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Title	User-centred Digital Health in Cardiovascular Rehabilitation and Self-management
Authors(s)	Tadas, Shreya
Publication date	2022
Publication information	Tadas, Shreya. "User-Centred Digital Health in Cardiovascular Rehabilitation and Self-Management." University College Dublin. School of Computer Science, 2022.
Publisher	University College Dublin. School of Computer Science
Item record/more information	http://hdl.handle.net/10197/13336

User-Centred Digital Health in Cardiovascular Rehabilitation and Self-Management

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This thesis is submitted to University College Dublin in fulfilment of the requirement for the degree of Doctor of Philosophy

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Doctoral Studies Panel Members: Prof. Brian Caulfield, Dr. Brian Mac Namee

Submitted: May 2022

Table of Contents

Abstract

An acute cardiac incident is a life changing event and people face emotional and physical challenges during their transition from hospitalisation to self-management. Supervised rehabilitation programs, like, cardiac rehabilitation play a vital role in supporting this transition. Lack of knowledge, transportation, and motivation limits the uptake of such programs. Increasingly, sensor technologies providing patient-generated data are showing potential to overcome these limitations. But, evidence regarding its routine use and effectiveness is mixed and the commonly reported barriers include insufficient time, data lacking context, unfamiliar structure, misaligned objectives, usability, and reliability issues. Therefore, a greater understanding of patients' experiences and factors that impact their behaviour after hospitalisation is needed to design such technologies. Also, to increase their success when deployed in real-world clinical contexts, designing by integrating both clinicians' and patients' perspectives is important.

User-centred design approaches emphasise the importance of situating user experiences, needs, and preferences as the driver of the digital intervention design. Given the strong evidence from the field of human-computer interaction that user-centred and iterative design methods increase the success of digital health interventions, limited studies were identified that involved users in the design process and applied iterative methods. To contribute new insights to an area lacking in empirical research, this thesis applies the user-centred design methods and the co-design framework to design technology-mediated solutions to support cardiac rehabilitation and self-management. This thesis engages more directly with patients' and clinicians' post-hospitalisation experiences and the impact of patient-generated data through a series of studies. Four studies were conducted to achieve the aims of the thesis: a qualitative systematic grounded theory literature review; semi-structured interviews with cardiac patients; co-design study with cardiac rehabilitation clinicians; and field study for system deployment in real-world clinical context.

Building on the collective findings of the studies conducted in this thesis, empirically grounded user-centred recommendations are presented to improve the design of technology-mediated support for CR and self-management. The key design recommendations presented in this thesis include: (i) the use of technology to support a normal life, leveraging social influences to extend participants' sense of normality; (ii) the use of technology to provide both emotional and physical safe zoning; (iii) a focus on recognising capability and providing recommendations that are positive and reinforce this capability; (iv) supplementing objective data from consumer wearable devices with

subjective patient experience data to enable meaningful and actionable insights for clinicians; (v) adopting structured approach to subjective data collection grounded in the clinicians' workflow and co-designed with the clinicians to allow for such data to be shared in a familiar presentation; (vi) the importance of carefully considering the timing, type of App, context, and type of data presentation while sharing data between patients to avoid negative consequences and to empower patients to use technology to self-manage their condition.

Statement of Authorship

I hereby certify that the submitted work is my own work, was completed while registered as a candidate for the degree stated on the Title Page, and I have not obtained a degree elsewhere on the basis of the research presented in this submitted work.

Signed:

Date: 6th May 2022

Role of Candidate and Collaborators

The candidate, Shreya Tadas, prepared this thesis and was responsible for every document of the study design, the ethics submissions, participant recruitment, data collection, data management, data analysis, prototype design and development, manuscript preparation and submission.

Dr. David Coyle, School of Computer Science, University College Dublin: Principal Supervisor, provided guidance throughout the study design and execution, data analysis, manuscript preparation, manuscript proofing.

Dr. Stephen J Leslie, University of the Highlands and Islands: assisted in participant recruitment and reviewed study design and analysis, Chapter 4.

Dr. Claudette Pretorious, University College Dublin: assisted in qualitative data analysis and manuscript review, Chapter 4.

Ms. Jane Dickson, Beacon Hospital**:** assisted in participant recruitment, actively collaborated in study design, prototype design, execution, and analysis, Chapter 5 and Chapter 6.

Acknowledgements

It is a genuine pleasure to express my deep sense of gratitude and warmest thank you to my supervisor, Professor David Coyle, for his wisdom, invaluable guidance, and unwavering support throughout the PhD. Thank you for making this work possible. I have learned a lot from your research approach, engaging writing, and straightforward thought process. Thank you to my Doctoral Research Panel, Professor Brian Caulfield and Professor Brian Mac Namee, for their insight and guidance.

Thank you to Dr Stephen Leslie for helping me with the recruitment and documentation needed for the cross-border collaboration between UHI and UCD to happen. Your guidance helped me run the study smoothly. To the cardiac rehabilitation staff at Beacon Hospital, especially Dr David Burke, Jane Dickson, and Caroline Kelly, for hosting me and helping with the logistics for the studies. The studies could not have run so smoothly without your help and trust in me. To all my participants, thank you for your honesty and enthusiasm. I will never forget the power of your stories in shaping this research.

Thank you to the European Union's INTERREG VA Program, ECME, for providing the funding for this project. Special mention to the ECME UCD programme manager, Jennifer Kelly, for being there and always solving my research's administrative needs.

Thank you to the writing group for hosting regular writing sessions. The encouragement and support received through this group has been invaluable throughout my writing journey.

This PhD gave me an opportunity to meet amazing people at UCD and make lifelong friendships. To Claudette, Louise, Vivek, Francisco, Mansura, Petra, Hidde, and Darragh thank you for being there for me. This experience would not have been memorable and special without you all.

I would like to give a special thank you to my parents, sister, in-laws, and friends for their love and encouragement. Appa and Amma, your lifelong encouragement, belief in me, interest in my work, and life lessons energise and motivate me to keep moving forward.

Finally, I would like to give a massive thank you to my husband, Shridhar Kulkarni, for being there at every step of this journey, keeping me calm and always bringing a smile on my face. Your love, support, patience, compassion, and sacrifice is beyond appreciation, and I could not have achieved this without you.

List of Publications

Peer-reviewed Publications

Tadas, S., & Coyle, D. (2020). Barriers to and facilitators of technology in cardiac rehabilitation and self-management: systematic qualitative grounded theory review. *Journal of medical Internet research*, *22*(11), e18025. DOI: 10.2196/18025

Tadas, S., Pretorius, C., Foster, E. J., Gorely, T., Leslie, S. J., & Coyle, D. (2021). Transitions in Technology-Mediated Cardiac Rehabilitation and Self-management: Qualitative Study Using the Theoretical Domains Framework. *JMIR cardio*, *5*(2), e30428. DOI: 10.2196/30428

Short Conference Papers

Tadas, S., & Coyle, D. (2022). Challenges, tensions, and opportunities in cardiac rehabilitation and self-management. *In 2022 ACM annual conference on Human Factors in Computing Systems Workshop on Challenges, Tensions, and Opportunities in Designing Ecosystems to Support the Management of Complex Health Needs - CHI '22 Workshop* **(Oral Presentation)**

Collaborative Work Completed during PhD

Monteiro-Guerra, F., Signorelli, G. R., **Tadas, S.**, Zubiete, E. D., Romero, O. R., Fernandez-Luque, L., & Caulfield, B. (2020). A personalized physical activity coaching app for breast cancer survivors: design process and early prototype testing. *JMIR mHealth and uHealth*, *8*(7), e17552.

List of Figures

List of Tables

Abbreviations

ACM	Association for Computing Machinery
CASP	Critical Appraisal Skills Program
HCI	Human-Computer Interaction
CVDs	Cardiovascular Diseases
TDF	Theoretical Domains Framework
CR	Cardiac Rehabilitation
QoL	Quality of Life
CSCW	Computer-supported Cooperative Work
GTLR	Grounded Theory Literature Review
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
NHS	National Health Service
REC	Research Ethics Committee
HR	Heart Rate

Chapter 1

Introduction

1.1 Introduction

Cardiovascular disease (CVDs) is a leading cause of morbidity and mortality worldwide, with an estimated 17.9 million deaths each year [42,69]. CVDs are a group of disorders of the heart and blood vessels, usually associated with a build-up of fatty deposits inside the arteries and occurs when the flow of oxygen-rich blood to the heart is blocked, leading to increased strain on the heart [121]. Four out of five cardiac-related deaths are due to acute events, such as heart attacks and strokes. One-third of these deaths occur prematurely in people under the age of 70 years [69]. Fortunately, the success rate of modern cardiac surgery and nonsurgical interventions, such as percutaneous coronary intervention (stent insertion), is high. As a result, an increasing number of people live with CVDs as a long-term chronic condition.

Along with medical or surgical intervention, chronic conditions like CVDs require lifelong lifestyle management, behaviour change, medication management, and health tracking activity. Many people face emotional and physical challenges during the transition from hospitalisation to self-management [136]. Supervised rehabilitation programs, for example, cardiac rehabilitation (CR) programs play a crucial role in supporting this transition. However, the uptake of such programs remains poor because of factors such as age, gender, lack of knowledge, transportation, motivation, and social support [56,189]. This also has an impact on people's subsequent ability to self-manage their condition. Recent research suggests that digital health interventions can play an important role in supporting both rehabilitation and self-management [15,96,135]. Although promising, evidence regarding its effectiveness and uptake of existing interventions is inconclusive. A greater understanding of patients' experiences and factors that impact their behaviour and behaviour change will provide the insight needed to design future technologies and increase their success when deployed in real-world contexts.

After hospitalisation, cardiac patients experience three key phases: recuperation, rehabilitation, and long-term self-management (Figure 1.1). There are various digital interventions to support patients during these phases. Some are administered and managed by health care providers while others are commercially available. Furthermore, treatment of cardiac conditions like many other health conditions, rely on a combination of medication and lifestyle changes. Researchers suggest that there exists an individual

difference in the disease management process and this refers to how people are similar or different in their ways of thinking, feeling, and behaving [44]. These differences commonly arise from patient demographics, situational or contextual changes, and environment. Catering to the needs arising in the various phases after hospitalisation and supporting patients across diverse demographics and perspectives makes designing such technologies complex. The non-adaptive nature of present technologies leads to gap in health management data, loss of motivation among users, and thus gradual decline in its use over time. Thus, supporting individuals towards healthy behavioural modifications requires innovative tools. Digital health technologies also emergingly known as connected health technologies, e.g. mobile phones, smartphones, tablets, wearable devices, smartwatches, personal health sensors, present an opportunity to provide personalised, convenient, and easily accessible behaviour change support [185].
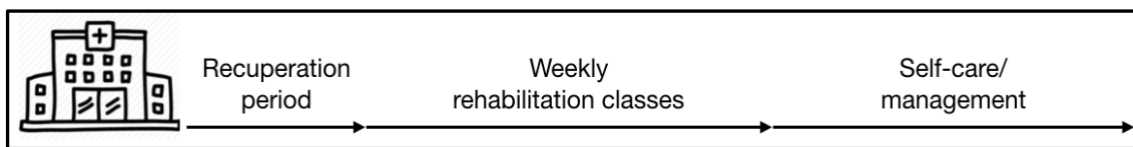
Figure 1.1: Participants' journey after their cardiac event

1.2 Background to Research

The past 10 years has seen an increasing focus of research in the CVDs domain due to its chronic nature and growing prevalence worldwide. Due to population growth and aging, especially in countries where the share of older persons is projected to double between 2019 and 2050, prevalent cases of total CVDs are likely to increase substantially [146]. For example, by 2035, more than 130 million adults in the US population (45.1%) are projected to have some form of CVD, with the total costs of CVDs expected to reach US $1.1 trillion [28]. Strategies to prevent CVDs therefore have global significance and both primary and secondary prevention strategies are considered essential to reduce the impacts of the disease. Primary prevention strategies attenuates risk in those patients who are at high risk and have not yet established the disease. Whereas, secondary prevention reduces risk in patients with established disease [90]. Digital health technologies supporting CVDs can be broadly classified to target three areas: detection or prevention, rehabilitation, and self-management.

1.2.1 CVDs Prevention

Digital health technologies have the potential to enable primary prevention of CVDs by providing early disease prediction and detection. For example, real-time non-obtrusive

remote monitoring technologies offer patients the ability to keep a check on their vitals and enable early detection of any abnormalities. Early detection allows patients to receive appropriate medical attention before the disease worsens leading to further complications [97]. Although there is vast literature on early detection and self-monitoring technologies, many questions remain unanswered regarding the real-world and long-term impact of these technologies. Studies focusing on technologies for cardiac prevention or detection are largely oriented towards techniques and algorithms with less focus on users' needs and experiences [141,158]. Literature in this area raises concerns on the design of these technologies and its effectiveness. For example, an interview based study about perceptions and experiences of patients and clinicians on the use of mobile phone based telemonitoring demonstrated that the success of a monitoring system is highly dependent on its features and design [105]. Another interview based study on prescribing electronic activity monitors for patients with CVDs stressed the need to develop an easy to use monitoring technology that provides understandable and motivational feedback [27]. Researchers suggest that all stakeholder requirements must be gathered early-on in the design process and special demands of patients and clinicians should be considered to create an acceptable health monitoring device [64,65,99,177]. Apart from mobile and sensor monitoring technologies, there is also an increased investment in multi-sensing and autonomous monitoring technologies, including smart-home technologies, for effective self-monitoring of cardiac conditions [50,79,176]. Although initial studies on monitoring technologies have been promising, limitations include small sample sizes, short study durations, and uncertainty about how technology will perform in real-world settings and integration into clinical practice [185].

Medical researchers have demonstrated that modification of lifestyle is an essential component for both primary and secondary prevention to avoid the etiopathogenesis of CVDs [182]. CR represents an efficient secondary prevention model that brings many benefits for patients with CVDs and also acts at the medical and social system levels [182]. As more people live with CVDs as a chronic condition and with the growth of CR as an effective and readily available intervention, appropriate attention should be devoted for further research and innovative solutions to support CR. The work presented in this thesis focuses on technologies to support CR and self-management.

1.2.2 Cardiac Rehabilitation

After a person is hospitalised and following a discharge and recuperation period, they are typically recommended to attend a CR program offered by hospitals. Following this, they need to continue to self-manage their cardiac health. CR is considered to play a vital role in a patient's transition from hospitalisation to self-management. CR is defined as a

secondary prevention model that reduces mortality and the risk of recurrent events and improves quality of life (QoL) in patients with CVDs [182]. There are variations in the provision and organization of cardiac rehabilitation (CR) services from country to country. Broadly however, CR programs follow a consistent structure. CR is typically supported by specialist medical teams and includes clinical assessment, medication review, risk factor modification, psychological support, and supervised exercises [41]. In the UK, for example, standardized CR is structured across four phases, starting with acute in-hospital rehabilitation (Phase 1) followed by outpatient clinic follow-up (Phase 2) and is the period at home before the start of phase 3, structured exercise and education programs (Phase 3) and longer-term maintenance (Phase 4) [29]. Phase 1 and 2 are the preludes to exercise-based phase 3 CR program. For this thesis, phase 1 and 2 are considered to be part of the recuperation phase (Figure 1.1). Phase 3 is considered as the rehabilitation phase and the studies presented in this thesis focus on phase 3 CR programs. Of the three key phases that patients go through after hospitalisation, presented in Figure 1.1, rehabilitation phase is considered vital [189]. This is a critical point in rehabilitation where patients still receive regular, structured support from a medical team, but the emphasis is on supporting the transition to longer term self-management of their health [29]. Phase 3 CR programs are targeted at patients who have recently been admitted for invasive interventions such as stent placement or open-heart surgery. These programs are usually 6 weeks long and are made up of a combination of monitored exercises and educational sessions. The overall aim of such programs are to build habits of regular exercise and to educate patients to enable them to continue with self-management once the program is completed. During this transition from hospitalisation to self-care or self-management people face emotional and physical challenges [136]. Behaviour and behaviour change are crucial for successful and long-term self-management [154]. The physical and emotional support provided at the CR programs play an important role in empowering patients during this transition to self-care or self-management [189]. However, lack of awareness of such programs, transportation to attend the progarm, individual motivation, high cost, and poor social support lead to low uptake of CR programs [56].

Jörntén-Karlsson et al. [96] found mobile health (mHealth) as an effective long-term alternative to face-to-face rehabilitation and consultation, with the potential to reach more patients at a relatively lower cost. Reviews on technology-mediated CR, for example, telerehabilitation [72] and virtual CR through mHealth [29,84] found similar favourable outcomes compared to face-to-face CR programs and is gradually being considered as a suitable alternative [34,43,167]. Technology-mediated CR programs can address the barriers to face-to-face CR programs [43,182]. However, research also concludes that this

potential has not yet been achieved and a number of key barriers have been identified [134]. As more CR programs are moving towards a hybrid structure that involves both in-person and remote support tailored to patient and situational needs – a move accelerated by the COVID-19 pandemic. There is an urgent need to validate and develop these technological tools to help patients in their recovery and prevent recurrent events [72].

1.2.3 Cardiac Self-Management

According to Barlow et al [24], "self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and lifestyle changes." Recent research suggests that digital health interventions can play an important role in supporting both rehabilitation and self-management. A systematic review of mobile phone apps to support self-care following heart failure by Athilingam and Jenkins [15] demonstrated positive trends and cost-effectiveness. These apps helped in enabling increased access to symptom monitoring and promoting patient engagement in their own homes. Similarly, a review by Piette et al [134] on mHealth technologies for CVD reduction and management found evidence that mHealth interventions can improve cardiovascular-related lifestyle behaviours and disease management. The authors emphasise the need for new interventions that build on evidence-based behavioural theories that are adaptive to a patient's unique and changing needs. Researchers suggest that digital interventions can have a positive impact on patients with CVDs but again stressed the need for easy-to-use, personalised, and user-friendly apps that can cater to patients from all age groups, especially older age groups. Similarly, investigations by Maitland et al. [108] on the role of self-monitoring found an overall reluctance toward unnecessary self-monitoring and suggest that technology should focus on self-awareness and self-determination.

Improved CVDs outcomes largely depends on how well affected people manage their condition [37]. Rehabilitation and self-management are clearly interconnected. Effective rehabilitation provides a foundation for successful self-management. Physical rehabilitation and lifestyle management are critical components of programs aimed at primary and secondary prevention of CVD. A major challenge in implementing these strategies is ensuring good patient engagement and compliance with prescribed exercise programs and nutrition plans. Evidence from the literature suggests that tightly supervised intervention programs are most successful and that self-directed management is less successful because of problems with engagement and adherence [20]. The problem lies in expecting patients with a wide variety of life patterns and personality types to conform to standardised programs that do not fit with their ever-changing context [20].

1.3 Thesis Aims and Objectives

The studies presented in this thesis start by first understanding the needs and experiences of patients after a cardiac incident focusing on the three phases and the transitions of their needs as they moved through the phases from recuperation, rehabilitation, to self-management (Figure 1.1). Here, opportunities and challenges for digital tools to support CR and self-management are explored. Based on findings from the first two studies and the existing literature on supporting transition from hospitalisation to self-management (explained further in Chapter 5), there is a strong connection between CR and self-management, where rehabilitation forms the basis for long-term self-management. As effective CR provides a foundation for successful self-management, addressing challenges during CR phase is important. Thus, the further two studies focus on CR phase. Here, based on the needs of patients and clinicians a technological solution on patient-generated data is designed and deployed in real-world CR programs and feedback is gathered.

The broad aim of the research presented in this thesis is to explore the barriers and facilitators for technology to support CR and self-management and how some of the barriers can be addressed through design. With this objective, the primary research questions (RQs) addressed are as follows:

1. **What are the primary barriers and facilitators to using technology for cardiac rehabilitation and self-management?**

   This includes the following:

   a. To systematically review and synthesise the literature around current technological support provided for CR and self-management.
   b. To understand patient's perspectives of using current digital interventions for CR and self-management.
   c. To review the design approaches applied in existing literature to design such technologies.
   d. To understand the limitations in current digital interventions and explore the opportunities for technology design.

2. **What are patients' experiences after a cardiac incident?**

   This includes the following:

   a. To develop a holistic understanding of patients' experiences after a cardiac hospitalisation.
   b. To explore how these experiences support or hinder rehabilitation and ongoing self-management.

c. To exploring the factors that impact patients' behaviour and behaviour change after hospitalisation.

d. To explore the key opportunities and challenges that technology mediation can address.

3. **In what ways does the combination of objective and subjective data-capturing support cardiac rehabilitation and self-management?**

   Building on answers to RQs 1 and 2, this includes the following:

   a. To develop an understanding of clinicians' experiences of CR program and requirements from technology to support CR.

   b. To design a data-capturing system building on both patients and clinicians' requirements.

   c. To design a technological system that addresses some of the challenges and opportunities identified from RQs 1 and 2.

   d. To examine the impact of the designed data-capturing system in real-world clinical context.

   e. To reveal limitations or difficulties for future iterations.

4. **What are the design recommendations that embody the needs of both patients and clinicians and addresses the barriers identified for technologies that support cardiac rehabilitation and self-management?**

1.4 Contributions

The primary contributions of this thesis include:

- A holistic understanding of the barriers and facilitators for technology to support cardiac rehabilitation and self-management. The design requirements presented in this thesis reflect on the factors that impact patient behaviour through the transition phases after cardiac surgery. The factors are derived through a grounded and comprehensive theoretical framework.

- An enhanced understanding of the experiences of different stakeholders involved in the CR and self-management process taking into consideration both patients and clinicians' perspectives.

- Informed design recommendations for future digital health interventions that are grounded in the real-world experiences of patients and clinicians.

The secondary contributions of this thesis include:

- Initial empirical evidence of the impact of the technological system that embodies the design recommendations. Providing an account of its use in a real-world clinical context. Design implications for wider health technologies that involve patient-generated data and focus on patient empowerment.

1.5 Overview of Methodology used for the PhD

This research applies the user-centred design methods and co-design framework to (i) further understand digital health stakeholder needs, specifically cardiac patients and clinicians; (ii) understand the context of CR and self-management; (iii) design technological solutions based on these understandings; and (iv) explore its impact in a real-world context. Therefore, this research begins with a thorough understanding of the current state of art, patients' perspectives, and usage of technology to support CR and self-management in the first study through a systematic qualitative literature review. This involved systematically reviewing the current literature and synthesising the findings from the literature through the grounded theory approach. Thereafter, semi-structured interviews with cardiac patients from an NHS hospital (further details in Chapter 4) were conducted in the second study, and the theoretical domains framework for behaviour change was used to rigorously and systematically identify the key determinants that impact patient behaviours post-hospitalisation. Finally, building on the patient's needs identified in the previous two studies, study 3 involved a co-design study with CR clinicians from a hospital in Ireland (further details in Chapter 5) to understand their needs and the contextual needs of the CR phase. In this study, a technological solution focusing on patient-generated data using readily available digital tools was co-designed with CR clinicians. This solution then went through initial real-world evaluation in study 4 involving ethnographic field study during CR programs in a hospital in Ireland (further details in Chapter 6) followed by feedback from patients and clinicians.

1.6 Thesis Structure

Chapter 2 presents the methodological approach used in this thesis. A description of the user-centred design methods and co-design framework are presented in the context of the overall thesis design.

Chapter 3 presents a qualitative systematic review of the current digital interventions to support cardiac rehabilitation and self-management. This chapter also explores the barriers and facilitators of cardiac rehabilitation, self-management, and patients' perspectives on usage of such technologies.

Chapter 4 presents patients' needs and perspectives of technologies to support cardiac rehabilitation and self-management. This chapter presents findings from a semi-structured interview study with cardiac patients.

Chapter 5 presents a co-design study conducted in collaboration with cardiac rehabilitation clinicians to understand clinicians' needs for technologies that support cardiac rehabilitation and to design a system that embodies both clinicians' needs, and patients' needs that were listed in Chapter 3 and 4. This chapter presents the data collection and sharing system that was designed and development through the co-design study.

Chapter 6 details the findings from an ethnographic field study of the co-designed data collection and sharing system described in Chapter 5. This chapter reports empirical evidence of the impact of the system when deployed in a clinical context and discusses subsequent design implications.

Chapter 7 integrates findings from chapter 3-6 and discusses empirically grounded key design implications and recommendations for technologies that aim to support CR and self-management. It also provides considerations for future digital health technologies targeting broader complex health conditions.

Chapter 2

Methodology

2.1 Introduction

Chapter 1 provided a brief overview of the different areas technology support is provided in the CVDs space and its gaps. This chapter provides an overview of the trends and opportunities for technology support in the broader chronic condition management space reported in the computer-supported cooperative work (CSCW) and Human-Computer Interaction (HCI) literature. It also presents the gap in HCI research in the CVDs space and the potential research opportunities. The remainder of this chapter focuses on the user-centred methods and the framework, the co-design framework, guiding the design and planning of the studies discussed in this thesis.

2.2 HCI Research in Chronic Condition Management

In recent years, rehabilitation and self-care or self-management have become significant issues within CSCW and HCI research. Examples include self-management technologies addressing chronic disease management for older adults [22,63,119], technologies for chronic obstructive pulmonary disease therapy [162,169], and self-management technologies addressing diabetes management [60,139]. Research in these areas demonstrate the importance of knowledge support, contextual data, and self-management education [63,139,162,169]. For example, Raj et al. [142] demonstrate the relationship between context and behaviour and the importance of context-aware apps for self-management. Within the literature specific to technologies for CR and self-management, research is mainly focused on interventions to increase physical activity [78], monitoring [2,76,81,165], virtual rehabilitation [25], medication and diet management [104,152], and aiding communication and data sharing between patients, clinicians, and care providers[168]. There is growing importance and calls for further research that involves designing technological solutions based on patient and clinician's contextual usage and experiences [6]. For example, Andersen et al. [8] presents three key concepts to consider while designing eHealth systems: (i) Meaningful, the system should make sense to both patients and clinicians; (ii) Actionable, it should help both clinicians and patients to take appropriate actions and; (iii) Feasible, easy and convenient to do so within the organisational and social context.

Recent research shows an increasing demand for self-management technology that supports people's mundane activities and informal ways of exercises [124]. Significant research also exists in the space of self-management technologies aimed at addressing chronic disease management in older adults [22,63,119]. For example, the study on managing multimorbidity in older adults by Doyle et al. [63], suggests the need for self-management apps to primarily focus on information support and teaching how to self-manage. There is also a growing body of work targeted at supporting chronic obstructive pulmonary disease therapy and training at home with the use of sensors, smartphones, television, and webcams [162,169]. Research in this area demonstrates the increasing accuracy of smartphone-based training apps and their acceptance. Shankaran et al. [152] argues that although digital health apps show effective results, they also show a gradual decline in use over time due to lack of motivation and resistance to behaviour change. Overall, there is a need for more research directly examining people's experiences after cardiac events in relation to digital tools to support CR and self-management.

A comprehensive review by Nunes et al. [125] present the trends and tensions in self-care technologies and found that diabetes was the most common condition addressed by HCI literature. It also showed that there is relatively less research in specific chronic conditions including cardiac conditions. Exploring stakeholder perspectives and technology usage in different clinical contexts could reveal specific barriers and can help design technologies to address these barriers effectively [125,180]. The existing research on broader chronic condition management as discussed in this section has clear relevance for the cardiac domain. However, to be effective, a detailed understanding of the specific requirements of the people experiencing CVDs is required.

2.3   Behaviour Change Theories

Behaviour change theories and methodologies have been widely applied to guide the design of technical systems and evaluation strategies [89,102,127]. A systematic review exploring potential of online self-management programs found that systems which incorporated behaviour change techniques were more effective than those which did not and also that online systems were more effective than no intervention [111]. There are many theoretical models of behaviour, including Health Belief Model HBM [3], the Theory of Reasoned Action TRA [107], the Theory of Planned Behaviour TPB [107], and Social Cognitive Theory SCT [21]. Whilst the large number of theoretical models presents opportunities, it also creates a challenge. Many theories either include a small number of constructs or share common or overlapping constructs such as intention, social norms,

beliefs, or control/ self-efficacy, etc. Therefore, in some cases it is difficult to decipher which are the most appropriate factors to target in behaviour change interventions. In other cases, it is also possible that the key determinants of the target behaviour are not represented. The Theoretical Domains Framework (TDF) [16, 115] was developed in a response to these challenges, in an effort to assimilate overlapping constructs in a pragmatic framework and improve researchers' access to and application of psychological theory.

2.4 Application of User-Centred Methods and Framework

'User-centred design' methodology originated and became widely used after the publication of Donald Norman's co-authored book entitled: *User-Centred System Design: New Perspectives on Human-Computer Interaction* [10]. User-centred design process (Figure 2.1) enables to focus on users and their needs in each phase of the design process [10,156]. In this process, end-users influence how the design takes shape by considering usability goals, user characteristics, environment, tasks, and workflow in the design of an interface. According to Dabbs et al. user-centred design approach during technology design allows for a more accurate assessment of user needs, higher level of user acceptability, reduced development time and improved functionality and usability [54].
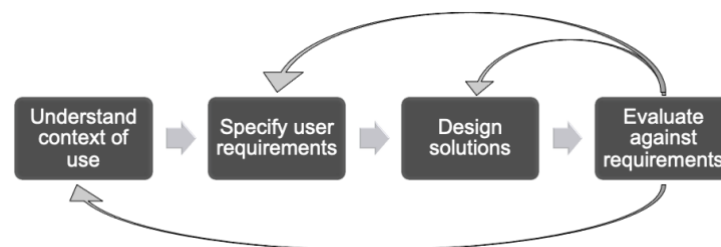
Figure 2.1: User-centred design process [10]

Gulliksen et al.'s [83] (Figure 2.2) influential paper on user-centred systems design bases the process on 12 key principles, some of them include: User focus: user's goals, tasks, needs and context of use should be an early guide to the process; Active user involvement: the users should be directly involved early and continuously in the entire development process; Evolutionary systems development: systems should follow incremental deliveries so that design solutions can be iterated and evaluated before they are made final; simple design representations: the design representations must be easily understood by all stakeholders so that they can fully appreciate the consequences of the design on their future use situation; evaluate use in context: users' behaviours, reactions,

opinions and ideas should be observed in context of their usage and early in the development process. The process used to design the system presented in this thesis applies these key principles and aims to deliver a digital solution that meets the needs of its users, patients and clinicians, and understands its consequences by deploying it in the context of its usage, real-world CR program.
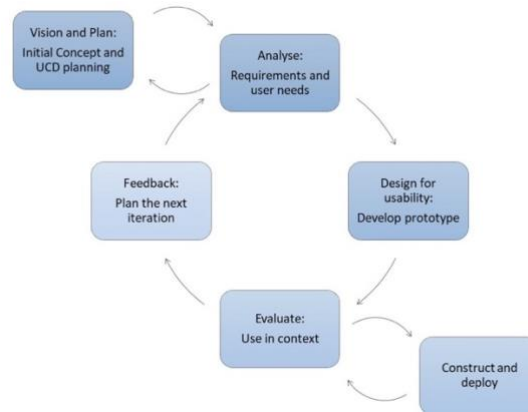
Figure 2.2: User-centred design process [83]

A large body of research advocates the inclusion of the user in development of digital health software and devices [30,109,187]. In a study by Shah et al. [155] 'user' is divided into two categories: the patient ('end-user') and the healthcare professional ('professional user'). They proposed a theoretical framework for involving users in the design of medical device technology and underline the importance of including both categories of users in user-centred design. Researchers believe that stakeholders of digital health systems can be involved in its design in better ways by using the co-design approach and this can lead to improved digital health or mHealth systems [36]. However, despite repeated calls to use co-design approach in digital health studies, there is a dearth of studies that have actually used co-design [123].

Although user-centred design acknowledges the need to design systems around their users' characteristics and needs, researchers have raised concerns that the design process relies more on domain experts' opinions and experiences than involving actual users [18]. Sanders and Strappers argue that co-design approach and conventional user-centred design differ. In that, conventional user-centred design constitutes a designer-centric process where its focus on end-user intends to create a better solution for, but not with, them. Whereas, co-design approach views users as experts in how they use the system and acknowledges that they may use them in ways the designer would not have intended. Sanders and Strappers' co-design framework [151] is one of the most widely

recognised resources in the co-design literature (as of April, 2022, it has 725 citations in Google Scholar). The framework is divided into four inter-connected phases (Figure 2.3):

1. Pre-design phase: Focuses on understanding the surrounding context and people's experiences. It aims to establish goals for future experiences. The pre-design phase commonly appears outside co-design and are similar to the problem-identification phase of the conventional user-centered design process.

2. Generative phase: Focuses on ideas, insights, and concepts that explores the design space. Here users take an active role to express ideas about how they wish to live their future life.

3. Evaluative phase: Focuses allowing users to assess the effects or effectiveness of the system either formatively or summatively. It allows the users to experience a situation that did not exist before.

4. Post-design phase: Focuses on investigating how people actually experience the system. By understanding their lived experiences, the system is expected to evolve based on their needs, habits, and usage patterns. "the tail end of the post-design phase leads to the front end of another design process." Sanders and Strappers' (2014).
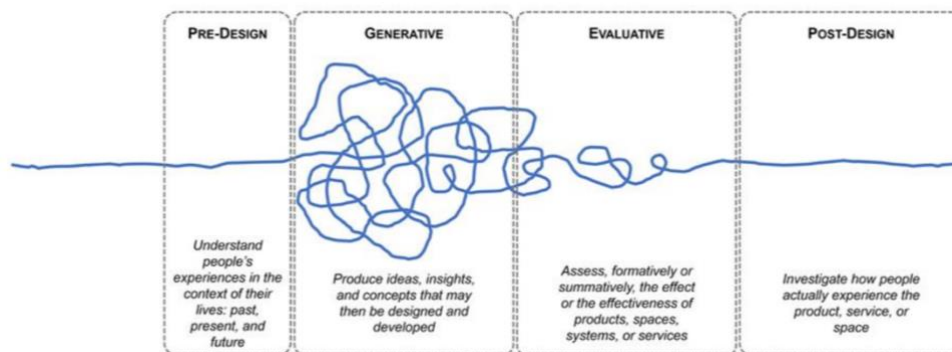
Figure 2.3: Sanders and Strappers' co-design framework [151]

Through the link between the post-design phase to front end of another co-design process, this framework suggests that no designed system is ever complete. Similarly, the research presented in this thesis starts by exploring the needs and perceptions of both patients and clinicians followed by co-designing a digital solution and investigating the lived experiences of patients and clinicians using the solution in real-world.
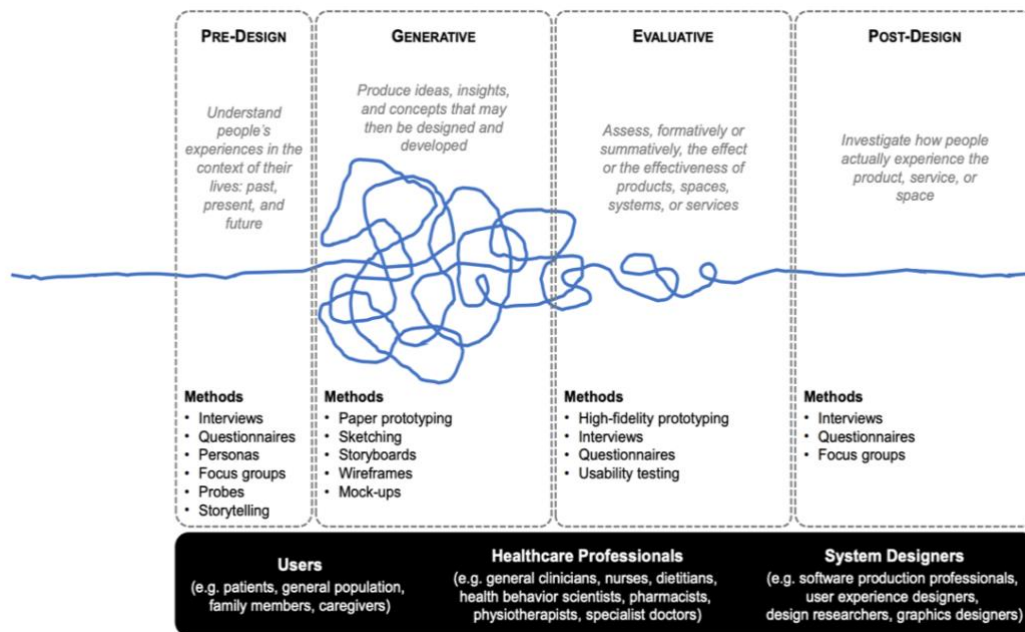
Figure 2.4: From review showing mapping of existing methods and stakeholders to Sanders and Strappers' co-design framework.

A recent systematic review of co-designed mHealth systems development provides a mapping of the different activities applied by current literature and the stakeholders that are usually involved (Figure 2.4) [123]. The review points to the gap of studies in current literature not engaging with user's in the post-design phase and emphasises on its importance as "people engage with systems in ways that were not planned by designers" [75]. Until a design solution has not been deployed in the real-world, the information required to refine the design of the system cannot be acquired [123]. Therefore, by making active use of the post-design phase and not ending the design process after the evaluation phase enables to continuously iterate and factor in changes incrementally. In this research, the evaluative and post-design phases are inter-connected and went through several continuous iterations. Following is a mapping of the methods applied in this research to Sanders and Strappers' co-design framework:

1. Pre-design: Literature review and interviews with cardiac patients
2. Generative: Focus group with clinicians and collaborative design of the initial data-capturing system
3. Evaluative: Deployment of the system in CR programs and clinician feedback
4. Post-design: Ethnographic observations of the CR programs and interviews with patients

Through the application of co-design framework, this thesis aims to provide contextually relevant insights about the actual usage of the digital solution and generate empirically grounded design recommendations that can be applied to the next iteration or co-design process of the digital solution. The ultimate desired outcome of applying the co-design process is to enable the development of a digital solution that is highly usable and functional, thereby increasing engagement in the rehabilitation process, improving rehabilitation outcomes, and empowering patients to transition towards self-management.

The co-design framework and the corresponding studies conducted and the methods applied in this thesis are presented in Figure 2.5.
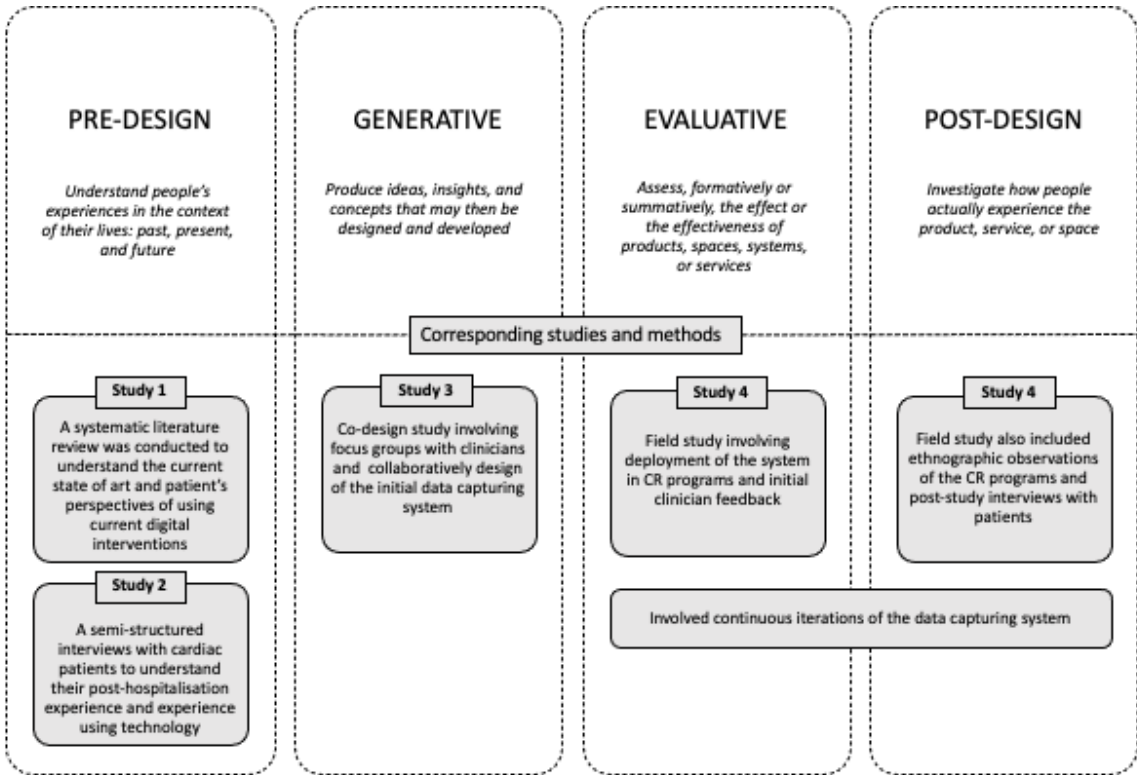
Figure 2.5: PhD research studies mapped to the user-centred design process [175]

The activities and methods implemented in this thesis are outlined in Table 2.1. It details each study and objectives according to each stage of the design process. The table also includes research questions in relation to the overall thesis as well as to each particular study.

Table 2.1: Research plan according to user centered design process

Co-design framework phase	Main activities	Research questions	Objectives
Pre-design phase Also similar to Understand context of use stage in the user-centred design process	Study 1: Systematic literature review	PhD RQ Answered: RQ1. **What are the primary barriers and facilitators to using technology for cardiac rehabilitation and self-management?** Study specific RQs: A. What experiences and attitudes do cardiac patients have with technology? B. What are the barriers of using technology for self-management after cardiac incident according to patients? C. What are the facilitators for using technology for self-management after cardiac incident according to patients? D. What are the design approaches applied?	1. To systematically review and synthesise the literature around current technological support provided for CR and self-management. 2. To understand patient's perspectives of using current digital interventions for CR and self-management. 3. Design approaches applied in existing literature to design such technologies. 4. To understand the limitations in current digital interventions and explore the opportunities for technology design.
Pre-design phase Also similar to Specify user requirements stage in the user-centred design process	Study 2: Semi-structured interview with CVD patients	PhD RQ Answered: RQ2. **What are patients' experiences after a cardiac incident?** Study specific RQs: A. What were the key experiences of patients after cardiac surgery and how did these experiences support or hinder rehabilitation and ongoing self-management? B. How did the experiences of patients change over different phases of recuperation, rehabilitation, and self-management?	1. To develop a holistic understanding of patients' experiences after a cardiac hospitalisation. 2. To explore how these experiences support or hinder rehabilitation and ongoing self-management. 3. To exploring the factors that impact patients' behaviour and behaviour change after hospitalisation. 4. To explore the key opportunities and challenges that technology mediation can address.

		C. What strategies can be applied in design to better support technology-mediated cardiac rehabilitation and self-management?	
Generative phase Also similar to Design solutions stage in the user-centred design process	Study 3: Co-design study	**PhD RQ Answered:** RQ3: **In what ways does the combination of objective and subjective data-capturing support cardiac rehabilitation and self-management?** Study specific RQs: A. What critical design features can improve the experience of cardiac rehabilitation and self-management? B. What are clinicians' needs and perspectives of technology-mediated CR?	1. To develop an understanding of clinicians' experiences of CR program and requirements from technology to support CR. 2. To design a data-capturing system building on both patients and clinicians' requirements. 3. To design a technological system that addresses some of the challenges and opportunities identified from RQs 1 and 2.
Evaluative phase **and** **Post-design phase** Also similar to Evaluate against requirements stage in the user-centred design process	Study 4: Ethnographic and field study	**PhD RQ Answered:** RQ3: **In what ways does the combination of objective and subjective data-capturing support cardiac rehabilitation and self-management?** RQ4: **What are the design recommendations that embody the needs of both patients and clinicians and addresses the barriers identified for technologies that support cardiac rehabilitation and self-management?** Study specific RQs: A. Is the data-capturing system acceptable by the users? B. Does it improve the experience of cardiac rehabilitation?	1. To examine the impact of the designed data-capturing system in real-world clinical context. 2. To reveal limitations or difficulties for future iterations.

		C. What are the collective design recommendations for technology-mediated CR and self-management?	

Chapter 3

Barriers and Facilitators of Technology in Cardiac Rehabilitation and Self-Management: A Systematic Qualitative Grounded Theory Review

3.1 Introduction

This chapter reports the findings of a systematic literature review conducted as part of the first step of the co-design framework, pre-design phase. As mentioned earlier, the first step of the co-design framework is similar to the first step in the user-centred design process, that is, understanding the context of use. The objective of the systematic review was to understand the barriers to and facilitators of digital technologies for CR and self-management. It aimed to synthesise evidence from both medical and computer science literature using the grounded theory method. By applying a qualitative approach, the study could engage more directly with people's needs and experiences of technologies that support CR and self-management. This study has been published in the Journal of Internet Medical Research (JMIR) (Appendix E).

3.2 Background

Although there is significant literature and a growing number of reviews on digital interventions for CVD rehabilitation and management, most previous studies base their conclusions on quantitative data. To better understand what drives the effectiveness and usage of technologies, there is also a need to analyse the collective perspectives of patients, focusing on their experiences, needs, and the barriers they face in using digital interventions. The literature outlined in Chapter 1 has provided evidence that personalisation [86] and the application of appropriate theory will play an important role in improving digital health technologies that target CVDs. For example, behaviour change theories and models can help inform the design of technical systems, guide evaluation strategies, and define target users [88,183]. In addition, persuasive design patterns can be used in digital interventions to address the challenge of obtaining sustained user engagement and behaviour change among patients with CVDs [152]. Building on this evidence, a greater understanding of patients' experiences will provide the insight needed to design future technology and increase the success of technologies when deployed in real-world contexts. By improving adherence to lifestyle changes, appropriately designed

digital health technologies that apply this insight can ultimately help to prevent recurrence of cardiac events.

The decision to focus on both rehabilitation and self-management resulted from multiple discussions among the authors and cardiologists, which reflected the degree to which these issues are interconnected. The papers selected in this review have dealt with some of the common issues and challenges. An overview of these interventions, along with the synthesis of patients' experiences, can be beneficial to both medical and HCI researchers. So far, no previous systematic reviews were found that combined qualitative review methods and an HCI perspective to identify challenges and opportunities in the design of technology to support CR and self-management.

3.2.1   Objectives

The primary objective of this Chapter is to provide answers to the following research question: What are the current barriers and facilitators to using technology for cardiac rehabilitation and self-management? This question is answered by synthesizing evidence from both medical and computer science literature. Using a qualitative approach, this study aimed to engage more directly with people's needs and experiences of technology that supports CR and self-management. Given the strong evidence from the field of HCI that user-centred and iterative design methods increase the success of digital health interventions, this chapter also assesses the degree to which user-centred and iterative methods have been applied in the studies included in this review.

This review follows the grounded theory literature review (GTLR) method [184]. GTLR aims at producing new insights and enables researchers to develop concept-centric yet accurate reviews through a 5-stage iterative process. The GTLR method adopts a rigorous search and selection process, eventually invoking the grounded theory method for the analysis stage. GTLR recommends that initial research questions are identified at the outset of the review process and allows for a bottom-up iterative approach in which new concepts are identified via a thorough and progressive analysis. Initial questions help focus on the review during the selection and analysis stages, but based on concepts identified during the analysis stage, it is acceptable for the final concepts to differ somewhat in focus from the initial questions. Following multiple rounds of discussion and refinement among the authors and cardiologists involved in this study, the following initial research questions were identified:

1. What kind of technological support is provided for CR and self-management?
2. What design approaches were applied in designing the technologies identified?
3. What experiences and attitudes do patients have of technology?

4. What are the barriers to using technology for rehabilitation and self-management after a cardiac incident?

5. What are the facilitators for using technology for rehabilitation and self-management after a cardiac incident?

3.3 Methods

This review follows the 5 stages recommended in the GTLR method [184]: (1) identifying the key research questions, appropriate sources, and search terms; (2) search for potential papers; (3) defined filtering for selection of papers and refining the sample for review; (4) a comparative and in-depth analysis of the papers through 3 coding levels; and (5) representing the emerging categories and concepts. In addition, the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) was used as guidance for conducting this review. The complete PRISMA checklist for this paper is included in Appendix A.

This section reports the inclusion and exclusion criteria of this review, database sources and search keywords used, the screening and selection process, data extraction process, and, finally, the analysis process.

3.3.1 Search Strategy

To include a wide range of perspectives on designing technologies for rehabilitation and self-management of cardiac conditions, papers were selected from PsycINFO, Scopus, PubMed, and ACM (Association for Computing Machinery) Digital Library. HCI literature about designing technology for cardiac conditions was gathered from the ACM Digital Library. Similarly, psychology and medical literature on these types of technologies were gathered from PsycINFO and PubMed. Other major journals and conferences, such as Biomed Central, IEEE (Institute of Electrical and Electronics Engineers), BMJ (British Medical Journal), International Journal of Telemedicine and Applications, SAGE (Scientific Advisory Group for Emergencies), and Global Telehealth, were included in Scopus.

Title, abstract, and keyword searches were carried out on the above mentioned databases to obtain the results for this review (Appendix A). On the basis of the studies the authors were familiar with and to follow a structured process to define the keywords, the keywords were selected to addressed 3 areas: domain, technology, and intervention. In each of these areas, the keywords that were most relevant to identify papers of interest were considered (Table 3.1). Domain keywords focused on CVD as the main field of interest, together with related medical terms (e.g., coronary artery disease). Technology keywords addressed diverse technologies used in inventions (e.g., mobile, wearable

sensors, and telehealth). Intervention keywords reflected on the different types of interventions addressing the field of CVD (e.g., tracking and behaviour change). It is important to note that the search strings used for this review include both Medical Subject Headings (MeSH) and non-MeSH terms. This decision was made because the study aimed at a broad exploration of research in both technology (e.g., HCI and software engineering) and medical disciplines. The technology databases included in this study (e.g., the ACM Digital Library) do not recognise MeSH terms. Including both MeSH and non-MeSH terms represented the most balanced approach and helped to ensure consistency of search terms across the different databases.

For this review, the search of papers was limited to papers published in the last 10 years and focused on papers in the English language and adult patients.

Table 3.1: Keywords used in the search terms

Domain	Technology	Intervention
Cardiovascular disease(CVD)	Mobile	Persuasive/persuasion
Cardiology	Wearable	Quantified self
Cardiac	Wearable sensors	Tracking
Heart disease	mHealth interventions	Behavior change/ behavior
Coronary heart disease	Smartphone	Personal informatics
Coronary artery disease	Tele-monitoring	Habit
Heart failure	Sensing system	Prevention
	Telehealth	Detection
	Telemedicine	Rehabilitation
		Management

3.3.2 Eligibility Criteria

The review was concerned with the use of technology for self-management and rehabilitation practices in the context of CVDs. This excluded several papers that would otherwise be featured in the review, such as those suggesting design concepts without evaluating them [112,152], those describing algorithms or software architectures to solve specific self-care problems [141,158], and those focusing on monitoring and detection techniques to support primary prevention of CVD [9,177]. These types of studies are very

relevant to CVD in a broader sense, but as they do not provide evidence on the use of technology to support self-management or rehabilitation, they were excluded from the review. The papers included in this review involved an active role for patients living with cardiac conditions and technology that could be controlled by the patients rather than those in which patients have a more passive role. This meant excluding a number of technologies used only in clinical settings and technologies based on biomarkers, photoplethysmogram, implantable devices, and defibrillators. Excluding them enabled the review to focus on the lived experience of people with CVD, rather than the clinical care.

Furthermore, this review focuses on studies of patients with cardiac conditions. This excluded self-management and rehabilitation technologies focusing on other chronic conditions [152], wellness and lifestyle [33,80], or quantifying habits for health [45,48]. By keeping the focus on cardiac conditions, the motivation for using the technology was to maintain cardiac health, not to pursue personal interest, leisure, or general well-being, which would likely bring different principles for design and use. To attain subjective perspectives of patients' needs and seek answers to the research questions, this review focused on qualitative study methods. Therefore, to be eligible for inclusion in this review, papers needed to include a technology intervention for CR or management, use qualitative study methods, and describe the use and evaluation of technology with users. Papers that did not follow this criteria were rejected. The inclusion and exclusion criteria are listed in Table 3.2.

Table 3.2: Eligibility criteria

	Inclusion	Exclusion
Domain	Cardiac condition.	Other chronic conditions, general wellbeing, and lifestyle.
Technology	Use of technology with evaluation, Technologies having active patient role, e.g.: Mobile, Wearable, mHealth, Telemedicine.	Design concepts, technology description, algorithms and software architecture without evaluation, technologies having passive patient role, e.g.: Biomarkers, Technology used in clinical settings, Photoplethysmogram, Implantable devices, Defibrillators.
Intervention	Secondary prevention involving self-management and rehabilitation.	Detection and monitoring for primary prevention.

3.3.3 Screening and Data Extraction

The search keywords retrieved 4282 articles, of which 3973 remained after removing duplicates. The papers first went through a pre-screening by reading the title and abstract and papers concerning research abstracts, systematic reviews, protocols, workshops, studies dealing with patients aged <18 years, studies involving chemical and biological sciences, and studies involving clinical procedures were removed. At this stage, the researcher Shreya Tadas (from here on referred to as ST) reviewed all papers, and the the researcher's supervisor, Dr David Coyle (from here on referred to as DC) was consulted in any situation where the researcher was uncertain. Where any disagreement occurred, the paper was not excluded at this stage. In the second phase of screening, ST reviewed the title and abstract of all remaining papers using the full eligibility checklist to decide if they should be included in preselection. This was done to exclude papers that involved studies inclined toward medical and clinical techniques, for example, studies related to biomarkers, photoplethysmogram, implantable devices, and defibrillators and studies related to algorithms, methods, and techniques. DC reviewed a random sample of 10% (170/1700) of the papers at this stage, and agreement was verified across both authors. Where any disagreement was found, the paper in question was reviewed again by both authors and discussed to reach an agreement. Both researchers then met and cross-checked 50% of the final preselection list, discussed inconsistencies, and agreed upon a final list that included 61 papers for potential inclusion.

Each of these papers were further assessed in the final stage of the screening process by ST to check if they applied qualitative methods and included qualitative data.

Any paper that contained both quantitative and qualitative data was included in the final review, but only qualitative data in these papers were analysed. A total of 25 papers were found to include no data, and 20 papers included only quantitative data. These papers were excluded. This left 16 papers that included qualitative data for the final analysis. Figure 3.1 provides an overview of the full screening process.
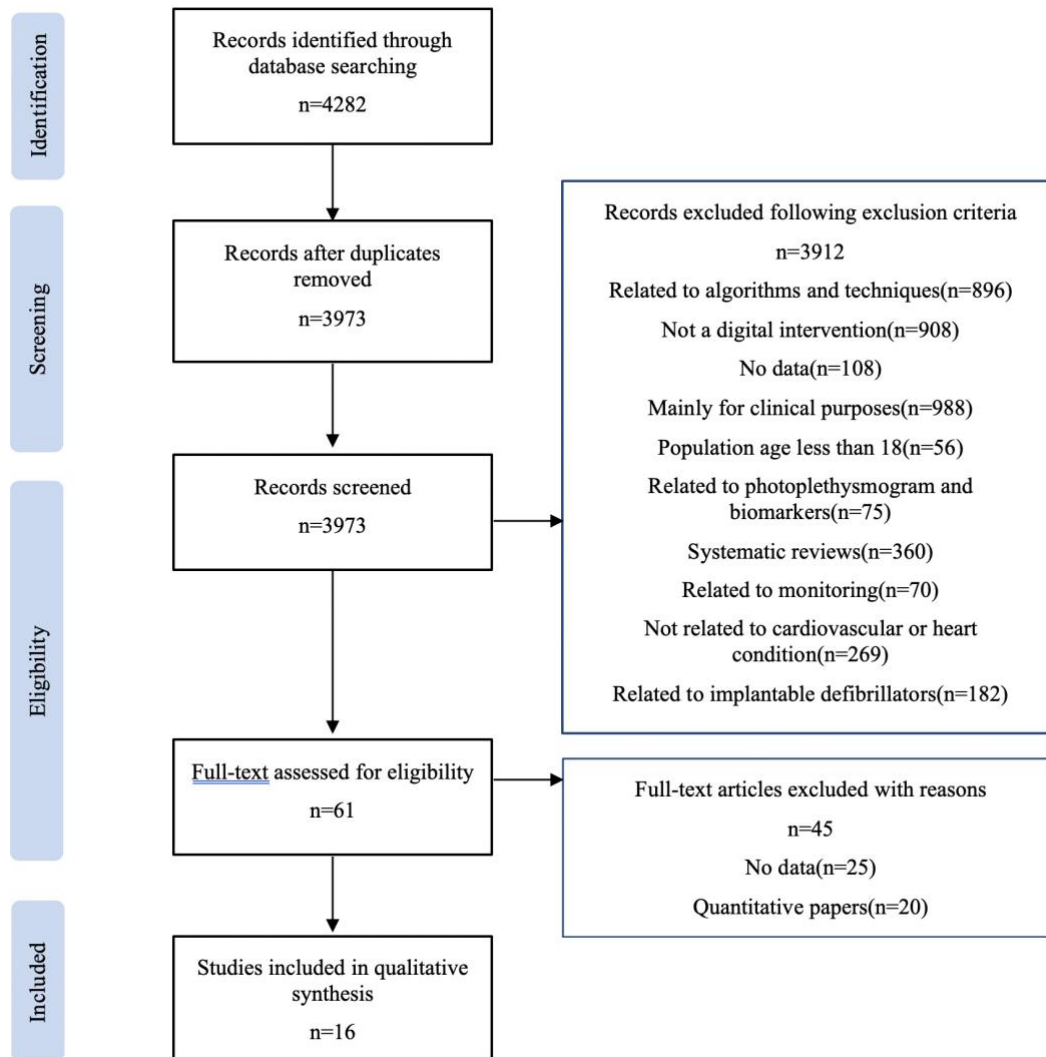
Figure 3.1: Overview of the full screening process

The critical appraisal skills program (CASP) checklist [53] was used to assess the quality of included studies and avoid the risk of bias. The CASP checklists are divided into 3 sections to assess internal validity, results, and relevance to the practice of published papers, and these sections are assessed by questions that can be answered with *yes*, *no*, or *can't tell*. On the basis of the number of questions scored *yes*, an overall rating of *strong*, *moderate*, or *weak* was given to each study. The results of the assessment indicate that

the majority of the papers included in the review are strong, whereas others are rated as moderate. Full details of the CASP assessment are included in Appendix A [177].

Data from the included papers were initially extracted based on the keywords used in the search terms and eligibility criteria (Tables 3.1 and 3.2). This included data such as the number of participants, study methods, and settings for each study. In the final stage of data extraction, the full findings and discussion sections of each of the 16 papers were extracted. This provided data for the subsequent analysis.

3.3.4 Analysis and Synthesis

The analysis step of the GTLR method involves a comparative analysis process with 3 levels of coding: open coding, axial coding, and selective coding. According to the GTLR method, the findings and discussion sections of each paper were considered for this step [184]. The initial research questions guided the coding process and themes. From the set of papers in the final review, ST selected a random paper and carefully read it again, highlighting principal findings, which the GTLR method calls excerpts. Similarly, excerpts from each paper were then listed. At the axial coding stage, these excerpts were articulated to form groups or insights. ST carried out an affinity mapping exercise on these excerpts with DC. This led to the formation of groups and subgroups of the excerpts. At the selective coding stage, these groups were then compared and moved around, followed by discussions among ST and DC to form themes (Appendix A). This process involved iterative back and forth analysis between the excerpts and groups identified, in which stages were repeated and papers reread until a final consensus was reached. The coding process was supported by Boardthing [32], a web-based notice board software that allows individual and collaborative coding and analysis. The themes were repeatedly discussed and refined among ST and DC, and the analysis was only complete as the final version of the review documentation was ready.

3.4 Results

3.4.1 Study Characteristics

As noted earlier, the keyword search retrieved 4282 articles, of which 16 were included in the final analysis. An overview of the included studies is provided in Appendix A [12,19,23,25,39,51,61,70,77,94,98,133,149,160,176,188].

3.4.2 Target Users

All studies in the final list focus on patients who had gone through or were going through a cardiac condition. Some of the studies specifically targeted patients diagnosed with heart

failure, myocardial infarction, and coronary heart disease. Furthermore, some studies particularly involved participants' post-cardiac condition awareness and those who were in their CR phase. Some studies also involved physicians, informal caregivers, nurses, and cardiologists as participants. The papers included studies on both CR [61,25,23,39] [45,46,50,51] and self-management [70,12,133,19,77,51,98,188,160,94,149,176] [40,41,42,43,44,47,48,49,52,53,55,56].

3.4.3   Different Technology Support Provided

In general, the papers in this review investigated mobile or web apps, with some integrating sensors, to manage cardiac conditions. Technology support was explored for both CR and self-management. This included papers featuring a web-based digital intervention [40,12,94], studies using mobile [19,61,25,51], tablets [98], and a combination of web and mobile systems [133,77,188,23,149,176] as digital interventions. 2 studies did not involve any particular system. Instead, they focused on patients' needs and perspectives of using an existing technology and the potential of digital interventions for cardiac self-management [39,160].

3.4.4   Motivation of the Studies

In general, support for self-management was provided through apps that aim to increase adherence, motivation, and engagement. These could be achieved through gamification [61], by providing guidance and education about the condition [70,19,51,160,149], through reminders and notifications, or by using patient data and sensor data to track and show their progress [25,188,160]. Many studies had involved interventions to increase physical activity and exercise for cardiac patients [12,77,25,98]. Studies also aimed to facilitate better connection between patients and care providers, nurses, or health professionals by providing a medium to communicate and share data [19,94,176]. Support for CR was provided through digital interventions that aim to support remote CR. Two papers were about virtual and remote CR to enable rehabilitation for patients in rural and distant locations [25,23]. One study focused on gathering the needs and interests of patients with CVD to effectively enable remote CR [39].

3.4.5   Design Approaches Used in the Studies

Table 3.3 provides an overview of the design methods and guiding theories used in the studies. Overall, as all the papers in the final list are qualitative studies, the studies presented in these papers used surveys, interviews, and usability tests and represented their evaluation and findings through themes (Table 4). Among these, some studies used theoretical frameworks of behaviour change and user-centred design approaches and methodologies. Examples include scenario-based tests, card sorting, goal-directed design,

and persuasive design [12,133,19,77,51,23,94,149,176]. One study used grounded theory to identify themes from participant responses [188]. Another study used gamification design principles to design the system with the aim of increasing motivation and adherence to lifestyle changes [61]. One study assessed the usability of technology using satisfaction surveys [98], another used a technology usage questionnaire to understand technology usage [39], and another used the system usability scale to assess the usefulness of a system [25].

Table 3.3: Overview of the theories and design approaches used in the final review

Name	Design method / guiding theory	Users' involvement
Dithmer M. et al. (2016) [61]	Gamification and gameful design principles (PERMA: Positive emotion, Relationships, Meaning, and Accomplishment) are used to design the application. Gamification principles like badges, levels and leader boards were used to increase engagement and motivation.	Requirements gathering Design/ Prototyping Evaluation/Validation
Yehle KS. et al. (2012) [188]	No particular design principles/ theory and design methodology mentioned.	Requirements gathering Evaluation/Validation
Villalba E. et al. (2009) [176]	Goal directed design methodology is applied. A three phase design process is used: conceptualization, implementation, and validation.	Requirements gathering Evaluation/Validation
Jarvis-selinger S. et al. (2011) [94]	Diffusion of innovation theory was used as the theoretical lens along with current telehealth literature for sensitizing concepts. Qualitative methodology, employing a constructivist approach.	Requirements gathering
Fischer S. et al. (2011) [70]	Used Common Sense Model of illness representation and showed visualization of body structure and behavior based on different symptoms through a web-based application.	Evaluation/Validation
Pfaeffli L. et al. (2012) [133]	A library of text and video messages were developed using self-efficacy theory framework and published exercise guidelines.	Requirements gathering Design/ Prototyping Evaluation/Validation
Katalinic O. et al. (2013) [98]	No particular design principles/ theory and design methodology mentioned.	Evaluation/Validation

Antypas K. and Wangberg SC. (2014) [12]	Different models of health behavior change are combined to form the tailoring algorithm. Tailoring is used as the theoretical framework. A methodological approach that is used to combine the user input and health behavior theory to develop a physical activity digital intervention for cardiac rehabilitation.	Requirements gathering Evaluation/Validation
Geurts E. et al. (2016) [77]	The prototype design was guided by three pillars: simplicity and ease of use, reduce fear and anxiety, and direct and indirect motivation. An HCI perspective is given by categorizing design decisions according to three pillars and show how these pillars resulted in concrete application features.	Requirements gathering Design/ Prototyping Evaluation/Validation
Buys R. et al. (2016) [39]	No particular design principles/ theory and design methodology mentioned.	Requirements gathering
Cornet VP. et al. (2017) [51]	Three frameworks guided the design process: SEIPS 2.0, Patient Work Lens for CHIT, and user-centered design.	Requirements gathering Design/ Prototyping Evaluation/Validation
Banner D. et al. (2015) [23]	No particular design principles/ theory and design methodology mentioned.	Evaluation/Validation
Baek H. et al. (2018) [19]	No particular design principles/ theory and design methodology mentioned.	Requirements gathering Design/ Prototyping Evaluation/Validation
Salvi D. et al. (2018) [149]	Fogg's Persuasive Systems Design principles were used when designing the GEx system, health belief models were used to classify patients on the basis of the perceived benefits and barriers to self-efficacy in healthy behavior. The system design and development were guided by a combination of methodologies: Goal Directed Design (GDD), Persuasive Systems Design (PSD) and agile software development. "desired behaviors" were mapped into specific system's specifications, borrowing concepts from Fogg's Persuasive Systems Design principles.	Requirements gathering Evaluation/Validation
Beatty AL. et al. (2018) [25]	No particular design principles/ theory and design methodology mentioned.	Requirements gathering Design/ Prototyping Evaluation/Validation

| **Smith R. et al. (2015)** [160] | No particular design principles/ theory and design methodology mentioned. | Requirements gathering |

The three main stages of the HCI design process included in the ISO 9241 HCI development lifecycle are requirements gathering, producing design solutions, and evaluating the design against the requirements [10]. There is also a recommendation that this process is iterative, typically involving multiple cycles of design and evaluation. The design process, also known as the user-centred design, focuses on users and their needs in each stage of the process, and iteration continues until it is fit for implementation. This review found limited evidence of studies applying a truly iterative approach and user-centred approach. A total of 9 of the 16 papers stated that a user-centred design approach was followed; however, it is not always clear that this involved multiple iterations of the design cycle [12,133,19,77,61,25,51,188,176]. Only 6 of the papers provided details of studies that involved users in each stage of the process [133,19,77,61,25,51]. Moreover, 3 of 16 studies involved users only in the final stage, that is, evaluation stage [70,98,23].

3.5 Users' Perspectives of Digital Interventions for Cardiac Self-Management and Rehabilitation

This section presents the final themes identified in this review through the grounded theory analysis.

3.5.1 Knowledge

Evidence from the review suggests that knowledge plays an important role in rehabilitation and self-management. Education and knowledge influence self-management and increase confidence. To explain this further, knowledge has been categorised into 2 types: general or background knowledge and personal and in-the-moment understanding.

3.5.1.1 *General Knowledge about CVD*

General knowledge or background knowledge about CVD is the fundamental information or awareness that is required to be known by all patients with CVD. This can be information about one's health condition, symptoms, body, medication, preventive measures, and advised lifestyle changes. Background knowledge also includes awareness about different support systems that help people to care for themselves, such as rehabilitation support and digital interventions.

There is a growing trend to use digital interventions to provide the required educational support. A study conducted to validate a self-care digital system to manage cardiovascular condition at home emphasized that education on symptoms and medication was highly valued by patients and health professionals; however, younger patients had reservations about lifestyle education, as they considered it to be intrusive and annoying. Similarly, patients who were initially scared of new technologies, later, after introductory explanations, found it easier to interact with the system [176]. Similarly, a study that evaluated the use of web-based visualizations of patient parameters to improve patients' understanding of their disease and increase their level of control over the rehabilitation process shows that enhanced knowledge and understanding of the illness and its symptoms can motivate protective action, such as for individuals with heart failure to improve self-management of the illness and the symptoms [70]. For example:

"Now I understand why my legs always swelled up." [70]

"We truly know how to, what is happening inside his heart, and why he's getting all these symptoms. In the 2 years that we've been dealing with this illness, it's so good to have it summarised up so that we know how to care for ourselves better." [70]

Participants also repeatedly referred to the need to find the right answers either through an online forum or some kind of knowledge bank. *"It should be a forum where you have the opportunity to get the right answers, access to a resource, this is what I believe it becomes. It has an effect."* [12]

CR classes are also popularly known to provide essential knowledge, guidance, and support for patients:

"...Your class (cardiac rehabilitation) because they stressed what is really bad for you and what is good for you so that makes you stop and think when you are even buying your groceries to make sure you are getting the right stuff." [188]

3.5.1.2 *Personal and In-the-Moment Understanding*

Personal and in-the-moment understanding is the supplementary information that patients seek to enhance their self-care process. This type of information is acquired through personal tracking and monitoring and refers to the ongoing knowledge people develop about their individual condition. Knowing one's body plays a key role in achieving control of the cardiac condition; however, it may be difficult to notice some changes and trends in

everyday life. Technology has been used to make health and contextual information more easily available to patients and caregivers on an ongoing basis [156]. Patients state that being monitored by technology increases their feeling of security and comfort by enabling a better ongoing understanding of their health [176]. Self-care technologies that use monitored data to guide people to exercise or train within recommended or safe zones boosted confidence and increased motivation:

> "The application is not only beneficial for people who are afraid to exercise, but also supports people that have a higher risk to train too much." [77]

A study conducted to understand the current technology usage of patients with CVD and to understand their needs and interests found that ongoing advice on exercise ideas, exercise prompts, information on local exercise opportunities, healthy meal ideas and recipes, and practical ideas to manage stress received the highest ratings for inclusion in a technology-based CR platform [39]:

> "I am unsure if I am doing the right thing, like food, so I like advice on that." [160]

3.5.2   Social versus Individual

Although most patients often manage their care autonomously, clinicians, other people living with the same condition, and caregivers play an equally important role.

3.5.2.1   Individual Responsibility

Responsibility for change in behaviour is personal [12]. Changing behaviour is easier if new habits are created by replacing old bad ones. To retain changes, it is important to make it part of the daily routine. Ubiquitous technology can support behaviour change in the challenging situations of everyday life and remind users of their own commitments:

> "If you could get a message every day, there and then?" [12]

> "I believe that someone gets used to it, if we make a system, habits. That it doesn't get too much, that we know that...we go online...and we get our own responsibility of our own training." [12]

Technology can support small personal achievements such as getting out of the house to get fit. The use of digital systems as a tool for self-management is valued, especially among the younger ones:

"It gave me the opportunity to get out of the home and try and get myself fit after the operation. I believe it has achieved that and more. I feel better in myself and I can achieve most jobs without taking about it." [149]

3.5.2.2 Connecting with Others

Patients often seek to connect with others living with the same condition, and they use these interactions to understand how to live with their condition, validate their assumptions about their body and self-care, and obtain emotional support [137]. A CR session is an excellent example of this type of environment. A theme repeatedly expressed by the patients of the CR program was the importance of not being alone in the rehabilitation and self-management process. This was an important factor that helped them during their visits to the rehabilitation centre, and it was something they wished to maintain after their discharge [12]. In addition, CR attenders found great value in being able to ask nurses, cardiologists, and dietitians questions according to their specific needs [133]. Digital interventions also provide easy access to others with the same condition, health professionals, and experts. A study on the experiences of patients undergoing virtual CR program (vCRP) demonstrated the potential of vCRP as a medium to provide easy access to health care professionals, nurses, exercise specialists, and dieticians. Although there were some concerns about trust and privacy [12], many of the participants explained that having ongoing monitoring from health care providers as well as support for self-management activities helped them adhere to their recommended program:

"You know I had stents four years ago, and you start off with the best of intentions, but nobody looks over your shoulder and you peter out. At this time, I felt this is a nifty program...somebody's watching it and I better do it. Keeps you honest, keeps you focused." [23]

Keeping in touch with the group helps to lift people's mood, is comforting, and provides support; therefore, many patients liked to use forums and web-based groups. Groups and forums on the internet are seen to help individuals be more committed to fitness by sharing goal completions and bragging about it for healthy competition. Forums brought more focus and motivation, as it makes individuals feel obliged to do activities. A study that used gamification for telerehabilitation program of patients with CVD also demonstrates the importance of social and family support, with patients stating that the most important aspect of the game was being able to play with a partner, thus enabling them to deal with rehabilitation as a team:

"Training diary on the Internet...And also have a group where someone can subscribe to a forum, or have a...to brag...yesterday I walked for an hour and today I have been to the training...and tomorrow I have thought, yes...So, it is like this that someone gets to, a bit, a bit like a competition, internally between each of us. We will train, as much as possible we will commit to ourselves a bit more also." [12]

"I am saying that if we have it fixed, one time per week, that we send a message to each other and then, then you feel committed to say yes, for as long as you like...Yes, then you must have something else that really, you have something else that you have to do, or else...you just do it." [12]

3.5.3 Motivation and Demotivation

The systems in the listed papers took a number of approaches to provide engagement and motivation toward self-management. Some of the key features of technology and patients' attitudes toward them are described below.

3.5.3.1 Feedbacks and Reminders

Digital health interventions such as text messages and mobile- and web-based app reminders push patients to maintain the desired changes [133]. Apps using gamification principles are considered motivating, as they allow score, activity and goal comparison, healthy challenges, and competitions. Creating small manageable tasks was positively received by heart patients. Apps use data visualizations to show meaningful comparisons and to see how well they progressed [188]:

"I went cycling without the application today, but it was less fun!" [77]

"Two teams explicitly stated that on a day with bad weather, they would not have gone for a walk had they not been motivated by the application." [188]

Reminders in any form were positively accepted by the patients. Text messages, although intrusive, pushed them to perform exercises, and many stated that reminders such as an alarm are needed for medication management [176]. On the other hand, some patients did not like reminders, as they constantly reminded them of their sickness.

3.5.3.2 Tracking and Monitoring

Digital health interventions that had the ability to track patients' activities, heart rate, and current health status and showed their progress over time were considered valuable and

engaging [77]. In a study to understand the current technology usage of patients with CVD, 68% of patients reported that heart rate monitoring was important when exercising at home [39]. In addition, patients also anticipated that they would be able to manage their disease more efficiently if their daily data could be easily entered in an app and shared with their doctors [19]:

> "I like the fact that I can put all of that and track it, and that my doctors can as well. I can show my doctor what I've been working on." [25]

> "I think that the idea of an app that records all of the information that this app is doing will be very valuable. Actually somewhat of a motivation for me to do this thing." [25]

3.5.3.3   Personalisation

Some studies in this review suggested that digital interventions that gave the user the ability to personalise the app based on personal interests contributed toward motivation [12,77]. For example, one of the patients in a study that evaluated patients' motivation when using a mobile app that guided them while cycling suggested that the app would be more engaging and fun if it had the flexibility to insert his preferred routes along with the preloaded ones. However, another patient in the same study preferred predefined routes [77]. Another study showed that although patients preferred simple interaction methods, they also asked for the possibility of applying advanced settings [39]. The findings of the same study also suggested that the future of technology-enabled CR might include different solutions to reach both men and women to better engage a broader target population of patients with CVD [39].

3.5.3.4   Increased Burden

Some studies in this review demonstrated patients' concerns regarding using technology. For instance, some patients suggested that adding a device on top of what they already have led to them getting side tracked and thus not using it every day [51]. Patients in the older age group were especially resistant to use technology; some of them lacked interest and found it burdensome:

> "I'm retired and I gave all the computerization that I wanted up, that is it I do not even look at it and I will not even turn it on." [70]

Furthermore, lack of time and other priorities is a barrier to self-management and use of technology. Most patients already have measuring devices at home, such as weight

scales and blood pressure cuffs, and preferred to continue using devices they already know [176]:

> "There are people who like this (application) kind of stuff...and got the time. So for these people it might be great." [51]

3.5.3.5 Acceptability of Technology

In contrast, studies in this review also demonstrated patients' willingness to use technology. For example, one study reported that patients' interest or intent to use an app for CVD management was high, despite the fact that most were older people who were unfamiliar with the information technology environment [19]. Overall, in most studies, patients as well as clinicians readily accepted and showed interest in learning about new technology [19] [98].

Nevertheless, to reach the entire target population of patients with CVD, a variety of technology solutions should be designed to reach both men and women [39].

3.5.3.6 Usability

Finally, usability and ease of use are crucial for the acceptance of any type of digital intervention and thereby influence engagement. Many studies in this review emphasize that simple interaction methods are preferable. For example, one study stated that 38% of the patients preferred an interaction of no more than a few mouse clicks [39]. Patients unfamiliar with technology positively stated that it was just a matter of getting accustomed, and if they learned and used the app regularly, they would find it simple. Some patients also suggested considering e-literacy issues and initial training [12]:

> "It was pretty easy… I like that it's simple." [25]

> "I'm not used to this. Once I get used to it, I'll know where everything is." [25]

3.6 Discussion

3.6.1 Principal Findings

This review aims to understand users' perspectives of technology in CR and self-management and identify barriers and facilitators of the use of technology. The results suggest that many patients have a positive attitude toward the use of technology. The grounded theory approach enabled to identify common themes across the included papers, resulting in 3 principal findings:

1. Designers of new technologies and clinicians recommending existing systems to patients should consider supporting both background knowledge and greater in the moment understanding. Background knowledge and awareness about the condition, its symptoms, medication, and post-hospital care measures is an important factor for effective self-management. But effective self-management also requires patients to be aware of their current body condition and changes in their body, providing reassurance and enabling them to take appropriate measures in self-management.

2. Self-care is a personal responsibility and people like to try different ways to keep themselves motivated to continue performing self-management activities. For some, but not all, opportunities to stay connected with family, caregivers, and others with similar health condition is considered as one of the most effective ways to stay motivated and driven towards rehabilitation activities. Again, technology that supports both approaches is likely to be most beneficial.

3. Technologies can use different approaches to support engagement and motivation towards rehabilitation and self-management, including personalisation, tracking, and monitoring, reminders, and feedbacks. However, they should take account of the potential to demotivate due to issues including overburdening caused by different devices and applications, privacy concerns, lack of trust, lack of interest, and system usability. If not properly accounted for, these issues can impact the acceptability of systems and become major hinderances to effective rehabilitation and self-management.

These key findings are discussed in greater detail below and also considered via the lens of relevant HCI literature.

The first principal finding emphasises the importance of different types of knowledge. Awareness of available resources, such as awareness of rehabilitation classes, existing online support groups, existing self-care digital apps, and remote rehabilitation videos and programs, is important so that patients can leverage these resources for better and sustained recovery and smoother transition to long-term self-management. In addition, ensuring that patients have knowledge of available emotional and physical support helps to foster self-efficacy if they feel overwhelmed by their CVD condition, leading to the inability to effectively self-manage [136]. Prior work in HCI has also identified knowledge as an important factor influencing self-care. For example, a study exploring patients' transition from hospitalisation to self-management emphasizes gaps in knowledge, resources, and self-efficacy after discharge and demonstrates an interconnection between them [136]. The study describes knowledge as information provided to patients about their condition,

medication, and management and resources as social and physical resources, for example, caregivers and access to health services. Self-efficacy is described as the patient's confidence in their ability to self-manage their condition. The gaps highlighted in that study are consistent with the principal findings of this review. The authors recommend that at a system or hospital level, emphasis on verbal communication of information should be avoided. Ubiquitous computing and embedded technologies could be used to capture and retain verbal information received during hospitalisation. In addition, hospitals should provide support and trusted sources of information for patients' access to expertise. Based on the findings in this chapter, these recommendations are also clearly applicable to CR. Similarly, work in HCI describes how patients' understanding of their illness and availability of social and physical resources mediate their self-efficacy [66]. In contrast with prior work, this study has also highlighted the importance of supporting in-the-moment knowledge, which can be acquired through tracking and monitoring. It appears that both types of knowledge can be an integral part of effective CR and self-management.

Effective self-management requires patients to change certain behaviours. An individual's inclination to change behaviour depends on the extent to which they are motivated to change [58,148]. Findings of this chapter highlight that motivation for action is driven by both individual factors, such as personal responsibility, emotions, and goals, and external influences, such as friends, family, caregivers, health professionals, and personalised and persuasive features of technology. These findings reflect on Deci and Ryan's [148] self-determination theory of motivation, which states that a human's optimal move toward growth is driven by 3 needs: autonomy, the need to have control over one's behaviour; relatedness, the need to interact or be connected to others; and competence, the need to experience positive effects of one's activity. Previous HCI research [125,132] provides helpful guidance on how technologies can support these basic needs and also highlights design-related tensions that can arise in balancing different needs. For example, Nunes et al. [125] highlighted tensions in the degree of autonomy to be provided to patients, noting that technologies should take into consideration the different levels of autonomy given to the patients for self-care, as it is highly dependent on the disease and the patient's current condition. Although patients are in charge of their health condition, it is important to reflect on the stages or decisions where a clinician's support is needed. Treatment of CVD relies on a combination of medication and lifestyle changes, and there exists an individual difference in the disease management process. Individual differences refer to how people are similar or different in their ways of thinking, feeling, and behaving [44]. This would include patient demographics, situational or contextual changes, and environment. The transtheoretical model of behaviour change [140] suggests that effective behaviour change

could be obtained if personalised feedback with different motivational levels or at different stages of the behaviour change process is provided to people. Therefore, it is important to take these differences into account and leverage technology to provide tailored care.

In the case of health care technologies, the one-size-fits-all approach could hamper effective self-care practices [68,164]. Nunes et al. [125] also stressed on integrating self-care technologies in everyday lives by prioritizing the lived experiences of patients. This is also emphasized in discussion of *lived informatics* and *design for interweaving* by Rooksby et al. [145]. In other words, for health care technologies to be successfully integrated into an individual's life, it is necessary to acknowledge the everyday life of the individual [20]. Moreover, the results of this review demonstrate that patients' adherence to self-management through health care technologies can be improved if technology does not act as a burden in their daily life and is easy to use.

Digital health interventions draw on 2 central domains of study, those originating in health (e.g., medicine, biomedical sciences, and psychology) and in technology disciplines (e.g., computer science, HCI, and software engineering). This trend is seen in the papers listed in this review. Blandford et al. [31] highlighted 7 areas of contrast in practice between technical and health research. They emphasize that skipping over stages of iterative design before investing in large-scale evaluation of digital health technology leads to suboptimally designed solutions. In the HCI community, there is a growing practice of involving end users early on in the design stage and then throughout the full design and evaluation process. In contrast, the studies listed in this review show limited evidence of applying user-centred and iterative design processes. Blandford et al. [31] also suggested that failing to learn how the nuances of design affect user interaction and engagement leads to failure in replicating it in different contexts and propagates risk from one design to another. Future research on technology to support CVD should address these limitations. Involving relevant users, in this case, patients, caregivers, and health professionals, in each stage of the design process will help reduce user experience challenges and increase acceptance, leading to more effective digital health interventions. Core to addressing this limitation is appropriate and focused engagement with key patient groups. In this context, although CVD impacts adults across all age groups, it is important to also recognize that CVD and other chronic illnesses are particularly prominent among older populations, and their distinct challenges and complex needs have important implications for the design of such systems [95]. The effectiveness of user-centred design with older adults can be seen in the increasing number of studies involving older populations in the early design stages [62,110].

3.7 Limitations

As the aim of this review is to investigate and obtain subjective evidence of the barriers and facilitators of using technology for CR and self-management, only qualitative papers were considered, and review was limited by the analysis of the included studies. The possibility of subjectivity in analysing the findings is acknowledged, although strategies to limit bias were undertaken through the process of grounded theory analysis and consultation with a second reviewer. In addition, the included studies had varied sample sizes, and the technology was used for different amounts of time in different studies. This thesis acknowledges that this variation could have had an impact on the themes emerging in this review.

3.8 Conclusions

The primary objective of this review was to apply qualitative methods to answer the following research question: What are the primary barriers and facilitators to using technology for CR and self-management? The findings of this review show that the use of technology is acceptable to many people undergoing CR and self-management. Although background knowledge is an important facilitator, technology should also support greater ongoing and in-the-moment understanding. Connectedness is valuable, but to avoid becoming a barrier, technology must also respect and enable individual responsibility. Personalisation and gamification can also act as facilitators of engagement, but care must be taken to avoid overburdening people. The findings also highlighted the limited use of iterative, user-centred approaches to guide design in this space.

Chapter 4

Transitions in Technology-Mediated Cardiac Rehabilitation and Self-management: A Qualitative Study

4.1 Introduction

Chapter 3 highlighted the perceived barriers and facilitators for technology usage to support CR and self-management. Findings suggest further exploration of patients' experiences and the application of iterative and user-centred design methods for the design of such technologies. This chapter details the second study which focused on the pre-design phase of the co-design framework and the requirements gathering phase of the user-centred design process. This was an exploratory study which aimed to investigate the experiences and behaviours of patients after a cardiac incident. The findings from this semi-structured interview study are reported in JMIR Cardio Publications (Appendix E).

4.2 Background

The review reported in Chapter 3 found that technology-mediated cardiovascular rehabilitation and self-management has generally been provided through mobile apps, web apps, sensors, or an integration of these. These systems aim to increase adherence, motivation, and engagement through different means, including gamification, guidance, and education about the condition, reminders, and data tracking through sensors. Most of these studies have focused on interventions to increase physical activity and exercise. Some aim to provide a medium for better communication and data sharing between patients and care providers, nurses, or health professionals. A recent systematic review [9] concluded that mobile apps in particular offer an important opportunity to improve access to secondary prevention for cardiac patients, but also concluded that this potential has not been achieved to date. The authors stress the need for personalised and user-friendly apps that can cater to the needs of individual patients from different age groups.

Despite recent calls for technology that supports personalisation and focuses on user needs, Chapter 3 found that - with notable exceptions - prior research in the cardiovascular domain has made limited use of user-centred approaches. This is consistent with the findings of Siegers et al. [157], who also report that most developers of digital

interventions for cardiac self-management did not engage with the direct experiences of patients, e.g. those who have attended rehabilitation programs. Prior studies have also tended to focus on specific aspects of self-management such as physical activity [13] or medication management [21,152]. They do not provide a holistic understanding of behavioural factors that impact people throughout recuperation, rehabilitation and self-management. The work presented in this chapter builds on existing research in a number of key areas, including literature on post-hospital transitions and support [135,136], rehabilitation, and self-management in chronic conditions [63,125], and theories and frameworks for behavioural change. It responds directly to calls for research in the cardiovascular domain to engage more deeply with both behaviour change theories and with patient experience.

4.2.1 Theoretical Domains Framework

The TDF is an integrated theoretical framework made up of domains synthesised from 33 prior theories and 128 theoretical constructs relevant to behaviour change [16]. It was developed in collaboration with behavioural scientists and implementation researchers to provide a comprehensive and holistic approach to identify determinants of behaviour and potential targets for behaviour change. The TDF contains 14 domains covering 84 constructs, examples of which include 'environmental context and resources', 'emotion', 'goals and intentions', 'beliefs about capabilities', 'knowledge and skills', and 'social influences'. A complete listing of the domain and the constructs related to each is available in Michie et al.'s guide to using TDF [16].

The TDF was initially developed to identify influences on health professional behaviour, but has been extended to many areas in which changing behaviour is important, including changing patient behaviour [16]. It supports assessment of problems and identification of potential solutions by providing a lens to view the cognitive, affective, social, and environmental influences on behaviour. As a pragmatic framework it signals opportunities and methods for intervention by first identifying key domains and constructs and subsequently providing a guide to relevant explanations of current behaviours [115]. TDF has been widely used in health research, in particularly where qualitative approaches are applied [40]. Examples of qualitative studies include using TDF to formulate interview questionnaires to address target behaviour [170,171], to analyse interview responses to identify barriers and facilitators in implementing intervention for families of people with schizophrenia [114], and increasing physical activity in stroke survivors [122].

By applying the TDF this study aimed to identify key determinants of behaviour in CR and self-management at the level of the individual. It also aimed to explore the key

barriers and facilitators to implementing technology-mediated CR and self-management solutions. In this study, TDF is applied in the following ways: (1) as a basis for the interview questionnaire to explore individual motivation and capability factors while also covering the physical and environmental influences; (2) to identify the relevant domains that are most likely to influence technology-mediated CR and self-management and associated behaviours; (3) to identify the key points during recuperation, rehabilitation, and self-management journey when different domains exert a strong influence on peoples experience and behaviour.

4.2.2   Objectives

The primary objective of this Chapter is to provide answers to the research question: what are patients' experiences after a cardiac incident? The contributions of the study include a comprehensive assessment of peoples' experiences of recuperation, rehabilitation and self-management, their attitude towards technology, and the ways in which it could better support rehabilitation and self-care. The analysis is framed via the TDF [16,115], an integrated theoretical framework synthesized from 33 prior theories of behaviour change. The key strength of the TDF is that it provides a rigorous and comprehensive framework through which to identify factors that impact behaviour and behaviour change. The analysis presented in this chapter is grounded in a semi-structured interview study with 19 participants who were hospitalised following an acute cardiac incident and subsequently attended a CR program.

The research questions that are addressed in this chapter include:

1. What were the key experiences of patients post cardiac surgery and how did these experiences support or hinder rehabilitation and on-going self-management?
2. How did these experiences change over time?
3. What strategies can be applied in designing to better support technology-mediated cardiac rehabilitation and self-management?

4.3   Methods

Semi-structured interviews were conducted with people who had been hospitalised due to a cardiac event and subsequently attended supervised rehabilitation programs. Interviews were framed using the TDF and explored participants' journeys and experiences post-hospitalisation, their CR experiences, and their attitudes towards technology. Thereafter, as supported by the TDF guidelines, inductive analysis was performed on the interview responses following Braun & Clarke's thematic approach [34].

4.3.1 Recruitment

This study was conducted in collaboration with the Cardiac Unit at Raigmore Hospital, an NHS Trust in the United Kingdom. 19 participants (11 female) were recruited. Participants all had either a cardiac incident or cardiac disease in the past. All participants were offered a CR program post-surgery at Raigmore Hospital [71]. The program consisted of a mix of education sessions and monitored exercises. To represent a range of views patients who attend some, but not all, rehabilitation classes and those who attended all classes were recruited (Table 4.1). Exclusion criteria were adolescents and people with severe cognitive impairments or terminal illness, as it was outside the scope for this study. Participant ages ranged from 50 to 86 (M=70, SD=9).

Table 4.1: Participant's demographic information

ID	Age	Gender	Rehab class attendance	Main form of exercise	Technology used in day-to-day life	First cardiac incident
P01	66	F	All	Walking	Mobile phone	4 yrs ago
P02	70	F	Some	Gardening, walking, looking after grandchildren	iPad, computer	3 yrs
P03	81	F	All	Walking	Fitbit, iPad, computer	10 yrs
P04	65	M	Some	Walking, exercise bike	Fitbit, iPad, computer	3 yrs
P05	75	F	All	Walking, gardening	Tablet	4 yrs
P06	70	F	All	Walking, exercise bike	Smartwatch, computer	3 yrs
P07	83	F	All	Walking	Mobile phone	4 yrs
P08	58	M	Some	Walking	Mobile phone	3 yrs
P09	86	F	All	Walking, gardening	No technology	3 yrs
P10	77	M	Some	Fishing, gardening	Computer, mobile phone	20 yrs
P11	79	F	All	Walking	Computer, Mobile phone	3 yrs
P12	57	M	All	Walking, Gym	Computer, Mobile phone	2 yrs
P13	71	M	All	Walking, gardening	Fitbit, Mobile phone	4 yrs
P14	67	F	Some	Walking, gardening	Fitbit, Mobile phone, computer	6 yrs
P15	68	F	All	Aqua fit, Pilates, walking	Mobile phone	3 yrs
P16	70	M	All	Fishing, walking	Mobile phone, computer	7 yrs
P17	50	M	All	Cycling, Gym	Fitbit, mobile phone, computer	3 yrs
P18	67	M	Some	Gym	Fitbit, computer, mobile phone	9 yrs
P19	66	F	Some	Walking	iPad, mobile phone	2 yrs

4.3.2 Procedure

This study was approved by the Health Research Authority, NHS Research Scotland and Human Research Ethics Committee, University College Dublin. 52 patients were sent interview requests through the post. 19 patients agreed to participate in the study. Interviews were conducted separately over phone calls and were audio recorded. Each interview took approximately forty-five minutes.

The interview questions were based on TDF and inquired about patient's experiences post-cardiac surgery focusing on domains of TDF related to knowledge and skills, individual goals and intentions, social and environmental influences, and emotional influence [16]. Questions about knowledge and skills inquired about their help seeking, new skills or techniques considered post-cardiac event, sources of information, and awareness of their cardiac condition. This included, but was not limited to, awareness about support resources like mainstream self-care technologies and rehabilitation programs. Individual goals and intentions questions were about their experience of rehabilitation program and its barriers and facilitators, post-hospitalisation life goals and changes, and progress tracking. Questions about social and environment probed on environmental and social sources of influence and motivation including role of health experts and technology on self-management post-cardiac event. Questions about emotional influences focused on their emotional reactions and feeling post-cardiac event. The interview guide is included as a supplemental file (Appendix B).

The interview questions were structured according to each phase the participant went through after hospitalisation (Figure 1). The semi-structured interview started with questions about the participants first cardiac incident including hospitalisation, initial awareness about cardiac condition and support resources. This was followed by questions related to rehabilitation program experience, and then the self-management experience.

4.3.3 Analysis

Audio recordings of the interviews were transcribed verbatim. The transcripts were analysed using QSR International's NVivo 12 software and inductively coded using thematic approach following Braun & Clarke's methodology [34]. Three researchers participated in the coding process, Shreya Tadas (ST), Dr David Coyle (DC) and Claudette Pretorious (CP). A codebook was created through an iterative process of coding and clean coding (Appendix B). ST coded all the interviews. 30 percent of the total interviews were coded by CP. Coding was performed through an inductive approach. Coding was performed through an inductive approach. Conflicts were discussed and resolved through discussion with DC. After reaching a consensus on the codebook, three randomly selected

interviews from the entire dataset were coded by ST and CP, followed by an iteration of comparison and refinement. Based on the final codebook refinements, remaining transcripts were coded by ST. Following coding, themes were identified by ST, and again reviewed and defined through an iterative process of independent and group analysis involving ST, DC, and CP. Table 4.2 shows the grouping of codes from the codebook (Appendix B) into themes, these themes are mapped to the TDF domains and further categorized into the three key phases post-hospitalisation.

4.4 Results

Analysis of interviews with participants about their post-hospitalisation experiences identified a number of key themes. In Table 4.2 these themes are categorized into the three key phases patients went through after hospitalisation: recuperation, rehabilitation, and self-management. As shown in the Table 4.2, findings are also classified in the context of TDF domains. It is important to note that there is some overlap in the themes identified in Table 4.2, with issues present in more than one phase. The study's analysis deliberately placed an emphasis on identifying themes in each phase. This has resulted in more overall themes than might typically be the case in thematic analysis. By structuring the findings in this way allowed us the benefit of identifying the point when specific experiences first emerged, and when they were felt most strongly. The Discussion section reflects on how specific needs (e.g., a desire for normality) changed over time and the implications these changes have for the design of technology.

Table 4.2: Mapping of post-hospitalisation transition phases, relevant TDF domains, and themes from findings

Transition	TDF Domains	Themes	Codes
Recuperation phase	Goals	A desire for normality	Feeling better after cardiac event
			Rebuilding strength
			Desire for a normal life
	Knowledge	Sources of information and role of official/expert resources	Initial help seeking
			Need for information
			Contact with health care professionals
			Resources recommended by experts
	Emotion	Gratitude	Gratitude/Appreciation
			Emotional response/reaction
Rehabilitation classes phase	Emotion Optimism	Mindset and emotion	Stress/anxiety and relaxation
			Positivity/Negativity
			Fear
	Environmental context and resources	Rehabilitation classes provide a safe space	Preference for local or in-person rehab
			Rehabilitation classes as a training place
			Classes as a safe zone
			Tailoring
			Barriers to local attendance
	Social influences	Rehabilitation classes provide a social space	Rehabilitation classes as a social place
Self-management phase	Environmental context and resources Social influences	The importance of family and social support	Environmental or contextual support
			Social support and types of social support
			Self-reliance
	Behavioural regulation	Monitoring	Bodily awareness
			Monitoring
			Motivation/ Demotivation
	Beliefs about capability	Capability	Emphasize what can be done
			Physical activity found in daily activity

4.4.1 Recuperation Phase

Recuperation phase is the period immediately after discharge from hospital following cardiac surgery.

4.4.1.1 A Desire for Normality

The desire for a normal life (defined as the life patients had pre-cardiac surgery) was identified across each of the three phases described in the results. However, it was during the recuperation phase that this desire first emerged and was expressed most strongly. While some patients experienced significant physical and mental effects, other patients described feeling better and healthier after surgery. Some went so far as to say procedures such as the insertion of stents had "*fixed them*" (i.e., cured the cardiac problem) and given them confidence to return to normal life:

> "Once the stents had been fitted, the pain had disappeared, and I felt that the care that I was getting in hospital gave me the confidence to go ahead" (P19)

> "I don't have a condition as far as I am concerned. I had the operation repaired and I've never looked back" (P8)

Others spoke positively about their post-hospitalisation recuperation, but described a more step-by-step, gradual process of rebuilding strength. Every day they would push themselves to do more, but in small increments.

> "Right enough, the next day I went out, I got a bit further. The day after that, a bit further. That was fine. So, I didn't actually have any low points. I didn't regress much at all. It was a fairly gradual and continuous improvement." (P13)

Overall participants expressed a strong desire to lead a *'normal life'* post-cardiac event, without the need to be reminded of their condition. While hospitals provide a lot of information during discharge on potential risks and the importance of aftercare, many were more interested in knowing how and when they could return to their normal way of living.

> "They had a lot of information on the aftercare definitely, what we should do, but I was more interested in would I return to my normal things 'cause I'm a physical person. I'm a walker and I'm always very active and they encouraged me to carry on just like that." (P3)

"I think we all change a wee bit but the whole point is, is not to make a fuss about it, you have to try and get back in your routine again with your family as much as possible and keep it as normal as possible." (P17)

This desire was also expressed in regard to relationships. People wanted to be treated as normal by their friends and family; that is, not over caring. They wanted *"to get on their feet"* and participate in family life in the same way they had normally done before the incident.

"Just treating you I suppose how you were before the incident, if you know what I mean. You're not any different. Maybe my family is just like that. Once I was up on my feet, that was it. Mum's back, sort of thing. I got away with making the Christmas dinner the first year 'cause I was away at the hospital, but I was back to it the next year. That did help because it makes things seem normal. I've had this incident and I can just go on with the rest of the life. So that helped me in that way." (P15)

Viewed through the TDF, returning to a normal life can be seen as a goal for the participants. It is likely to have a strong influence on participants behaviour. The fact that this goal has strong links to participants' sense of role and identity (e.g. the family role) is likely to act as further reinforcement. However, the goal of returning to their life pre-surgery creates a potential tension, as it may come into conflict with the life-style change goals recommended for rehabilitation and long-term health management. Resolving this tension is therefore important for technology designs in this space.

4.4.1.2 Sources of Information and Role of Official / Expert Resources

Patients stressed the need of information about their condition. Increasing awareness and information was important to building confidence.

"Having a heart attack was quite a shock to me and as I said I read as much as I could about it." (P18)

There is a need for reliable information and a need to help people retain this information. Those who had a family history or prior awareness of cardiac symptoms were better prepared in handling the repercussions. When asked about how they sought information initially, the most common response was the Internet and booklets given by their hospital. However, patients also expressed concerns about the credibility and possibility of harm in seeking information on Internet.

"If I had a problem or if I wanted to find out anything about health I will look it up on the computer." (P10)

"Googling too much messes with the head - panic due to sharp info content." (P4)

In the initial stages of recuperation resources recommended by experts were highly valued, as patients trusted these resources. Participants were strongly of the view that there is a need for access to and contact with experts and health professionals after discharge. Any type of contact with health professionals was found to be reassuring during the transition from hospital to self-care and recovery. Talks from experts at the rehabilitation programs were considered very valuable. However, this contact was sometimes restrained, due to time restrictions on health professionals. But also due to a concern on the part of patients that they might burden health professionals.

"Maybe just more contact or freer to contact the cardiac advice line because, me personally, you tend not to want to be contacting them unnecessarily but sometimes just after in the first two or three months … It's just that you feel that you weren't encouraged to do it. No one said, 'Just contact us if you're concerned about anything'." (P3)

Participants desire for information is consistent with the TDF 'Knowledge' domain. During the recuperation phase participants had a need for general knowledge about cardiac conditions and rehabilitation procedures. They placed a strong emphasis on official knowledge sources. As will be seen in later sections, the types of knowledge participants prioritized evolved during subsequent phases, with a greater emphasis also placed on detailed personalised understanding and informal information sources.

4.4.1.3 Gratitude

Acute cardiac events are typically sudden, and unsurprisingly they trigger strong emotional responses. Some participants were physically fit, had no other prior health issues, no symptoms, and no one in their family had prior heart problems. But suddenly they experienced a life-treating event, were hospitalised and underwent surgery. This came as a big shock. One participant described being so surprised that it took him a few months to come to terms with the fact that he had a heart attack. Recovering from such an incident requires emotional as well as physical healing.

"It was a huge shock to have a heart attack, a real shock to the system and it just shows you how vulnerable we are and I think that in itself was an incentive" (P18)

Following on from this initial shock, many patients described a newfound appreciation of life and did not want to take their health for granted. They also expressed immense gratitude and appreciation towards healthcare providers.

"I was aware that this is real, what happened to me, and you know, I used to think I was invincible. Well, I never really thought I was anything other than fit and nothing would go wrong, but now I'm aware, much more aware, that something could go wrong, and I'm very grateful for what they did to me." (P16)

The TDF emphasises the important role that emotion plays in driving behaviour. Participant's sense of shock clearly shows how the emotions experienced have the potential to drive emotional and physical tension. Interestingly, while shock delayed some patients' ability to move forward, in others it helped to raise awareness and acted as an incentive. In contrast gratitude always triggered strongly positive responses during the recuperation phase.

4.4.2 Rehabilitation Classes Phase

All the participants of this study were offered a CR program post-surgery at a hospital in the NHS Trust [71]. This section discusses participants' experiences of rehabilitation classes and this phase more broadly.

4.4.2.1 Mindset and Emotions

Patients' emotional responses developed and evolved during the rehabilitation phase. While cardiac events brought out both positive and negative emotions, many described how their mindset or outlook played a major role in recovery and rehabilitation. Participants pointed out that their confidence, determination, and acceptance of their condition helped to reduce the event's impact on their life.

"I'm generally quite a positive person and reasonably confident. I think not unnaturally confident, but if I understand a situation and I know about it and I know what to expect, then I'm fine with it." (P13)

Participants realized the importance of reducing stress or anxiety and noted the benefits of relaxation exercises, which were introduced in rehabilitation classes and were new to many.

"I really liked the relaxation type of stuff, I had never done that in my life, never knew anything about that." (P13)

On the other hand, some participants emphasised that a lack of attention to mental health support, post discharge from hospital and in the rehabilitation program, had an impact on their recovery. One patient was moved to look for private psychological support outside of the public NHS system.

"Half of the problem's with my head to be quite honest with you and if anything I feel that you get let down a wee bit on the recovery part or the mental side of the trauma and I don't feel there's enough done in cardio rehab." (P4)

Fear was a common emotion during the rehabilitation process. Some, for example, were apprehensive about pushing themselves to perform exercises as they were constantly afraid of harming themselves. Others expressed a general concern about an uncertain future. Participants felt this build-up of fear in their minds hindered their progressive recovery and potential for self-management.

"I didn't sleep very well. In fact, I slept in a chair most of the time. It was just apprehension, I suppose, wondering if your life was going – I just thought it was going to drastically change and I wasn't going to be able to do anything, if you know what I mean. I got over that, but it was always at the back of my mind how much will I be able to do because I didn't want to be having to just sit about all the time, but that wore off the better that I got. I did pick up quite quickly." (P15)

The TDF domain 'Emotion' includes the constructs 'fear', 'anxiety', 'positive/negative affect', and 'stress'. Helping people to address these emotions is clearly an important priority in enabling effective rehabilitation and self-management, but one that may be overlooked in some traditional rehabilitation programs. This emphasises the importance of supporting both physical and mental health during the rehabilitation process. Technologies that can provide emotional and mental support, along with reinforcement of a positive mindset and self-reliance therefore have significant potential in this space.

4.4.2.2 Rehabilitation Classes Provide a Safe Space

Although participants identified some barriers, they generally expressed a strong preference for local and in-person rehabilitation. Common barriers reported included transportation, distance, schedule delays, low attendance, limited expert availability, and logistic difficulties. While the preference for in-person rehabilitation is perhaps unsurprising given the participants recruited, the reasons behind this preference point to important factors for technology design.

Rehabilitation classes provided support for training, giving people with an opportunity to gain information and practice physical exercises that they could continue during self-management. They liked the personal interaction with health professionals as it gave them confidence and reassurance that they were doing things properly and progressing. Critically, rehabilitation classes provided a controlled environment –a *"safe zone"*– while exercising and people felt that they could push themselves without the risk of overburdening their body. This safe zoning was important in helping participants to overcome emotions such as fear.

> "I benefitted greatly from the program – the exercise program. Principally because it was monitored because if I get breathless now doing things, I don't want to push it because I don't know how serious that would be, but in the classes when I got nearly breathless, the physio really checked carefully and I felt perfectly relaxed. I knew that nothing untoward would happen while I was in their care." (P9)

Patients found that tailored support focusing on individual needs was encouraging. The rehabilitation program was appreciated for treating every patient individually, helping to set appropriate individual goals, where everybody felt they were achieving something. This encouraged them to continue progressing. However, some patients did find the rehabilitation classes a bit slow and also pointed out that the official self-management information resources received from the hospital were generic. Patients wanted the rate of exercise, the type of exercises and information they received to be determined by their particular needs and how they progressed individually.

> "My feeling is slightly that each person's recovery is very individual and not everybody would want to read through the British Heart Foundation." (P1)

Importantly, rehabilitation classes also provided a structured approach, compartmentalized physical activity and monitoring to set time, separated from regular day-

to-day activities. This was key for some participants, as it supported a sense of normality outside of classes, by allowing for time-bound engagement in physical activity and reserving a set time and place to completely focus on recovery.

The TDF emphasises the behavioural impact of environmental context and resources. Findings show that individual and tailored support, safe zoning, structure/compartmentalization are important elements in the environment provided by rehabilitation classes. Designs that leverage or recreate these environmental factors therefore have significant potential.

4.4.2.3 Rehabilitation Classes Provide a Social Space

Together with environmental benefits, rehabilitation classes were also a social place. This provided several clear benefits – consistent with the TDF's social influences domain. In particular it provided a sense of community and gave people the opportunity to talk to others in similar positions.

> "I think when you are face-to-face with a group of people who are recovering, the same way as you are, I think you encourage each other and I think also the information that you receive collectively adds force to the information that you are given." (P18)

In contrast to formal information provided by health professionals during the recuperation phase, information at this point also came in the form of shared experiences. While this information is less formal, it is also more personal and had a collective power. Patients discussed their direct experiences of dealing with various aspects of recovery process and reassured each other.

> "One other big advantage was being able to talk to other people who were in a similar position. That was really useful, and I think we could reassure each other, and we could talk to each other about how we dealt with various aspects of the recovery process. That was a very valuable part of it." (P13)

A contrast was also seen in the case of normality. In the recuperation phase normality was associated with life before cardiac surgery. The social aspect of rehabilitation classes had the potential to help participants normalise their new experiences, which in turn helped them to adjust to a changing life post-hospitalisation.

> "The classes were good, mainly the fact that we were talking to people who had gone through the same problem, and come out the other end, and we were

getting the feedback from them, making us feel, well, they've been through it, they're looking well, so maybe we can do the same." (P11)

Finally, the social nature of rehabilitation classes was a clear source of motivation. Many participants had experienced technology as "*solitary*" and not something that was shared with other people. Many were reluctant to replace human contact with technology. A "*human touch*" was considered very important, whereas technology was considered optional or supplementary.

> "The motivation is meeting up with people and you all join in and that's the motivation I think and you would find time to go to a class, whereas if you were busy during the day doing other things, you sort of put it off and maybe the grandchildren will come and you want to spend time with them and you think I will do that later, the motivation isn't there." (P19)

4.4.3   Self-management Phase

Following the recuperation and rehabilitation class phase, participants moved to the self-management phase, requiring them to take greater responsibility to manage their own condition, without regular professional support.

4.4.3.1   The Importance of Family and Social Support

Social influence was again a key factor in the self-management phase, but here the focus shifted towards pre-established and longer-term relationships. Family was a key enforcer in every phase, but became particularly important in the self-management phase, with close partners particularly important. Family or partners influenced patients physical state by accompanying them for fitness activities or caring for their diet. They influenced their mental state by being encouraging and caring, or just being normal.

> "My wife is very encouraging of me to do healthy things. She leaves it to me, but she's very positive about it, very helpful. She doesn't badger me at all, but she encourages me. I think that's important. If there is someone close to you who cheers your goals and wants you to do well in those goals. I think that makes a huge difference." (P13)

Other social support included friends, common interest groups, or online support groups. Online support groups, although not described favourable by many participants, enabled continuity of communication and mutual support for people who are maybe living in remote areas or are unable to get together with others.

"Interacting with people is much more important because it's social. It prevents depression. I could quite see how you come home from hospital, you're living on your own, I'm frightened." (P2)

Participants also described the influence of environmental or contextual factors like the home, workplace, and surroundings in recovery and self-management. Stress in home and workplace causes anxiety that could have detrimental effects. Most patients found scenic surroundings and nature walks beneficial.

"I'm very lucky. We live in the country, we own our own house, I have a most amazing view from where I'm sitting talking to you just now and I don't have pressures that a lot of people will have." (P2)

While many participants valued social support, some patients preferred to be self-reliant, not liking to be told what to do and wanting to be in control of their life. Some did not want to be a burden on their family and would not bother their GPs unless absolutely necessary. But two patients stressed that they did not need any type of help or support as they considered themselves to be self-sufficient.

"I'm fortunate that I've not got people around at all to assist me or help me in any way and that I maintain is a great, because I strive to do these things." (P9)

"I've lived on my own for most of my life and I'm very sort of self-sufficient I suppose, in a way." (P7)

In the self-management phase, there is a clear overlap between the TDF domains 'Social influences' and 'Environmental context and resources'. This is unsurprising given the interconnected nature of home, work and social/family lives in the day-to-day life of many people. Leveraging technology to provide increased opportunities for family involvement has clear potential and has been widely explored in other areas of health focused research. Maintaining a balance between peoples' desire to be self-reliant and their desire to be connected is also critical in designing such technology.

4.4.3.2 Monitoring

Many participants described becoming more aware of their body, of the link between their mind and body, and *"listened to their body"* more post cardiac event. As described above, rehabilitation classes provided a safe zone. Monitoring was a key part of this, with close overall monitoring by health professionals and regular pulse and blood pressure monitoring. During the self-management phase, self-monitoring in daily life was common and again

gave many patients confidence to continue with physical activities and push themselves. The most commonly monitored measurements reported by participants were heart rate, blood pressure, steps, sleep, and medication. Among these steps was the most frequently monitored unit. The most widely used and well-known monitoring technology among participants was Fitbit. All the patients who owned a Fitbit started using it post-hospitalisation. This was mainly for self-motivation, safety, and to get other useful insights about their body. Monitoring was also done to share with GPs.

> "I probably wouldn't push myself to do things, whereas now, with the Fitbit, I try where possible to be able to fulfil my steps every day." (P18)

The TDF describes the behavioural regulation domain as anything aimed at managing or changing objectively observed or measured actions. Self-monitoring is an important construct in this domain. This quote shows how some participants used monitoring technologies for behaviour regulation during the self-management phase. Monitoring also helped to provide on-going insight and a more personalised knowledge about their own body. However, continuous monitoring could also cause stress and some patients liked monitoring only when they are performing physical activity. Warnings were seen as valuable, but only where something specific and unusual is detected, and not in a more routine or general way that highlights limitations.

> "That could actually cause more of a kind of worrying aspect to people, it could lead to more stress, having to do that and to also find if their heart rate wasn't good, it would be more of a worry to them." (P19)

> "It would be useful if … it could issue a warning if something irregular began to happen." (P13)

This perspective suggests that for some people long-term monitoring will work best when it can be structured or compartmentalised. By combining this approach with warnings that are largely focused on irregular events, it may be possible to develop systems that provide a safe zoning effect similar to that identified in face-to-face classes in the rehabilitation phase. To achieve this monitored safe zone it will be critical that people trust in the privacy of monitoring technologies. Some participants questioned the integrity and transparency of technologies and were unsure if online resources could be trusted. Surprisingly, others also questioned their own potential honesty when entering own information to seek help through a digital application.

"You can put into a computer whatever you like. You can say I'm a six-foot leggy blonde, how do you advise me to get better, but you can type anything in. You're not going to have to be honest into a computer but face-to-face…" (P2)

4.4.3.3 Capability

One of the most interesting recommendations made by participants was that technology should act as an empowering agent. In particular it should focus on what can be done rather than identifying or tracking limitations. Patients believed that technology should guide them by letting them see what kind and how much exercise they can do. In this way technology would more closely mirror the guidance provided by health professionals in rehabilitation classes.

"If there was any kind of technology or anything that would say to them you could actually do this after so many weeks, with care, I think so because all you get told, 'Don't do this,' and then you're sitting there and you think, oh, and everything just seizes up and your confidence does go, to be honest with you." (P15)

Respect for people's autonomy was also important, with one participant negatively describing technology as 'assertive'. To be successful it was essential that technology respected peoples' autonomy.

"That you're always in control of them. What they're providing you with is information and suggestions rather than commands." (P13)

It was found that patients accomplished physical activity through activities in daily life. The preferred type of physical activity for most of the patients was walking and gardening. Their occupation and where they lived reflected on the type of physical activity they preferred.

"My husband's a farmer. We live on a farm. We have no problem with exercise at all." (P2)

As discussed above, self-monitoring is an important construct within the TDF 'Behavioural regulation' domain. Habit is also an important construct in this domain. Alongside encouraging targeted life-style change, the data in this chapter suggests the long-term rehabilitation technology will be most effective if it draws on previously established healthy habits and activities of daily life. This can be combined with recommendations that emphasize capability and reinforce positive opportunities, allowing

designers to build on the empowerment construct, which is emphasised in the TDF 'Belief about Capability' domain. This overall approach is complementary to participants desire for a normal life and should thus be a key focus for designers.

4.5 Discussion

As described in section 4.2.1, the TDF is a synthesis of previous theories of behaviour change. Mapping the themes to the TDF domains provided with key domains and behaviour constructs to consider in each phase after the cardiac event. The key strength of the TDF is that it provides a rigorous and holistic framework through which to identify a wide range of factors that impact behaviour. Unsurprisingly, this has resulted in individual findings that are consistent with prior research on health behaviour change, both in the cardiac domain and beyond. Critically however, use of the TDF has also allowed us to see how factors that influence behaviour evolve over time and identify potential sources of tension. For example, participants experienced a strong initial need for formal knowledge and access to health experts. This subsequently shifted to desire for detailed personal insight and shared peer knowledge. Findings from the review presented in Chapter 3 suggested patient's need from technology to support both background and in-the-moment knowledge during CR and self-management. Findings from this study resonate with this expectation from technology and further suggest that background knowledge is valued during the recuperation phase and in-the-moment knowledge is desired during the CR phase. Findings also show how participants experienced a strong desire for a normal life post-surgery and how a redefinition of normality is important in long-term recovery. This section discusses the findings of this chapter, focusing on five key issues: extended normality, safe zoning, a focus on capability, different types of knowledge, and emotional support. Figure 4.1 provides an overview of key points and recommendations addressed in this Discussion.
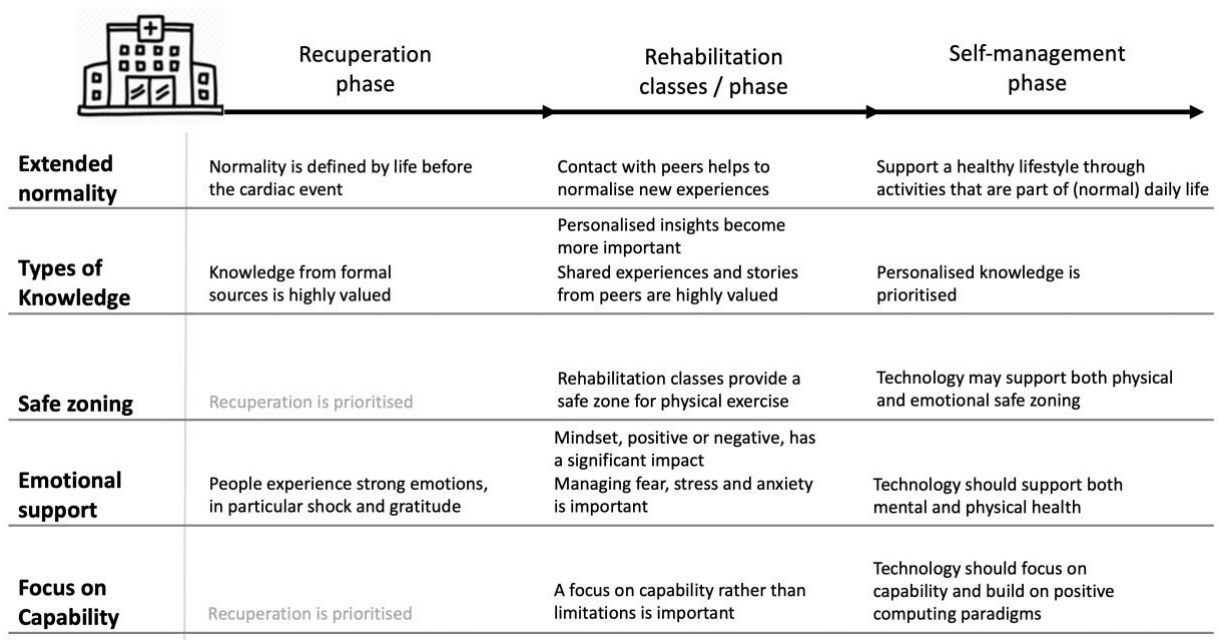
	Recuperation phase	Rehabilitation classes / phase	Self-management phase
Extended normality	Normality is defined by life before the cardiac event	Contact with peers helps to normalise new experiences	Support a healthy lifestyle through activities that are part of (normal) daily life
Types of Knowledge	Knowledge from formal sources is highly valued	Personalised insights become more important Shared experiences and stories from peers are highly valued	Personalised knowledge is prioritised
Safe zoning	Recuperation is prioritised	Rehabilitation classes provide a safe zone for physical exercise	Technology may support both physical and emotional safe zoning
Emotional support	People experience strong emotions, in particular shock and gratitude	Mindset, positive or negative, has a significant impact Managing fear, stress and anxiety is important	Technology should support both mental and physical health
Focus on Capability	Recuperation is prioritised	A focus on capability rather than limitations is important	Technology should focus on capability and build on positive computing paradigms

Figure 4.1: Key experiences and recommendations during recuperation, rehabilitation, and self-management.

4.5.1 Extended Normality

Existing literature has described the mundane nature of day-to-day self-care [125] and the degree to which people prefer to not be reminded of chronic health conditions [108]. It was also found that a desire for normality is a strong motivating factor, indeed it is a stated goal, for many people following cardiac surgery. This creates an obvious source of tension, as life-style change is an important part of CR and is critical to long-term health. Given participants strength of feelings, it is unlikely that behaviour change strategies that run counter to the goal of normality will be successful. Interestingly the findings show how some participants conception of normality evolved over time and suggest ways to address this challenge. We call this '*extended normality*'.

During the recuperation phase normality is defined as a return to the life participants lived before their acute cardiac event. Official knowledge sources and contact with experts provided information on recommended changes. However, in rehabilitation classes participants also began to normalise their new experiences through social interaction and sharing experiences with other cardiac patients. In the self-management phase, the participants who were most successful in sustaining healthy behaviour were those who integrated their health management with their preferred activities of daily life, e.g. walking or gardening. This helped them to reclaim a sense of their old routine, independence, and 'normal life'. Viewed through the TDF this also engages with the importance of self-identify in either hindering or supporting healthy behaviour. The study with stroke survivors by

Ploderer et al. [135] also highlight the peoples' efforts to both manage the illness as well as everyday life activities and to reconstruct their identity.

This leads to a number of recommendations for technology. Critically, technologies should recognize that exceptional goals and external incentives may not be necessary. Normal life is a goal and incentive in and of itself. Care should also be taken to resolve the potential conflict that might arise between participant's goal for normality and the life-style change goals recommended by professionals for rehabilitation and long-term health management. Personalised rehabilitation programs that respect personal autonomy and provide tailored recommendations linked to daily life can help to address this tension. As people transition to life post-surgery, technology that supports enhanced contact with peers and shared stories can also help to develop a new sense of normality.

4.5.2 Types of Knowledge

A previous work by Pollack et al. [136] has provided a detailed exploration of the experience of patients when discharged from hospital. They describe how people are often unprepared for a transition from hospital and identified three important challenges for patients recovering from illness and needed to engage in successful self-management: (1) lack of support for health knowledge, (2) no opportunity to access resources, and (3) no opportunities to promote self-efficacy. This section discusses knowledge and access. Self-efficacy is discussed in greater detail in the section focusing on capability below (Section 4.5.5). Findings again show that peoples' knowledge needs changed over time.

During the recuperation phase people placed a high value on formal knowledge, in this thesis it means information provided by health professionals and official sources. Much of this was standardised information about CR and life-style management, including standardised official booklets. Participants also sought information online but were often mistrusting of such sources. During the rehabilitation phase a change occurred in the information participants valued. Formal knowledge remained important, but participants no longer wanted generic information. They place a high value on both shared experiential knowledge and detailed personal insight. Shared experience was facilitated through contact with peers in rehabilitation classes, and occasionally through online support groups. As noted above it played an important role in normalising peoples' new experience. Personal knowledge was initially facilitated through the tailored support provided by health professionals in classes and later, although typically to a lesser degree, through self-monitoring technology. Findings regarding the types of knowledge are consistent with the systematic review of barriers and facilitators of technology for CR and self-management presented in Chapter 3. This review emphasised the need for technology designers to

support background knowledge as well as personal and in-the-moment knowledge; where background knowledge is awareness of their medical conditions, medication, post-hospital care measures, and available support systems; and in-the-moment knowledge is awareness of current body condition and changes in their body.

Moving forward, technologies that support different types of knowledge have significant potential. However, it was striking that many of the participants in this study expressed a view that technology is a "solitary" thing. Within the HCI field there are significant bodies of research on the design of technologies that support social connectedness in health [132] and on personal and lived informatics [145], and the use of technology to support informal care giving [82]. The development of effective social network in self-monitoring technologies in health domain is clearly not a trivial task. But research in the cardiac space will benefit from building on this prior work.

4.5.3 Safe Zoning

During the rehabilitation phase, participants liked the controlled environment, intensive monitoring and detailed personalised support provided by health professionals. It provided insight about their current health status and increased confidence by assuring that they are within a safe zone of physical activity. This *'safe zoning'* helped participants to overcome emotions such as fear. Critically it did not provide safety by reducing activity. Rather it provided a space where people could push themselves without the fear of overburdening their body.

Technology that supports this safe zoning on an ongoing basis is likely to be highly valuable. Importantly safe zoning should consider not just physical, but also emotional safe zones. During the self-management phase self-monitoring gave some patients confidence to continue physical activities and push themselves. However, many patients also did not want to be monitored continuously, as this could cause anxiety and interfere with their desire for normality. This finding is consistent with previous findings of Maitland et al. [108] that cardiovascular patients were reluctant to accept unnecessary monitoring. Warnings were also considered valuable only when something unusual is detected and not in a more routine or general way. Structured or compartmentalized monitoring approach with warnings largely focused on irregular events may help to provide 'safe zone' effect similar to face-to-face rehabilitation classes. Transparency and trust in the privacy of monitoring technologies will be critical to achieving this goal.

4.5.4 Emotional Support

Acute cardiac events impact people both physically and mentally. In recent decades health research has increasingly recognized and addressed the inter-related nature of physical

and mental health. Take for example the recognition of psycho-oncology as a key element of rehabilitation for cancer survivors [11,52,55].

As participants transitioned from the recuperation to rehabilitation phase, their emotions transitioned from shock and gratitude to long-term emotions. Multiple emotions build up and left unchecked can affect a person's mental health, inducing fear, anxiety, negativity, and loss of confidence. Many patients stressed on the importance of emotional support. Family and close friends were often a vital source of emotional support. Participants pointed out that although a lot was done to educate and motivate them on physical exercise and diet, less attention was given on emotional strength. Although, in-person emotional or mental support is preferred, there is increasing evidence in recent years that technology can play a significant role in providing support for mental health [150]. Examples range from systems specifically design to integrate with traditional care [163] to the more exploratory use of voice interfaces and chatbots using artificial intelligence to provide emotional support [26]. Importantly, alongside negative emotional experiences, participants also expressed positive emotions such as gratitude and renewed appreciation of the natural world. Many also described the beneficial impact of a positive mindset and an increased sense of the link between mind and body – including an appreciation of the stress reduction in rehabilitation classes. This suggests significant potential in the application of positive computing approaches [192], that emphasis human potential and reinforce emotions such as kindness and gratitude. Approaches such as computer supported mindfulness also have significant potential to support stress reduction and enhance the sense of a positive mind-body link [172].

4.5.5   Focus on Capability

Building on the value of positive computing approaches, this study strongly suggests that designers should focus on capability, rather than limitations. Particularly in the self-management phase, participants in this study expressed a strong desire for technology that can recognise renewed strength and make positive recommendations. They wanted technology that shows what is possible by tailoring to their capabilities rather than focusing on limitations. They also wanted technology that respects their autonomy, places them in control, and offers suggestions rather than being directive. Interestingly, some participants placed a significant value on self-sufficiency. They did not like to be helped by family or friends. It is possible that people in this group would also consider technology as encroaching on their preference for self-sufficiency. But it is more likely that autonomy respecting, and capability focused systems will have a significant potential with this group. This analysis resonates with the conclusions in Andersen et al. [7] study where reintroducing patients as active diagnostic agents in the telemonitoring system showed

patient's willingness to take on the added workload and become actively engaged in their monitoring and diagnosis. The systematic review presented in chapter 3 also found that motivation for action was driven by both individual factors and external influences and that patients wanted technology to support both connectedness and individual responsibility. These findings are consistent with the analysis presented in this section.

Through the growing capabilities of recommendation system techniques, technology is envisioned to be key in enabling personalised rehabilitation and self-care by focusing on individual capability. Tailoring recommendations around daily activities will be important in achieving this. Applications should also take into account the effect of progress awareness, wherein, tailored programs based on step-by-step progress and presentation of the progress would contribute towards motivation. Previous HCI literature on person-centred recommender systems, by researchers such has Konrad et al. [103] and Hollis et al [91], offers valuable guidance in this area.

4.6 Limitations

This thesis recognises the potential limitations of using TDF to analyse the interview data and structure the findings. As with the application of most frameworks and models, this thesis acknowledges that classifying the themes into the 14 domains of TDF could have limited the findings of this study. Although we interviewed a relatively diverse group of people with cardiac problems, including people who both withdrew from and attended a full rehabilitation program, it will be beneficial if future studies include more people aged less than 55 years and more people from urban areas. Although our findings are directed toward supporting patients, we understand that the opinions of caregivers are crucial and involving them will provide a broader view of the impact technology in support rehabilitation and self-care. Similarly, including health care professionals in the design process will also be crucial to the development of technologies that are acceptable and effective in improving the rehabilitation and self-management practices of patients. This work is beyond the scope of this study.

4.7 Conclusions

This chapter has applied the TDF to explore the experiences of people with CVDs, focusing specifically on recuperation, rehabilitation, and self-management phases after an acute cardiac event. Through these three phases this chapter described how factors such as desire for normality, types of knowledge, safe zoning, connectedness, and capability impact

patients. It then highlighted the TDF domains that link to the factors arising in the three phases. Building on the findings, this chapter provides implications of these factors and the TDF domains on the design of technology-mediated CR and self-management. The next chapter, Chapter 5, focuses on the rehabilitation phase and further explores the factors and considerations for design arising in this phase.

Chapter 5

Co-Designing a Data-Capturing and Sharing System for Cardiac Rehabilitation

5.1 Introduction

This chapter describes a co-design study that was undertaken as part of the generative phase of the co-design framework. The generative phase is similar to the solution design phase of the user-centred design process. However, it focuses on users taking an active role in co-creating concepts and expressing ideas about how they wish to live their future life. The co-design study presented in this chapter involves CR clinicians playing an active role in the design decisions. This study is also based on the patient's needs and design considerations of the rehabilitation phase presented in Chapters 3 and 4. By considering the needs of both patients and clinicians, this study aimed to gather the experiences of different stakeholders involved in the rehabilitation phase and to verify the findings discussed in Chapters 3 and 4. Finally, this chapter presents the initial technological solution resulting from the co-design study.

5.2 Background

This chapter builds on the findings from the requirements gathering studies of the pre-design phase presented in Chapters 3 and 4. These studies focused on the needs of cardiac patients after hospital discharge. They demonstrated the importance of shared experiences or connectedness, physical and emotional safe zoning, background and in-the-moment knowledge, recognition of capability, and emotional support during the three phases post hospitalisation. Among the three phases, which are recuperation, rehabilitation, and self-management phases presented in the previous chapters, the rehabilitation phase is considered to play a critical role in changing and influencing a patient's behaviour toward successful self-management. Rehabilitation and self-management are clearly interconnected, in that, effective rehabilitation provides a foundation for successful self-management. Thus, studies presented in Chapters 5 and 6 focuses on the rehabilitation phase, which involves phase 3 CR programs. It reports on the ideation of a technological solution that embodies some of the key factors impacting patients' behaviour during this phase. These include: normalising patient's new experiences through contact with peers and shared experiences, importance of personalised and in-the-

moment insights, the need for physical and emotional safe zoning and support, and focus on capability. In addressing these recommendations, Chapters 5 and 6 focus on the use of patient-generated data in the context of CR. Many papers have argued that data generated through self-tracking wearable devices has the potential to 'bridge the gap' between formal medical settings and day-to-day life, capturing and sharing patients' activities and symptoms outside medical settings. However, here too, a wide range of barriers are observed in the routine and effective use of patient-generated data clinical contexts [59]. Chung et al. [46] found that clinicians, nurses, and specialists found patient-generated data hard to use due to time constraints and a lack of standardized formats. As mentioned in Chapter 2, Andersen et al. [8] identify three key targets in designing eHealth systems. Systems should (1) make sense to both patients and clinicians, (2) be actionable to both clinicians and patients; and (3) be feasible within the organizational and social context.

It is evident from Chapters 3 and 4 that patients like to attend in-person CR programs as they give them an opportunity to talk to experts and share their experiences with others going through similar conditions. However, with the onset of the COVID19 pandemic, more CR programs are moving towards a hybrid structure by using technological tools that support online video and audio communication. Lack of resources and busy workflow brings the need to support clinicians in monitoring and managing patients during such hybrid programs [47,59]. As discussed in previous chapters, studies have shown that technology-mediated remote CR programs have the potential to support the transition toward self-care by engaging patients in an active lifestyle, improving quality of life, and reducing re-hospitalisation [73,165]. For example, physiological and behavioural signals via wearable activity monitors like Fitbits provide a promising avenue to support patients and clinicians during CR. Since its debut a decade ago, Fitbit devices have become increasingly ubiquitous. However, studies also conclude that the potential of technology-mediated CR programs has not yet been achieved. A number of key barriers have been identified, including lack of trust in such technologies, technology being a burden, technology not addressing the needs and concerns of both patients and clinicians, and users' lack of technical knowledge [15,73,166,168]. To be fully successful and engaging for both patients and clinicians, such technologies need to be designed and implemented by integrating patients' and clinicians' perspectives.

There is growing importance and calls for further research that involves designing technological solutions based on patients' and clinicians' contextual usage and experiences [6,8]. For example, Andersen et al. [8] report that the design of patient-centred digital health services involves an inherent tension between the concerns of clinicians and those of patients. So far, in Chapters 3 and 4, emphasis was given to gathering patients' experiences

and concerns. This chapter focuses on gathering clinicians' concerns and perspectives on CR and technology-mediated CR.

Chapter 3 found that current digital health literature in the cardiac domain lacks the application of user-centred design methods and iterative approaches. There is a need for more participatory and iterative approaches to design patient-centred eHealth systems [8,128]. Andersen et al. [7] demonstrated the use of user-centred design methods for reintroducing patients as active diagnostic agents to design a collaborative digital tool for monitoring heart patients after hospitalisation. They emphasise the importance of increasing patient and provider participation in the design of eHealth systems and telemonitoring practices. The study presented in this chapter furthers this conversation on the importance of participatory and iterative design by designing and implementing a data-capturing system iteratively through collaboration with clinicians. This chapter demonstrates a co-design study that results in solutions that meet both clinicians' and patients' needs.

5.2.1   Patient-Generated Data and Integrating them into Clinical Practice

Patient-generated data has been explored widely. It has the potential to provide unique insights and help support effective diagnosis and patient care [92]. One form of patient-generated data is the sensor-captured data from wearable devices. Through sensors in devices like Fitbit, it is possible to automatically and continuously track signals such as step count, heart rate, and sleep. The use of commercially available fitness trackers and smartphone health apps in clinical practice has become increasingly popular to generate patient data, improve clinical consultations, and provide a remote diagnosis for clinicians [113]. Recently, the implementation and usage of patient-generated data have gained popularity as remote care and diagnosis are becoming more common with the onset of the COVID19 pandemic.

Despite the potential benefits, the diffusion of patient-generated data into routine clinical practice has uncovered several barriers to its practical use. These include insufficient time, unfamiliar structure, and irrelevant information [84]. Few studies have examined the use of patient-generated data from a clinical specialist's perspective and in a real-world clinical context [84,93,180]. Understanding clinicians' perspectives could reveal barriers within different clinical settings [180], and this forms the grounding for the studies presented in this chapter and Chapter 6. Researchers suggest that there exists a difference between patients' and clinicians' expectations with technologies involving patient-generated data; for example, Zhu et al. [190] have pointed to the difference between clinician-initiated tracking and patient-initiated tracking. Clinician initiated tracking was often for specific medical reasoning, and therefore the value of the data was high as compared

to patient-initiated, which was usually due to obsessive behaviour. To make patient-generated data useful, it is essential to understand clinicians' needs and workflow.

Furthermore, in a study by Jacobs et al. [93], clinicians expressed the need to receive both physical and emotional health factors. The need for sharing subjective experiences with objective data points to make meaning of the collected data is gaining importance [147]. The research presented in this thesis aligns with these needs from patient-generated data. It extends this body of literature by presenting findings on the use of structured, clinician initiated, and patient captured objective and subjective data.

It is no longer a surprise that patient-generated data can be helpful for patients themselves and can have an impact on changing their behaviour [130]. Examples of the reported impact of such data and expectations from such data on patients include increased physical activity and encouraging involvement [49], provided a reflection on their health condition [17,38], and increased patient-provider collaborations [46]. There is less research that explores the usage and impact of patient-generated data and engagement with the data in the context of real-world clinical practice.

5.2.2 Importance of Peer Sharing and Shared Experiences

One of the most important motivating factors during a CR program is the opportunity to share experiences and frustrations with others in the same condition [12]. Peer-experience sharing is helpful for patients to understand if what they are experiencing is "normal" and make sense of their specific symptoms, triggers, and treatments [126]. Normality or "normal" refers to a person's acceptance of their own health experience when they discover it to be close to what is experienced by others [74,131]. For example, studies reported in Chapters 3 and 4 found that patients normalise their new experiences after a cardiac surgery during the rehabilitation classes by interacting and sharing experiences with other cardiac patients. Another example is that people with diabetes spend great efforts to validate their personal experiences of their condition and determine whether these experiences were "normal" [126,178]. Chapter 4 found that "Normal" life for patients is a goal and incentive in and of itself, and technology that supports contact with peers and shared stories can help in this seek towards normality. Consequently, research is moving towards developing ways to articulate the knowledge that patients develop and use in their daily lives and make it transferable and useful to others. Research shows that patient knowledge can be understood as a form of practical knowledge that patients use to make sense of the medical and technical knowledge. Patients then translate this into useful information to help manage their daily life with the disease [138].

This importance of peer-experience sharing is consistent with the findings from studies presented in Chapters 3 and 4. In that, patients liked to learn from others' experiences of similar conditions. Technology has the potential to enable this by capturing and sharing patient-generated data. Furthermore, health reporting via mobile devices has the potential to encourage reflection on the illness [101]. However, it was observed in the studies presented in Chapters 3 and 4 that patients hesitate to use online forums and web-based groups to share experiences and learn from each other; this is mainly due to a lack of trust and privacy.

This research aligns with above mentioned perspectives on peer-experience. It extends this body of literature by investigating the impact of structured patient experience data-capturing and sharing on both peers and clinicians in the context of a real-world clinical practice. It aims to provide design implications for future clinical and peer-sharing applications based on patients' perspectives of such sharing.

5.2.3 Technology Supporting Transition from Post-Hospitalisation to Self-Management for Chronic Conditions

The core aim of rehabilitation programs is to support patients in the transition from formal medical care and to prepare them for long-term self-managed care better. Studies on post-hospital transitions in patients with chronic conditions describe how discharged patients are often unprepared to self-manage their condition at home [136]. Being discharged from the hospital involves a transition from a safe environment at the hospital to an unsupervised home environment [135,186]. Patients are often unprepared for a transition from hospital to self-care. Researchers suggest that sufficient health knowledge, opportunities to access resources, and promoting self-efficacy can help patients to engage in self-management successfully [136]. Likewise, chapters 3 and 4 found that after hospital discharge, cardiac patients desired health or background knowledge, ongoing and in-the-moment knowledge, connectedness, supporting their capability and autonomy. Literature in HCI addresses patient empowerment and transition support through the improvement of information engagement and supporting patient-clinician communication during in-clinic visits [113,118,129]. The research presented in this thesis shows how timing and context enable commercially available tracking devices to become empowering agents for patients to transition towards self-management.

5.2.4 Objectives

The primary objectives of this study were to:

1. To develop an understanding of clinicians' experiences of CR program and requirements from technology to support CR

2. To design a data-capturing system building on both patients and clinicians' requirements

3. To design a technological system that addresses some of the challenges and opportunities identified from RQs 1 and 2.

5.3 Methods

The co-design stage involved working collaboratively with a CR team to develop a data gathering and sharing system. Reflecting the recommendations of Andersen et al., the aim was to design a system that would be meaningful and actionable for both patients and clinicians and feasible within the organizational and social context. Understanding the CR team's experiences in running a Phase 3 CR program, including activities involved, how they were run, clinicians involved in the program, their concerns and needs were key to achieving these aims. Whilst patients were not directly involved in the co-design activities reported here, it is important to emphasize that this work built directly on prior studies reported in Chapters 3 and 4, which did involve working directly with cardiac patients and focused on understanding their needs and experience of the CR process. Throughout the co-design process the researcher ST acted to represent the views of patients based on this direct experience and related patient-centred literature. While the co-design reported here was undertaken in collaboration with clinicians, the emphasis was on representing and addressing the needs to both patients and clinicians. Potential limitations in this approach are addressed further in the Limitations section of this chapter.

The study presented in this chapter aimed to gather insight into CR clinicians' current workflow, their concerns, and their experiences working in the Phase 3 CR programs based at the Beacon Hospital. Beacon Hospital is a private hospital in Dublin, Ireland. The hospital runs CR programs in their physiotherapy department. CR clinicians' experiences were gathered by first understanding the structure of the CR program offered by the hospital, including activities involved, how they were run, clinicians involved in the program, their experiences, concerns, and needs. After that, clinicians' expectations of a data-capturing and sharing system were gathered. Within this thesis, the word 'clinician' is used to describe members of these roles who specifically work with and treat patients [174].

The co-design process involved a combination of focus groups, small group meetings, regular discussion of design decisions, and shared prototypes. At the beginning of the first focus group, and to emphasis a patient perspective, findings from previous studies reported in Chapters 3 and 4 with cardiac patients in CR programs were presented. These included: patients need for physical and emotional safety; the importance of

normalizing new experiences through social interactions and peer-experience sharing; the importance of both general knowledge of cardiovascular health and personalized insights; and a focus on capability rather than limitations. Clinicians were informed that the aim was to understand their clinical needs and workflows and to develop a data system that would support the CR program, addressing both their needs and the needs of their patients. As the focus groups took place while COVID-19 restrictions were in force, they were held remotely over Zoom. The focus groups and meetings were moderated by the first author and notes were taken.

The co-design study started with regular interaction and collaboration between the researcher (ST) and the chief physiotherapist of the Beacon hospital CR program. This involved understanding the current workflow of the CR program at the hospital and the logistic needs for running the study. An initial field study plan was created. In initial discussions, the chief physiotherapist emphasized the importance of monitoring patients' physical activity in exercise classes. This allowed physiotherapists to ensure the patient's heart rate (HR) stayed within safe limits, teach patients about their safe HR zones when exercising, and monitor improvements over the course of the program. They now wanted a way to monitor patient's activity level and HR outside of the class to check if they were complying with the recommended activity levels and identify patients who needed immediate attention. They felt this would help reduce their workload, allowing them to check patients remotely and follow up with patients who needed further and immediate attention. With this aim in mind, the CR team had previously purchased a number of Fitbits. However, the Fitbits had not actually been used with patients. Therefore, the initial focus of our data system was on collecting objective data related to patient's physical activity outside of CR class. Given their availability and familiarity to the CR team, and thus feasibility, we decided to use the available Fitbits during the CR program. This plan involved providing patients with Fitbits during the course of the CR program to monitor their physical activity and allow further social interactions during the class.

Following this, the study involved conducting 2 focus groups with the CR team. The CR team consisted of 2 physiotherapists, including the chief physiotherapist, one dietitian, one pharmacist, one occupational therapist, and 2 CR nurses. Both the focus groups ran for 60 minutes and took place remotely, over a Zoom call. The focus group was moderated by ST and notes were taken. The first focus group involved the ST and the CR team. In the first focus group, the author presented the initial field study plan to the CR team. The aim of this focus group was to understand the experiences and workflows of all the clinicians involved in the CR program, their needs, and their expectations of the study. Here, the clinicians shared their data collection needs, past experiences, the structure of the CR

program, and their workflow. Clinicians expressed the need for more information about patients' experience, progress, and post-talk feedback during the CR program. The focus group resulted in a potential data-capturing system that involved the usage of Fitbits and sending weekly questionnaires to the patients. During this focus group, requirements for the weekly questionnaires were gathered. After this focus group, ST drafted an initial set of questions for the weekly questionnaire and a field study plan to deploy the data-capturing system.

The second focus group involved ST and 2 CR physiotherapists who were also present in the first focus group. The aim of this focus group was to finalise the data-capturing system and the field study plan. During this focus group, the principal investigator presented the data-capturing system including the initial set of the questionnaires and field study plan. A complete list of weekly questionnaires was collaboratively designed and feedback about the field study plan was gathered. Thereafter, the complete list of weekly questionnaires and the field study plan were shared with the other clinicians of the CR team for their approval. Any changes that were suggested were made. Following this, a field study was conducted (reported in Chapter 6). The 2 CR physiotherapists were involved during the entire field study by providing feedback and suggesting changes to the system.

5.4 Results

5.4.1 Structure of the CR Program

Phase 3 CR programs at the Beacon Hospital run for 6 weeks and intakes patients who were hospitalised due to a cardiac incident. A phase 3 CR program is composed of one hour of supervised exercise classes twice a week (Tuesdays and Thursdays) conducted by the physiotherapists and a 30-minute educational talk once a week after one of the exercise classes. Each educational talk was given by a different clinical specialist, including physiotherapist, dietician, occupational therapist, pharmacist, and cardiac nurse specialist.

5.4.2 Clinician Requirements for the Data-Capturing System

The hospital did not have a dedicated full-time CR team. The CR programs were managed mainly by two physiotherapists who were also responsible for attending to other treatments provided by the hospital. Other specialised clinicians are involved part-time, specifically for the educational talks. Due to the COVID19 pandemic and the restriction on the number of people in indoor areas, the CR program had to be moved to a hybrid format. This meant patients had an option to either take the classes online through zoom video calls or in-class at the hospital. There was also a lack of staff for the administrative needs of the CR

program. As this was a new format adopted by the hospital and due to the restriction on the number of patients in a class, the CR team had to increase the number of CR programs. For example, before the pandemic, the hospital ran one CR program for 6 weeks with 3 to 4 physiotherapists; now, the hospital had to manage, at times, 2 CR programs during the same 6 weeks with 1 to 3 physiotherapists. Therefore, this increased the workload on the physiotherapists. They desired a way to monitor the physical activity of all their patients inside and outside of the class during the CR program to check if they were complying with the recommended physical activity levels and identify patients who needed immediate attention. This would help reduce their workload by checking on their patients remotely and following up with patients who needed further and immediate attention. Therefore, clinicians wanted the data-collection system to monitor the weekly physical and behavioural data of patients attending the CR program.

The part-time clinical specialists were mainly concerned about their talk reaching the audience. For them, it was essential to know what kind of audience they were giving the talk to and if they needed to tailor the talk accordingly. Therefore, from the system they desired information about the mindset of the patients, their medical condition, and their current knowledge specific to the topic covered by their talk. For example, the pharmacist was interested to know before their talk what was the patient's medical history, what kind of health condition do they have, what medications they are currently taking, their mindset towards medication, do they know how and when to take their medication, and who would they approach if they had a question regarding medication.

During the focus groups with clinicians and frequent interaction with the chief physiotherapist, the following needs were expressed for the data-capturing system:

Requirements for the Fitbit data collection

1. Provide Fitbits to patients and set it up for them on the first day of the CR program.
2. Would like to see heart rate (HR), steps, calories, time spent performing intense activity, and sleep.
3. Would like to be able to access all patients' data on a single screen in a dashboard format.
4. Would like to see day-wise data ranging up to the last 7 days.
5. Would like to be able to see HR trends.

Requirements for the weekly questionnaires

1. The first week's questionnaire would be a general questionnaire mainly focusing on patients' confidence and concerns about engaging in physical activity and their emotional state.

2. Each weekly questionnaire should have a maximum of 12 questions as patients already receive many information emails and questionnaires from the hospital after their surgery and asking them many questions could overwhelm them and affect their responses.

3. The questionnaires should be asked in such a way that there are baseline questions and follow-up questions in order to compare the responses and tailor their consultations accordingly.

4. Some questions were needed to be asked every week while some only once or twice during the program. For example, questions on their level of motivation and how informed they felt should be asked every week while questions related to physical injury and emotional state should be asked only once or twice during the 6 weeks.

5. Questions that repeated every week should be scaled questions ranging from 1 to 10 to observe weekly changes. Patients should be given an option to elaborate their answers.

6. The language and content of these questions should be based on the standard QoL questionnaires (e.g. SF-12, MacNew health-related QoL, the HeartQoL questionnaire, and the Dartmouth [1,4,87,191]). These standard questionnaires, e.g. SF-12, are self-reported outcome measure assessing the impact of health on an individual's everyday life. Such questionnaires are widely used as QoL measure in medical studies.

7. Part-time clinicians wanted to check if patients had reflected on the information received during the class. Therefore, questions relating to the educational talk should be asked the week before the talk and follow up questions should be asked during the week and after the talk is given.

8. Questions relating to emotions, mental health, and social issues were taken out during the first few weeks as they were not considered important enough during the initial weeks. According to clinicians, such data made more sense during the later weeks of the program and during the week of the occupational therapist's educational talk.

5.4.3 Design of weekly questionnaires

It was decided that the patient's physical or objective data would be collected using Fitbit Charge 2 and shared collectively with the CR clinicians twice a week and before each CR class. The experience or subjective data would be collected through weekly questionnaires

and the responses would be shared every week before the first class (Tuesday) of each week as educational talks usually took place on Tuesdays.

The initial list of questions for the weekly questionnaire reflected on the key patient needs and factors influencing patient behaviour during the CR phase that were identified in Chapters 3 and 4, and these were: the importance of normalising new experiences through social interaction and peer-experience sharing, importance of personalised insights, physical and emotional safe zoning, and the importance of recognising capability. However, after the focus groups with the CR team, these questions evolved to also consider the needs of the CR clinicians (Figure 5.1). Therefore, the final list of weekly questionnaires also represented clinicians' requirements as mentioned above and their knowledge of possible patient experiences during the 6 weeks of the CR program (complete list included in Appendix C). The resulting weekly questionnaires included questions relating to the following:

1. Questions relating to patients' confidence levels to manage their condition, how informed they felt, and their motivation levels. These were asked through a scale ranging from 1 to 10, with 1 being least motivated and 10 being highly motivated. These questions were included every week.

2. Questions relating to patients' physical activity were included to understand their physical state, injuries, motivation to perform physical activity, energy levels, and how they kept themselves active.

3. Questions on their stress levels and feelings about engaging in social interaction were asked through a scale ranging from 1 to 10, with 1 being least stressed and 10 being highly stressed. These questions were included twice during the 6 weeks of the program.

4. Questions relating to each educational talk were included. These were about: dietary changes and knowledge, medication knowledge, stress management and relaxation techniques, changes made to their modifiable risk factors, and guidelines on physical activity.
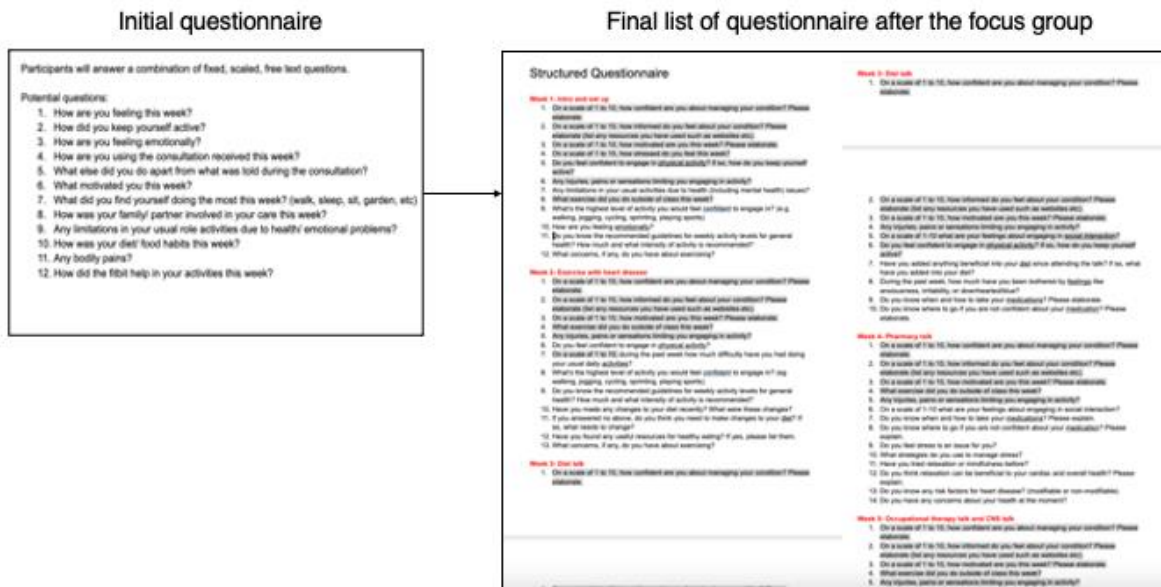
Figure 5.1: Study plan according to the clinician talk schedule in the cardiac rehabilitation program.

5.4.4 Finalising the field study plan and design of the data-capturing system

The focus groups with the CR team enabled to collaboratively design the field study plan and enabled to gather clinicians' requirements for the data-capturing system. The final field study involved the deployment of the data-capturing system during the CR programs and ethnographic observations of the CR programs without disturbing the current workflow of the programs. It was decided that all patients would be provided Fitbit Charge 2 on the first day of their CR program along with a pre-study questionnaire (included in Appendix D) to collect their demographics, smartphone and smartwatch usage in their daily-to-day life, and their attitudes towards sharing their Fitbit and weekly experience data with their peers and the CR clinicians.

Building on the clinicians' requirements mentioned above, the system developed for the field study consisted of a simple web application with functionality to answer questionnaires and have a record of the responses from the patients (Figure 5.2) and a web application to collectively view all the patient's Fitbit data (Figure 5.3). These web applications were developed by the author (ST). Focus groups with clinicians revealed that one of the effective ways to engage clinicians with patient data, keeping in mind their workflow and schedule, was to share questionnaire responses and web application link to view Fitbit data through emails.
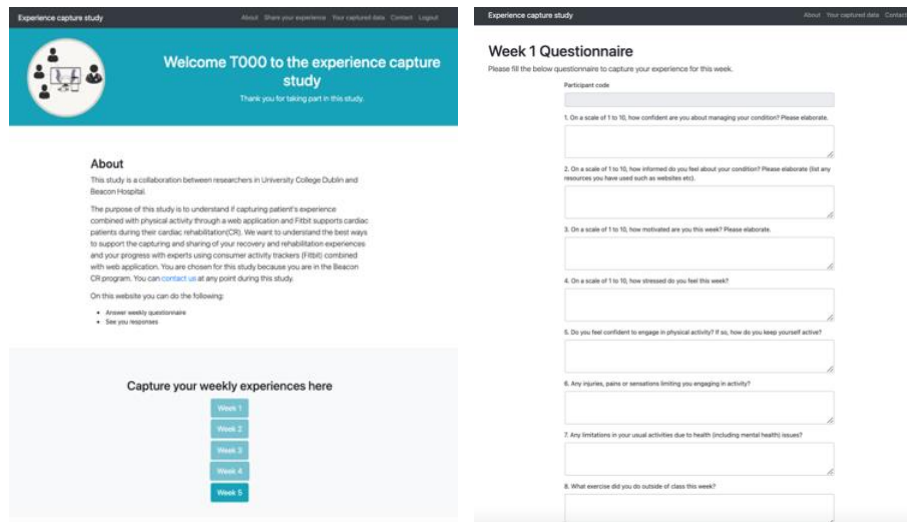
Figure 5.2: Patient facing interface for weekly questionnaire.

Figure 5.3: Clinician facing interface for viewing patient's Fitbit data.

The decided data-capturing system was designed and implemented in such a way that it could be tweaked or was flexible to change during the course of the study. This mirrored the Wizard-of-Oz technique used in studies. The Wizard-of-Oz approach allows the observation of a user interacting with an interface without knowing that the responses are being generated by a human rather than a computer [179]. It helps to gain an early understanding of the user experience factors and uncovers limitations in the technology early on. In order to achieve this, several functionalities of the data-capturing system including the reminders sent to the patients to respond to the questionnaires, data extraction and presentation of patient's weekly questionnaire responses, data extraction and presentation of patient's Fitbit data, and sharing the extracted data with clinicians on a

weekly basis were handled manually by the author (ST) of this study in a way that it replicated an automated background process. However, from the patients' and clinicians' perspective, it appeared as an automated system. Not implementing a fully automated system was deliberate decision as this allowed flexibility for the system to be modified, iterated, and accommodated throughout the CR programs. The evaluative and post-design phase of Sanders and Strappers co-design framework suggests that by understanding users' lived experiences, the system is expected to evolve based on their needs, habits, and usage patterns. Therefore, the aim here was to investigate how patients and clinicians actually used the system and make ad-hoc changes to the system based on their experiences. Figure 10 shows the 6 week CR program schedule at the Beacon Hospital. Physiotherapy sessions and educational talks were usually conducted on Tuesdays and Thursdays of each week, the author as the human working behind-the-scene in the Wizard-of-Oz approach would extract data from patients Fitbit devices and weekly questionnaire responses and share them in an understandable consolidated format to the CR clinicians on Monday. Patient's weekly questionnaire response data would be consolidated in excel sheets and shared through emails. Patient's Fitbit data would be consolidated and presented as a dashboard on the clinician's facing web application. Only those patients that are part of the running CR program would be shown to avoid unnecessary confusion and to maintain patients' data protection and consent rules. Alerts through SMS and email would be sent to patients by the end of each week, specifically on Fridays and Saturdays, to fill out the questionnaire of that week. The patients were controlled to only fill that specific week's questionnaire by disabling the buttons of other weeks. This was done to avoid unnecessary confusion for patients. An example of this can be seen in Figure 5.4.
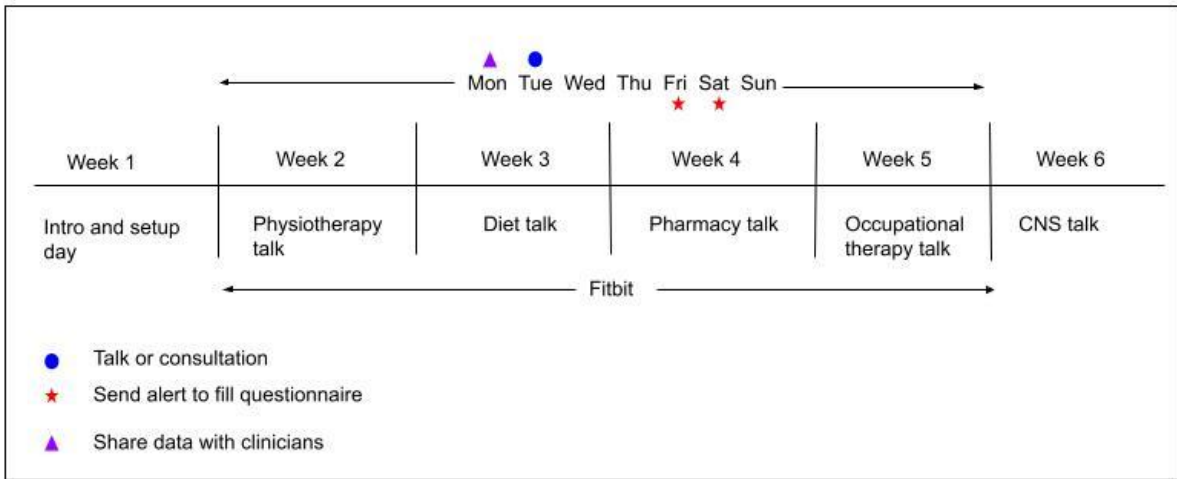

Figure 5.4: Study plan according to the clinician talk schedule in the cardiac rehabilitation program.

5.5 Discussion

5.5.1 Alignment of Patients' and Clinicians' needs

Chapters 3 and 4 focused on gathering patients' experiences and needs after a cardiac incident and the use of technology to support the key phases after the cardiac incident (recuperation, CR, and self-management). Given the strong connection between CR and self-management and the vital role that CR plays towards long-term self-management, this chapter focus on the needs during the CR phase. The co-design study presented in this chapter gathered experiences of clinicians during the CR phase and perspectives about technology to support CR. Findings from patient studies in chapters 3 and 4 and findings from the clinician study in this chapters suggested that during the CR phase:

1. Social interaction and peer-experiences normalised a patient's new experiences. Similarly, physiotherapists also valued social interactions and peer-experience sharing among patients. They were hoping that patients wearing Fitbits during the class would help increase social interaction between patients and foster conversations.

2. Although they seek background knowledge about their health condition, personalised insights become more important. Similarly, physiotherapists needed personalised information of their patients like hourly information about their patients' vitals and its trends, including HR, steps, calories, and sleep.

3. Attending CR made them feel they were in their safe zone during physical activity as their vitals were monitored while performing exercises. Similarly, physiotherapists wanted to ensure patient's safety and make sure their patients are in their safe vital zones. For this, they needed a way to monitor patient's vitals inside and outside of class.

4. Their emotional state had an impact on their progress, and managing fear, stress, and anxiety was considered necessary. Emotional state of patients was also considered vital by the CR clinicians. All clinicians in the CR team needed insight into their patient's knowledge, mindset, and emotional state so that they can keep a track on their progress and address any issues if needed.

5. They expressed a need for self-efficacy and for technology to recognise their capability. Similarly, the aim of the CR team was to make sure their patients were grasping the knowledge received and complying with the recommended physical activity and lifestyle recommendations so that their patients become self-efficient and will be able to continue managing their condition after the CR classes.

As it comes out from the above, an alignment is observed between patients' needs and clinicians' needs (Table 5.1).

Table 5.1: Patients and clinicians' needs from the technology-mediated CR

Patients' needs	Clinicians' needs
Social interaction and peer-experiences are valued	Increase social interaction between patients during the class
Personalised insights become more important	Information about their patients' vitals and its trends including HR, steps, calories, and sleep
Ensure they were in their safe zone during physical activity	Monitor patients' vitals inside and outside of class so that they can make sure their patients are in safe zone
Emotional safe zoning was important for motivation and progress	Insight into their patients' knowledge, mindset, and emotional state
Need for self-efficacy and for technology to recognise their capability	To make sure that their patients were grasping the knowledge received and complying with the recommended physical activity and lifestyle recommendations so that their patients become self-efficient and will be able to continue managing their condition after the CR classes

5.5.2   Design of Data-Capturing System that Embodies Patients' and Clinicians' Needs

The data-capturing system designed through this co-design study aimed to meet both patients' and clinicians' needs and perspectives. The data-capturing system involved Fitbits and weekly questionnaires. It was decided to provide Fitbits to patients on the first day of their CR program and they were invited to wear it for the entire duration for their program. Fitbits were included in the study with an aim to meet the patients' needs for personalised insights related to their vitals, providing monitoring capability to stay in safe zones, and promote self-efficacy. It also aimed to meet clinicians' needs by giving day-to-day information about their patients' physical and behavioural data like HR, steps, calories, and sleep and provided a way to monitor them outside of class. It would allow clinicians to monitor patients' activity outside of class to ensure they are safe and following the recommended physical activity levels. The web application for clinicians gathered all their patients' Fitbit data and presented it on one screen as a dashboard.

The weekly questionnaires aimed to address the patient's needs of shared experiences and understanding of the knowledge received in the classes. Findings from Chapters 3 and 4 showed that patients valued sharing stories and experiences with peers during the CR phase. However, their attitudes and comfort towards sharing their experiences through the mode of technology were uncertain, as findings from previous chapters suggested that people refrained from using online forums and groups on social media. Therefore, for the field study reported in Chapter 6, patients' experiences captured through weekly questionnaire responses were shared only with clinicians and not with the other patients. However, to understand patient's willingness to sharing their questionnaire responses with their peers, the pre-study questionnaire had questions asking about their initial attitude towards sharing experiences with peers. These questions were repeated again during the post-study interviews. The weekly questionnaires also aimed to enable patients to view their lifestyle changes made due to the CR classes and progress made throughout their CR program.

The weekly questionnaire also aimed to address clinicians' needs by including questions which would give them insight into their patients' knowledge, mindset, and emotional state. Questions that were included to enable patients to reflect on the educational talks given by part-time clinical specialists aimed to provide clinicians feedback on their talk and to ensure if the information given through their talk was comprehended. Questions also aimed to address clinicians' need to ensure patients were complying with their recommendations of day-to-day physical activity.

Lastly, to ensure that the system did not overburden patients and especially clinicians, as the high workload and the busy schedule were an important concern, the link to the clinician facing interface for viewing Fitbit data and the weekly responses were shared through emails. Patients were also not expected to learn new technological features. They would be invited to wear Fitbits and would not be expected to engage with it actively. The only action they had to perform as part of the study was to fill out the weekly questionnaires.

5.6 Limitations

Whilst patients were not directly involved in the co-design activities reported in this Chapter, throughout the co-design process the researcher (ST) acted to represent the views of patients based on direct experience of studies and findings presented in Chapters 3 and 4. While the co-design reported here was undertaken in collaboration with clinicians, the emphasis was on representing and addressing the needs to both patients and clinicians. This thesis acknowledges the possibility of bias towards clinicians' priorities in the design.

This thesis also acknowledges that the design of the system might have been different if patients were also actively involved in the co-design.

5.7 Conclusions

Centring the system design on the factors impacting the rehabilitation phase identified in Chapters 3 and 4 and involving the clinicians in the design process revealed valuable insights and considerations for designing the data-capturing system to support patients and clinicians during CR. These design decisions were essential for increasing the acceptability and meeting the needs of a real-world clinical context. Along with informing the system's design, focus groups with clinicians enabled to confirm the findings of the studies presented in Chapters 3 and 4. Once the functional prototype of the system was developed, it was deployed in a field study to understand its impact.

Chapter 6

Ethnographic Field Study of the Data-Capturing and Sharing System

6.1 Introduction

Building on Chapters 4 and 5, which included detailed interviews with patients and a co-design study with clinicians, a field study was conducted to deploy the initial data-capturing and sharing system. The field study also involved observations of the CR programs to gather an ethnographic account of the system in the context of a real-world clinical workflow. This study aimed to understand the impact of capturing and sharing patients' objective (Fitbit) data and subjective (experience) data with clinicians. Thereafter, it explored patient's and clinician's perspectives of sharing and receiving such data between patients i.e., peers.

6.2 Background

Findings from Chapters 3 and 4 presented the needs and factors that influence patients during the CR phase and these included: normalising new experiences through social interactions and peer-experience sharing, importance of personalised insights, physical and emotional safe zoning, and capability. Chapter 5, which focused on understanding needs and perspectives of CR clinicians revealed that clinicians' perceptions and patient needs presented in the previous chapters aligned. The design decisions made during the co-design study were applied and a data-capturing and sharing system was designed to address both patients' and clinicians' needs. The co-design process and steps involved in designing this system were presented in Chapter 5.

The evaluative and post-design phase of Sanders and Strappers' co-design framework [151] involves users using the system. In the evaluative phase, users experience a situation that did not exist before thereby enabling them to assess the effects of a system. Thereafter, in the post-design phase the lived experiences of people using the system in their daily life is investigated. During these phases the system needs to evolve along with the needs and usage patterns of the users. The study presented in this chapter reports on the lived experiences of patients and clinicians using the system and the changes made to the system during the study.

The ultimate goal of the data-capturing system was to further support the CR program's aim of helping patients transition from hospital-care to self-care or self-management. As mentioned in Chapter 5, patient empowerment and transition support through technology can support self-efficacy [113,118,129]. On the contrary, existing literature [12] and Chapter 3 shows patients' hesitation to use technology to share experiences and information due to lack of trust and privacy on the technology. In this study, patient data is collected using Fitbits (objective data) and structured weekly questionnaire (subjective data). This study explores the impact of the data-capturing system by deploying it in real-world CR programs to understand its usage and limitations for future iterations. It aims to address the following RQ: In what ways does the combination of objective and subjective data-capturing support CR and self-management?

6.2.1 Objectives

The primary objectives of this study were to:

1. To examine the impact of the designed data-capturing system in real-world clinical context.
2. To reveal limitations or difficulties for future iterations.

6.3 Methods

This study involved deploying the data-capturing system in real-world CR programs, conducting ethnographic observations of its usage and impact on both patients and clinicians, and collecting feedback on the system through post-study interviews.

6.3.1 Recruitment

After the research ethics committee (REC) approval was obtained, data collection for this study took place between Aug - Dec 2021 at the Beacon Hospital, Dublin which offered phase 3 CR programs. Group size for CR classes was limited to 4 people exercising together in a class due to COVID-19 restrictions. Some CR programs had patients who opted for online CR program and were present in the classes via Zoom video calls.

With the help of the chief CR physiotherapist, patients who met the eligibility criteria for this study were recruited. The exclusion criteria included: patients should be aged >= 18 years, they should be in ongoing CR program, should be open to the use of technology, should be a smartphone user, should have access to an internet connection or mobile data, should be intellectually, visually and auditorily capable to communicate, and should be able to understand and comply with the requirements of the study. Participants were recruited

through purposive sampling of patients who participated in the 6-week CR program at a hospital. Across the 4 CR programs, a total of 16 patients participated in the study, with a mean age of 59.25 years, and including 13 males (Table 6.1).

6.3.2 Field Study

The study ran across 4 separate CR programs. The CR programs hosted at Beacon followed the standardised activities in phase 3 CR programs. Each CR program ran for 6 weeks and was composed of one hour exercise classes twice a week (Tuesdays and Thursdays) conducted by physiotherapists and 30-minute educational talks once a week (Figure 6.1). The educational talks were given by different clinical specialists including physiotherapist, dietician, occupational therapist, pharmacist, and cardiac nurse specialist. All patients who had expressed interest in participating were asked to provide study-specific written informed consent prior to recruitment. After the consent was received, participants were asked to fill a pre-study questionnaire (Appendix D). The pre-study questionnaire had questions about participant's demographic information, current smartphone and smartwatch knowledge and usage, and reflection on their current health condition including physical and emotional health. Thereafter, a Fitbit and web App to receive weekly questionnaires was set up for each person who consented to participate. The Fitbit was used to collect their physical data (objective data) and the web App was used to collect their weekly CR experience data through questionnaires (subjective data).

The field study also involved ethnographic observations of the CR programs. Here the researcher ST attended the CR programs and observed the in-person and online classes. Observations were collected by taking notes during the class. The aim of this observation was to understand the real-world usage and impact of the data-capturing system (Fitbit and weekly questionnaires) during the classes and to collect lived-experiences of patients and clinicians. ST did not interfere in any proceedings of the classes during these observations. The notes taken during the observations were guided by the following checklist:

- Fitbit usage during classes:
    - How are the patients using Fitbit during class? - Interaction with Fitbit during the class
    - Interaction of Fitbit during class by physiotherapists
    - Impact of wearing Fitbit
    - Any conversations related to the data collected by Fitbit while performing exercises
        - Do they talk to each other about their HR/ calories burned/ steps during the class?
    - Any barriers of using Fitbit during class
    - Any advantages of using Fitbit during class
- Weekly questionnaire impact assessment:

- o Did patients have any conversations with each other related to the weekly questionnaires asked in the webapp? If yes, what kind?
  - o Did patients have any conversations with CR clinicians during the class related to the weekly questionnaires asked in the webapp? If yes, what kind?
  - o Did clinicians bring up any topics during their talks related to the questionnaires asked in the webapp? If yes, what kind?
  - o Any difficulties with the webapp usage mentioned in the class?
- General:
  - o Observation of the functioning of the in-class cardiac rehab class.
  - o Observation of the functioning of the online cardiac rehab class.
  - o Operational facilitators and barriers
  - o Any other needs that arise during the class that could be provided or supported using technology
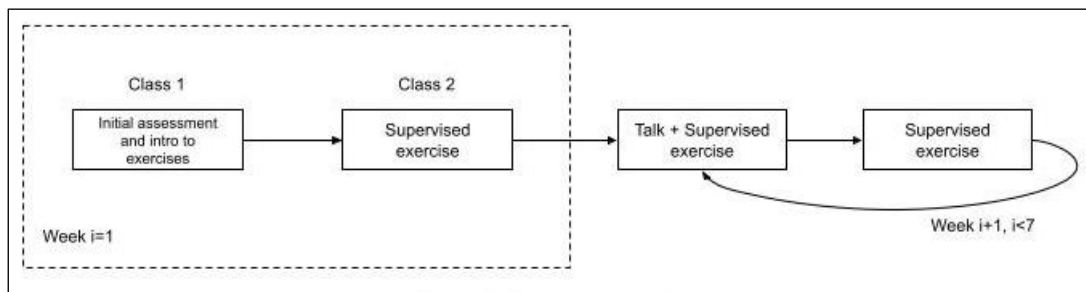
Figure 6.1: 6-week cardiac rehabilitation program.

After the deployment of the data-capturing system in each of the 4 CR programs, a semi-structured interview with the participants was conducted (interview guide included in Appendix D). All 16 patients participated in the interviews. The participants were asked feedback and their experience of wearing the Fitbit and answering weekly questionnaires for the entire duration of their CR program and the impact it had on them including reflection on their current physical and emotional health condition. The interview also included questions to understand their needs for designing a patient-to-patient (peer) experience sharing smartphone application and their willingness to share their experiences with peers if such a functionality is provided in the application.

A follow-up focus group with the CR team was also conducted after each CR program to understand the impact of the patient-generated Fitbit data and weekly questionnaire responses on their consultations, workflow, and future CR classes.

6.3.3 Data Analysis

The semi-structured interviews with patients were audio recorded and transcribed verbatim for analysis. The transcribed data was coded using a combination of inductive and deductive thematic analysis approach was applied to this data [35]. This hybrid approach

allowed to base the analysis on the findings from Chapters 3 and 4 and complemented the overall research questions presented in this thesis. The initial codes were derived from the findings reported in Chapter 3 and 4 and these included "normalising new experiences", "personalised insights", "shared experiences", "safe zone for physical exercise", "emotional support", and "focusing on capabilities". Any new codes identified were added to the list and it was then iterated to produce higher-level themes and then finally abstracted out to three main themes: *importance of data beyond physical activity, engaging with data, and attitude towards data sharing*.

According to the ethics permission received for this study, the Fitbit and weekly questionnaire data was only shared with the CR team and was not permitted to be analysed or directly shared with the other patients in the CR program. This data was thus not subject to detailed analysis.

Table 6.1: Participant Demographics (Patients)

CR program 1			
Participant	Gender	Age	Type of CR Class
P1	M	70	Online
P2	M	54	Online
P3	M	57	Online
P4	M	56	In class
P5	M	72	In class

CR program 2			
Participant	Gender	Age	Type of CR Class
P6	M	67	In class
P7	M	58	In class
P8	M	66	In class

CR program 3			
Participant	Gender	Age	Type of CR Class
P9	F	65	Online
P10	F	71	In class
P11	F	59	In class
P12	M	62	In class

CR program 4			
Participant	Gender	Age	Type of CR Class
P13	M	52	In class
P14	M	36	In class
P15	M	62	In class
P16	M	41	In class

6.4 Results

6.4.1 System Iterations

Mirroring the Wizard-of-Oz technique of system deployment allowed flexibility for the system to be modified, iterated, and accommodated throughout the CR programs. The

system continued to evolve until the end of the field study and this mirroring of the izard-of-Oz technique facilitated the continuous iterations of the system.

Changes made due to this iterative process included but were not limited to:

1. Inclusion and exclusion of questions. Initially some patients were sent structured questionnaire and others were sent unstructured questionnaires with an aim to understand which type of questionnaire offered more information in its responses. However, unstructured questionnaire was found to be overly open ended and as a result gave repetitive and vague responses. Furthermore, these responses did not offer useful information to the clinicians.

2. The wording of some questions were changed after observing the patient responses for 2 weeks. Rephrasing was done to make them clearer and get more elaborate responses.

3. Change in questionnaire schedule was made due to change in educational talk schedule of the part-time clinical specialists.

4. Type of Fitbit data shown, for e.g. as reported in Chapter 5, it was initially decided to capture patient's hourly HR data, however, after the deployment of the system in the first iteration of CR program, clinicians felt hourly data was unnecessary. Decision was made to capture HR on a daily basis.

5. Additional Fitbit data like patient's resting HR, time spent performing high intensity activity, and the maximum HR was also included on the clinician facing interface.

6. Time window of Fitbit data shown to the clinicians was changed from last 7 days to last 5 days. Initially clinicians were only sent emails to see and access patient data. However, after the deployment of the system in the first iteration of the CR program and feedback from clinicians, it was observed that physiotherapists were forgetting to view the Fitbit data due to their work schedule. They wanted to view their patients' data one day before the CR class. Therefore, it was decided to send additional alert emails to physiotherapists every Monday to check the Fitbit data.

7. During the initial weeks, clinicians were sent a website link to view patients' Fitbit and weekly questionnaire responses. However, this approach was found to be not engaging. Discussions with the physiotherapists after the first and second iteration of the CR program revealed that some clinicians missed clicking on the link while some felt they had to be in front of a computer to access the link. Although the website was made responsive to access on smaller screens, they preferred viewing it on a computer. Due to the nature of their work, most clinicians, especially the physiotherapists spent less time in front of the computer. To address this issue, screenshots of Fitbit data and highlights of weekly responses were shared through

email along with the website link (Figure 6.2 and 6.3). This was observed to be more engaging as clinicians got an overview of the data on a single screen and in their email which was part of their existing workflow.

8. The Wizard-of-Oz technique allowed researchers to experiment with data presentation. During the first iteration of the CR program, patient's weekly experience data was shared as an excel attachment through email and to enable clinicians to get an overview of the attached data, responses that poped out were included as part of the email. After the first iteration of the CR program, clinicians gave feedback that the pop outs from the patients' weekly questionnaire responses that were included in the email did not provide enough information and that they wanted a way to view the important responses in the response sheet. They also found the presentation of the response data overwhelming and needed a better way to glace the data. Therefore, the data extraction process and data presentation was iterated to include this feedback and was applied in the next CR programs. This iteration involved the highlighting of important information in the weekly responses by the author before sharing with the clinicians. However, from the clinician's perspective, this felt like an automated system equivalent to an artificial intelligence system. Figure 6.4 shows the clinicians' view of the weekly responses highlighting important text. The iterated approach was found to be more engaging and provided glanceable and actionable information to clinicians.

Figure 6.2: Initial data sharing with Clinicians

Figure 6.3: Revised data sharing after clinicians' feedback

ParticipantID	1. On a scale of 1 to 10, how confident are you about managing your condition? Please elaborate.	2. On a scale of 1 to 10, how informed do you feel about your condition? Please elaborate (list any resources you have used such as websites etc).	3. On a scale of 1 to 10, how motivated are you this week? Please elaborate.	4. What exercise did you do outside of class this week?	5. Any injuries, pains or sensations limiting you engaging in activity?	6. On a scale of 1-10, what are your feelings about engaging in social interaction?	7. Do you know when and how to take your medications? Please explain.	8. Do you know where to go if you are not confident about your medication? Please explain.
P18	1. My condition seems to be changing and needs medical intervention to manage it.	2. I am not clear on my condition(s) nor do know my prognosis. I don't feel part of my own medical team and I don't know what to look out for or ignore.	7. I am happy to do anything and everything to improve my well being	Just walking.	My palpitations / bigeminy / drop in pulse while exercising. In the Tuesday class, my pulse dropped from 90 to 38 while participating in squats. Then it continued up and down throughout the rest of the session meaning that I really didn't have any exercise worth noting.	6 Happy to. i think that I have to take it easy, so I avoid more active social interactions.	Yes. Morning and evening	Yes. Pharmacist
P19	8	8	8 pretty motivated	None	Pain around my scar area when lifting my 2 year old son	6	Yes the talk from the pharmacist was very informative	Yes call the pharmacy
P20	6 feeling more in control	6 web resources are unreliable too much noise from unscientific source in relation to things like statins and diet	10 I am anxious to complete successful program to resume a healthy and normal lifestyle	Trying to get a 3 k walk in every day when work allows	Booster jab made my arm sore which limited my efforts with the upper body exercises	6 this score relates to current covid status and does not relate to anything cardiac	Yes. Aspirin, bloodpressure, blood thinners and beteblocker in the am and statin and blood thinner in the evening. Talk this week covered what to do in the event of missing a dose	GP, pharmacist can also advise if necessary to consult with Medical professional
P23	5 still worried about how I can track my progress going forward. All the talks have been very helpful but my personality does make me tend to dive into further details	7 I am continuing to update myself and all the classes have helped with that	7 I enjoy pushing myself in the fitness classes and enjoy having other classmates there too.	Had a full morning of kids training on Saturday and have maintained over 10000 steps a day for the rest of the week	Was very tired following the kids training on Saturday	5 happy to meet people in low key environments but I am not interested in meeting in larger groups.	Yes	Yes - I would discuss with my GP and pharmacist

ParticipantID	9. Do you feel stress is an issue for you?	10. What strategies do you use to manage stress?	11. Have you tried relaxation or mindfulness before?	12. Do you think relaxation can be beneficial to your cardiac and overall health? Please explain.	13. Do you know any risk factors for heart disease? (modifiable or non-modifiable)	14. Do you have any concerns about your health at the moment?
P18	Prior to my heart attack, for sure. These days I am actively avoiding stressful situations. That's a lie. Another child expected in June, New house in March, Wedding on a week before Christmas. However, I'd like to think I will not be stressed	Actively mentally letting go or delegating things that I find stressful	yes. I find it tedious	I think that is generally accepted these days.	Diet, exercise, stress, sleep, genetics, smoking, ...	Yes, My LVEF has dropped from 40% to 35% last August. I feel less able to exercise and I get frequent palpitations that leave me feeling weak. I get twinges in my chest and sometimes down my left arm. Sometimes I get breathless with very little exertion and sometimes I don't. I am not sure if this is due to PVC's or heart failure. I am concerned that any further reduction in LVEF will have a major impact on my well being and life expectancy. My cardiologist has spoken of an ICD and I believe this would significantly reduce my day to day concerns with my heart performance. I would also like to think that it would help to manage / eliminate the drop in pulse when exercising.
P19	Yes I get a build up of stress from work & a home	None	No	Yes	No	No
P20	Yes. Work can be stressful at times. Also with so much working from home family members don't get the breaks from each other which in itself can cause additional stress in the home	Currently walks and trying to get adequate sleep. Occasionally some yoga exercises	Yes	Stress reduction leads to better mental and physical health	Genetic factors, bad diet, lack of exercise, buildup of fat around waist. Salt usage and excess alcohol.	I realise that having had a stent fitted I am in better health than I was 3 months ago, so I am not concerned at the moment
P23	Yes - following classes on diet recently I feel that I am reasonably good at maintaining a healthy diet previously. I now feel that stress must have been a factor in why my condition deteriorated. I am working hard to try and understand my triggers and manage them better	Breathing exercises and I now understand that exercise is a huge release for me going forward	I am going to breathing classes and CBT since my operations in September. These are helpful but I do find it one of the most difficult elements to get comfortable with	Absolutely - I think body health, diet but most importantly mental health are all required.	No	I still worry when I get over tired which can play on my mind alot

Figure 6.4: Screen shots of patient weekly questionnaire responses

6.4.2 Observation Notes from the Field Study

The researcher ST observed two complete CR programs and made notes about how the system was used including, functioning of the classes, Fitbit usage and impact, and impact of weekly questionnaire.

During the first class of the first week of the CR program, online and in-class patients were called in together by the physiotherapists to provide them with chest bands and a watch connected to the chest band which showed their real-time HR, they also took a step test to assess their current capacity to perform exercises, and to fill a baseline questionnaire given by the hospital. They were instructed to wear the chest band and the linked watch during the classes. This class was also used to give the patients pre-study questionnaire, Fitbits, and information about the weekly questionnaire. The second class of the first week was the first 60 minute physiotherapy exercise class. This involved patients performing various exercises, including warm up, high intensity, and cool down exercises, following the instructions provided by the physiotherapists. After each exercise patient's HR reading was noted by the physiotherapist. The online patients were in the same class but through Zoom video call. In-class and online patients could see each other and performed exercises together. If any patient could not perform an exercise, they were instructed an alternative exercise. Thereafter, each week consisted of two such 60 minute exercise classes and one 30 minute educational talk at the end of one of the exercise classes.

It was observed that sometimes patients used Fitbit HR measurement when their chest band failed to work. Although physiotherapists had a separate HR measuring equipment, many times they noted the HR measurement from patient's Fitbit device. This initiated conversations between patients and physiotherapists. It was observed that these conversations were about how to measure other activities on Fitbit and any usage difficulties faced with the device. Physiotherapists also encouraged patients to wear their Fitbit devices while exercises outside class to ensure they are meeting their recommended HR. Although physiotherapists had access to their patient's historical Fitbit data before the class, they did not collaboratively look at the data during the class. They instead probed patients about their wellbeing to reflect on the captured data.

In general, conversations and social interaction in the classes depended on the type of patients in the CR programs. It was observed that apart from the Fitbit topic, patients mainly chatted about casual happenings in their life and other news topics. Patients did not openly discuss about their health condition or emotions. Patients also did not have any conversations about questions asked in the weekly questionnaire or their responses with other patients and physiotherapists. It was observed that some patients expressed more

through the questionnaire than during the class. For example, P15 expressed in the questionnaire about his feelings and did not share it during the class with the physiotherapists even though at the beginning of each class physiotherapists asked patients about their health and feelings one-to-one.

> "Feeling a little downhearted as I have to attend for blood tests to monitor the INR in my blood quite often" P15

6.4.3 Findings from the Field Study

The field study findings describe the impact of patient-generated data on clinicians and patients and the various factors that influence the engagement with such data in a real-world clinical workflow. This includes the importance of experience data along with physical activity data, usage expectations of such data, and attitudes towards sharing such data with other patients.

During the 6 weeks of the CR program, a pattern was observed in the usage of Fitbit and questionnaire data. During the first week, clinicians were interested in patient's baseline health measurements. Thereafter, they monitored the patients outside the classes through Fitbit data. Fitbit HR data was also used to measure patient's in-the-moment HR after each exercise in the class. Weekly questionnaire responses were looked at a day before the next class. Patients used the Fitbit to match the activity levels attained in the class and checked their progress. During the classes, some patients would use Fitbit to check their HR. Patients expressed that answering questionnaires at the end of the week refreshed the knowledge received in the class and reflect on their health. Figure 6.5 shows interaction with Fitbit and experience data by patients and clinicians during the CR program.
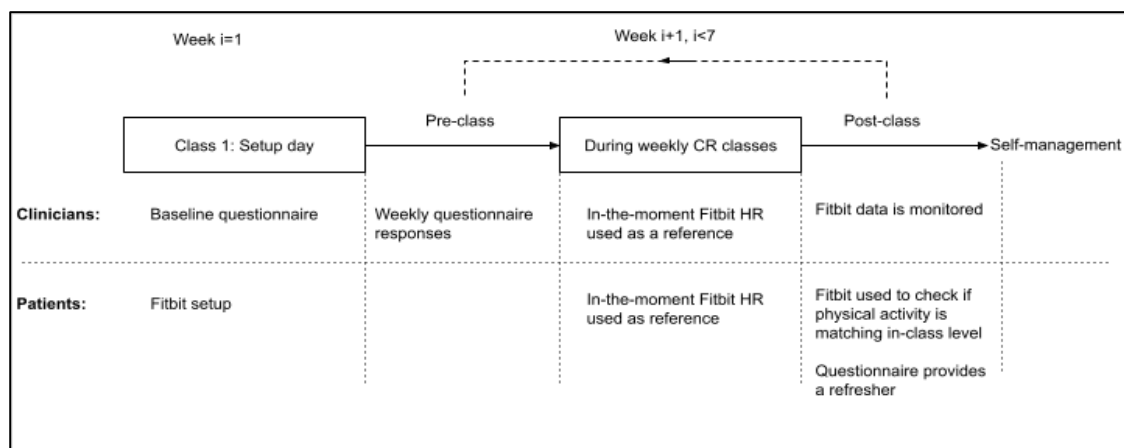
Figure 6.5: Interaction with collected data by patients and clinicians.

96

6.4.3.1 Importance of Data Beyond Physical Activity

Recent research shows the importance of collecting objective and subjective data [93] [147]. This study also examined the impact of such data on clinicians and patients. Table 6.2 provides a summary of key findings.

Table 6.2: Impact of collected data on patients and clinicians

Impact on	Fitbit	Questionnaire responses
Patients	Enabled personal activity, HR, and sleep tracking.	Were like revision of the information they received during the classes.
	Guided breathing was found useful.	Enabled reflection of their current health.
	Initiated conversations during the class.	Medium to share physical and emotional issues with clinicians that they would not during the classes.
	Motivated them on low days.	
Physiotherapists	Enabled to monitor if patients are continuing recommended activity levels outside of class.	Provided them with patient's physical and emotional health issues.
	Enabled to monitor HR.	Enabled to check patient's compliance with the information received during the classes.
	Was used as a secondary device to check HR after each exercise during the class.	Enabled them to tailor their conversations with patients.
Other CR Clinicians	No impact.	Gave a sense of patients' mindset before the educational talk.
		Enabled to check patient's compliance with the information received during the educational talk.
		Enabled to tailor the information given during the talk.

6.4.3.1.1 Impact on Patients

Wearing a smartwatch device like Fitbit allowed patients to track their HR and physical activity outside the CR classes and enabled them to stay in a safe HR zone. *"That particular system that you had with the monitoring with the Fitbit, helped alleviate all my worries, you know, I'm not worried any more about doing some activity."* (P1)

Participants reported that wearing the Fitbit gave them a sense of motivation and confidence to keep themselves active outside of the class. It motivated them to be active even on low days. Nudging features of Fitbit like vibration if sitting down too long and reminders to be physically active made them feel like someone is monitoring them like how they were during the CR class. It helped them to see if they were achieving a target HR zone for exercise.

> "It vibrates to let me know that you are sitting down too long and to walk about. I like that because, well, what happens is when you go to the CR class you will, you will do what you're told to do because you're there. But when you're at home, when you are alone, you would say, I'm not going to do it, there's no one pushing. You have to tell you. So you think to yourself, I won't do it, I'll do it tomorrow. But when this thing goes off, it's like telling me and then I am like, yeah right I will get up, I will get up and walk around. So I think it's a good thing. I really do, you know." (P7)

> "I found it very helpful, found it motivational…..once I got this one up and running I looked at it many times a day, mostly in the evenings and just got into the Fitbit app on the phone….there were some days I would have no active minutes and there'd be other days I might be busy….I need to get these active minutes going. So whether that was a walk or whether it was a swim or whether it was the help of the two classes a week were very good for getting into that sort of routine to get your heart rate up." (P2)

For participants who were using smartwatch for the first time, wearing a Fitbit during the CR program changed their attitude towards smartwatches and created a positive impact on their motivation to be active. For example, few first-time users liked the feature of the Fitbit which reminds them to get up and walk. *"Well I'd never had a Fitbit before and it was a first for me but I was able to manage it no problem and the information was very useful in the sense that you know, for heart rate. I didn't freak out when I went over a hundred [laugh] because I knew it was in my safe zone."* (P1) Online participants especially reported that Fitbit was like a companion for them during the program and had a significant impact on their rehabilitation process.

According to participants, one of the main uses of Fitbit was to reach the HR achieved in class outside of class. Participants observed the HR and calories they were achieving while performing exercises in the class and used that as a reference while performing activities on their own outside of the classes. Patients were educated by the

physiotherapists on the importance of purposeful exercise within a HR zone, corresponding to moderate exercise and were guided individually on their target HR zones. This was also based on the individual health conditions and age of the patient. Wearing a Fitbit gave patients the opportunity to maintain that HR during exercises and activities at home outside the class.

> "We were told the maximum figures that we were supposed to be at, and then the target figures we were supposed to be at, and then the resting figures. And then depending upon the exercise I was doing, I found that when I was exercising at the start of it, I was at my maximum, but then that started reducing down. Likewise, the exercise heart-rate was reducing, and the resting heart rate was reduced so you can actually see the trend, yeah." (P4)

Answering weekly questions was found to be useful as a way of revising the educational and physical guidance received during that week. One participant expressed, *"Well it just made you reflect on what you were doing. As I say most of mine, I focused the time actually trying to get through the actual physio but the questionnaires just made you look back and how you're getting on with it, how you're enjoying it, all that, you know how you're feeling."* (P3).

6.4.3.1.2 Impact on Clinicians

Physical activity data collected by Fitbit allowed clinicians to track patient's HR and activity beyond the CR classes. However, this data was not monitored daily, rather once or twice a week. This was because CR clinicians did not find it necessary to monitor such data on a daily basis. Lack of staff and busy work schedule also affected regular monitoring of this data. During the CR class, a patient's Fitbit device was used to track HR after each exercise. Their HR was tracked for mainly two purposes: to check for any outlying readings while they perform the exercise, and to check if they are attaining the desired HR for each exercise. It also initiated conversations between patient and clinician and between patients during the classes.

Patient experience data that was obtained through the weekly questionnaire responses gave clinicians an understanding of the needs and attitudes of their patients. Physiotherapists stated that *"Tracking the experiences each week was useful, it gave an understanding of their mindset before the class next week."* Weekly questionnaire responses also gave them further insight about the collected Fitbit data. For example, if the Fitbit data had indicated low measurements of the time spent performing exercises or if there were no physical activity measurements collected by Fitbit for a certain timeframe,

the questionnaire responses from patients would reveal more information about this inactivity. Based on the information in their responses, physiotherapists would check-in with the patients and make changes to their exercises if needed. For the other CR clinicians, reading questionnaire responses before their talk gave them an understanding of the patient's current knowledge and their mindset. With this information, they tailored their talk if necessary. Along the same lines, the questionnaire responses post-talk provided them with feedback to consider for their talk in the future sessions.

Interestingly, it was observed during the ethnographic field study that patient's shared problems through the questionnaire and that they did not share in the class. An example for this is reported in the observation notes in Section 6.4.2. Thus, the questionnaire was used as a medium to share health and emotional issues that patients would hesitate to share in the face-to-face classes. This helped the clinicians to alter their talks with the patients to address their issues directly or indirectly.

6.4.3.2 Engaging with Data

Patients and clinicians' engagement and expectations of the collected patient-generated data varied and is based on different factors which are presented in this section. Table 6.3 summarises the difference in engagement and frequency with the data.

Table 6.3: Engagement with collected data by patients and clinicians

	Fitbit	Questionnaire responses
Patients	Interaction with data: Highly important	Interaction with data: Important
	Frequency: Daily	Frequency: Weekly
Physiotherapists	Interaction with data: Important	Interaction with data: Important
	Frequency: 1-2 times a week	Frequency: Once a week
Other CR Clinicians	Interaction with data: not important	Interaction with data: before and after their talk
	Frequency: 0	Frequency: Twice each session

6.4.3.2.1 Patients' Expectations.

It was observed that most patients engaged with their Fitbit data daily. Most popular Fitbit feature used by patients was the step count and HR monitoring as almost all patients liked walking as their daily exercise. Patients liked the Fitbit App visualizations that represented their physical data showing progress. They also liked to monitor their sleep. Some reported to have explored features on the device which they might not have if it wasn't for the classes and the educational talks. For example, few patients started using the guided breathing feature of Fitbit after they attended the educational talk by the occupational therapist.

> "After the education talk by the occupational therapist, I explored the breathe feature. When you tap it shows you how to breathe in. I use that a lot and now it probably is not giving me any benefit because I've just been watching it but it's helped me breathe properly, if you know what I'm saying. Yeah, I am actually using that as well. I showed my daughter as well on how to use the breathing feature. Oh yeah. It's been a feature on it which is good. I think it's good." (P7)

The field study also showed that the timing of introducing Fitbit to patients played an important role. When asked about patients' attitude towards using Fitbit if it was given to them at the end of their CR program vs before, most patients said that they might not use it. Introducing Fitbit at the beginning of the CR program enabled them to engage with it during the program and made them capable of using it after the program for self-management.

> "If I had been given after I probably wouldn't realise what it was doing, you know, and because in fact it was given to me at the start of it and made me realize, OK, how does this work and what do I do now? And then when I realised I could do so much with it, I was like oh brilliant. If I was given after the class I might have felt I actually do not need it. When you actually realise now what it's actually doing, you think, oh, well, hold on a minute, this is a good thing to have. OK, so I actually think yeah, yeah. Give it up to somebody after could be a problem. I think when you when you get them using it or forced it's great. It is definitely a great thing to have." (P7)

When asked about what information they would like to see on a web app during the CR program, many participants suggested to include the information received during the educational talks and resource recommendations by clinicians. For example, few participants wanted more information and resources related to relaxation exercises: *"We*

were given handouts after the educational talks, but I would like to have access to more relaxation videos recommendations" (P11).

6.4.3.2.2 Clinicians' Expectations

Clinicians' interaction and engagement with patient-generated data changes according to the phase of rehabilitation their patient is in. Clinicians' need for patient-generated data decreases gradually as the patient transitions from one rehabilitation phase to another. In the case of cardiac conditions, the level of engagement is higher during the recovery phase, i.e. a few weeks after surgery and decreases as patients transition through 1st, 2nd and 3rd phases of CR. For example, physiotherapists reported that consultations are more frequent for patients in their recovery phase and that it was essential to monitor patient's vitals frequently. As patients progress to phase 2 and 3 of the CR program, frequent monitoring and consultations are no longer necessary. During these phases, trends in their patient's HR and activity levels across a timeframe are considered more valuable. Behavioural data indicating changes made by their patients to their lifestyle and emotional health were also regarded as valuable during this stage. This helps them to ensure their patient's ability to self-manage their condition after the CR program.

Clinician's level of engagement with data also changes based on the role of the clinician. In the case of the CR program, physiotherapists were interested to monitor and engage with patient-generated physical and experience data as they were the main clinicians running the CR program and met patients twice a week for 6 weeks whereas the other CR clinicians were interested to see specific parts of the experience data as they met patients once or twice during an entire course of the CR program. In general, all CR clinicians had a very busy work schedule and they preferred the patient data to be shared with them through email alerts and reminder emails. Clinicians reported that they could easily make sense of the experience data as the questionnaire was co-designed with them. They also reported that the highlights made to the experience response data made it more glanceable and resonated with the data selection that were considered for highlights.

The application that was used to present patient's data to the clinicians provided a dashboard of Fitbit data, but many clinicians did not log into it. So, a new approach of extracting the data from the application and sending it as summary emails proved to be more useful and engaging. This is because clinicians preferred a technological solution that fits in their current workflow, structure, and schedule. To further stress on the importance of understanding clinicians' work structure, another important aspect of data sharing that was observed was the timing for sharing the data with clinicians. Further clinician

engagement with the data could be achieved by sharing the data with the clinicians on the day and time of the week they preferred.

6.4.3.3 Attitude towards Data Sharing

Somewhat surprisingly, participants had no reluctance towards sharing their own Fitbit and questionnaire response data with others in their class. However, there were some interesting and important differences in their attitudes to seeing other peoples' data. When asked if they would like to see other patients' Fitbit data, many of them expressed hesitancy. They felt CR was a personal journey and seeing others' Fitbit data will not have any impact or possibly could have a negative impact on them. They also felt that some patients in their class did not represent their condition, so they did not find it useful to compare with them.

> "There could be a guy doing half the active minutes that I do and half the steps, he could be doing a much better job than I am with the heart that he has and the stage that he's at you know so it's trying to – the information that is being provided it would have to be very well explained that everybody is different. You know don't look at other people's data and say I have to mimic that. If that fella's doing 30,000 steps a day and doing 300 active minutes, you know that's completely you know alien to most people." (P2)

Another interesting finding was that patients were interested to see others' questionnaire responses to learn from others' experiences, especially about the changes in diet, relaxation, and lifestyle. However, they wanted to be able to see such information a week or more after they had responded. This was because they did not want to get influenced by others' experiences, they would rather try out things on their own first and then like to look at what others are doing.

> "I do not want to get influenced. Do the survey, answer the survey questions, and then let it be seen. I can see them all afterwards, not during..The next week you see the response of the previous week." (P5)

When asked about staying connected and sharing experiences with others in the class many were interested in a more passive digital App for sharing experiences rather than a real time or more active ones like WhatsApp. Moreover, they preferred face-to-face interaction to share and connect with each other, for example, online participants suggested keeping the zoom call open 15 - 20 minutes before the start of the class just for social interaction.

"Certainly a WhatsApp like App can be intrusive and it ends up being a conversation if you know what I mean. It can be over and back and over and back whereas reading all their experiences on the screen later would be more formal and I can read it at any time." (P23)

Clinicians, on the other hand, expressed that it could be harmful to share Fitbit data between patients as they felt it could have a negative impact on the patients. Exercises in CR classes are tailored to each patient and progress of each patient could be misinterpreted if such data is presented. Prior research in the context of patient-generated data also share clinicians' concerns about patients becoming obsessed over aspects of their health and becoming compulsive or fastidious while engaging in such data [5,180].

6.5 Discussion

This section discusses the factors that influence the usage of patient-generated objective and subjective data and its impact on patients and clinicians during real-world CR programs. It also presents how technology played a role in enabling patients to self-manage and in their attitude towards peer-sharing. The findings are discussed in relation to previous literature and its implications for the future design of data sharing technologies. Summary of the design considerations are provided in Table 6.4.

Table 6.4: Design considerations.

Impact on	Design considerations
Patients	Key factors to consider while designing a meaningful patient peer-data sharing app are: timing, type of App, context, and type of data.
	Context and timing for introducing self-care technology has potential to empower patients during transition from clinical care to self-care.
Clinicians	Automatically collected objective data could be made more meaningful by collecting subjective data in the form of patient's weekly experiences.
	A structured approach to experience data collection grounded in the clinicians' workflow and co-designed with clinicians can provide more glanceable and actionable data.

6.5.1 Using Patient-Generated Data in Clinical Context: Subjective and Objective Data-Capturing

The study in this paper was motived by the findings reported in Chapters 3 and 4, and also by studies such as West et al.'s [180] that identified barriers expressed by clinicians on the use of patient-generated data in clinical setting. This included: incomplete data, data lacking context, insufficient time, unfamiliar structure, and misaligned objectives. Potential solutions suggested for these barriers were: automated data collection to be supported by contextual data collection, present data in clinical standards, filter data to show relevant information, and clinically validate self-tracking tools. In this study, it was possible to apply some of these solutions and explore its impact in the context of real-world clinical practice and workflow. Reflections of applying some of these solutions here are presented here.

6.5.1.1 *Giving Context to Collected Physical Activity Data*

Collecting experience data along with physical activity data on a regular basis provided context to the objective data that was collected automatically using Fitbit. For example, clinicians could get a better understanding of what limited patients physical activity, why their recommended HR levels were not achieved outside of class, and their motivation levels to maintain physical activity outside of class. Pantzar and Ruckenstein suggest that due to the automated and standardised collection of data by tracking devices, their measurements are perceived as essentially objective [153]. They, yet, argue that to offer

reliable insights, sensor-captured data must be appropriately situated as the meaning of the data is in fact deeply tied to particular contexts in which the data was collected. An example from the findings of the study reported in this Chapter showed that Fitbit data might indicate a patient's low activity levels in a certain timeframe. There could be multiple reasons for this pattern; the patient's ability to function can be impaired due to anxiety and stress; or low motivation due to external factors; or it could be because of a fault with Fitbit capturing the activity due to technical issues, the patient simply not wearing the device, or where the battery is drained. Therefore, to combine mechanical objectivity with the important role of context in knowledge formation, Pantzar and Ruckenstein propose the concept of 'situated objectivity'. A mental health study by Ada et al. suggest that providers view clinical interactions as a promising site for developing situated objectivity for their patient's Fitbit data [120]. The findings reported in this chapter suggest that, in the context of CR where clinicians are under time constraints to collaboratively make sense of Fitbit data during the class, the experience data collected through weekly questionnaires played a vital role for developing situated objectivity.

A structured approach of collected experience data allowed collection of data that could be easily made sense of and provided actionable insights to the clinicians. This could help solve challenges like loss of meaning and interpretability that arise in patient studies that use automatic data collection methods through consumer devices. Collecting contextual information to overcome the flaws of automatically collected sensor data is growing.

6.5.1.2 Structured Data Collection

West et al. reports that clinicians want patient-generated data to be interpretable 'at a glance' in a short amount of time and this is possible if the data is presented to them in a familiar representation [180]. Collecting patient experience data through a structured questionnaire that was designed by the clinicians and drew from published standardised QoL questionnaires allowed for quick interpretation of the collected data.

In this study, the data collection and filtration was automated to show relevant information through the Wizard-of-Oz system design and implementation. For example, it was possible to filter out the important information from the gathered data and present it to the clinicians in the form of a summary or highlights. This made the captured experience data quicker to interpret and glanceable for the clinicians. After experiencing the system in this study, clinicians proposed for a future App that could show dashboard for Fitbit data along with the corresponding experience data highlights with an ability to select timeframe and an option to see more information of a specific experience data highlight if needed.

There is also potential for making the highlighting process automated through natural language processing. One possibility for automating the process is to define a set of keywords by clinicians and annotate the collected data with the predefined keywords. Machine learning algorithms could then be used to identify patient responses containing those words [57, 85].

Therefore, this study gives an example of how patient-generated data that is easily interpretable can be gathered and presented in a real-world clinical context. It also demonstrates the importance of gathering both patients' physical activity and experience data to support clinicians' decision making of appropriate care path for the patient.

6.5.2   Reflections on Data Sharing between Patients

In this study, patients first experienced the data-capturing system and then their attitudes towards sharing and receiving their Fitbit and experience data with other patients in their class was gathered. Although patients were not shown the actual peer data that was collected during the study, they were given examples of such data during the post-study interviews, patients' perspectives gave interesting insights. HCI literature and literature in the medical field have discussed the importance of sharing recovery experience with peers. For example, recovery narratives has been largely explored in research focused on mental health and provides evidence on the benefits of receiving recovery narratives [106,144]. "Recovery narratives" are first person lived experience accounts of recovery. Recovery narratives are also used in other healthcare research, e.g. narratives of recovery after stroke [67]. Patients interviewed in this study also showed interest in receiving their peer's weekly experience data to know if they were experiencing the same things and to learn from the lifestyle changes and resources their peers used to manage their condition. However, this interest was found to be not common. Although all patients were enthusiastic about sharing their data with others, receiving others' data was a concern for many. Patients perception on receiving peer's Fitbit data depended on if the patient felt their peers were as physically fit or in similar medical condition as they were. Therefore, care must be taken when showing such data, as each patient has a different underlying medical condition and demographic. Personalisation is key while presenting such data. Therefore, the amount and type of information shown would require careful consideration as that could make patients worry even more [143].

Perceptions on receiving experience data of their peers depended on when the data was shared. For example, patients suggested that peer experience sharing could have a positive or negative impact and this depended on when the data was shown to them. If it was shown during the same week they were told to answer the questionnaire, it could

"negatively influence" their motivation and decision making. Findings from studies reported in Chapter 3 and 4 suggested that during the CR phase, patients normalised their new experiences through social interaction and valued the opportunity for peer-experience sharing during in-person CR classes. In this study, which focused on using technology for peer-experience sharing, patients suggested that they are willing to share their experience data with peers but to avoid negative influence timing of receiving such data is important. Although findings from this study echo with the findings from Chapter 3 and 4, there seems to be a difference between patients' perceptions about peer-experience sharing in in-person CR classes compared to sharing experiences through a technology. Findings also suggested that patients perceptions about sharing experience with their peers through technology was influenced by the type of App used: active or passive.

One of the important reasons for patients to attend a CR program is the opportunity to meet people going to similar conditions, share experiences, and normalise their experiences. Chapter 5 showed an alignment of this patient perspective with that of clinicians'. Moreover, clinicians were expecting that Fitbit usage in the class would increase patients' social interaction. Ethnographic observations in the field study showed that while Fitbit did increase conversations in the class, these conversations were often between patient and clinicians and less between patients. However, this finding is inconclusive as clinicians suggest and speculate that the amount of social interactions between patients could depend on the personalities of patients attending the program. They would like to experiment the impact of making their patients' Fitbit data more visible during the CR class so that patients are able to see each other's' in-the-moment Fitbit data during the class. To enable this, a suggestion by clinicians for the future was to enable attendees to view each other's Fitbit data on a shared screen during the class and examine its impact on social interaction and peer-sharing.

As seen in the findings section, the timing, type of data, and type of App used for peer data sharing are important factors to be considered for such data to make a meaningful and positive impact.

6.5.3 Empowering to Transition from Clinical Care to Self-Care

A recent article on what an empowered patient means puts self-efficacy as one of the essential components of empowerment [181]. Providing patients with the ability to track a variety of health parameters, outcomes, and actions gives them a better understanding of how their actions impact their health and helps in closing the gap between monitored care and self-management [136]. Although benefits of self-tracking have been explored extensively outside of the clinical setting, e.g. general wellness [49,130] and chronic

disease management [159], little is known about its impact on patients in clinical settings [136]. Findings from Chapter 4 suggested that technology should act as an empowering agent and should increase patient's capability by allowing them to see what kind and how much exercise they could perform. This study found that introducing a technology at the start of the CR program guided them in effectively using it outside of the program. It helped patients gain knowledge of their "safe zones" [166] and realise the benefits of the technology. Even those who were new to such technology became experts by the end of the CR program and could continue achieving the recommended HR and activity levels after the program with the help of their smartwatch. Furthermore, introducing a technology at the beginning of the program rather than at the end, allowed patients to get more involved in their treatment process. In past research, clinicians have expressed the need for new technological tools that assist them in motivating patients to stay engaged in their care [143]. Even though there exist technological solutions that address patient motivation, it is possible that the timing and context for introducing such technologies could play an important role in its long-term use and user retention.

6.6   Limitations

This thesis acknowledges that as the study took place in a single hospital in the European continent, all our participants were of western European demographic. All participants were classified as middle-income. This thesis acknowledges these limitations in our study and recognises that the future work could look at participants with more diverse ethical and cultural backgrounds. However, it should also be noted that the participant demographics reflect the real-world situation in many European countries.

6.7   Conclusions

The findings of this chapter suggest that structured subjective data capturing can make objective data, for example physical activity data from consumer devices more meaningful for the clinicians. Furthermore, structured approach to collecting subjective data generated actionable information that helped clinicians to tailor their talks in their future classes and consultations. This study also provides an empirical account of the importance of introducing a self-care technology in a clinical context and the importance of timing to empower patients to self-manage their condition. This chapter identified patient's and clinicians' attitudes and expectations from technology and proposed key considerations for the design of future patient-generated data and peer-sharing technologies.

Chapter 7
Discussion, Limitations, and Future work

7.1 Introduction

This thesis aimed to employ the user-centred design methods and co-design framework to qualitatively explore the barriers and facilitators of CR and self-management and the potential technology-mediated solutions that can support and address these barriers. This concluding chapter presents a summary of the thesis. Following this, the empirical and methodological contributions of this PhD thesis, along with design recommendations for health technologies, are presented. Finally, limitations and insights on potential directions for future work are discussed.

7.2 Summary of the Findings

The work presented in this thesis focused on understanding the challenges and opportunities in designing technologies for cardiac care. It explored the factors that affect cardiac patients post hospitalisation. These are broadly applicable and can be extended to other chronic conditions, and healthcare needs post hospitalisation. This section presents a brief collected summary of the findings from the studies presented in this thesis and its generalisability to broader areas like complex healthcare needs and other chronic conditions.

The systematic literature review presented in Chapter 3 aimed to understand users' perspectives of technology in CR and self-management and identify barriers and facilitators to the use of technology. The study addresses **RQ1: What are the primary barriers and facilitators to using technology for CR and self-management?** The study found that barriers and facilitators for technology-mediated CR and self-management fell into three key themes. These are: the need for both background knowledge and in-the-moment understanding; self-care being a personal responsibility versus self-care being influenced by social connectedness; and the need for technologies to support engagement while avoiding overburdening people. Catering to the broad spectrum of patient needs and providing tailored care can make designing healthcare technologies complex. For example, it was found that opportunities to stay connected with family, caregivers, and others with a similar health condition are valuable, but to avoid becoming a barrier, technology must also respect and enable individual responsibility and autonomy. This is because often, patients

prefer managing their care independently and think of it as a personal responsibility and journey. However, it is important to note that technologies should take into consideration the different levels of autonomy given to the patients for self-care, as it is highly dependent on the disease and the patient's current condition. Although patients are in charge of their health condition, it is important to reflect on the stages or decisions where a clinician's support is needed [125]. The review also found that digital interventions for CR and self-management lacked the application of user-centred design methods and iterative design processes. Involving relevant users in each stage of the design process will help reduce user experience challenges and increase acceptance, leading to more effective technology-mediated health solutions. The research presented in this thesis applied Sanders and Strappers' co-design framework to involve cardiac patients and clinicians as active collaborators during the design process. Chapters 3 and 4 presented the context understanding and requirement gathering studies of the pre-design phase. User-centred design methodologies were applied and focused on cardiac patients' needs and perspectives.

The interview study with cardiac patients presented in Chapter 4 showed patients' experiences across the three phases that arise post-hospitalisation, namely, recuperation, rehabilitation, and long-term self-management. The study addresses **RQ2: What are patients' experiences after a cardiac incident?** It showed how patients' experiences evolve over time and describes the factors impacting patients' health needs across the three phases. The use of the TDF in this study allowed exploring factors that influence behaviour over the three phases and identifying potential sources of tension in implementing technology-mediated cardiac care. These factors include the desire for and redefinition of normal life; the need for different types of formal and informal knowledge; the benefits of safe zoning and connectedness; and the need to recognise capability. These findings were consistent with the barriers and facilitators identified in Chapter 3. Therefore, technology that supports self-efficacy and capability through different types of knowledge and that provides physical and emotional safe zoning through compartmentalised monitoring and connectedness has the potential to support CR and subsequent long-term self-management. Complex health needs are also defined by the different phases patients go through after hospitalisation, and findings from Chapters 3 and 4 contribute to the current knowledge about patient needs post-hospitalisation [136].

Among the three phases post-hospitalisation, the CR phase is considered a vital step toward enabling the patient's transition to long-term self-management. More healthcare services, including CR programs, are moving towards a hybrid structure using technological tools that support online video and audio communication and sensor

technologies. Chapters 3 and 4 have focused on understanding patients' needs, however, further research is also needed to support clinicians in monitoring and managing patients during the CR phase due to challenges like lack of resources and busy work schedule [47,59]. Patient-generated data, such as that collected by wearable devices, has the potential to provide important insights for clinicians, a wide range of barriers are observed in its routine and effective use [59]. Moreover, technology-mediated care has not yet achieved its potential and several key barriers have been identified including, lack of trust, technology being a burden, not addressing the needs and concerns of both patients and clinicians, and lack of technical knowledge [14,74]. Therefore, technology-mediated CR involving patient-generated data needs to be designed and implemented by integrating both clinicians' and patients' perspectives to be fully successful. Chapters 5 and 6 address **RQ3: In what ways does the combination of objective and subjective data-capturing support CR and self-management?** In the studies presented in Chapters 5 and 6, a structured data-capturing and sharing system was designed by considering both patients' and clinicians' needs. The system collected objective data through a consumer wearable tracking device, here Fitbit, and subjective data through structured weekly questionnaires. Deployment of the data-capturing and sharing system during real-world CR programs provided an empirical account of the impact of the system on patients and clinicians. The findings suggested that collecting subjective data along with physical or objective data made the objective data more meaningful for clinicians. Subjective data provided context and filled the gap in the data from tracking devices. A structured approach to collecting subjective data generated actionable information helping clinicians tailor patient care and CR classes. The ethnographic field study revealed that although patients were very open to sharing their health data with other patients, they were more reluctant about viewing other patients' data. They preferred seeing others' data on a delayed basis rather than viewing it immediately out of concern that it might negatively influence their rehabilitation progress.

All the studies presented in this thesis collectively provide design implications for technologies that support CR and self-management. These recommendations embody the needs of both patients and clinicians. These recommendations are presented in the next section and address the final research question: **RQ4: What are the design recommendations that embody the needs of both patients and clinicians and addresses the barriers identified for technologies that support cardiac rehabilitation and self-management?**

7.3   Design Recommendations

Designing digital health solutions that effectively support the management of the health care needs of cardiac patients involves catering to the needs of various stakeholders including clinicians, patients, and caregivers and designing such systems by striking a balance between this broad spectrum of needs is difficult. This section consolidates the findings from the studies presented in this thesis and provides the following design recommendations for future technology-mediated CR and self-management. A summary of these findings are presented in Table 7.1.

7.3.1   Support Different Types of Knowledge

To better manage their healthcare needs, patients were in need of both background knowledge and ongoing and in-the-moment understanding. Technologies supporting both awareness of their condition along with current body changes help to improve their self-management abilities. It is important to note that the type of knowledge needed changes over the three phases that patients go through after hospitalisation. For example, patients initially experience a strong need for formal knowledge and access to health expert resources. This subsequently shifts to a desire for detailed personal insights and peer experience knowledge.

7.3.2   Support Normality and Social Connectedness

Patients experience a strong desire for a normal life after surgery and technologies should recognise that exceptional goals and external incentives may not be necessary. Normal life is a goal and incentive in and of itself. Opportunities to stay connected with family, caregivers, and others with a similar health conditions are considered one of the most effective ways to stay motivated and driven toward healthcare management activities. Shared experiences and stories from peers were highly valued post-hospitalisation. Digital health apps that enable such peer-sharing should consider the following key components: timing, type of App, context, and presentation. Furthermore, to avoid becoming a barrier, technology must also respect and enable individual responsibility. Respecting personal autonomy and providing tailored recommendations linked to daily life can help address this tension. As people transition to life after surgery, technology that supports enhanced contact with peers and shared stories can also help develop a new sense of normality. Care should also be taken to resolve the potential conflict that might arise between participants' goals for normality and the lifestyle change goals recommended by health professionals.

7.3.3 Support Physical and Emotional Safe Zoning

Tracking and monitoring through wearable devices provide patients insights into their current health status and increase their confidence by assuring them that they are within their safe zone of their vital signs during physical activities. Technologies that support safe zoning should consider not only physical but also emotional safe zones. Patients do not want to be monitored continuously, as for some, this led to anxiety and interfered with their desire for normality. A structured or compartmentalised monitoring approach with warnings primarily focused on irregular events may help to provide a safe zone effect similar to face-to-face healthcare services. Transparency and trust in the privacy of monitoring technologies are critical for achieving this goal. Furthermore, choosing the right context and timing for introducing self-care technology has the potential to empower patients during the transition from clinical care to self-care. Introducing a technology at the start of a face-to-face healthcare service, for example, at the start of a rehabilitation program and in a clinical context, guides patients in effectively using it at home.

7.3.4 Enhancing Objective Data

Patient-generated data from wearable devices has the potential to provide important insights for clinical teams. To be effective in real-world clinical workflow and context, automatically collected data should be made more meaningful by collecting subjective data. Experience data collected through structured weekly questionnaires allow clinicians for developing 'situated objectivity'. Due to demanding workflow, clinicians want patient-generated data to be interpretable 'at a glance' in a short amount of time and easily made sense of. This can be addressed by supplementing objective data from wearable devices with subjective patient experience data. It is also crucial for such data to be presented to the clinicians or healthcare providers in a familiar representation for the data to be more glanceable and actionable. This can be addressed through a structured approach to subjective data collection grounded in clinicians' workflow and co-designed with the clinicians.

7.3.5 Fitting Patient-Generated Data in a Clinical Context

Clinicians' engagement with the collected data varied based on the phase the patient is in after hospitalisation and the clinician's organisational responsibilities. Their engagement with data decreased the further their patient is in the transition to self-management. To be effective in helping clinicians provide appropriate care to their patients in different phases post-hospitalisation, patient-generated data based technologies should avoid the one-size-fits-all approach [68,164] and consider the needs of each phase. Further, simple, reliable communication and data presentation techniques that fit with clinicians' workflow, including

114

notification type, alert schedules, and data visualisations, are observed to be more engaging. Clinicians should have control over the data shown; for example, clinicians saw weekly HR trends instead of daily.

7.3.6 Designing for Patient's Peer-Sharing Perspectives

Although prior work suggests that there exists a difference between patients' and clinicians' expectations with technologies involving patient-generated data [120,190], in the CR space, the needs and expectations were similar. CR clinicians emphasised achieving higher levels of social interaction, motivation, and confidence in their patients and expected technology to help them achieve these goals. Interestingly, even in terms of Fitbit and experience data sharing between patients, the perspectives of patients and clinicians matched. Both had concerns about the negative consequences of peer data sharing. For example, patients feared being affected by seeing their peer's Fitbit data without knowing the other's demographic and underlying medical condition. However, some types of peer data like diet changes and relaxation methods were valued. To avoid the negative influence of peer data, careful consideration of the information that is shown and when it is shown is crucial. To address this, patients suggested that technology should carefully time the sharing of their peer's data, and it should be on a delayed basis. Negative influences of peer data could also be addressed through better visual representations that allow subjective interpretation and prompt reflection and mindfulness. Recent research in HCI space highlights a shift from the numeric presentation of patient-generated data to instead emphasise on multiple possible meanings of data, potentially reducing fixation with quantified monitoring data [100,161,173].

Table 7.1: Design recommendations for technology-mediated cardiac rehabilitation and self-management and implications to healthcare technologies for chronic conditions

Design recommendations	Specific to cardiac rehabilitation and self-management	Healthcare technologies for chronic conditions
Support different types of knowledge	Type of the knowledge needed by patients changes over the three phases- recuperation, rehabilitation, and self-management. Background knowledge is needed during recuperation phase and there after personal insights and peer experience knowledge is desired.	Support both awareness of condition and current body changes
Support normality and social connectedness	Recognise patients' desire to feel normal during recuperation and rehabilitation phases Provide opportunities to connect with family, caregivers, and peers during rehabilitation and self-management phases	Enable peer experience and story sharing post hospitalisation but also respect personal autonomy Consider the following key components wile designing peer-sharing Apps: timing, type of App, context, and presentation.
Support safe zoning	Supporting physical along with emotional safe zoning can provide a safe zone effect like face-to-face cardiac rehabilitation. Introduce technology for self-management at the start of the cardiac rehabilitation program rather than at the end.	Provide emotional along with physical safe zoning Consider a compartmentalised monitoring approach largely focusing on irregular events to avoid overburdening Enable patient empowerment by choosing the right context and timing for introducing self-care technologies.
Support actionable insights from patient data	Collect subjective data in the form of patient's weekly experiences to gain actionable insights from automatically collected physical activity data during cardiac rehabilitation. Provide glanceable and actionable data to clinicians through structured approach of patient experience data collection	Enhance the usability of automatically collected patient data by supplementing it with structured collection of subjective data. A structured approach to experience data collection grounded in the clinicians' workflow and co-designed with clinicians can provide more glanceable and actionable data.
Designing for patient's peer-	Carefully consider timing, type of App, and type of data presentation while	Enable positive reflection and mindfulness by considering timing, type of App, and type of

| sharing perspectives | sharing data between patients to avoid negative consequences of the data. | data presentation while designing peer-sharing technologies. |

7.4 Limitations and Future Research Directions

7.4.1 Limitations

As the aim of the literature review presented in Chapter 3 was to investigate and obtain subjective evidence of the barriers and facilitators of using technology for CR and self-management, only qualitative papers were considered, and the review was limited by the analysis of the included studies. The possibility of subjectivity in analysing the findings is acknowledged, although strategies to limit bias were undertaken through the process of grounded theory analysis and consultation with a second reviewer. In addition, the included studies in the review had varied sample sizes, and the technology was used for different amounts of time in different studies. The thesis acknowledges that this variation could have had an impact on the themes that emerged in the review.

Whilst the participants interviewed in the study presented in Chapter 4 constituted a relatively diverse group of people with cardiac conditions, including people whom both withdrew from and attended a full rehabilitation program, it will be beneficial if future studies include more people aged less than 55 and more people from urban areas. While the final study presented in Chapter 6 represented more people aged between 40 to 60 from an urban area, the study was over representative of patients who took the CR program in-class at the hospital compared to online. Future research should include a study that can compare the perspectives of patients taking online CR programs along with in-class CR programs.

The studies presented in Chapters 5, and 6 were limited due to restrictions enforced during COVID-19. These limitations included lack of access to CR patients, restrictions on the number of patients in a CR program, and restrictions on face-to-face interactions with patients and clinicians. Due to COVID-19, the hospital faced lack of staff. This affected access to clinicians and limited the number of clinicians that could be involved in the study. The co-design activities and techniques applied in conducting these studies were influenced by these restrictions. This thesis acknowledges that these studies might have been conducted differently if such restrictions were not in place.

Whilst the findings of this thesis are directed toward supporting patients and clinicians, previous research suggests that the opinions of caregivers are also crucial and involving them will provide a broader view of the impact of technology in supporting CR and self-care.

7.4.2 Future Work

Through the application of the co-design framework which connects the post-design phase of one process to the pre-design phase of a new process, this thesis provides a foundation for further ideation and investigation. It provides challenges for technology-mediated rehabilitation and self-management that forms a starting point to further new co-design processes. The findings in Chapter 3 stress on the limited use of user-centred design methodologies and iterative processes. The overall findings of this thesis shows the impact of using user-centred methods by uncovering stakeholder needs which would not have been possible without their involvement in the design process. Therefore, future digital health technology research and design should adopt user-centred design methods and co-designing so that they can address real-world barriers and improve the reliability and usability of the technology.

Findings from Chapter 4 has identified a number of important avenues for research on the design of technology to support CR and self-management. Continuing to address the theoretical basis for the research will be a key focus for future work. As described in the related work section, the TDF is an integrated theoretical framework comprising domains synthesised from theories and theoretical constructs relevant to behaviour change. Building on the TDF, researchers in behaviour change have also developed the Behaviour Change Wheel (BCW) [16,40]. This supports intervention designers in selecting intervention and behaviour change techniques by mapping the TDF domains to the BCW. The BCW is based on three components: capability, opportunity, and motivation (the COM-B model). It presents human behaviour (B) as resulting from the interaction between physical and psychological capabilities (C), opportunities provided by physical and social environment (O), and reflective and automatic motivation (M) [116,117]. For example, TDF domains linked to capability (C) are knowledge, skills, memory, and behavioural regulation. The BCW proposes following interventions to address factors related to capability: education, training, and enablement. In this way, BCW proposes interventions and policies for each of the three components. Building on the identification of important TDF domains and constructs in Chapter 4, the application of the BCW is a key priority for future research.

The design and deployment of the data-capturing and sharing system presented in Chapters 5 and 6 identified several opportunities and strategies that can be included in further iterations of the system. The Wizard-of-Oz technique enabled early iterations and ad-hoc modifications to the system during the study and this provided important considerations for the development of a fully automated system. This included considering more options for system customisation and potential for AI for data extraction. Further exploration of the use of AI through natural language processing to extract glanceable and

actionable information from the patient-generated data is needed. Future iterations of the system can focus on data presentation strategies for patients and clinicians. For example, clinicians expressed the need for a single dashboard that presents Fitbit data and corresponding contextual information extracted through questionnaire responses. Therefore, these should be explored in future iterations.

The current literature and findings from this thesis reported gaps in using technologies involving patient-generated data and these were: patient's lacked trust and privacy on online platforms for peer-sharing, patients and clinicians were concerned about the negative influences of viewing other's data, clinicians' lacked trust in patient's ability to collect reliable data, and lack of ethical framework in such systems to protect patient integrity. Future research on patient-generated data and peer-sharing can explore the impact of ethics by investigating if privacy and trust on online peer-sharing platforms can be achieved through ethical frameworks. Broadly, further research is needed to make peer-communication and story sharing on online platforms more trustable.

As AI and machine learning methods are gradually being applied to generate insights from patient-generated data, care should be taken to prevent potential privacy invasion of patients. Research in trustworthy AI and explainable AI is gaining importance due to the misuse of patient-generated data. Therefore, future exploration of the research presented in this thesis can explore the transformative effects of AI on conceptualising patient-generated data and its potential impact on its collaborative usage between patients and clinicians for decision making.

7.5 Final Reflections

Transitioning from the occurrence of a cardiac incident to lifelong self-management is challenging and life changing. Change in behaviour and self-efficacy to manage their condition is needed and rehabilitation programs are reported to play a crucial role in achieving this. In a time where healthcare are moving to a hybrid structure, technologies should enable patients and clinicians to maximise the rehabilitation outcomes. They should provide additional support to clinicians and empower patients with self-management strategies. Although connected health technologies involving patient-generated data are increasingly becoming more acceptable by patients and clinicians, evidence regarding its routine use and effectiveness is mixed.

It is important to understand the factors that affect patient's behaviour and behaviour change post-hospitalisation to increase the uptake and impact of digital technologies. This thesis presents cardiac patient's experiences and factors that affect their behaviour change

through the three transitioning phases towards self-management that arise post-hospitalisation. It discusses the potential role of technology mediation in enabling the barriers and supporting the facilitators during the transition.

The development of technological tools which can benefit patients and effectively support clinicians in real-world clinical context is evidently a complex task. Designing such technologies by understanding both patients and clinicians' requirements and understanding the complexities of its usage in real-world context can improve its outcome. This thesis provides an empirical evidence of the impact of a technological solution that involved patient-generated data and includes both patients and clinicians requirements. A key contribution of this thesis includes design recommendations that are grounded in the real-world experiences of patients and clinicians. These practical recommendations also informs the design of technology-mediated rehabilitation and self-management for broader chronic health conditions and can be implemented by digital health technology designers and developers.

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Appendices

Appendix A

Supplementary material for Chapter 3.

3.1 Prisma Checklist

The following pages provide the PRISMA 2009 Checklist for the paper.

We note that the PRISMA website[1] states that it was designed with a focus on the reporting of reviews evaluating randomized trials. The website also states that it can be used as a basis for reporting systematic reviews of other types of research, and hence we have used it in this paper. However, the PRISMA focus on reviews of randomized trials means there are important clarification to note in regard to specific questions.

Question 2:
Part of question 2 refers to the registration of systematic reviews. We chose not to register the review in this paper as it is qualitative in nature and makes use of grounded theory methods.

Question 5:
This question again makes reference to advance registration of the study and its protocol. As noted above we did not register the study and protocol in a archival format.

Question 13:
This question focuses on quantitative measure and as such is not relevant to our qualitative review.

Question 14:
This question focuses on reviews where data synthesis is done using quantitative / statistical methods. We have answered 'Yes' to this question as our synthesis methods are described in the paper (see page 6). However we note that the methods applied are qualitative rather than quantitative.

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	Yes, Pg 1
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	Yes, Pg 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	Yes, Pg 5
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	Yes, Pg 5
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	No
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	Yes, Pg 7
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	Yes, Pg 6
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	Yes, Appendix 1
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	Yes, Pg 8
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	Yes, Pg 8
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	Yes, Pg 7-8
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	Yes, Appendix 2
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A *
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	Yes *, Pg 6

PRISMA 2009 Checklist

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	Yes, Appendix 2
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	Yes, Pg 8
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	Yes, Pg 9
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	Yes, Pg 9
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	Yes, Appendix 2
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Yes, Pg 11-16
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	Yes, Appendix 2
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	Yes, Pg 18-24
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	Yes, Pg 25
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research.	Yes, Pg 25
FUNDING			
Funding	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	Yes, Pg 25

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit: **www.prisma-statement.org**.

Page 2 of 2

141

3.2 Search Strategy

ACM	recordAbstract:(mobile OR wearable OR mhealth OR sensing OR tele* OR smartphone) AND recordAbstract:(cardiac OR coronary OR cardiovascular OR "heart failure" OR "heart disease") AND recordAbstract:(behavio*r OR "health*care" OR prevention OR detection OR rehabilitation OR persuasion OR persuasive OR informatics OR tracking OR monitoring OR quantified OR habit) OR acmdlTitle:(mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone OR coronary OR "heart failure" OR "heart disease" OR cardiovascular OR behavio*r OR persuasive OR persuasion OR informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection) OR keywords.author.keyword:(mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone OR coronary OR "heart failure" OR "heart disease" OR cardiovascular OR behavio*r OR persuasive OR persuasion OR informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection)	88
Scopus	ABS (mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone) AND ABS (coronary OR "heart failure" OR "heart disease" OR cardiovascular) AND ABS (behavio*r OR persuasive OR persuasion OR informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection) OR AUTHKEY((mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone) AND (coronary OR "heart failure" OR "heart disease" OR cardiovascular) AND (behavio*r OR persuasive OR persuasion OR informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection)) OR TITLE(mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone OR coronary OR "heart failure" OR "heart disease" OR cardiovascular OR behavio*r OR persuasive OR persuasion OR	2862

	informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection) AND (PUBYEAR > 2007) AND (LIMIT-TO (LANGUAGE,"English "))	
PsycINFO	(AB(mobile OR wearable OR mhealth OR sensing OR "tele-monitoring" OR telehealth OR smartphone) AND AB(cardiac OR coronary OR cardiovascular OR "heart failure" OR "heart disease") AND AB(behavio*r OR "health*care" OR prevention OR detection OR rehabilitation OR persuasion OR persuasive OR informatics OR tracking OR monitoring OR quantified OR habit)) OR (TI(mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone) AND TI(coronary OR "heart failure" OR "heart disease" OR cardiovascular) AND TI(behavio*r OR persuasive OR persuasion OR informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection)) OR (IF(mobile OR wearable OR mhealth OR sensors OR "tele-monitoring" OR telehealth OR smartphone) AND IF(coronary OR "heart failure" OR "heart disease" OR cardiovascular) AND IF(behavio*r OR persuasive OR persuasion OR informatics OR tracking OR quantified OR prevention OR rehabilitation OR monitoring OR habit OR detection))	102
PubMed	((mobile[Title/Abstract] OR wearable[Title/Abstract] OR mhealth[Title/Abstract] OR sensing[Title/Abstract] OR "tele-monitoring"[Title/Abstract] OR telehealth[Title/Abstract] OR smartphone[Title/Abstract]) AND (cardiac[Title/Abstract] OR coronary[Title/Abstract] OR cardiovascular[Title/Abstract] OR "heart failure"[Title/Abstract] OR "heart disease"[Title/Abstract])) AND (behavio*r[Title/Abstract] OR "health*care"[Title/Abstract] OR prevention[Title/Abstract] OR detection[Title/Abstract] OR rehabilitation[Title/Abstract] OR persuasion[Title/Abstract] OR persuasive[Title/Abstract] OR informatics[Title/Abstract] OR tracking[Title/Abstract] OR monitoring[Title/Abstract] OR	1230

	quantified[Title/Abstract] OR habit[Title/Abstract]) Filters: in the last 10 years, Humans	

3.3 Critical Appraisal Skills Program Qualitative Checklist[1]

Quality Assessment for Qualitative Studies Table

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?
7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?

Name (year)	1	2	3	4	5	6	7	8	9	Rating
Dithmer M. et al. (2016)	Yes	Yes	Can't tell	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Moderate
Yehle KS. et al. (2012)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong
Villalba E, et al. (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Moderate
Jarvis-selinger S. et al. (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Strong
Fischer S. et al. (2011)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Moderate
Pfaeffli L. et al. (2012)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong
Katalinic O, et al. (2013)	Yes	Yes	Can't tell	Yes	Yes	Yes	Can't tell	Yes	Yes	Moderate
Antypas K. and Wangberg SC. (2014)	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Strong
Geurts E. et al. (2016)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong
Buys R. et al. (2016)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong
Cornet VP. et al. (2017)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong

Banner D. et al. (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Moderate
Baek H. et al. (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Strong
Salvi D. et al. (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Moderate
Beatty AL. et al. (2018)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong
Smith R. et al. (2015)	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Strong

3.4 Analysis
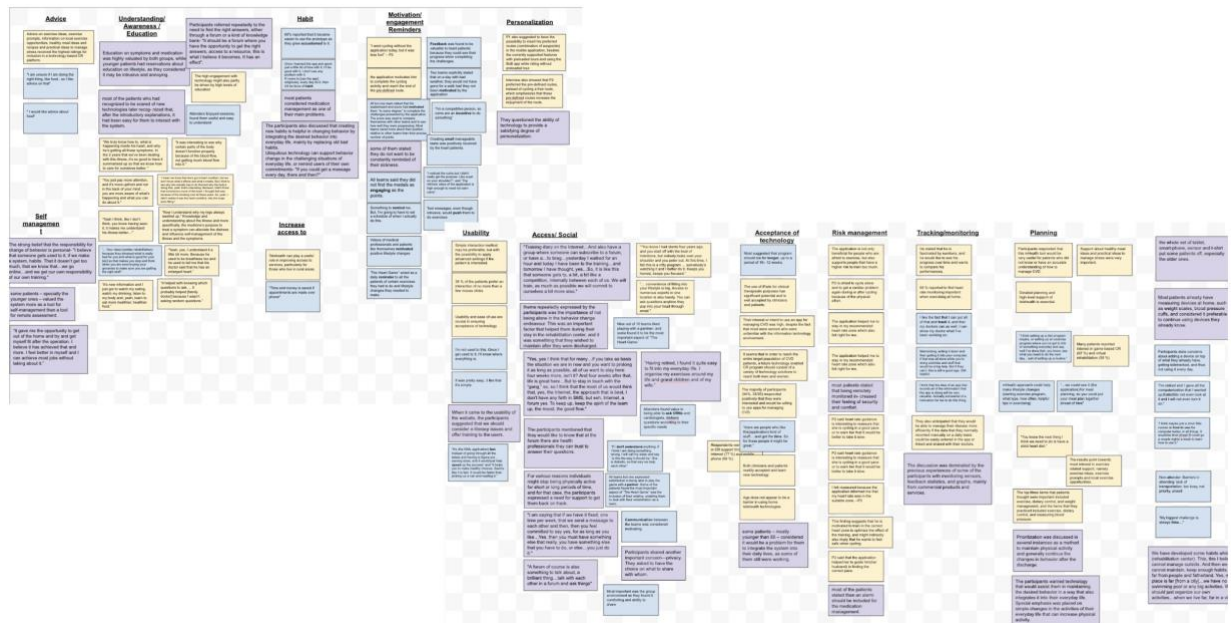
Social vs Individual

Individual responsibility
- Responsibility for change in behaviour is personal
- Self-management is more valued than self-assessment
- Small personal achievements like getting out of the house to get fit are achieved through the use of technology
- Changing behaviour is easier if new habits are created by replacing old ones. To retain changes, it is important to make it part of the daily routine
- Medication management

Connecting with others
- Group/ forum on the internet to share goal completions and brag about it for healthy competition to help being more committed to fitness
- Being part of a group facing common health condition helps in the behaviour change endeavour. Keeping in touch with the group uplifts the mood, is comforting and gives supports
- Forums give the sense of "somebody is watching so I better do it" , gives focus and motivation
- Easy access to health professionals and experts through technology
- Concerns on privacy

- Inadequate facilities in far away areas hinders in keeping up with changed habits developed during rehabilitation

Acceptance vs Refusal

Refusal of technology
-Using tablet, smartphone, sensors etc are burdensome and stressful for old people
- Lack of time and priorities is a barrier to self-management and use of technology

Acceptance of technology
- Interest in making CR programs run longer
- Interest or intent to use application for CVD management is high. Willing to learn new technology
- Age is not a barrier to acceptance of technology
- Technology should be designed to reach both men and women

Increase access to
- Increases access to services especially for those who live far
- Saves time and money

Usability
- Simple interaction methods with access to advanced settings
- Ease of use increases acceptance of technology
- Getting accustomed increases acceptance of technology
- Offering e-literacy increases acceptance of technology

Planning	Personalization	Motivation/ engagement/ reminders	Tracking and monitoring	Understanding/ awareness/ education
- Suggesting diet and exercise programs to help set up a routine - Prioritization helps maintain behaviour change	- Giving the ability to the user to personalize the application according to personal interests and ability	- Using an application pushes them to maintain changes - Comparing activity/ goal accomplished with others is motivating. Competition leads to motivation - Videos of medical professionals and patients like them motivated positive lifestyle changes - Reminders were useful in maintaining the exercise and lifestyle changes along with feedback about their progress - Small manageable tasks are better - Don't like to be constantly reminded of their sickness	- Ability to track, see progress over time and comparing them is motivating - Heart rate monitoring, checking current health status is important - Sharing tracked data with doctor encourages self-management **Risk management/ confidence** - Technology to guide people to exercise or train within recommended/ safe zone gives confidence and increases motivation - Remote monitoring increases comfort and reassured	- Education on medication, symptoms, their cardiac condition, current health condition, food, how to self-manage their heart disease (education on lifestyle was considered intrusive and annoying) - Introductory explanations about how to use a technology - Knowledge and education influences self-management and increases confidence **Advice** - Advice/ guidance about right food, exercise ideas, recipes, managing stress - Information about local exercise opportunities

3.5 Overview of Included Studies

Overview of the studies included in the final review.

Name	Participants	System	Research methodology	Findings
Dithmer et al [1]	Patients in a rehabilitation program diagnosed with heart failure, myocardial infarction, or angina pectoris.	"The heart game" is an app prototype developed for Android running tablets. It presents heart patients with a game-like challenge every day and is designed to be played by a two-person team. It was designed to be used soon after discharge from the hospital and when the patient begins the rehabilitation process.	The prototype has been developed through a user-driven process, and a triangulation of data collection techniques was applied. Evaluation was based on log files of app usage followed by qualitative interviews with 10 patients and 6 teammates.	Inclusion of a close relative or spouse in the game motivated the patients to perform rehabilitation activities. Gamification design principles engaged the users.
Yehle et al [2]	Patients with CHD[a] and their informal caregivers from cardiopulmonary rehabilitation	Two food decision support systems, web based: Food for the Heart and mobile based: Mobile Magic	Three focus group sessions with 20 patients with CHD and 7 informal caregivers. During the focus group	Five themes emerged: decreasing carbohydrate intake and portion size are common

	clinic in Indiana, serving predominantly rural-based population.	Lens, were developed to aid in daily dietary choices.	sessions, participants were asked about their favorite foods, dietary changes made since CHD diagnosis, challenges in making dietary changes, and ways of overcoming these challenges. Content analysis of qualitative data was performed to find themes through a grounded theory approach.	challenges, clinician and social support makes dietary adherence easier, the systems could make meal planning and adherence less complicated, the systems helped save time and assist healthy choices, and additional features would be required to make tools more comprehensive.
Villalba et al [3]	Participants included those who were diagnosed with heart failure or those who had a cardiovascular accident, business managers, and cardiologists.	CUORE is divided into 3 main areas: the user interaction system running on Microsoft's .NET framework, professional interaction through a web-based portal, and a common platform.	A total of 26 people including 10 cardiac patients, 10 cardiologists, and 6 business people were interviewed. The validation comprised 2 phases: first, the system was validated with	Some patients considered it would be a problem for them to integrate the system into their daily lives. Some felt that the app constantly reminded of their sickness. Most

		The sensors and electronics to monitor patients in their daily routines include a blood pressure cuff, a weight scale, an electrocardiogram /heart rate monitor, and an oxygen saturation monitor.	patients; then, the system was validated with health professionals.	patients stated that being remotely monitored increased their feeling of security and comfort. Education on symptoms and medication was highly valued. Preference is given to continue using the devices they already own.
Jarvis-selinger et al [4]	Participants included cardiac patients, physicians, nurses, and health professionals.	The study aimed at understanding how internet-based platforms could be used to support self-management and communication among patients, physicians, and health professionals.	Semistructured interviews of a total of 48 participants over a period of 6 months was conducted. An iterative approach to data analysis was taken, employing a constant comparative method as a way to explore subjective experience.	Most important feature of the technology was considered to be sharing of patient health records. Majority of the health professionals felt that providing patients with accurate educational resources would be the best use of

				technology for self-management. Patients preferred face-to-face contact with doctors.
Fischer et al [5]	Participants were diagnosed with heart failure and attended the Manukau Super Clinic.	Web-based visualizations for educating patients and promoting behavioral change through interactive web graphics to visualize relationships between lifestyle, symptoms, patient parameters, and the disease.	Usability of the app was tested using surveys. The effectiveness of the app was evaluated through semistructured interviews with 18 participants.	The tool promoted knowledge and understanding of illness and associated symptoms, thereby alleviating the distress and influencing self-management and behavior change.
Pfaeffli et al [6]	Participants included patients diagnosed with CVDs[b] and CR[c] nurses.	Mobile SMS and brief video vignettes through participant website.	Intervention was developed with patient input using the following steps: conceptualization, formative research, pretesting, and pilot testing. Interviews with 38 CR patients were conducted	The mHealth[d] format was considered to be particularly useful for patients who found it difficult to attend center-based CR. Older participants viewed technology

			after the CR program. Interview analysis used thematic approach.	as a barrier because of unfamiliarity.
Katalinic et al [7]	Participants included patients of stroke, pediatric palliative, brain injury, and cardiac coaching.	Two home telehealth technologies (the Intel Health Guide and the Apple iPad) were trialed by 4 clinical services. The Intel Health Guide for cardiac coaching services and iPad for pediatric palliative care, the stroke and brain injury rehabilitation services.	A total of 102 patients were involved in the study. Intel health guide and iPad were given to use for 3 months. Satisfaction surveys were used to assess the usability and usefulness of videoconferencing and home telehealth devices and clinical advantages of using technology.	Apart from technical issues such as poor broadband and connectivity, Telehealth was found to play a useful role in improving access to services, especially for people who lived in rural areas. Both clinicians and patients readily accepted new technology; however, usability and ease of use are crucial in ensuring acceptance of technology.

Antypas and Wangberg [8]	Participants attending the CR program.	Website based on open source content management framework Drupal. It consisted of profile page; activity calendar; a discussion forum; and general information about cardiac disease, training, and symptoms. Users receive feedback regarding their level of activity.	Conducted a focus group with 11 participants (3 women and 8 men) of a CR program. Thematic analysis was used to identify and analyze transcribed data.	Seven themes were identified: social, motivation, integration into everyday life, information, planning, monitoring and feedback, and concerns and potential problems.
Geurts et al [9]	This study involved patients with cardiac condition, cardiologists, and HCI[e] experts for different stages of data collection.	The Back on Bike system consists of a mobile- and browser-based app that monitors cycling efforts of CR patients along with a dashboard for the medical staff.	Observations and contextual inquiries were held in the rehabilitation center with a physiotherapist. Followed by a co-design workshop with 4 HCI experts and 1 cardiologist in training nine patients	The system reassured patients that they were cycling at the right heart rate zone. The system also encouraged healthy people accompanying the patients to adapt their pace to the patient's safe

			participated in a field study, and results for 4 of the 9 patients are described in detail in this paper.	zone. The app reduced fear as it supported patients to cycle with others. Supportive messages and predefine routes motivated them to complete a tour.
Buys et al [10]	Study patients were recruited from a supervised phase 2 ambulatory CR program, 2 community based phase 3 CR programs, and adult congenital heart disease clinic.	The study aimed at understanding current technology usage of patients with CVD. Survey questions related to following technologies: mobile phone, internet, computer games, heart rate monitor, and physical activity monitor.	A technology usage questionnaire was completed by 310 patients. The questions were related to patients' characteristics, current technology usage, and patients' interests and needs from a technology-based virtual CR intervention. Data analysis was conducted using a statistical software.	Patients were interested in CR support through mobile or internet. Patients reported interest in virtual-based and game based CR. Advice on exercise ideas, opportunities, diet, and stress received rating for including in technology. Technology should be designed for all ages including men and women.

Cornet et al [11]	Participants diagnosed with heart failure and their informal caregivers.	Engage is a mHealth system designed for mobile or tablet devices to be used by patients or informal caregivers.	15 participants used Engage for 30 days. Two usability studies, task based and scenario based, generated a set of findings, and design guidelines were proposed by triangulating the complementary results from task-based tests, scenario-based evaluation, and quantitative instruments.	Participants were concerned about adding a device on top of what they already have. Participants desired a simpler interface; there is a need to consider affective design and individual differences, in addition to technical usability and performance requirements.
Banner et al [12]	Participants were patients with acute coronary syndrome or following a revascularization.	The vCRP[f] was designed to mimic a standard hospital-based CRP. It includes web-based intake forms; scheduled one-on-one chat sessions with the program nurse, case manager, exercise specialist,	78 cardiac participants were enrolled in the study. Control group received routine care from their primary care provider, and intervention group received an orientation to the vCRP. The	Five themes were identified: accessibility, making healthy choices, surveillance, barriers to participation, and perceptions of vCRP. Participants reported

		and dietician; weekly education sessions; and data capture for the exercise stress test and blood test results.	program lasted 4 months in duration and a final semistructured interview was undertaken with 22 participants. Evaluation included descriptive analysis of the data and thematic coding.	increased awareness and motivation to manage their health condition. Poor computer literacy was identified as a barrier.
Baek et al [13]	User research was conducted on cardiac patients and doctors at a tertiary general university hospital located in the Seoul metropolitan area of South Korea.	An mHealth mobile phone app was designed using a mock-up tool. The app provides health information, health questionnaire, self-management, and dairy.	Three types of user research and user experience investigations including surveys and interviews with 35 patients, focus group interviews with doctors, and a usability test were conducted. Evaluation was carried out by analyzing the opinions of doctors using the card sorting method, and interview transcripts were	Top 3 items that patients thought important included exercise, dietary control, and weight management. The commonly required features were easy app use, up-to-date information on health, self-assessment, current health status, and communication with doctors.

			analyzed using the constant comparative method.	
Salvi et al [14]	Patients who had experienced a cardiac event were selected and analyzed for suitability by physicians involved in the project.	The GEx, General exercise, system is composed of 3 main parts: the Mobile station, for monitoring physical exercise and providing live guidance during exercise sessions; the Patient station, which acts as a collector and gateway of patients' data and is responsible for delivering educational content to the user; and the Professional station, a web-based app which is used by doctors to prescribe and tailor each exercise	A randomized controlled trial was conducted with 118 participants to compare mobile-based rehabilitation, 55 patients versus standard care, and 63 patients. User acceptance and perceived usefulness were measured with a questionnaire inspired by the Technology Acceptance Model.	Educational level about heart-related health improved more in the intervention group than the control. Exercise habits at 6-month follow-up also improved.

		program, visualize patient progress, and be alerted in case of problems.		
Beatty et al [15]	Patients from a cardiology clinic who were eligible for CR were the participants.	A mobile app was designed to be used as a tool for home CR and includes physical activity goal setting, logs for physical activity, and health measures.	A total of 13 participants completed the System Usability Scale, rated likelihood to use the mobile app, questionnaires on mobile app use, and participated in a semistructured interview.	There was a desire for introductory training. Family and peer support were reported to influence mobile technology use. Participants desired ease of use and simplicity.
Smith et al [16]	Cardiac patients, physicians, and accredited social health activists.	Assessing the potential for using mHealth and mobile phone usage.	15 participants were involved in semistructured interviews over a period of 6 weeks. Evaluation involved thematic analysis of the interviews.	Challenges of CVD management were stated as poor patient disease knowledge, usability, and lifestyle. Family support, knowledge support, health work, and physician support

				are considered motivating.

aCHD: coronary heart disease.

bCVD: cardiovascular disease.

cCR: cardiac rehabilitation.

dmHealth: mobile health.

eHCI: human-computer interaction.

fvCRP: virtual cardiac rehabilitation program.

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Appendix B

Supplementary material for Chapter 4.

4.1 Ethics Approval

UCD CONNECT

Shreya Tadas <shreya.tadas@ucdconnect.ie>

LS-E-19-49-Tadas-Coyle Exemption
1 message
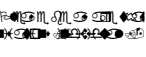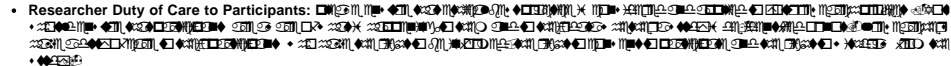
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exemptions.ethics@ucd.ie <exemptions.ethics@ucd.ie>
To: Shreya Tadas <shreya.tadas@ucdconnect.ie>
Cc: David Coyle <d.coyle@ucd.ie>

1 April 2019 at 15:08

Dear Shreya

Thank you for notifying the Human Research Ethics Committee - Sciences(HREC-LS) of _your declaration_ that you are exempt from a full ethical review. Should the nature of your research change and thereby alter your exempt status you will need to submit an application form for full ethical review. Please note for future correspondence regarding this study and its exemption that your Research Ethics Exemption Reference Number (REERN) is: **LS-E-19-49-Tadas-Coyle.** **This exemption from full ethical review is being accepted by the Office of Research Ethics on the condition that you observe the following:**

- **External REC Approval and/or Permission to Access/Recruit Human Participants/or their Data:** *(if applicable)* ▨◆▨▥◨◧◨▨◨▨ ▨◨◨▨◨◨▨◨◨▨◨◨ ▨◨▨◨◨◨▨◨◨▨◨ ◨◨◨◨▨◨◨◨▨◨◨◨ ◨◨◨▨◨◨◨◨◨ ◨◨◨◨◨◨◨

- **UCD Insurance Requirement:** ◨◨◨◨ ◨◨◨◨◨◨◨◨◨◨◨ ◨◨◨◨◨◨◨ ◨◨◨◨◨◨◨◨◨◨◨

- **Researcher Duty of Care to Participants:** ◨◨◨◨ ◨◨◨◨◨◨◨◨◨◨◨ ◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨ ◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨ ◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨◨ ◨◨◨◨

Any additional documentation should be emailed to exemptions.ethics@ucd.ie quoting your assigned reference number (provided above) in the subject line of your email.

Please note that your research does not require a committee review and also note that this is an acknowledgment of your declared exemption status. All Exemptions from Full Review are subject to Research Ethics Compliance Review. You should ensure that your Exemption Form is signed by you, your supervisor (if applicable) and your Head of School, and that this signed document is retained in your school as part of your record.

Regards

Jan

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- www.ucd.ie/researchethics

From: Shreya Tadas <shreya.tadas@ucdconnect.ie>
Sent: Thursday 28 March 2019 11:53

4.2 Interview Guide

Checklist:

1. Participant has already received the Information leaflet and has given consent.
2. Send interview date and time confirmation email to participants
3. During the interview:
   a. Introduce self and brief about the study:
   b. Start questionnaire

Example questions about knowledge and skills

1. When did you first become **aware** of your cardiac condition?

   (First cardiac incident, tell me what happened)

2. How **much did you know about your condition**? What **sources of information** did you use to learn about it and the impact it could have on your day-to-day life?

   (Did you receive any advice or information during your hospital admission?)

3. How much did you **know about cardiac rehabilitation** and management and the steps to be taken towards it? (how did you learn)
4. Did you have to consider any **changes** in **your day-to-day life**?
5. Were there any **new skills or techniques** you had to acquire to manage your condition (for recovery/ to maintain recovery)? What are they?
6. Were you initially **confident** in your ability to make lifestyle changes after you learnt about your cardiac condition (or confident to begin the recovery process and begin day-to-day life)?
7. **Do you use technology** in your day-to-day life? If yes, what kind of technology do you use? How? (to manage cardiac condition/ health?)
8. Are you **aware of any applications/ technologies** used for cardiac management (or used to maintain health)? (e.g. Blood pressure monitor, heart rate monitor, weighing scales…)

Example questions about individual goals and intentions

1. Choice of question depends on participant's response in previous questions.
   1. If you have attended a **rehabilitation program**, how long did the program last? Tell me about it. (Did you use/ were you advised to use any technology during the rehabilitation program? Is there anything you would recommend adding to the classes/ program?)
   2. If you are **using a technology** for health management, how do you use it? If stopped, why did you stop? how strong is your intention to use it for long term? Why?
   3. If you are **not using a technology** for management, would you be willing to use it if it gave useful information and guidance on health? Why?

      (what are the barriers in using technology?)

      (If you could recommend technology to someone with a cardiac condition to help with the rehabilitation progress, what features do you think it should have?)

2. When you realised about your health condition, did the **goals** in your life change? How?

3. Are the techniques that you mentioned earlier help you **stick to your goals**?
4. Do you keep **track** of your **overall progress** towards a healthy lifestyle? How and how often?
5. Do you **remember and use** all the **information** received during the rehabilitation classes?
6. Do you feel that rehabilitation programs and/or technology can help you get the right information in order to focus on your wellbeing? (If no, what approach would you consider? or Are you satisfied with your approach towards recovery?)

Questions about social and environment (sources of influence and motivation)

1. Does your **day-to-day environment impact** your ability to maintain your cardiac condition? (e.g. home, work, social environment)
   a. If work environment interferes with cardiac management? How?
   b. If home environment interferes with cardiac management? How?
   c. If social environment interferes with cardiac management? How?
2. Does meeting with health professionals help or hinder you towards cardiac management (maintaining recovery)?

   (e.g. cardiologists, consultants, nurses, physiotherapists...)

   a. How 'x' impact you?
3. Do the people in your life help or hinder you towards cardiac management?

   (e.g. family, friends, online communities, support groups...)

   a. How 'x' impact you?
4. Do any of these: competitiveness, recognition, achievement, bragging; in any form, influence you in maintaining healthy lifestyle?
5. If you use technology, what aspects of 'technology x' do you like and what do you not like? (e.g. features, design...)

Questions about emotional influence

1. How **did it feel** when you first realised about the cardiac condition?
2. Did your feelings **change over time**? How?
3. What was your **overall experience** of the rehabilitation process (or recovery)?
4. Were there **any major high or low points** during the rehabilitation (or recovery)?

Is there anything else you would like to add about anything we have discussed?

Conclude: Thank you again for your time.

Ask permission to follow up later if needed.

4.3 Code Book

	Code	Meaning
1	**Initial help seeking**	What was their first source of information after hospitalization or What is their goto source for information?
2	**Contact with health care professionals**	Need for or contacting experts or health professionals during recovery
3	**Resources recommended by experts**	Use of or need for any official or expert resources during any point of recovery/ after hospitalization.
4	**Need for information**	The need to understand. Information that they found important? Information that gave them confidence. Do they retain the given information? (benefits of information)
5	**Feeling better after surgery**	Related to feeling fitter after the surgery.

	Code	Meaning
6	Perceptions or attitudes towards technology	What are their feelings or opinions when asked about technology? What do they think technology is?
7	Barriers to use of technology	Any barriers mentioned?
8	Needs from technology	Do they talk about needs or features that could be provided by technology? Any concerns mentioned?
9	Tech tells what can be done	When they talk about tech being reassuring or telling them what to do or what they can do. If they are in a safe zone.

	Code	Meaning
10	Type of technology used	What type of tech do they use

	Code	Meaning
11	Rehab classes as a training place	When they talk about rehab classes teaching them something and they could/are continuing it later
12	Rehab classes as a social place	When they talk about the group or social aspects of rehab classes
13	Hindrances to attending in-person rehab	Barriers to cardiac rehab classes
14	Preference for local/ in-person interaction	When they talk about "human" contact (can be health professionals or other people) or preference for "face-to-face" interaction. Also, related to feeling reassured when monitored in-person by physios

	Code	Meaning
15	Self-reliance	Prefers not to be told what to do, in control of life or they like doing things on their own
16	Physical activity found in daily activities	Is fitness/ physical activity accomplished through activities in daily life? or Do they continue previously enjoyed activities?
17	Tailoring	Related to individual needs or personalisation.
18	Monitoring	Anything related to being monitored or "monitoring" (includes monitoring by tech or in rehab classes or GP)

	Code	Meaning
19	Desire for normal life	Related to wanting or going back to "normal life"
20	Bodily awareness	Related to being more aware of body/ diet/ health. Being in tuned with the body.
21	Stress/ anxiety and relaxation	Any examples where they talk about stress or benefits of relaxation.
22	Motivation or demotivation	Things that motivate or demotivate them to perform self-care activities.
23	Cardiac is sudden	When they talk about unexpectedness of cardiac event
24	Prior awareness	Related to having a family history of cardiac event. Had prior awareness about cardiac condition. How does having prior awareness make them feel?-Prepared?
		This can also include comments where the participants indicate limited prior awareness.
25	Fear	Fear of overdoing it alone. Loss of confidence to do physical activities. Fear after cardiac event.
26	Positivity/negativity	A mindset or outlook
27	Gratitude/ appreciation	Gratitude of being healthy, for living.
		Appreciation towards healthcare providers and family.
28	Environmental/ contextual support	Work/ home/ environment. How it influenced them?
29	Social support and type of social support	Includes friends, family, and other social support (benefits and disadvantages)
30	Emotional response or reaction	Any place where the participant expresses a strong emotion or reaction to events.

Appendix C

Supplementary material for Chapter 5.

5.1 Final List of Questions in the Weekly Questionnaire
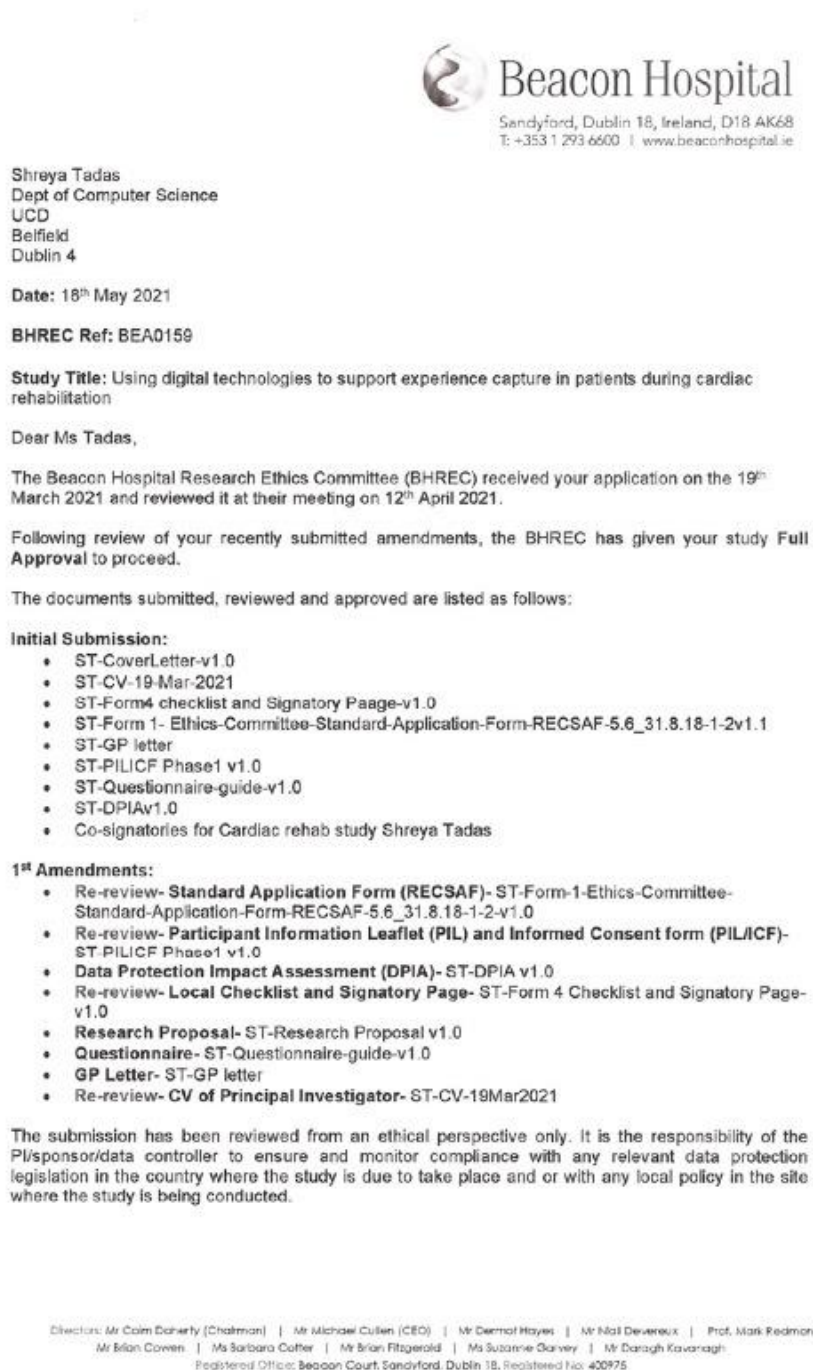
Week 1- Intro and set up

1. On a scale of 1 to 10, how confident are you about managing your condition? Please elaborate.
2. On a scale of 1 to 10, how informed do you feel about your condition? Please elaborate (list any resources you have used such as websites etc).
3. On a scale of 1 to 10, how motivated are you this week? Please elaborate.
4. On a scale of 1 to 10, how stressed do you feel this week?
5. Do you feel confident to engage in physical activity? If so, how do you keep yourself active?
6. Any injuries, pains or sensations limiting you engaging in activity?
7. Any limitations in your usual activities due to health (including mental health) issues?
8. What exercise did you do outside of class this week?
9. What's the highest level of activity you would feel confidant to engage in? (e.g. walking, jogging, cycling, sprinting, playing sports)
10. How are you feeling <u>emotionally</u>?
11. Do you know the recommended guidelines for weekly activity levels for general health? How much and what intensity of activity is recommended?
12. What concerns, if any, do you have about exercising?

Week 2- Exercise with heart disease

1. On a scale of 1 to 10, how confident are you about managing your condition? Please elaborate.
2. On a scale of 1 to 10, how informed do you feel about your condition? Please elaborate (list any resources you have used such as websites etc).
3. On a scale of 1 to 10, how motivated are you this week? Please elaborate.
4. What exercise did you do outside of class this week?
5. Any injuries, pains or sensations limiting you engaging in activity?
6. Do you feel confident to engage in physical activity?
7. On a scale of 1 to 10, during the past week how much difficulty have you had doing your usual daily <u>activities</u>?
8. What's the highest level of activity you would feel confidant to engage in? (eg walking, jogging, cycling, sprinting, playing sports)
9. Do you know the recommended guidelines for weekly activity levels for general health? How much and what intensity of activity is recommended?
10. Have you made any changes to your diet recently? What were these changes?
11. If you answered no above, do you think you need to make changes to your <u>diet</u>? If so, what needs to change?
12. Have you found any useful resources for healthy eating? If yes, please list them.
13. What concerns, if any, do you have about exercising?

Week 3- Diet talk

1. On a scale of 1 to 10, how confident are you about managing your condition? Please elaborate.
2. On a scale of 1 to 10, how informed do you feel about your condition? Please elaborate (list any resources you have used such as websites etc).
3. On a scale of 1 to 10, how motivated are you this week? Please elaborate.
4. Any injuries, pains or sensations limiting you engaging in activity?
5. On a scale of 1-10 what are your feelings about engaging in social interaction?
6. Do you feel confident to engage in physical activity? If so, how do you keep yourself active?
7. Have you added anything beneficial into your <u>diet</u> since attending the talk? If so, what have you added into your diet?
8. During the past week, how much have you been bothered by <u>feelings</u> like anxiousness, irritability, or downhearted/blue?
9. Do you know when and how to take your <u>medications</u>? Please elaborate.
10. Do you know where to go if you are not confident about your <u>medication</u>? Please elaborate.

Week 4- Pharmacy talk

1. On a scale of 1 to 10, how confident are you about managing your condition? Please elaborate.
2. On a scale of 1 to 10, how informed do you feel about your condition? Please elaborate (list any resources you have used such as websites etc).
3. On a scale of 1 to 10, how motivated are you this week? Please elaborate.
4. What exercise did you do outside of class this week?
5. Any injuries, pains or sensations limiting you engaging in activity?
6. On a scale of 1-10 what are your feelings about engaging in social interaction?
7. Do you know when and how to take your <u>medications</u>? Please explain.
8. Do you know where to go if you are not confident about your <u>medication</u>? Please explain.
9. Do you feel stress is an issue for you?
10. What strategies do you use to manage stress?
11. Have you tried relaxation or mindfulness before?
12. Do you think relaxation can be beneficial to your cardiac and overall health? Please explain.
13. Do you know any risk factors for heart disease? (modifiable or non-modifiable)
14. Do you have any concerns about your health at the moment?

Week 5- Occupational therapy talk and CNS talk

1. On a scale of 1 to 10, how confident are you about managing your condition? Please elaborate.

2. On a scale of 1 to 10, how informed do you feel about your condition? Please elaborate (list any resources you have used such as websites etc).
3. On a scale of 1 to 10, how motivated are you this week? Please elaborate.
4. What exercise did you do outside of class this week?
5. Any injuries, pains or sensations limiting you engaging in activity?
6. Do you think relaxation can be beneficial to your overall and cardiac health?
7. Have you learned any new strategies for managing stress?
8. Have you implemented or tried any of the stress management / relaxation strategies discussed during the session?
9. Do you feel better equipped to recognise and manage stress?
10. Are you confident to make the necessary changes to your modifiable risk factors?
11. What changes have you made?
12. Did you find the cardiac rehab programme beneficial including the presentations?

Appendix D

Supplementary materials for Chapter 6.

6.1 Ethics Approval from Beacon Hospital

Beacon Hospital

Sandyford, Dublin 18, Ireland, D18 AK68
T: +353 1 293 6600 | www.beaconhospital.ie

Shreya Tadas
Dept of Computer Science
UCD
Belfield
Dublin 4

Date: 18th May 2021

BHREC Ref: BEA0159

Study Title: Using digital technologies to support experience capture in patients during cardiac rehabilitation

Dear Ms Tadas,

The Beacon Hospital Research Ethics Committee (BHREC) received your application on the 19th March 2021 and reviewed it at their meeting on 12th April 2021.

Following review of your recently submitted amendments, the BHREC has given your study **Full Approval** to proceed.

The documents submitted, reviewed and approved are listed as follows:

Initial Submission:
- ST-CoverLetter-v1.0
- ST-CV-19-Mar-2021
- ST-Form4 checklist and Signatory Paage-v1.0
- ST-Form 1- Ethics-Committee-Standard-Application-Form-RECSAF-5.6_31.8.18-1-2v1.1
- ST-GP letter
- ST-PILICF Phase1 v1.0
- ST-Questionnaire-guide-v1.0
- ST-DPIAv1.0
- Co-signatories for Cardiac rehab study Shreya Tadas

1st Amendments:
- Re-review- **Standard Application Form (RECSAF)**- ST-Form-1-Ethics-Committee-Standard-Application-Form-RECSAF-5.6_31.8.18-1-2-v1.0
- Re-review- **Participant Information Leaflet (PIL) and Informed Consent form (PIL/ICF)**- ST-PILICF Phase1 v1.0
- **Data Protection Impact Assessment (DPIA)**- ST-DPIA v1.0
- Re-review- **Local Checklist and Signatory Page**- ST-Form 4 Checklist and Signatory Page-v1.0
- **Research Proposal**- ST-Research Proposal v1.0
- **Questionnaire**- ST-Questionnaire-guide-v1.0
- **GP Letter**- ST-GP letter
- Re-review- **CV of Principal Investigator**- ST-CV-19Mar2021

The submission has been reviewed from an ethical perspective only. It is the responsibility of the PI/sponsor/data controller to ensure and monitor compliance with any relevant data protection legislation in the country where the study is due to take place and or with any local policy in the site where the study is being conducted.

The application was reviewed by the Beacon Hospital Data Protection Committee and the Data Protection Officer, Mr Brian Fitzgerald.

Approval will be rescinded if the following terms are also not adhered to:

- **Annual Progress Reports** must be submitted to the REC for the duration of the project, with the first report due within a period of no later than 12 months from the date of this letter

- A **Final Report** must be submitted to the REC following completion of the project

- All application/protocol amendments must be submitted for review and approval to the REC **prior to implementation**

- The REC must be notified of all/any **Serious Adverse Events (SAEs) or new issues/events likely to affect the conduct or safety of the study and/or participants**

Name	Position	Signature	Date
Assoc Prof David Burke	Vice-Chair, REC, Beacon Hospital		18/01/2021
Mr. Brian Fitzgerald	Data Protection Officer		18/01/2021

*Please inform the BHREC of **any dissemination outputs** arising from conducting your research study concerning Beacon Hospital patients.*

Please acknowledge receipt of this letter and if you have any queries relating to the terms and conditions outlined in this letter, please do not hesitate to contact me.

Kind regards,

Beacon Hospital Research Ethics Committee Administrator
Beacon Hospital
Suite 13
Sandyford
Dublin 18
Email: ethics@beaconhospital.ie

6.2 Ethics Exemption from UCD

UCD CONNECT

Shreya Tadas <shreya.tadas@ucdconnect.ie>

LS-E-21-145-Tadas-Coyle Exemption
4 messages

exemptions.ethics@ucd.ie <exemptions.ethics@ucd.ie>
To: Shreya Tadas <shreya.tadas@ucdconnect.ie>
Cc: David Coyle <d.coyle@ucd.ie>

21 June 2021 at 12:43

Dear Shreya,

Thank you for notifying the Human Research Ethics Committee – [Sciences (HREC-LS)] of _your declaration_ that you are exempt from a full ethical review. Should the nature of your research change and thereby alter your exempt status you will need to submit an application form for full ethical review. Please note for future correspondence regarding this study and its exemption that your Research Ethics Exemption Reference Number (REERN) is: **LS-E-21-145-Tadas-Coyle.** **This exemption from full ethical review is being accepted by the Office of Research Ethics on the condition that you observe the following:**

- **External REC Approval and/or Permission to Access/Recruit Human Participants/or their Data:** _(if applicable)_ Please be aware that recruitment of participants or data collection should not begin until written permissions are secured from external organisations/individuals.

- **COVID-19:** Please note that for any future changes to face-to-face data collection will require a complete a self-assessment using the Human Research Risk Assessment form from SIRC**.** This may be required as part of any future request to amend.

- **Researcher Duty of Care to Participants:** please ensure that ethical best practice is considered and applied to your research projects. You should ensure that participants are aware of what is happening to them and to their data whether a study is de-identified or not. All researchers have a duty of care to their participants who have the right to be informed, the right to consent to participate and the right to withdraw from the study.

Any additional documentation should be emailed to exemptions.ethics@ucd.ie quoting your assigned reference number (provided above) in the subject line of your email.

Please note that HREC no longer process **insurance cover** on behalf of the researcher. Researchers are required to complete a self-assessment form from the UCD SIRC office – please see www.ucd.ie/sirc/insurance/ humanresearchinsurance

Please note that your research does not require a committee review and also note that this is an acknowledgment of your declared exemption status. All Exemptions from Full Review are subject to Research Ethics Compliance Review.

Kind regards,

Tom

From: Shreya Tadas <shreya.tadas@ucdconnect.ie>
Sent: Sunday 20 June 2021 16:06
To: Ethics Exemptions <exemptions.ethics@ucd.ie>
Subject: Re: Research ethics exemption application

Hi Tom,

Attaching the filled updated form and supporting documents. The form did not have a signature page, do I need to get the signatures again?

According to the Insurance checklist, I will need the General Liability Insurance. Would you know how I could obtain that?

6.3 Patient Information Sheet and Consent Form

Beacon Hospital

Sample Patient Information Leaflet and Consent Form

Study Title: Using digital technologies to support experience capture in patients during cardiac rehabilitation

Study Code (REC ref. No.):
Protocol Version/date: 1.1/ March 19th 2021

Investigator Names: Shreya Tadas (UCD), Jane Dickson (Beacon Hospital), Assoc Prof David Burke (Beacon Hospital) and Prof David Coyle (UCD)

Investigator Department: School of Computer Science (UCD), Allied Health (Beacon Hospital) and Cardiology Department (Beacon Hospital).

Sponsor Name and Address (if not Beacon Hospital): European Commission Interreg Programme through the Eastern Corridor Medical Engineering Centre (ECME)

Data Controller's/joint Controller's Identity: Shreya Tadas (UCD), Jane Dickson (Beacon Hospital) and David Burke (Beacon Hospital)

Data Controller's/joint Controller's Contact Details:
Shreya Tadas   Email: shreya.tadas@ucdconnect.ie   Tel: 0899882380
Jane Dickson   Email: jane.dickson@beaconhospital.ie   Tel: 0874314753
David Burke   Email: david.burke@beaconhospital.ie   Tel: 0874402868

Data Protection Officer: Brian Fitzgerald

DPO's Contact Details:
Beacon DPO Email: data.protection@beaconhospital.ie;
UCD DPO Email: gdpr@ucd.ie

Introduction and Background Information

What is the purpose of the study?
The purpose of this study is to understand if capturing patient experience combined with physical activity through a web/smartphone application supports cardiac patients during their cardiac rehabilitation(CR). You have been invited to take part in this study because you are in the CR program.

Previous research suggests that sharing experiences with experts and with people going through similar conditions (peers) maybe important for patients during their recovery and rehabilitation period; however, it is hard to find efficient and trustable ways to replicate this sharing and communication process in a remote environment.

We want to understand the best ways to support the capturing and sharing of your rehabilitation experiences with experts using consumer activity trackers (Fitbit) combined with a web/smartphone application.

Who is organising the research?
This research is a collaboration between researchers in University College Dublin and Beacon Hospital.

What will happen during the study?
If you agree to participate in this study by signing the consent form, the following will take place:

Set-up
If you are eligible, the Beacon physiotherapist (Jane Dickson) will chose a convenient date and time for researcher (Shreya Tadas) to meet you at Beacon to set up the Fitbit device and smartphone application. We will also ask you to complete a brief questionnaires about your current smartphone and Fitbit usage, your current health condition, and quality of life.

After receive your consent and starting from the first week through to the last week of your cardiac rehabilitation consultations (4-6 weeks), your will need to wear the Fitbit device and you will receive a weekly/ biweekly questionnaire to answer. The questionnaires will be related to your experiences for that week/weeks, facilitators, and barriers towards your physical and emotional health care. Your questionnaire responses and Fitbit data will be shared with your physiotherapist weekly/ biweekly.

The questionnaire will be sent to you through a web/smartphone application. We will help you with the application set up at the beginning of the study.

Post-Study Session
After your CR period (4-6 weeks), the researcher will contact you to organize a suitable time to conduct a post-study session. This session will be conducted remotely over phone call and will take approximately 30 mins. This session will involve a brief interview to help us understand your experiences during the study and the impact of experience capturing and sharing with physiotherapist. You will then be invited to participate in a follow-up focus group session.

How many people will take part in the study?
In total we are seeking to include 12 participants for this study.

How long will I be in the study?
The study will run for the duration of your cardiac rehabilitation (4-6 weeks).

Do I have to take part?
No, it is up to you to decide whether or not to take part.

What are the alternatives for treatment?
Participation is voluntary and will not directly impact the type of treatment which you receive from the Beacon Hospital. Therefore, if you decide not to participate or you withdraw from the study, your Beacon Hospital Cardiology care will not be impacted in any way. The purpose of this study is to understand if experience and activity capturing through questionnaires will help support remote cardiac rehabilitation.

What are the possible risks/side effects of participating in this study?
We perceive that the risks associated with participation in this study are low. As you will be asked to wear Fitbit for the duration of your cardiac rehabilitation program, there is a small risk that the device may cause skin chafing if not removed or cleaned regularly. We will inform you on how to correctly secure, regularly remove and clean the device in order to ensure minimal risk of skin chafing, as per manufacturer's instructions. Millions of these devices have been sold and are used by consumers worldwide. Therefore, the risks associated with the use of these devices is low.

What are the possible benefits from taking part in this study?
While this study focuses on investigating the feasibility of using a digital technology to capture CR experiences and physical activity, it is anticipated that your reflection on your physical and emotional health may improve as a result of participation in this study. Participation in the study may also have a positive impact on your self-care behaviour. Furthermore, while not directly realised by you, participation in this research project may help other patients with similar problems gain access to better communication and sharing techniques, supporting patient care and CR in the future.

What if new information becomes available?
If any new information that is relevant to the study becomes available your CR team will inform you immediately via phone.

Can I stop being in the study?
Yes, you can decide to stop at any time. This will not affect the standard of care you receive.

Can anyone else stop me from being in the study?
The study doctor may stop you from taking part in this study at any time if:
- It is in the best interest for your health
- You do not follow your responsibilities for taking part in the study
- It is discovered at a later time that you do not meet the study participation requirements
- The study is stopped by the sponsor
- Administrative reasons require your withdrawal

What happens if I am injured because I took part in this study?
As this study mainly involves responding to questionnaire, there is low risk of injury. However, if you become ill or receive a bodily injury as a result of participating in this study, please contact the lead physiotherapist or researcher immediately: you will be treated or referred for treatment. UCD and Beacon Hospital have arranged appropriate insurance cover for this study.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators or involved institutions from their legal and professional responsibilities.

Will my taking part in this study be kept confidential?
Yes, only the study team will have access to your data.

❖ *The purpose for processing your personal data* – Your data will be processed, with your informed consent, for the specific scientific purposes outlined above.

❖ *The legal basis under which we are processing your data* – We will only process your data with your explicit written informed.

❖ *Who are the recipients of the data and will have access to the information?* –Jane Dickson (Beacon Hospital), David Burke (Beacon Hospital), and Shreya Tadas (UCD) are the controllers of your data. Your data will be processed by members of the study team in UCD and DCU.

❖ *How long will the data be stored for?-* Audio interview data will be transcribed and coded and any identifiable statements from the interviews will be redacted. Participants will be given a two week window after their interviews to listen to the files and review the transcripts if they wish to. The Audio files will then be destroyed, and the transcribed data will be used in the thematic analysis. The study key code and the pseudonymised dataset will be stored separately for a period of 5 year following the study. During this time, data controllers Jane Dickson (Beacon Hospital), David Burke (Beacon Hospital), and Shreya Tadas (UCD) will be responsible for the security of your data, and for making sure that none of your personal identifiable information is linked to your data. At the end of this 5 year period we will destroy the study data.

❖ *Will there be automated decision making, including profiling?*
While the activity tracker will be automatically monitoring your physical activity, no automatic decisions about your treatment will be made.

❖ *Will my data be used for other purposes beyond those involved in this study*?
No

❖ *Will my data be accessed by people outside the EU?*
It is important for you to understand that this study uses Fitbit devices. Fitbit is a multinational company which operates internationally and transfers data lawfully to the United States and other countries. Fitbit transfers these data legally using your consent, the EU-US and Swiss-US Privacy Shield, and EU Commission approved model contractual clauses, which require certain privacy and security protections. As stated above, No medical or identifiable data will be shared with Fitbit. Furthermore, it will not be possible for Fitbit or anyone outside of the study team to identify that you are a member of a research study based on these data. Further

information about Fitbits data privacy policy can be accessed here:
https://www.fitbit.com/uk/legal/privacy-policy?utm_source=ET&utm_medium=EM&utm_campaign=20180411_PrivacyPolicy_UK_FM_O_LG_FT_00_NA

❖ *All participants have the right to:*
  ❖ *W*ithdraw consent up to the time at which we destroy the study key code and the dataset is irrevocably anonymised.
  ❖ Lodge a complaint with the Data Protection Commissioner https://www.dataprotection.ie/en/individuals/raising-concern-commission
  ❖ Obtain a copy of the data we are holding on your behalf, up to the point at which your data is irrevocably anonymised
  ❖ Restrict or object to processing of your data
  ❖ Correct or delete any inaccurate information held about me.
  ❖ Delete my data, up to the point at which the dataset is irrevocably anonymised
  ❖ Move my data, up to the point at which the dataset is irrevocably anonymised

What are the costs of taking part in this study?
You will not be charged for the cost of tests done for the purpose of this study. You will not be paid for your participation in this study. If you incur travel expenses, we can reimburse them. At the end of the study, you may keep the Fitbit devices if you wish. In that case, you will be required to set-up your own Fitbit profile at the end of the study period. If you do not wish to keep the Fitbit device, you can return it back to the Beacon physiotherapist (Jane Dickson).

Who has reviewed and approved this study?
This study has been reviewed and approved by the Beacon Hospital Research Ethics committee. It has also been noted, and approved under exemption from approval status by the ethics committee of UCD.

Contact for further information:

PI contact/ Researcher:
Shreya Tadas (Principal Investigator, UCD). Shreya.tadas@ucdconnect.ie Tel: 0899882380
Jane Dickson (Co-investigator, Beacon). jane.dickson@beaconhospital.ie Tel: 087-431 4753
David Burke (Co-investigator, Beacon). david.burke@beaconhospital.ie Tel: 087 440 2868
David Coyle (Co-investigator, UCD). d.coyle@ucd.ie Tel: 017162818

For questions about your participation in this study, or if you wish to make a complaint while taking part in this study, call Shreya Tadas at 0899882380 and your complaint will be dealt with promptly.

Informed Consent Form

Study Title: Using digital technologies to support experience capture in patients during cardiac rehabilitation

PI Name: Shreya Tadas   **Hospital Name:** Beacon Hospital

Please Initial box

1. I confirm that I have been given a copy of all 7 pages of the Patient Information Leaflet and Consent form. I have read the patient information leaflet and consent form or it has been read to me. This information was explained to me and my questions were answered.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.

3. I understand and give informed consent that my participation in this study will be shared with my General Practitioner.

4. I understand and give informed consent that data related to me collected during this study will be processed and analysed as is required by this clinical study and according to the Data Protection Act.

5. I agree to being audio recorded during the post-study interview session.

6. I voluntarily agree to take part in this study having been fully informed of the risks, benefits and alternatives.

(If applicable) Please initial the appropriate box:
- I agree that my pseudonymised activity tracker data will be stored using Fitbit servers within and outside the EU.

- I understand I will not be entitled to a share of any profits that may arise from the future use of my material/data or products derived from it.

- I give permission for material/data to be stored for possible future research unrelated to the current study without further consent being required but only if the research is approved by a Research Ethics Committee.

_____   _____   _____
Name of Patient (Print)   Signature of Patient   Date

_____   _____   _____
Name of Witness (Print)   Signature of Witness   Date
(IF APPLICABLE)

_____   _____   _____
Name of Investigator (Print)   Signature of Investigator   Date

6.3 Pre-study Questionnaire with Patients

Pre-study questionnaire

1. Age

   _____

2. Marital status

   Mark only one oval.

   ◯ Single

   ◯ Married

   ◯ Permanent partnership

   ◯ Other: _____

3. Do you use a smartphone?

   Mark only one oval.

   ◯ Yes

   ◯ No

   ◯ Maybe

4. What are the most common smartphone apps you use?

   _____

   _____

   _____

   _____

   _____

5. Do you use a smart watch? If yes, which one?

_____

6. How comfortable are you sharing your recovery experiences with CR experts? (CR experts are the health professionals running the classes)

Mark only one oval.

	1	2	3	4	5	
Not comfortable	◯	◯	◯	◯	◯	Very comfortable

7. How comfortable are you sharing your Fitbit data with CR experts?

Mark only one oval.

	1	2	3	4	5	
Not comfortable	◯	◯	◯	◯	◯	Very comfortable

8. How comfortable are you sharing your recovery experiences with other patients in the CR program?

Mark only one oval.

	1	2	3	4	5	
Not comfortable	◯	◯	◯	◯	◯	Very comfortable

9. How comfortable are you sharing your Fitbit data with other patients in the CR program?

Mark only one oval.

	1	2	3	4	5	
Not comfortable	◯	◯	◯	◯	◯	Very comfortable

10. How comfortable are you sharing your recovery experiences with other patients in the CR program using a website/ smartphone?

Mark only one oval.

	1	2	3	4	5	
Not comfortable	◯	◯	◯	◯	◯	Very comfortable

184

6.4 Post-study Semi-structured Interview Guide with Patients

Quantitative + semi-structured: Related to impact of creating narratives, willingness to share with other patients, impact of sharing data with experts, impact of sharing fitbit data each week.

About the web app:

1. What was your experience using the web app?
2. Did you find it useful? In what way?
3. Did it have any impact on you in any way?
4. Did it have any impact on your conversations with the CR clinicians?
5. Did you use the "your captured experiences" tab? If yes, what did you use it for?
6. The aim of the "your captured experiences" was to display any changes/ progress from week to week during the CR program? Was it used for that at any point? If not, how would you like to see this information if interested?
7. Would you have liked to see or do anything else on the web app?
8. Was the timing of the reminder sms right? (every Friday and Saturday)
9. What are your feelings about sharing the captured experiences with other patients?
10. Would you have shared information differently if you knew that they would be shared with other patients in the CR?
11. In remote CR, would you like to read about what others are experiencing during the CR program?
12. If yes, what kind of information would you like to receive/ read from other patients in the CR program?
13. What are your thoughts on sharing and receiving other CR patients' experiences during such a remote CR program?

About Fitbit:

1. How was it to wear Fitbit during the CR program?
2. How did you use it?
3. What impact did it have on you?
4. Is it valuable to wear a smartwatch during such a remote CR program?
5. What are your thoughts on receiving other CR patients' Fitbit data (e.g. steps, workout, calories burnt, etc.)?
6. How comfortable are you sharing your Fitbit data with other CR patients?
7. If Fitbit was given after CR program vs at the start

Appendix E

Publications

Review

Barriers to and Facilitators of Technology in Cardiac Rehabilitation and Self-Management: Systematic Qualitative Grounded Theory Review

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Abstract

Background: Dealing with cardiovascular disease is challenging, and people often struggle to follow rehabilitation and self-management programs. Several systematic reviews have explored quantitative evidence on the potential of digital interventions to support cardiac rehabilitation (CR) and self-management. However, although promising, evidence regarding the effectiveness and uptake of existing interventions is mixed. This paper takes a different but complementary approach, focusing on qualitative data related to people's experiences of technology in this space.

Objective: Through a qualitative approach, this review aims to engage more directly with people's experiences of technology that supports CR and self-management. The primary objective of this paper is to provide answers to the following research question: What are the primary barriers to and facilitators and trends of digital interventions to support CR and self-management? This question is addressed by synthesizing evidence from both medical and computer science literature. Given the strong evidence from the field of human-computer interaction that user-centered and iterative design methods increase the success of digital health interventions, we also assess the degree to which user-centered and iterative methods have been applied in previous work.

Methods: A grounded theory literature review of articles from the following major electronic databases was conducted: ACM Digital Library, PsycINFO, Scopus, and PubMed. Papers published in the last 10 years, 2009 to 2019, were considered, and a systematic search with predefined keywords was conducted. Papers were screened against predefined inclusion and exclusion criteria. Comparative and in-depth analysis of the extracted qualitative data was carried out through 3 levels of iterative coding and concept development.

Results: A total of 4282 articles were identified in the initial search. After screening, 61 articles remained, which were both qualitative and quantitative studies and met our inclusion criteria for technology use and health condition. Of the 61 articles, 16 qualitative articles were included in the final analysis. Key factors that acted as barriers and facilitators were background knowledge and in-the-moment understanding, personal responsibility and social connectedness, and the need to support engagement while avoiding overburdening people. Although some studies applied user-centered methods, only 6 involved users throughout the design process. There was limited evidence of studies applying iterative approaches.

Conclusions: The use of technology is acceptable to many people undergoing CR and self-management. Although background knowledge is an important facilitator, technology should also support greater ongoing and in-the-moment understanding. Connectedness is valuable, but to avoid becoming a barrier, technology must also respect and enable individual responsibility. Personalization and gamification can also act as facilitators of engagement, but care must be taken to avoid overburdening people. Further application of user-centered and iterative methods represents a significant opportunity in this space.

(J Med Internet Res 2020;22(11):e18025) doi: 10.2196/18025

KEYWORDS

telemedicine; cardiovascular diseases; self-management; self-care; systematic review; grounded theory; mobile phone

186

Introduction

Background

Cardiovascular diseases (CVDs) are the leading cause of death worldwide. An estimated 17.9 million people died from CVD in 2016, representing 31% of all global deaths [1,2]. By 2035, more than 130 million adults in the US population (45.1%) are projected to have some form of CVD, with the total costs of CVD expected to reach US $1.1 trillion [3]. Improved cardiovascular outcomes depend largely on how well affected people manage their condition [4]. Physical rehabilitation and lifestyle management are critical components of programs aimed at primary and secondary prevention of CVD. A major challenge in implementing these strategies is ensuring good patient engagement and compliance with prescribed exercise programs and nutrition plans. Evidence from the literature suggests that tightly supervised intervention programs are most successful and that self-directed management is less successful because of problems with engagement and adherence. The problem lies in expecting patients with a wide variety of life patterns and personality types to conform to standardized programs that do not fit with their ever-changing context [5].

After a person is hospitalized and following a discharge and recuperation period, they are typically recommended to attend a cardiac rehabilitation (CR) program offered by hospitals. Following this, they need to continue to self-manage their cardiac health. CR is considered a vital part of long-term recovery by targeting risk factor modification, supervised exercise, psychological support, and medication review [6]. However, the uptake of CR programs remains poor because of factors such as age, gender, lack of knowledge, transportation, motivation, and social support [7,8]. This also has an impact on people's subsequent ability to self-manage their condition. Barlow et al [9] state, "self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and lifestyle changes." Recent research suggests that digital health interventions can play an important role in supporting both rehabilitation and self-management. A systematic review of mobile phone apps to support self-care following heart failure by Athilingam and Jenkins [10] demonstrated positive trends and cost-effectiveness, enabling increased access to symptom monitoring and promoting patient engagement in their own homes. Similarly, a review by Piette et al [11] on mobile health (mHealth) technologies for CVD reduction and management found evidence that mHealth interventions can improve cardiovascular-related lifestyle behaviors and disease management. The authors emphasize the need for new interventions that build on evidence-based behavioral theories and are adaptive to a patient's unique and changing needs. Jörntén-Karlsson et al [12] also suggested mHealth as an effective long-term alternative to face-to-face rehabilitation and consultation, with the potential to reach more patients at a relatively lower cost. They found evidence that digital interventions can have a positive impact on patients with CVD but again stressed the need for easy to use, personalized, and user-friendly apps that can cater to patients from all age groups, especially older age groups. This recognition of the specific needs of older adults is critical, given the significant

impact of CVD among this age group. However, recognizing the potential of technology to support patients with CVD across diverse age groups is also important, given the evidence from Foster et al [13] and Andersson and Vasan [14] that CVD impacts adults in all age groups. In line with this, a survey conducted by Gallagher et al [15], to assess the use of mobile technology among different demographics, demonstrates that mobile technology, when modified to suit different subgroups, offers an important opportunity to improve access to secondary prevention for cardiac patients.

Although there is a significant literature and a growing number of reviews on digital interventions for CVD rehabilitation and management, most previous studies base their conclusions on quantitative data. To better understand what drives the effectiveness and usage of technologies, there is also a need to analyze the collective perspectives of patients, focusing on their experiences, needs, and the barriers they face in using digital interventions. The literature outlined earlier has provided evidence that personalization [16] and the application of appropriate theory will play an important role in improving digital health technologies that target CVD. For example, behavior change theories and models can help inform the design of technical systems, guide evaluation strategies, and define target users [17,18]. In addition, persuasive design patterns can be used in digital interventions to address the challenge of obtaining sustained user engagement and behavior change among patients with CVD [19]. Building on this evidence, a greater understanding of patients' experiences will provide the insight needed to design future technology and increase the success of technologies when deployed in real-world contexts. By improving adherence to lifestyle changes, appropriately designed digital health technologies that apply this insight can ultimately help to prevent recurrence of cardiac conditions.

The analysis in this paper draws strongly on research in the field of human-computer interaction (HCI). Our findings are analyzed from an HCI perspective, which emphasizes the benefits of iterative development of technology and user involvement throughout the design and evaluation process [20-23]. HCI approaches have been successfully applied to rehabilitation and self-management in other health domains [24-27]. Our decision to focus on both rehabilitation and self-management followed multiple discussions among the authors and cardiologists, which reflected the degree to which these issues are interconnected. The papers selected in this review have dealt with some of the common issues and challenges. An overview of these interventions, along with the synthesis of patients' experiences, can be beneficial to both medical and HCI researchers. To the best of our knowledge, no previous systematic review has combined qualitative review methods and an HCI perspective to identify challenges and opportunities in the design of technology to support CR and self-management.

Objectives

The primary objective of this paper is to provide answers to the following research question: What are the primary barriers to and facilitators and trends of digital interventions to support CR and self-management? This question is answered by synthesizing evidence from both medical and computer science

187

literature. Using a qualitative approach, we aim to engage more directly with people's needs from and experiences of technology that supports CR and self-management. Given the strong evidence from the field of HCI that user-centered and iterative design methods increase the success of digital health interventions, we also assess the degree to which user-centered and iterative methods have been applied in the studies included in this review.

This review follows the grounded theory literature review (GTLR) method [28]. GTLR aims at producing new insights and enables researchers to develop concept-centric yet accurate reviews through a 5-stage iterative process. The GTLR method adopts a rigorous search and selection process, eventually invoking the grounded theory method for the analysis stage. GTLR recommends that initial research questions are identified at the outset of the review process and allows for a bottom-up iterative approach in which new concepts are identified via a thorough and progressive analysis. Initial questions help focus on the review during the selection and analysis stages, but based on concepts identified during the analysis stage, it is acceptable for the final concepts to differ somewhat in focus from the initial questions. Following multiple rounds of discussion and refinement among the authors and cardiologists involved in this project, the following initial research questions were identified:

1. What kind of technological support is provided for CR and self-management?
2. What design approaches were applied in designing the technologies identified?
3. What experiences and attitudes do patients have of technology?
4. What are the barriers to using technology for rehabilitation and self-management after a cardiac incident?
5. What are the facilitators for using technology for rehabilitation and self-management after a cardiac incident?

Methods

Overview

This review follows the 5 stages recommended in the GTLR method [28]: (1) identifying the key research questions, appropriate sources, and search terms; (2) search for potential papers; (3) defined filtering for selection of papers and refining the sample for review; (4) a comparative and in-depth analysis of the papers through 3 coding levels; and (5) representing the emerging categories and concepts. In addition, we used the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) as guidance for conducting this review. The complete PRISMA checklist for this paper is included in Multimedia Appendix 1.

In this section, we describe the inclusion and exclusion criteria of our review, database sources and search keywords used, the screening and selection process, data extraction process, and, finally, the analysis process.

Search Strategy

To include a wide range of perspectives on designing technologies for rehabilitation and self-management of cardiac conditions, we selected papers from PsycINFO, Scopus, PubMed, and ACM (Association for Computing Machinery) Digital Library. HCI literature about designing technology for cardiac conditions was gathered from the ACM Digital Library. Similarly, psychology and medical literature on these types of technologies were gathered from PsycINFO and PubMed. Other major journals and conferences, such as Biomed Central, IEEE (Institute of Electrical and Electronics Engineers), BMJ (British medical journal), International Journal of Telemedicine and Applications, SAGE (Scientific Advisory Group for Emergencies), and Global Telehealth, are included in Scopus.

Title, abstract, and keyword searches were carried out on the above mentioned databases to obtain the results for this review (Multimedia Appendix 2). On the basis of the studies we were familiar with and to follow a structured process to define the keywords, we selected keywords to address 3 areas: domain, technology, and intervention that we considered most relevant to identify papers of interest (Textbox 1). Domain keywords focused on CVD as the main field interest, together with related medical terms (eg, coronary artery). Technology keywords addressed diverse technologies used in inventions (eg, mobile phones, sensors, and telehealth). Intervention keywords reflect the different types of interventions addressing the field of CVD (eg, tracking and behavior change). It is important to note that our search strings include both Medical Subject Headings (MeSH) and non-MeSH terms. This decision was made because the study aimed at a broad exploration of research in both technology (eg, HCI and software engineering) and medical disciplines. The technology databases included in our study (eg, the ACM Digital Library) do not recognize MeSH terms. Including both MeSH and non-MeSH terms represented the most balanced approach and helped to ensure consistency of search terms across the different databases.

We limited our search to papers published in the last 10 years and focused on papers in the English language and including adult patients.

188

Textbox 1. Keywords used in the search terms.

Domain
- Cardiovascular disease
- Cardiology
- Cardiac
- Heart disease
- Coronary heart disease
- Coronary artery disease
- Heart failure

Technology
- Mobile
- Wearable
- Wearable sensors
- mHealth interventions
- Smartphone
- Tele-monitoring
- Sensing system
- Telehealth
- Telemedicine

Intervention
- Persuasive or persuasion
- Quantified self
- Tracking
- Behavior change or behavior
- Personal informatics
- Habit
- Prevention
- Detection
- Rehabilitation
- Management

Eligibility Criteria

The review was concerned with the use of technology for self-management and rehabilitation practices in the context of CVDs. This excluded several papers that would otherwise be featured in the review, such as those suggesting design concepts without evaluating them [29,30], those describing algorithms or software architectures to solve specific self-care problems [31,32], and those focusing on monitoring and detection techniques to support primary prevention of CVD [33,34]. These types of studies are very relevant to CVD in a broader sense, but as they do not provide evidence on the use of technology to support self-management or rehabilitation, they were excluded from the review. The papers included in this review involved an active role for patients living with cardiac conditions and technology that could be controlled by the patients rather than those in which patients have a more passive role. This meant excluding a number of technologies used only in clinical settings and technologies based on biomarkers, photoplethysmogram, implantable devices, and defibrillators. Excluding them enabled us to focus on the lived experience of people with CVD, rather than the clinical context of care.

Furthermore, this review focuses on studies of patients with cardiac conditions. This excluded self-management and rehabilitation technologies focusing on other chronic conditions [19], wellness and lifestyle [35,36], or quantifying habits for health [37,38]. By keeping the focus on cardiac conditions, the motivation for using the technology was to maintain cardiac health, not to pursue personal interest, leisure, or general well-being, which would likely bring different principles for design and use. To attain subjective perspectives of patients' needs and seek answers to our research questions, we focused

189

on qualitative study methods for this review. Therefore, to be eligible for inclusion in this review, papers needed to include a technology intervention for cardiac management or rehabilitation, use qualitative study methods, and describe the use and evaluation of technology with users. Papers that did not follow the criteria were rejected. The inclusion and exclusion criteria are listed in Textboxes 2 and 3, respectively.

Textbox 2. Inclusion criteria.

Domain

- Cardiac condition

Technology

- Use of technology with evaluation
- Technologies having active patient role (eg, mobile, wearable, mobile health, and telemedicine)

Intervention

- Secondary prevention involving self-management and rehabilitation

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Textbox 3. Exclusion criteria.

Domain

- Other chronic conditions and general well-being and lifestyle

Technology

- Design concepts, technology description, algorithms, and software architecture without evaluation
- Technologies having passive patient role: biomarkers
- Technology used in clinical settings
- Photoplethysmogram
- Implantable devices
- Defibrillators

Intervention

- Detection and monitoring for primary prevention

Screening and Data Extraction

The search keywords retrieved 4282 articles, of which 3973 remained after removing duplicates. We first performed a prescreening of these papers by reading the title and abstract and removed papers concerning research abstracts, systematic reviews, protocols, workshops, studies dealing with patients aged <18 years, studies involving chemical and biological sciences, and studies involving clinical procedures. At this stage, the first author (ST) reviewed all papers, and the second author was consulted in any situation where the first author was uncertain. Where any disagreement occurred, the paper was not excluded at this stage. In the second phase of screening, the first author reviewed the title and abstract of all remaining papers using the full eligibility checklist to decide if they should be included in preselection. This was done to exclude papers that involved studies inclined toward medical and clinical techniques, for example, studies related to biomarkers, photoplethysmogram, implantable devices, and defibrillators and studies related to algorithms, methods, and techniques. The second author reviewed 10% (170/1700) of the papers at this stage, and agreement was verified across both authors. Where any disagreement was found, the paper in question was reviewed again by both authors and discussed to reach an agreement. Both researchers then met and cross-checked 50% of the final preselection list, discussed inconsistencies, and agreed upon a final list that included 61 papers for potential inclusion.

Each of these papers was further assessed in the final stage of the screening process to check if they applied qualitative methods and included qualitative data. Any paper that contained both quantitative and qualitative data was included in the final review, but only qualitative data in these papers were analyzed. A total of 25 papers were found to include no data, and 20 papers included only quantitative data. These papers were excluded. This left 16 papers that included qualitative data in our final analysis. Figure 1 provides an overview of the full screening process.

190

Figure 1. Flow diagram illustrating the screening and selection process of papers.
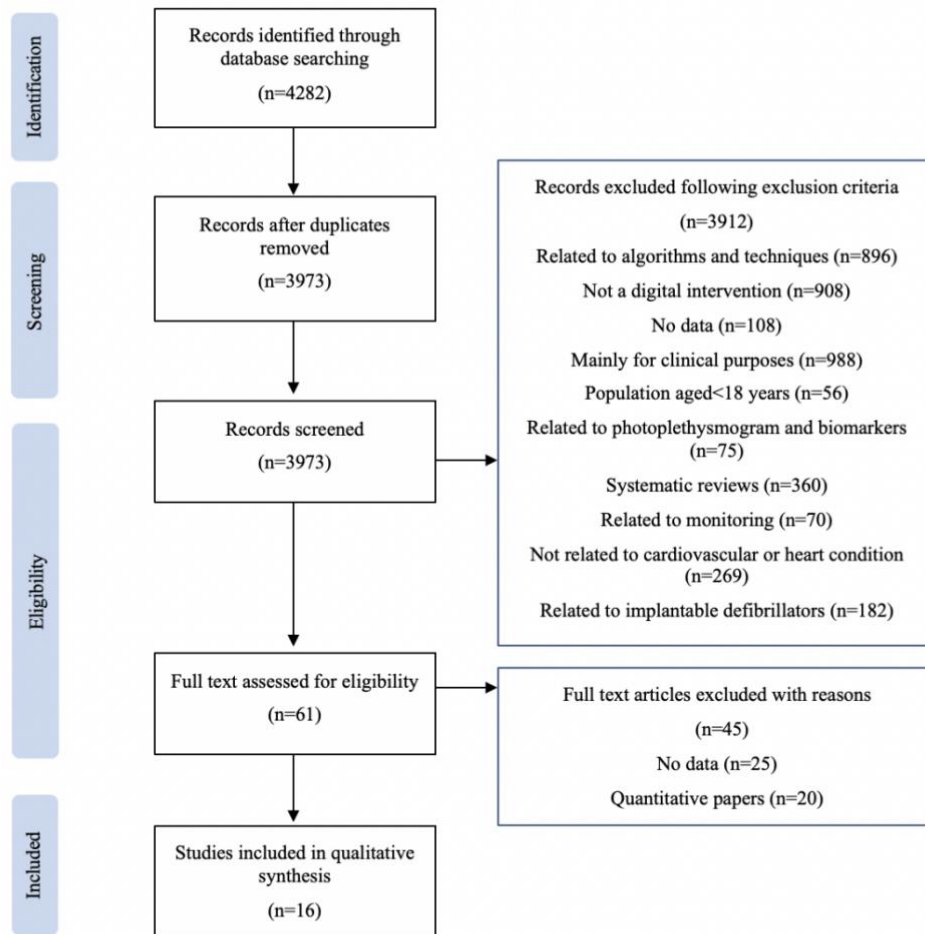
The critical appraisal skills program (CASP) checklist [39] was used to assess the quality of included studies and avoid the risk of bias. The CASP checklists are divided into 3 sections to assess internal validity, results, and relevance to the practice of published papers, and these sections are assessed by questions that can be answered with *yes*, *no*, or *can't tell*. On the basis of the number of questions scored *yes*, an overall rating of *strong*, *moderate*, or *weak* was given to each study. The results of the assessment indicate that the majority of the papers included in the review are strong, whereas others are rated as moderate. Full details of the CASP assessment are included in Multimedia Appendix 3 [33,40-53].

Data from the included papers were initially extracted based on the keywords used in the search terms and eligibility criteria (Textboxes 1 and 2). This included data such as the number of participants, study methods, and settings for each study. In the

final stage of data extraction, the full findings and discussion sections of each of the 16 papers were extracted. This provided data for our subsequent analysis.

Analysis and Synthesis

The analysis step of the GTLR method involves a comparative analysis process with 3 levels of coding: open coding, axial coding, and selective coding. From the set of papers in the final review, ST selected a random paper and carefully read it again, highlighting principal findings, which the GTLR method calls excerpts. Similarly, excerpts from each paper were then listed. At the axial coding stage, these excerpts were articulated to form groups or insights. Both authors carried out an affinity mapping exercise on these excerpts. This led to the formation of groups and subgroups of the excerpts. At the selective coding stage, these groups were then compared and moved around,

191

followed by discussions among the authors to form themes. This process involved iterative back and forth analysis between the excerpts and groups identified, in which stages were repeated and papers reread until a final consensus was reached. The coding process was supported by Boardthing [54], a web-based notice board software that allows individual and collaborative coding and analysis. The themes were repeatedly discussed and refined among the authors, and the analysis was only complete as the final version of the review documentation was ready.

Results

Study Characteristics

As noted earlier, the keyword search retrieved 4282 articles, of which 16 were included in the final analysis. An overview of the included studies is provided in Multimedia Appendix 4 [40-53,55,56].

Target Users

All studies in the final list focus on patients who had gone through or were going through a cardiac condition. Some of the studies specifically targeted patients diagnosed with heart failure, myocardial infarction, and coronary heart disease. Furthermore, some studies particularly involved participants' postcardiac condition awareness and those who were in their CR phase. Some studies also involved physicians, informal caregivers, nurses, and cardiologists as participants. The papers included studies on both CR [45,46,50,51] and self-management [40-44,47-49,52,53,55,56].

Different Technology Support Provided

In general, the papers in this review investigated mobile or web apps, with some integrating sensors, to manage cardiac conditions. Papers featuring a web-based digital intervention were included [40,41,53]. Some studies used mobile [43,45-47], tablets [48], and a combination of web and mobile systems [42,44,49,50,55,56] as digital interventions. Overall, 2 studies did not involve any particular system. Instead, they focused on patients' needs and perspectives of using an existing technology

and the potential of digital interventions for cardiac management [51,52].

Motivation of the Studies

In general, support for self-management was provided through apps that aim to increase adherence, motivation, and engagement. These could be achieved through gamification [45], by providing guidance and education about the condition [40,43,47,52,55], through reminders and notifications, or by using patient data and sensor data to track and show their progress [46,49,52]. Many studies have involved interventions to increase physical activity and exercise for cardiac patients [41,44,46,48]. Studies also aimed to facilitate better connection between patients and care providers, nurses, or health professionals by providing a medium to communicate and share data [43,53,56]. Two papers were about virtual and remote CR to enable rehabilitation for patients in rural and distant locations [46,50]. One study focused on gathering the needs and interests of patients with CVD to effectively enable remote CR [51].

Design Approaches Used in the Studies

Table 1 provides an overview of the design methods and guiding theories used in the studies. Overall, as all the papers in the final list are qualitative studies, most of the papers used surveys, interviews, and usability tests and represented their evaluation and findings through themes (Table 1). Among these, some studies used theoretical frameworks of behavior change and user-centered design approaches and methodologies. Examples include scenario-based tests, card sorting, goal-directed design, and persuasive design [41-44,47,50,53,55,56]. One study used grounded theory to identify themes from participant responses [49]. Another study used gamification design principles to design the system with the aim of increasing motivation and adherence to lifestyle changes [45]. One study assessed the usability of technology using satisfaction surveys [48], another used a technology usage questionnaire to understand technology usage [51], and another used the system usability scale to assess the usefulness of a system [46].

192

Table 1. Overview of the theories and design approaches used in the final review.

Study	Design method or guiding theory	Users involvement
Dithmer et al [45]	Gamification and gameful design principles (PERMA[a]) are used to design the app. Gamification principles such as badges, levels, and leader boards were used to increase engagement and motivation.	Requirements gathering, design or prototyping, and evaluation or validation
Yehle et al [49]	No particular design principles or theory and design methodology mentioned.	Requirements gathering and evaluation or validation
Villalba et al [56]	Goal-directed design methodology is applied. A three-phase design process is used: conceptualization, implementation, and validation.	Requirements gathering and evaluation or validation
Jarvis-selinger et al [53]	Diffusion of innovation theory was used as the theoretical lens along with the current telehealth literature for sensitizing concepts. The study used a qualitative methodology, employing a constructivist approach.	Requirements gathering
Fischer et al [40]	Used common sense model of illness representation and showed visualization of body structure and behavior based on different symptoms through a web-based app.	Evaluation or validation
Pfaeffli et al [42]	A library of text and video messages were developed using self-efficacy theory framework and published exercise guidelines.	Requirements gathering, design or prototyping, and evaluation or validation
Katalinic et al [48]	No particular design principles or theory and design methodology mentioned.	Evaluation or validation
Antypas and Wangberg [41]	Different models of health behavior change are combined to form the tailoring algorithm. Tailoring is used as the theoretical framework. A methodological approach that is used to combine the user input and health behavior theory to develop a physical activity digital intervention for cardiac rehabilitation.	Requirements gathering and evaluation or validation
Geurts et al [44]	The prototype design was guided by 3 pillars: simplicity and ease of use, reduce fear and anxiety, and direct and indirect motivation. A human-computer interaction perspective is given by categorizing design decisions according to 3 pillars and show how these pillars resulted in concrete app features.	Requirements gathering, design or prototyping, and evaluation or validation
Buys et al [51]	No particular design principles or theory and design methodology mentioned.	Requirements gathering
Cornet et al [47]	Three frameworks guided the design process: Systems Engineering Initiative for Patient Safety (Version 2.0), Patient Work Framework, and user-centered design.	Requirements gathering, design or prototyping, and evaluation or validation
Banner et al [50]	No particular design principles or theory and design methodology mentioned.	Evaluation or validation
Baek et al [43]	No particular design principles or theory and design methodology mentioned.	Requirements gathering, design or prototyping, and evaluation or validation
Salvi et al [55]	Fogg's Persuasive Systems Design principles were used when designing the GEx system, and health belief models were used to classify patients on the basis of the perceived benefits and barriers to self-efficacy in healthy behavior. The system design and development were guided by a combination of methodologies: Goal-Directed Design, Persuasive Systems Design, and agile software development. The desired behaviors were mapped into specific system's specifications, borrowing concepts from Fogg's Persuasive Systems Design principles.	Requirements gathering and evaluation or validation
Beatty et al [46]	No particular design principles or theory and design methodology mentioned.	Requirements gathering, design or prototyping, and evaluation or validation
Smith et al [52]	No particular design principles or theory and design methodology mentioned.	Requirements gathering

[a]PERMA: Positive emotion, Relationships, Meaning, and Accomplishment.

The 3 main stages of the HCI design process included in the ISO 9241 HCI development lifecycle are requirements gathering, producing design solutions, and evaluating the design against the requirements [57]. There is also a recommendation that this process is iterative, typically involving multiple cycles of design and evaluation. The design process, also known as the user-centered design, focuses on users and their needs in each stage of the process, and iteration continues until it is fit for implementation. We found limited evidence of studies applying a truly iterative approach and user-centered approach. A total of 9 of the 16 papers stated that a user-centered design approach was followed; however, it is not always clear that this involved multiple iterations of the design cycle [41-47,49,56]. Only 6 of the papers provided details of studies that involved users in each stage of the process [42-47]. Moreover, 3 of 16 studies involved users only in the final stage, that is, evaluation [40,48,50].

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193

Users' Perspectives of Digital Interventions for Cardiac Self-Management and Rehabilitation

This section presents the final themes identified in our grounded theory analysis.

Knowledge

Evidence from the review suggests that knowledge plays an important role in rehabilitation and self-management. Education and knowledge influence self-management and increase confidence. To explain this further, we have categorized knowledge into 2 types: background knowledge and personal and in-the-moment understanding.

General Knowledge About CVD

General knowledge or background knowledge about CVD is the fundamental information or awareness that is required to be known by all patients with CVD. This can be information about one's health condition, symptoms, body, medication, preventive measures, and advised lifestyle changes. Background knowledge also includes awareness about different support systems that help people to care for themselves, such as rehabilitation support and digital interventions.

There is a growing trend to use digital interventions to provide the required educational support. A study conducted to validate a self-care digital system to manage cardiovascular condition at home emphasized that education on symptoms and medication was highly valued by patients and health professionals; however, younger patients had reservations about lifestyle education, as they considered it to be intrusive and annoying. Similarly, patients who were initially scared of new technologies, later, after introductory explanations, found it easier to interact with the system [56]. Similarly, a study that evaluated the use of web-based visualizations of patient parameters to improve patients' understanding of their disease and increase their level of control over the rehabilitation process shows that enhanced knowledge and understanding of the illness and its symptoms can motivate protective action, such as for individuals with heart failure to improve self-management of the illness and the symptoms [40]. For example:

> Now I understand why my legs always swelled up. [40]

> We truly know how to, what is happening inside his heart, and why he's getting all these symptoms. In the 2 years that we've been dealing with this illness, it's so good to have it summarised up so that we know how to care for ourselves better. [40]

Participants also repeatedly referred to the need to find the right answers either through an online forum or some kind of knowledge bank [41]:

> It should be a forum where you have the opportunity to get the right answers, access to a resource, this is what I believe it becomes. It has an effect. [41]

CR classes are also popularly known to provide essential knowledge, guidance, and support for patients:

> ...Your class (cardiac rehabilitation) because they stressed what is really bad for you and what is good for you so that makes you stop and think when you are even buying your groceries to make sure you are getting the right stuff. [49]

Personal and In-the-Moment Understanding

Personal and in-the-moment understanding is the supplementary information that patients seek to enhance their self-care process. This type of information is acquired through personal tracking and monitoring and refers to the ongoing knowledge people develop about their individual condition. Knowing one's body plays a key role is achieving control of the cardiac condition; however, it may be difficult to notice some changes and trends in everyday life. Technology has been used to make health and contextual information more easily available to patients and caregivers on an ongoing basis [23]. Patients state that being monitored by technology increases their feeling of security and comfort by enabling a better ongoing understanding of their health [56]. Self-care technologies that use monitored data to guide people to exercise or train within recommended or safe zones boosted confidence and increased motivation:

> The application is not only beneficial for people who are afraid to exercise, but also supports people that have a higher risk to train too much. [44]

A study conducted to understand the current technology usage of patients with CVD and to understand their needs and interests found that ongoing advice on exercise ideas, exercise prompts, information on local exercise opportunities, healthy meal ideas and recipes, and practical ideas to manage stress received the highest ratings for inclusion in a technology-based CR platform [51]:

> I am unsure if I am doing the right thing, like food, so I like advice on that. [52]

Social Versus Individual

Although most patients often manage their care autonomously, clinicians, other people living with the same condition, and caregivers play an equally important role.

Individual Responsibility

Responsibility for change in behavior is personal [41]. Changing behavior is easier if new habits are created by replacing old bad ones. To retain changes, it is important to make it part of the daily routine. Ubiquitous technology can support behavior change in the challenging situations of everyday life and remind users of their own commitments:

> If you could get a message every day, there and then? [41]

> I believe that someone gets used to it, if we make a system, habits. That it doesn't get too much, that we know that...we go online...and we get our own responsibility of our own training. [41]

Technology can support small personal achievements such as getting out of the house to get fit. The use of digital systems as a tool for self-management is valued, especially among the younger ones:

> It gave me the opportunity to get out of the home and try and get myself fit after the operation. I believe it

194

has achieved that and more. I feel better in myself and I can achieve most jobs without taking about it. [55]

Connecting With Others

Patients often seek to connect with others living with the same condition, and they use these interactions to understand how to live with their condition, validate their assumptions about their body and self-care, and obtain emotional support [58]. A CR session is an excellent example of this type of environment. A theme repeatedly expressed by the patients of the CR program was the importance of not being alone in the rehabilitation and self-management process. This was an important factor that helped them during their visits to the rehabilitation center, and it was something they wished to maintain after their discharge [41]. In addition, CR attenders found great value in being able to ask nurses, cardiologists, and dietitians questions according to their specific needs [42]. Digital interventions also provide easy access to others with the same condition, health professionals, and experts. A study on the experiences of patients undergoing virtual cardiac rehabilitation program (vCRP) demonstrated the potential of vCRP as a medium to provide easy access to health care professionals, nurses, exercise specialists, and dieticians. Although there were some concerns about trust and privacy [41], many of the participants explained that having ongoing monitoring from health care providers as well as support for self-management activities helped them adhere to their recommended program:

> *You know I had stents four years ago, and you start off with the best of intentions, but nobody looks over your shoulder and you peter out. At this time, I felt this is a nifty program...somebody's watching it and I better do it. Keeps you honest, keeps you focused.* [50]

Keeping in touch with the group helps to lift people's mood, is comforting, and provides support; therefore, many patients liked to use forums and web-based groups. Groups and forums on the internet are seen to help individuals be more committed to fitness by sharing goal completions and bragging about it for healthy competition. Forums brought more focus and motivation, as it makes individuals feel obliged to do activities. A study that used gamification for telerehabilitation program of patients with CVD also demonstrates the importance of social and family support, with patients stating that the most important aspect of the game was being able to play with a partner, thus enabling them to deal with rehabilitation as a team:

> *Training diary on the Internet...And also have a group where someone can subscribe to a forum, or have a...to brag...yesterday I walked for an hour and today I have been to the training...and tomorrow I have thought, yes...So, it is like this that someone gets to, a bit, a bit like a competition, internally between each of us. We will train, as much as possible we will commit to ourselves a bit more also.* [41]

> *I am saying that if we have it fixed, one time per week, that we send a message to each other and then, then you feel committed to say yes, for as long as you like...Yes, then you must have something else that*

really, you have something else that you have to do, or else...you just do it. [41]

Motivation and Demotivation

The systems in the listed papers took a number of approaches to provide engagement and motivation toward self-management. Some of the key features of technology and patients' attitudes toward them are described below.

Feedbacks and Reminders

Digital health interventions such as text messages and mobile- and web-based app reminders push patients to maintain the desired changes [42]. Apps using gamification principles are considered motivating, as they allow score, activity and goal comparison, healthy challenges, and competitions. Creating small manageable tasks was positively received by heart patients. Apps use data visualizations to show meaningful comparisons and to see how well they progressed [45]:

> *I went cycling without the application today, but it was less fun!* [44]

> *Two teams explicitly stated that on a day with bad weather, they would not have gone for a walk had they not been motivated by the application.* [45]

Reminders in any form were positively accepted by the patients. Text messages, although intrusive, pushed them to perform exercises, and many stated that reminders such as an alarm are needed for medication management [56]. On the other hand, some patients did not like reminders, as they constantly reminded them of their sickness.

Tracking and Monitoring

Digital health interventions that had the ability to track patients' activities, heart rate, and current health status and showed their progress over time were considered valuable and engaging [44]. In a study to understand the current technology usage of patients with CVD, 68% of patients reported that heart rate monitoring was important when exercising at home [51]. In addition, patients also anticipated that they would be able to manage their disease more efficiently if their daily data could be easily entered in an app and shared with their doctors [43]:

> *I like the fact that I can put all of that and track it, and that my doctors can as well. I can show my doctor what I've been working on.* [46]

> *I think that the idea of an app that records all of the information that this app is doing will be very valuable. Actually somewhat of a motivation for me to do this thing.* [46]

Personalization

Some studies in this review suggested that digital interventions that gave the user the ability to personalize the app based on personal interests contributed toward motivation [41,44]. For example, one of the patients in a study that evaluated patients' motivation when using a mobile app that guided them while cycling suggested that the app would be more engaging and fun if it had the flexibility to insert his preferred routes along with the preloaded ones. However, another patient in the same study preferred predefined routes [44]. Another study showed that

195

although patients preferred simple interaction methods, they also asked for the possibility of applying advanced settings [51]. The findings of the same study also suggested that the future of technology-enabled CR might include different solutions to reach both men and women to better engage a broader target population of patients with CVD [51].

Increased Burden

Some studies in this review demonstrated patients' concerns regarding using technology. For instance, some patients suggested that adding a device on top of what they already have led to them getting side tracked and thus not using it every day [47]. Patients in the older age group were especially resistant to use technology; some of them lacked interest and found it burdensome:

> I'm retired and I gave all the computerization that I wanted up, that is it I do not even look at it and I will not even turn it on. [53]

Furthermore, lack of time and other priorities is a barrier to self-management and use of technology. Most patients already have measuring devices at home, such as weight scales and blood pressure cuffs, and preferred to continue using devices they already know [56]:

> There are people who like this (application) kind of stuff...and got the time. So for these people it might be great. [47]

Acceptability of Technology

In contrast, studies in this review also demonstrated patients' willingness to use technology. For example, one study reported that patients' interest or intent to use an app for CVD management was high, despite the fact that most were older people who were unfamiliar with the information technology environment [43]. Overall, in most studies, patients as well as clinicians readily accepted and showed interest in learning about new technology [43,48].

Nevertheless, to reach the entire target population of patients with CVD, a variety of technology solutions should be designed to reach both men and women [51].

Usability

Finally, usability and ease of use are crucial for the acceptance of any type of digital intervention and thereby influence engagement. Many studies in this review emphasize that simple interaction methods are preferable. For example, one study stated that 38% of the patients preferred an interaction of no more than a few mouse clicks [51]. Patients unfamiliar with technology positively stated that it was just a matter of getting accustomed, and if they learned and used the app regularly, they would find it simple. Some patients also suggested considering e-literacy issues and initial training [41]:

> It was pretty easy...I like that it's simple. [46]

> I'm not used to this. Once I get used to it, I'll know where everything is. [46]

Discussion

Principal Findings

This review aims to understand users' perspectives of technology in CR and self-management and identify barriers and facilitators of the use of technology. The results suggest that many patients have a positive attitude toward the use of technology. The grounded theory approach enabled us to identify common themes across the included papers, resulting in 3 principal findings:

1. Designers of new technologies and clinicians recommending existing systems to patients should consider seeking the support of both background knowledge and greater in-the-moment understanding. Background knowledge and awareness about the condition and its symptoms, medication, and posthospital care measures are important factors for effective self-management. However, effective self-management also requires patients to be aware of their current body condition and changes in their body, providing reassurance and enabling them to take appropriate measures in self-management.

2. Self-care is a personal responsibility, and people like to try different ways to keep themselves motivated to continue performing self-management activities. For some, but not all, opportunities to stay connected with family, caregivers, and others with a similar health condition are considered as one of the most effective ways to stay motivated and driven toward rehabilitation activities. Again, technology that supports both approaches is likely to be most beneficial.

3. Technologies can use different approaches to support engagement and motivation toward rehabilitation and self-management, including personalization, tracking and monitoring, reminders, and feedback. However, they should take into account the potential to demotivate because of issues including overburdening caused by different devices and apps, privacy concerns, lack of trust, lack of interest, and system usability. If not properly accounted for, these issues can impact the acceptability of systems and become major hindrances to effective rehabilitation and self-management.

These principal findings are discussed in greater detail below and also considered via the lens of relevant HCI literature.

Our first principal finding emphasizes the importance of different types of knowledge. Awareness of available resources, such as awareness of rehabilitation classes, existing online support groups, existing self-care digital apps, and remote rehabilitation videos and programs, is important so that patients can leverage these resources for better and sustained recovery and smoother transition to long-term self-management. In addition, ensuring that patients have knowledge of available emotional and physical support helps to foster self-efficacy if they feel overwhelmed by their CVD condition, leading to the inability to effectivity self-manage [59]. Prior work in HCI has also identified knowledge as an important factor influencing self-care. For example, a study exploring patients' transition from hospitalization to self-management emphasizes gaps in knowledge, resources, and self-efficacy after discharge and

196

demonstrates an interconnection between them [59]. The study describes knowledge as information provided to patients about their condition, medication, and management and resources as social and physical resources, for example, caregivers and access to health services. Self-efficacy is described as the patient's confidence in their ability to self-manage their condition. The gaps highlighted in that study are consistent with the principal findings of this review. The authors recommend that at a system or hospital level, emphasis on verbal communication of information should be avoided. Ubiquitous computing and embedded technologies could be used to capture and retain verbal information received during hospitalization. In addition, hospitals should provide support and trusted sources of information for patients' access to expertise. On the basis of our findings, these recommendations are also clearly applicable to CR. Similarly, work in HCI describes how patients' understanding of their illness and availability of social and physical resources mediate their self-efficacy [60]. In contrast with prior work, our study has also highlighted the importance of supporting in-the-moment knowledge, which can be acquired through tracking and monitoring. It appears that both types of knowledge can be an integral part of effective CR and self-management.

Effective self-management requires patients to change certain behaviors. An individual's inclination to change behavior depends on the extent to which they are motivated to change [61,62]. Our findings highlight that motivation for action is driven by both individual factors, such as personal responsibility, emotions, and goals, and external influences, such as friends, family, caregivers, health professionals, and personalized and persuasive features of technology. These findings reflect on Deci and Ryan's [61] self-determination theory of motivation, which states that a human's optimal move toward growth is driven by 3 needs: autonomy, the need to have control over one's behavior; relatedness, the need to interact or be connected to others; and competence, the need to experience positive effects of one's activity. Previous HCI research [24,63] provides helpful guidance on how technologies can support these basic needs and also highlights design-related tensions that can arise in balancing different needs. For example, Nunes et al [24] highlighted tensions in the degree of autonomy to be provided to patients, noting that technologies should take into consideration the different levels of autonomy given to the patients for self-care, as it is highly dependent on the disease and the patient's current condition. Although patients are in charge of their health condition, it is important to reflect on the stages or decisions where a clinician's support is needed. Treatment of CVD relies on a combination of medication and lifestyle changes, and there exists an individual difference in the disease management process. Individual differences refer to how people are similar or different in their ways of thinking, feeling, and behaving [64]. This would include patient demographics, situational or contextual changes, and environment. The transtheoretical model of behavior change [65] suggests that effective behavior change could be obtained if personalized feedback with different motivational levels or at different stages of the behavior change process is provided to people. Therefore, it is important to take these differences into account and leverage technology to provide tailored care.

In the case of health care technologies, the one-size-fits-all approach could hamper effective self-care practices [66,67]. Nunes et al [24] also stressed on integrating self-care technologies in everyday lives by prioritizing the lived experiences of patients. This is also emphasized in discussion of *lived informatics* and *design for interweaving* by Rooksby et al [68]. In other words, for health care technologies to be successfully integrated into an individual's life, it is necessary to acknowledge the everyday life of the individual [5]. Moreover, the results of this review demonstrate that patients' adherence to self-management through health care technologies can be improved if technology does not act as a burden in their daily life and is easy to use.

Digital health interventions draw on 2 central domains of study, those originating in health (eg, medicine, biomedical sciences, and psychology) and in technology disciplines (eg, computer science, HCI, and software engineering). This trend is seen in the papers listed in this review. Blandford et al [69] highlighted 7 areas of contrast in practice between technical and health research. They emphasize that skipping over stages of iterative design before investing in large-scale evaluation of digital health technology leads to suboptimally designed solutions. In the HCI community, there is a growing practice of involving end users early on in the design stage and then throughout the full design and evaluation process. In contrast, the studies listed in this review show limited evidence of applying user-centered and iterative design processes. Blandford et al [69] also suggested that failing to learn how the nuances of design affect user interaction and engagement leads to failure in replicating it in different contexts and propagates risk from one design to another. Future research on technology to support CVD should address these limitations. Involving relevant users, in this case, patients, caregivers, and health professionals, in each stage of the design process will help reduce user experience challenges and increase acceptance, leading to more effective digital health interventions. Core to addressing this limitation is appropriate and focused engagement with key patient groups. In this context, although CVD impacts adults across all age groups, it is important to also recognize that CVD and other chronic illnesses are particularly prominent among older populations, and their distinct challenges and complex needs have important implications for the design of such systems [70]. The effectiveness of user-centered design with older adults can be seen in the increasing number of studies involving older populations in the early design stages [71,72].

Limitations

As the aim of this review is to investigate and obtain subjective evidence of the barriers and facilitators of using technology for CR and self-management, only qualitative papers were considered, and review was limited by the analysis of the included studies. The possibility of subjectivity in analyzing the findings is acknowledged, although strategies to limit bias were undertaken through the process of grounded theory analysis and consultation with a second reviewer. In addition, the included studies had varied sample sizes, and the technology was used for different amounts of time in different studies. We acknowledge that this variation could have had an impact on the themes emerging in this review.

197

Reflective Statement by Authors

This research was conducted in the Republic of Ireland. It is part of the Eastern Corridor Medical Engineering (ECME) collaborative research project, which seeks to improve cardiovascular health with a broad focus on enhancing user-ready sensor technology; improving smart wearables; reducing the complexity of point-of-care diagnostics; and improving smart, clinically relevant monitoring in the assisted living and rehabilitation environments. ECME is a partnership between 5 academic research centers in Northern Ireland, the Republic of Ireland and Scotland, and the Southern Health & Social Care Trust. It involves collaboration between researchers in the medical and technology fields. Both the authors of this paper are based at the Insight Centre for Data Analytics at Dublin when this study was conducted. ST was raised in India and had lived in Dublin for 2 years at the time of the study. She has experience in User Experience design in mobile and assistive technologies. DC has multigenerational roots in Ireland and is an expert in the field of HCI with a focus on the design of digital health technologies. None of the authors have direct lived experience of CVD. This study did not seek to directly address issues such as ethnicity, social and cultural background, and gender, and standard checklists, including the CASP tool, were used to assess the quality of included studies. However, we recognize the potential for bias, both in its own analysis and in the original research papers.

Conclusions

The primary objective of this review was to apply qualitative methods to answer the following research question: What are the primary barriers to and facilitators and trends of digital interventions to support CR and self-management? Our findings show that the use of technology is acceptable to many people undergoing CR and self-management. Although background knowledge is an important facilitator, technology should also support greater ongoing and in-the-moment understanding. Connectedness is valuable, but to avoid becoming a barrier, technology must also respect and enable individual responsibility. Personalization and gamification can also act as facilitators of engagement, but care must be taken to avoid overburdening people. The findings also highlighted the limited use of iterative, user-centered approaches to guide design in this space. Going forward, further application of user-centered and iterative methods represents a significant opportunity.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist.
[PDF File (Adobe PDF File), 409 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Search strategy.
[PDF File (Adobe PDF File), 74 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Qualitative assessment table.
[PDF File (Adobe PDF File), 150 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Table with overview of included studies.
[PDF File (Adobe PDF File), 183 KB-Multimedia Appendix 4]

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201

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Abbreviations

CASP: critical appraisal skills program
CR: cardiac rehabilitation
CVDs: cardiovascular diseases
ECME: Eastern Corridor Medical Engineering
EU: European Union
GTLR: grounded theory literature review
HCI: human-computer interaction
MeSH: Medial Subject Headings
mHealth: mobile health
PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis
vCRP: virtual cardiac rehabilitation program

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202

Original Paper

Transitions in Technology-Mediated Cardiac Rehabilitation and Self-management: Qualitative Study Using the Theoretical Domains Framework

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Abstract

Background: An acute cardiac incident is a life-changing event that often necessitates surgery. Although surgery has high success rates, rehabilitation, behavioral changes, and self-care are critical to long-term health. Recent systematic reviews have highlighted the potential of technology in this area; however, significant shortcomings have also been identified, particularly with regard to patient experience.

Objective: This study aims to improve future systems and to explore the experiences of cardiac patients during key phases after hospitalization: recuperation, initial rehabilitation, and long-term self-management. The key objective is to provide a holistic understanding of behavioral factors that impact people across these phases, understand how experiences evolve over time, and provide user-centered recommendations to improve the design of cardiac rehabilitation and self-management technologies.

Methods: Semistructured interviews were conducted with people who attended rehabilitation programs following hospitalization for acute cardiac events. Interviews were developed and data were analyzed via the Theoretical Domains Framework, a pragmatic framework that synthesizes prior theories of behavioral change.

Results: Three phases that arise posthospitalization were examined, namely, recuperation, rehabilitation, and long-term self-management. Through these phases, we describe the impact of key factors and important changes that occur in patients' experiences over time, including the desire for and redefinition of normal life, the need for different types of formal and informal knowledge, the benefits of safe zoning and connectedness, and the need to recognize capability. The use of the Theoretical Domains Framework allows us to show how factors that influence behavior evolve over time and to identify potential sources of tension.

Conclusions: This study provides empirically grounded recommendations for the design of technology-mediated cardiac rehabilitation and self-management systems. Key recommendations include the use of technology to support a normal life, leveraging social influences to extend participants' sense of normality, the use of technology to provide a safe zone, the need to support both emotional and physical well-being, and a focus on recognizing capability and providing recommendations that are positive and reinforce this capability.

203

Introduction

Background

Cardiovascular disease (CVD) is a leading cause of morbidity and mortality worldwide, with an estimated 17.9 million deaths each year [1]. CVDs are a group of disorders of the heart and blood vessels, usually associated with a buildup of fatty deposits inside the arteries that occur when the flow of oxygen-rich blood to the heart is blocked, leading to increased strain on the heart [2]. Four out of five cardiac-related deaths are due to acute events, such as heart attacks and strokes. One-third of these deaths occur prematurely in people under 70 years of age [1]. Fortunately, the success rate of modern cardiac surgery and nonsurgical interventions, such as percutaneous coronary intervention (stent insertion), is high. As a result, an increasing number of people live with CVD as a long-term chronic condition. Following acute events, which are often sudden, ongoing treatment for CVD involves lifestyle changes and medicines. Cardiac rehabilitation is considered a vital part of long-term recovery and a key component of patient management.

It may include clinical assessment, medication review, risk factor modification, psychological support, and supervised exercise [3]. After a person is hospitalized and after discharge, they go through a recuperation period (Figure 1). Many patients attend rehabilitation programs. Individualized cardiac rehabilitation programs are usually for a duration of 6-8 weeks and comprise a mix of monitored exercises and educational sessions. Following these initial stages, people must continue self-management. According to Barlow et al [4], "self-management refers to the individual's ability to manage the symptoms, treatment, physical and psychological consequences and lifestyle changes." Many people face emotional and physical challenges during the transition from hospitalization to self-management [5]. For successful and long-term self-management, behavior and behavioral change play a central role [6]. Evidence suggests that rehabilitation programs can play a vital role in the transition from hospitalization to self-care [7]. Despite the proven benefits, uptake and adherence in traditional face-to-face programs are often low due to barriers such as lack of awareness, transport, motivation, cost, and poor social support [8].

Figure 1. Participants' journey after their cardiac event.
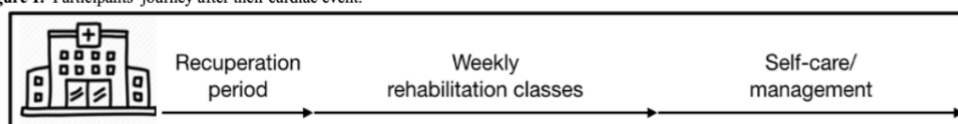
Recent systematic reviews have highlighted the potential of digital health interventions to support rehabilitation and subsequent self-management of cardiovascular conditions [9-11]. However, significant shortcomings were identified. Evidence suggests that tightly supervised intervention programs are most successful and that self-directed management is less successful due to problems with engagement and adherence. Piette et al [10] highlighted the need for future interventions to incorporate advances in behavioral theories and artificial intelligence in order to be more effective and adaptive to the changing needs of patients. Despite recent calls for technology that supports personalization and focuses on user needs, Tadas et al [11] found that, with notable exceptions, prior research in the cardiovascular domain has made limited use of user-centered approaches. This is consistent with the findings of Siegers et al [12], who also reported that most developers of digital interventions for cardiac self-management did not engage with the direct experiences of patients, such as those who have attended rehabilitation programs. Prior studies have also tended to focus on specific aspects of self-management, such as physical activity [13] and medication management [9,14]. They do not provide a holistic understanding of the behavioral factors that impact people throughout recuperation, rehabilitation, and self-management.

This paper builds on recent research on posthospital transitions [5,15] and on rehabilitation and self-management in chronic conditions [16,17]. It responds directly to calls for research in the cardiovascular domain to engage more deeply with both behavioral change theories and with patient experience. The contributions of this paper include a comprehensive assessment

of people's experiences of recuperation, rehabilitation, and self-management, their attitude toward technology, and the ways in which it could better support rehabilitation and self-care. The analysis is framed via the Theoretical Domains Framework (TDF), an integrated theoretical framework synthesized from 33 prior theories of behavioral change. The key strength of the TDF is that it provides a rigorous and comprehensive framework to identify factors that impact behavior and behavioral change. Our analysis was grounded in a semistructured interview study with 19 participants who were hospitalized following an acute cardiac incident and subsequently attended a cardiac rehabilitation program.

Our research questions include:

1. What were the key experiences of patients after cardiac surgery and how did these experiences support or hinder rehabilitation and ongoing self-management?
2. How did the experiences of patients change over different phases of recuperation, rehabilitation, and self-management?
3. What strategies can be applied in design to better support technology-mediated cardiac rehabilitation and self-management?

Related Work

Overview

The work presented in this paper builds on existing research in a number of key areas, including literature on posthospitalization transitions and support, rehabilitation, and self-management in chronic conditions, and theories and frameworks for behavioral change. We begin with an overview of key recent work specific

204

to cardiovascular care and then consider related work outside of the cardiovascular domain. In addition to research in the health domain and reflecting the emphasis in the paper on understanding user experience, we consider relevant literature in the field of human-computer interaction (HCI).

Technology in Cardiovascular Care

Technology-mediated cardiovascular rehabilitation and self-management has generally been provided through mobile apps, web apps, sensors, or an integration of these [11]. These systems aim to increase adherence, motivation, and engagement through different means, including gamification, guidance, and education about the condition, reminders, and data tracking through sensors. Most of these studies have focused on interventions to increase physical activity and exercise. Some aim to provide a medium for better communication and data sharing between patients and care providers, nurses, or health professionals. A small number facilitate remote cardiac rehabilitation. A recent systematic review [9] concluded that mobile apps in particular offer an important opportunity to improve access to secondary prevention for cardiac patients, but also concluded that this potential has not been achieved to date. The authors stress the need for personalized and user-friendly apps that can cater to the needs of individual patients from different age groups. A systematic review of mobile health apps for CVD, including commercially available apps, by Athilingam et al [18] identified a trend toward cost-effectiveness and potential solutions for symptom monitoring and promoting patient engagement in their own homes. However, evidence of impact on heart failure–related outcomes is inconclusive. The review also found that most apps focused on monitoring patients' symptoms and activity but provided limited feedback on unusual or irregular events. Andersen et al [19] emphasized the importance of aligning concerns of patients and clinicians and proposed three key concepts to consider while designing eHealth systems: the system should be meaningful and actionable to both clinicians and patients and feasible within the organizational and social context. Another study by Andersen et al [20] demonstrated the use of user-centered design methods for reintroducing patients as active diagnostic agents to design a collaborative digital tool for monitoring heart patients after hospitalization. This study emphasizes the importance of increasing patient participation in the design of eHealth systems and telemonitoring practices. Similar studies on posthospital transitions in chronic patients describe how discharged patients are often unprepared to self-manage their condition at home [5]. Being discharged from hospital meant a transition from a safe environment at the hospital to an unknown environment at home [15,21]. The transition of people with cardiac conditions from hospital after surgery to their homes is equally likely to create challenges and design opportunities, which this paper seeks to address; there is a need for more participatory and iterative approaches to design patient-centered eHealth systems [19,22]. A qualitative systematic review by Tadas et al [11] identified the limited use of user-centered design methods and theoretical models to guide the design of technology for cardiovascular care.

Digital apps for cardiac-specific rehabilitation and self-management are focused on physical activity monitoring [23], virtual rehabilitation programs [24], medication management [14], and heart rate and blood pressure monitoring [25-27]. Although recent digital apps show effective results, self-management and rehabilitation using digital apps generally show a gradual decline in use over time due to resistance to behavioral change and lack of motivation [14]. Investigations by Maitland et al [28] on the role of self-monitoring found an overall reluctance toward unnecessary self-monitoring and suggested that technology should focus on self-awareness and self-determination. Overall, there is a need for more research directly examining the experiences of people after cardiac events in relation to digital tools to support cardiac rehabilitation and self-management.

The HCI community, which promotes and practices user-centered design methods, has relatively less research on technologies for cardiac conditions, an observation also noted by Nunes et al [17] in their comprehensive review of HCI research on self-care technologies. Of the 30 studies included in their review, only 3 addressed cardiac conditions. Diabetes was found to be the most common condition addressed by the HCI research on self-care technologies. Examples of self-care technology used for diabetes management include the AssistingInsulin smartphone app by Preuveneers et al [29], which recommends insulin dosages based on predictions of the user's activity, and exploration of contextual frames by Raj et al [30] that demonstrates the relationship between context and behavior and the importance of context-aware apps for self-management. Furthermore, recent research shows an increasing demand for self-management technology that supports people's mundane activities and informal ways of exercise [31]. Significant research also exists in the space of self-management technologies aimed at addressing chronic disease management in older adults [16,32,33]. For example, the study on managing multimorbidity in older adults by Doyle et al [16], suggests the need for self-management apps to primarily focus on information support and teaching how to self-manage. There is also a growing body of work targeted at supporting chronic obstructive pulmonary disease therapy and training at home with the use of sensors, smartphones, television, and webcams [34,35]. Research in this area demonstrates the increasing accuracy of smartphone-based training apps and their acceptance. Existing research on other chronic conditions has clear relevance for the cardiovascular domain. However, to be most effective, we require a detailed understanding of the specific requirements of the people experiencing CVD.

Theoretical Domains Framework

Behavioral change theories and methodologies have been widely applied to guide the design of technical systems and evaluation strategies [36-38]. A systematic review exploring the potential of web-based self-management programs found that systems that incorporated behavioral change techniques were more effective than those that did not, and that web-based systems were more effective than no intervention [39]. There are many theoretical models of behavior, including the Health Belief Model [40], the theory of reasoned action [41], the theory of planned behavior [41], and the social cognitive theory [42]. Although a large number of theoretical models present opportunities, they also create challenges. Many theories either

205

include a small number of constructs or share common or overlapping constructs, such as intention, social norms, beliefs, or control or self-efficacy. Therefore, in some cases, it is difficult to decipher which the most appropriate factors to target are in behavioral change interventions. In other cases, it is also possible that the key determinants of the target behavior are not represented. TDF [10,43] was developed in response to these challenges, in an effort to assimilate overlapping constructs in a pragmatic framework and to improve researchers' access to and application of psychological theory.

TDF is an integrated theoretical framework composed of domains synthesized from 33 prior theories and 128 theoretical constructs relevant to behavioral change [43]. It was developed in collaboration with behavioral scientists and implementation researchers to provide a comprehensive and holistic approach to identify determinants of behavior and potential targets for behavioral change. The TDF contains 14 domains covering 84 constructs, examples of which include *environmental context and resources, emotion, goals and intentions, beliefs about capabilities, knowledge and skills,* and *social influences.* A complete listing of the domains and the constructs related to each is available in Lou Atkins et al [43]. TDF was initially developed to identify influences on health professional behavior, but has been extended to many areas in which changing behavior is important, including changing patient behavior [43]. It supports the assessment of problems and identification of potential solutions by providing a lens to view the cognitive, affective, social, and environmental influences on behavior. As a pragmatic framework, it signals opportunities and methods for intervention by first identifying key domains and constructs and subsequently providing a guide to relevant explanations of current behaviors [10].

TDF has been widely used in health research, particularly for qualitative approaches [44]. Examples of qualitative studies include using TDF to formulate interview questionnaires to address target behavior [45,46], to analyze interview responses to identify barriers and facilitators in implementing interventions for families of people with schizophrenia [47], and increasing physical activity in stroke survivors [48]. In applying TDF, we aimed to identify key determinants of behavior in cardiac rehabilitation and self-management at the individual level. We also aimed to explore the key barriers and facilitators to implementing technology-mediated cardiac rehabilitation and self-management solutions. In this paper, we use TDF in the following ways: (1) as a basis for the interview questionnaire to explore individual motivation and capability factors while also covering the physical and environmental influences; (2) to identify the relevant domains that are most likely to influence technology-mediated cardiac rehabilitation and self-management and associated behaviors; and (3) to identify the key points during recuperation, rehabilitation, and self-management journey when different domains exert a strong influence on peoples' experiences and behaviors. The key advantage of TDF is that it provides a pragmatic, yet rigorous, and holistic framework to address these issues.

Methods

Overview

We conducted semistructured interviews with people who had been hospitalized due to a cardiac event and subsequently attended supervised rehabilitation programs. Interviews were framed using TDF and explored participants' journeys and experiences after hospitalization, their cardiac rehabilitation experiences, and their attitudes toward technology. Thereafter, as supported by the TDF guidelines, we performed an inductive analysis of the interview responses following the Braun and Clarke thematic approach [49].

Recruitment

This study was conducted in collaboration with the cardiac unit at Raigmore Hospital, a National Health Service (NHS) Trust in the United Kingdom. A total of 19 participants (11 women) were recruited. All participants had had either a cardiac incident or a cardiac disease in the past. All participants were offered a postsurgery cardiac rehabilitation program at the Raigmore Hospital [50]. The program consisted of a mix of education sessions and monitored exercises. To represent a range of views, we recruited patients who had attended some, but not all, rehabilitation classes and others who had attended all classes (Multimedia Appendix 1). The exclusion criteria were adolescents and people with severe cognitive impairment or terminal illness, as it was outside the scope of this study. Participants' ages ranged between 50 and 86 years, mean 70 (SD 9).

Procedure

This study was approved by the Health Research Authority, NHS Research Scotland, and the Human Research Ethics Committee, University College Dublin. A total of 52 patients were sent interview requests over post. Nineteen patients agreed to participate in the study. The interviews were conducted separately over telephone calls and audio recorded. Each interview took approximately 45 minutes.

The interview questions were based on TDF and inquired about patients' experiences after cardiac surgery, focusing on domains of TDF related to knowledge and skills, individual goals and intentions, social and environmental influences, and emotional influence [43]. All TDF domains were examined, and only those relevant to the aims of this study were considered. This is consistent with the guidelines for the use of TDF. Questions about knowledge and skills inquired about their help seeking, new skills or techniques considered after cardiac events, sources of information, and awareness of their cardiac condition. This included, but was not limited to, awareness of support resources such as mainstream self-care technologies and rehabilitation programs. Individual goals and intentions questions were about their experience of the rehabilitation program and its barriers and facilitators, posthospitalization life goals and changes, and progress tracking. Questions about social and environmental factors probed environmental and social sources of influence and motivation, including the role of health experts and technology on self-management postcardiac events. Questions

206

about emotional influences focused on emotional reactions and feelings of after cardiac events.

The interview questions were structured according to each phase the participant went through after hospitalization (Figure 1). The interview protocol was designed in collaboration with all the authors and is available in Multimedia Appendix 2. The interviews were conducted by the first author (ST), who has a background in HCI and is an experienced qualitative researcher. The semistructured interview started with questions about the participants' first cardiac incident, including hospitalization, initial awareness about the cardiac condition, and support resources. This was followed by questions related to the rehabilitation program experience, and then the self-management experience.

Analysis

Audio recordings of the interviews were transcribed verbatim. The transcripts were analyzed using the NVivo 12 (QSR International) software and inductively coded using a thematic approach following the Braun and Clarke methodology [49]. A codebook was created through an iterative process of coding and clean coding. This was performed by dividing 30% of the total interviews between the two authors. Coding was performed using an inductive approach. Conflicts were discussed and resolved through discussions with a third researcher. After reaching a consensus on the codebook, three randomly selected interviews from the entire data set were coded. The Cohen κ coefficient was computed to assess the interrater reliability at this point, with a score across all codes of 0.53. Further discussion and refinement of codes took place to clarify and agree with the final set of codes. On the basis of this final codebook, the remaining transcripts were coded by the first author (ST). Following coding, themes were identified and again reviewed and defined through an iterative process of independent and group analysis involving all 3 authors.

Results

Overview

An analysis of interviews with participants about their posthospitalization experiences identified a number of key themes. In Table 1, these themes are categorized into the three key phases the patients went through after hospitalization, namely, recuperation, rehabilitation, and self-management. As shown in Table 1, the findings are also classified in the context of the TDF domains. It is important to note that there is some overlap in the themes identified in Table 1, with issues present in more than 1 phase. Our analysis deliberately placed emphasis on identifying the themes in each phase. This has resulted in more overall themes than might typically be the case in thematic analysis. However, structuring our findings in this way has the benefit of allowing us to identify the point when particular experiences first emerged, and when they were felt most strongly. In the Discussion section, we will reflect on how specific needs (eg, a desire for normality) change over time and the implications these changes have on the design of technology.

Table 1. Mapping of posthospitalization transition phases, relevant Theoretical Domains Framework (TDF) domains, and themes from findings.

Transition and TDF domains	Themes	Codes
Recuperation phase		
• Goals	A desire for normality	• Feeling better after cardiac event • Rebuilding strength • Desire for a normal life
• Knowledge	Sources of information and role of official or expert resources	• Initial help seeking • Need for information • Contact with health care professionals • Resources recommended by experts
• Emotion	Shock and gratitude	• Gratitude or appreciation • Emotional response or reaction
Rehabilitation classes phase		
• Emotion • Optimism	Mindset and emotion	• Stress or anxiety and relaxation • Positivity or negativity • Fear
• Environmental context and resources	Rehabilitation classes provide a safe space	• Preference for local or in-person rehab • Rehabilitation classes as a training place • Classes as a safe zone • Tailoring • Barriers to local attendance
• Social influences	Rehabilitation classes provide a social space	• Rehabilitation classes as a social place
Self-management phase		
• Environmental context and resources • Social influences	The importance of family and social support	• Environmental or contextual support • Social support and types of social support • Self-reliance
• Behavioral regulation	Monitoring	• Bodily awareness • Monitoring • Motivation or demotivation
• Beliefs about capability	Capability	• Emphasize what can be done • Physical activity found in daily activity

Recuperation Phase

Recuperation phase is the period immediately after discharge from hospital following cardiac surgery.

Desire for Normality

The desire for a normal life (defined as the life patients had before cardiac surgery) was identified across each of the three phases described in our results. However, this desire first emerged and was expressed most strongly during the recuperation phase. While some patients experienced significant physical and mental effects, other patients described feeling better and healthier after surgery. Some went so far as to say procedures such as the insertion of stents had *fixed them* (ie, cured the cardiac problem) and given them confidence to return to normal life:

> Once the stents had been fitted, the pain had disappeared, and I felt that the care that I was getting in hospital gave me the confidence to go ahead. [P19]

> I don't have a condition as far as I am concerned. I had the operation repaired and I've never looked back. [P8]

Others spoke positively about their posthospitalization recuperation but described a more step-by-step, gradual process of rebuilding strength. Every day, they would push themselves to do more, but in small increments:

> Right enough, the next day I went out, I got a bit further. The day after that, a bit further. That was fine. So, I didn't actually have any low points. I didn't regress much at all. It was a fairly gradual and continuous improvement. [P13]

Overall, participants expressed a strong desire to lead a *normal life* after the cardiac event, without the need to be reminded of their condition. Although hospitals provide a lot of information during discharge on potential risks and the importance of aftercare, many were more interested in knowing how and when they could return to their normal way of living:

208

They had a lot of information on the aftercare definitely, what we should do, but I was more interested in would I return to my normal things 'cause I'm a physical person. I'm a walker and I'm always very active and they encouraged me to carry on just like that. [P3]

I think we all change a wee bit but the whole point is, is not to make a fuss about it, you have to try and get back in your routine again with your family as much as possible and keep it as normal as possible. [P17]

This desire was also expressed with regard to relationships. People wanted to be treated as normal by their friends and family, that is, not being overcared for. They wanted *to get on their feet* and participate in family life in the same way they had normally done before the incident:

Just treating you I suppose how you were before the incident, if you know what I mean. You're not any different. Maybe my family is just like that. Once I was up on my feet, that was it. Mum's back, sort of thing. I got away with making the Christmas dinner the first year 'cause I was away at the hospital, but I was back to it the next year. That did help because it makes things seem normal. I've had this incident and I can just go on with the rest of the life. So that helped me in that way. [P15]

Viewed through TDF, returning to normal life can be seen as a goal of our participants. It is likely to have a strong influence on the participants' behavior. The fact that this goal is strongly linked to participants' sense of role and identity (eg, the family role) is likely to act as further reinforcement. However, the goal of returning to their life before surgery creates a potential tension, as it may come into conflict with the lifestyle change goals recommended for rehabilitation and long-term health management. Resolving this tension is therefore important for technology designs in this space.

Sources of Information and Role of Official or Expert Resources

The patients stressed the need for information about their condition. Increasing awareness and information is important for building confidence, "Having a heart attack was quite a shock to me and as I said I read as much as I could about it" [P18].

There is a need for reliable information and a need to help people retain this information. Those who had a family history or earlier awareness of cardiac symptoms were better prepared to handle the repercussions. When asked about how they sought information initially, the most common response was from the internet and booklets given by their hospital. However, patients also expressed concerns about the credibility and possibility of harm in seeking information on the internet:

If I had a problem or if I wanted to find out anything about health I will look it up on the computer. [P10]

Googling too much messes with the head - panic due to sharp info content. [P4]

In the initial stages of recuperation, the resources recommended by experts were highly valued, as patients trusted these resources. Participants were strongly of the view that there was a need for access to and contact with experts and health professionals after discharge. Any type of contact with health professionals was found to be reassuring during the transition from hospital to self-care and recovery. Talks from experts in rehabilitation programs were considered valuable. However, this contact was sometimes restrained because of time restrictions on health professionals. However, it is also due to concerns on the part of patients that they might burden health professionals:

Maybe just more contact or freer to contact the cardiac advice line because, me personally, you tend not to want to be contacting them unnecessarily but sometimes just after in the first two or three months...It's just that you feel that you weren't encouraged to do it. No one said, "Just contact us if you're concerned about anything." [P3]

Participants' desire for information is consistent with the TDF *Knowledge* domain. During the recuperation phase, participants had a need for general knowledge about cardiac conditions and rehabilitation procedures. They placed a strong emphasis on official knowledge sources. As will be seen in later sections, the types of knowledge participants prioritized evolved during subsequent phases, with a greater emphasis on detailed personalized understanding and informal information sources.

Shock and Gratitude

Acute cardiac events are typically sudden, and unsurprisingly, trigger strong emotional responses. Some participants were physically fit, had no other earlier health issues, no symptoms, and no one in their family had had heart problems earlier. However, suddenly, they experienced a life-threatening event, were hospitalized, and underwent surgery. This was a significant shock. One participant described being so surprised that it took him a few months to come to terms with the fact that he had had a heart attack. Recovering from such incidents requires both emotional and physical healing,

It was a huge shock to have a heart attack, a real shock to the system, and it just shows you how vulnerable we are and I think that in itself was an incentive. [P18]

Following this initial shock, many patients described a newfound appreciation of life and did not want to take their health for granted. They also expressed immense gratitude to and appreciation of health care providers:

I was aware that this is real, what happened to me, and you know, I used to think I was invincible. Well, I never really thought I was anything other than fit and nothing would go wrong, but now I'm aware, much more aware, that something could go wrong, and I'm very grateful for what they did to me. [P16]

TDF emphasizes the important role that emotion plays in driving behavior. Participants' sense of shock clearly shows how the emotions experienced have the potential to drive emotional and physical tension. Interestingly, while shock delayed some

209

patients' ability to move forward, in others, it helped raise awareness and acted as an incentive. In contrast, gratitude always triggered strongly positive responses during the recuperation phase.

Rehabilitation Phase

All participants were offered a cardiac rehabilitation program after surgery at a hospital in the NHS Trust [50]. This section discusses the participants' experiences of rehabilitation classes and this phase more broadly.

Mindset and Emotions

The patients' emotional responses developed and evolved during the rehabilitation phase. Although cardiac events brought out both positive and negative emotions, many described how their mindset or outlook played a major role in recovery and rehabilitation. Participants pointed out that their confidence, determination, and acceptance of their condition helped to reduce the impact of the event on their life:

> I'm generally quite a positive person and reasonably confident. I think not unnaturally confident, but if I understand a situation and I know about it and I know what to expect, then I'm fine with it. [P13]

Participants realized the importance of reducing stress or anxiety and noted the benefits of relaxation exercises, which were introduced in the rehabilitation classes and were new to many, "I really liked the relaxation type of stuff, I had never done that in my life, never knew anything about that" [P13].

On the contrary, some participants emphasized that a lack of attention to mental health support, after discharge from hospital and in the rehabilitation program had an impact on their recovery. One patient was moved to look for private psychological support outside the public NHS system,

> Half of the problem's with my head to be quite honest with you and if anything I feel that you get let down a wee bit on the recovery part or the mental side of the trauma and I don't feel there's enough done in cardio rehab. [P4]

Fear was a common emotion during rehabilitation. Some, for example, were apprehensive about pushing themselves to perform exercises as they were constantly afraid of harming themselves. Others expressed a general concern about an uncertain future. Participants felt that this buildup of fear in their minds hindered their progressive recovery and potential for self-management:

> I didn't sleep very well. In fact, I slept in a chair most of the time. It was just apprehension, I suppose, wondering if your life was going – I just thought it was going to drastically change and I wasn't going to be able to do anything, if you know what I mean. I got over that, but it was always at the back of my mind how much will I be able to do because I didn't want to be having to just sit about all the time, but that wore off the better that I got. I did pick up quite quickly. [P15]

The TDF domain *Emotion* includes the constructs *fear, anxiety, positive/negative affect*, and *stress*. Helping people address these emotions is clearly an important priority in enabling effective rehabilitation and self-management, but one that may be overlooked in some traditional rehabilitation programs. This emphasizes the importance of supporting both physical and mental health during rehabilitation. Technologies that can provide emotional and mental support, along with reinforcement of a positive mindset and self-reliance, have significant potential in this space.

Rehabilitation Classes Provide a Safe Space

Although participants identified barriers, they generally expressed a strong preference for local and in-person rehabilitation. Common barriers reported included transportation, distance, schedule delays, low attendance, limited expert availability, and logistic difficulties. Although the preference for in-person rehabilitation is perhaps unsurprising given the participants recruited, the reasons behind this preference point to important factors for technology design.

Rehabilitation classes provided support for training, giving people the opportunity to gain information and practice physical exercises that they could continue during self-management. They liked the personal interaction with health professionals as it gave them confidence and reassurance that they were doing things properly and progressing. Critically, rehabilitation classes provided a controlled environment—a *safe zone*—while exercising and people felt that they could push themselves without the risk of overburdening their body. This safe zoning was important in helping participants overcome emotions such as fear:

> I benefitted greatly from the program – the exercise program. Principally because it was monitored because if I get breathless now doing things, I don't want to push it because I don't know how serious that would be, but in the classes when I got nearly breathless, the physio really checked carefully and I felt perfectly relaxed. I knew that nothing untoward would happen while I was in their care. [P9]

The patients found that the tailored support focusing on individual needs was encouraging. The rehabilitation program was appreciated for treating every patient individually and helping set appropriate individual goals and where everybody felt they were achieving something. This encouraged them to continue their progress. However, some patients found the rehabilitation classes a bit slow and pointed out that the official self-management information resources received from the hospital were generic. Patients wanted the rate of exercise, type of exercise, and information they received to be determined by their particular needs and how they progressed individually,

> My feeling is slightly that each person's recovery is very individual and not everybody would want to read through the British Heart Foundation. [P1]

Importantly, rehabilitation classes also provided a structured approach, compartmentalized physical activity, and monitored to set time, separated from regular day-to-day activities. This was key for some participants, as it supported a sense of normality outside of classes, by allowing for time-bound

210

engagement in physical activity and reserving a set time and place to completely focus on recovery.

TDF emphasizes the behavioral impact of the environmental context and resources. Our findings show that individual and tailored support, safe zoning, and structure or compartmentalization are important elements in the environment provided by rehabilitation classes. Therefore, designs that leverage or recreate these environmental factors have significant potential.

Rehabilitation Classes Provide a Social Space

Together with the environmental benefits, rehabilitation classes were also a social place. This provided several clear benefits, consistent with the TDF social influence domain. In particular, it provided a sense of community and gave people the opportunity to talk to others in similar positions,

> I think when you are face-to-face with a group of people who are recovering, the same way as you are, I think you encourage each other and I think also the information that you receive collectively adds force to the information that you are given. [P18]

In contrast to formal information provided by health professionals during the recuperation phase, information at this point also came in the form of shared experiences. Although this information is less formal, it is also more personal and has collective power. Patients discussed their direct experiences of dealing with various aspects of the recovery process and reassured each other:

> One other big advantage was being able to talk to other people who were in a similar position. That was really useful, and I think we could reassure each other, and we could talk to each other about how we dealt with various aspects of the recovery process. That was a very valuable part of it. [P13]

A contrast was observed in the case of normality. In the recuperation phase, normality was associated with life before cardiac surgery. The social aspect of rehabilitation classes had the potential to help participants normalize their new experiences, which in turn helped them adjust to a changing life after hospitalization,

> The classes were good, mainly the fact that we were talking to people who had gone through the same problem, and come out the other end, and we were getting the feedback from them, making us feel, well, they've been through it, they're looking well, so maybe we can do the same. [P11]

Finally, the social nature of the rehabilitation classes was a clear source of motivation. Many participants had experienced technology as *solitary* and not something that was shared with other people. Many were reluctant to replace human contact with technology. *Human touch* was considered very important, whereas technology was considered optional or supplementary,

> The motivation is to meet with people and you all join in and that's the motivation I think and you would find time to go to a class, whereas if you were busy during the day doing other things, you sort of put it

> off and maybe the grandchildren will come and you want to spend time with them and you think I will do that later, the motivation isn't there. [P19]

Self-management Phase

Following the recuperation and rehabilitation class phase, participants moved to the self-management phase, requiring them to take greater responsibility to manage their own condition, without regular professional support.

Importance of Family and Social Support

Social influence was again a key factor in the self-management phase, but here the focus shifted toward preestablished and longer-term relationships. Family was a key enforcer in every phase, but became particularly important in the self-management phase, with close partners particularly important. Family or partners influenced patients' physical state by accompanying them for fitness activities or caring for their diet. They influenced their mental state by encouraging and caring, or just being normal:

> My wife is very encouraging of me to do healthy things. She leaves it to me, but she's very positive about it, very helpful. She doesn't badger me at all, but she encourages me. I think that's important. If there is someone close to you who cheers your goals and wants you to do well in those goals. I think that makes a huge difference. [P13]

Other social support included friends, common interest groups, or web-based support groups. Web-based support groups, although not described favorably by many participants, enabled continuity of communication and mutual support for people who may be living in remote areas or are unable to get together with others:

> Interacting with people is much more important because it's social. It prevents depression. I could quite see how you come home from hospital, you're living on your own, I'm frightened. [P2]

Participants also described the influence of environmental or contextual factors, such as the home, workplace, and surroundings on recovery and self-management. Stress at home and workplace causes anxiety, which could have detrimental effects. Most patients found scenic surroundings and nature walks beneficial:

> I'm very lucky. We live in the country, we own our own house, I have a most amazing view from where I'm sitting talking to you just now, and I don't have pressures that a lot of people will have. [P2]

Although many participants valued social support, some patients preferred to be self-reliant, not liking to be told what to do, and wanting to be in control of their lives. Some did not want to be a burden on their family and would not bother their general practitioners unless absolutely necessary. However, 2 patients stressed that they did not need any type of help or support, as they considered themselves to be self-sufficient:

> I'm fortunate that I've not got people around at all to assist me or help me in any way and that I maintain is a great, because I strive to do these things. [P9]

211

I've lived on my own for most of my life and I'm very sort of self-sufficient I suppose, in a way. [P7]

In the self-management phase, there is a clear overlap between the TDF domains, social influences, and environmental context and resources. This is unsurprising given the interconnected nature of home, work, and social or family lives in the day-to-day lives of many people. Leveraging technology to provide increased opportunities for family involvement has clear potential and has been widely explored in other areas of health-focused research. Maintaining a balance between people's desire to be self-reliant and their desire to be connected is also critical in designing such technology.

Monitoring

Many participants described becoming more aware of their body, the link between their mind and body, and *listened to their body* more after cardiac events. As described above, rehabilitation classes provided a safe zone. Monitoring was a key part of this, with close overall monitoring by health professionals and regular pulse and blood pressure monitoring. During the self-management phase, self-monitoring in daily life was common and again gave many patients confidence to continue with physical activities and push themselves. The most commonly monitored measurements reported by participants were heart rate, blood pressure, steps, sleep, and medication. Among these steps was the most frequently monitored unit. Fitbit (FitBit Inc) is the most widely used and well-known monitoring technology among participants. All patients who owned a Fitbit started using it after hospitalization. This was mainly for self-motivation and safety, and to obtain other useful insights about their body. Monitoring was also done to share information with the general practitioners,

I probably wouldn't push myself to do things, whereas now, with the Fitbit, I try where possible to be able to fulfil my steps every day. [P18]

TDF describes the behavioral regulation domain as anything aimed at managing or changing objectively observed or measured actions. Self-monitoring is an important component of this domain. This quote shows how some participants used monitoring technologies for behavioral regulation during the self-management phase. Monitoring also helped to provide ongoing insight and more personalized knowledge about their own body. However, continuous monitoring could also cause stress, and some patients liked monitoring only when they were performing physical activity. Warnings were seen as valuable, but only where something specific and unusual was detected, and not in a more routine or general way that highlights limitations:

That could actually cause more of a kind of worrying aspect to people, it could lead to more stress, having to do that and to also find if their heart rate wasn't good, it would be more of a worry to them. [P19]

It would be useful if...it could issue a warning if something irregular began to happen. [P13]

This perspective suggests that for some people, long-term monitoring will work best when it is structured or compartmentalized. By combining this approach with warnings

that are largely focused on irregular events, it may be possible to develop systems that provide a safe zoning effect similar to that identified in face-to-face classes in the rehabilitation phase. To achieve this monitored safe zone, it is critical that people trust the privacy of monitoring technologies. Some participants questioned the integrity and transparency of technologies and were unsure if web-based resources could be trusted. Surprisingly, others also questioned their own potential honesty when entering their own information to seek help through digital apps:

You can put into a computer whatever you like. You can say I'm a 6-foot leggy blonde, how do you advise me to get better, but you can type anything in. You're not going to have to be honest into a computer but face-to-face... [P2]

Capability

One of the most interesting recommendations made by the participants was that technology should act as an empowering agent. In particular, it should focus on what can be done, rather than identifying or tracking limitations. Patients believed that technology should guide them by allowing them to see what kind and how much exercise they could perform. In this way, technology would more closely mirror the guidance provided by health professionals in rehabilitation classes,

If there was any kind of technology or anything that would say to them you could actually do this after so many weeks, with care, I think so because all you get told, 'Don't do this', and then you're sitting there and you think, oh, and everything just seizes up and your confidence does go, to be honest with you. [P15]

Respect for people's autonomy was also important, with 1 participant negatively describing technology as *assertive*. To be successful, it was essential that technology respected peoples' autonomy:

That you're always in control of them. What they're providing you with is information and suggestions rather than commands. [P13]

It was found that patients accomplished physical activity through activities in daily life. The preferred type of physical activity for most patients was walking and gardening. Their occupation and where they lived reflected on the type of physical activity they preferred:

My husband's a farmer. We live on a farm. We have no problem with exercise at all. [P2]

As discussed above, self-monitoring is an important construct within the TDF *behavioral regulation* domain. Habit is an important construct in this domain. Alongside encouraging targeted lifestyle changes, our data suggest that long-term rehabilitation technology will be most effective if it draws on previously established healthy habits and activities of daily life. This can be combined with recommendations that emphasize capability and reinforce positive opportunities, allowing designers to build on the empowerment construct, which is emphasized in the TDF's *Belief about Capability* domain. This

212

overall approach is complementary to participants' desire for a normal life and should thus be a key focus for designers.
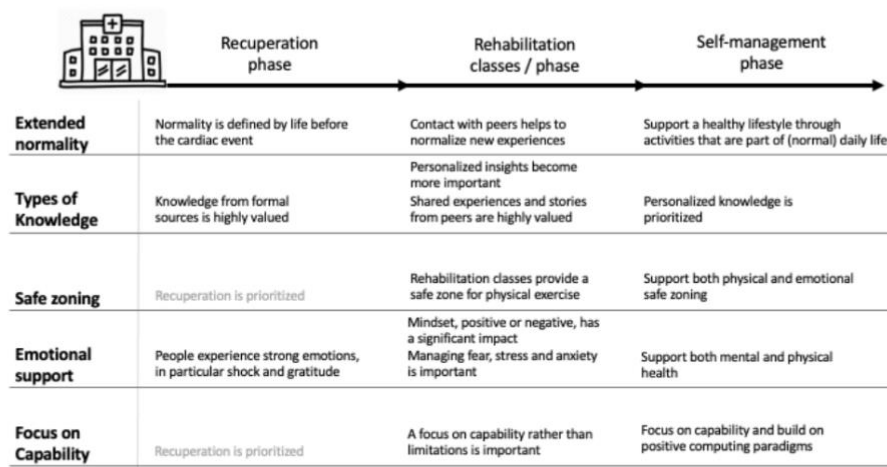
Discussion

Principal Findings

As described in the Related Work section, TDF is a synthesis of previous theories of behavioral change. Mapping the themes to the TDF domains provided us with key domains and behavioral constructs to consider in each phase after the cardiac event. The key strength of TDF is that it provides a rigorous and holistic framework for identifying a wide range of factors that impact behavior. Unsurprisingly, this has resulted in individual findings that are consistent with earlier research on health behavioral change, both in the cardiac domain and beyond. Critically, however, the use of TDF has also allowed us to see how factors that influence behavior evolve over time and identify potential sources of tension. For example, participants experienced a strong initial need for formal knowledge and access to health experts. This subsequently shifted to a desire for detailed personal insight and shared peer knowledge. We also see how participants experienced a strong desire for a normal life after surgery and how a redefinition of normality is important in long-term recovery. In this section, we discuss our findings, focusing on five key issues, namely, extended normality, safe zoning, focus on capability, different types of knowledge, and emotional support. Figure 2 provides an overview of the key points and recommendations addressed in the *Discussion*.

Figure 2. Key patient experiences and areas where technology can provide support during recuperation, rehabilitation, and self-management.

Extended Normality

Existing literature has described the mundane nature of day-to-day self-care [17] and the degree to which people prefer not to be reminded of chronic health conditions [28]. We also find that a desire for normality is a strong motivating factor; indeed, it is a stated goal for many people after cardiac surgery. This creates an obvious source of tension, as lifestyle change is an important part of cardiac rehabilitation and is critical to long-term health. Given participants' strength of feelings, it is unlikely that behavioral change strategies that run counter to the goal of normality will be successful. Interestingly, our findings show how some participants' conceptions of normality evolved over time and suggest ways to address this challenge. We call this *extended normality*.

During the recuperation phase, normality is defined as a return to the life participants lived before their acute cardiac event. Official knowledge sources and contact with experts provided information on the recommended changes. However, in rehabilitation classes, participants also began to normalize their new experiences through social interaction and by sharing experiences with other cardiac patients. In the self-management phase, the participants who were most successful in sustaining healthy behavior were those who integrated their health management with their preferred activities of daily life, such as walking or gardening. This helped them reclaim a sense of their old routine, independence, and *normal life*. Viewed through TDF, this also engages with the importance of self-identification in either hindering or supporting healthy behavior. The study of stroke survivors by Ploderer et al [15] also highlighted the people's efforts to manage the illness as well as everyday life activities and to reconstruct their identities.

This has led to several recommendations for technology. Critically, technologies should recognize that exceptional goals and external incentives may not be necessary. Normal life is a goal and incentive in and of itself. Care should also be taken to resolve the potential conflict that might arise between participants' goal for normality and the lifestyle change goals recommended by professionals for rehabilitation and long-term health management. Personalized rehabilitation programs that respect personal autonomy and provide tailored recommendations linked to daily life can help address this

213

tension. As people transition to life after surgery, technology that supports enhanced contact with peers and shared stories can also help develop a new sense of normality.

Types of Knowledge

A previous study by Pollack et al [5] provided a detailed exploration of the experience of patients discharged from the hospital. They describe how people are often unprepared for a transition from the hospital and identified three important challenges for patients recovering from illness and needed to engage in successful self-management: (1) lack of support for health knowledge, (2) no opportunity to access resources, and (3) no opportunities to promote self-efficacy. We discuss self-efficacy in greater detail in the section focusing on capability below. Here, we consider knowledge and access. Our findings again show that people's knowledge needs changed over time.

During the recuperation phase, people place a high value on formal knowledge, by which we mean information provided by health professionals and official sources. Much of this was standardized information about cardiac rehabilitation and lifestyle management, including standardized official booklets. Participants also sought web-based information but were often mistrusting of such sources. During the rehabilitation phase, a change occurred in the information that participants valued. Formal knowledge remained important, but participants no longer wanted generic information. They placed a high value on both shared experiential knowledge and detailed personal insight. Shared experience was facilitated through contact with peers in rehabilitation classes and occasionally through web-based support groups. As noted above, it played an important role in normalizing people's new experiences. Personal knowledge was initially facilitated through the tailored support provided by health professionals in classes and later, although typically to a lesser degree, through self-monitoring technology.

Our findings regarding types of knowledge are consistent with a recent systematic review of barriers and facilitators of technology for cardiac rehabilitation and self-management. It also emphasized the need for technology designers to support background knowledge as well as personal and in-the-moment knowledge, where background knowledge is awareness of their medical conditions, medication, posthospital care measures, and available support systems; and in-the-moment knowledge is awareness of current body condition and changes in their body [11].

Moving forward, technologies that support different types of knowledge have significant potential. However, it was striking that many of our participants expressed the view that technology is a *solitary* thing. Within the HCI field, significant research has been conducted on the design of technologies that support social connectedness in health [51], and in personal and lived informatics [52] and the use of technology to support informal caregiving [53]. We do not have the scope to elaborate on this work at this point, except to state that the development of effective social networks in self-monitoring technologies in the health domain is clearly not a trivial task. However, research

in the cardiac space will benefit from building on this earlier work.

Safe Zoning

During the rehabilitation phase, participants liked the controlled environment, intensive monitoring, and detailed personalized support provided by health professionals. It provided insight about their current health status and increased confidence by assuring them that they were within a safe zone of physical activity. This *safe zoning* helped participants overcome emotions such as fear. Critically, it did not provide safety by reducing the activity. Rather, it provided a space where people could push themselves without the fear of overburdening their body.

Technology that supports this safe zoning on an ongoing basis is likely to be highly valuable. Importantly, safe zoning should consider not only physical, but also emotional safe zones. During the self-management phase, self-monitoring gave some patients confidence to continue physical activities and push themselves. However, many patients also did not want to be monitored continuously, as this could cause anxiety and interfere with their desire for normality. This finding is consistent with previous findings of Maitland et al [28] that cardiovascular patients were reluctant to accept unnecessary monitoring. Warnings were also considered valuable only when something unusual was detected and not in a more routine or general way. A structured or compartmentalized monitoring approach with warnings largely focused on irregular events may help to provide a *safe zone* effect similar to face-to-face rehabilitation classes. Transparency and trust in the privacy of monitoring technologies are critical for achieving this goal.

Emotional Support

Acute cardiac events affect people both physically and mentally. In recent decades, health research has increasingly recognized and addressed the interrelated nature of physical and mental health. For example, the recognition of psycho-oncology is a key element in rehabilitation for cancer survivors [54,55].

As participants transitioned from recuperation to the rehabilitation phase, their emotions transitioned from shock and gratitude to long-term emotions. Multiple emotions built up and left unchecked can affect a person's mental health, inducing fear, anxiety, negativity, and loss of confidence. Many patients have stressed the importance of emotional support. Family and close friends are often vital sources of emotional support. Participants pointed out that although a lot was done to educate and motivate them on physical exercise and diet, less attention was given to emotional strength. Although in-person emotional or mental support is preferred, there is increasing evidence in recent years that technology can play a significant role in providing support for mental health [56]. Examples range from systems specifically designed to integrate with traditional care [57] to the more exploratory use of voice interfaces and chatbots using artificial intelligence to provide emotional support [58]. Importantly, alongside negative emotional experiences, participants also expressed positive emotions such as gratitude and renewed appreciation of the natural world. Many also described the beneficial impact of a positive mindset and an increased sense of the link between mind and body, including

214

an appreciation of the stress reduction in rehabilitation classes. This suggests significant potential in the application of positive computing approaches [59] that emphasize human potential and reinforce emotions such as kindness and gratitude. Approaches such as computer-supported mindfulness also have significant potential to support stress reduction and enhance the sense of a positive mind-body link [60].

Focus on Capability

Building on the value of positive computing approaches, this study strongly suggests that designers should focus on capability rather than limitations. Particularly in the self-management phase, our participants expressed a strong desire for technology that could recognize renewed strength and make positive recommendations. They wanted technology to show what is possible by tailoring to their capabilities rather than focusing on limitations. They also wanted technology that respected their autonomy, placed them in control, and offered suggestions rather than being directive. Interestingly, some participants placed a significant value on self-sufficiency. They did not like to be helped by their families or friends. It is possible that people in this group would also consider technology as encroaching on their preference for self-sufficiency. However, we consider it more likely that autonomy-respecting and capability-focused systems will have a significant potential with this group. This analysis resonates with the conclusions of Andersen et al [20], where reintroducing patients as active diagnostic agents in the telemonitoring system showed patient willingness to take on the added workload and become actively engaged in their monitoring and diagnosis.

Through the growing capabilities of recommendation system techniques, we envision technology to be key in enabling personalized rehabilitation and self-care by focusing on individual capabilities. Tailoring recommendations for daily activities will be important in achieving this. Apps should also take into account the effect of progress awareness, wherein tailored programs based on step-by-step progress and presentation of the progress would contribute toward motivation. Previous HCI literature on person-centered recommender systems by researchers such as Konrad et al [61] and Hollis et al [62] offers valuable guidance in this area.

Limitations

Although we interviewed a relatively diverse group of people with cardiac problems, including people who both withdrew from and attended a full rehabilitation program, it will be beneficial if future studies include more people aged less than 55 years and more people from urban areas. Although our findings are directed toward supporting patients, we understand that the opinions of caregivers are crucial and involving them

will provide a broader view of the impact technology in support rehabilitation and self-care. Similarly, including health care professionals in the design process will also be crucial to the development of technologies that are acceptable and effective in improving the rehabilitation and self-management practices of patients. This work is beyond the scope of this study. Our future studies will involve both patients and health professionals and will apply co-design methods to implement systems that operationalize and evaluate the recommendations provided in this paper.

Future Work

The *Discussion* section has identified a number of important avenues for research on the design of technology to support cardiovascular rehabilitation and self-management. Continuing to address the theoretical basis for this research will be a key focus of our work. As described in the related work section, TDF is an integrated theoretical framework composed of domains synthesized from theories and theoretical constructs relevant to behavioral change. Building on TDF, researchers in behavior change have also developed the behavior change wheel (BCW) [43,44]. This supports intervention designers in selecting intervention and behavioral change techniques by mapping the TDF domains to the BCW. BCW is based on three components, namely, capability, opportunity, and motivation (the COM-B model). It presents human behavior (B) as resulting from the interaction between physical and psychological capabilities (C), opportunities provided by the physical and social environment (O), and reflective and automatic motivation (M) [63,64]. For example, TDF domains linked to capability (C) are knowledge, skills, memory, and behavioral regulation. BCW proposes the following interventions to address factors related to capability: education, training, and enablement. In this way, BCW proposes interventions and policies for each of the three components. Building on the identification of important TDF domains and constructs in this study, application of BCW is a key priority in our future research.

Conclusions

This paper has applied the TDF to explore the experiences of people with CVD, focusing specifically on recuperation, rehabilitation, and self-management phases after an acute cardiac event. Through these three phases, we have described how factors such as desire for normality, types of knowledge, safe zoning, connectedness, and capability impact patients. We then highlight the TDF domains that are linked to the factors arising in the three phases. Building on our findings, we have provided implications of these factors and the TDF domains in the design of technology-mediated cardiac rehabilitation and self-management.

Conflicts of Interest

None declared.

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215

Multimedia Appendix 1

Demographic information about the participants.
[DOCX File , 15 KB-Multimedia Appendix 1]

Multimedia Appendix 2

Interview guide.
[DOCX File , 20 KB-Multimedia Appendix 2]

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216

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217

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218

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Abbreviations

BCW: behavior change wheel
CVD: cardiovascular disease
HCI: human-computer interaction
NHS: National Health Service
TDF: Theoretical Domains Framework

219