Involving Families in Cardiac Care: Actionable Recommendations for Effective Remote Patient and Family Management

Julian Houwen, Veronica R. Janssen, Sara M. Hondmann, Niels H. Chavannes, Maaike Kleinsmann, Douwe E. Atsma, Valeria Pannunzio

Submitted to: JMIR Cardio
on: August 27, 2025

Table of Contents

Involving Families in Cardiac Care: Actionable Recommendations for Effective Remote Patient and Family Management

Julian Houwen[1, 2]; Veronica R. Janssen[1, 3]; Sara M. Hondmann[3]; Niels H. Chavannes[4, 5]; Maaike Kleinsmann[1, 2, 5]; Douwe E. Atsma[1, 2, 5]; Valeria Pannunzio[2]

[1]Department of Cardiology Leiden University Medical Center Leiden NL
[2]Department of Design, Organization and Strategy Faculty of Industrial Design Engineering Delft University of Technology Delft NL
[3]Unit of Health, Medical and Neuropsychology Faculty of Social and Behavioral Sciences Leiden University Leiden NL
[4]Department of Public Health and Primary Care (PHEG) Leiden University Medical Center Leiden NL
[5]National eHealth Living Lab Leiden University Medical Center Leiden NL

Corresponding Author:
Julian Houwen
Department of Cardiology
Leiden University Medical Center
Albinusdreef 2
Leiden
NL

Abstract

Background: In cardiovascular care, illness and recovery affect patients and their families, particularly within home-based Remote Patient Management (RPM). A recent American Heart Association scientific statement highlighted the importance of involving family systems, identifying digital technologies as a key opportunity. Despite this, research into families' needs and RPM implications remains limited.

Objective: This study explored the lived experiences of patients and relatives across RPM-supported perioperative and myocardial infarction care trajectories. Based on these experiences, we co-designed actionable recommendations for Remote Patient and Family Management (RPFM) to address identified gaps.

Methods: This qualitative study was conducted at a Dutch university hospital with over a decade of RPM experience. A multi-step co-design approach was employed, including focus groups with 24 participants (13 patients, 11 relatives). Subsequent thematic analysis and expert consensus discussions informed the identification of unmet needs and the development of actionable RPFM recommendations.

Results: Experiences were summarised in a family-centred journey map. We identified 59 unmet needs across six domains: informational (n=17), psycho-emotional (n=17), social (n=11), physical (n=7), practical (n=6), and spiritual (n=1). The most significant gaps, described as ‘black holes’ in care and support, emerged during pre-admission and early post-discharge. Based on these needs, 74 RPFM recommendations were co-created.

Conclusions: This study highlights experience-based opportunities to enhance RPM-supported cardiac care, particularly in terms of informational and psycho-emotional support for families. Drawing on extensive RPM experience, we advocate a shift toward RPFM. For this, we propose a strategy that offers guidance for developing RPFM across cardiovascular and other care contexts.

(JMIR Preprints 27/08/2025:83055)
DOI: https://doi.org/10.2196/preprints.83055

2) If accepted for publication in a JMIR journal, would you like the PDF to be visible to the public?

✓ **Yes, please make my accepted manuscript PDF available to anyone at any time (Recommended).**

Yes, but please make my accepted manuscript PDF available only to logged-in users; I understand that the title and abstract will remain v

Yes, but only make the title and abstract visible (see Important note, above). I understand that if I later pay to participate in <a href="http

No. Please do not make my accepted manuscript PDF available to anyone. I understand that if I later pay to participate in <a href="https:/

Original Manuscript

Involving Families in Cardiac Care: Actionable Recommendations for Effective Remote Patient and Family Management

Authors:

Julian Houwen[1,2], MSc; Veronica R. Janssen, PhD[3,1]; Sara M. Hondmann[3], MSc; Niels H. Chavannes[4,5], MD, PhD; Maaike Kleinsmann[2,1,5], PhD; Douwe E. Atsma[1,2,5], MD, PhD; Valeria Pannunzio, PhD[2]

[1] Department of Cardiology, Leiden University Medical Center, Leiden, The Netherlands
[2] Department of Design, Organization and Strategy, Faculty of Industrial Design Engineering, Delft University of Technology, Delft, The Netherlands
[3] Unit of Health, Medical and Neuropsychology, Faculty of Social and Behavioral Sciences, Leiden University, Leiden, The Netherlands
[4] Department of Public Health and Primary Care (PHEG), Leiden University Medical Center, Leiden, The Netherlands
[5] National eHealth Living Lab, Leiden University Medical Center, Leiden, The Netherlands

Corresponding Author:

Julian Houwen, MSc
Department of Cardiology
Leiden University Medical Center
Albinusdreef 2, 2333 ZA
Leiden
The Netherlands
Phone: 0643991522
Email: j.houwen@lumc.nl

Abstract:

Background: In cardiovascular care, illness and recovery affect patients and their families, particularly within home-based Remote Patient Management (RPM). A recent American Heart Association scientific statement highlighted the importance of involving family systems, identifying digital technologies as a key opportunity. Despite this, research into families' needs and RPM implications remains limited.

Objective: This study explored the lived experiences of patients and relatives across RPM-supported perioperative and myocardial infarction care trajectories. Based on these experiences, we co-designed actionable recommendations for Remote Patient and Family Management (RPFM) to address identified gaps.

Methods: This qualitative study was conducted at a Dutch university hospital with over a decade of RPM experience. A multi-step co-design approach was employed, including focus groups with 24 participants (13 patients, 11 relatives). Subsequent thematic analysis and expert consensus discussions informed the identification of unmet needs and the development of actionable RPFM recommendations.

Results: Experiences were summarised in a family-centred journey map. We identified 59 unmet needs across six domains: informational (n=17), psycho-emotional (n=17), social (n=11), physical (n=7), practical (n=6), and spiritual (n=1). The most significant gaps, described as ‘black holes’ in care and support, emerged during pre-admission and early post-discharge. Based on these needs, 74 RPFM recommendations were co-created.

Conclusion: This study highlights experience-based opportunities to enhance RPM-supported cardiac care, particularly in terms of informational and psycho-emotional support for families. Drawing on extensive RPM experience, we advocate a shift toward RPFM. For this, we propose a strategy that offers guidance for developing RPFM across cardiovascular and other care contexts.

Keywords: family-centred care; cardiovascular disease; remote patient management; journey mapping; digital health; unmet needs

Introduction

Digital health technologies, including remote patient management (RPM), are increasingly embedded in cardiovascular care pathways with the goal of improving clinical outcomes, facilitating patient self-management, and decreasing pressure on the healthcare system.[1-4] RPM enables continuous guidance, real-time monitoring and early clinical interventions, while encouraging active patient engagement in self-care and recovery.[5-8] In turn, active patient engagement enables a range of opportunities for sustained lifestyle change, which significantly reduces cardiovascular risk.[9]

Despite these developments and the growing emphasis on home-based self-care, most cardiovascular care models remain focused on in-hospital, staff-delivered care, underemphasising the broader psychosocial and relational contexts in which cardiovascular illness is experienced.[10,11] As a result, the role of informal caregivers, such as family, is often overlooked.[12] However, these actors play a crucial role in terms of cardiovascular risk management, home-based care, medication adherence, symptom monitoring, and emotional support.[13] Yet, they are often unrecognised in care delivery systems and therefore underprepared for their responsibilities, despite evidence of their impact on care quality and patient outcomes.[10,12,13]

In a recent scientific statement, the American Heart Association has pointed out the importance of involving family systems in cardiovascular care. [14] Here the term "family" is defined in a broad sense, including not only biological relatives but also close friends, neighbours, or others whom the patient wishes to involve. The statement identifies digital technologies, including telehealth, as a key opportunity to support this integration.[14] This direction aligns with the goals of European health systems, where ageing populations and healthcare staff shortages are increasing dependency on informal care.[15,16]

Thus, there is now a clear need to advance RPM into Remote Patient and Family Management (RPFM), a model that actively includes and supports families throughout the care trajectory. As such, there is an urgent need to understand how RPM-supported models of cardiovascular care can effectively involve relatives throughout the care pathway, empower them in their role, and support them as individuals coping with the cardiac illness of a loved one.

Yet, empirical research on the needs of relatives and the implications of RPM for their caregiving experience and what is required to design family-centred digital interventions that respond to their real needs remains limited. This study addresses this gap by exploring the lived experiences of patients and their relatives following RPM-supported cardiac care provided by a major university hospital in the Netherlands and by translating these experiences into concrete RPFM intervention recommendations.

In this study, we build on earlier research on family involvement in cardiac RPM[17] and employ a multi-step co-design approach, involving patients, family, clinical experts and design experts in a meaningful and iterative manner throughout the research process[18]. Using focus groups and journey mapping[19-24], we identify key care moments, unmet needs, and opportunities for family-centred RPM. Our analytical framework draws on the Family Systems Illness Model[25] and the Supportive Care Framework[26] to situate informal caregiving within a broader relational and psychosocial context.

By studying these often-overlooked family experiences and co-design solutions, we aim to contribute to the development of more inclusive, 'real-life' RPM-enabled cardiovascular care pathways that support both patients and their relatives in effectively coping with the disease trajectory and lifestyle modification. In doing this, we aim to contribute to improving both experiential and health outcomes for the patient and their loved ones.

Methods

Setting and design

This qualitative study was conducted at a university hospital in the Netherlands with over a decade of RPM experience.[8,27-31] It explored patient and relative experiences within two cardiovascular disease (CVD) care pathways: myocardial infarction (MI) and perioperative care (Peri-OP), which covers different types of elective cardiac surgery. Both care pathways are supported by an RPM program, *The Box*[8,27-31], which enables hybrid care using eHealth devices (e.g. smartwatch, blood pressure monitor, digital scale, thermometer) and a connected mobile application.

To develop actionable recommendations for RPFM interventions, a multi-step co-design approach was employed. The process involved four stages: (1) identification of patient and family experiences through focus groups; (2) structuring insights via journey mapping; (3) expert consensus to develop RPFM intervention recommendations; and (4) validating the journey map, including RPFM recommendations, with patients and their relatives.

Ethical approval was obtained from the local nWMO-div1 ethics board, and written informed consent was obtained from all participants. The study followed the COREQ guidelines for qualitative research reporting5.[32]

Participants and recruitment

Patients in the MI and Peri-OP pathways ≥2 months after hospital admission and still in hospital-based follow-up through the hybrid care program were purposively sampled. They were invited via email, followed by phone-based confirmation. Participants were encouraged to bring a family member, caregiver, neighbour or friend who is closely involved in their care. Recruitment aimed for variation in age, gender, and caregiving relationships. There were no pre-existing relationships between the researchers collecting the data and the participants.

Data collection

Seven focus group sessions were conducted at the hospital, divided by care pathway. In six sessions, patients and relatives participated in separate groups to enable open discussion; one session combined both due to practical reasons. Each session lasted approximately two hours. And ended with a validation question whether the most important things were said. Moderation was carried out by two researchers (JH, male PhD candidate, & SH, female PhD candidate), supported by a medical psychology intern.

Discussions were structured around the "*Care and Well-being Journey*" template (available in Appendix A), a participatory mapping tool designed for this study based on existing journey mapping approaches[19]. Discussions covered three phases: *pre-admission, admission, and post-admission*. Participants discussed key moments, challenges, and support experiences across the need domains of the Supportive Care Framework.[26] Post-its were used to annotate experiences on the template.

Data analysis

The discussions were recorded, and the audio was transcribed and thematically analysed using Braun and Clarke's[33] six-step method, supported by ATLAS.ti 2025 software. Coding was performed inductively by two researchers (JH & VP, Female Assistant Professor) and refined through iteration.

Emerging themes were mapped onto the three phases of the care pathway and analysed, informed by the Family Systems Illness Model[25] and the Supportive Care Framework[26] to structure identified unmet needs. To better reflect the data, we made a minor adaptation to Fitch's[26] domains: the psychological and emotional needs were combined into a single psycho-emotional category, as participants did not distinguish between these aspects during discussion.

The themes and corresponding unmet needs were used by the first author (JH) to ideate recommendations for RPFM interventions. These were further refined during multidisciplinary consensus discussions involving clinical (VJ, female associate professor and medical psychologist, & DA, male professor of cardiology) and design experts (VP & MK, female professor of design for digital transformation). The resulting journey map and intervention concepts were presented to the original patient and caregiver participants for validation. This iterative co-design process ensured that recommendations were grounded in the lived experience of families and aligned with clinical and psychosocial realities.

Results

Participant characteristics

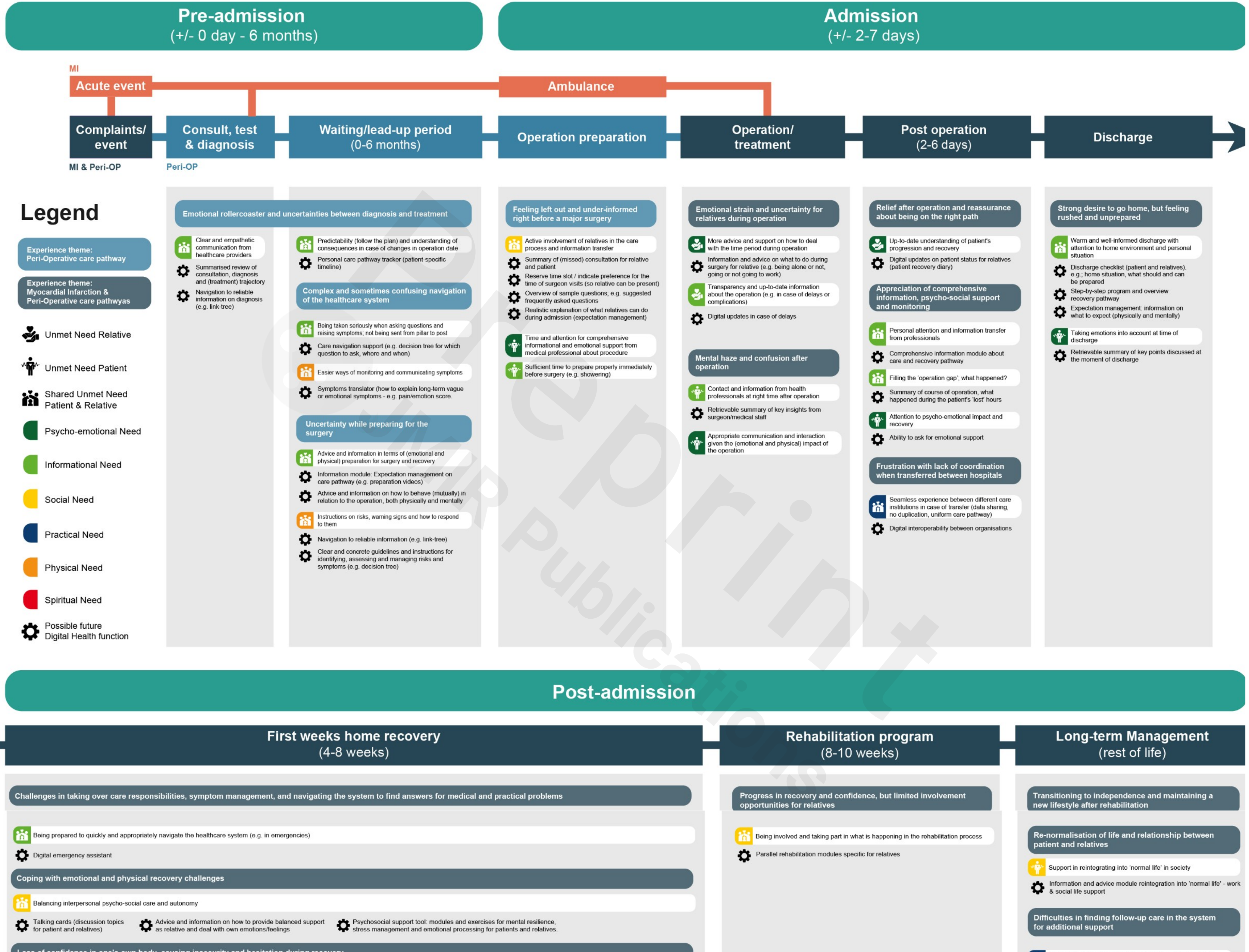
A total of 42 individuals were invited to participate in the study, comprising 22 patients and 20 relatives. Of these, 18 individuals did not participate, citing reasons such as illness, forgetting the scheduled session, or providing no explanation. This resulted in the inclusion of 24 participants. All participants received care and support primarily from the same university medical centre and affiliated rehabilitation centre. An overview of participants' characteristics is presented in Table 1.

Table 1. Overview of participants' characteristics

Focus group	CVD care path	#	Type	Relation to patient	Sex	Age Group
F1.A	Peri-OP	1	Patient	-	F	70-80
		2	Patient	-	M	65-75
		3	Patient	-	F	50-60
		4	Patient	-	F	30-40
F1.B	Peri-OP	5	Relative	Father	M	75-85
		6	Relative	Child	F	45-55
		7	Relative	Partner	F	55-65
		8	Relative	Partner	M	30-40
F2.A	MI	9	Patient	-	F	50-60
		10	Patient	-	F	70-80
		11	Patient	-	F	55-65
F2.B	MI	12	Relative	Father	M	75-85
		13	Relative	Partner	M	70-80
		14	Relative	Child	M	20-30
F3	Peri-OP	15	Patient	-	M	70-80
		16	Patient	-	M	60-70
		17	Relative	Partner	F	55-65
F4.A	MI	18	Patient	-	F	60-70
		19	Patient	-	M	55-65
		20	Patient	-	F	35-45
		21	Patient	-	M	55-65
F4.B	MI	22	Relative	Partner	F	55-65
		23	Relative	Partner	F	55-65
		24	Relative	Partner	M	40-50

Journey map

Through our multi-step co-design process, we mapped the real-life experiences of individuals and their families dealing with cardiac events and symptoms, cardiovascular surgery, and the aftermath. The full journey map, shown in Figure 1, visualises a unified care pathway for MI and Peri-OP care, structured across three phases: pre-admission (symptoms, diagnosis, waiting time), admission (pre- to post-operation/intervention, discharge), and post-admission (recovery at home, rehabilitation, long-term management). Within these phases, we identified unmet needs and divided them by experience themes, specifying whether they apply to patients, relatives, or families as a whole. These are colour-coded by need domain (adapted from Fitch's[26] Supportive Care Framework; see Methods). Additionally, actionable recommendations to address these unmet needs are mapped in the journey (indicated by gear icons ⚙) under the related unmet needs.



Pre-admission
(+/- 0 day - 6 months)

Admission
(+/- 2-7 days)

MI

Acute event

Ambulance

Complaints/ event
MI & Peri-OP

Consult, test & diagnosis
Peri-OP

Waiting/lead-up period
(0-6 months)

Operation preparation

Operation/ treatment

Post operation
(2-6 days)

Discharge

Legend

Experience theme: Peri-Operative care pathway

Experience theme: Myocardial Infarction & Peri-Operative care pathways

Unmet Need Relative
Unmet Need Patient
Shared Unmet Need Patient & Relative
🟩 Psycho-emotional Need
🟩 Informational Need
🟨 Social Need
🟦 Practical Need
🟧 Physical Need
🟥 Spiritual Need
⚙ Possible future Digital Health function

Emotional rollercoaster and uncertainties between diagnosis and treatment

- Clear and empathetic communication from healthcare providers
- ⚙ Summarised review of consultation, diagnosis and (treatment) trajectory
- ⚙ Navigation to reliable information on diagnosis (e.g. link-tree)

- Predictability (follow the plan) and understanding of consequences in case of changes in operation date
- ⚙ Personal care pathway tracker (patient-specific timeline)

Complex and sometimes confusing navigation of the healthcare system

- Being taken seriously when asking questions and raising symptoms; not being sent from pillar to post
- ⚙ Care navigation support (e.g. decision tree for which question to ask, where and when)
- Easier ways of monitoring and communicating symptoms
- ⚙ Symptoms translator (how to explain long-term vague or emotional symptoms - e.g. pain/emotion score.

Uncertainty while preparing for the surgery

- Advice and information in terms of (emotional and physical) preparation for surgery and recovery
- ⚙ Information module: Expectation management on care pathway (e.g. preparation videos)
- ⚙ Advice and information on how to behave (mutually) in relation to the operation, both physically and mentally
- Instructions on risks, warning signs and how to respond to them
- ⚙ Navigation to reliable information (e.g. link-tree)
- ⚙ Clear and concrete guidelines and instructions for identifying, assessing and managing risks and symptoms (e.g. decision tree)

Feeling left out and under-informed right before a major surgery

- Active involvement of relatives in the care process and information transfer
- ⚙ Summary of (missed) consultation for relative and patient
- ⚙ Reserve time slot / indicate preference for the time of surgeon visits (so relative can be present)
- ⚙ Overview of sample questions; e.g. suggested frequently asked questions
- ⚙ Realistic explanation of what relatives can do during admission (expectation management)

- Time and attention for comprehensive informational and emotional support from medical professional about procedure
- Sufficient time to prepare properly immediately before surgery (e.g. showering)

Emotional strain and uncertainty for relatives during operation

- More advice and support on how to deal with the time period during operation
- ⚙ Information and advice on what to do during surgery for relative (e.g. being alone or not, going or not going to work)
- Transparency and up-to-date information about the operation (e.g. in case of delays or complications)
- ⚙ Digital updates in case of delays

Mental haze and confusion after operation

- Contact and information from health professionals at right time after operation
- ⚙ Retrievable summary of key insights from surgeon/medical staff
- Appropriate communication and interaction given the (emotional and physical) impact of the operation

Relief after operation and reassurance about being on the right path

- Up-to-date understanding of patient's progression and recovery
- ⚙ Digital updates on patient status for relatives (patient recovery diary)

Appreciation of comprehensive information, psycho-social support and monitoring

- Personal attention and information transfer from professionals
- ⚙ Comprehensive information module about care and recovery pathway
- Filling the 'operation gap'; what happened?
- ⚙ Summary of course of operation, what happened during the patient's 'lost' hours
- Attention to psycho-emotional impact and recovery
- ⚙ Ability to ask for emotional support

Frustration with lack of coordination when transferred between hospitals

- Seamless experience between different care institutions in case of transfer (data sharing, no duplication, uniform care pathway)
- ⚙ Digital interoperability between organisations

Strong desire to go home, but feeling rushed and unprepared

- Warm and well-informed discharge with attention to home environment and personal situation
- ⚙ Discharge checklist (patient and relatives). e.g.; home situation, what should and can be prepared
- ⚙ Step-by-step program and overview recovery pathway
- ⚙ Expectation management: information on what to expect (physically and mentally)
- Taking emotions into account at time of discharge
- ⚙ Retrievable summary of key points discussed at the moment of discharge

Post-admission

First weeks home recovery
(4-8 weeks)

Rehabilitation program
(8-10 weeks)

Long-term Management
(rest of life)

Challenges in taking over care responsibilities, symptom management, and navigating the system to find answers for medical and practical problems

- Being prepared to quickly and appropriately navigate the healthcare system (e.g. in emergencies)
- ⚙ Digital emergency assistant

Coping with emotional and physical recovery challenges

- Balancing interpersonal psycho-social care and autonomy
- ⚙ Talking cards (discussion topics for patient and relatives)
- ⚙ Advice and information on how to provide balanced support as relative and deal with own emotions/feelings
- ⚙ Psychosocial support tool: modules and exercises for mental resilience, stress management and emotional processing for patients and relatives.

Loss of confidence in one's own body, causing insecurity and hesitation during recovery

Progress in recovery and confidence, but limited involvement opportunities for relatives

- Being involved and taking part in what is happening in the rehabilitation process
- ⚙ Parallel rehabilitation modules specific for relatives

Transitioning to independence and maintaining a new lifestyle after rehabilitation

Re-normalisation of life and relationship between patient and relatives

- Support in reintegrating into 'normal life' in society
- ⚙ Information and advice module reintegration into 'normal life' - work & social life support

Difficulties in finding follow-up care in the system for additional support

Figure 1. Journey map of real-life experiences of patients and relatives in cardiovascular disease management

Unmet needs and actionable recommendations

Our analysis revealed a broad range of unmet needs of patients, relatives, and families across different phases of the care pathways. A total of 59 unmet needs were identified and displayed in the journey map. These reflect significant gaps extending well beyond clinical management to the informational (17), psycho-emotional (17), social (11), physical (7), practical (6) and spiritual (1) domains. Furthermore, a total of 74 unique recommendations for RPFM interventions were co-created. Some of them are repeated throughout the journey as they respond to needs in multiple phases. These recommendations are intended to enhance family-centred care by actively empowering family participation, improving information transmission, assisting navigation within health systems, aligning expectations, and providing holistic support throughout the cardiac care continuum for patients and relatives.

Below, we present the key unmet needs, categorised by domain, together with corresponding co-created RPFM recommendations.

Informational

Perioperatively, families reported inadequate communication from healthcare providers about the care process. They experienced uncertainty due to insufficient information (e.g. about changes in surgery schedules and their impact) and felt they were not taken seriously and dismissed without clear explanations when expressing their concerns and questions. Guidance on behavioural, emotional and physical preparation for surgery and recovery was perceived as inadequate, with some families feeling rushed and unprepared due to limited consultation time and unclear instructions on expected behaviour and protocols. Family members also missed timely and transparent updates on the progress of the surgery, especially in cases of delays or complications.

In the preoperative phase, RPFM could support families in preparing for the unknown and reducing anxiety by providing clear information about the diagnosis and the entire care pathway. This could include summarised reviews of consultations and guided navigation to trusted sources. It may also offer preparation guidance and expectation management materials, such as videos explaining what to expect and advice on mutual physical and psychological readiness for surgery, including lifestyle considerations. A personal care pathway tracker could offer families an overview of the care process. To further empower families to navigate the healthcare system, care navigation support could be included, for example, in the form of a decision tree indicating where and when to ask specific questions. On the day of surgery, RPFM might deliver real-time digital updates in the event of delays or complications; for instance, if the procedure takes more time, a digital notification could be sent to the waiting family.

Postoperatively, patients missed direct and timely contact with their surgeon to discuss the process and outcome of the procedure. Families required more personalised information about the expected impact of heart disease on their care pathway and life. Discharge from the hospital to home was often perceived as rushed, and the patient's environment and circumstances were not sufficiently considered. At home, there was no easily accessible contact person for questions and support, nor clear guidance on navigating the healthcare system, especially in the case of alarming symptoms. Families also experienced problems accessing medical records from different organisations and needed explanations to understand them. Time to discuss lifestyle changes for recovery was often perceived as limited, with insufficient personalised advice and guidance.

In this postoperative phase, RPFM could support families with expectation management on both physical and mental recovery, alongside a discharge checklist and advice tailored to the home situation. Instead of receiving a confusing stack of papers, families could be provided with a personalised digital recovery plan, outlining clear next steps and offering access to a digital Q&A system for immediate concerns. The platform could also offer a summary of the operation’s course to clarify the patient’s “lost hours” and provide a step-by-step guide to the recovery pathway. For ongoing support, RPFM might feature a digital emergency assistant and facilitate access to low-threshold advice for informal guidance through a “buddy” system. It could also support personalised and balanced lifestyle coaching, facilitated by assessment tools and a trustworthy information database. Finally, RPFM could provide explanations of the collected data and offer a retrievable medical dossier summary in accessible language, empowering families to better understand the health status of the patient.

Psycho-emotional

Families felt inadequately prepared for the care process due to limited consultation time and a lack of guidance regarding the emotional impact of surgery. Both patients and their relatives experienced increased anxiety, stress and frustration due to unclear or insufficiently empathetic communication by healthcare providers, especially during key moments such as consultation, hospitalisation, discharge and early recovery. Family members indicated that involvement in updates on the patient's condition was limited, indirect, and not tailored to their emotional needs. During the recovery phase, both patients and family members struggled with the emotional impact of the illness and the effort to regain a sense of normality. Patients struggled to cope with ‘being a patient’, and with regaining emotional stability and autonomy. Family members felt inadequately prepared to support the coping process and reported a lack of accessible emotional support or structured channels to express their own fears, doubts and emotional burden. There was also a sense of uncertainty in the reliability of the home monitoring systems due to limited feedback and doubt about whether data was being actively monitored by professionals.

We propose that an RPFM approach could be adopted to address these psycho-emotional unmet needs, through providing empathetic digital updates for relatives and guidance during critical moments like surgery. To build trust and reduce distress related to monitoring, RPFM could offer automatic reassurance notifications and proactive feedback with personal data analysis. Additionally, it could provide direct emotional support avenues (e.g., a helpline), integrate individual emotional processing tools for relatives, and feature a mental health check. For broader coping and support, RPFM could facilitate peer connection through modules on living with chronic conditions, buddy systems, and shared experiences.

Social

Families reported insufficient opportunities for active involvement of relatives throughout the care journey and information transfer. Relatives lacked support in balancing psycho-social care with patient autonomy and struggled to stay engaged in the care process due to their own responsibilities and other constraints. Relatives felt unequipped to assist patients and themselves in regaining trust in the body and physical and emotional recovery, and wished to be more included in care. Support to adopt a healthier lifestyle together was often lacking, as was guidance on how to help the patient without causing friction. Also, the opportunity for family members to connect with peers for emotional or experience exchange was not accessible or structurally arranged.

To support greater social involvement and role clarity, RPFM could provide realistic expectation management for patients and relatives regarding active participation during admission. To navigate the delicate balance between support and patient autonomy, it could offer communication advice (e.g., "How do I talk about this?") and modules on discovering new boundaries for both patients and relatives (e.g., a “Care & Release” coaching module). RPFM could also include patient support training and parallel rehabilitation modules specifically for relatives, equipping them to provide effective, shared support. For sustained engagement and community building, RPFM could integrate an online peer support/matching platform for group or individual discussions for both patients and relatives, along with guidance on how to foster mutual support within the family unit.

Physical

Patients and families lacked concrete, step-by-step guidance for preparing for surgery and home recovery, including support in restoring confidence in the body, safely weighing risk-taking, and recognising and responding to warning signs. There was a need for simple, user-friendly tools to enable understanding, tracking, and communication of symptoms to healthcare providers. Furthermore, families required a shared understanding of recovery progress, medication adherence, and the patient's emotional state to support understanding and confidence in both the body and the care process.

To meet these physical needs, RPFM could provide concrete guidelines for families to monitor and manage peri- and post-operative risks and symptoms, coupled with easy access to reliable information and a symptom "explainer" (e.g., a pain/emotion score) for clear communication with the healthcare system. The platform could integrate rehabilitation modules and a personalised recovery planner, leveraging data to ensure patients and families have a clear, shared understanding of the recovery journey. Furthermore, it could increase engagement through motivation modules and support for setting realistic, joint lifestyle change goals, while also offering a shared health overview providing insight into progress and routines on medication or behaviour change adherence.

Practical

Patients and relatives experienced practical issues due to insufficient data interoperability between institutions, which led to duplication and a lack of uniformity in care processes. Digital care services, such as the patient portal and installation, were frequently experienced as complicated or inconsistent, obstructing effective use. Relatives lacked remote access to touchpoints and information when they could not attend consultations due to work or household commitments. The provision of accessible, proactive follow-up care was perceived as inadequate. Additionally, there was limited practical support for accessing social services, e.g. for maintaining daily household routines and managing finances alongside the ongoing care.

To address these practical challenges, RPFM could streamline care by facilitating digital interoperability and offering a unified, user-friendly digital platform. It could offer a family-centred hub that ensures consistent information and centralised data storage and exchange. For instance, if a relative misses a consultation due to work, RPFM could offer remote access to summaries and a logbook for questions, empowering them to stay involved. It could also enable proactive care planning with features like a shared routine planner. Additionally, it could integrate digital guidance for social services and follow-up care navigation in the region, easing the burden of managing daily life alongside care.

Spiritual

Finally, patients mentioned the lack of existential, religious, or spiritual guidance in processing and coping with the impact of the condition, a dimension that received little attention in the care pathway. RPFM could support this through dedicated modules designed to offer guidance for dealing with existential questions and finding meaning.

Discussion

Our study provides insights into the lived experiences of patients and their relatives following MI or Peri-OP RPM-supported care pathways in a university hospital in the Netherlands, informing actionable recommendations for enhanced family-centred care. Through a multi-step co-design approach, we identified unmet psycho-emotional, informational, social, practical, physical and spiritual needs for both patients and their relatives. These results align with previous studies on family involvement in cardiovascular care[34-38] and deepen previous knowledge by detailing lived experiences across a broad spectrum of needs. Particularly, our results reinforce the importance of both improved information provision and improved psychological and emotional support to patients and family members. To achieve both goals, we recommend several RPFM interventions to the current RPM-supported care pathways in the examined hospital. In doing so, we directly contribute to a research gap identified by Goldfarb et al.[14], who point towards the potential of health technology to advance family engagement in cardiovascular care.

Our results indicate that two stages in the pathway were particularly under-supported: the period prior to admission (for the Peri-OP pathway) and the early recovery phase at home (for both pathways). These phases were described by patients and family as a ‘black hole’ in care, characterised by a lack of information and psycho-emotional support, leading to uncertainty, worries, inaccessibility and limited guidance. These findings are consistent with previous research reporting similar challenges during the perioperative and early recovery phases.[39-42]

While medical professionals tend to focus on optimising the care experience during the in-contact periods, such as consultations and admissions, the biggest gaps occur during the periods at home, which are significantly longer than consultations and admission intervals. These phases impose a considerable burden on both patients and their relatives, such as challenges in taking over care responsibilities, (fluctuating) symptom management, learning to navigate the health system, and dealing with the emotional rollercoaster of coping with heart disease, all while attempting to re-establish a certain normalcy in life.

From a systems perspective, these identified ‘black holes’ in care seem to correspond to the existing structural divisions between different levels of health care. This suggests systemic flaws affecting the continuity and effectiveness of RPM-supported care. Therefore, future research should not only focus on the experiences of patients and families but also analyse this systemic weakness from the perspective of the broader health system, healthcare providers and insurers, as this is a key area for substantial improvement in healthcare delivery.

The proposed RPFM approach could be uniquely suited to address the gaps in care experiences, as it offers opportunities for continuous support and tailored interventions to be delivered directly into the living environments of the patients and relatives, where the 'black holes' in information and support occur. Notably, it is these ‘black hole’ periods that offer an evidence-based window of opportunity for behaviour change, as described in the framework of teachable moments.[43] Our results also align with and expand the findings of Schmid et al.[44], who observe that peri-operative education is foundational for shaping cardiac patients' subsequent behaviours and expectations regarding their treatment, particularly concerning physical activity, nutrition, and mental health. Furthermore, they find that active patient and family engagement in the treatment process, including physiotherapy and mental support, significantly improves postoperative care, leading to faster recovery outcomes. Strategically supporting and educating families with RPFM interventions during these highly receptive periods could serve as a dual prevention mechanism; secondary prevention for patients and primary prevention among family members, who may have similar risk profiles due to a common lifestyle, genetic predisposition, or shared environmental factors. Illness and care cannot be separated from everyday life, in which patients live together with their loved ones in a caring ecosystem.[25] As most of care, health behaviour, and recovery take place outside professional settings in the routines of daily living[10,45], it is essential that the healthcare system extends its reach and actively supports the everyday context, especially as hybrid home-based care models shift more care responsibility to patients and their family members.

It is important to note that the identified unmet needs are not just ‘soft’, medically irrelevant experiential issues, but have direct clinical and health system implications.[46,47] In this, we build on previous research describing the interconnectedness between patient experiences of RPM and broader health system outcomes.[48] Based on our results and on previous studies on family involvement in cardiovascular care, we identify several pathways through which RPM-mediated improvements in family involvement in cardiovascular care could lead to improved care outcomes in terms of the components of the Quadruple Aim: health outcomes, patient experience, staff experience, and cost-effectiveness.[49]

Notably, increased involvement and empowerment of the family in observing symptoms and following care recommendations may contribute to mitigating both unplanned surgical postponements and postoperative adverse events, positively impacting health outcomes and cost-effectiveness.

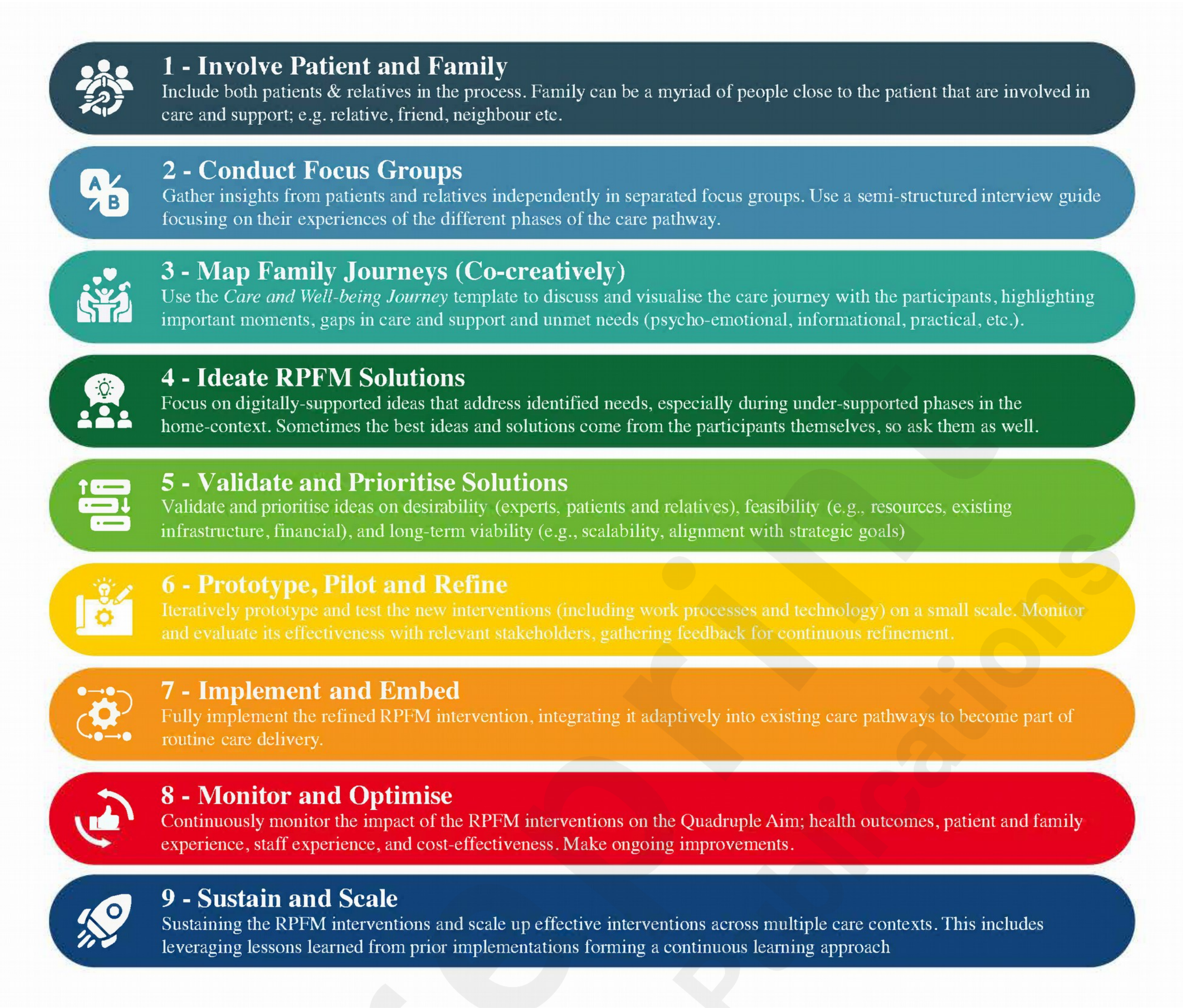
Tailored information about pre-operative and post-discharge care, recovery trajectories, and appropriate contact points, delivered digitally, could enhance patient and family experience and knowledge, reduce miscommunication, and in doing so, potentially decrease staff workload by streamlining inquiries and support processes. RPFM's ability to support joint remote management and lifestyle changes may also extend its benefit beyond the patient, promoting primary prevention for family members who may have similar risk profiles as patients.

Finally, by integrating therapeutic modules to address and support mental health, RPFM could proactively mitigate anxiety, post-traumatic stress disorder, and depression, issues affecting both cardiac patients and their relatives.[50,51] Such interventions may also reduce anxiety-driven overprotectiveness, which can hinder rehabilitation.[52]

Overall, we propose a shift in the approach towards home-based cardiac RPM towards RPFM. RPFM builds on the existing RPM infrastructure but expands towards an explicit integration of family. This may include educational content, emotional support tools, and role-specific guidance tailored to the experiences of the family. This new paradigm acknowledges the relational dynamics of illness and recovery in home-based care models. Effectively involving and meeting the needs of families can lead to improving psychological health, self-efficacy, caregiving skills, quality of life, social support and problem coping skills, which in turn may lead to improved self-care and a reduction in hospital readmissions and unnecessary clinical visits.[53] However, empirical research is required to establish the impact and cost-effectiveness of the proposed RPFM interventions.

Building on our research and identified opportunities, we propose a strategy for healthcare innovators aimed at co-designing RPFM interventions, presented in Figure 2. This strategy builds on the multi-step co-design approach performed in this study. It presents a set of actionable steps, starting with an in-depth empathic understanding of patients and families through focus group discussions and journey mapping and concluding with the scaling of effective interventions to other care pathways. This overview also illustrates our own plans for future RPFM research in relation to The Box[8,27-31], which includes the steps from 6 to 9.

While developed in the context of cardiovascular care, we find that the proposed strategy is transferable to other clinical trajectories and disease areas. By following this strategy, innovators may find new opportunities for RPFM solutions that address real-life needs and achieve positive societal impact for families and healthcare systems.



1 - Involve Patient and Family
Include both patients & relatives in the process. Family can be a myriad of people close to the patient that are involved in care and support; e.g. relative, friend, neighbour etc.

2 - Conduct Focus Groups
Gather insights from patients and relatives independently in separated focus groups. Use a semi-structured interview guide focusing on their experiences of the different phases of the care pathway.

3 - Map Family Journeys (Co-creatively)
Use the *Care and Well-being Journey* template to discuss and visualise the care journey with the participants, highlighting important moments, gaps in care and support and unmet needs (psycho-emotional, informational, practical, etc.).

4 - Ideate RPFM Solutions
Focus on digitally-supported ideas that address identified needs, especially during under-supported phases in the home-context. Sometimes the best ideas and solutions come from the participants themselves, so ask them as well.

5 - Validate and Prioritise Solutions
Validate and prioritise ideas on desirability (experts, patients and relatives), feasibility (e.g., resources, existing infrastructure, financial), and long-term viability (e.g., scalability, alignment with strategic goals)

6 - Prototype, Pilot and Refine
Iteratively prototype and test the new interventions (including work processes and technology) on a small scale. Monitor and evaluate its effectiveness with relevant stakeholders, gathering feedback for continuous refinement.

7 - Implement and Embed
Fully implement the refined RPFM intervention, integrating it adaptively into existing care pathways to become part of routine care delivery.

8 - Monitor and Optimise
Continuously monitor the impact of the RPFM interventions on the Quadruple Aim; health outcomes, patient and family experience, staff experience, and cost-effectiveness. Make ongoing improvements.

9 - Sustain and Scale
Sustaining the RPFM interventions and scale up effective interventions across multiple care contexts. This includes leveraging lessons learned from prior implementations forming a continuous learning approach

Figure 2. Multi-step innovation strategy for co-designing Remote Patient and Family Management

Strengths and Limitations

A strength of our approach lies in the integration of families` lived experiences into a structured journey map, in alignment with Zøylner's[54] methodology for mapping patient and relative experiences. In addition, our study expands on existing family journey mapping methodology by integrating theoretical contributions from the Family Systems Illness Model[25] and the Supportive Care Framework[26], embedded in the focus group sessions through the *Care and Well-Being Journey* template (Appendix A). In this way, we could distinguish between domains of family needs in a structured, theory-informed fashion. The proposed actionable recommendations offer starting points for clinicians and innovators seeking to embed family-centred RPM-supported care within cardiac care pathways. However, these are preliminary ideas, based on assumptions that require structured testing. Future research should include concept testing, pilot implementation, health economic evaluations, and studies to measure impact on both patient- and family-reported outcomes and experiences. Another strength in our approach lies in its applicability to care domains other than cardiology, and especially to other acute and chronic care pathways where long-term management and self-care take place at home, such as in the fields of oncology, nephrology and obstetrics.

This study has several limitations. First, selection bias may have affected the findings, as the sample consisted mainly of digitally literate, native Dutch people willing to participate in a scientific study on care and support needs. As such, the identified unmet needs may be even more pronounced in more underserved or non-digitally literate populations, and additional, undiscovered unmet needs may be affecting these patients and their relatives.

Second, our sample size limits generalisability. While qualitative depth was prioritised, a more diverse sample and a less time-consuming data collection method would strengthen the generalisability of our insights.

Although this study was limited to the context of a single Dutch university hospital, many of the identified challenges and opportunities, particularly those related to care and informal caregiving, are likely to be relevant across the larger healthcare system and other care pathways. It is important to note that in this study, we mainly focus on digital opportunities. However, the identified improvements can potentially also be addressed through non-digital solutions.

Furthermore, the thematic analysis and construction of the care journey may have been influenced by our individual perspectives and professional interests, particularly our engagement with RPM and digital innovation. While we strived for reflexivity throughout the analysis process, our perspectives may have shaped how certain codes and themes were interpreted and prioritised.

Future studies should include more diverse settings and participants to ensure a more inclusive and representative data collection.

Conclusion

By exploring the lived experiences of patients and their relatives following MI or Peri-OP RPM-supported care trajectories, this study identified experience-based gaps in RPM-supported cardiac care, especially during pre-admission and early post-discharge phases. Through a multi-step co-design process, we created an overview of unmet informational, psycho-emotional, social, physical, practical, and spiritual needs of families, alongside co-created actionable RPFM recommendations. In addition, we present a scalable innovation strategy for innovators and clinicians in and outside cardiology to co-design RPFM.

Our findings underscore the importance of recognising that care and support extend beyond hospital admission and discharge; most of the care, health behaviour, and recovery occur in the home, within the relational ecosystem of the patient and their loved ones. Actively supporting this family ecosystem, particularly in the identified 'black hole' periods, holds the potential to significantly improve the experience of care, long-term health outcomes, and the overall efficiency of care delivery. Within this context**,** Remote Patient and Family Management (RPFM) emerges as a promising conceptual and practical lens for advancing hybrid and family-centred cardiovascular care.

Acknowledgement

We extend our sincere thanks to all the participants for generously sharing their lived experiences, which constitute the core of this paper.

During the preparation of this manuscript, ChatGPT (OpenAI) was used to assist with spelling, grammar, and overall readability. The first author subsequently reviewed and edited the content as necessary and takes full responsibility for the final version and its integrity.

Funding

This research was made possible through funding from Medical Delta Healthy Society lifestyle & prevention programme.

Conflict of interest

None declared

Data availability

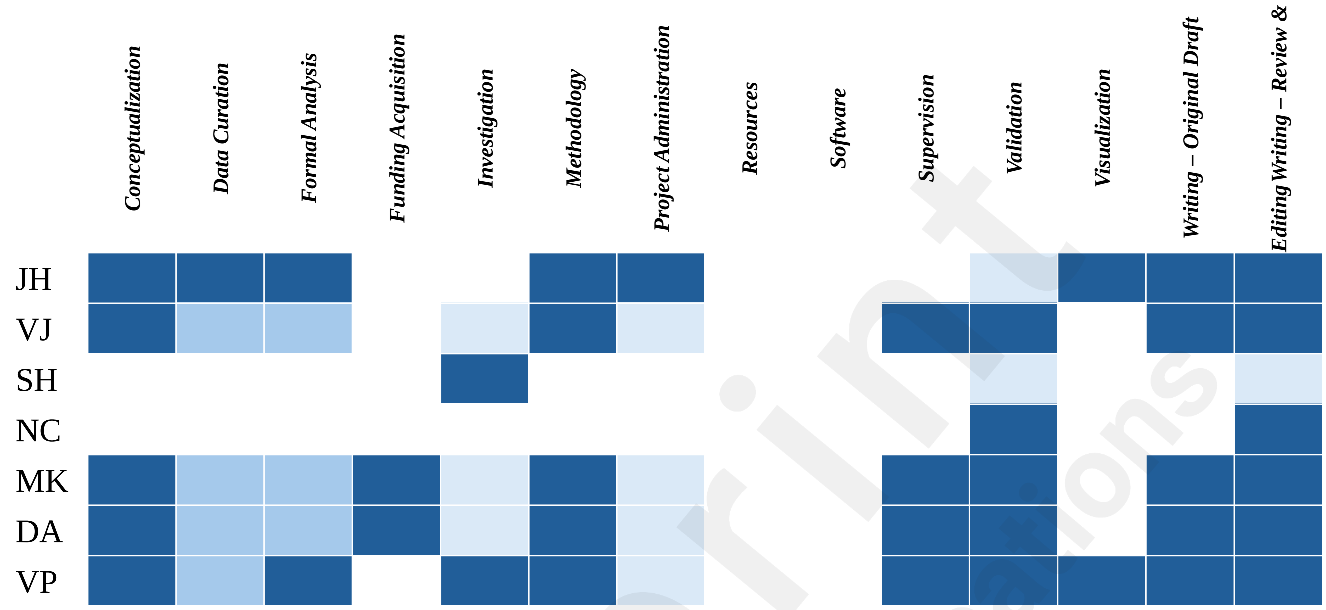
The de-personalised data supporting this article are available on reasonable request to the corresponding author.

Authors’ contributions

The authors’ contributions are presented in Table 2 below following the Contributor Roles Taxonomy

(CRediT).[55]

Table 2. Authors' contributions per CRediT



	Conceptualization	Data Curation	Formal Analysis	Funding Acquisition	Investigation	Methodology	Project Administration	Resources	Software	Supervision	Validation	Visualization	Writing – Original Draft	Writing – Review & Editing
JH	■	■	■			■	■				░	■	■	■
VJ	■	▨	▨		░	■	░			■	■		■	■
SH					■						░			░
NC											■			■
MK	■	▨	▨	■	░	■	░			■	■		■	■
DA	■	▨	▨	■	░	■	░			■	■		■	■
VP	■	▨	■		■	■	░			■	■	■	■	■

Abbreviations

CVD: cardiovascular disease

CRediT: Contributor Roles Taxonomy

MI: myocardial infarction

Peri-OP: perioperative care

RPM: Remote Patient Management

RPFM: Remote Patient and Family Management

References

1. Cowie MR, Bax J, Bruining N, Cleland JGF, Koehler F, Malik M, et al. e-Health: a position statement of the European Society of Cardiology. *Eur Heart J* 2016;**37**:63–6. doi:10.1161/CIR.0b013e3181e8edf1

2. Cowie MR, Lam CSP. Remote monitoring and digital health tools in CVD management. *Nat Rev Cardiol* 2021;**18**:457–8. doi:10.1038/s41569-021-00548-x

3. Frederix I, Caiani EG, Dendale P, Anker S, Bax J, Böhm A, et al. ESC e-Cardiology Working Group position paper: overcoming challenges in digital health implementation in cardiovascular medicine. *Eur J Prev Cardiol* 2019;**26**:1166–77. doi:10.1177/2047487319832394

4. Takahashi EA, Schwamm LH, Adeoye OM, Alabi O, Jahangir E, Misra S, et al. An overview of telehealth in the management of cardiovascular disease: a scientific statement from the American Heart Association. *Circulation* 2022;**146**. doi:10.1161/CIR.0000000000001107

5. Gannamani R, Forte JC, Folkertsma P, Hermans S, Kumaraswamy S, van Dam S, et al. A digitally enabled combined lifestyle intervention for weight loss: pilot study in a Dutch general population cohort. *JMIR Form Res* 2024;**8**:e38891. doi:10.2196/38891

6. Hughes A, Shandhi MMH, Master H, Dunn J, Brittain E. Wearable devices in cardiovascular medicine. *Circ Res* 2023;**132**:652–70. doi:10.1161/CIRCRESAHA.122.322389

7. Shcherbina A, Hershman SG, Lazzeroni L, King AC, O’Sullivan JW, Hekler E, et al. The effect of digital physical activity interventions on daily step count: a randomised controlled crossover substudy of the MyHeart Counts Cardiovascular Health Study. *Lancet Digit Health* 2019;**1**:e344–52. doi:10.1016/S2589-7500(19)30129-3

8. Treskes RW, van Winden LA, van Keulen N, van der Velde ET, Beeres SLMA, Atsma DE, et al. Effect of smartphone-enabled health monitoring devices vs regular follow-up on blood pressure control among patients after myocardial infarction: a randomized clinical trial. *JAMA Netw Open* 2020;**3**:e202165. doi:10.1001/jamanetworkopen.2020.2165

9. Artinian NT, Fletcher GF, Mozaffarian D, Kris-Etherton P, Van Horn L, Lichtenstein AH, et al. Interventions to promote physical activity and dietary lifestyle changes for cardiovascular risk factor reduction in adults: a scientific statement from the American Heart Association. *Circulation* 2010;**122**:406–41.

10. Knowles KA, Xun H, Jang S, Pang S, Ng C, Sharma A, et al. Clinicians for CARE: A systematic review and meta-analysis of interventions to support caregivers of patients with heart disease. *J Am Heart Assoc* 2021;**10**:e019706. doi:10.1161/JAHA.120.019706

11. Lyons KS, Lee CS. The theory of dyadic illness management. *J Fam Nurs* 2018;**24**:8–28. doi:10.1177/1074840717745669

12. Bjørnnes AK, Moons P, Parry M, Halvorsen S, Tønnessen T, Lie I. Experiences of informal caregivers after cardiac surgery: a systematic integrated review of qualitative and quantitative studies. *BMJ Open* 2019;**9**:e032751. doi:10.1136/bmjopen-2019-032751

13. Riegel B, Moser DK, Buck HG, Dickson VV, Dunbar SB, Lee CS, et al. Self-care for the prevention and management of cardiovascular disease and stroke: a scientific statement for healthcare professionals from the American Heart Association. *J Am Heart Assoc* 2017;**6**:e006997. doi:10.1161/JAHA.117.006997

14. Goldfarb MJ, Bechtel C, Capers Q, de Velasco A, Dodson JA, Jackson JL, et al. Engaging families in adult cardiovascular care: a scientific statement from the American Heart Association. *J Am Heart Assoc* 2022;**11**:e025859. doi:10.1161/JAHA.122.025859

15. Barriball L, Bremner J, Buchan J, Craveiro I, Dieleman M, Dix O, et al. Recruitment and retention of the health workforce in Europe: final report. Luxembourg: Publications Office of the European Union; 2015. Report No.: EB-02-15-512-EN-C.

16. Rechel B, Grundy E, Robine J-M, Cylus J, Mackenbach JP, Knai C, et al. Ageing in the European Union. *Lancet* 2013;**381**:1312–22. doi:10.1016/S0140-6736(12)62087-X

17. Houwen J, Karki RS, Janssen VR, Pannunzio V, Atsma DE, Kleinsmann MS. Designing remote patient and family centred interventions: an exploratory approach. *Proc Des Soc* 2024;**4**:1597–1606. doi:10.1017/pds.2024.162

18. Sanz MF, Acha BV, García MF. Co-design for people-centred care digital solutions: a literature review. *Int J Integr Care* 2021;**21**:1-17. doi:10.5334/ijic.5573

19. Bulto LN, Davies E, Kelly J, Hendriks JM. Patient journey mapping: emerging methods for understanding and improving patient experiences of health systems and services. *Eur J Cardiovasc Nurs* 2024;**23**:429–33. doi:10.1093/eurjcn/zvae012

20. Davies EL, Bulto LN, Walsh A, Pollock D, Langton VM, Laing RE, et al. Reporting and conducting

patient journey mapping research in healthcare: a scoping review. *J Adv Nurs* 2023;**79**:83–100. doi: 10.1111/jan.15479

21. Howard T. Journey mapping: a brief overview. *Commun Des Q Rev* 2014;**2**:10–3. doi:10.1145/2644448.2644451

22. Mery CM, Well A, Taylor K, Carberry K, Colucci J, Ulack C, et al. Examining the real-life journey of individuals and families affected by single-ventricle congenital heart disease. *J Am Heart Assoc* 2023;**12**:e027556. doi:10.1161/JAHA.122.027556

23. Van Schalkwijk DL, Widdershoven JWMG, Elias-Smale S, Hartzema-Meijer M, Den Oudsten BL, Slatman J, et al. ShareHeart: a patient journey map of patients with ischemia and non-obstructive coronary artery disease based on qualitative research. *J Clin Nurs* 2023;**32**:3434–44. doi:10.1111/jocn.16409

24. Kumar SS, Andreakou E, Tzachsan M, Maier AM. Mapping the journeys of atrial fibrillation patients and citizens using wearable devices for remote cardiac monitoring. *Proc Des Soc* 2023;**3**:2575–84. doi:10.1017/pds.2023.258

25. Rolland JS. Cancer and the family: an integrative model. *Cancer* 2005;**104**:2584–95. doi:10.1002/cncr.21489

26. Fitch MI. Supportive care framework. *Can Oncol Nurs J* 2008;**18**:6–24. doi:10.5737/1181912x181614

27. Biersteker TE, Boogers MJ, Schalij MJ, Braun J, Groenwold RHH, Atsma DE, et al. a *Eur Heart J Digit Health*. 2023;**4**(4):347–56. doi:10.1093/ehjdh/ztad035

28. de Frel DL, Schroijen MA, Aardoom JJ, van Gils W, Huisman SD, Janssen VR, et al. Participatory development of an integrated, eHealth supported, educational care pathway (the Diabetes Box) for people with type 2 diabetes: development and usability study. *JMIR Hum Factors*. 2024;**11**:e45055. doi: 10.2196/45055

29. van Hattem NE, Mijnsbergen NJ, van Os HJA, Mertens BA, Eekhof JAH, Chavannes NH, et al. The effect and implementation of the COVID Box, a remote patient monitoring system for patients with a COVID-19 infection in primary care: a matched cohort study. *Fam Pract*. 2024;**42**:1–7. doi:10.1093/fampra/cmae045

30. Rakers M, van Hattem N, Hiddink E, van Peet P, Vos R, Chavannes N, et al. Tailoring remote patient management to optimise cardiovascular risk management in primary care: a mixed-methods

implementation study informing large-scale implementation. *BMC Prim Care*. 2025;**26**:214. doi: 10.1186/s12875-025-02906-x

31. Treskes RW, van Winden LA, van Keulen N, Atsma DE, van der Velde ET, van den Akker-van Marle E, et al. Using smart technology to improve outcomes in myocardial infarction patients: rationale and design of a protocol for a randomized controlled trial, The Box. *JMIR Res Proctoc*. 2017;**6**(9):e186–6. doi:10.2196/resprot.8038

32. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. I*nt J Qual Health Care* 2007;**19**:349–57. doi:10.1093/intqhc/mzm042

33. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101. doi:10.1191/1478088706qp063oa

34. Drakenberg A, Sundqvist A, Fridlund B, Ericsson E. Family involvement in relation to elective open-heart surgery: a critical incident technique study from a family member perspective. *Scand J Caring Sci* 2025;**39**:e70003. doi:10.1111/scs.70003

35. Fleury J, Moore SM. Family-centered care after acute myocardial infarction. *J Cardiovasc Nurs* 1999;**13**:73–82. doi:10.1097/00005082-199904000-00007

36. Tuomisto S, Koivula M, Åstedt-Kurki P, Helminen M. Family involvement in rehabilitation: coronary artery disease—patients' perspectives. *J Clin Nurs* 2018;**27**:3020–31. doi:10.1111/jocn.14494

37. Huriani E. Myocardial infarction patients' learning needs: perceptions of patients, family members and nurses. *Int J Nurs Sci* 2019;**6**:294–9. doi:10.1016/j.ijnss.2019.05.001

38. Birtwistle SB, Jones I, Murphy R, Gee I, Watson PM. "Do what you can with a happy heart": a longitudinal study of patient and family members' lived experiences of physical activity post-myocardial infarction. *Disabil Rehabil* 2022;**44**:3661–70. doi:10.1080/09638288.2021.1878560

39. Blair J, Volpe M, Aggarwal B. Challenges, needs, and experiences of recently hospitalized cardiac patients and their informal caregivers. *J Cardiovasc Nurs* 2014;**29.** doi:10.1097/JCN.0b013e3182784123

40. Davies N. Patients' and carers' perceptions of factors influencing recovery after cardiac surgery. *J Adv Nurs* 2000;**32**:318–26. doi:10.1046/j.1365-2648.2000.01479.x

41. Doering LV, McGuire AW, Rourke D. Recovering from cardiac surgery: what patients want you to know. *Am J Crit Care* 2002;**11**:333–43.

42. Hernández-Palazón J, Fuentes-García D, Falcón-Araña L, Roca-Calvo MJ, Burguillos-López S, Doménech-Asensi P, et al. Assessment of preoperative anxiety in cardiac surgery patients lacking a history of anxiety: contributing factors and postoperative morbidity. *J Cardiothor Vasc Anesth* 2018;**32**:236–44. doi:10.1053/j.jvca.2017.04.044

43. Brust M, Gebhardt WA, Numans ME, Jong JCK. 'Teachable moments': het juiste moment voor leefstijlverandering. *Ned Tijdschr voor Geneeskd* 2020;**164**.

44. Schmid ME, Stumm J, Stock S, Girdauskas E. Patient perspectives on health care models in cardiac surgery: a qualitative evaluation. *BMC Health Serv Res* 2024;**24**:1309. doi:10.1186/s12913-024-11791-6

45. Krist AH, Tong ST, Aycock RA, Longo DR. Engaging patients in decision-making and behavior change to promote prevention. *Stud Health Technol Inform* 2017;**240**:284–302.

46. Doyle C, Lennox L, Bell D. A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *BMJ Open* 2013;**3**:e001570. doi:10.1136/bmjopen-2012-001570

47. Kettunen S, Solovieva S, Laamanen R, Santavirta N. Myocardial infarction, spouses' reactions and their need of support. *J Adv Nurs* 1999;**30**:479–88. doi:10.1046/j.1365-2648.1999.01103.x

48. Pannunzio V, Morales Ornelas HC, Gurung P, van Kooten R, Snelders D, van Os H, et al. Patient and staff experience of remote patient monitoring - what to measure and how: systematic review. *J Med Internet Res* 2024;**26**:e48463. doi:10.2196/48463

49. Bodenheimer T, Sinsky C. From triple to quadruple aim: care of the patient requires care of the provider. *Ann Fam Med* 2014;**12**:573–6. doi:10.1370/afm.1713

50. Kaihara T, Scherrenberg M, Intan-Goey V, Falter M, Kindermans H, Frederix I, et al. Efficacy of digital health interventions on depression and anxiety in patients with cardiac disease: a systematic review and meta-analysis. *Eur Heart J Digit Health* 2022;**3**:445–54. doi:10.1093/ehjdh/ztac037

51. Moser DK, Dracup K. Role of spousal anxiety and depression in patients' psychosocial recovery after a cardiac event. *Psychosom Med.* 2004;**66**(4):527–32. doi:10.1097/01.psy.0000130493.80576.0c

52. O'Bertos SE, Holmberg D, Shields CA, Matheson LP. Partners' attachment styles and overprotective

support as predictors of patient outcomes in cardiac rehabilitation. *Rehabil Psychol* 2020;**65**:258–67. doi:10.1037/rep0000331

53. Zhai S, Chu F, Tan M, Chi N-C, Ward T, Yuwen W. Digital health interventions to support family caregivers: an updated systematic review. *Digit Health* 2023;**9**. doi:10.1177/20552076231171967

54. Zøylner IA, Lomborg K, Christiansen PM, Kirkegaard P. Surgical breast cancer patient pathway: experiences of patients and relatives and their unmet needs. *Health Expect* 2019;**22**:262–72. doi: 10.1111/hex.12869

55. Brand A, Allen L, Altman M, Hlava M, Scott J. Beyond authorship: attribution, contribution, collaboration, and credit. *Learn Publ* 2015;**28**:151–155. doi:10.1087/20150211

Appendix A – The Care and Well-Being Journey

We designed and employed a journey mapping template called *The Care and Well-Being Journey* to guide the discussions, see Figure 3 below.

WELLBEING	Pre-admission	Admission	Post-admission
Important moments			
Care and support			
Physical			
Informational			
Practical			
Social			
Psychological			
Emotional			
Spiritual			

Figure 3. The Care and Well-Being Journey

The semi-structured focus group interview guide included the following main questions:

- What key moments (positive and negative) in the cardiac disease journey have stayed with you, and how did you experience them?
- In what ways has there been support and care for your well-being both as individuals and as families from the care system?
- Do you feel responsibility/involvement towards each other regarding health and well-being? And to what extent are/were you able to help each other?
- What improvements could help the whole family navigate the journey, and what form could they take (e.g. coaching, tools, extra help)?

Supplementary Files

Multimedia Appendixes

Journey map of real-life experiences of patients and relatives in cardiovascular disease management.
URL: http://asset.jmir.pub/assets/3dc50a3eddf50069659c440e70425358.pdf

The care and well-being journey.
URL: http://asset.jmir.pub/assets/15806a083ad2639140e070f210ab2e32.docx

CONSORT (or other) checklists

COREQ_Checklist.
URL: http://asset.jmir.pub/assets/41169c3dbefa71e3f6fa854b58cfd3b2.pdf