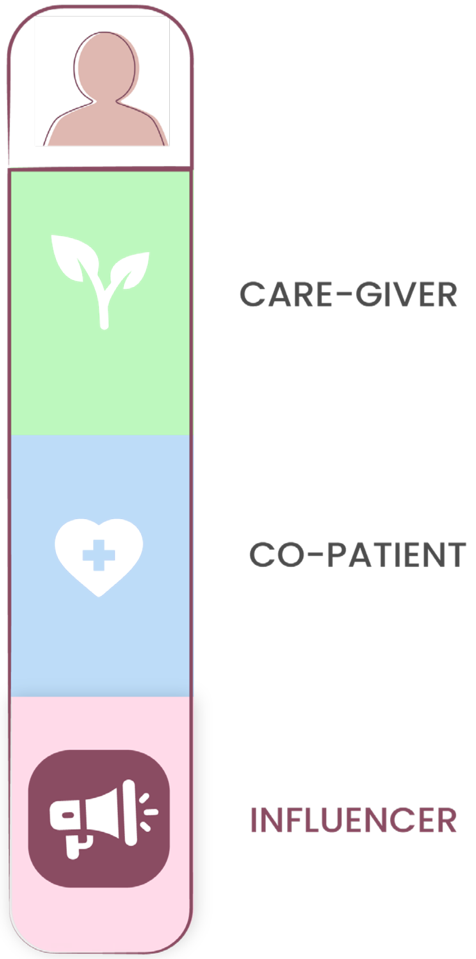


Fig 9: Perspective Used for Family Members as health partners

AIM & METHODOLOGY

A human-centered approach revealed the multitude of roles that family members may play in an individuals life, upon reflecting on existing studies, it became apparent that the depth and diversity of these roles were not adequately represented in the current literature. A narrative approach was used to confront the heterogeneity of data available via previously conducted literature and expert interviews. Keywords & terminologies used in literature and the perspectives used in expert interview responses where closely examined and clustered. The goal of narrative analysis was to identify patterns & to reveal themes within the range of roles family members assume.
The aim was to understand the pivotal implications of using these identified roles as 'frames' (Dorst, 2015) to inform the development of remote patient management strategies.

RESULTS & DISCUSSION

Family members, whether as parents, siblings, children or spouses, play diverse and essential roles in an individual's life, impacting various aspects of their well-being and development. These roles can vary across cultures and family structures, but some common functions include source of emotional, social, and sometimes financial support. Families also promote a sense of security and safety by meeting fundamental needs such as running a household, providing food and much more. However, a clustering of studies involving family members in association with a patient, shows that these were dominantly conducted from either of the two perspectives.-

CARE GIVER

As some individuals may struggle with autonomous management of health related activities and rely on the support of their family members who then assume the role of caregivers, providing instrumental support and assistance in the management of the patient's health. Often this support is also emotional, which helps patients deal with other characteristics of the syndrome itself (depression, cognitive limitation, social isolation etc). This support from family members also plays a big role in maintaining the motivation required for adherence to lifestyle changes (Kitko, et al., 2020).

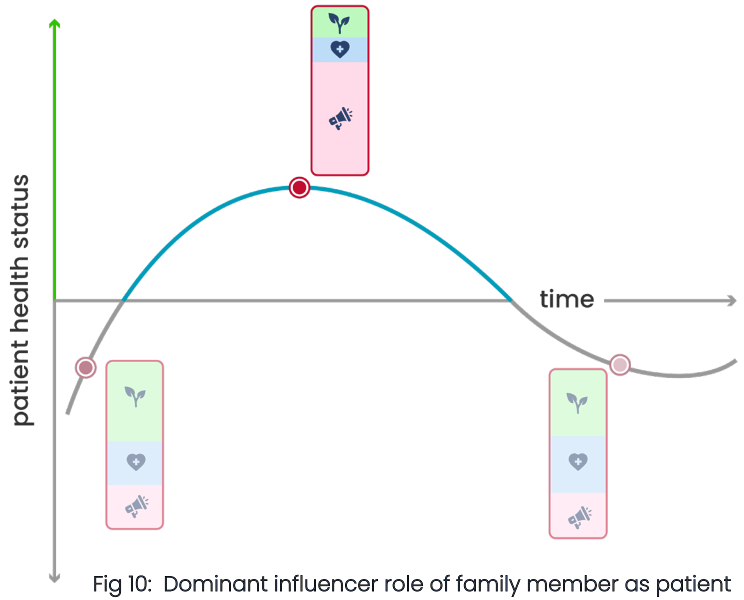


Fig 10: Dominant influencer role of family member as patient health improves with the passage of time

CO-PATIENT
As an unforutnate consequence of their care giving role, family members may experience high burden and poor physical and psychological health outcomes (Giunta et al., 2022). Family members may feel overwhelmed and unprepared for the challenges of caregiving, and may experience a range of emotions, including anxiety, depression, and frustration. In some situations family members also share the experience of illness or health challenges alongside the patient, facing similar lifestyle modifications and healthcare needs.

However, when the patient progresses in their recovery journey, they seek to preserve their autonomy and return to 'normal' life (Bente et al., 2021). It can be expected in this phase, that the role of the family member as a caregiver may gradually decrease, while their influence on the patient's health behavior may become more significant. In the context of chronic health management for maintaining positive health, understanding this prevalence of family influence becomes crucial. Recognizing the possible health behavior influences present within a family unit context, can help healthcare provideWrs identify how family members impact the patient's adherence to lifestyle recommendations and treatment plans.

INFLUENCER ROLE
Further examination into the role of family members via this perspective reveals that in pediatric care researchers have studied how family members can influence health behaviors, particularly in parent-child relationships, primarily examining eating habits and physical activity. However, recognizing that families operate as socially organized units of individuals within a group, we can integrate the concepts of social cognitive theory (Bandura , 1986) and the family systems theory (Bowen, 1966) as theoretical frameworks to provide insights on the mechanism through which family members can influence each other's health behaviors through their own actions (Nicholas Dionne-Odom et al., 2017).

Understanding the influence of family members as the context of patients family allows HCPs to prescribe interventions at the family level rather than just the individual level, ensuring sustainable adherence to lifestyle changes. This approach not only provides secondary prevention for the patient but also promotes primary prevention for other family members, preventing the onset of health issues and enhancing overall family health.

CONCLUSION & DESIGN CHALLENGE

The role of family members as influencers is essential in developing and prescribing interventions that address the collective needs of the entire family and enhance the likelihood of sustainable behavior change. Family members can serve as powerful role models, showcasing behaviors and attitudes that patients are encouraged to adopt. Conversely, if they do not lead healthy lifestyles themselves, it can create an unsupportive environment for the patient to maintain recommended behaviors. This approach ensures that the family collectively supports the patient's behavior change efforts, increasing the chances of success. Moreover, interventions that support family members in their own health journeys can have a positive ripple effect, benefiting both the patient and their family members.

With this principle in mind, the following design challenge is posed for involving family members:

Create a strategy for healthcare providers to leverage remote patient management services to identify and harness the influential capacity of family members for collective lifestyle change.

4

Influence as the Social Context

This chapter presents an exploration into the impact of family members on a patient's health, providing insights into the patient's social context. These findings could serve as a fundamental basis for healthcare providers to suggest sustainable interventions that cater to the entire family's needs. Drawing upon literature from behavioral and psychological theories, this exploration also explores the potential for behavior change interventions to target the family as a unit.

To determine the varying influential capacities of family members, the research employs a research through design approach. This approach seeks to understand the patients' and family members' perspectives in recognizing these influences and utilizing them to support their health goals.

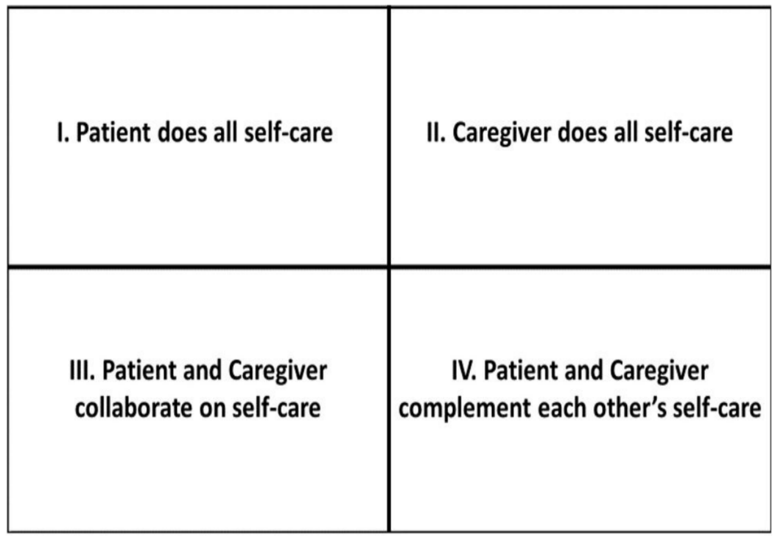
The research sheds light on the diverse forms of health involvement that can be observed in different families. These findings lay the groundwork for developing a remote patient management strategy that aligns with the preferences and dynamics of each unique family.

4.1 TYPOLOGIES OF INFLUENCE

Understanding how lifestyle behaviour of family members may influence the behaviour of the patient, opens a window to a pragmatic understanding of the family context of the patient. Examining the behaviour of individuals within a family unit, reveals factors that shape the patients physical and social context. This is described as the 'opportunity' that prompts behaviour (Michie et al., 2011). Recognizing these factors that are external to the patient's own physiological and psychological capacity, allow the prescription of modifications necessary at a family level, not only to improve motivation but also to achieve essential lifestyle behaviour (Michie et al., 2011).

This family member as an influencer approach can be enriched further by drawing inspiration from the Dyadic Illness Theory (Lyons & Lee, 2018), which has gained widespread acceptance in the field of healthcare. The Dyadic Illness Theory focuses on understanding the impact of chronic illness not only on the individual patient but also on their close family members or caregivers. It recognizes that the illness experience is a shared journey between the patient and their family members, and their interactions influence each other's well-being.

To overcome the lack of clinical operatability of the dyadic theory, researchers and clinicians have developed typologies based on the Theory of Dyadic Illness Management. An example of such progress is shown in the figure 11. These typologies have since served as practical tools in clinical practice by providing healthcare providers with valuable insights into the unique dynamics of each dyadic relationship. They help clinicians tailor interventions and care plans to address the specific needs and challenges faced by patients and their family members as a unit.



I. Patient does all self-care	II. Caregiver does all self-care
III. Patient and Caregiver collaborate on self-care	IV. Patient and Caregiver complement each other's self-care

Fig 11: Heart Failure Care Dyadic Typology ()

The HF Care Dyadic typology was conceptualised using two parameters, one focusing on the individual level i.e self care and the other on the relational level i.e collaboration on the self care task. Based on this the resultant typologies were (Figure 8)-

1. The patient takes sole responsibility of self-care
2. The caregiver takes sole responsibility of patient-care
3. They work together collaboratively on the same self-care tasks.
4. They work together but on different self-care tasks.

CREATING TYPOLOGIES OF INFLUENCE

By following the rationale behind these axes, the following axes were chosen to create the 'typologies of influence' -

The individually oriented Y-axis, focuses on ALIGNMENT: As discussed earlier, a family member's own behaviour can play a major role in determining the behaviour of the patient. Therefore this axis is chosen to reflect the extent to which family members demonstrate positive health behaviours.

Alignment would therefor reflect the cumulative behaviours of individual family members. For example, if a family unit consists of four individuals and only one member exhibits positive health habits, the family's alignment will be low. Conversely, if all four members exhibit positive health habits, the family's alignment will be high.

The relationally oriented Y-axis, focuses on INVOLVEMENT: This refers to the level of collaboration the patient receives from the family members. This dimension also takes into considers an individual's autonomy in determining the extent to which the family members' are involved each others lifestyle factors. By placing involvement as a variable, it also accounts for cultural and social considerations, such as the organization of activities in individualistic versus group-oriented societies.

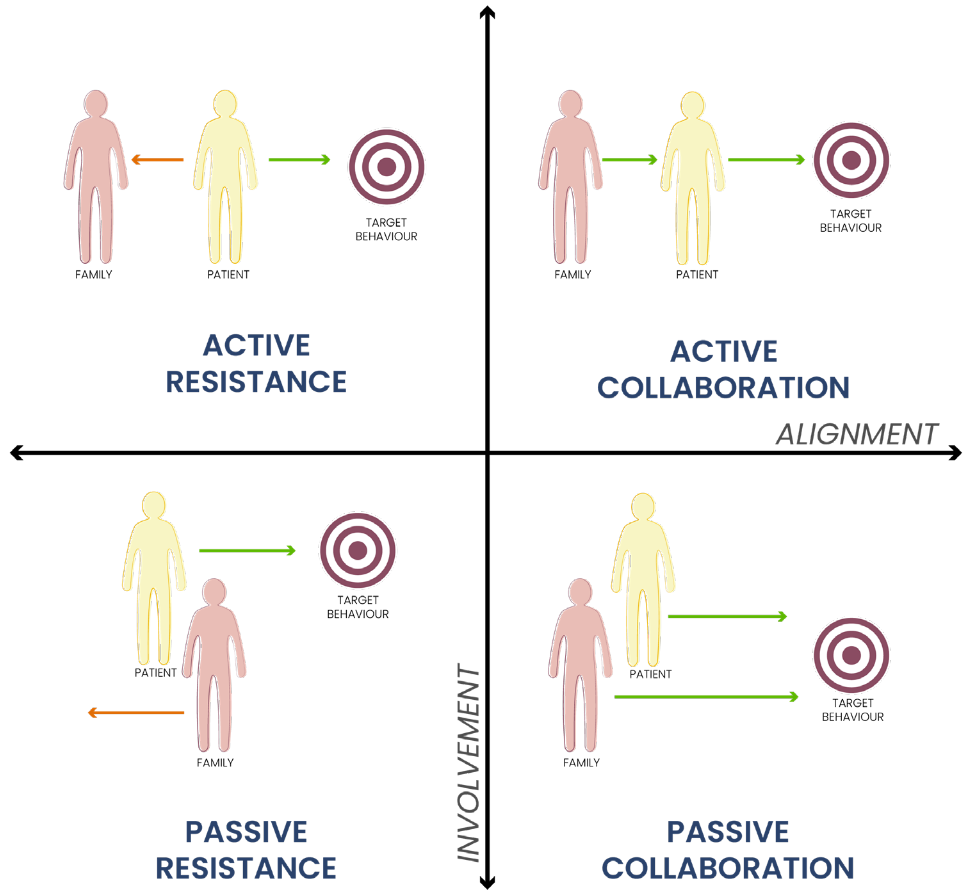


Fig 12: Family Influence on Positive Health Behaviour Typology

Based on these axes, the resulting typologies of influence were derived-

1.ACTIVE COLLABORATION

This type of influence would mean that the family member(s)' lifestyle is closely connected with the patient's lifestyle and they collectively engage in positive health behaviours.

2. PASSIVE COLLABORATION

This type of influence would mean that the family member(s)' lifestyle is not inter-linked with the patient's lifestyle and they independently engage in positive health behaviours.

3. ACTIVE RESISTANCE

This type of influence would mean that the family member(s)' lifestyle is closely connected with the patient's lifestyle but the family members do not engage in positive health behaviours.

4. PASSIVE RESISTANCE

This type of influence would mean that the family member(s)' lifestyle is not linked with the patient's lifestyle and the family members do not engage in positive health behaviours.

These typologies of influence provide a classification framework for clustering distinct patterns of influence of family members on the patient's health behaviour. While these typologies were initially derived based on theoretical considerations, their practical applicability and validity were put to the test by presenting them to Dr. V.R. Janssen, who was introduced earlier. Dr. Janssen, with her experience of working with MI patient families and lifestyle behaviour, provided valuable insights into the typologies' real-world relevance. She shared numerous examples of frequently encountered family dynamics related to lifestyle behavior influence. Two such examples were-

..the patient is eager to engage in regular walks. However, the spouse neither encourages the patient nor engages in any physical activities themselves.. the patient to loses motivation over time..

In this situation, the spouse is not deliberately sabotaging or discouraging the patient. However, their **passive resistance** lies in their lack of creating an environment suitable for supporting the patient's adherence to recommended lifestyle habits.

...the patient is determined to adopt a more active lifestyle and go cycling. However, the patient's son frequently expresses concerns about safety and potential injuries, which becomes a significant barrier to the patient's physical activity goals...

In this situation, the child's discouragement stems from fear of the patients health condition and a lack of knowledge regarding safe rehabilitation. However, their **active resistance** also creates an unsuitable environment for sustaining behaviour.

By relaying such real-life examples to the created typologies, it became evident that it was possible to classify the different family dynamics into these typologies. This understanding of typical patterns seen across different family units can enable the creation and prescription of behaviour change interventions at family levels.

LIMITATIONS

The typologies presented in their current state have limitations that should be considered-

Lack of Qualitative Characterization:
One limitation is the lack of detailed qualitative characterization for each typology. While the typologies offer distinct categories for family influence on patient health behaviors, they do not provide a nuanced understanding of the underlying motivations and complexities that shape these dynamics. Qualitative insights could enrich these further by providing deeper context and meaning to each typology and tailor them further.

Methodology to Determine Typologies:
No specific methodology has been developed to determine the postion of the individual on the axes. Depending on subjective interpretations or self-reporting from patients and family members might introduce biases or inaccuracies in classifying the influence types. A standardized and objective methodology to determine family members position on the axes would enhance the reliability and validity of the typologies.

Stability of Typologies:
It is essential to explore the stability of the typologies over lifestyle activites and over time. Understanding whether these influence types can change and what factors drive such changes is crucial. Family dynamics and health behaviors can evolve, and the typologies should be able to adapt to these changes. Longitudinal studies could help assess the stability of the typologies.

Despite these limitations, the typologies can be a valuable tool for understanding the involvement of family members in health-oriented behaviors. For the purpose of the thesis, the typologies served as a valuable starting point, offering a chance to explore the perceptions of family members and patients into involvement in health-oriented behaviors.

RELEVANCE OF TYPOLOGIES FOR RPM STRATEGY

For developing a remote patient management strategy, using the influence typologies provides a robust framework for understanding and addressing the dynamics within the family unit surrounding their current and desired lifestyle routines.

(1)Understanding Family Dynamics Regarding Involvement:
The Y axis, focusing on involvement, allows to raise questions around level of support and collaboration within the family unit. Considering an individual's perception of their family members' involvement in their health habits allows for a human-centered approach. This understanding enables the designer to develop services that respect cultural and social considerations. Promoting family involvement tailored to the needs and preferences of each family is crucial in creating a strategy for remote patient management that aims to involve family members in the patients health.

(2) Development of DBCI functionalities for RPM service:
This approach creates way to understand the social context of the patient, which is essential in developing functionalities for a DBCI, which are the main components that for the persuasive capabilities of technology to be used to modify or maintain behaviour. Such contextually sensitive DBCIs that are reportedly more effective (McLean, 2020).

(2)Promoting Family-Centric Care:
The X-axis, centered on alignment, emphasizes the importance of individual health and habits of family members. Additionally, this approach creates a mechanisms to identify family members who may have an undesirable influence on the patients behaviour and refer them to appropriate interventions. Ultimately monitoring the health of the patient's and their family members and identifying their strengths and limitations in supporting the patient's health journey creates an informed opportunity for healthcare providers to engage with family members.

4.2 PREFERENCE FOR HEALTH INVOLVEMENT

How do individuals desire to involve family members in their lifestyle recommendations?

AIM

The aim of this generative design study is to gain a comprehensive understanding of the preferences and perspectives of patients and family members regarding their involvement in health-related matters. This knowledge is also important for fostering service adoption and ensuring long-term engagement with healthcare services because if the technology does not fit their daily lives or rituals, people stop using the service (Van Gemert-Pijnen et al., 2011) . The ultimate objective is to develop a vision for a family-oriented remote monitoring e-health service that takes into account the current practices of family involvement in patient health.

To achieve this aim, the study conducts interviews with a diverse and heterogeneous demographic, representing a wide range of family dynamics (Figure-10). The interviews aim to answer the following essential questions:

How are family members currently involved in each other's health behaviors?
This question seeks to explore the existing interactions within family units concerning health-related decisions and actions. Understanding the present level of involvement provides insights into the strengths and limitations of family support systems.

How do family members want to be involved in each other's health behavior?

This question delves into the aspirations of family members regarding their role in each other's health journey. It aims to uncover their desires for collaboration, communication, and support in matters of health.

By answering these questions through the generative interviews, the design study aims to identify patterns and trends in family involvement.

This information is then used to envision and design a family-centric remote monitoring e-health service that aligns with the needs and expectations of both patients and family members.

METHODOLOGY

SEMI STRUCTURED GENERATIVE INTERVIEWS

The interviews were designed to encompass both qualitative inquiry and generative exercises, aiming to provide a comprehensive understanding of the preferences and considerations of patients and

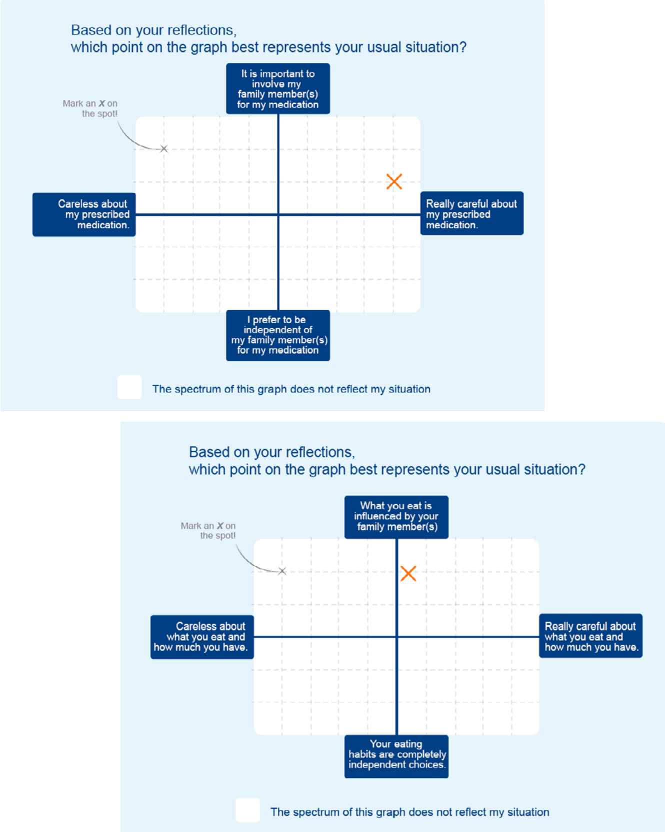


Fig 13: Examples of Involvement Matrix Per Modifiable Risk Factor

family members regarding their involvement in each other's health.

RESEARCH TOOLS

Prior to the interview, the following tools were created to support the process of inquiry and support the participants in sharing their experiences and preferences

Qualitative Component:
With the use of a semi-structured interview guide(Appendix-C), participants were asked open-ended questions to explore and understand the current dynamics of family involvement in each other's health. These questions aimed to elicit rich and detailed responses, providing valuable qualitative data on the various aspects of family participation in healthcare decisions and behaviors.

Generative Component:
The generative component involved two main activities aimed at encouraging participants to reflect on their current health-oriented behaviors and future aspirations for family involvement:

a) Reflective Questions and Matrix Activity:
Participants were guided through a series of reflective questions that prompted them to assess their position in five modifiable risk-factor moderating activities (Appendix D). Using a matrix-based activity, participants positioned themselves on the continuum of involvement for each activity (shown in Figure-13). This exercise enabled them to reflect on the influence of family members on their own health behaviors and to identify the desired modifications to family influence necessary to achieve their personal health goals.

Fig 14: Examples of Visual Probes

b) Probing with Images:
Participants were presented with a series of images (shown in Figure-14) that depicted several components of e-health offerings (Appendix D). A mapping of digital health offerings was used to curate the images and included - Visual Dashboards, Goal Tracking, Notifications and Reminders, Personalised Recommendations, Educational Resources and Family Challenge & Rewards. These were selected for their ability to represent the persuasive design principles found in the social support category that are used to motivate individuals by leveraging social influence (McLean, 2020). These images served as probes to elicit responses based on perceived rewards and costs of engaging with the presented service offerings. Through this exercise, participants could articulate their preferences and concerns related to the potential e-health services.

PARTICIPANT RECRUITMENT & INCLUSION CRITERIA

Participants were recruited with the help and support of the Product Evaluation Lab of IDE, TU Delft, utilizing a brief questionnaire as a screening tool. A significant response was received from 200 individuals, considering the time and scope limitations of the thesis, 10 participants were selected and invited for the interviews. To encompass a wide range of family views, no exclusion criteria was established. Participants were prioritised based on their preference to speak English, their family structure and ultimately their experience with CVDs. The demography is detailed in Appendix D.3. Nine of these interviews were conducted in person, while one interview was carried out via video call using Microsoft Teams. Following the interviews, the audio recordings were transcribed and anonymized for data analysis and confidentiality.

ETHICS

The research was conducted in accordance with the ethical guidelines set by the Human Research Ethical Committee (HREC) at TU Delft and examined by the Data Steward of the IDE faculty. To ensure safety and privacy, all collected data was anonymized, thereby safeguarding the identity of the contributors.

DATA ANALYSIS

The data was analyzed using the ATLAS.ti.23 software. Transcripts of all interviews were uploaded into the software, and each section of text was assessed to determine its pertinence to involving family members in health or health oriented lifestyle activities. The sections that were found to be relevant were marked with corresponding words or short phrases (codes) representing objective insights from the section.

The primary coding process yielded 40 codes, which were subsequently clustered and labeled based on their overarching categories. During this process, the connections between the clusters were examined in parallel with the patient and family journey presented earlier in this report. This approach allowed for a comprehensive analysis of the data, ensuring that relevant themes and patterns were identified and aligned with the context of family involvement in health-oriented activities.

RESULTS

The analysis resulted in 11 distinct categories, each representing specific aspects of family engagement in a patient's health journey. The clusters are listed below in random order, along with the number of codes associated with each cluster and a brief description of what they represent:

Inform(3 codes): This code refers to instances in which family members actively share information and knowledge related to the patient's health and medical condition. It includes the exchange of insights, education about health topics, and providing guidance based on their own experiences or acquired knowledge.

Integrate (6 codes): This code signifies the involvement of family members in the integration of health-related activities and lifestyle changes with the patient's daily routines. It encompasses collaborative efforts in setting health goals, planning and engaging in physical activities, and incorporating healthier habits into their everyday lives.

Influence (3 codes): This code represents the extent to which family members impact the patient's health behaviors through their own actions and choices. It includes both active forms of influence, such as coaching or providing direct support, and passive forms, such as being a role model for healthier behaviors.

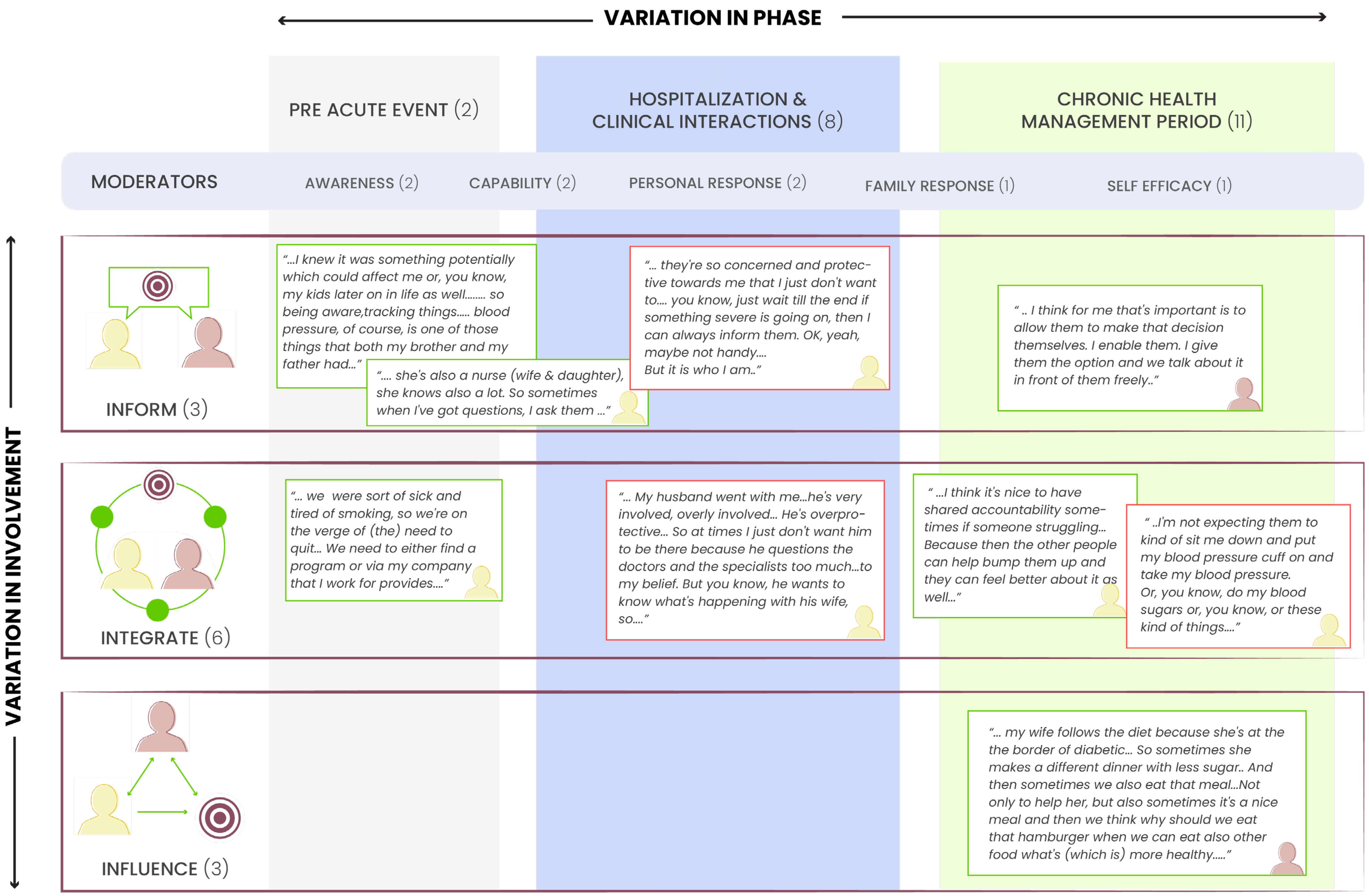
Awareness (2 codes): Family members provide the patient with valuable information and knowledge related to health and well-being.

Capability (2 codes): This code refers to the family members' capacity to actively participate in the patient's health management. It includes their skills, resources, and ability to provide physical and emotional support to the patient, thereby contributing to the patient's overall well-being.

Personal Response(2 codes): This code encompasses the patients own emotional and psychological responses to receiving a CVD diagnosis. It includes their reactions, coping mechanisms.

Family Response(1 code): This code encompasses the family members (perceived) emotional and psychological responses to a CVD diagnosis. It includes their reactions, coping mechanisms.

Self Efficacy(1 code): This refers to the individuals own perceived capability of carrying out an activity.



"...I knew it was something potentially which could affect me or, you know, my kids later on in life as well........ so being aware,tracking things..... blood pressure, of course, is one of those things that both my brother and my father had..."

".... she's also a nurse (wife & daughter), she knows also a lot. So sometimes when I've got questions, I ask them ..."

"... they're so concerned and protective towards me that I just don't want to.... you know, just wait till the end if something severe is going on, then I can always inform them. OK, yeah, maybe not handy....
But it is who I am.."

" .. I think for me that's important is to allow them to make that decision themselves. I enable them. I give them the option and we talk about it in front of them freely.."

"... we were sort of sick and tired of smoking, so we're on the verge of (the) need to quit... We need to either find a program or via my company that I work for provides...."

"... My husband went with me...he's very involved, overly involved... He's overprotective... So at times I just don't want him to be there because he questions the doctors and the specialists too much...to my belief. But you know, he wants to know what's happening with his wife, so...."

" ...I think it's nice to have shared accountability sometimes if someone struggling... Because then the other people can help bump them up and they can feel better about it as well..."

" ..I'm not expecting them to kind of sit me down and put my blood pressure cuff on and take my blood pressure.
Or, you know, do my blood sugars or, you know, or these kind of things...."

"... my wife follows the diet because she's at the the border of diabetic... So sometimes she makes a different dinner with less sugar.. And then sometimes we also eat that meal...Not only to help her, but also sometimes it's a nice meal and then we think why should we eat that hamburger when we can eat also other food what's (which is) more healthy....."

Fig 15: Examples of Visual Probes

Pre Acute Event (2 codes): This code relates to the involvement of family members in the patient's health management before the occurrence of the acute event.

Hospitalisation & Clinical Interactions (8 codes): This code encompasses the family members' involvement during the hospitalization and interactions with healthcare professionals. It includes their support during medical procedures, communication with healthcare providers, and involvement in decision-making.

Chronic Health Management(11 codes):
This code pertains to the family members' role in supporting the patient's long-term health management after the acute event. It includes their contributions to behaviour change, adherence to treatment plans or participation in activities relevant for risk factor modification.

The quotations from interviews were assimilated to provide verbatim examples (see Figure - 15) of how family members are involved throughout the timeline of a patient's health journey.

Family involvement in health-related activities typically commences before the onset of the acute event and extends throughout the chronic health management period. Through the analysis, discernible types of involvement among family members in each other's health activities emerged - Inform, Integrate and Influence. These types of involvement are not seen as definitive preferences of interaction but rather as representations of how family members' engagement can vary within a family unit.
Inform: signified the sharing of information and knowledge among family members.

Integrate: reflected an active degree of participation in health activities which could mean collaboration in setting health goals, planning and engaging in physical activities, preparing nutritious meals, and jointly navigating healthcare resources.

Influence: is characterized by a family members impact each other's health behaviours through their own actions and choices. This level recognizes the power of role modeling.

DISCUSSION & CONCLUSION

The results of this study offer valuable insights to answer the research question - How do individuals desire to involve family members in their lifestyle recommendations? - as a potential avenue for building service offerings that promote family engagement in health through remote patient monitoring. The three types of involvement - inform, integrate, and influence - serve as a foundation for designing interventions tailored to family-oriented care. However, identifying the preferred level of involvement among family members presents a significant challenge.

Even with a relatively small participant group, a multitude of interconnected factors emerged as possible moderators of preferred involvement levels. These factors encompassed individual personality traits, relational dynamics within the family and across lifestyle activities. The existence of an involvement hierarchy among family members in health involvements further complicates the process of understanding and accommodating varied preferences. A consistent finding throughout the interviews was that individuals expressed contentment with their current level of involvement and exhibited resistance to altering their established patterns of engagement. Preserving their existing "level of influence" within the family appeared to be a primary concern.

In conclusion, this study highlights the need of a dynamic system that is able to meet the involvement preferences of families, that may vary over time and lifestyle activity. This also opens up new possibilities for developing family-centric remotely delivered behaviour interventions that can be tailored to meet the involvement preferences of the families, to increase the effectiveness and engagement of family members in adopting and sustaining healthy lifestyle changes.

5 The PSS Vision

In this chapter, a service vision created based on all insights so far is presented to demonstrate healthcare delivery via a family-centered approach. This vision embraces the need for a comprehensive and personalized healthcare ecosystem that caters to the unique context and preferences of families.

The vision underscores the importance of data-driven insights. This is used to lay the groundwork for effective family-centered care, that is backed by evidence for clinical and cost effectiveness required for its implementation in real healthcare settings.

Additionally, this chapter highlights that the successful implementation of realizing family- centered care hinges on coordination between a diverse array of stakeholders within the healthcare system. The final recommendation is to utilize the service vision as a means to mobilize relevant stakeholders, ranging from healthcare professionals to policymakers, to iterate and expand the service vision, ensuring that it delivers value across different levels within the healthcare system.

5.1 THE PRODUCT SERVICE SYSTEM VISION

The research undertaken using the influencer lens to explore family member involvement has led to two significant findings. Firstly, it has shed light on the potential influences that family members can exert on a patient's health. This recognition emphasizes the important role family members play in shaping health behaviors and outcomes. Secondly, the research has identified distinct types of involvement that family members have with each other's health, ranging from information sharing to integration and passive or active influence.

By correlating the different types of involvement with their corresponding impact on the patient's health, the study has revealed possible contexts (Figure-16) of the family where the service could exist. Each context represents a unique pattern of involvement and influence, providing a foundation for addressing the diverse preferences and needs of family members when it comes to their involvement in the healthcare journey.

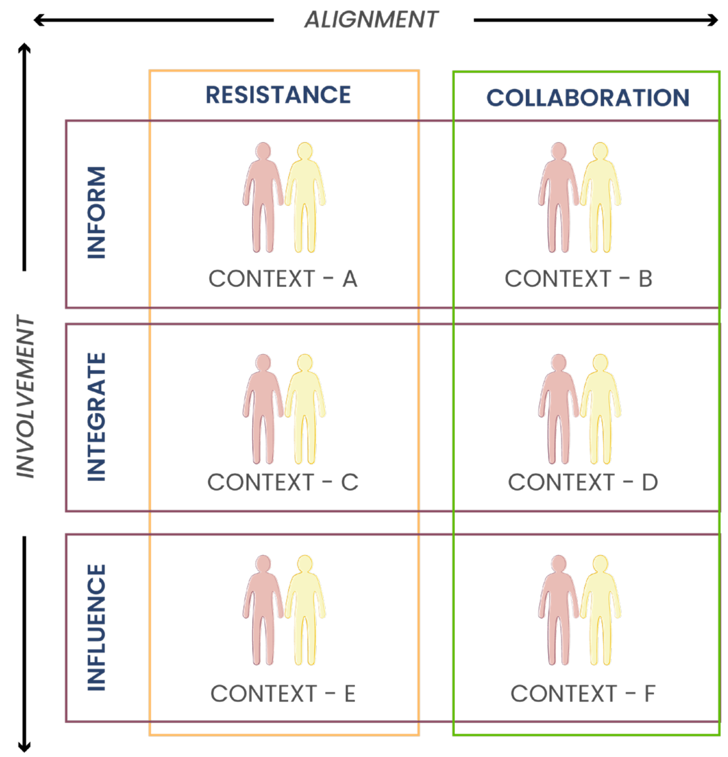


Fig 16: Possible Contexts for Family Centre Care Management Serivce

While the thesis does not delve further into the specifics of these resultant contexts, it uses it's existence to rationalizes the importance of including different family contexts for service creation. This insight underscores the necessity of developing a dynamic and modular remote patient management service capable of accommodating family members based on their preferred level of involvement. Such a service should be designed to interact with family members, learn about their needs, and adapt itself to deliver personalized interventions that suit their specific requirements.

This product-service system can be described as an intelligent ecosystem (Kollenburg & Bogers, 2019), an interconnected and adaptive network that responds to the unique dynamics of each family's healthcare journey. This serves as the basis for a strategic future vision for a patient and family-centered remote e-health service.

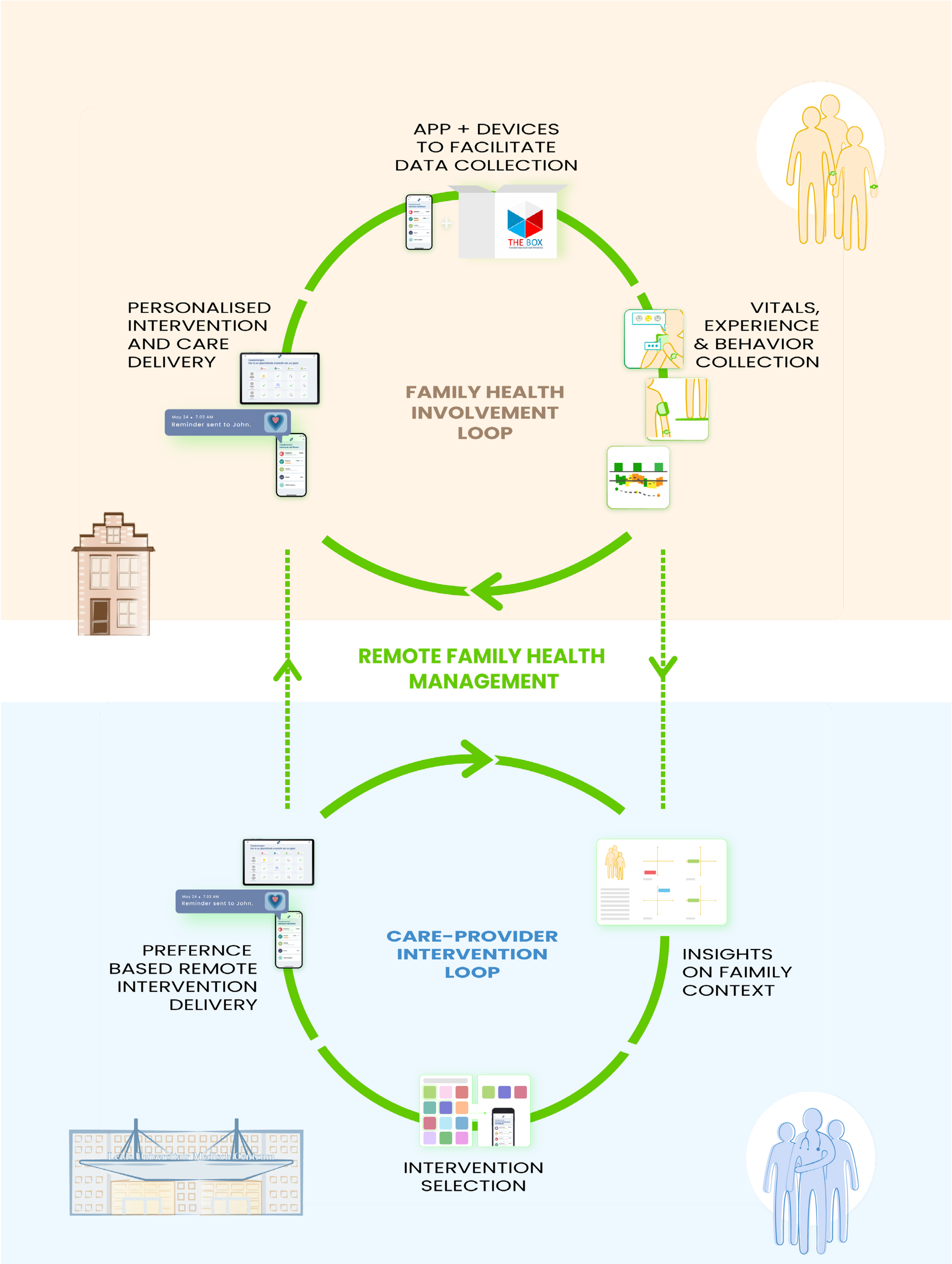


Fig 18: The Envisioned Product Service System Loop

What does this Product-Service- System Vision mean?

The product service system vision is centered on catering to the unique needs and preferences of family members, offering them a personalized and tailored service that aligns with their desired level of involvement. Leveraging the insights from the earlier discussion on involvement typologies, the system is designed to be dynamic and modular, allowing for continuous evolution and adaptation based on the ongoing interactions and engagement of family members.

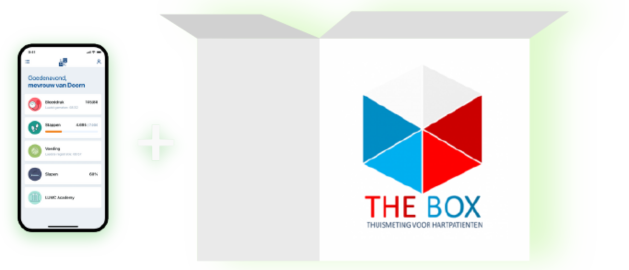
The core objective of this vision is to provide a comprehensive and holistic approach to family-oriented remote patient monitoring and healthcare interventions. By understanding the influence informed context and recognizing the diverse ways in which family members prefer to be involved in each other's health, the system can offer customized and relevant service offerings to cater to their individual requirements.

The dynamic nature of the service architecture ensures that the system remains responsive and adaptable to the changing needs and preferences of family members. As they interact with the system and provide feedback, the service offerings can be fine-tuned and adjusted to suit their evolving demands. This continuous evolution allows the system to maintain its relevance and effectiveness over time, ensuring that it continues to meet the needs of the family members effectively.

Moreover, the modular design of the system permits flexibility and scalability. It allows the addition of new features, services, or components as required, ensuring that the service offerings can be expanded and improved based on advancements in technology and healthcare practices. This modularity also facilitates seamless integration with existing healthcare infrastructures, enabling a smooth and efficient implementation process.

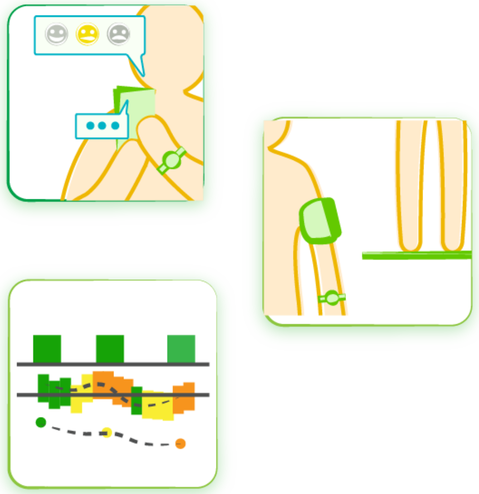
By combining the insights from the involvement typologies with a dynamic and modular service architecture, the product service system vision aims to revolutionize family-oriented remote patient monitoring and healthcare interventions. It aspires to empower family members with the tools and resources they need to actively participate in each other's health journey, fostering a culture of support, collaboration, and well-being within the family unit.

VISION ELEMENTS



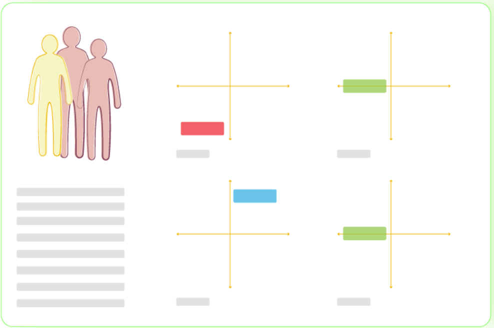
THE FAMILY BOX + LUMC CARE APP

In this vision, a combination of the box and service app is employed. The box is customised to contain smartwatch(es) for family member(s) whom the patient lives with. Additionally, other devices such as blood pressure monitor and weighing scale can be shared amongst the family member(s). The service app, independently accessible on each family members' respective smartphones, offers a means for data collection. These interconnected devices, in conjunction with the hospital's care app, synergistically collect data, monitor health and gather the additional data to comprehend the family's context.



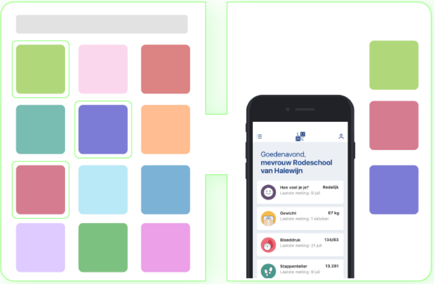
DIVERSE DATA COLLECTION

The preliminary data collection concentrates on ascertaining the family's context through the evaluation of alignment and involvement. The scope of data collected in this vision extends beyond solely relying on sensor-based data. It also encompasses the utilization of the service app to gather experience data and behavioral data. Experience data is used to measure the user's feelings and concerns, while behavioural data measures the users engagement levels and frequency with the service app. This integrated collection improves the quality of the analysis through triangulation (Van Gemert-Pijnen et al., 2011)



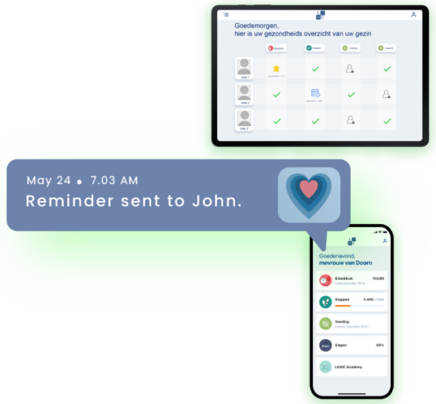
INFLUENCE BASED - CONTEXTUAL INSIGHTS

After conducting the preliminary assessment of involvement and alignment, a family profile is generated. This classifies the family according to their distinct combination of needs and preferences. The profile effectively highlights specific requirements of the family, enabling a framework for care providers to address their respective needs (Michie et al., 2017). As the app continues to be utilized over an extended period, and with continuous data collection, the family profile undergoes constant updates, ensuring its relevance and accuracy in representing any changes in their context.



MODULAR SERVICE ARCHITECTURE

The service, guided by the family profile, customizes specific features that align with the family's requirements. This adaptability is made possible through a modular service architecture, allowing for the delivery of various service features within a single comprehensive application. Tailoring interventions through a modular approach improves engagement and accessibility for a wide range of users (Michie et al., 2017). To prevent overwhelming healthcare providers with excessive data, the system flags health anomalies, prompting personal attention and consideration for only these critical aspects.



PERSONALISED INTERVENTIONS

Tailored to the context of each family, the service provides customized features and configurations facilitated by its modular design. Additionally, the integration of push notifications and prompts in the service app enables delivery of targeted interventions for promoting positive health behaviour. The effect on health outcomes based on the intervention is recorded. The service also provides the option for tele-consultations, allowing interactions involving the entire family. This approach ensures that the service is adaptable, engaging, and responsive to the specific needs of each family.

How does it connect to the 'The Box' currently provided by the LUMC?

The proposed service vision is closely connected to 'The Box' currently provided by the LUMC, which offers allows patients to monitor their health outside the hospital. In 'The Box,' various wearables such as a smart watch collects health data from the patients. It also includes a blood pressure monitor weighing scale and ECG device. Patients are asked to make measurements about three times a week, and the data is stored the patient's application and Medical Patient Record (MPR), where healthcare professionals can access it. Retaining the use of the same peripherals the proposed 'Family Box' should have supplementary smart watches for the family members of the patient, whereas the other devices can be shared amongst the members of a family.

In terms of the three central functions of the current Box service, the Sensing function involves collecting data through wearables and sensors, the Analysing function focuses on creating a timeline of data points and the Feedback function facilitates communication between healthcare providers and patients, though the feedback is mainly aimed at the healthcare professional. The proposed service vision aims to scale these features to the family members and would enhance the service by providing context relevant features based on the family profiles.

The Hart Long Centrum is also working on software that uses Artificial Intelligence to process the data and aims to develop a system that gives warnings for abnormal values. They are also exploring functionalities towards a 'chat bot' coach to guide patients through the rehabilitation process and lifestyle changes. Developing a modular service architecture, facilitated by machine learning and supplemented by AI will allow families to independently configure the application functionalities.

In conclusion, the proposed service vision builds upon the existing 'The Box' technology provided by the LUMC by incorporating family-centered care and involving them in the health monitoring process. The use of wearable technology, data analysis through Artificial Intelligence, and the development of a chatbot coach are some steps being taken to enhance patient engagement. Including family members in this service, further enhances this quality of engagement and experience of the entire family while supporting healthcare professionals in recommending tailored lifestyle modifications.

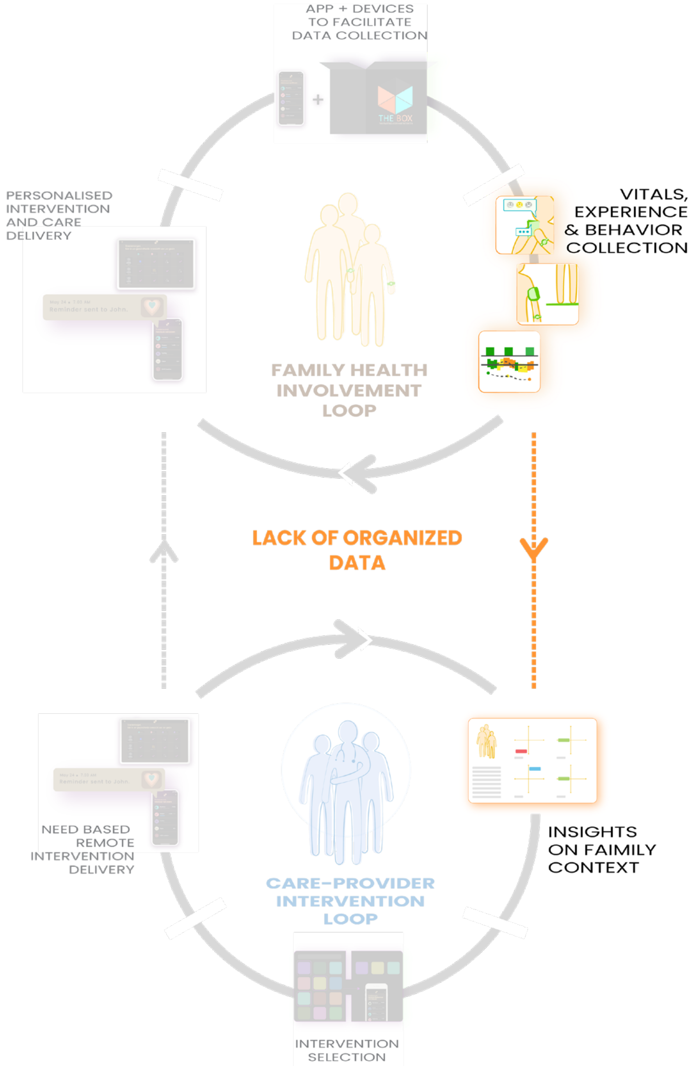


Fig 18: Data Gap preventing family involvement in remote patient management

What is required to realise this vision?

Based on the research conducted throughout the thesis, the service vision proposes a method to acknowledge and account for the potential influences of family members on a patient's prescribed lifestyle routines. This approach serves as a basis for involving family members in the patient's healthcare journey, aiming to enhance adherence and encourage collective lifestyle changes. The vision also explores the various preferences of families concerning their participation in diverse lifestyle activities. Nevertheless, it is essential to recognize that this approach is currently a theoretical concept, and its actual effectiveness remains uncertain.

The service vision highlights the prominent barrier of insufficient data to successfully implement a

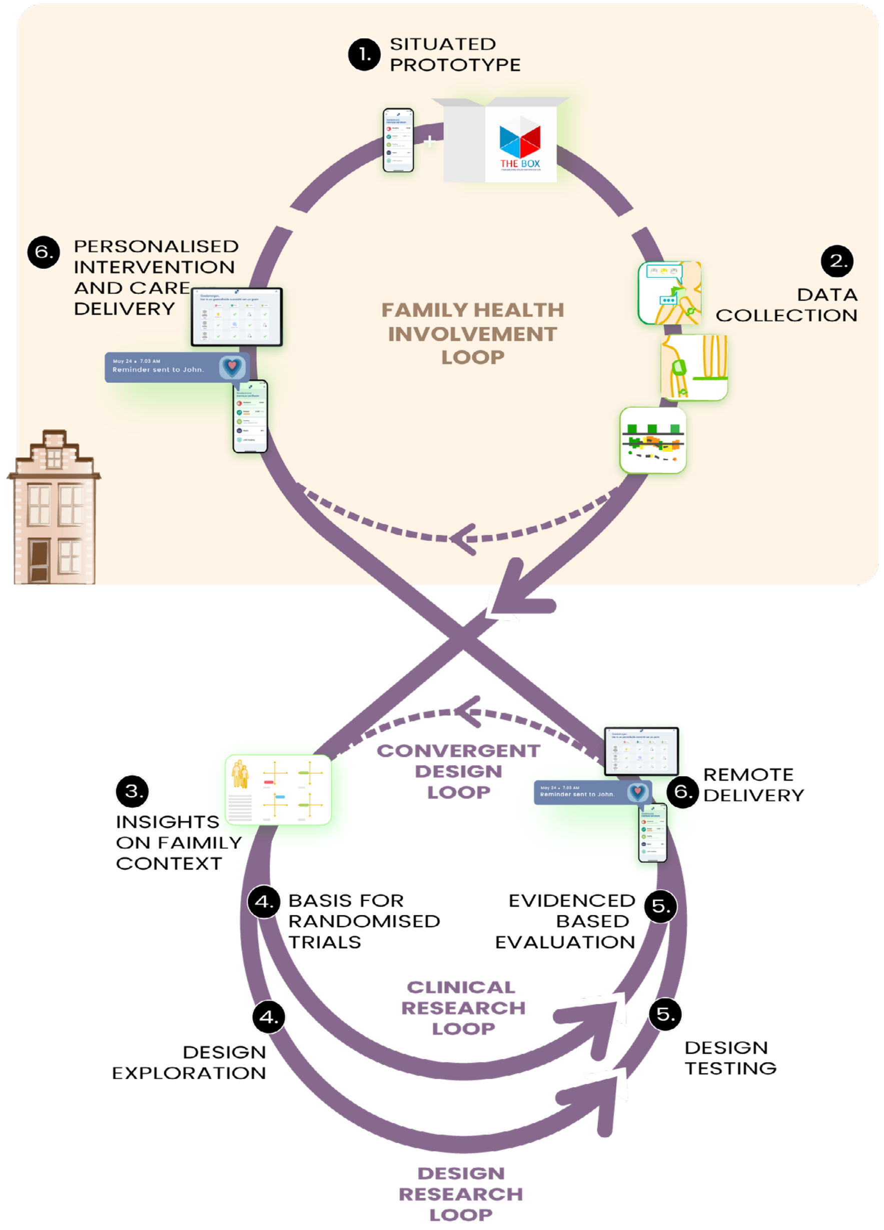


Fig 19: A proposition for a Data-Enabled Design Approach for Patient and Family-Centered Remote Patient Monitoring Strategy

patient and family-centered remote monitoring strategy. Currently, there exists limited data that can determine the requirements for family involvement and corresponding interventions that could yield positive effects on patient health outcomes.
It is advised to evaluate digital interventions to determine their potential in promoting self-management and fostering a healthy lifestyle, thus shifting the healthcare focus from health to overall well-being. Despite these recommendations, the adoption of positive health practices remains relatively low. Therefore, it is crucial to collect this data to draw evidence-backed conclusions that could facilitate the implementation of such a strategy in actual healthcare settings. By addressing the data gap (Figure 18), stakeholders within the healthcare system can gain valuable insights and empirical evidence to support the integration of family-centric care.

A CASE FOR DATA-ENABLED DESIGN

The service vision introduced earlier showcases its capability to comprehend the unique context of family members, adapt to their specific requirements, and continuously learn from interactions, thereby exemplifying the characteristics of an intelligent ecosystem (Sanders and Bogers, 2019). For designing such an ecosystem they propose a data-enabled design methodology to iteratively materialize such a solution, by enabling the collection of sensor-based and qualitative data directly from users within their individual contexts, which in turn informs advancements in design.

This approach is beneficial to further informing a strategy for family involvement and patient-centered care for lifestyle adherences due to its following advantages-

1. The focus on data

By combining qualitative insights obtained through manual data collection methods with data gathered from sensor-based approaches, a more comprehensive and detailed understanding of family context, behavior, and the overall experience of engaging with the service can be achieved. This approach utilizes technological solutions that offer real-time and real-world measurements of various phenomena, enabling the prompt, time-stamped, and secure transfer of patient data. This private data collection process can also help reduce potential bias from the Hawthorne effect, that may appear during focus groups (McLean, 2020). This combined allows for a deeper exploration of how and why behavior changes occur within individuals over time and how these changes are influenced by internal physiological and psychological factors as well as external environmental factors (Michie et al., 2017).

The data collected through this approach can be used as creative material for designers but also provide insights for clinical researchers. This data enabled understanding of the influence of families on behaviour, facilitates the possibility of a convergent design process (Pannunzio et al., 2019) necessary for effective development of an ehealth service (Michie et al., 2017)..

2. Utilizing a situated prototype

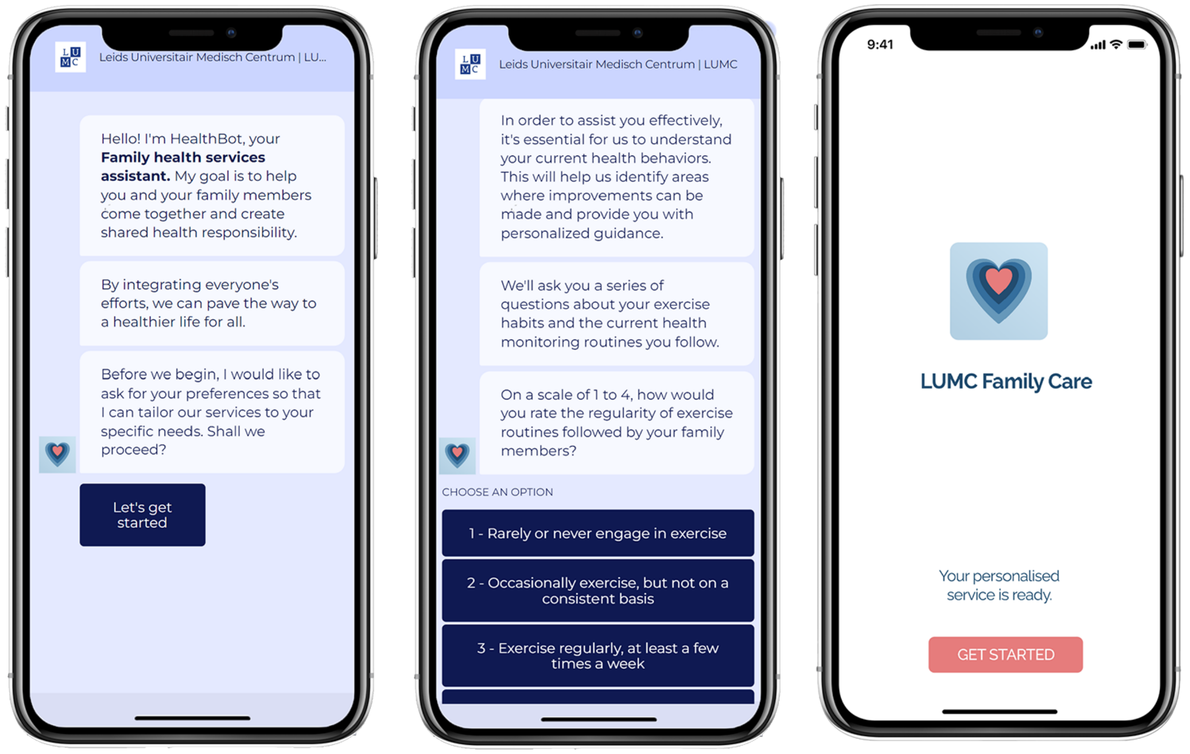
The incorporation of a situated prototype engages patients and family members with the service in their daily lives, allowing them to interact and evaluate the service as a part of their routine at home. This approach can offer insights into how the contextual factors within their homes influence their needs.

Given the novel nature of this care-delivery paradigm, the prototype also serves as a simulation of the potential service, allowing participants to interacting with a new reality to understand their values (Boenink & Kudina, 2020). By experiencing the prototype, individuals are empowered to introspect and better articulate their requirements.

Furthermore, a situated prototype facilitates longer duration of engagement with the service with an opportunity for periodic modifications, which can provide a better assessment of its effectiveness as what users considered to be important might change once digital technologies are introduced (ie, value mediation)(Smits et al., 2022). User engagement with technology leads to continuous reshaping. As users reflect on the content, the system can be modified, followed by a continuous, reflexive evaluation process that considers human, organizational, and technology factors (Van Gemert-Pijnen et al., 2011).

The following page showcases an example of a prototype to illustrate the potential features that can be tested and explored with patients and family members, eliciting their preferences and needs in a real-world setting.
These protoypes were developed using-
1. Landbot.io - A chatbot simulation software.
2. Figma- Web application Interactive web application for interface prototyping.

Health related outcome management platforms like Ethica can be used in combination with these prototypes, as it allows participants to sync their wearable data, which is recorded and can processed for further analysis.



Hello! I'm HealthBot, your **Family health services assistant.** My goal is to help you and your family members come together and create shared health responsibility.

By integrating everyone's efforts, we can pave the way to a healthier life for all.

Before we begin, I would like to ask for your preferences so that I can tailor our services to your specific needs. Shall we proceed?

In order to assist you effectively, it's essential for us to understand your current health behaviors. This will help us identify areas where improvements can be made and provide you with personalized guidance.

We'll ask you a series of questions about your exercise habits and the current health monitoring routines you follow.

On a scale of 1 to 4, how would you rate the regularity of exercise routines followed by your family members?

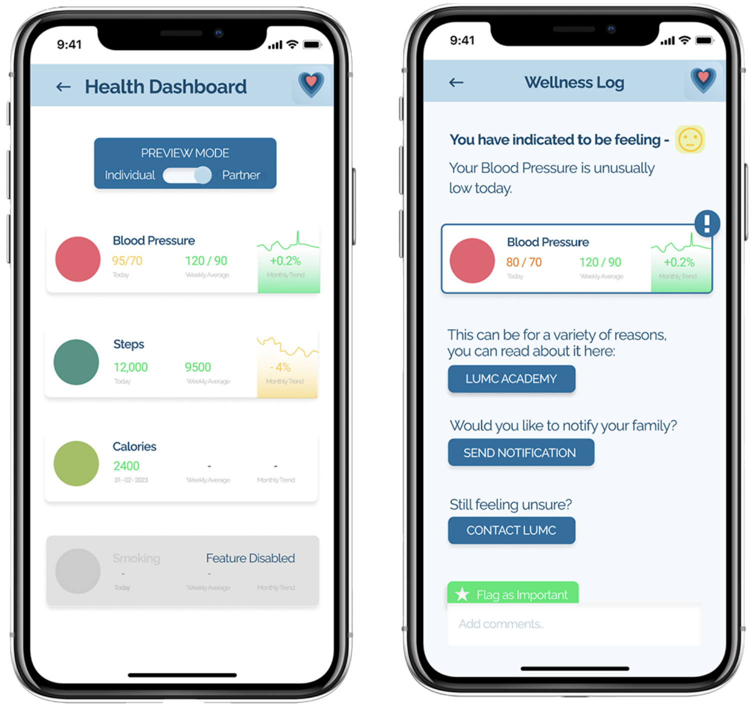
Your personalised service is ready.

CONTEXT BASED SERVICE PERSONALISATION

The above screens illustrate an initial chat-bot configuration that leads the user through a series of questions to assess the influence and involvement of the patient's family.

This data is utilized to understand the patient and family context, enabling the algorithm to select the most suitable interventions or functionalities for the personalized LUMC care application offered to the family.

Interaction with such a simulation can reveal peoples values about interacting with AI agents and utilizing ML algorithms for their health.



You have indicated to be feeling -

Your Blood Pressure is unusually low today.

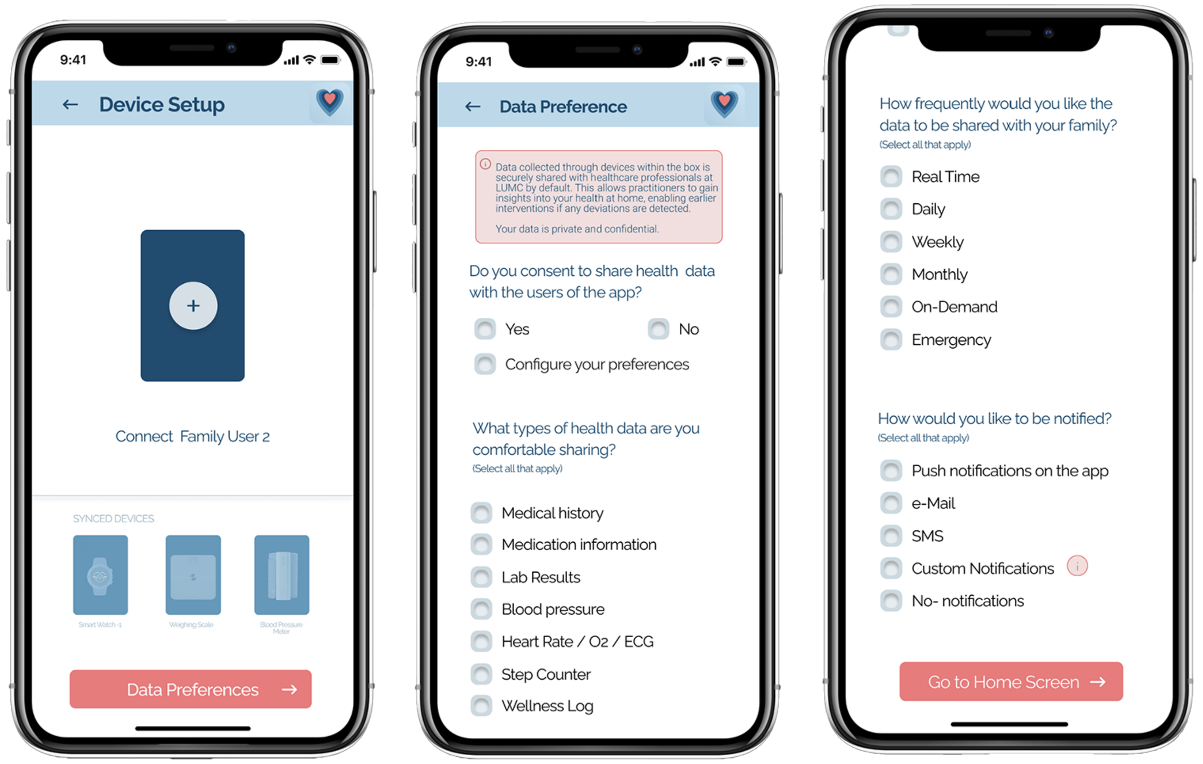
This can be for a variety of reasons, you can read about it here:

Would you like to notify your family?

Still feeling unsure?

FUNCTIONALITY EXAMPLES

The app can offer a range of functionalities designed to accommodate different levels of health interactions within the family. Among these features, a shared health dashboard provides a comprehensive overview of the family's health data, fostering collaborative care decision-making among family members. Additionally, an experiencing sampling-based wellbeing log allows family members to input real-time data on the their emotional and physical state, enabling a deeper understanding of their overall well-being. Sustained interaction with such features can reveal their effectivity on health outcomes.



Data collected through devices within the box is securely shared with healthcare professionals at LUMC by default. This allows practitioners to gain insights into your health at home, enabling earlier interventions if any deviations are detected.

Your data is private and confidential.

Do you consent to share health data with the users of the app?

☐ Yes ☐ No

☐ Configure your preferences

What types of health data are you comfortable sharing?
(Select all that apply)

☐ Medical history
☐ Medication information
☐ Lab Results
☐ Blood pressure
☐ Heart Rate / O2 / ECG
☐ Step Counter
☐ Wellness Log

How frequently would you like the data to be shared with your family?
(Select all that apply)

☐ Real Time
☐ Daily
☐ Weekly
☐ Monthly
☐ On-Demand
☐ Emergency

How would you like to be notified?
(Select all that apply)

☐ Push notifications on the app
☐ e-Mail
☐ SMS
☐ Custom Notifications
☐ No- notifications

PREFERENCE BASED MODIFICATIONS

The screens demonstrate how the personalized LUMC App guides users through the data sharing options necessary to enable the desired functionality of the application. This process ensures that users are informed about the data collected, its recipients, and provides them with the flexibility to customize non-essential data requirements according to their preferences. By offering this level of control and transparency, the app empowers users to make informed decisions about their data sharing, promoting a sense of trust and ownership over their health information.

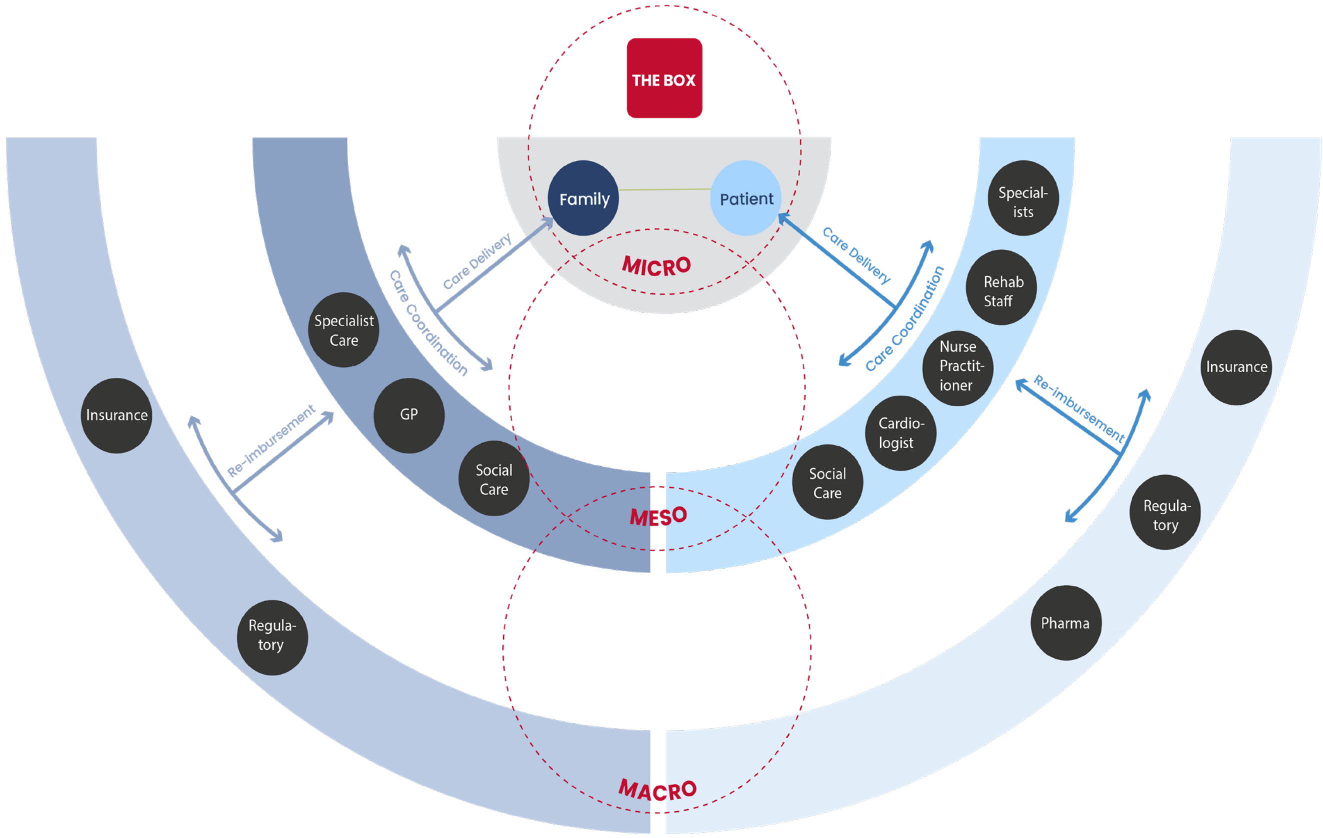


Fig 20: A stakeholder map for patient and family centered e-health service.

5.2 IMPLEMENTATION & RECOMMENDATIONS

Implementing a new service often forces us to clarify how the process of health care delivery actually runs—for example, who the key stakeholders are and how payment is organized(Van Gemert-Pijnen et al., 2011). While the healthcare system is a complex network over multiple stakeholders, this stakeholder map (Figure-20) identifies the stakeholders that emerged in conversation with healthcare experts from the LUMC and desk research. This map also aims to visualize the relation between them when care is extended to the homes and towards a family instead of an individual.

The envisioned product service system proposes a strategic shift and expansion of the current service involve family members in patient care through eHealth interventions. While for effective adoption and implementation, it is essential to engage all relevant stakeholders, a dearth of research conducted in understanding the preferences of patients and family members (i. stakeholders present in the micro-level of the service) represented a suitable scope to answer the research question of the thesis. The challenges surrounding family involvement, however have implications that extend beyond the family unit itself. There are uncertainties surrounding liability and the scope of practice when intervening with individuals who are not the primary patients. Another major challenges faced in implementing a family-oriented eHealth service is the lack of established payment and reimbursement mechanisms for healthcare providers to offer direct care to family members. This financial barrier hinders the integration of family members into the healthcare ecosystem, limiting their ability to contribute effectively to the collective health and well-being of the family.

Nonetheless, for a service to exist within the healthcare system, value delivery and exchange is important across all stakeholder levels. Therefore the recommendation of this project is to use the service vision created to serve as a starting point and a boundary object to facilitate deeper conversation with stakeholders, around the domain of family and patient centered care.

6 References

Abrams, K., Balan-Cohen, A., & Durbha, P. (2018, August). Growth in outpatient care. Deloitte Insights. https://www2.deloitte.com/za/en/insights/industry/health-care/outpatient-hospital-services-medicare-incentives-value-quality.html

Akinosun, A. S., Polson, R., Diaz - Skeete, Y., De Kock, J. H., Carragher, L., Leslie, S., Grindle, M., & Gorely, T. (2021). Digital Technology Interventions for Risk Factor Modification in Patients With Cardiovascular Disease: Systematic Review and Meta-analysis. JMIR MHealth and UHealth, 9(3), e21061. https://doi.org/10.2196/21061

Alonso, S. G., De La Torre Díez, I., & Zapiraín, B. G. (2019). Predictive, Personalized, Preventive and Participatory (4P) Medicine Applied to Telemedicine and eHealth in the Literature. Journal of Medical Systems, 43(5), 140. https://doi.org/10.1007/s10916-019-1279-4

Asbjørnsen, R. A., Smedsrød, M. L., Solberg Nes, L., Wentzel, J., Varsi, C., Hjelmesæth, J., & Van Gemert-Pijnen, J. E. (2019). Persuasive System Design Principles and Behavior Change Techniques to Stimulate Motivation and Adherence in Electronic Health Interventions to Support Weight Loss Maintenance: Scoping Review. Journal of Medical Internet Research, 21(6), e14265. https://doi.org/10.2196/14265

Azoulay, E., Pochard, F., Chevret, S., Jourdain, M., Bornstain, C., Wernet, A., Cattaneo, I., Annane, D., Brun, F., Bollaert, P.-E., Zahar, J.-R., Goldgran-Toledano, D., Adrie, C., Joly, L.-M., Tayoro, J., Desmettre, T., Pigne, E., Parrot, A., Sanchez, O., … Lemaire, F. (2002). Impact of a Family Information Leaflet on Effectiveness of Information Provided to Family Members of Intensive Care Unit Patients: A Multicenter, Prospective, Randomized, Controlled Trial. American Journal of Respiratory and Critical Care Medicine, 165(4), 438–442. https://doi.org/10.1164/ajrccm.165.4.200108-006oc

Bandura, A. (1986) Social Foundations of Thought and Action: A Social Cognitive Theory. Prentice-Hall, Inc, Englewood Cliffs, NJ.

Bente, B. E., Wentzel, J., Groeneveld, R. G., IJzerman, R. V., De Buisonjé, D. R., Breeman, L. D., Janssen, V. R., Kraaijenhagen, R., Pieterse, M. E., Evers, A. W., & Van Gemert-Pijnen, J. E. (2021). Values of Importance to Patients With Cardiovascular Disease as a Foundation for eHealth Design and Evaluation: Mixed Methods Study. JMIR Cardio, 5(2), e33252. https://doi.org/10.2196/33252

Bidenko, K., & Bohnet-Joschko, S. (2022). Supporting family care: A scoping app review. BMC Medical Informatics and Decision Making, 22(1), 162. https://doi.org/10.1186/s12911-022-01906-6

Bidwell, J. T., Vellone, E., Lyons, K. S., D'Agostino, F., Riegel, B., Juárez-Vela, R., Hiatt, S. O., Alvaro, R., & Lee, C. S. (2015). Determinants of Heart Failure Self-Care Maintenance and Management in Patients and Caregivers: A Dyadic Analysis: DETERMINANTS OF HEART FAILURE SELF-CARE IN DYADS. Research in Nursing & Health, 38(5), 392–402. https://doi.org/10.1002/nur.21675

Bowen, M. (1966). The use of family theory in clinical practice. Comprehensive Psychiatry, 7(5), 345–374. https://doi.org/10.1016/S0010-440X(66)80065-2

Burrell, A., Zrubka, Z., Champion, A., Zah, V., Vinuesa, L., Holtorf, A.-P., Di Bidino, R., Earla, J. R., Entwistle, J., Boltyenkov, A. T., Braileanu, G., Kolasa, K., Roydhouse, J., Asche, C., Redekop, K., Pfeiffer, C., Le, L., Janodia, M., Sharkawy, M., … Paul, S. (2022). How Useful Are Digital Health Terms for Outcomes Research? An ISPOR Special Interest Group Report. Value in Health, 25(9), 1469–1479. https://doi.org/10.1016/j.jval.2022.04.1730

Butterworth, J. E., & Campbell, J. L. (2014). Older patients and their GPs: Shared decision making in enhancing trust. British Journal of General Practice, 64(628), e709–e718. https://doi.org/10.3399/bjgp14X682297

Christou, A., & Christodoulou Fella, M. (2023). Health Behavioral Change Interventions in Caregivers: The Prolepsis Project. In A. Charalambous (Ed.), Informal Caregivers: From Hidden Heroes to Integral Part of Care (pp. 189–209). Springer International Publishing. https://doi.org/10.1007/978-3-031-16745-4_11

Dansky, K. H., Thompson, D., & Sanner, T. (2006). A framework for evaluating eHealth research. Evaluation and Program Planning, 29(4), 397–404. https://doi.org/10.1016/j.evalprogplan.2006.08.009

Digital Therapeutics (DTX). (2023, July 28). European Data Protection Supervisor. https://edps.europa.eu/press-publications/publications/techsonar/digital-therapeutics-dtx_en

Dorst, K. (2015). Frame Creation and Design in the Expanded Field. She Ji: The Journal of Design, Economics, and Innovation, 1(1), 22–33. https://doi.org/10.1016/j.sheji.2015.07.003

Eliacin, J., Salyers, M. P., Kukla, M., & Matthias, M. S. (2015). Factors influencing patients' preferences and perceived involvement in shared decision-making in mental health care. Journal of Mental Health, 24(1), 24–28. https://doi.org/10.3109/09638237.2014.954695

Goldfarb, M. J., Bechtel, C., Capers, Q., De Velasco, A., Dodson, J. A., Jackson, J. L., Kitko, L., Piña, I. L., Rayner-Hartley, E., Wenger, N. K., Gulati, M., & the American Heart Association Council on Clinical Cardiology; Council on Cardiovascular and Stroke Nursing; Council on Lifelong Congenital Heart Disease and Heart Health in the Young; Council on Cardiovascular Radiology and Intervention; Council on Hypertension; Council on the Kidney in Cardiovascular Disease; and Council on Lifestyle and Cardiometabolic Health. (2022). Engaging Families in Adult Cardiovascular Care: A Scientific Statement From the American Heart Association. Journal of the American Heart Association, 11(10), e025859. https://doi.org/10.1161/JAHA.122.025859

Golics, C. J., Basra, M., Salek, & Finlay. (2013). The impact of patients' chronic disease on family quality of life: An experience from 26 specialties. International Journal of General Medicine, 787. https://doi.org/10.2147/IJGM.S45156

Gupta Strategists & Edwards Lifesciences. (2021). Prevent the next wave: Why labour-saving innovations are needed in healthcare and how an innovative ecosystem ena-bles progression.

Hanna, A., Yael, E.-M., Hadassa, L., Iris, E., Eugenia, N., Lior, G., Carmit, S., & Liora, O. (2020). ``It's up to me with a little support'' – Adherence after myocardial infarction: A qualitative study. International Journal of Nursing Studies, 101, 103416. https://doi.org/10.1016/j.ijnurstu.2019.103416

Houwen, J. (2021). Supporting a healthy dyadic lifestyle following a myocardial infarction using eHealth technology: Experiencing a Myocardial Infarction together. https://repository.tudelft.nl/islandora/object/uuid%3Acf920428-6515-4ac8-a809-67dc6b67b969

Joseph, A. L., Monkman, H., Kushniruk, A., & Quintana, Y. (2023). Exploring Patient Journey Mapping and the Learning Health System: Scoping Review. JMIR Human Factors, 10, e43966. https://doi.org/10.2196/43966

Kitko, L., McIlvennan, C. K., Bidwell, J. T., Dionne-Odom, J. N., Dunlay, S. M., Lewis, L. M., Meadows, G., Sattler, E. L. P., Schulz, R., Strömberg, A., & On behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Quality of Care and Outcomes Research; Council on Clinical Cardiology; and Council on Lifestyle and Cardiometabolic Health. (2020). Family Caregiving for Individuals With Heart Failure: A Scientific Statement From the American Heart Association. Circulation, 141(22). https://doi.org/10.1161/CIR.0000000000000768

Kokorelias, K. M., Gignac, M. A. M., Naglie, G., & Cameron, J. I. (2019). Towards a universal model of family centered care: A scoping review. BMC Health Services Research, 19(1), 564. https://doi.org/10.1186/s12913-019-4394-5

Kollenburg, J. V., & Bogers, S. (n.d.). A situated design approach that uses data as creative material when designing for intelligent ecosystems.

Krack, G., Holle, R., Kirchberger, I., Kuch, B., Amann, U., & Seidl, H. (2018). Determinants of adherence and effects on health-related quality of life after myocardial infarction: A prospective cohort study. BMC Geriatrics, 18(1), 136. https://doi.org/10.1186/s12877-018-0827-y

Krist, A. H., Tong, S. T., Aycock, R. A., & Longo, D. R. (2017). Engaging patients in decision-making and behavior change to promote prevention. Information Services & Use, 37(2), 105–122. https://doi.org/10.3233/ISU-170826

McLean, A. (2020). mHealth Apps as Effective Persuasive Health Technology: Contextualizing the "Necessary" Functionalities. JMIR Nursing, 3(1), e19302. https://doi.org/10.2196/19302

Meier, C. A., Fitzgerald, M. C., & Smith, J. M. (2013). eHealth: Extending, Enhancing, and Evolving Health Care. Annual Review of Biomedical Engineering, 15(1), 359–382. https://doi.org/10.1146/annurev-bioeng-071812-152350

Michie, S., Yardley, L., West, R., Patrick, K., & Greaves, F. (2017). Developing and Evaluating Digital Interventions to Promote Behavior Change in Health and Health Care: Recommendations Resulting From an International Workshop. Journal of Medical Internet Research, 19(6), e232. https://doi.org/10.2196/jmir.7126

Nicholas Dionne-Odom, J., Hooker, S. A., Bekelman, D., Ejem, D., McGhan, G., Kitko, L., Strömberg, A., Wells, R., Astin, M., Metin, Z. G., Mancarella, G., Pamboukian, S. V., Evangelista, L., Buck, H. G., & Bakitas, M. A. (2017). Family caregiving for persons with heart failure at the intersection of heart failure and palliative care: A state-of-the-science review. Heart Failure Reviews, 22(5), 543–557. https://doi.org/10.1007/s10741-017-9597-4

Pannunzio, V., Kleinsmann, M., & Snelders, D. (2019). Design research, eHealth, and the convergence revolution. ResearchGate. https://www.researchgate.net/publication/335612269_Design_research_eHealth_and_the_convergence_revolution

Porter, M. E. (2009). A Strategy for Health Care Reform—Toward a Value-Based System. New England Journal of Medicine, 361(2), 109–112. https://doi.org/10.1056/NEJMp0904131

Rakers, M. M., Van Os, H. J. A., Recourt, K., Mosis, G., Chavannes, N. H., & Struijs, J. N. (2023). Perceived barriers and facilitators of structural reimbursement for remote patient monitoring, an exploratory qualitative study. Health Policy and Technology, 12(1), 100718. https://doi.org/10.1016/j.hlpt.2022.100718

Rippe, J. M. (2019). Lifestyle Strategies for Risk Factor Reduction, Prevention, and Treatment of Cardiovascular Disease. American Journal of Lifestyle Medicine, 13(2).

Riva, J. J., Malik, K. M. P., Burnie, S. J., Endicott, A. R., & Busse, J. W. (n.d.). Commentary What is your research question? An introduction to the PICOT format for clinicians.

Ruyobeza, B., Grobbelaar, S. S., & Botha, A. (2022). Hurdles to developing and scaling remote patients' health management tools and systems: A scoping review. Systematic Reviews, 11(1), 179. https://doi.org/10.1186/s13643-022-02033-z

Sharon, T. (2017). Self-Tracking for Health and the Quantified Self: Re-Articulating Autonomy, Solidarity, and Authenticity in an Age of Personalized Healthcare. Philosophy & Technology, 30(1), 93–121. https://doi.org/10.1007/s13347-016-0215-5

Simonse, L. (2018). Design roadmapping: Guidebook for Future Foresight Techniques. BIS Publishers.

Simonse, L., Albayrak, A., & Starre, S. (2019). Patient journey method for integrated service design. Design for Health, 3(1), 82–97. https://doi.org/10.1080/24735132.2019.1582741

Sin, J., Henderson, C., Spain, D., Cornelius, V., Chen, T., & Gillard, S. (2018). eHealth interventions for family carers of people with long term illness: A promising approach? Clinical Psychology Review, 60, 109–125. https://doi.org/10.1016/j.cpr.2018.01.008

Smits, M., Ludden, G. D. S., Verbeek, P.-P., & Van Goor, H. (2022). How Digital Therapeutics Are Urging the Need for a Paradigm Shift: From Evidence-Based Health Care to Evidence-Based Well-being. Interactive Journal of Medical Research, 11(2), e39323. https://doi.org/10.2196/39323

Taylor, C. N., Wang, D., Larson, M. G., Lau, E. S., Benjamin, E. J., D'Agostino, R. B., Vasan, R. S., Levy, D., Cheng, S., & Ho, J. E. (2023). Family History of Modifiable Risk Factors and Association With Future Cardiovascular Disease. Journal of the American Heart Association, 12(6), e027881. https://doi.org/10.1161/JAHA.122.027881

Timmis, A., Townsend, N., Gale, C. P., Torbica, A., Lettino, M., Petersen, S. E., Mossialos, E. A., Maggioni, A. P., Kazakiewicz, D., May, H. T., De Smedt, D., Flather, M., Zuhlke, L., Beltrame, J. F., Huculeci, R., Tavazzi, L., Hindricks, G., Bax, J., Casadei, B., … Bardinet, I. (2020). European Society of Cardiology: Cardiovascular Disease Statistics 2019. European Heart Journal, 41(1), 12–85. https://doi.org/10.1093/eurheartj/ehz859

Ton, T. G. N., Fogg, T. T., Fong, C.-T., John, C., Li, S. X. L., Marshall, J. A., Peters, K., Neal, W., & Pearson, T. A. (2011). Knowledge, Perception, and Behaviors of Relatives of People With Premature Heart Disease: A Systematic Literature Review. Circulation, 124(8), 958–964. https://doi.org/10.1161/CIRCULATIONAHA.110.940593

Treskes, R. W., Van Den Akker-van Marle, M. E., Van Winden, L., Van Keulen, N., Van Der Velde, E. T., Beeres, S., Atsma, D., & Schalij, M. J. (2022). The Box—eHealth in the Outpatient Clinic Follow-up of Patients With Acute Myocardial Infarction: Cost-Utility Analysis. Journal of Medical Internet Research, 24(4), e30236. https://doi.org/10.2196/30236

Van Gemert-Pijnen, J. E., Nijland, N., Van Limburg, M., Ossebaard, H. C., Kelders, S. M., Eysenbach, G., & Seydel, E. R. (2011). A Holistic Framework to Improve the Uptake and Impact of eHealth Technologies. Journal of Medical Internet Research, 13(4), e111. https://doi.org/10.2196/jmir.1672

Viitanen, J., Valkonen, P., Savolainen, K., Karisalmi, N., Hölsä, S., & Kujala, S. (2022). Patient Experience from an eHealth Perspective: A Scoping Review of Approaches and Recent Trends. Yearbook of Medical Informatics, 31(01), 136–145. https://doi.org/10.1055/s-0042-1742515

World Health Organization (WHO, n.d) Social determinants of health. (accessed on 2023, July 25). https://www.who.int/teams/social-determinants-of-health

World Health Organization [WHO]. (n.d.). Health and Well-Being. https://www.who.int/data/gho/data/major-themes/health-and-well-being

7 Appendix

APPENDIX -A

INITIAL SEARCH KEYWORDS USING PICO APPROACH FOR LITERATURE STUDY

P: Population - Individuals with cardiovascular health issues, chronic health conditions, caregivers, family and peers.

I: Intervention - Behavioral interventions, lifestyle recommendations.

C: Comparison - None (not applicable in this case).

O: Outcome - Improved health, improved well-being, improved experience.

This lead to the creation of the following search filter with boolean operators :

("cardiovascular health" OR "heart health" OR "heart disease" OR "cardiovascular disease" OR "chronic health conditions" OR "caregivers" OR "family" OR "peers") AND ("behavioral interventions" OR "behavioral therapies" OR "lifestyle recommendations" OR "lifestyle modifications") AND ("improved health" OR "improved well-being" OR "improved experience").

APPENDIX -B

KEY INFORMANT INTERVIEW GUIDES

B.1

1. **Name: Dr. V.R. Janssen**
   Designation: Psychologist, LUMC, Leiden, NL

2. **Name: Prof. dr. Douwe Atsma**
   Designation: Cardiologist, LUMC, Leiden, NL

- Can you share some insights into the demographic characteristics of patients using remote monitoring solutions compared to traditional in-person care?
- How has the response been from patients regarding the adoption of remote monitoring solutions? Have most people been accepting of this approach?
- What are some specific clinical measures that you consider when dealing with patients who have cardiac health problems?
- How do you distinguish between patients who are considered fit versus unfit using the remote monitoring data?
- Could you share some common challenges and needs that patients with cardiac health problems (MI patients) and their families face during their healthcare journey?
- How has remote monitoring addressed some of these challenges and needs for MI patients and their families compared to traditional care methods?
- In your experience, what support do MI patients and their families often require, and how can remote monitoring strategies accommodate these needs?
- Do you see them being owned by the family for the patient's use, or does the patient typically own the device for family monitoring purposes?
- What factors influence whether the remote monitoring device is owned by the patient or the family?
- Could you explain the reasons and differences between various boxes used for remote monitoring?
- In your perspective, how can family data from remote monitoring be leveraged to enhance the collective wellbeing of patients and their family members?
- How do you define wellbeing in the context of remote patient monitoring, and what role does family involvement play in achieving this?
- Can you elaborate on the concept of prescribing well-being in the context of remote monitoring?
- How does 'the family box' fit into the equation - is it primarily for disability management, or does it also act as a driver for overall wellbeing?
- What challenges do you anticipate in implementing remote monitoring strategies that involve family members?
- Are there any specific ethical considerations or privacy concerns associated with sharing patient data with family members in the context of remote monitoring?

B.2

1. **Name: Sara Hondmann**
   Designation: PhD Candidate, LUMC, Leiden, NL

- Thank you for participating in this interview. Could you please provide a summary of your work on data-driven personification of users?
- How have patients perceived the advantages of using 'The Box' in their care?
- What are some reported advantages for the families of patients involved in remote monitoring via 'The Box'?
- Can you highlight some of the challenges faced by patients who don't use 'The Box' for remote monitoring?
- How does the social environment affect behavior change?
- Do you think 'The Box' has the potential to influence behavior change based on the social environment? Why or why not?
- Have you recognized any enablers of engagement in your study? If so, what are they, and how do they contribute to technology-based behavior change?
- Have you recorded any barriers to engagement with 'The Box'? If yes, could you elaborate on them?
- Is there a difference in how patients respond to self-reported data compared to measured data? Why do you think this difference exists?
- Are there recognizable phases during the use of 'The Box' where patients expect human support for remote monitoring?
- Can you share any emerging patterns or insights related to adherence over time in patients using 'The Box'?
- Have you observed any instances of teachable moments during the use of 'The Box'? If yes, could you provide examples?
- Are there any theories of family-supported behavior change (e.g., group therapy for anxiety and depression, breast cancer rehabilitation programs) that you think could inform the design of interventions for 'The Box'?
- Do you see 'The Box' being able to contribute to any of the family-supported behavior change theories mentioned earlier? If so, how?
- Are there any shortcomings or limitations of 'The Box' that you have identified during your research?
- How do you think your study could contribute to building better e-health interventions?
- Thank you for your valuable insights. Is there anything else you would like to add or any specific points you think are crucial for this research?

B.3

1. **Name: Dr. Ajay Garg**
   Designation Director, Home Based Primary Care

2. **Name: Dr. Vinay Malhotra**
   Designation: Medical Director, Cardiology, Puget Sound Region

- Introduce yourself and your current work..
- Could you briefly share your experience with family-centered care and your expertise in geriatric and palliative care?
- In your perspective, what does healthcare delivery to a family vs. an individual look like?
- When do you believe the maximum influence of families occurs during the care-path of patients?
- Can you provide examples of cases where the family has been involved in patient care, particularly in the context of chronic care and behavior change adherence?
- Specifically, how does family involvement look like for patients with cardiovascular conditions like myocardial infarction (MI)?
- How do communication and education play a role in your practice, especially in the context of involving families in patient care? Is it primarily patient-directed or family-directed?
- Are there any specific approaches or strategies you use to effectively communicate with families and patients regarding lifestyle changes and treatment plans?
- What is your opinion on family-centered lifestyle interventions, such as those targeting diet or smoking cessation? How can families be instrumental in supporting patients' adherence to these changes?
- Have you encountered teachable moments in your practice, and do you see opportunities to utilize technology to identify and leverage such moments?
- I'm exploring possibilities of collecting family data for remote monitoring strategies. What benefits do you see in accessing family data to enhance patient care?
- On the other hand, what challenges do you perceive in making this shift towards using family data for healthcare?
- As we move towards value-based healthcare, how do you determine the suitable degree of personalization in care plans, considering the involvement of family members?
- When evaluating the effectiveness of remote monitoring and family involvement, do you prioritize engagement with technology or other health parameters like blood pressure or weight maintenance? Are there any other measures you consider?
- What are your thoughts on providing financial incentives to promote the tracking of certain health parameters by both patients and their families? Do you see potential benefits or drawbacks in this approach?
- Can you share some insights into the current e-health practices that you employ in your home-based primary care, especially those that involve family members?
- Is there anything else you would like to add or any additional information that you think would be valuable for my research on family involvement in remote monitoring strategies for patient care?

B.4

1. **Name: Tammi Hudspeth**
   Designation: Nurse Practitioner, Cardio Mems Program

- Please tell me about your experience working with remote heart monitoring and the Cardio MEMS program.
- Can you describe the type of data and data variability you track through remote heart monitoring?
- What kind of outcome measures are currently being tracked? Are they self-reported or experiential in nature?
- In your experience, what are some of the challenges associated with remote heart monitoring?
- How do family members or caregivers typically participate in the remote heart monitoring process?
- Have you noticed any differences in patient outcomes when family members or caregivers are involved in remote heart monitoring?
- What strategies are currently used to encourage patients to adopt self-monitoring behaviors?
- What strategies have you found effective in engaging family members or caregivers in remote heart monitoring?
- I aim to create a family service delivered via a health app where health data can be shared with consent. What challenges do you foresee in setting up such a service?
- How do you expect your role to evolve if the current monitoring service is extended to include family data?
- How do you ensure that patients and family members or caregivers understand the data collected through remote heart monitoring?
- In your opinion, what are some of the key factors that contribute to a successful remote heart monitoring program?
- How do you communicate with other healthcare professionals, such as physicians or specialists, about patient data collected through remote heart monitoring?
- Are there any specific interventions or approaches you think would be helpful in supporting family members or caregivers in remote heart monitoring?
- Is there anything else you would like to share or any other insights you believe are relevant to this research?

APPENDIX -C

C.1 SEMI- STRUCTURED INTERVIEW GUIDE A (EXPERIENCE WITH CVD)

1. SENSITISATION

Could you introduce me to your family?

Would you be comfortable telling me about the time that they experienced an MI?

How would you describe the first few weeks after coming home?

What was challenging for you?

How have things changed over time?

2. IMMERSION - Focus on our daily lives and routine.

Could you walk me through a regular day in your lives? Let's start from waking up

How does the process of buying groceries look like? Challanges?

What are some of the physical activities that you engage in? Challanges?

What are some other activities that you do together as a family?
Let's start with within home - Away from home

How would you describe your involvement in each others health?
- How do you and your family help each other stay healthy?
-Can you think of any specific examples?

What do doctors visits look like? Expectations > Reality > Opinions / Feelings

Whos responsible for activities surrounding your health? Are other people involved?

3. IDENTIFICATION- By being around each other socially and physically

Could you think of some examples of how family members can influence each other's health behaviours?

We identify 5 Key areas, for maximum influence on family health:

1. Diet & Nutrition:
How do you decide what to eat for meals in your family?
Can you describe any differences in how each family member approaches and cares about their diet?
Do you usually eat meals together as a family or do you often eat by yourself?

2. Physical Activity
Do you typically participate in physical activities as a family, or does each person have their own preferred wa
of staying active?
Are all members of your family conscious about the importance of physical activity and exercise?
Can you share a time when you and your family engaged in physical activity together? How did that make yo

3. Monitoring Habits:
How do you keep track of your health, such as monitoring your weight, blood pressure, calories, or steps?
Are all members of your family also mindful of monitoring their health in similar ways?
Can you think of a time when you and your family discussed your health information together? Tell me more

4. Medication
Are you the only one in your family who follows a specific medication routine, or do others also have their own regimens?
Does you play a role in reminding them to take medications
How do you feel about being more involved in managing your partners medication?

5. Smoking
Are all the members of your family smokers, or is there a combination of smokers and non-smokers?
How determined is each family member to quit smoking?
an you think of a time when your family discussed smoking and its impact on health? How did that conversation

4. RECEIVE BACK

isual Dashboards: Present the collected data in a visually appealing and easy-to-understand dashboard format. tilize graphs, charts, and color-coded indicators to highlight key information, trends, and progress over time.

oal Tracking: Enable family members to set personalized goals related to their dietary engagement. Provide isual progress trackers that show goal attainment, milestones achieved, and areas for improvement.

otifications and Reminders: Send timely notifications and reminders to family members to encourage healthy ating behaviors, such as meal planning reminders, hydration reminders, or notifications for balanced meal option

ersonalized Recommendations: Provide personalized recommendations based on the collected data. For xample, suggest healthier food alternatives, recipe ideas, or meal planning strategies tailored to each family ember's dietary needs and goals.

ducational Resources: Include educational resources, such as articles, videos, or recipes, to enhance family embers' understanding of nutrition, healthy eating habits, and the impact of their dietary choices.

amily Challenges and Rewards: Implement gamification elements where family members can participate n challenges, compete with each other, and earn rewards for meeting specific dietary goals or ngaging in healthy eating behaviors.

How much time / effort are you willing to put into this?
How much are you willing to share?
What do you want to get back?
Do you have any concerns about this?

4. CLOSING

How would you like to be involved in your families health?
How do you want to be involved in your families health?
What would you like to be able to track or share with your family? and doctors?

Any questions for me?

C.2 SEMI- STRUCTURED INTERVIEW GUIDE A (NO EXPERIENCE WITH CVD)

1. SENSITISATION

Could you introduce me to yourself?

Could you walk me through a regular day in your life? Let’s start from waking up

How does the process of buying groceries look like? Challanges?

What are some of the physical activities that you engage in? Challanges?

What are some other activities that you do with other people that may impact your health?

Is there someone in your social circle involvement in each others health?

- *How do you could help each other stay healthy?*
- *Can you think of any specific examples?*

What do doctors visits look like? Expectations > Reality > Opinions / Feelings

How would you describe your role in your partners heatlh?

How would you describe your role in their health?

SERVICE SIMULATION

Could you think of some examples of how external factors can influence your health behaviour?

We identify 5 Key areas, for maximum influence on family health:

1. Diet & Nutrition:

How do you decide what to eat for meals?
Can you describe any differences in how your dietry patterns differ over time?
What makes it difficult to stay true to your pattern?

2. Physical Activity

Do you typically participate in physical activities?
Have you ever felt external factors influence your motivation to engage in P.A?
How does being aware of p.a make you feel?

3. Monitoring Habits:

How do you keep track of your health, such as monitoring your weight, blood pressure, calories, or steps?
Is that something youve done consistently?
Can you think of a time when you and your doctor discussed your health information together?
Are you able to lead the conversation?

4. Medication

Are you the only one in your family who follows a specific medication routine, or do others also have their own regimens?
Does you play a role in reminding them to take medications
How do you feel about being more involved in managing your partners medication?

5. Smoking

Are all the members of your family smokers, or is there a combination of smokers and non-smokers?
How determined is each family member to quit smoking?
an you think of a time when your family discussed smoking and its impact on health? How did that conversation go?

APP SCREENS

Visual Dashboards: Present the collected data in a visually appealing and easy-to-understand dashboard format. Utilize graphs, charts, and color-coded indicators to highlight key information, trends, and progress over time.

Goal Tracking: Enable family members to set personalized goals related to their dietary engagement. Provide visual progress trackers that show goal attainment, milestones achieved, and areas for improvement.

Notifications and Reminders: Send timely notifications and reminders to family members to encourage healthy eating behaviors, such as meal planning reminders, hydration reminders, or notifications for balanced meal options.

Personalized Recommendations: Provide personalized recommendations based on the collected data. For example, suggest healthier food alternatives, recipe ideas, or meal planning strategies tailored to each family member's dietary needs and goals.

Educational Resources: Include educational resources, such as articles, videos, or recipes, to enhance family members' understanding of nutrition, healthy eating habits, and the impact of their dietary choices.

Family Challenges and Rewards: Implement gamification elements where family members can participate \in challenges, compete with each other, and earn rewards for meeting specific dietary goals or engaging in healthy eating behaviors.

How much time / effort are you willing to put into this?
How much are you willing to share?
What do you want to get back?
Do you have any concerns about this?

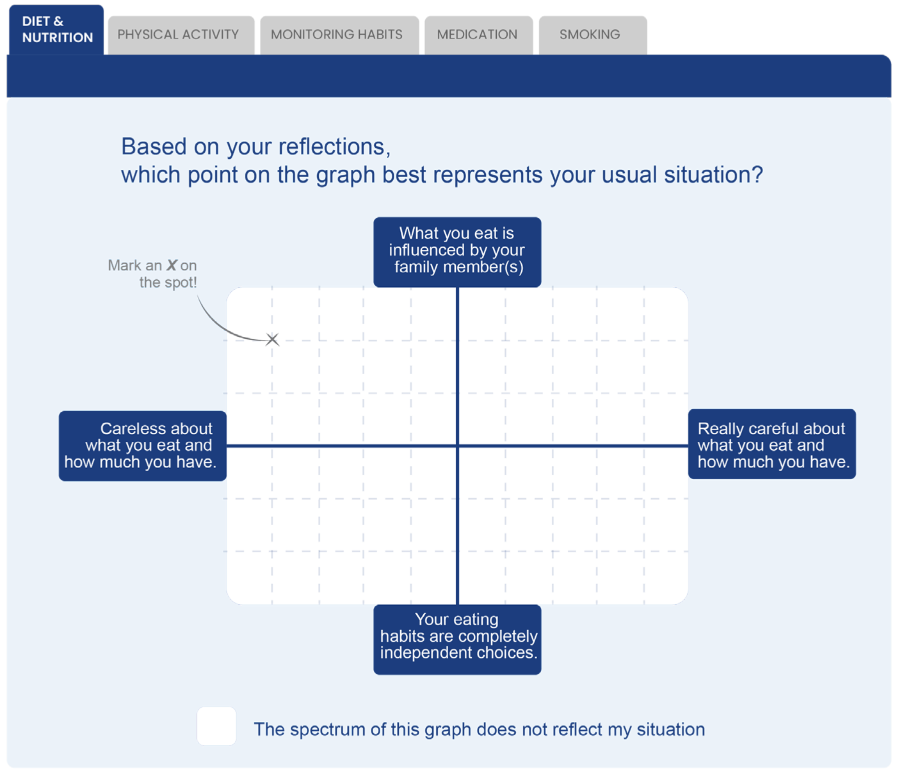
4. CLOSING

How do you perceive the utilisation of such a service by your family?

What are your biggest concerns about using such a service?

APPENDIX -D

D.1 RISK FACTOR INVOLVEMENT MATRIX



Based on your reflections,
which point on the graph best represents your usual situation?

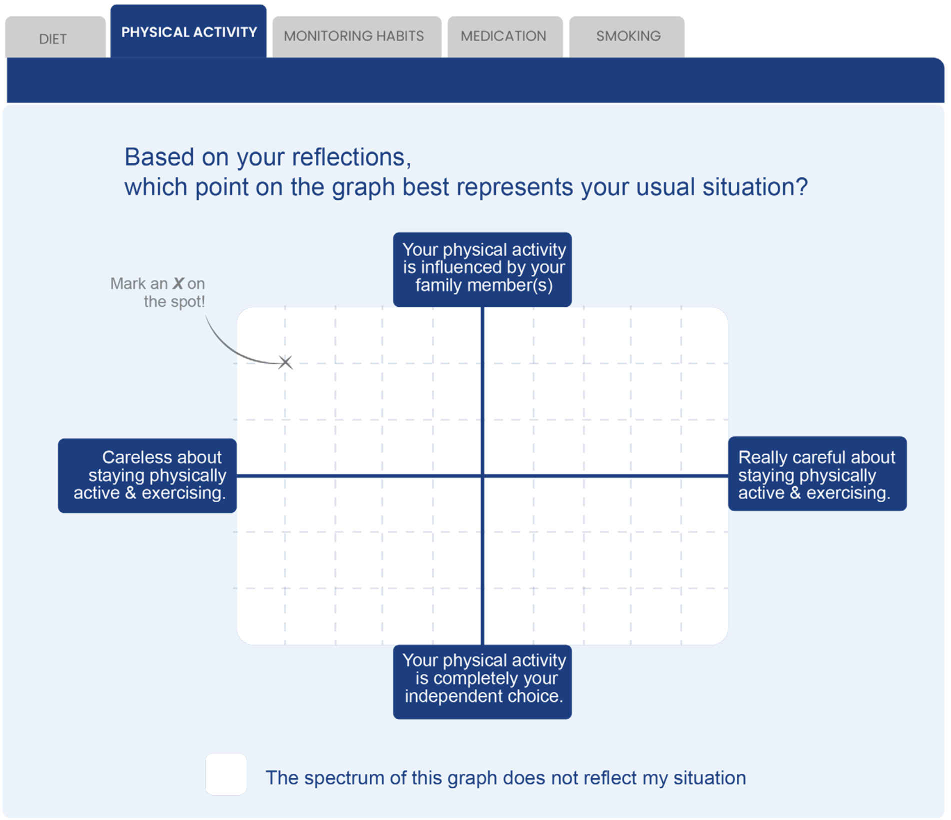
What you eat is influenced by your family member(s)

Careless about what you eat and how much you have.

Really careful about what you eat and how much you have.

Your eating habits are completely independent choices.

☐ The spectrum of this graph does not reflect my situation



Based on your reflections,
which point on the graph best represents your usual situation?

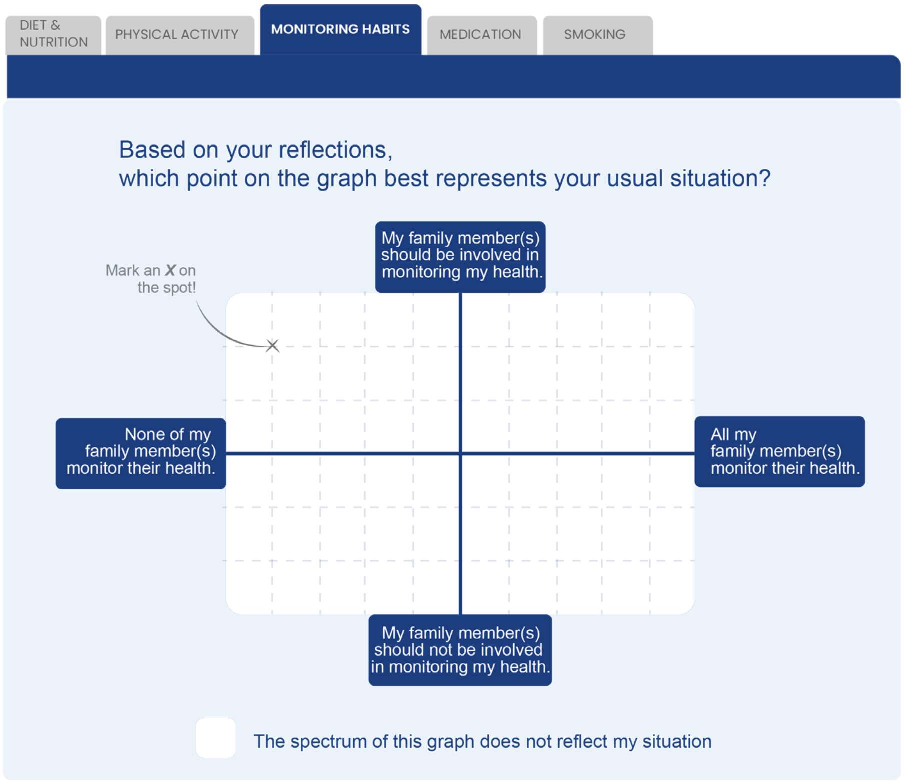
Your physical activity is influenced by your family member(s)

Careless about staying physically active & exercising.

Really careful about staying physically active & exercising.

Your physical activity is completely your independent choice.

☐ The spectrum of this graph does not reflect my situation



Based on your reflections,
which point on the graph best represents your usual situation?

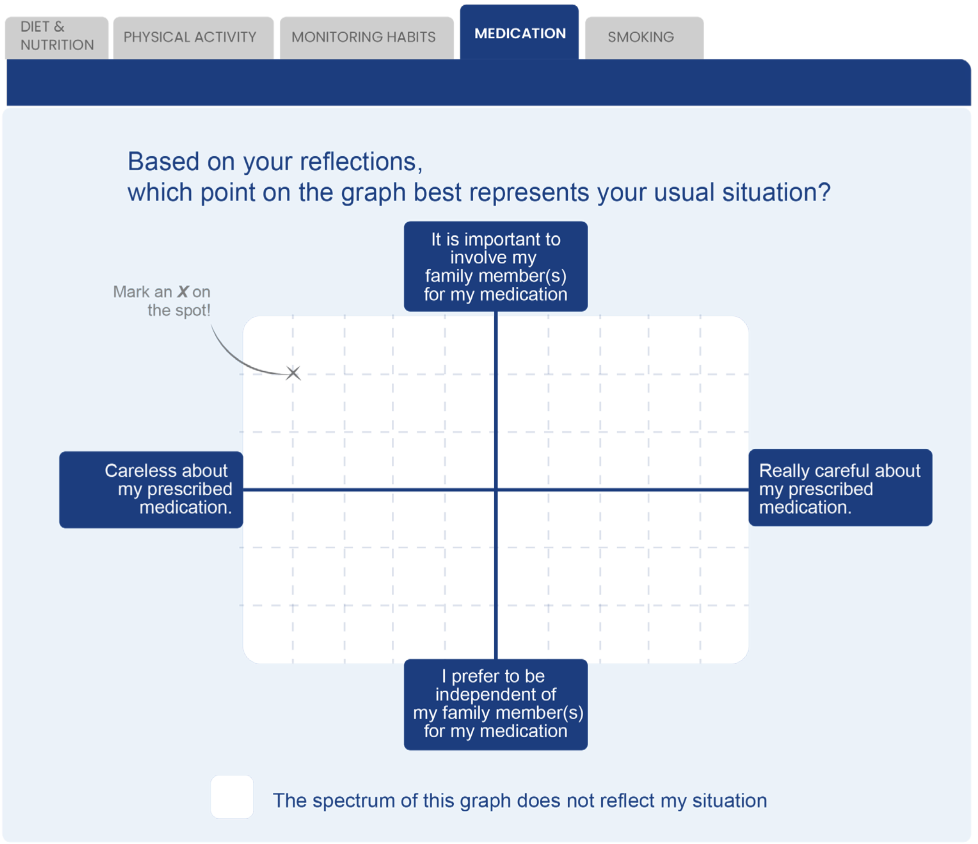
My family member(s) should be involved in monitoring my health.

None of my family member(s) monitor their health.

All my family member(s) monitor their health.

My family member(s) should not be involved in monitoring my health.

☐ The spectrum of this graph does not reflect my situation



Based on your reflections,
which point on the graph best represents your usual situation?

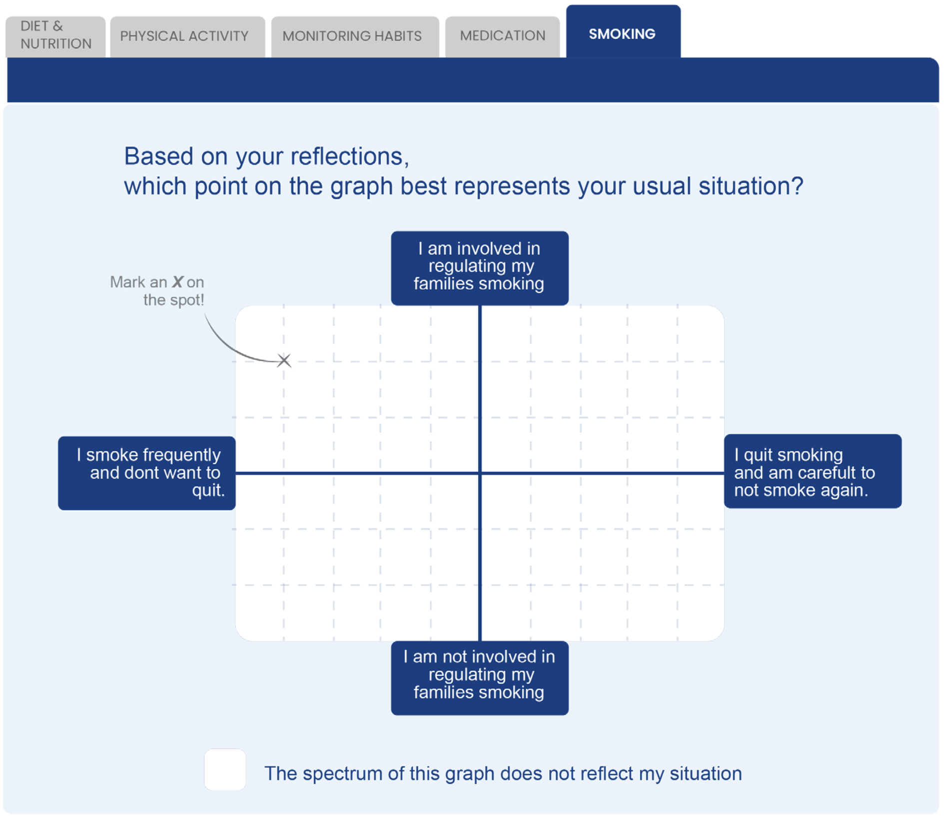
It is important to involve my family member(s) for my medication

Careless about my prescribed medication.

Really careful about my prescribed medication.

I prefer to be independent of my family member(s) for my medication

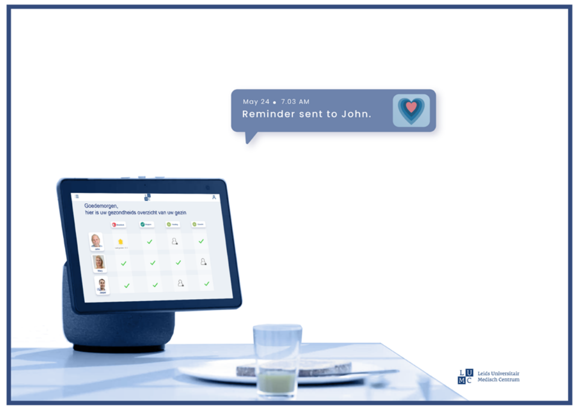
☐ The spectrum of this graph does not reflect my situation



Based on your reflections,
which point on the graph best represents your usual situation?

☐ The spectrum of this graph does not reflect my situation

D.2 VISUAL PROBES FOR INTERVIEWS

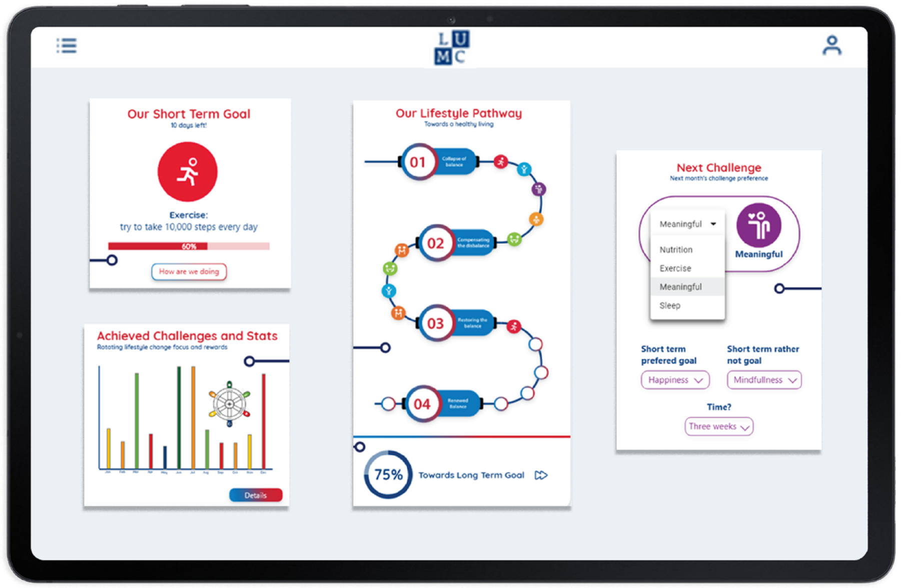


- Self Developed Image

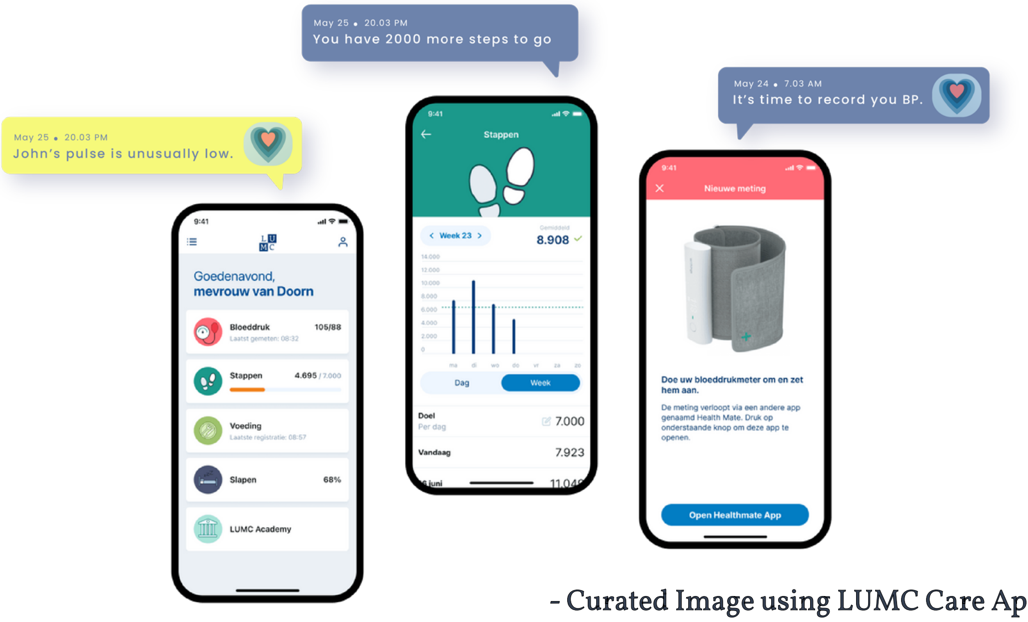
- Self Developed Image

Goedemorgen,
hier is uw gezondheids overzicht van uw gezin

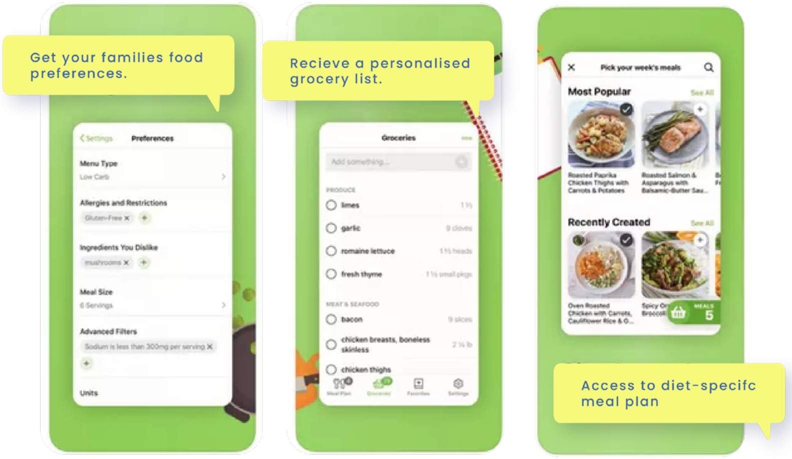
- Self Developed Image



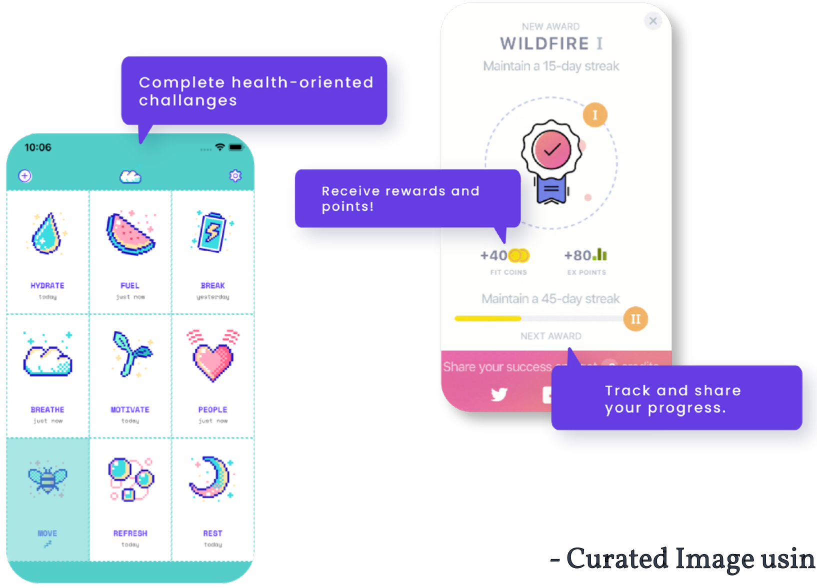
- Curated Image from (Houwen, 2021)



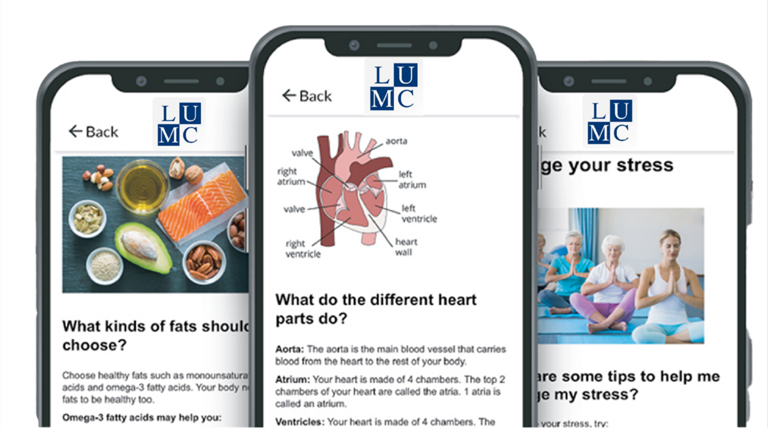
- Curated Image using LUMC Care App



- Curated Image using Prepear App



- Curated Image using Aloebud. App



- Curated Image using LUMC Care App

D.3 PARTICIPANT DEMOGRAPHICS

PARTICIPANT NO	GENDER	FAMILY (LIVING) CONTEXT	HEALTH EXPERIENCE
1 & 2	M/ F	Husband & Wife	Husband with Myocardial Infarction
3	M	Wife & 2 Children	Personal Experience with CVD
4	F	Partner	Personal Experience with CVD
5	M	Wife & 1 Child	Personal Experience with CVD, Wife boderline Diabetic
6	F	Husband & 1 Child	No CVD Experience
7	F	Husband	No CVD Experience
8	M	Wife & 1 Child	No CVD Experience
9 & 10	M/ F	Partner & Wife	Husband with Myocardial Infarction

The study has limitations regarding the sampling, as participants were convenience sampled and had direct experience with cardiovascular disease but not specifically myocardial infarction. Additionally, a subset of participants (3 of 10) were healthy individuals. While their inclusion provided insights into engagement from a perspective of being distant from disease symptoms, it also introduced heterogeneity which may impact the generalizability of the findings specifically related to post-myocardial infarction health management.

Finally, the limited number of group interviews (2) with only one type of family relationship (patient -partner) restricts the understanding of diverse dynamics. However, despite these limitations, the findings have implications beyond post-myocardial infarction, extending to family engagement in other chronic illnesses.