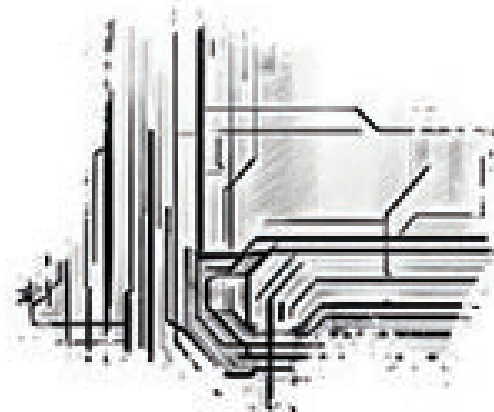
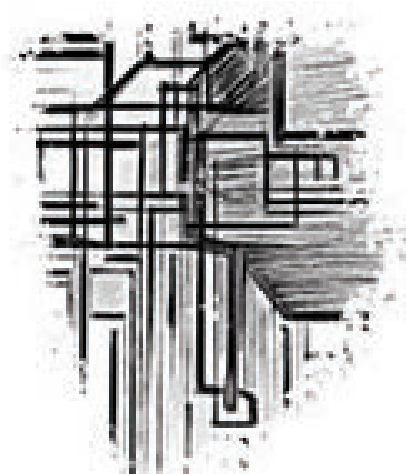


# SUPPORTING **SELF-CARE** WITH **EHEALTH**

ADVANCING THEORY-BASED RESEARCH AND DEVELOPMENT OF INTERVENTIONS  
TO SUPPORT PATIENTS WITH A CARDIOVASCULAR DISEASE



**Roberto Rafael Cruz Martínez**

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DISSERTATION

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on account of the decision of the Doctorate Board  
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on Friday 15 September 2023 at 16.45 hours

by

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# Chapter 1

## General introduction

*“Self-management is good medicine. If the huge benefits of these few habits were put into a pill it would be declared a scientific milestone in the field of medicine.”*

**Albert Bandura in “The Primacy of Self-Regulation in Health Promotion” (2005)**

## INTRODUCTION

### A vision of self-care: Part 1

How would our lives improve if we could harvest the full potential of digital technologies to maintain, monitor, and manage our own health and well-being?

Imagine the life of Albert, who lives in the near future. Albert is entering his fifties, living together with his wife and children and having what could be called a ‘busy life’. He has a full-time job and is passionate about his work. However, that still comes with its stressful moments and personal challenges. Throughout his life, Albert struggled with the maintenance and management of his health. What marked him the most was a high awareness of his family’s health history, which predisposed him to suffer from certain illnesses. For instance, his father and other close relatives had suffered from chronic cardiac conditions. Because of those experiences, Albert learned early about the importance of a healthy lifestyle for disease prevention. He was never in ‘top form’, but he tried his best to be physically active and follow a balanced diet. Unfortunately, despite his numerous efforts, Albert was one day diagnosed with hypertension.

At first, Albert felt defeated and powerless. He felt himself doomed to repeat his family’s history. After the diagnosis and initial tests, he was recommended by his physician to perform periodic blood pressure monitoring at home. The doctor also suggested Albert to make healthy lifestyle changes. Upon receiving this advice, Albert opened up to them and shared his struggles with health maintenance. To Albert’s surprise, the doctors offered the option to try out a novel ‘self-care support system’, which they claimed had been recently-developed by a team of scientists.

‘What is a self-care support system?’—was the first thought in Albert’s mind. The doctors explained that this system would help him monitor and manage his own health and well-being. ‘Ok, but how?’ was Albert’s second thought. The doctors assured Albert that the system would help him acquire and maintain whatever healthy lifestyle habits he desired to take. Albert was puzzled, and after further questioning he found out that the so-called ‘system’ did not consist of much in concrete. He was provided with an internet-enabled weigh scale and a blood pressure monitor. Besides that, the doctors indicated the system would function mostly ‘behind the scenes.’ It was capable of connecting with his smartphone and any other digital gadgets he already owned. The doctors also emphasised that the deployment and installation of this system was easy and intuitive. Perhaps unsurprisingly, Albert was naturally sceptical about all of these promises. How could such a thing help him realise the intentions and goals he had struggled with so much and often throughout his life?

What happened in the next two years following diagnosis and the provision of this support system astonished Albert and his family. Little by little, day by day, Albert managed to regain a sense of control over his own health and well-being. He learned, practiced, and adopted new healthy habits, as well as different behavioural techniques to stay motivated and to be mindful about his own well-being. Albert’s new daily routine typically looked a bit like this: In the morning, Albert would get up and get ready for work. The system would then remind him to take his medicine and occasionally suggest to monitor his weight and blood pressure. In the afternoon, Albert could follow a self-care plan which he previously prepared with the guidance of the system. Among other things, the plan facilitated behavioural recommendations targeting healthy eating, guided-exercises to cope with stress, and tips on how to avoid sedentary behaviours at work.

In the evening, Albert could monitor his health and reflect on the habits he had engaged in during that day. If desired, Albert could adjust his self-care plan for the next day or weeks. Whenever he had questions, the system also facilitated remote communication with caregivers. If necessary, it was even possible to schedule an appointment for a telephone or face-to-face consultation.

What pleased Albert the most was neither the numerous support options offered by the system, nor the fancy gadgets he was provided with. ‘The best thing about it...’—Albert enthusiastically noted—‘is how well the system adapted to my needs and preferences.’ No matter how chaotic or unpredictable his day became, the system was able to provide useful recommendations. Step by step, Albert regained a sense of control and confidence in his own health management skills.

After one year of use, Albert had experienced many of the great benefits that were promised by this support system. Of course, the road was not without obstacles. For instance, Albert had used the system to learn more about his own condition, but that sometimes raised doubts and stirred negative emotions in him. However, often he could resolve his concerns with the help of the system’s features, such as the ability to consult with caregivers remotely. Similarly, Albert had set many personal health goals which were not achieved in the first try. However, every attempt had been promoted by the system as a learning experience towards the long-term objective of finding healthy habits that fit his lifestyle. Importantly, at busy or difficult periods of his personal life, Albert could easily adjust the system so that it would not inconvenience him. If Albert desired so, he could enable the system to ‘invite’ his own family and involve them in the pursuit of his personal health goals and self-care plan.

After two years, the results were clear. Albert’s health maintenance, monitoring, and management skills had remarkably improved and made an impact on the clinical parameters of his condition. Because of this, he made the decision to slowly discontinue the use of the support system. He no longer felt that he needed constant reminders to take his medication. He now also felt more intrinsically motivated to exercise and avoid unhealthy habits. He performed healthy behaviours because he enjoyed them and not because he felt obliged to do so. Albert was now determined to keep on living his life without giving much thought to fears about his family’s health history. Albert now had the knowledge and skills to take adequate care of himself.

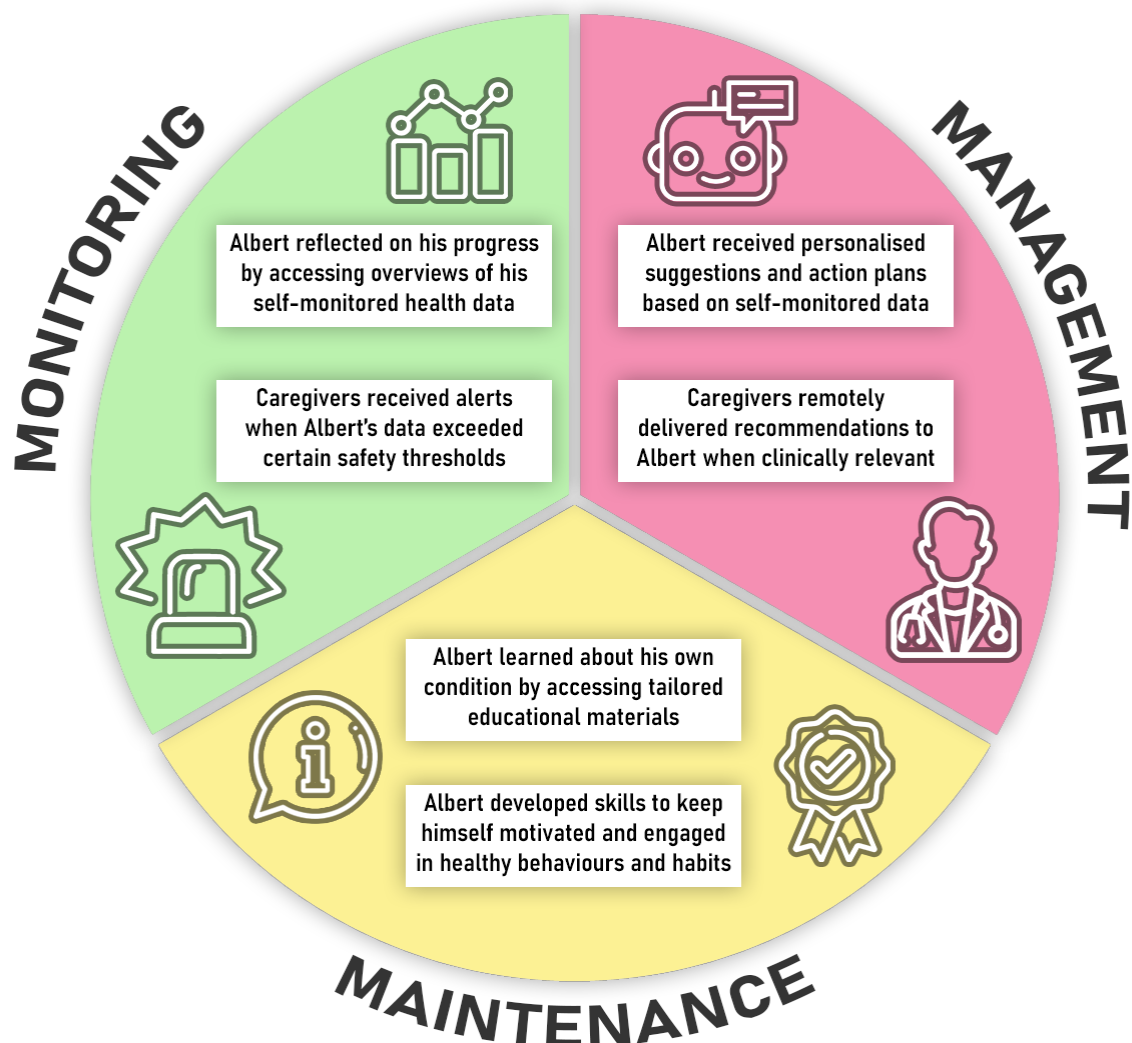
One day sitting at home, Albert was reflecting about his experience and began to think about this self-care support system and the ‘team of scientists’ who had developed it. How had they managed to identify his needs so accurately? How is it possible that they figured out a way to take such knowledge and integrate it into such an effective and intuitive system? Albert wondered if others like him had experienced the same success with the system. He found it difficult to even imagine the amount of information that had to be considered in order to build such a thing. All of the assumptions and predictions that had to be made about peoples’ cognitions and behaviours. Albert concluded it could not have been easy to develop and design a technology that adjusted so well to the personal needs and goals of individuals, especially considering their diverse cultures, learning preferences, and their varying levels of starting knowledge, attitudes, and skills.

## Focus of the present thesis

The present thesis envisions an idealistic future such as the one experienced in fiction by Albert. In such a future, self-care support systems have become a cornerstone of treatment for individuals in need of psychological and behavioural support. The thesis leaves fiction behind and, based on a set of scientific studies, addresses questions very similar to those Albert wondered about at the end of his self-care journey. For instance, how can effective self-care support systems be developed? What knowledge about patients' needs is necessary to tailor and personalise their design and implementation? Or more fundamentally, what assumptions and predictions of human behaviour must be made in order to ensure a support system's fit and success? Figure 1.1 illustrates a summary of Albert's idealistic, fictional case. The present thesis aims to explain, throughout its various chapters, why the elements depicted in Figure 1.1 are the key targets for the provision of self-care support.

To begin, the present chapter (**Chapter 1**) introduces what served as a general case of study for this thesis: the alarming burden caused by chronic cardiovascular diseases to health care systems worldwide. Within this context, the chapter provides an overview of key scientific literature, defines key concepts under study, and finally exposes the research questions addressed by the empirical and conceptual investigations composing this thesis.

Figure 1.1. An illustrated summary of how Albert, a fictional patient diagnosed with hypertension, was assisted by a self-care support system in the maintenance, monitoring, and management of his health and well-being.



## BACKGROUND LITERATURE

### Case study: Cardiovascular diseases add an alarming burden to health care systems

Noncommunicable chronic diseases are by far the leading cause of death in the world. Around 41 million people die each year from chronic disorders such as cardiovascular illnesses, cancers, chronic respiratory diseases, or diabetes (World Health Organization, 2020b). Out of those, **cardiovascular diseases** (CVDs) are identified as the major cause for premature death and chronic disability worldwide (Roth et al., 2020). CVDs are a class of different illnesses that relate to the heart or blood vessels, such as hypertension, heart failure, stroke, coronary artery disease, peripheral artery disease, or atrial fibrillation. In 2019, CVDs caused around 17,9 million deaths, representing 32% of all global deaths (World Health Organization, 2020a). Many factors have contributed to this crisis, but it is evident that a major culprit is the unhealthy lifestyles of individuals in modern societies. Unhealthy lifestyles are broadly characterised by physical inactivity, poor nutrition, harmful use of alcohol, and tobacco use (World Health Organization, 2020a). These unhealthy habits contribute to an increase of risk factors such as overweight and obesity, which then relate directly to chronic illnesses and other forms of disability.

The provision of care for patients with CVDs adds an enormous burden to **health care systems** because of the need for continuous management. To exemplify this burden, consider the case of heart failure (Greenhalgh, A'Court, et al., 2017). Individuals recently diagnosed with this condition typically experience profound tiredness, shortness of breath, weight gain, and unpredictable acute somatic crises. These symptoms often reduce their abilities to perform work or even meet the basic demands of daily life. Following diagnosis, a typical treatment for these patients includes a prescription of different medications, according to the severity of their condition. Treatment likely includes a reduction of fluids by diuretics and fluid restriction, which requires careful balancing and frequent clinical monitoring (Greenhalgh, A'Court, et al., 2017). To deliver effective care, heart failure care must ideally be provided by a multidisciplinary team including cardiologists, nurse specialists, and primary care clinicians (Greenhalgh, A'Court, et al., 2017). The communication and coordination between the members of the health care team—as well as their communication and relationship with the patient—will be critical to determine the success of treatment (Greenhalgh, A'Court, et al., 2017).

Worryingly, the burden caused by CVDs is only expected to increase due to an aging population, an increase of risk factors, and the rising prevalence of other chronic conditions (Riegel, Moser, et al., 2017). In consequence, the costs of health care dedicated to patients with CVDs keep increasing. For example, in the United States the estimated costs combining both formal and informal care summed up to a total of 616 billion dollars in 2015, and were expected to increase to 1,2 trillion dollars by 2035 (Dunbar et al., 2018). Positively, deaths from CVDs have been reduced in high-income nations that implemented policies to facilitate the adoption of healthier lifestyles and provision of equitable health care (Roth et al., 2020). However, in middle- and low- income nations these government policies are less frequently in place. This is concerning because, in fact, over three quarters of CVD deaths take place in middle- and low-income countries (World Health Organization, 2020a). Such inequalities can also be observed regionally, for example, in Europe CVDs account for 45% of all deaths but higher rates are found in Eastern European countries (Townsend et al., 2021; Townsend et al., 2016). Due to the alarming and growing crisis caused by CVDs and other (chronic) illnesses, a paradigm shift is needed in the way health care is provided. To alleviate the aforementioned burden, it has been deemed necessary to create health care models that motivate individuals to take an active role and assume their responsibility to learn, develop, and master the necessary skills required for the routinely performance of self-care.



## Self-care for patients with a cardiovascular disease

As previously stated, the promotion of health-promoting and illness-management behaviours has become a cornerstone of treatment for chronic conditions. For instance, patients with a CVD are typically recommended to make key lifestyle changes, including to stop smoking, maintain or reduce their body mass index, engage in frequent physical activity, adhere to a healthy diet, and ensure they maintain normal blood pressure levels by routine (self-)monitoring (Riegel, Moser, et al., 2017). The compliance with these recommendations has been described using multiple terms across scientific literature, the most common being ‘self-regulation’, ‘self-management’, and ‘self-care’.

**Self-regulation** is perhaps the broadest term englobing self-enacted behaviours. Self-regulation has been used to refer to the various processes involved in how individuals set and pursue their goals (Vancouver & Day, 2005). In contrast, the **self-management** term has been more often used in health care settings, although not exclusively. In such contexts, self-management has been used to refer to an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences, as well as the lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002). Because terms such as self-regulation and self-management have been broadly used across multiple settings, **self-care** is the preferred term in recent times (Matarese et al., 2018). Mainly, because self-care is applicable to both healthy and unhealthy states. Moreover, self-care as a concept has benefited from the development and validation of a middle-range theory, originated from the field of nursing (Riegel et al., 2012).

The **middle-range theory of self-care of chronic illness** generally defines self-care as a process whereby individuals and their families maintain health through health-promoting practices and managing illness (Riegel, Moser, et al., 2017). The theory proposes how self-care can be distinguished by three core elements: self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012). **Self-care maintenance** entails the performance of behaviours to improve well-being, preserve health, or to maintain physical and emotional stability (Riegel et al., 2012). The goal of maintenance is to preserve health and prevent symptom exacerbations (Riegel, Jaarsma, et al., 2019). For example, when one performs physical activity with the goal of losing weight (Riegel, Jaarsma, et al., 2019). In turn, **self-care monitoring** refers to the process of routine, vigilant body monitoring, surveillance, or ‘body listening’ (Riegel et al., 2012). The goal of monitoring is recognition that a change has occurred (Riegel, Jaarsma, et al., 2019). For example, to monitor one’s weight in order to identify meaningful changes. Finally, **self-care management** refers to the evaluation of changes in physical and emotional signs or symptoms to determine if action is needed (Riegel et al., 2012). The goal of management is the effective treatment of symptoms (Riegel, Jaarsma, et al., 2019). For example, when one deems it necessary to call the health care providers in response to the worsening of symptoms.

Importantly, the theory offers a view of self-care that is not limited to the physical boundaries of a hospital or clinic. Instead, self-care is understood to be a dynamic process undertaken by individuals while they live their own life and pursue their own goals at their homes and communities. Therefore, self-care also involves the family (e.g., when acting as informal caregivers) and the community (e.g., when facilitating access to health care services) around the individual (Riegel, Moser, et al., 2017). In these naturalistic settings, the demands of living with a chronic condition add up to daily and personal struggles, often leaving individuals with limited motivation and energy to engage in self-care. To quantify this, it is estimated that of the 8760 hours in a year, patients spend only around 10 hours with their health care providers (0.1% of their time) (Riegel, Moser, et al., 2017). Therefore, to support self-care, help must be delivered to individuals while they are at their homes and communities, which demands that supportive interventions fit in and work effectively under that reality (Riegel et al., 2022).

## The promise of eHealth for self-care support

To avoid the worsening of the health care crisis, effective self-care interventions must not only improve the lives of patients but must also try to lessen the burden posed by chronic conditions to health care workers and systems. Because the objective is to inform and guide patients remotely, technology-based interventions are one of the most promising solutions for the provision of self-care support. The use of technology to support health, well-being, and health care is known by the concept of *electronic health* or **eHealth** (van Gemert-Pijnen, Kip, et al., 2018). Technology in this case typically refers to information and communication (digital) technologies such as smartphones, wearable sensors, or internet-enabled health monitoring devices such as blood pressure monitors. These different devices are usually interconnected with each other, constituting together a support system that is tailored to a target population with a specific chronic condition.

The potential of eHealth to support the self-care of patients with chronic conditions has in fact been widely shown and supported by multiple evidence reviews (Greenwood et al., 2017; Hanlon et al., 2017; Kebapci et al., 2020; Kim & Lee, 2017; Villarreal & Berbey-Alvarez, 2020). All in all, the promise of eHealth support rests on the various features that could potentially facilitate the performance of self-care behaviours (Kim & Lee, 2017; Riegel, Moser, et al., 2017). For example, by facilitating self-care monitoring through remote monitoring devices. Similarly, eHealth can also deliver personalised and timely coaching to patients (and their families) with the goal of promoting engagement with self-care maintenance, or communication with care providers to inform self-care management. In the case of CVD, systematic reviews of evidence have shown that eHealth interventions can have a positive impact on the patients' (digital) health literacy (Verweel et al., 2023), their adherence to a healthy diet (Thom et al., 2023) and physical activity (Patel et al., 2023), and on important health outcomes such as reduced mortality, hospitalization, and quality of life (Ding et al., 2023). Adding to this, qualitative studies have also noted how patients recognise and value the perceived benefits of technology-based interventions (Sivakumar et al., 2023). However, in many of these interventions the precise contributions of self-care support is often unclear. In part due to the heterogeneity among interventions, but also the fact that some do not seem to provide any form of self-care support at all (Kallas et al., 2023; Patel et al., 2023; Thom et al., 2023; Verweel et al., 2023). In any case, recent studies continue to endorse the promise of eHealth for CVD, but keep noting the challenges both for implementation, such as low adoption (Son & Kim, 2023), and for evaluation, such as the inconsistency of outcome measures (Patel et al., 2023).

All in all, while the promise is high, the development, implementation, and evaluation of eHealth comes across many challenges and pitfalls (Michie et al., 2017). In general, some of the most remarkable obstacles have been related to the *pace and efficiency* of development (e.g., because technological innovations arrive faster than scientific validations), the *engagement* with digital interventions (e.g., because many end users do not accept these modes of delivery), the use of *theory* (e.g., because there is a lack of theoretical clarity in published literature), the evaluation of *effectiveness* (e.g., because interventions are multi-component and therefore complex to assess), the evaluation of *cost-effectiveness* (e.g., because of a lack of techniques to evaluate digital innovations), or the surrounding *regulations, including ethics and information governance* (e.g., because of a lack of quality standards and regulatory processes) (Michie et al., 2017). The aforementioned obstacles have also been reported repeatedly in the literature focused on eHealth, CVD, and self-care (Greenhalgh, A'Court, et al., 2017; Hanlon et al., 2017; Kim & Lee, 2017; Villarreal & Berbey-Alvarez, 2020). For instance, using again heart failure as an example, a thorough review found that **telehealth** applications, a form of eHealth focused on remote communication and monitoring, might be typically based on standards and values that come into conflict with those actually held by patients and health care professionals (Greenhalgh, A'Court, et al., 2017).

In the case of self-care promotion, reviewers observed a striking tension between the assumption many interventions make on how patients are activated, empowered, self-managing individuals, versus the reality of frightened and bewildered persons that are actually reported in qualitative studies (Greenhalgh, A'Court, et al., 2017). In light of this, it can be argued that eHealth research and development requires a proper and thorough understanding of how self-care impacts individuals (e.g., their motivation), communities (e.g., facilitators and barriers), and societies (e.g., new or adjusted work processes). An advanced comprehension is also necessary if the goal is to realise the promise of technology for self-care support. The need to support self-care of chronic conditions is at its roots a behavioural problem, but it crosses other key areas such as health care, policy-making, and technology-driven innovations. As such, multiple fields of science, with their theories, models, and evidence-based practices, should be positioned at the forefront of eHealth research and development.

## **The importance of theory-based research and development of interventions**

Theoretical thinking is a fundamental practice in scientific research (Hagger et al., 2020). Theories can contribute to the accumulation, curation, and dissemination of knowledge about what works, when, and how (Hekler et al., 2013; Hekler et al., 2016; Moller et al., 2017; Riley et al., 2011). Consequently, the use of theory plays a fundamental role in the development of behavioural, evidence-based interventions. However, the usefulness of theory-based interventions in real-world settings is still under debate (Hagger & Weed, 2019). Therefore, more transparency, clarity, and evidence seems to be needed about methods and guidelines for the integration of scientific knowledge and theories in the research and development of behavioural interventions.

The **key elements or features of interventions** are often of a multidimensional nature. They can refer to psychological, behavioural, technological, or contextual factors. In that sense, psychological theories are useful in the specification of constructs and mechanisms that are important targets or mediators for change (Michie et al., 2017; Moller et al., 2017). In the case of self-care, the aforementioned middle-range self-care theory offers a comprehensive understanding, as it puts forward multiple assumptions and propositions that outline self-care as a complex, dynamic, and subjective decision-making process (Riegel et al., 2012). The assumptions and propositions of this theory have been extensively studied and validated in the context of CVDs and other chronic conditions (Fivecoat et al., 2018; Jaarsma et al., 2017; Lee & Riegel, 2018; Osokpo & Riegel, 2019; Riegel, Dickson, et al., 2017; Riegel, Moser, et al., 2017). Nevertheless, there are still questions left to answer and the theory continues to be refined (Jaarsma et al., 2020; Riegel, Dunbar, et al., 2019). For instance, with more explicit assumptions about how symptoms can influence self-care (e.g., symptoms can sometimes motivate self-care maintenance) (Riegel, Jaarsma, et al., 2019). Case in point, also for self-care one of the most important tasks on the research agenda is the need to advance practical knowledge on how to apply a complex, theory-based understanding in the development of supportive interventions (Jaarsma et al., 2020; Riegel, Dunbar, et al., 2019). The premise is that a comprehensive understanding of self-care will help developers and designers create more effective interventions.

In the specific case of eHealth interventions, a similar call has been made to improve their characterisation in scientific works, such as by adding more detail to the reported description of key intervention features, modes of delivery, and contexts of use (Michie et al., 2017). Resting on solid theoretical foundations, eHealth could offer new opportunities for the testing of theories and techniques for behaviour change (Moller et al., 2017). For example, by collecting large amounts of data in real-time and unobtrusively, thus facilitating data-driven analyses of behavioural change processes and their outcomes. Nonetheless, in the research and development of eHealth, understanding self-care as a complex problem to tackle is only one part of the process. What is also needed is a proper understanding on how technology can function, fit, and be most effective as a supportive solution.

What features or characteristics of technology are most effective? Or more precisely, what design strategies work best, for whom, and under what circumstances? Positively, in this area there are already investigations that have resulted in models and frameworks that seek to guide or inform eHealth development and design. For example, the **persuasive systems design** model offers a list of guiding principles that aim to *persuade* users to reach their personal goals by means of digital behaviour change support systems (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjuma, 2009). This model has been used in the study and design of eHealth for the support of many chronic conditions, including CVDs, chronic obstructive pulmonary disease, and diabetes (Karppinen et al., 2016; Oyebode et al., 2020; Wais-Zechmann et al., 2018). For instance, a study found that design principles such as facilitating self-monitoring, or providing suggestions, reminders, praise, or rewards can persuade individuals to have healthier diets (Oyebode et al., 2020).

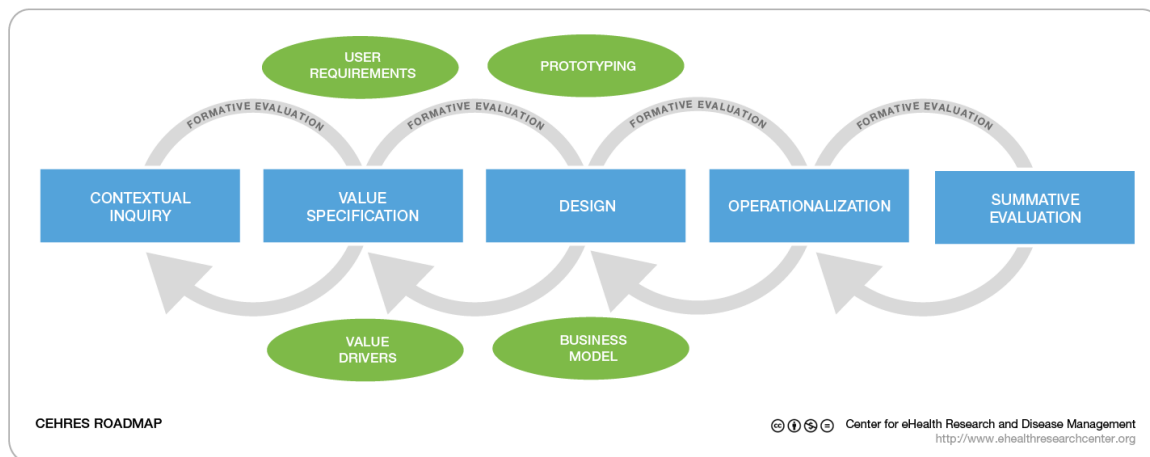
## Integrating multidisciplinary theories in a holistic approach to eHealth

The prevalence of a health care crisis and the proposal of eHealth as a solution is an example of a wicked problem because of all the factors, known and unknown, that must come together in order for an intervention to succeed (Mohan, 2021). The factors can range from much-needed ‘micro’ changes in individual cognitions and behaviours, to ‘macro’ structural modifications in work processes and policies of health care systems (Covvey, 2018). Because of this, eHealth research and development should ideally be conducted from the perspective of multiple scientific disciplines (Pagliari, 2007). However, the need for a multidisciplinary perspective often unveils the challenge of the accumulation and translation of knowledge within and across disciplines, as they tend to speak different ‘languages’ or hold different stakes. For example, applied fields might be interested in innovation rather than the accumulation or validation of scientific knowledge. In practice, multidisciplinary teams might also struggle with the distribution and management of tasks and responsibilities, due to the different backgrounds, perspectives, and skills of their members. Consider, for instance, how eHealth must partake from the assessment or recommended treatment of a health care provider (informed by the most updated evidence from *medical sciences*), then move into the selection of behavioural or cognition change strategies (operationalised with refined knowledge from *psychology*), to finally deliver support in a salient, persuasive way to the patient (guided by principles from the field of *human-technology interaction*).

To tackle these remarkable challenges, a holistic, multidisciplinary approach is recommended for the development, implementation, and evaluation of eHealth. For instance, the CeHRes roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011) illustrated in Figure 1.2 is a guideline for the holistic eHealth development that integrates multiple frameworks and is grounded in persuasive technology design (van Gemert-Pijnen, Kelders, et al., 2018), human-centred design (Burns, 2018), and business modelling (Nieuwenhuis, 2018). The term **holistic** refers to the importance of the whole and the interdependence of its parts (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). Fundamentally, the CeHRes roadmap proposes five key principles:

1. eHealth development is a participatory development process.
2. eHealth development creates new infrastructures for improving health care, health, and well-being.
3. eHealth development is intertwined with implementation.
4. eHealth development is coupled with persuasive design.
5. eHealth development requires continuous evaluation cycles.

Figure 1.2. The CeHRes roadmap for holistic development, implementation, and evaluation of eHealth (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011).

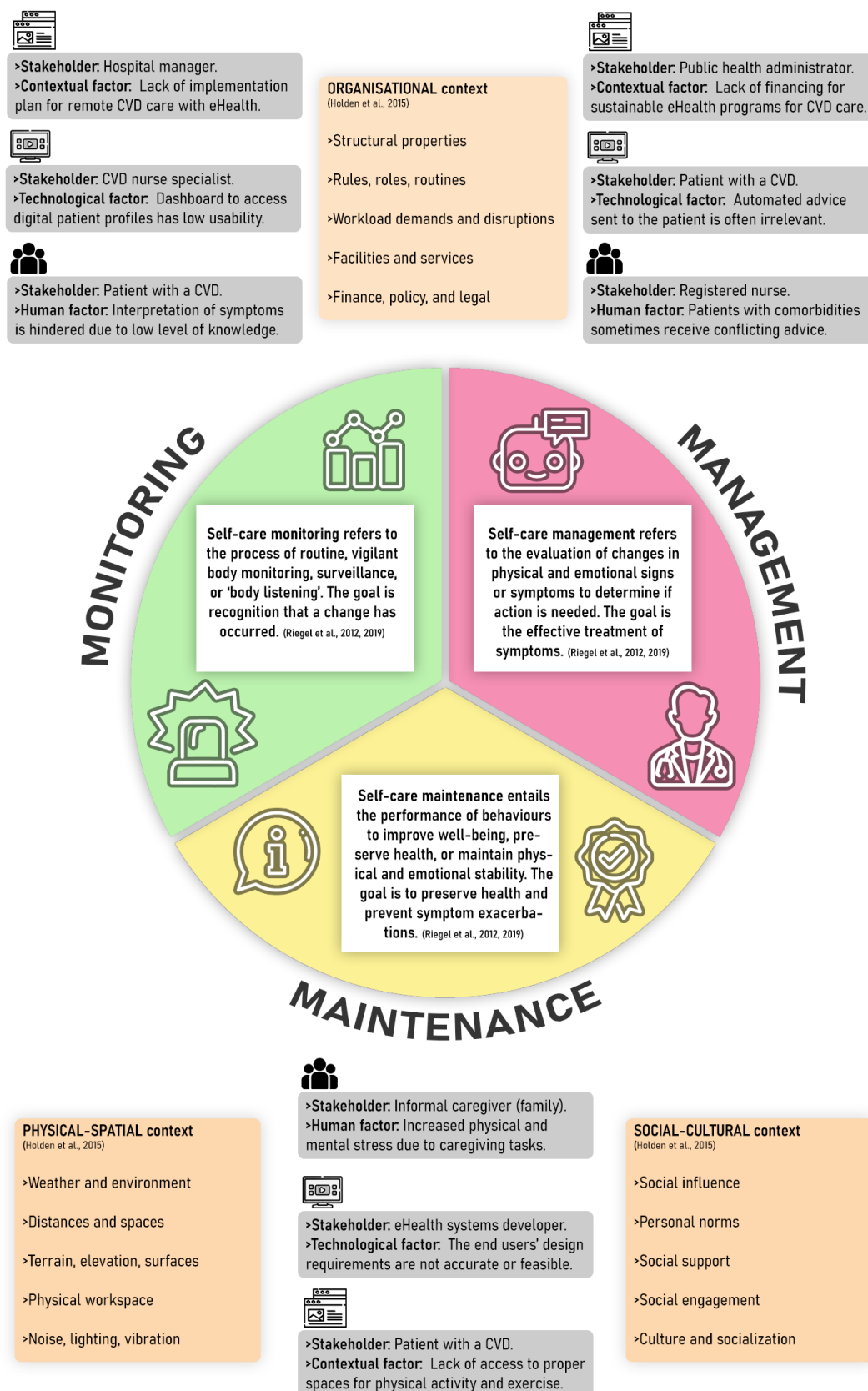


In practical terms, the principles of the roadmap promote that the interaction and reciprocal influence between contextual, technological, and human factors should be emphasised early and often during eHealth development and design, and be informed by multidisciplinary perspectives (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). In consequence, this requirement demands the involvement of multiple stakeholders, who come from different but relevant settings and contexts, and who might have varying stakes and sometimes conflicting roles or interests in solving the problem or delivering a solution. Thus, the accumulated knowledge and practical perspectives of different stakeholders must be analysed and integrated. Through a holistic approach, the end goal of research and development is to account for all of the key factors that will most likely ensure the uptake and success of eHealth.

Returning to the case at hand, at the crossroads of self-care, CVD, and eHealth, undertaking a holistic approach seems to be more than necessary. As has been reiterated, the opportunities offered by new technologies open up doors in the way self-care support can be delivered to individuals. In order to be most effective, self-care support must be context-aware and dynamic. Therefore, there is a shift in the way theories and scientific knowledge have been and will be used to design and guide behavioural interventions. Figure 1.3 attempts to illustrate the complex reality of self-care support through eHealth, recalling the fictional case of Albert (a patient with a CVD). The figure uses a macro perspective from Holden et al. (2015) to display relevant contexts in a patient's work system. At such a macro level, key stakeholders and contextual factors can already be identified. For example, within the organisational context the access and effectiveness of remote self-care support might vary. It could be that no program exists at all to support the self-care of patients at their home and communities. Adding to that, Figure 1.3 also displays the self-care theory of Riegel et al. (2012) at the centre of a micro perspective which addresses the specific behaviours and their goals that have to take place to reach the outcome of health maintenance and illness management.

Our fictional case, Albert, does not need to know about all of the elements depicted in Figure 1.3. For him, support should be perceived as timely, effective, and as simple as possible. Who really should think about the elements of such a figure are the researchers, designers, developers, implementers, and policy-makers of supportive interventions. How much of that has actually occurred and where to go from there will be thoroughly discussed in the following chapters of the present thesis.

Figure 1.3. A holistic view on the complex reality of eHealth CVD self-care support, which must consider the interdependency between multidimensional factors, contextual influences, and the diverse perspectives of key stakeholders.



## AIM OF THE THESIS

The present thesis undertakes a holistic approach to the study of eHealth research and development under the scope of self-care support for CVDs. In other words, the thesis collects and integrates the views of different stakeholders, who play a key role in the successful provision of self-care support through technology (e.g., cardiologists, technology designers, and patients themselves). The overarching aim of the thesis is to accumulate and refine the scientific knowledge on the matter, and by those means to promote improvement for the research and development practices of eHealth technologies. Each element of the present thesis developed and built upon the findings of the previous one.

The thesis begins with a broad, in-depth view on the state-of-the-art of theory-based development of eHealth interventions designed for CVD self-care support. What follows then are more focused efforts attempting to bridge some of the observed gaps. Especially, the thesis investigates how theory can be used to tackle some of the most remarkable challenges reported to hinder the success of eHealth interventions. In broad strokes, the objectives of the thesis are to (i) revise the contemporary use of frameworks, models, and theories for research and development, (ii) identify promising theory-based approaches to eHealth design, and (iii) propose eHealth features that are based on self-care theory and technology design models. Under the context of eHealth, self-care, and CVD, the research questions addressed by this thesis are:

1. What and how have theories, models, or frameworks been used to develop, implement, or evaluate eHealth interventions?
2. What are some of the most promising eHealth (persuasive) design strategies that can be tailored to the theory-based, key elements of self-care?
3. What eHealth design features honour or can be connected to the values of patients (i.e., their health-related ideals and interests)?
4. What and how can theory-based eHealth design features, or combinations thereof, meet the values of patients in order to best support their self-care?

## OUTLINE OF THE THESIS

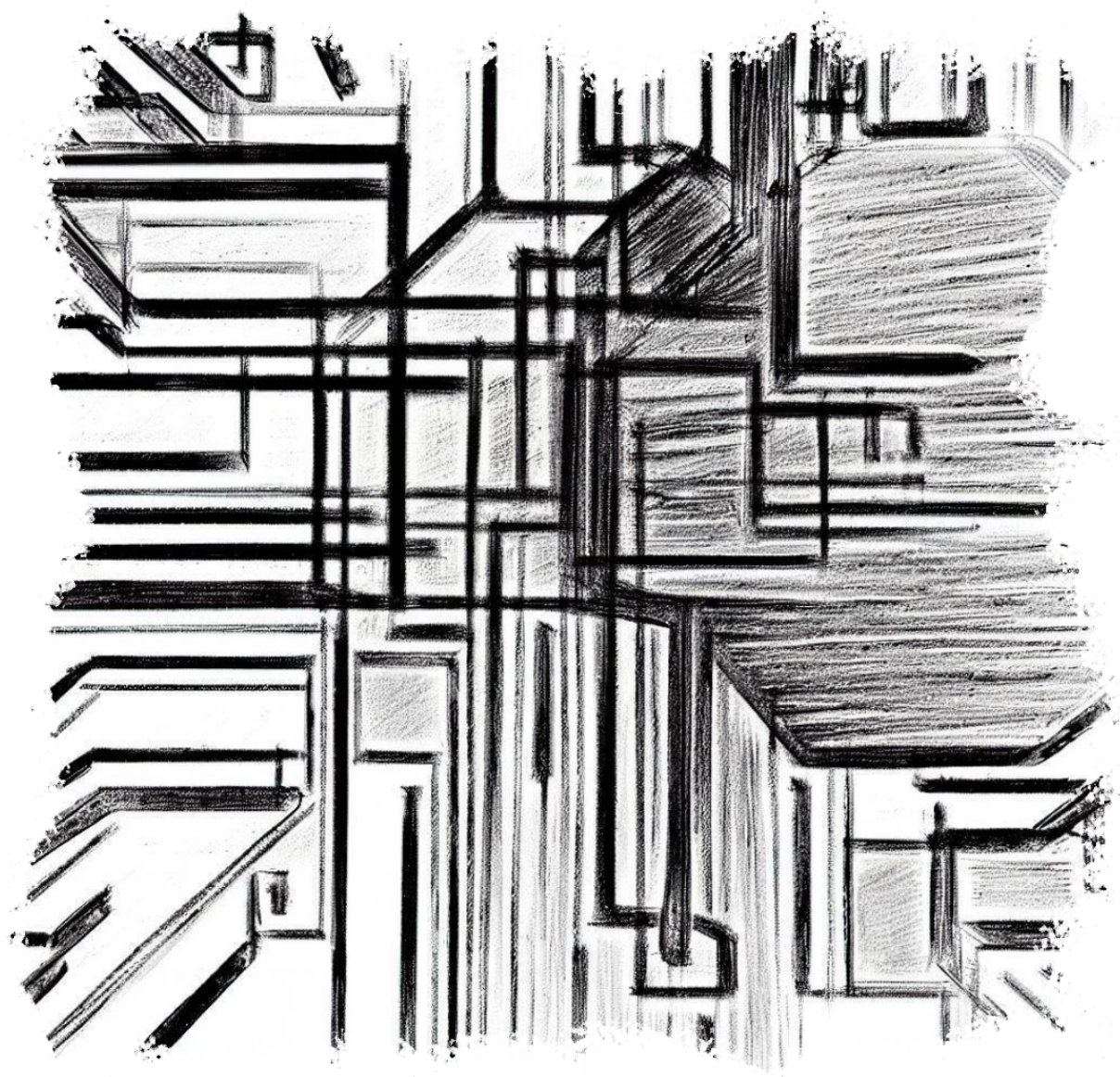
The present thesis is divided in two main parts, each composed by multiple chapters. Each chapter relates to at least one of the aforementioned research questions. The first part of the thesis presents two studies that focused on the *revision of theory- and expert-based knowledge* within the scope of eHealth applications for CVD self-care. **Chapter 2** describes in detail the methodological approach of a meta-ethnographic systematic literature review tackling the first research question. The chapter presents different methods that were used by the review to identify, extract, and analyse the descriptions of eHealth interventions found in published reports. **Chapter 3** presents the results of the literature review, namely on the theories, models, and frameworks from different scientific disciplines that had informed or guided eHealth research or development under the scope of CVD self-care support. **Chapter 4** describes an expert-centred study addressing the second research question. This study went beyond what was found in published literature by directly involving eHealth researchers and developers in an online vignette survey experiment about the tailoring of eHealth design. The second part of the thesis presents two studies that explored the *design and proposition of theory-based and value sensitive eHealth features*. **Chapter 5** presents a content analysis study that directly addresses the third research question. This study took the first steps towards a value sensitive approach to eHealth design for CVD self-care. Namely, by means of hypothetically connecting the design features of existing eHealth technologies with a set of empirically-validated values of patients with a CVD.

Next up, **Chapter 6** describes a study that, through theoretical and design work, directly addresses the fourth research question. This study proposes and discusses the potential of specific theory-based and value sensitive eHealth design features. In this study, mock-ups and a low-fidelity prototype of eHealth design features were developed and aligned with a proposed theoretical foundation. Finally, **Chapter 7** contains a general discussion of the different findings and outcomes of the present thesis. It summarises the findings of the research and discusses their implications, deriving recommendations for future research and development of eHealth. This chapter also notes the strengths and limitations of this thesis and delivers a reflection on how to move forward towards the realisation of more and better theory-based research and development of eHealth for self-care.





# **PART 1: REVISION OF THEORY- AND EXPERT-BASED KNOWLEDGE**



# Chapter 2

## Protocol for a meta-ethnography review of frameworks, models, and theories used in eHealth research and development aiming to support self-management of cardiovascular diseases

**This chapter is based on the following publications:**

- Cruz-Martínez, R. R., Noort, P. D., Asbjørnsen, R. A., van Niekerk, J. M., Wentzel, J., Sanderman, R., & van Gemert-Pijnen, L. (2019). Frameworks, Models, and Theories Used in Electronic Health Research and Development to Support Self-Management of Cardiovascular Diseases Through Remote Monitoring Technologies: Protocol for a Meta-ethnography Review [Protocol]. *JMIR Res Protoc*, 8(7), e13334. doi:10.2196/13334.
- Cruz-Martínez, R. R., Wentzel, J., Asbjørnsen, R. A., Noort, P. D., van Niekerk, J. M., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (2020). Supporting Self-Management of Cardiovascular Diseases Through Remote Monitoring Technologies: Meta-ethnography Review of Frameworks, Models, and Theories Used in Research and Development [Review]. *J Med Internet Res*, 22(5), e16157. doi:10.2196/16157.

## ABSTRACT

**Background:** Electronic health (eHealth) is a multidisciplinary and rapidly evolving field, and thus requires research focused on knowledge accumulation, curation, and translation. A holistic understanding of eHealth projects, interventions, and technologies is required to bridge the multidisciplinary gap formed by the wide range of aims and approaches taken by the various disciplines involved. This protocol used as a case study the global health care crisis caused by the prevalence of cardiovascular diseases, and the promise of eHealth to provide novel solutions that improve the efficiency and reach of support for patients where they most need it: their homes and communities.

**Objective:** The protocol aimed to facilitate a holistic interpretation of eHealth projects, interventions, and technologies under a specific scope. The case under study was the self-care support provided to patients with a cardiovascular disease in their natural setting, thus priming the use of remote monitoring and coaching technologies. The final aim was to synthesize the operationalisation of frameworks, models, and theories applied to the research and development process of eHealth.

**Methods:** The protocol adopted Noblit and Hare's meta-ethnography approach to review and synthesize researchers' and practitioners' reports on how they applied frameworks, models, and theories for the development of eHealth projects, interventions, or technologies. A systematic search for literature was planned in 7 databases: Scopus, Web of Science, EMBASE, CINAHL, PsycINFO, ACM Digital Library, and the Cochrane Library. Next, selected studies were to be thoroughly read and coded to extract both raw and contextual data for the synthesis. The relation of the studies would then be determined according to the elements of the frameworks, models, or theories the studies applied. A translation of these elements between each other would take place, before finally attempting to synthesize the findings into holistic principles for eHealth research and development.

**Results:** The protocol was preregistered and subsequently published as a registered report. At the point of its publication, the search strategy had been completed, data extraction was almost finalised, and the first synthesis approaches were underway. The search yielded 1224 citations and, after applying the selection criteria, 17 articles remained. Various insights and lessons learned about the analytical process are hereby reported, such as the remarkable challenge of identifying and specifying the key ingredients of eHealth interventions with the intent of providing a holistic view on the phenomena they tackle, their proposed solutions, and underlying rationale for development.

**Conclusions:** This protocol was important because it aimed to create a holistic understanding of a multidisciplinary and complex topic. The value of meta-ethnography in contrast to other systematic review methods is that its synthesis approach seeks to generate a new understanding of a topic, while preserving the social and theoretical contexts in which findings emerge. In that regard, the preliminary results showed promised in the usefulness of this method to bridge the multidisciplinary gap of eHealth research and development, and consequently to inform and advance the importance of holistic examinations of projects, interventions, and technologies. However, in the process remarkable challenges were found that should be kept in mind for future reviews of this nature.

## INTRODUCTION

### A vision of self-care: Part 2

The introduction of the present thesis envisioned an idealistic future of self-care support through digital technologies. The fictional case of Albert uncovered some questions to pursue, such as how to effectively develop self-care support systems or what knowledge about patients' needs is necessary to consider for their design. Importantly, the introduction proposed that to answer such complex questions a *holistic vision* was necessary. Figure 1.3 illustrated that, for the case at hand, multiple factors on various dimensions could be considered, including macro-level factors such as the physical-spatial, social-cultural, and organisational contexts. This figure is, in fact, already informed by the knowledge collected and revised by the studies described in the following chapters, the procedures of a systematic literature review. For instance, Figure 1.3 already integrates a macro ergonomic framework that was found through that review (more to be said in **Chapter 3**). At the same time, Figure 1.3 integrates a behavioural theory of self-care, which was, remarkably, not found through the aforementioned review. It can be noted, for instance, that in the present chapter the term *self-management* is used over *self-care*, as at this point the latter had not yet been integrated in the research process of the present thesis. Therefore, a first important gap was identified, one that had to be consequently addressed in later stages. It all started, however, with a plan to collect as much relevant knowledge as possible, with the goal of binding it all together under a holistic vision.

### Focus of this chapter

The present chapter details a systematic literature review protocol aiming to take the first steps towards a holistic view on the topic of CVD self-care support through eHealth. Under this context, the protocol details a study plan to tackle the question: *what and how have theories, models, or frameworks been used to develop, implement, or evaluate eHealth interventions?* As will be described below, searching and analysing the use of multidisciplinary scientific theories and models, or eHealth development frameworks was considered as a systematic way to structure a view on the complex topic at hand. Therefore, the present chapter focuses on the underlying methods and tools that aimed to synthesise multiple perspectives and contexts of relevance. In practice, the protocol sought to identify multidimensional factors (ideally) based on scientific theories, models, and frameworks, as described in published reports of existing eHealth projects, interventions, and technologies.

## BACKGROUND LITERATURE

### Holistic electronic health research and development

Electronic health (eHealth) can be defined as the use of technology to support health, well-being, and health care (van Gemert-Pijnen, Kip, et al., 2018). As a field of science and innovation, eHealth is characterised by its multidisciplinary and rapidly evolving nature. In eHealth development, various disciplines such as computer, health, and behavioural sciences and design are involved. Ideally, researchers and practitioners are frequently engaged in iterative phases of eHealth development, implementation, or evaluation. The knowledge and technology generated by such processes is often grounded in a wide and overwhelming variety of frameworks, models, theories, methods, or guidelines. Because of this, accumulation, curation, and translation of the output of research and development has become a challenge and thus an important target for research itself (Michie et al., 2017).

Research has also made it clear that development of eHealth entails several challenges, such as maintaining the pace and efficiency of development cycles, promoting engagement, and applying a theoretical foundation (Michie et al., 2017). In practical terms, multidisciplinary teams (health care providers, software developers, etc.) are confronted with the need to determine the best approach for a project very early in the process. They are required to define the aims, the methods, and the overarching process that will guide development. Thus, frameworks, models, or theories not only facilitate the task, but also can increase the success of eHealth. Success in research and development can be determined by how much an intervention improves health and well-being (effectiveness), but also by providing explanations and advancing scientific knowledge on ‘what works for whom in what settings to change what behaviours, and how?’ (Michie et al., 2017).

A holistic approach that combines multidisciplinary knowledge with novel methods and techniques is recommended to tackle the various development challenges and to ensure the effectiveness and efficacy of eHealth (Kip & van Gemert-Pijnen, 2018). The term holistic refers to the importance of the whole and the interdependence of its parts (Kip & van Gemert-Pijnen, 2018). In other words, when developing, implementing, or evaluating eHealth, fragmented analysis should be avoided, and each part, with its reciprocal influence on other parts, should be emphasised (e.g., across contextual, technological, and human levels) (van Gemert-Pijnen et al., 2011). The usefulness of taking a holistic approach was recently noted during the development of a framework to understand the non adoption, abandonment, scale-up, spread, and sustainability of eHealth (Greenhalgh, Wherton, et al., 2017). In the development process, a holistic view was a helpful starting point to analyse and understand data and theory, and to integrate other frameworks (Greenhalgh, Wherton, et al., 2017). Therefore, we propose that both researchers and practitioners should recognise the value of making a conscious decision to strive for optimal holism, or at least to combine the most suitable, validated, and useful guidelines that reflect on their decision. Health care is a complex and adaptive system, and this makes eHealth a potential source for innovative solutions to some of society’s most alarming health care problems (Covvey, 2018). The Center for eHealth Research (CeHRes) roadmap is an example of a holistic approach built on reviews of previous frameworks and on empirical research that has been extensively employed for cases such as chronic diseases, antimicrobial stewardship programs (Beerlage-de Jong et al., 2017), and others (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). Thus, such a guideline offers researchers and developers several tools and methods to integrate into a project, in order to monitor the many different stakes and processes that are at play when tackling a certain health issue.

## **Case study: Self-management of cardiovascular diseases through electronic health monitoring technology**

Cardiovascular diseases (CVDs) constitute a global health care crisis due to their high prevalence, long duration, and slow progression (Roth et al., 2017; World Health Organization, 2014). A key factor to lessen the burden of CVDs is to support the patients' abilities to self-manage their own condition (Riegel, Moser, et al., 2017). Self-management refers to an individual's ability to manage the symptoms, treatment, and physical and psychosocial consequences, as well as the lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002). For instance, individuals living with CVD are recommended to manage their blood pressure, control their cholesterol, reduce their blood sugar levels, become physically active, eat better, lose weight, and stop smoking (Riegel, Moser, et al., 2017). An important aspect of these recommendations is that self-management has to be done outside the clinical setting, as patients have to integrate these intensive and timely activities into their daily lives. In fact, one estimate is that of the 8760 hours in a year, patients are spending only around 10 hours (0.1%) with their health care providers (Riegel, Moser, et al., 2017). To ensure that patients are seen by or under the supervision of their health care providers when they do not have face-to-face contact, remote self-monitoring is crucial. Remote self-monitoring can be defined as the process of observing changes in signs and symptoms (Riegel et al., 2012), a behaviour that is primarily conducted by the patient but made visible to the health care providers via technology. It supports safety because the health care team can check and be alerted in a timely manner in case of potentially dangerous changes in the patient's health status. Also, patients often feel more comfortable being able to return to their daily lives with the knowledge that important measurements are being monitored by their health care providers (Middlemass et al., 2017). Because of this, remote self-monitoring technologies have become a vital part, almost a prerequisite, of home- and community-based care. In this light, recent metareviews have shown that technology-supported interventions can be at least as effective as usual care in supporting self-management of chronic conditions (Greenwood et al., 2017; Hanlon et al., 2017).

Despite promising results, the accumulation, curation, and translation of knowledge is also challenging when research in eHealth technology (computer science, design), CVDs (health sciences), and self-management (behavioural sciences) intersects. This leaves a gap that has been observed by previous reviews. The multidisciplinary gap is formed by the usage of different terms and concepts to explain the same phenomena (Hekler et al., 2013), and by a lack of clarity or standardization in reporting the key ingredients of an intervention (Hoffmann et al., 2014). To exemplify from the behavioural science perspective, a review of eHealth physical activity interventions for adults with CVDs found that most studies did not sufficiently detail the operationalisation of behaviour change techniques as key components of their intervention (Duff et al., 2017). Likewise, another review of similar interventions showed that only half of the studies had named a theory or model as the foundation (Winter et al., 2016).

The literature often provides lessons learned on a case-by-case basis in eHealth research and development to support self-management (Greenwood et al., 2017; Hanlon et al., 2017; Jacelon et al., 2016; Kim & Lee, 2017). For example, the most common recommendations reflect the importance of applying technology integration models and a theoretical foundation. Even though this is valuable knowledge, testing should also include process evaluation for intermediate outcomes (mechanisms, mediators), derived ideally from the aforementioned theoretical background. Developers should also provide a sufficiently detailed description of the evidence-based components of the intervention (e.g., behaviour change techniques). Nevertheless, from these detached recommendations it is still unclear which overall development approaches have been applied in eHealth research to support self-management of CVD, and what their unique contributions have been.












Even more so, the extent to which holistic principles have been considered is unknown. The uncertainty is highlighted because these interventions are coupled with rapidly evolving technologies such as body sensors, personalisation algorithms, and automatic feedback systems (Kim & Lee, 2017) that mark a significant shift from the traditional telephone or face-to-face delivery. In sum, much is known about development processes in eHealth, based on the many examples that exist. What is lacking at this point is an overarching understanding that relates the findings of such studies across the phases of development and across disciplines.

## Aim and focus

The aim of this review is to facilitate a holistic interpretation of eHealth projects aimed at self-management support of CVDs in a natural setting of the patients. We intend to identify the frameworks, models, and theories applied in these projects and synthesize how their elements were applied to research and development. This seeks to fill in the gap of knowledge translation and dissemination resulting from the multidisciplinary of eHealth. Figure 2.1 illustrates an initial framework of proposed interdependent elements for a holistic interpretation in terms of the context, the technology, and the human level.

Figure 2.1. Holistic interpretation of eHealth monitoring technology to support self-management of CVD. As reported by (Cruz-Martínez et al., 2019).

<b>CONTEXT</b>	 <b>CVD</b>	 <b>Lifestyle changes</b>	 <b>Home or community</b>
<b>TECHNOLOGY</b>	 <b>Monitoring technologies</b>	 <b>Real-time data</b>	 <b>Feedback to patient</b>
<b>HUMAN</b>	 <b>Mechanisms or Parameters</b>	 <b>Self-management</b>	 <b>Health outcomes</b>

As Figure 2.1 shows, the context of the review is broad. It includes patients with any particular CVD who are faced with lifestyle changes inherent to their disease and who have to cope with them predominantly at home or in their communities (not in a clinical setting). In terms of technology, we have narrowed the review aim down to the use of remote monitoring technologies such as blood pressure monitors, weigh scales, or wearables, which collect real-time data and provide feedback to the patient as a key component. This scope allows for the collection of specific knowledge on self-management support in the context of remote care.

Although excluding interventions that did not use monitoring technology could be seen as a limitation, we hold that any of these applications could, and more importantly should, still be adapted to remote care; therefore, we expect our findings to showcase the missing potential. Finally, in terms of the human element, the aim is specific but also difficult to identify in published studies. The human element is represented by theory-based ingredients such as profiling or tailoring mechanisms and parameters of effectiveness to target patients' behaviour change with the intention to improve health.

The review is focused on the following research questions. First, what frameworks, models, or theories have been used to develop, implement, or evaluate eHealth interventions to support self-management of patients with CVDs outside the clinical setting? Second, how do these models address the 5 principles of a holistic eHealth research and development approach (as depicted by the CeHRes roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011)? Third, what parameters of effectiveness, profiling mechanisms, and target outcomes are used in these models to address heterogeneity between patients with CVD?

### Phase 1: Selecting meta-ethnography

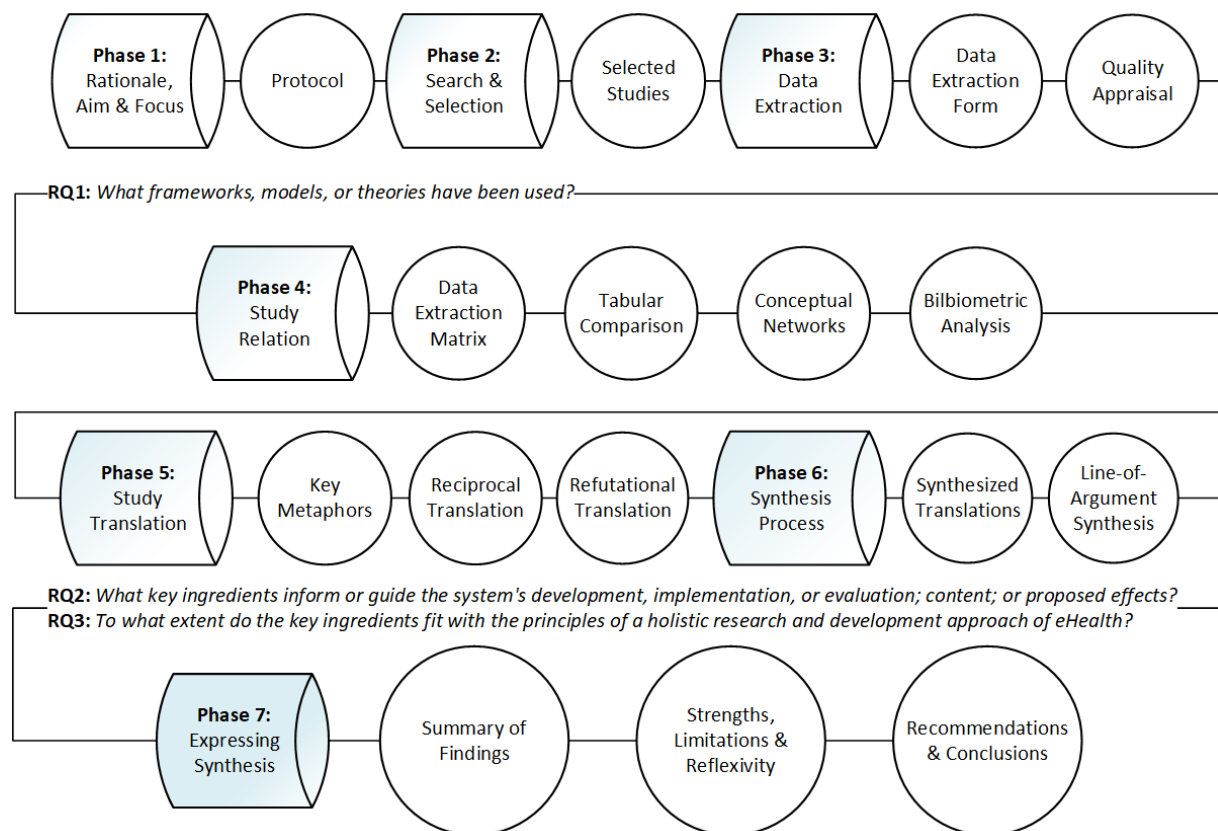
Study reports of how researchers and practitioners applied frameworks, models, and theories are the qualitative data of interest for this review, which is thus based on meta-ethnography, a qualitative synthesis approach developed by Noblit and Hare (Noblit & Hare, 1988). Meta-ethnography is an interpretative approach to qualitative evidence synthesis that seeks to generate a new understanding of a topic, while preserving the social and theoretical contexts in which findings emerge (Booth, Sutton, et al., 2016). Noblit and Hare outlined meta-ethnography as a 7-stage process that compares and analyses texts, creates new interpretations in the process, and by doing this strives to build a holistic interpretation (Noblit & Hare, 1988). In practice, it mainly involves open coding to identify emergent categories and then constant comparison of key metaphors across studies. **Key metaphors** can be phrases, ideas, concepts, perspectives, organisers, or themes revealed by a study (Noblit & Hare, 1988). Both the guidelines on choosing qualitative evidence synthesis methods (Booth, Noyes, et al., 2016) and the support of an information specialist for social sciences (PDN) led us to choose meta-ethnography over other approaches (e.g., grounded theory or critical interpretative synthesis). We preferred meta-ethnography because it includes a synthesis approach matching the interest of the review to 'move beyond description to a more interpretative examination of [themes,] their relationships and indeed any inherent contradictions' (pg 48) (Booth, Sutton, et al., 2016). More importantly, meta-ethnography is by its very essence a technique used to translate concepts across individual studies (Booth, Sutton, et al., 2016), which is a perfect fit for our aim to synthesize the elements of frameworks, model, or theories. Our review is also informed by meta-ethnographies in related topics or with similar aims (Campbell et al., 2011; Erasmus, 2014; Morton et al., 2017; Siau & Long, 2005; Toye et al., 2013).

## METHODS

### Overview of phases

Figure 2.2 visualises the phases and the key output of this review in relation to the research questions. Phase 1 generated the published protocol (Cruz-Martínez et al., 2019). Phases 2 and 3 sought to answer the first research question regarding the identification of frameworks, models, and theories (Cruz-Martínez et al., 2019). Phases 4 to 6 operationalised an answer to the second and third research questions through an interpretative characterisation of the key ingredients of frameworks, models, and theories (Cruz-Martínez et al., 2019). The present article adheres to the recently developed Meta-Ethnography Reporting Guidance (eMERGe) (France, Cunningham, et al., 2019).

Figure 2.2. Phases and key output of the meta-ethnography review. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review. RQ: research question.



## Phase 2: Searching and selecting studies

### Search strategy

In phase 2, an exhaustive search was conducted to find published studies of interest. The search consisted of (1) a systematic database literature search, followed by (2) backward and forward reference tracking from selected articles. The databases searched were Scopus, Web of Science, EMBASE, the CINAHL, PsycINFO, the ACM Digital Library, and the Cochrane Library. Web of Science and Scopus were chosen based on their coverage of multidisciplinary fields of science, including technology, medicine, and social sciences. Both of these also cover MEDLINE, which is a database of interest due to its focus on the life sciences and biomedical literature. EMBASE and CINAHL were selected because of their discipline-specific literature on biomedicine and nursing, respectively. PsycINFO was included to ensure we would miss no studies from the behavioural field. Likewise, ACM Digital Library was included due to its focus on computer science. The Cochrane Library covers medicine and other health care specialties, including systematic reviews. The search was adapted to the features of each database. In general, the main search limiters were the time span (2008-2018) and the language (English, Dutch, or Spanish) of publication. The time span of 10 years was determined by taking into consideration the growth of the research field and the technological developments of interest. When possible, the search was limited to articles that included an abstract and that are peer reviewed. The search consisted of multiple key terms. Terms were chosen based on the existing literature, as well as valuable synonyms of interest, and were refined through pilot searches. Related terms and synonyms were identified by using the Medical Subject Headings and EMBASE subject headings databases.

The result was a very structured query consisting of 4 sets, aiming for results about frameworks, models, and theories (set 1), eHealth interventions (set 2), self-management (set 3), and CVDs (set 4). Given the above, the probability of missing relevant articles after the systematic search, followed by the reference tracking and the screening procedure, was deemed to be negligible. This strategy intended to identify articles and studies that add information about overarching eHealth projects within the scope of our review. A project was defined as the overarching research project, usually identified by the name of the eHealth technology and integrating several research goals or development aims. A project could consist of one or more studies with specific aims (e.g., usability or effectiveness). Finally, a study can be published in one or more articles (e.g., protocol and results). The database search and reference tracking were conducted by the main reviewer (RCM). The search results were uploaded to EndNote X8 (Clarivate Analytics) and duplicates were eliminated.

## Study selection

The selection was performed by uploading the citations to the Covidence Web-based software platform (Veritas Health Innovation Ltd). Records were screened by 2 reviewers, first by title and abstract, and then by full text. The main reviewer conducted the screening throughout all stages. A co-reviewer (RAA) screened 15% of the records at each stage, by default order of appearance in Covidence (alphabetically by first author's name). Discrepancies between reviewers were discussed and resolved at every stage.

The selection criteria were structured in a similar way to the PICO framework to facilitate decision-making in the selection of relevant studies (Booth et al., 2019). That is, to ensure that an article fit within the interest of the review in terms of the *population and context* (e.g., CVDs as a target group), the *intervention* (e.g., self-management support through eHealth), the *content of interest* for the synthesis (e.g., a framework, model, or theory applied and sufficiently described), and the *study characteristics* (e.g., date and language of publication). Textbox 2.1 presents the selection criteria, which were hierarchically ordered and grouped up. Covidence software allows for record selection on a “yes,” “no,” or “maybe” basis. Therefore, to validate the 85% of citations that were screened by only the main reviewer, those tagged as “maybe” from the single review were also screened by the co-reviewer. The full text of articles were screened using the same approach. The outcome of the systematic search and selection process in the final report was planned to be presented in adherence to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher et al., 2009) (e.g., flowchart), giving reasons for exclusion at full-text screening, especially for articles on which the reviewers did not reach agreement at once.

Textbox 2.1. Selection criteria, hierarchically-ordered, categorised, and specified as inclusion or exclusion.

	= Inclusion criteria
	= Exclusion criteria
<b>Population/Context</b>	
	<b>1a.</b> Focuses on cardiovascular diseases (Also when specifically mentioned: heart failure, hypertension, atrial fibrillation, coronary artery disease, peripheral artery disease; Include also if focused on CVD risk factors as long as the target is clear and specific)
	<b>1b.</b> Focuses or includes target groups located outside the clinical setting (e.g., at home or in a community)
	<b>1c.</b> Target group is treated mainly within a clinical setting (e.g., hospital inpatients)
<b>Intervention</b>	
	<b>2a.</b> Refers to an eHealth supported intervention that focuses or includes self-management support as a key component (Consider as equivalent terms: self-care, self-treatment, self-regulation, self-help, self-monitoring, self-medication; Include if mentioned in terms of the patient's perspective: disease management, disease controllability)
	<b>2b.</b> The eHealth technology provides feedback to the patient based on self-monitoring data (collected via remote monitoring technologies such as wearables, blood pressure monitors, or weigh scale)
	<b>2c.</b> Focuses only on disease management from the health care provider's (HCP) perspective
	<b>2d.</b> Feedback is provided only via remote consultation with the HCP (e.g., by chat, telephone or video)
	<b>2e.</b> Self-monitoring is performed only by self-reports and not by the use of a remote monitoring technology
<b>Content of interest</b>	
	<b>3a.</b> Refers to the use of a framework, model or theory applied to develop, implement, or evaluate the eHealth technology (Include when specifically mentioned: participatory design, persuasive design, user or human centred, and business modelling)
	<b>3b.</b> The framework, model or theory is focused on health care service delivery (e.g., Chronic Care Model) or economic evaluation rather than on design or development guidelines for an eHealth supported intervention (e.g., participatory design, iterative evaluations)
	<b>3c. [Full text screening only]</b> The framework, model or theory is not sufficiently described or not enough information is provided about its operationalisation. Sufficiency is determined if two sub-criteria are met: i) The article includes a section that describes how a framework, model or theory was operationalised or applied for the development, implementation or evaluation of the intervention (e.g., a design/intervention section that describes development procedures, or a methods section that describes an –iterative– evaluation process). ii) The article provides a description or background information about the underlying framework, model or theory applied (within the same text, via supplementary materials or by references to the original sources).
<b>Study characteristics</b>	
	<b>4a.</b> Quantitative or qualitative (Including protocols, reviews and articles published in conference proceedings) (Abstracts of conference proceedings are included if they hint towards an article of possible interest, which can be screened during the full text stage)
	<b>4b.</b> It is published before 2008
	<b>4c. [Full text screening only]</b> Full text cannot be accessed
	<b>4d. [Full text screening only]</b> It is not written in English, Dutch or Spanish language
	<b>4e. [Full text screening only]</b> It is a doctoral thesis
	<b>4f. [Full text screening only]</b> It is not peer reviewed

### Phase 3: Reading and extracting data from studies

The main reviewer led and conducted all phases, while the rest of the team provided feedback on the growing output at intervals.

#### Data extraction form

The data extraction form was based on the Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth (CONSORT-EHEALTH) checklist v.1.6 (Baker et al., 2010; Eysenbach, 2011). The CONSORT-EHEALTH checklist was chosen as the base because it is an accepted standard for reporting on eHealth studies. However, since this standard was created for describing trials, it was adapted to reflect the qualitative aims of this review. The form was designed to collect information about (1) the study description, (2) eHealth intervention, and (3) underlying framework, model, or theory, and (4) their principles and key elements according to a holistic perspective.

Textbox 2.2 and Textbox 2.3 present the first two sections of the data extraction form. These sections are focused on collecting key *methodological and contextual* information of the study. The data extracted here are thus strictly derived from the paper. However, a minor degree of interpretation is implicit by the reviewer when organising the data. Notes were added when necessary to provide justification and transparency to the process. Textbox 2.4 presents the third section of the data extraction form. This section contains a higher degree of interpretation by the reviewer. Namely, to identify the most suitable description of a framework, model or theory applied in the study, and to better reflect its operationalisation. The reviewer also provides a categorisation of the framework, model or theory, and identifies its general approach to eHealth according to the study

Textbox 2.5 presents the fourth section of the data extraction form. This section contains the highest degree of interpretation by the reviewer. Namely, to interpret or characterise the key ingredients of a framework, model or theory according to holistic principles of eHealth development as proposed by the CeHRes Roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). Alternatively, to interpret or characterise them as proposed key ingredients to enable intervention effectiveness of an eHealth intervention to support self-management of CVD, whether in terms of behaviour change, technology adoption, or health-related outcomes. Textbox 2.6 presents the fifth section of the data extraction form. This section provides an overview of the raw data for the synthesis, referred to as the primary and secondary key metaphors of the selected papers.

Each section of the data extraction form was aligned to a research question of the literature study. Textbox 2.7 presents the relation between the research questions, the data extraction categories, and the type of data extracted. To increase its validity, the form was piloted and iteratively refined throughout all phases. Textbox 2.8 reports the substantial changes that were recorded reported later on with the results, in order to reflect on the usefulness of the extraction form.

Textbox 2.2. First section of the data extraction form, focused on the description of the selected studies. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

I. Study description	
1a Title	
1b Author(s)	
1c Affiliation(s)	i) Author(s) affiliations. Include institutions and countries and mark the corresponding author.
	ii) Reported conflicts of interest
1d Year of publication	
1e Journal	i) Name
	ii) Focus and scope. Extracted from journal's website.
1f Target condition(s)	
1g Aim	i) General study aim. Including description of overarching or related project(s).
	ii) Research question(s) and study objective(s)
1h Design	i) Study classification. Based on the Oxford Centre for Evidence-based medicine ( <a href="https://www.cebm.net/2014/04/study-designs/">https://www.cebm.net/2014/04/study-designs/</a> ). If necessary, clarify if design is cross-sectional or longitudinal, prospective or retrospective, single or multi-group, randomised or non-randomised, and if blinded or open-label.
	ii) Setting. General description of the organisation of the study, including location(s) where study was conducted.
	iii) Institutions involved. Hospitals, universities or other organisations involved. Which roles they had and how (if) these affiliations were displayed to participants.
1i Participants	i) Eligibility criteria
	ii) Recruitment procedure. How participants were recruited (online vs. offline). If online-only, clarify if there were any anonymization measures. How participants were briefed for recruitment and in the informed consent procedures. Ethical approval information (if applicable).
	iii) Sample characteristics. Baseline demographics, size, and other reported data.
	iv) Computer / Internet literacy
1j Study outcomes	i) Primary outcome(s)
	ii) Secondary outcomes(s)
	iii) Process outcome(s). Including use or adoption metrics and how they were defined (e.g., what was considered a 'session').
	iv) Data collection method(s), tools, and analysis. How outcomes were (self-)assessed, measured, monitored, and analysed.

Textbox 2.3. Second section of the data extraction form, focused on the description of the eHealth intervention referred to in a selected study. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

II. eHealth intervention	
<b>2a</b> Name	
<b>2b</b> Developers, sponsors, and owners	i) Developers & sponsors. <i>Clarify the relation of the study team towards the system being evaluated. For example, if the authors are distinct from or identical with the developers of the intervention.</i>
	ii) Owners. <i>Include names, credential and affiliations. Clarify if intervention/technology is still available and provide links for additional information if necessary.</i>
<b>2c</b> Development aim	i) General aim of development
	ii) Specific objectives of development
<b>2d</b> Device(s) and main functionalities	<i>Include description (if) of interoperability between technological devices.</i>
<b>2e</b> Main content features	i) Summary of main content features
	ii) In-depth description of content components. <i>Including behaviour change techniques or persuasive design features with author(s) definitions. How (if) each component was tailored to individual circumstances.</i>
<b>2f</b> Mode of delivery and implementation	i) How participants accessed the intervention. <i>Required credentials to access the intervention components (e.g., web-based platform). Include if they had to pay (or were paid) to become members of a specific group.</i>
	ii) Use parameters. <i>Intended 'doses' and optimal timing for use.</i>
	iii) Instructions of use given to participants. <i>Such as timing, frequency or heaviness of use.</i>
<b>2g</b> Feedback	i) Main description of feedback process and features
	ii) Level of human involvement. <i>Automated only vs. blended care. Number, specific roles and type of assistance of humans involved (e.g., health professionals, technical assistants), and medium by which involvement occurred.</i>
	iii) Communication channels. <i>Synchronous vs asynchronous. Textual vs. visual. If prompts or reminders were used and what triggered them (e.g., frequency).</i>
	iv) Presentation principles or strategies. <i>Descriptive information about the design and aesthetics of the intervention. Include principles or strategies used in page design, as well as basic information such as average amount of text on pages.</i>
<b>2h</b> Development process	i) Historical summary. <i>Narrative commentaries, notes, and observations from the authors about the development process <u>not</u> derived from the underlying framework, model or theory.</i>
	ii) Formative evaluations. <i>Include list of reported methods with keywords (e.g., focus groups, usability testing).</i>
	iii) Digital preservation. <i>Include URL of the application, archived public materials (links to screenshots/videos/demo pages).</i>
	iv) Published studies or grey literature. <i>List of related works by project. Include and mark references that were also screened for inclusion in the present review.</i>
<b>2i</b> Intervention results	i) Results on primary and secondary outcome(s)
	ii) Report on process outcome(s). <i>Including attrition.</i>
	iii) Report on technical problems or unintended effects. <i>Not only including physical "harm" to participants, but also incidents such as perceived or real privacy breaches and other unexpected/unintended incidents.</i>
	iv) Interpretation and principal findings. <i>Presented and summarised as per study question. Include limitations of study/project when reported, as well as unanswered new questions and suggestions for future research.</i>



Textbox 2.4. Third section of the data extraction form, focused on the identification of the underlying frameworks, models, or theories identified by the selected studies. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

III. Underlying framework, model or theory	
3a Name	
3b Description	i) Original source(s) referenced by the study author(s)
	ii) General description. <i>If provided by selected study, otherwise cite original source.</i> [Described by study authors] / [Extracted from original source]
	iii) Key framework, model or theory ingredients. <i>List of main principles, assumptions, concepts, components, parameters, conditions, phases or stages. Include definitions of each preferably provided by selected study, otherwise cite original source.</i> [Described by study authors] / [Extracted from original source]
	iv) Visual representation. <i>If applicable and provided by selected study, otherwise cite original source.</i> [Provided by study authors] / [Extracted from original source]
	3c Operationalisation
3d Categorization	Mark with an X if it meets any of the following definitions:
	<input type="checkbox"/> Framework. An <b>extensive</b> set of principles, such as assumptions, constructs, quality criteria, and ideas that can guide research and development. It can also contain strategies such as guidelines, design heuristics, and methods to assist on a <b>staged, phased, or time oriented process</b> .
	<input type="checkbox"/> Model. A <b>simplified representation</b> of a reality, hypothesis, theory, or knowledge. It can contain a set of concepts, statements, or both that specify how constructs relate to each other. Although, it can be both ' <b>precise and quantified</b> ' or ' <b>imprecise and qualitative</b> '.
	<input type="checkbox"/> Theory. Set of concepts and/or statements with <b>specification of how phenomena relate to each other</b> . Theory provides an organizing description of a system that accounts for what is known, and <b>explains and predicts phenomena</b> .
3e Approach to eHealth	Mark with an X if framework, model or theory was applied to any of the following:
	<input type="checkbox"/> Development. Refers to an <b>iterative process</b> of development of eHealth, entailing activities for pre-design, design, implementation and evaluation.
	<input type="checkbox"/> Implementation. Refers <b>exclusively</b> to activities that are undertaken to realise the adoption, dissemination and long-term use of a product in its intended context.
	<input type="checkbox"/> Evaluation. Refers <b>exclusively</b> to formative evaluation or summative evaluation. <b>Formative evaluation</b> englobes the activities throughout the entire development process that provide ongoing information on how to improve the development process, outcomes of activities and eHealth technology. <b>Summative evaluation</b> is the development phase which studies the influence and role of the technology on health, the context, behaviour and stakeholder perspective via evaluations of impact and uptake of the technology.

Textbox 2.5. Fourth section of the data extraction form, focused on the characterisation of the key ingredients identified by the reviewer in the selected studies. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

IV. Characterisation of key ingredients	
4a Key ingredient(s) addressing CeHRes Roadmap principles	Mark with an X if a principle is met and name the key ingredients (3b-iii) that relate to it:
	<div></div> <p>Participatory development. The structural cooperation of eHealth developers with potential end users and other stakeholders during its development. <b>Including user or human centred design</b>, both generally defined as a framework that aims to develop solutions to problems by involving the human perspectives in all steps of the process, via observing the problem within context, brainstorming, conceptualising, developing and implementing the solution.</p>
	<div>Ingredients</div> <p>Framework, model or theory: Key ingredient 1; Key ingredient 2; ...</p>
	<div></div> <p>Creation of new ecosystems for improving health and health care. The creation of novel structures and processes for health and health care through eHealth. Some of these changing characteristics are a change in place-dependent delivery, a new division of labour, new regulations for the use of technology financing, and a shift from hospital to home-based care.</p>
	<div>Ingredients</div>
	<div></div> <p>Intertwined with implementation. The inclusion in the development process of activities that are undertaken to realise the adoption, dissemination and long-term use of a product in its intended context. <b>Including business modelling</b>, defined as how an organisation creates, delivers and captures value. It can be a conceptual and analytical framework to discuss the added value of an eHealth intervention.</p>
	<div>Ingredients</div>
	<div></div> <p>Persuasive technology design. Designing technology that aims to reinforce, change, shape or influence behaviour and attitudes by being compelling and without being coercive or deceptive.</p>
	<div>Ingredients</div>
<div></div> <p>Continuous evaluation cycles. Employment of iterative design methodologies based on a cyclic process of needs assessment, prototyping, testing, analysing and refining a product, during which changes and refinements are made to the product based on the results of the most recent iteration of a design.</p>	
<div>Ingredients</div>	
4b Key ingredients proposed to enable effectiveness of an eHealth intervention to support self-management of CVD	<p>Behaviour change. Key ingredients to enable intervention effectiveness in terms of <b>behaviour change</b>, such as <b>practical applications</b> or <b>parameters of effectiveness</b> of behaviour change methods. <b>Practical applications</b> are the translations of theoretical methods of behaviour change to practical intervention elements. Applications are by definition specific, ideally tailored to populations, intervention contexts and behavioural domains. <b>Parameters for effectiveness</b> are the characteristics that a practical application must manifest for it to accurately reflect the theoretical method. When these parameters are lost in translation from method to application, effective behaviour change is undermined and may even result in counterproductive effects. Evidence for the existence of such parameters can range from theoretical to meta-analytical.</p>
	<p><b>Parameters of effectiveness of behaviour change methods</b></p> <p>Key ingredient 1</p> <p>Key ingredient 2</p> <p>...</p> <p><b>Practical applications of behaviour change methods</b></p> <p>Key ingredient 3</p> <p>Key ingredient 4</p> <p>...</p>
	<p>Technology adoption. Key ingredients to enable effectiveness in terms of <b>technology adoption</b>, such as those that aim to increase the engagement, use, adherence, uptake or adoption of the technology. For example, the use of <b>profiling mechanisms</b>, defined as ingredients that are employed to adapt an eHealth intervention to the characteristics of an individual or cohort (e.g., motivation levels as measured in a pre-test).</p>
	<p><b>Profiling mechanisms</b></p> <p>Key ingredient 1</p> <p>Key ingredient 2</p> <p>...</p>
	<p>Health-related outcomes. Key ingredients to enable intervention effectiveness in terms of the <b>outcomes</b> of an intervention that directly or indirectly have an impact on the health or well-being of the target group. For example, changes in health parameters (e.g., blood pressure control), risk factors (e.g., weight), or performance of self-care or healthy behaviours (e.g., physical activity levels).</p>

Textbox 2.6. Fifth section of the data extraction form, focused on providing an overview of the key metaphors identified by the reviewer in the selected studies. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

V. Overview of key metaphors										
Primary key metaphors. Key ingredients of frameworks, models and theories applied in eHealth studies and projects aiming to support self-management of CVD.										
Source	Key ingredient	Description	Exemplary quote(s)	CeHRes holistic principles					Effectiveness	
				PD	NE	Iwl	PTD	CeC	BC	TA
Secondary key metaphors. Key phrases, ideas, concepts, perspectives, organisers, and/or themes of a study that are <u>not</u> derived from an underlying framework, model or theory.										
Concept/Idea		Description	Exemplary quote(s)							

Textbox 2.7. Relation between the research questions, the data extractions categories, and the type of data extracted. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

Research question	Data extraction category	Type of data extracted
1) What frameworks, models, or theories have been used to develop, implement, or evaluate interventions to support self-management of patients with CVD through the use of remote monitoring technologies?	I. Study description II. eHealth intervention III. Underlying framework, model or theory	Methodological and contextual data: e.g., context and participants of study; underlying theoretical approach Key ingredients of applied framework, model, or theory
2) What are the key ingredients of these frameworks, models, or theories that inform or guide the system's <b>a)</b> development, evaluation, or implementation; <b>b)</b> content design to promote behaviour change and technology adoption; or <b>c)</b> proposed effects in terms of health-related outcomes?	IV. Characterisation of key ingredients	Key ingredients to enable intervention effectiveness in terms of behaviour change, technology adoption, or health-related outcomes
3) To what extent do the key ingredients of these frameworks, models, or theories fit with the five principles of a holistic research and development approach of eHealth? As proposed by the CeHRes Roadmap.	IV. Characterisation of key ingredients  V. Overview of key metaphors	Holistic principles for eHealth development as proposed by the CeHRes Roadmap  Primary and secondary key metaphors

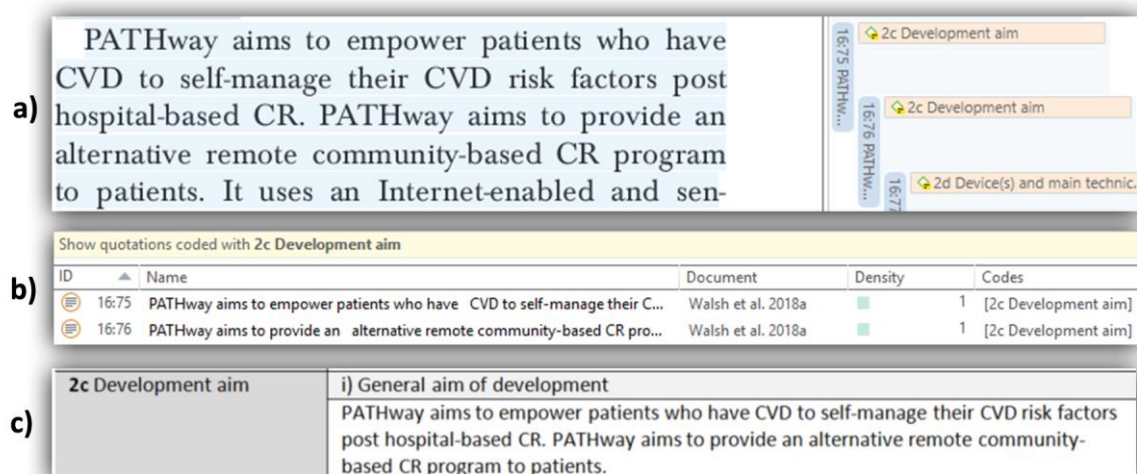
Textbox 2.8. Changes to research questions and data extraction form. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.

- Research questions were refined throughout the meta-ethnography to better communicate the raw data of the review (e.g., key ingredients of frameworks) and the aims of the synthesis (e.g., characterisation of key ingredients)
- In section IV, one of the CeHRes Roadmap's holistic principles used by the main reviewer during data extraction (phase 3) changed. Initially, the second principle stating that '*eHealth development creates new infrastructures for improving health care, health, and well-being*' was thought to be self-evident given the narrow search and selection process (i.e., all selected studies would implicitly entail a new infrastructure). In turn, the underpinning pillar of '*Business modelling*' was used in the previous form. However, preliminary analysis found that almost all studies neglected this. Therefore, the choice was reversed and the second principle was considered again for all phases of the review. The observed gap was noted in the resulting synthesis.
- In section IV, pointers were added to data elements when it was necessary for the reviewer to make a certain categorisation of the data (e.g., differentiating between 'parameters of effectiveness' or 'practical applications' in the characterisation of behaviour change key ingredients).
- Section V was added to facilitate an overview of key metaphors identified from each study. This format was used to translate all key metaphors into a Microsoft Excel format, which was used during the translation process.
- Minor changes in the language and the format of the data extraction form were applied.

## Data extraction process

The included articles were uploaded to the qualitative software package ATLAS.ti version 8 (ATLAS.ti Scientific Software Development GmbH). The content of each article was coded, in most cases sentence-by-sentence, according to the elements of the data extraction form. Figure 2.3 shows an example of how the data flowed through the reading-and-coding approach. To begin, PDF versions of the selected articles were imported to ATLAS.ti and codes were set up to reflect each element of the data extraction form. To facilitate a close and critical reading, as required in a meta-ethnography, this stage consisted of the following steps. First, the reviewer read the article and coded it at the same time according to the elements of the data extraction form (Figure 2.3, part a). Open coding was used at this point to label potential key concepts or ideas (metaphors). Second, after the article had been read and fully coded, the quotation manager tool of ATLAS.ti was used to review the coding results per category (Figure 2.3, part b). For example, if nothing was coded for "General aim of development," the reviewer screened the article again to ascertain whether this element was skipped while reading or if it was not reported by the authors. This process was repeated for every element of the data extraction form. In the third and final step, the reviewer translated the coded data into a data extraction form in Microsoft Word 2016 (Microsoft Corporation) (Figure 2.3, part c). This means that, for each selected article, there was a data extraction form filled in with all the data of interest. The process was highly iterative, as the main reviewer continually cross-referenced and refined the coding of the article and its filled-in data extraction form. All of the data extraction output was reviewed and refined with input from three co-reviewers (RAA, JW, and LGP).

Figure 2.3. Example of the data extraction process using ATLAS.ti and Microsoft Word. CR: cardiac rehabilitation; CVD: cardiovascular disease.



## Quality appraisal

The main reviewer also appraised the quality of studies using items from the Critical Appraisal Skills Program's (CASP) checklists. CASP checklists were employed because they are a suggested and frequently used tool for meta-ethnographies (Atkins et al., 2008; Britten & Pope, 2012; Cahill et al., 2018; Campbell et al., 2011; Malpass et al., 2009; Tong et al., 2012; Toye et al., 2013; Toye et al., 2014). Quality appraisal is not a strict requirement for meta-ethnography because the richness and relevance of the content is more important (Tong et al., 2012), but it is considered good practice. In addition, in the range of qualitative evidence synthesis methods, meta-ethnography is considered to have an objective idealism grounding (the acknowledgement that a world of collectively shared understandings exists) (Tong et al., 2012). Therefore, this step will not exclude any articles based on (methodological) quality, but was used to encourage the reviewer to read the articles carefully and systematically (Campbell et al., 2011). The characteristics of the selected articles for phase 3 were planned to be presented in tabular and narrative format by year of publication; author(s); author's affiliation(s) (institutions and countries); journal of publication; target condition; aim; and methodological design.

## Phase 4: Determining how studies are related

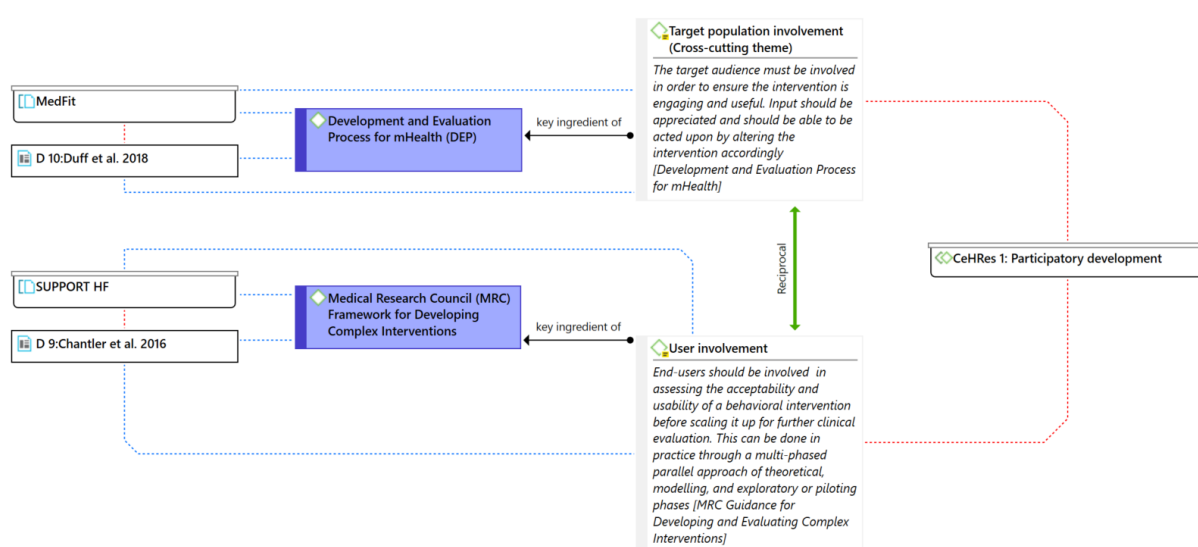
The relation of studies was performed at three levels, with the aim to provide a deep analysis of the data and their context.

### Relating studies according to underlying frameworks, models, or theories

At the first level, the frameworks, models, theories, and their key ingredients were compared in tabular form, along with their definitions and occurrence in studies. As presented before, to make this process possible the data extraction form was designed to identify such elements (see Textbox 2.4 and Textbox 2.5). In the data extraction form for each article, the reviewer added notes when necessary to clarify annotations. For example, if the reviewer had to identify and screen the original source of a framework cited in the reviewed article, to contrast it with how it is reported in it (e.g., to determine whether all elements of the framework are considered or only some of them). A list of key terms and definitions was used to facilitate the characterisation of the frameworks, models, and theories applied in the selected studies (also seen in the corresponding section of the data extraction form, see Textbox 2.4).

A **framework** was defined as an extensive set of principles, such as assumptions, constructs, quality criteria, and ideas that can guide research and development. It can also contain strategies such as guidelines, design heuristics, and methods to assist on a staged, phased, or time oriented process. A **model** was defined as a simplified representation of a reality, hypothesis, theory, or knowledge. It can contain a set of concepts, statements, or both that specify how constructs relate to each other. It can be both ‘precise and quantified’ or ‘imprecise and qualitative’. A **theory** was defined as a set of concepts and/or statements with specification of how phenomena relate to each other. Theory provides an organizing description of a system that accounts for what is known, and explains and predicts phenomena. Other key terms were grounded in the conceptualisations of the CeHRes roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011), but are also informed by the multidisciplinary literature related to eHealth and intervention development (Hekler et al., 2013; Michie, West, et al., 2014; Peters et al., 2015). Additionally, conceptual networks were created in ATLAS.ti using key metaphors as nodes to visualise and explore potential relations (see example in Figure 2.4).

Figure 2.4. Example of a conceptual network created in ATLAS.ti to visualise relations between the key metaphors of studies. As reported by Cruz-Martínez et al. (2020) with the outcomes of the review.



## Relating studies according to study and project characteristics

At the second level, the characteristics of included studies and their overarching projects were compared in tabular form. Moreover, the general context of the underlying approaches was compared according to the extracted data. To do this, a ‘comparison matrix’ was created to visualise the perceived level of clarity and extent of the extracted data. Table 2.1 presents an example of the comparison matrix. In the matrix each row represents a category and field of the data extraction form, and each column represents a reviewed article. The columns were organised to cluster selected papers from the same projects. Each cell was coded to identify if data items were clearly identifiable in the paper, if they were partially identifiable or incomplete, or were not applicable or reported at all.

Table 2.1. Example of comparison matrix, to provide an overview of the clarity and extent of extracted data.

		Project Paper	Project A			Project B		
			P1	P2	P3	P4	P5	P6
<b>I. Study description</b>								
1d Year of publication								
1f Target condition(s)								
1g Aim	i) General study aim							
	ii) Research question(s) and study objective(s)							
1h Design	ii) Setting							
	iii) Institutions involved							
1i Participants	i) Eligibility criteria							
	ii) Recruitment procedure							
	iii) Sample characteristics							
	iv) Computer / Internet literacy							
1j Study outcomes	i) Primary outcome(s)							
	ii) Secondary outcomes(s)							
	iii) Process outcome(s)							
	iv) Data collection method(s) and tools							

## Relating studies and their underlying approaches through a bibliometric analysis

The third level focused on the sources of the underlying approaches identified or cited in included studies. For example, the cited reference of a theory applied in a study. This approach used an explorative **bibliometric analysis** to assess the multidisciplinary range of such literature and investigate any potential relationships or trends. The references were snowballed and accompanied with **co-citation analysis** and topic modelling (Blei et al., 2003; Gleich, 2015; Knutas et al., 2015). **Snowballing** can be an alternative to traditional systematic review methods used to identify literature pertaining to a topic of interest by scanning reference lists of studies (Badampudi et al., 2015).

To conduct the snowballing process, the initial set of literature of was restricted to those references identified in the Web of Science database. External references were added to the initial set and the process was repeated. Backward snowballing was performed on the references of cited underlying approaches until no further records were deemed relevant to include. To make sure that the process converged, the requirement for the number of references to an external study increased every step, starting from 2 at the initial step. **Topic modelling** was then used to identify common logical topics across multiple studies based on their keywords and abstracts. The results of all iterations delivered descriptive graphs about the most popular publications, as well as the most productive and most cited authors for each step.

## Phase 5: Translating studies

Key metaphors were systematically translated across studies in order to arrive at concepts that embodied more than one study (France, Uny, et al., 2019). The translation in a meta-ethnography is *idiomatic* (translating the meaning of the text) rather than *literal* (word-for-word), and it must take into account the context of the study (France, Uny, et al., 2019; Noblit & Hare, 1988). This stage of the meta-ethnography is characterised by two types of translation: reciprocal and refutational.

**Reciprocal translation** aims to identify or generate metaphors which can better enable holistic accounts of phenomena (Noblit & Hare, 1988). On the other hand, **refutational translation** aims to give explicit attention to incongruities and inconsistencies in the data (France, Uny, et al., 2019). To avoid missing valuable insights, the review collected two types of metaphors distinguished by their source. **Primary key metaphors** were the key ingredients of frameworks, models, or theories operationalised by the authors of a study. **Secondary key metaphors** were remarkable phrases, concepts, ideas or perspectives by the authors of a study, but not apparently derived from a structured underlying approach. In the translation process, both types of metaphors were clustered.

In the translation process, and at higher interpretative level, the reviewer examined if principles for holistic eHealth development could be identified in the reviewed studies and their underlying approaches. To facilitate the characterisation of frameworks, models, and theories according to a holistic view, the principles of the CeHRes roadmap were applied as an initial interpretative framework (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). The roadmap is a guideline for holistic eHealth development which is itself based on a review of multiple frameworks, and grounded in the integration of persuasive technology design (Oinas-Kukkonen & Harjuma, 2009), human-centred design, and business modelling (van Gemert-Pijnen et al., 2011). It proposes five principles: (1) eHealth development is a participatory development process; (2) eHealth development creates new infrastructures for improving health care, health, and well-being; (3) eHealth development is intertwined with implementation; (4) eHealth development is coupled with **persuasive systems design**; and (5) eHealth development requires continuous evaluation cycles. The principles of the roadmap underpin several stages and recommended activities for development (as previously described in **Chapter 1**). The roadmap was only used to confront what has been done in the literature with an initial assumption of principles for a holistic approach.

Five predefined clusters referred to each principle of the CeHRes roadmap. A metaphor in a reviewed study could fall under one or several principles. In the same manner, three additional clusters were used: *behaviour change* (**parameters for effectiveness of behaviour change methods** or **practical applications of behaviour change methods**), *technology adoption* (including **profiling mechanisms**), or *health-related outcomes*. These clusters were used to collect key features or elements of eHealth interventions that were identified as potential enablers of intervention effectiveness. Clustering the metaphors allowed the reviewers to deal with a smaller amount of metaphors at a time so idiomatic translations were performed under each cluster. These clusters were part of the data extraction form, when the interpretative stage began (see Textbox 2.5). In the translation process, concept maps and other forms of visual diagrams were used to describe the context and the meaning of the relationships between concepts within and across studies (as exemplified already in Figure 2.4). Of utmost importance was to consider potential alternative interpretations or explanations in the translation, and to ensure their presentation in the final results.

## Phase 6: Synthesis process

As can be noted in the previous sections, the relation and translation of studies as well as the synthesis process are considered complex analytical and highly overlapping phases of a meta-ethnography, without a ‘one size fits all’ recipe (France, Uny, et al., 2019). To clarify the resulting approach of this review, Table 2.2 presents an overview of the activities undertaken in phases four to six.

Table 2.2. Overview of relation, translation, and the synthesis process. Adapted from Cruz-Martínez et al. (2020).

Phases	Key output	Activity
4 – Relation of selected studies	Tabular comparison	Summarise data and create tables
	Conceptual networks	Visualise potential relations
	Data extraction matrix	Comparing perceived clarity of reported data
	Bibliometric analysis	Conduct explorative analysis
5 – Translation of selected studies	Key metaphors; Reciprocal and refutational translations	Collective interpretation and translation of studies and their key metaphors
	Clustering of metaphors	Collective clustering of key metaphors
	Synthesised translations	Development of overarching concepts, themes, and principles
6 – Synthesis process	Line-of-argument synthesis	Development of line-of-argument



As can also be seen in Table 2.2, from the activities and interpretative findings of the previous phases, a textual line-of-argument synthesis was created. A **line-of-argument synthesis** is a new storyline or overarching explanation of a phenomenon (France, Uny, et al., 2019) (the third type of relation after reciprocal and refutational analysis). The synthesis was structured by revising the assumed holistic principles and emphasising the key metaphors that extended over several themes. Each key metaphor could either contribute to a holistic understanding, highlight important relations across multidisciplinary literature, or even suggest new knowledge derived from integrating unrelated approaches.

## RESULTS

The systematic review was conceived early in 2018. The protocol was preregistered in PROSPERO [CRD42018104397] in August 2018, and subsequently published as a registered, complying with best-practice recommendations protocol (Cruz-Martínez et al., 2019). The final search was conducted in July 2018. By December 2018, phases 1 to 3 were completed and phases 4 to 6 were finalised in July 2019. The results were first submitted for publication in September 2019, marking the completion of phase 7, the expression of the synthesis. The results are presented in **Chapter 3**.

## DISCUSSION

This protocol describes a methodological adaptation of the meta-ethnography approach that served the purpose of the review: a holistic interpretation of a multidisciplinary and rapidly evolving topic. All in all, an exhaustive systematic search was conducted to find published studies within the scope of interest. The protocol guided the complex, iterative and highly-analytical interpretative phases. The main variation from other systematic reviews lied in the synthesis approach, which sought to preserve the context in which findings emerged from the various research disciplines at the crossroads of eHealth, CVDs, and self-management. In other words, the conceptual richness of the literature was needed to identify and understand the role of frameworks, models, and theories in the development of eHealth interventions. This would not have been possible by aggregative methodologies or purely descriptive approaches. Furthermore, the methodology adopted for this review showed how several tools (Covidence, ATLAS.ti, and Microsoft Office) could be employed to conduct a thorough systematic qualitative evidence synthesis, as demanded by the meta-ethnography approach. Several steps not unique to meta-ethnography were also applied (quality appraisal, data comparison matrix, and bibliometric analysis) to provide clarity and depth to the analysis and synthesis. Of added value was also that the review adhered to the (at the time) recently developed eMERGe reporting guidelines for meta-ethnographies (France, Cunningham, et al., 2019). The results aimed to show how the meta-ethnography method could contribute to overcoming the challenges derived from the multidisciplinary and rapidly evolving nature of eHealth research and development.

# Chapter 3

**Outcomes of a meta-ethnography review of frameworks, models, and theories used in eHealth research and development aiming to support self-management of cardiovascular diseases**

**This chapter is based on the following publication:**

Cruz-Martínez, R. R., Wentzel, J., Asbjørnsen, R. A., Noort, P. D., van Niekerk, J. M., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (2020). Supporting Self-Management of Cardiovascular Diseases Through Remote Monitoring Technologies: Meta-ethnography Review of Frameworks, Models, and Theories Used in Research and Development [Review]. *J Med Internet Res*, 22(5), e16157. doi:10.2196/16157.

## ABSTRACT

**Background:** Electronic health (eHealth) is a rapidly evolving field informed by multiple scientific disciplines. Because of this, the use of different terms and concepts to explain the same phenomena and lack of standardization in reporting interventions often leaves a gap that hinders knowledge accumulation. Interventions focused on self-management support of cardiovascular diseases through the use of remote monitoring technologies are a cross-disciplinary area potentially affected by this gap. A review of the underlying frameworks, models, and theories that have informed projects at this crossroad could advance future research and development efforts.

**Objective:** This research aimed to identify and compare underlying approaches that have informed interventions focused on self-management support of cardiovascular diseases through the use of remote monitoring technologies. The objective was to achieve an understanding of the distinct approaches by highlighting common or conflicting principles, guidelines, and methods.

**Methods:** The meta-ethnography approach was used to review and synthesize researchers' reports on how they applied frameworks, models, and theories in their projects. Literature was systematically searched in 7 databases: Scopus, Web of Science, EMBASE, CINAHL, PsycINFO, Association for Computing Machinery Digital Library, and Cochrane Library. Included studies were thoroughly read and coded to extract data for the synthesis. Studies were mainly related by the key ingredients of the underlying approaches they applied. The key ingredients were finally translated across studies and synthesized into thematic clusters.

**Results:** Of 1224 initial results, 17 articles were included. The articles described research and development of 10 different projects. Frameworks, models, and theories (n=43) applied by the projects were identified. Key ingredients (n=293) of the included articles were mapped to the following themes of eHealth development: (i) it is a participatory process; (ii) it creates new infrastructures for improving health care, health, and well-being; (iii) it is intertwined with implementation; (iv) it integrates theory, evidence, and participatory approaches for persuasive design; (v) it requires continuous evaluation cycles; (vi) it targets behaviour change; (vii) it targets technology adoption; and (viii) it targets health-related outcomes.

**Conclusions:** The findings of this review support and exemplify the numerous possibilities in the use of frameworks, models, and theories to guide research and development of eHealth. Participatory, user-centred design, and integration with empirical evidence and theoretical modelling were widely identified principles in the literature. On the contrary, less attention has been given to the integration of implementation in the development process and supporting novel eHealth-based health care infrastructures. To better integrate theory and evidence, holistic approaches can combine patient-centred studies with consolidated knowledge from expert-based approaches.

## INTRODUCTION

### A vision of self-care: Part 3

The previous chapter showcased a systematic approach attempting to grasp the complexity found at the crossroads of self-care, CVD, and eHealth. To construct a holistic view, multiple and multidimensional factors are present, but these had to be identified and defined—thereby applying varying degrees of interpretation in the process—and finally thoroughly translated across different studies and their contexts. At the end of **Chapter 1**, a preview of the multiple contexts of relevance and multidimensional factors was already presented (to recall, see Figure 3.1 below).

Figure 3.1. To achieve a holistic view of eHealth CVD self-care support that includes multiple contexts of relevance and multidimensional factors, a review of scientific theories, models, and frameworks was conducted.

### Theories, models, or frameworks could facilitate a holistic view of:

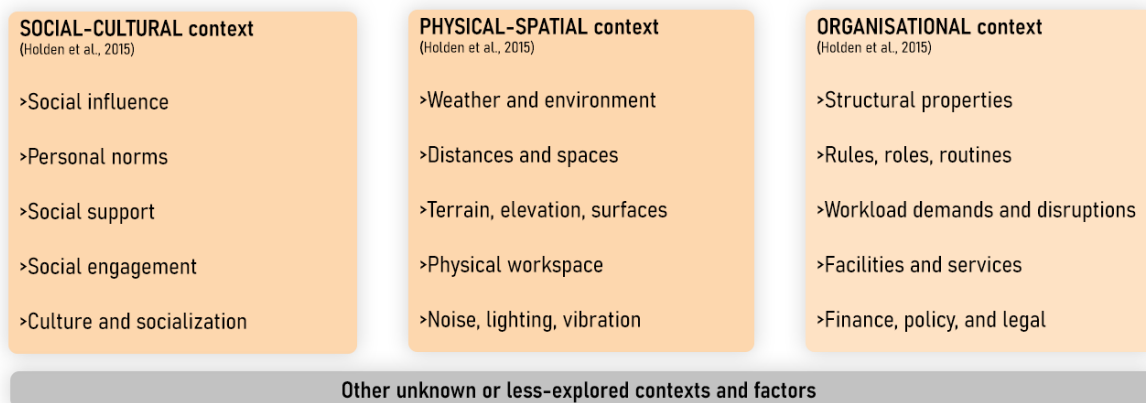


Figure 3.1 provides examples only of macro ergonomic factors or context. However, much more is needed to achieve a holistic view that facilitates understanding of cases like Albert's (see introduction of **Chapter 1**). What are the key behaviours that should be supported? What are the motivations of individuals driving these behaviours? How can we tap on underlying motivations to facilitate behaviour change? The answer to these and similar questions, was expected to be a product of the systematic review. Nevertheless, as will be described in the present chapter, while the clarity and understanding of the case study increased in general, so did also the notion that there existed gaps in our knowledge and assumptions, blurring the vision that self-care could one day be effectively supported by technology.

### Focus of the present chapter

The present chapter shows and discusses the results of an ambitious literature study that sought to achieve a holistic view of self-care support through eHealth. To recall, the overarching question of the study was: *what and how have theories, models, or frameworks been used to develop, implement, or evaluate eHealth interventions?* The findings supported and exemplified the numerous possibilities in the use of frameworks, models, and theories to guide research and development of eHealth. However, at the same time, important gaps and limitations were identified in the approaches that had been adopted in the reviewed literature and project. Gaps and limitations that could be understandable considering the goal, but gaps and limitations that still need be identified, discussed, and addressed, if the goal is to provide effective support for human behaviour and its complexity.

## BACKGROUND LITERATURE

### Holistic electronic health research and development

Electronic health (eHealth) can be defined as the use of technology to support health, well-being, and health care (van Gemert-Pijnen, Kip, et al., 2018). As a field of science and innovation, eHealth is characterised by its multidisciplinary and rapidly evolving nature. In eHealth development, various disciplines such as computer, health, and behavioural sciences and design are involved. Ideally, researchers and practitioners are frequently engaged in iterative phases of eHealth development, implementation, or evaluation. The knowledge and technology generated by such processes is often grounded in a wide and overwhelming variety of frameworks, models, theories, methods, or guidelines. Because of this, accumulation, curation, and translation of the output of research and development has become a challenge and thus an important target for research itself (Michie et al., 2017).

Research has also made it clear that development of eHealth entails several challenges, such as maintaining the pace and efficiency of development cycles, promoting engagement, and applying a theoretical foundation (Michie et al., 2017). In practical terms, multidisciplinary teams (health care providers, software developers, etc.) are confronted with the need to determine the best approach for a project very early in the process. They are required to define the aims, the methods, and the overarching process that will guide development. Thus, frameworks, models, or theories not only facilitate the task, but also can increase the success of eHealth. Success in research and development can be determined by how much an intervention improves health and well-being (effectiveness), but also by providing explanations and advancing scientific knowledge on ‘what works for whom in what settings to change what behaviours, and how?’ (Michie et al., 2017).

A holistic approach that combines multidisciplinary knowledge with novel methods and techniques is recommended to tackle the various development challenges and to ensure the effectiveness and efficacy of eHealth (Kip & van Gemert-Pijnen, 2018). The term holistic refers to the importance of the whole and the interdependence of its parts (Kip & van Gemert-Pijnen, 2018). In other words, when developing, implementing, or evaluating eHealth, fragmented analysis should be avoided, and each part, with its reciprocal influence on other parts, should be emphasised (e.g., across contextual, technological, and human levels) (van Gemert-Pijnen et al., 2011). The usefulness of taking a holistic approach was recently noted during the development of a framework to understand the non adoption, abandonment, scale-up, spread, and sustainability of eHealth (Greenhalgh, Wherton, et al., 2017). In the development process, a holistic view was a helpful starting point to analyse and understand data and theory, and to integrate other frameworks (Greenhalgh, Wherton, et al., 2017). Therefore, we propose that both researchers and practitioners should recognise the value of making a conscious decision to strive for optimal holism, or at least to combine the most suitable, validated, and useful guidelines that reflect on their decision. Health care is a complex and adaptive system, and this makes eHealth a potential source for innovative solutions to some of society’s most alarming health care problems (Covvey, 2018). The Center for eHealth Research (CeHRes) roadmap is an example of a holistic approach built on reviews of previous frameworks and on empirical research that has been extensively employed for cases such as chronic diseases, antimicrobial stewardship programs (Beerlage-de Jong et al., 2017), and others (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). Thus, such a guideline offers researchers and developers several tools and methods to integrate into a project, in order to monitor the many different stakes and processes that are at play when tackling a certain health issue.

## **Case study: Self-management of cardiovascular diseases through electronic health monitoring technology**

Cardiovascular diseases (CVDs) constitute a global health care crisis due to their high prevalence, long duration, and slow progression (Roth et al., 2017; World Health Organization, 2014). A key factor to lessen the burden of CVDs is to support the patients' abilities to self-manage their own condition (Riegel, Moser, et al., 2017). Self-management refers to an individual's ability to manage the symptoms, treatment, and physical and psychosocial consequences, as well as the lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002). For instance, individuals living with CVD are recommended to manage their blood pressure, control their cholesterol, reduce their blood sugar levels, become physically active, eat better, lose weight, and stop smoking (Riegel, Moser, et al., 2017). An important aspect of these recommendations is that self-management has to be done outside the clinical setting, as patients have to integrate these intensive and timely activities into their daily lives. In fact, one estimate is that of the 8760 hours in a year, patients are spending only around 10 hours (0.1%) with their health care providers (Riegel, Moser, et al., 2017). To ensure that patients are seen by or under the supervision of their health care providers when they do not have face-to-face contact, remote self-monitoring is crucial. Remote self-monitoring can be defined as the process of observing changes in signs and symptoms (Riegel et al., 2012), a behaviour that is primarily conducted by the patient but made visible to the health care providers via technology. It supports safety because the health care team can check and be alerted in a timely manner in case of potentially dangerous changes in the patient's health status. Also, patients often feel more comfortable being able to return to their daily lives with the knowledge that important measurements are being monitored by their health care providers (Middlemass et al., 2017). Because of this, remote self-monitoring technologies have become a vital part, almost a prerequisite, of home- and community-based care. In this light, recent metareviews have shown that technology-supported interventions can be at least as effective as usual care in supporting self-management of chronic conditions (Greenwood et al., 2017; Hanlon et al., 2017).

Despite promising results, the accumulation, curation, and translation of knowledge is also challenging when research in eHealth technology (computer science, design), CVDs (health sciences), and self-management (behavioural sciences) intersects. This leaves a gap that has been observed by previous reviews. The multidisciplinary gap is formed by the usage of different terms and concepts to explain the same phenomena (Hekler et al., 2013), and by a lack of clarity or standardization in reporting the key ingredients of an intervention (Hoffmann et al., 2014). To exemplify from the behavioural science perspective, a review of eHealth physical activity interventions for adults with CVDs found that most studies did not sufficiently detail the operationalisation of behaviour change techniques as key components of their intervention (Duff et al., 2017). Likewise, another review of similar interventions showed that only half of the studies had named a theory or model as the foundation (Winter et al., 2016).

The literature often provides lessons learned on a case-by-case basis in eHealth research and development to support self-management (Greenwood et al., 2017; Hanlon et al., 2017; Jacelon et al., 2016; Kim & Lee, 2017). For example, the most common recommendations reflect the importance of applying technology integration models and a theoretical foundation. Even though this is valuable knowledge, testing should also include process evaluation for intermediate outcomes (mechanisms, mediators), derived ideally from the aforementioned theoretical background. Developers should also provide a sufficiently detailed description of the evidence-based components of the intervention (e.g., behaviour change techniques). Nevertheless, from these detached recommendations it is still unclear which overall development approaches have been applied in eHealth research to support self-management of CVD, and what their unique contributions have been.

Even more so, the extent to which holistic principles have been considered is unknown. The uncertainty is highlighted because these interventions are coupled with rapidly evolving technologies such as body sensors, personalisation algorithms, and automatic feedback systems (Kim & Lee, 2017) that mark a significant shift from the traditional telephone or face-to-face delivery. In sum, much is known about development processes in eHealth, based on the many examples that exist. What is lacking at this point is an overarching understanding that relates the findings of such studies across the phases of development and across disciplines.

## **Aim and focus**

The aim of this review is to facilitate a holistic interpretation of eHealth projects aimed at self-management support of CVDs in a natural setting of the patients. We intend to identify the frameworks, models, and theories applied in these projects and synthesize how their elements were applied to research and development. This seeks to fill in the gap of knowledge translation and dissemination resulting from the multidisciplinary of eHealth. The context of the review is broad, because it examines interdependent elements in terms of the context, the technology, and the human level (see **Figure 2.1** in **Chapter 2**). It includes patients with any particular CVD who are faced with lifestyle changes inherent to their disease and who have to cope with them predominantly at home or in their communities (not in a clinical setting). In terms of technology, we have narrowed the review aim down to the use of remote monitoring technologies such as blood pressure monitors, weigh scales, or wearables, which collect real-time data and provide feedback to the patient as a key component. This scope allows for the collection of specific knowledge on self-management support in the context of remote care.

Although excluding interventions that did not use monitoring technology could be seen as a limitation, we hold that any of these applications could, and more importantly should, still be adapted to remote care; therefore, we expect our findings to showcase the missing potential. Finally, in terms of the human element, the aim is specific but also difficult to identify in published studies. The human element is represented by theory-based ingredients such as profiling or tailoring mechanisms and parameters of effectiveness to target patients' behaviour change with the intention to improve health.

The review is focused on the following research questions. First, what frameworks, models, or theories have been used to develop, implement, or evaluate eHealth interventions to support self-management of patients with CVDs outside the clinical setting? Second, how do these models address the 5 principles of a holistic eHealth research and development approach (as depicted by the CeHRes roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011)? Third, what parameters of effectiveness, profiling mechanisms, and target outcomes are used in these models to address heterogeneity between patients with CVD?

## **Selecting meta-ethnography**

Study reports of how researchers and practitioners applied frameworks, models, and theories are the qualitative data of interest for this review, which is thus based on meta-ethnography, a qualitative synthesis approach developed by Noblit and Hare (Noblit & Hare, 1988). Meta-ethnography is an interpretative approach to qualitative evidence synthesis that seeks to generate a new understanding of a topic, while preserving the social and theoretical contexts in which findings emerge (Booth, Sutton, et al., 2016).

Noblit and Hare outlined meta-ethnography as a 7-stage process that compares and analyses texts, creates new interpretations in the process, and by doing this strives to build a holistic interpretation (Noblit & Hare, 1988). In practice, it mainly involves open coding to identify emergent categories and then constant comparison of key metaphors across studies. Key metaphors can be phrases, ideas, concepts, perspectives, organisers, or themes revealed by a study (Noblit & Hare, 1988). Both the guidelines on choosing qualitative evidence synthesis methods by (Booth, Noyes, et al., 2016) and the support of an information specialist for social sciences (PDN) led us to choose meta-ethnography over other approaches (e.g., grounded theory or critical interpretative synthesis). We preferred meta-ethnography because it includes a synthesis approach matching the interest of the review to ‘move beyond description to a more interpretative examination of [themes,] their relationships and indeed any inherent contradictions’ (pg 48) (Booth, Sutton, et al., 2016). More importantly, meta-ethnography is by its very essence a technique used to translate concepts across individual studies (Booth, Sutton, et al., 2016), which is a perfect fit for our aim to synthesize the elements of frameworks, model, or theories. Our review is also informed by meta-ethnographies in related topics or with similar aims (Campbell et al., 2011; Erasmus, 2014; Morton et al., 2017; Siau & Long, 2005; Toye et al., 2013).

## METHODS

For the present thesis, the protocol of this systematic review has been presented in **Chapter 2**, detailing all of its phases. In this section, only a general description of the methods are presented. Phase 1 generated the published protocol (Cruz-Martínez et al., 2019). Phases 2 and 3 sought to answer the first research question regarding the identification of frameworks, models, and theories (Cruz-Martínez et al., 2019). Phases 4 to 6 operationalised an answer to the second and third research questions through an interpretative characterisation of the key ingredients of frameworks, models, and theories (Cruz-Martínez et al., 2019). The present article adheres to the recently developed Meta-Ethnography Reporting Guidance (eMERGe) (France, Cunningham, et al., 2019).

A comprehensive search was conducted to find published studies (articles) of interest (Cruz-Martínez et al., 2019). The search consisted of a systematic database search. Seven databases were used: Scopus, Web of Science, EMBASE, the CINAHL, PsycINFO, the ACM Digital Library, and the Cochrane Library. The databases were chosen based on their coverage of various fields of science related to eHealth. Multiple key terms were used as part of a highly structured query consisting of four sets aiming for results about frameworks, models, and theories (set 1), eHealth interventions (set 2), self-management (set 3) and cardiovascular diseases (set 4).

### Study selection

The selection was performed using the Covidence Web-based software platform (Veritas Health Innovation Ltd). Records were screened by two reviewers, first by title and abstract, and then by full text. The main reviewer conducted the screening throughout all stages. A co-reviewer (RAA) screened 15% of the records at each stage. Discrepancies between reviewers were discussed and resolved at every stage. The selection criteria has been presented in **Chapter 2, Textbox 2.1**.

### Reading studies and extracting data

The included articles were uploaded to the qualitative software package ATLAS.ti version 8 (ATLAS.ti Scientific Software Development GmbH). Their content was coded according to the elements of a highly detailed data extraction form created to fit the scope of this review (see **Textbox 2.2, Textbox 2.3, Textbox 2.4, Textbox 2.5, and Textbox 2.6 in Chapter 2**).



The data extraction form was based on the Consolidated Standards of Reporting Trials of Electronic and Mobile Health Applications and Online Telehealth (CONSORT-EHEALTH) checklist v.1.6 (Baker et al., 2010; Eysenbach, 2011). The form was piloted and iteratively refined throughout all phases. All coded data was also translated to a single form per study. The main reviewer iteratively read, coded, and updated all of the data extraction output based on input from three co-reviewers (RAA, JW, and LGP). The main reviewer also appraised the quality of studies using items from the Critical Appraisal Skills Program's (CASP) checklists. CASP checklists were employed because they are a suggested and frequently used tool for meta-ethnographies (Atkins et al., 2008; Britten & Pope, 2012; Cahill et al., 2018; Campbell et al., 2011; Malpass et al., 2009; Tong et al., 2012; Toye et al., 2013; Toye et al., 2014). Quality appraisal is not a strict requirement for meta-ethnography because the richness and relevance of the content is more important (Tong et al., 2012), but it is considered good practice and was used to get further familiarized with the studies (Campbell et al., 2011).

## Determining how studies are related

The relation of studies was performed at three levels, with the aim to provide a deep analysis of the data and its context. At the first level, the frameworks, models, theories, and their key ingredients were compared in tabular form, along with their definitions and occurrence in studies. Additionally, conceptual networks were created in ATLAS.ti using key metaphors as nodes to visualise and explore potential relations (see **Figure 2.4** in **Chapter 2**). At the second level, the characteristics of included studies and their overarching projects were compared in tabular form. Moreover, the general context of the underlying approaches was compared according to the extracted data. To do this, a matrix was created to visualise the perceived level of clarity and extent of the extracted data (Cruz-Martínez et al., 2019). The third level focused on the sources of the underlying approaches identified or cited in included studies (e.g., the cited reference of a framework applied in a study). This approach used an explorative bibliometric analysis to assess the multidisciplinary range of such literature and investigate any potential relationships or trends.

The references were snowballed and accompanied with co-citation analysis and topic modelling (Blei et al., 2003; Gleich, 2015; Knutas et al., 2015). Snowballing can be an alternative to traditional systematic review methods used to identify literature pertaining to a topic of interest by scanning reference lists of studies (Badampudi et al., 2015).

## Translating studies

Key metaphors were systematically translated across studies in order to arrive at concepts which embodied more than one study (France, Uny, et al., 2019). The translation in a meta-ethnography is *idiomatic* (translating the meaning of the text) rather than *literal* (word-for-word), and it must take into account the context of the study (France, Uny, et al., 2019; Noblit & Hare, 1988). This stage of the meta-ethnography is characterised by two types of translation: reciprocal and refutational. Reciprocal translations aim to identify or generate metaphors which can better enable holistic accounts of phenomena (Noblit & Hare, 1988). On the other hand, refutational translations aim to give explicit attention to incongruities and inconsistencies in the data (France, Uny, et al., 2019). To avoid missing valuable insights, the review collected two types of metaphors distinguished by their source. Primary key metaphors were the key ingredients of frameworks, models, or theories operationalised by the authors of a study. Secondary key metaphors were remarkable phrases, concepts, ideas or perspectives by the authors of a study but not apparently derived from a structured underlying approach.

To assist the translation process it was decided to use the principles of the Center for eHealth Research (CeHRes) roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). The roadmap is a guideline for holistic eHealth development which is itself based on a review of multiple frameworks, and grounded in the integration of persuasive technology design (Oinas-Kukkonen & Harjumaa, 2009), human-centred design, and business modelling (van Gemert-Pijnen et al., 2011). It proposes five principles: (1) eHealth development is a participatory development process; (2) eHealth development creates new infrastructures for improving health care, health, and well-being; (3) eHealth development is intertwined with implementation; (4) eHealth development is coupled with persuasive design; and (5) eHealth development requires continuous evaluation cycles. The roadmap was only used to confront what has been done in the literature with an initial assumption of principles for a holistic approach.

This step was operationalised by collectively characterising both types of metaphors under one or several principles. This process created five clusters representing each principle. In the same manner, metaphors were also characterised to clusters of 'behaviour change', 'technology adoption', or 'health-related outcomes' if they were identified as potential enablers of intervention effectiveness. Clustering the metaphors allowed the reviewers to deal with a smaller amount of metaphors at a time so idiomatic translations were performed under each cluster.

## **Synthesis process**

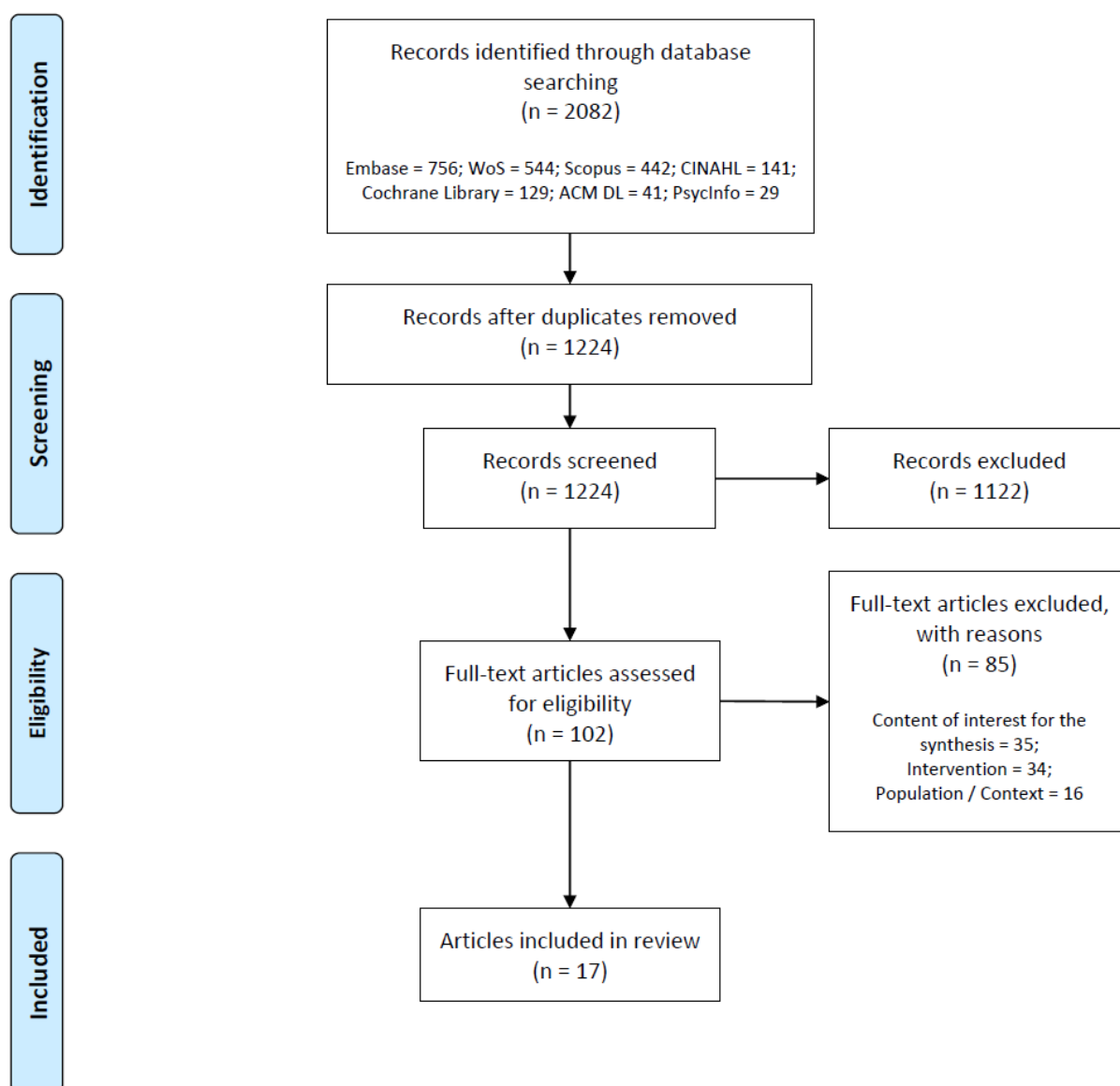
## **RESULTS**

### **Selected studies**

The initial search resulted in 1224 potentially eligible records after removing duplicates. In the title and abstract screening phase 1122 records were excluded. Further on, 85 articles were excluded after full-text screening, 35 out of 85 (41%) because of the lack of relevant content for the synthesis (e.g., no apparent framework applied), 34 out of 85 (40%) by the irrelevant characteristics of the intervention (e.g., not focused on self-management), and 16 out of 85 (19%) due to an irrelevant population or context (e.g., not focused on CVD). Multimedia Appendix 3, reported by Cruz-Martínez et al. (2020), lists the articles excluded at full-text screening and the reasons for exclusion.

In the end, 17 articles met all inclusion criteria. Figure 3.2 overviews the selection process via the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) flowchart (Moher et al., 2009). The search terms and search strings used for the database search have been reported as preliminary results in the protocol of the review (Cruz-Martínez et al., 2019).

Figure 3.2. Flowchart of included and excluded articles.



## Study characteristics

An overview of the characteristics of included articles can be found in Table 3.1. The table is also reported with more detail in Multimedia Appendix 4 by Cruz-Martínez et al. (2020). The articles address 10 different overarching projects, identified as HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam, Jenkins, et al., 2018; Athilingam et al., 2016), Home and Online Management and Evaluation of Blood Pressure (HOME BP) (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017), Seamless User-Centred Proactive Provision of Risk-Stratified Treatment for Heart Failure (SUPPORT HF) (Chantler et al., 2016; Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015), PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018; Walsh, Moran, Cornelissen, Buys, Cornelis, et al., 2018), Congestive Heart Failure—Personalised Self-Management System (CHF PSMS) (Bartlett et al., 2014), MedFit (Duff et al., 2018), Smartphone Medication Adherence Stops Hypertension (SMASH) (McGillicuddy et al., 2012), Engage (Srinivas et al., 2017), MyHeart (Villalba et al., 2009), and a mock-up (Baek et al., 2018) standalone study. The year of publication of the articles ranged from 2009 to 2018. The United Kingdom (n=7) and United States (n=5) were the most common affiliations of the authors. The most frequent journals in which the articles were published are the Journal of Medical Internet Research (3/17), BMC Medical Informatics and Decision Making (2/17), and Applied Nursing Research (2/17). The articles were also divided across three target conditions: heart failure (9/17), hypertension (4/17), and CVDs in general (4/17).

Study design classification was done according to the Oxford Centre for Evidence-Based Medicine (Centre for Evidence-Based Medicine, 2014). Analytic experimental studies are those in which the researcher manipulates the exposure, allocating subjects to the intervention or exposure group. Analytic observational studies are those in which the researcher simply measures the exposure or treatments of the groups without manipulating the exposure or allocation of subjects. Descriptive (qualitative) studies do not try to quantify the relationship but try to give a picture of what is happening in a population.

A total of 35% (6/17) of articles (Athilingam, Clochesy, et al., 2018; Band et al., 2017; Band et al., 2016; Triantafyllidis, Velardo, Chantler, et al., 2015; Villalba et al., 2009; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) focused on describing the development process of an intervention and often generally discussed results from more than one study. In these cases, classification by study design was not applicable. For the remaining articles, study design classification revealed three types of study designs used for eHealth research: analytic observational (Athilingam et al., 2016; Baek et al., 2018; Bartlett et al., 2014; Rahimi et al., 2015; Srinivas et al., 2017), descriptive qualitative (Athilingam, Jenkins, et al., 2018; Bradbury et al., 2017; Chantler et al., 2016; Duff et al., 2018; Walsh, Moran, Cornelissen, Buys, Cornelis, et al., 2018), and analytic experimental (McGillicuddy et al., 2012). Multimedia Appendix 5, as reported in Cruz-Martínez et al. (2020), presents the quality appraisal of selected studies.

Table 3.1. Characteristics of included articles.

Project	Reference; country <sup>a</sup>	Journal	Target
MyHeart	(Villalba et al., 2009); Spain	Conference publication; International Conference on eHealth, Telemedicine, and Social Medicine	HF <sup>b</sup>
SMASH <sup>c</sup>	(McGillicuddy et al., 2012); US	Conference publication; Wireless Health	HTN <sup>c</sup>
CHF PSMS <sup>e</sup>	(Bartlett et al., 2014); UK	BMC Medical Informatics and Decision Making	HF <sup>b</sup>
SUPPORT HF <sup>f</sup>	(Rahimi et al., 2015); UK	European Heart Journal – Quality of Care and Clinical Outcomes	HF <sup>b</sup>
SUPPORT HF <sup>f</sup>	(Triantafyllidis, Velardo, Chantler, et al., 2015); UK	International Journal of Medical Informatics	HF <sup>b</sup>
SUPPORT HF <sup>f</sup>	(Chantler et al., 2016); UK	Digital Health	HF <sup>b</sup>
HOME BP <sup>g</sup>	(Band et al., 2016); UK	BMJ Open	HTN <sup>c</sup>
HOME BP <sup>g</sup>	(Band et al., 2017); UK	Implementation Science	HTN <sup>c</sup>
HOME BP <sup>g</sup>	(Bradbury et al., 2017); UK	BMC Medical Informatics and Decision Making	HTN <sup>c</sup>
HeartMapp	(Athilingam et al., 2016); US	Applied Nursing Research	HF <sup>b</sup>
HeartMapp	(Athilingam, Clochesy, et al., 2018); US	CIN: Computers, Informatics, Nursing	HF <sup>b</sup>
HeartMapp	(Athilingam, Jenkins, et al., 2018); US	Applied Nursing Research	HF <sup>b</sup>
Engage	(Srinivas et al., 2017); US	International Journal Of Human–Computer Interaction	HF <sup>b</sup>
MedFit App	(Duff et al., 2018); Ireland	JMIR Formative Research	CVD <sup>d</sup>
no project	(Baek et al., 2018); South Korea	JMIR Cardio	CVD <sup>d</sup>
PATHway	(Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018); Ireland, Belgium, Italy, Greece	Translational Behavioural Medicine	CVD <sup>d</sup>
PATHway	(Walsh, Moran, Cornelissen, Buys, Cornelis, et al., 2018); Ireland, Belgium;	Journal of Medical Internet Research	CVD <sup>d</sup>

<sup>a</sup> Countries are included according to the reported affiliations of the authors. <sup>b</sup> HF: heart failure. <sup>c</sup> SMASH: Smartphone Medication Adherence Stops Hypertension <sup>d</sup> HTN: hypertension. <sup>e</sup> CHF PSMS: Congestive Heart Failure—Personalised Self-Management System. <sup>f</sup> SUPPORT HF: Seamless User-Centred Proactive Provision of Risk-Stratified Treatment for Heart Failure. <sup>g</sup> HOME BP: Home and Online Management and Evaluation of Blood Pressure. <sup>h</sup> CVD: cardiovascular disease (in general).

## Frameworks, models, and theories applied to research and development

In total, 43 frameworks, models, or theories were identified as underlying approaches of the included studies. Textbox 3.1 and Textbox 3.2 present all of the identified approaches. Multimedia Appendix 6, reported by Cruz-Martínez et al. (2020), includes the list of all key ingredients with their definitions per study. Multimedia Appendix 7 and 8, also reported by Cruz-Martínez et al. (2020), present the full relation between each underlying approach and the operationalised key ingredients by the included studies. In total, 27 different approaches were used to inform the system's development, implementation, or evaluation (Bartholomew, 2001; Blank & Dorf, 2012; Campbell et al., 2007; Collins et al., 2005; Cooper, 2007; Craig et al., 2008; Craig et al., 2013; Daniels et al., 2007; Dumas et al., 1999; Hearn & Foth, 2005; Holden et al., 2013; Holden et al., 2016; Humayoun et al., 2011; International Organization for Standardization, 1999; Marchal et al., 2012; Matthew-Maich et al., 2016; McGillicuddy et al., 2012; Meso & Jain, 2006; Michie, Atkins, et al., 2014; Michie et al., 2011; Monk, 2000; Pawson et al., 1997; Quesenberry & Design, 2003; Sotirovski, 2001; Sreejesh, 2014; Triantafyllidis, Velardo, Chantler, et al., 2015; Valdez et al., 2015; Villalba Mora et al., 2008; Whittaker et al., 2012; Winter & Munn-Giddings, 2001; Yardley, Ainsworth, et al., 2015; Yardley, Morrison, et al., 2015).

In contrast, 16 theoretical models were used to inform the system's content (Bandura, 1977; Bandura, 1986; Bandura, 2004; Bradbury et al., 2017; Carman et al., 2013; Carver & Scheier, 1982; Davis et al., 1989; Fisher et al., 2003; Hirsch & Silverstone, 2003; Leventhal et al., 2003; May, 2006; May et al., 2007; Mayer & Moreno, 1998; Moreno, 2005; Murray et al., 2010; Ryan & Deci, 2000; Ryan et al., 2008; Savery & Duffy, 1995; Silverstone & Haddon, 1996; Sweller, 1988; Venkatesh et al., 2007; Venkatesh et al., 2012). The analysis shows that approaches to system development undertaken by the included studies often promote a participatory, user-centred approach—for example, the development and evaluation process for mHealth (Whittaker et al., 2012) or the person-based approach (Yardley, Ainsworth, et al., 2015; Yardley, Morrison, et al., 2015).

Several types of user-centred models were also identified (Baek et al., 2018; Holden et al., 2016; Humayoun et al., 2011; Matthew-Maich et al., 2016). Similarly, some frameworks were used to broaden the designer's perspective. For example, the systems engineering initiative for patient safety 2.0 (Holden et al., 2013) and the patient work lens for consumer-facing health (Valdez et al., 2015) 'encouraged the design team to 'think systems' and 'think bigger,' which in this case meant consideration of patients' long-term goals, overall workload, and integration of self-care recommendations into daily life' (Srinivas et al., 2017). Among some focused approaches were, for example, the business-oriented frameworks applied in the HeartMapp project (Athilingam, Jenkins, et al., 2018).

The analysis also shows that the wide variety of theoretical models that were used to inform the system's content in the included studies. For instance, social cognitive theory (Bandura, 1977; Bandura, 1986; Bandura, 2004) was used to outline the behavioural perspective of three different projects. Additionally, some theories were used to understand the process of technology adoption as an outcome, such as the domestication of technology theory (Hirsch & Silverstone, 2003; Silverstone & Haddon, 1996) or the normalization process theory (May, 2006; May et al., 2007; Murray et al., 2010). Comparably, technology acceptance was also analysed through the unified theory of acceptance and use of technology model (Venkatesh et al., 2007; Venkatesh et al., 2012) and the technology acceptance model (Davis et al., 1989).

In general, the integration of multidisciplinary frameworks was frequent in the included studies and their overarching projects. Multimedia Appendix 9, as reported in Cruz-Martínez et al. (2020), presents how the overarching projects of included studies and their underlying approaches were compared across several levels. The analyses make evident that the HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam, Jenkins, et al., 2018; Athilingam et al., 2016), HOME BP (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017), SUPPORT HF (Chantler et al., 2016; Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015), PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018; Walsh, Moran, Cornelissen, Buys, Cornelis, et al., 2018), CHF PSMS (Bartlett et al., 2014), MedFit (Duff et al., 2018), SMASH (McGillicuddy et al., 2012), and MyHeart (Villalba et al., 2009) projects were all informed by a combination of approaches from different areas of science.

In contrast, the Engage (Srinivas et al., 2017) project focused on macro ergonomic sociotechnical frameworks while the mock-up (Baek et al., 2018) study concentrated on a user-centred design research process. However, comparability across projects was influenced by the clarity and extent of the reported data in the selected articles. Multimedia Appendix 10, reported by Cruz-Martínez et al. (2020), exemplifies the differences in clarity across studies and projects, while the full comparative analysis can be observed in Multimedia Appendix 9. The multidisciplinary-based approach was sometimes an explicit goal of researchers. For example, the MedFit study aimed to adopt a 'multidisciplinary approach to development [...] drawing on theories from engineering, computer science, and health psychology' (Duff et al., 2018). In this line, frameworks were sometimes used to inspire tailored approaches. The most remarkable case was the guidance from the Medical Research Council (MRC) for developing and evaluating complex interventions (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013), which informed four projects and in general was cited repeatedly in the included studies (see also its relative importance identified in the bibliometric analysis in Multimedia Appendix 9). However, sometimes how a framework informed another one was not completely clear. For example, the iterative software design approach of the MyHeart project (Villalba et al., 2009) was stated to be informed by goal-directed design (Cooper, 2007) and user-centred design (International Organization for Standardization, 1999) principles, but this statement was not elaborated in the selected article.

Another example is the iterative refinement and patient participatory approach of the SUPPORT HF project (Triantafyllidis, Velardo, Chantler, et al., 2015), which is informed by action research (Hearn & Foth, 2005; Winter & Munn-Giddings, 2001) and agile software development (Meso & Jain, 2006) frameworks. Although such approach is clearly described, its explicit relation to the underpinning frameworks is not explicitly established.

Textbox 3.1. Frameworks and models that informed the system's development, implementation, or evaluation.

- 5E usability approach (Quesenbery & Design, 2003)
- Action research (Hearn & Foth, 2005; Winter & Munn-Giddings, 2001)
- Agile software development (Meso & Jain, 2006)
- Behaviour change wheel / capability, opportunity, motivation and behaviour model (Michie, Atkins, et al., 2014; Michie et al., 2011)
- Business model canvas
- Business research method (Sreejesh, 2014)
- Development and evaluation process for mHealth (Whittaker et al., 2012)
- Goal directed design (Cooper, 2007)
- Holistic patient interaction model (Villalba Mora et al., 2008)
- Intervention mapping (Bartholomew, 2001)
- Iterative design model (McGillicuddy et al., 2012)
- Iterative refinement and patient participatory approach (Triantafyllidis, Velardo, Chantler, et al., 2015)
- Iterative software design process (Villalba Mora et al., 2008)
- Iterative software development (Sotirovski, 2001)
- Medical Research Council's guidance for developing and evaluating complex interventions (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013)
- Multiphase optimisation strategy (Collins et al., 2005)
- Patient work lens for consumer-facing health (Valdez et al., 2015)
- Person-based approach (Yardley, Ainsworth, et al., 2015; Yardley, Morrison, et al., 2015)
- Practical guide to usability testing (Dumas et al., 1999)
- Realistic evaluation framework (Marchal et al., 2012; Pawson et al., 1997)
- Startup owner's manual (Blank & Dorf, 2012)
- Systems engineering initiative for patient safety 2.0 (Holden et al., 2013)
- User-centred design (ad hoc) (Humayoun et al., 2011; Matthew-Maich et al., 2016)
- User-centred design (Monk, 2000)
- User-centred design of consumer-facing health information technology (Holden et al., 2016)
- User-centred design (International Organization for Standardization, 1999)
- Usability framework (Daniels et al., 2007)

Textbox 3.2. Theoretical models that informed the system's content.

- Cognitive load theory (Sweller, 1988)
- Cognitive theory of multimedia learning (Mayer & Moreno, 1998)
- Common-sense model of self-regulation (Leventhal et al., 2003)
- Congratulate, ask, reassure, encourage approach (Bradbury et al., 2017)
- Control theory framework for personality-social, clinical, and health psychology (Carver & Scheier, 1982)
- Domestication of technology theory (Hirsch & Silverstone, 2003; Silverstone & Haddon, 1996)
- Information, motivation, behavioural skills model (Fisher et al., 2003)
- Instructional design approach utilizing a pedagogical agent (Moreno, 2005)
- Multidimensional framework for patient and family engagement in health and health care (Carman et al., 2013)
- Normalization process theory (May, 2006; May et al., 2007; Murray et al., 2010)
- Problem based learning (Savery & Duffy, 1995)
- Self-determination theory (Ryan & Deci, 2000; Ryan et al., 2008)
- Social cognitive theory (Bandura, 1977; Bandura, 1986; Bandura, 2004)
- Social ecological model
- Technology acceptance model (Davis et al., 1989)
- Unified theory of acceptance and use of technology model (Venkatesh et al., 2007; Venkatesh et al., 2012)

## Key ingredients that inform or guide development, content, or outcomes

The key ingredients facilitate a more detailed comparison of how underlying approaches were used. Mainly, the approaches to system development contain key ingredients that mostly represent stages of development, implementation, or evaluation. The stage-based ingredients that focus on creating a fit between the user and the proposed solution (e.g., through co-design and formative evaluation) are eHealth-specific frameworks (Whittaker et al., 2012; Yardley, Ainsworth, et al., 2015; Yardley, Morrison, et al., 2015), guidelines for (software) iterative evaluation (McGillicuddy et al., 2012; Triantafyllidis, Velardo, Chantler, et al., 2015; Villalba Mora et al., 2008), or user-centred design methods (Holden et al., 2016; Humayoun et al., 2011; International Organization for Standardization, 1999; Matthew-Maich et al., 2016; Monk, 2000). On the other hand, some stage-based key ingredients guided systematic exploration, selection, and integration of theory with empirical evidence (e.g., establishing why or how the intervention works through theoretical modelling). These ingredients are instead derived from research and intervention-building frameworks from behavioural (Bartholomew, 2001), medical (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013), or sociological (Marchal et al., 2012; Pawson et al., 1997) areas of science.

Other key ingredients did not represent stages of development but were constructs used to broaden the designers' perspectives—for instance, to understand human-technology interaction (Villalba Mora et al., 2008), the patient's work system (Holden et al., 2013; Valdez et al., 2015) (i.e., the workflow), ecosystem levels in health care (Walsh, Moran, Cornelissen, Buys, Cornelis, et al., 2018), or key insights for business modelling (Athilingam, Jenkins, et al., 2018). The bibliometric analysis on the cited references of underlying approaches also observed a distinction between topics of intervention development, behaviour change, and health care.

In contrast, theoretical models provide key ingredients that were used to inform the content or outcomes of interventions. These ingredients could be psychological determinants (Bandura, 1977; Bandura, 1986; Bandura, 2004; Fisher et al., 2003; Leventhal et al., 2003; Michie, Atkins, et al., 2014; Michie et al., 2011; Ryan & Deci, 2000; Ryan et al., 2008) (e.g., self-efficacy), mechanisms of action (self-monitoring (Carver & Scheier, 1982)), or mediators (engagement (Carman et al., 2013)) for behaviour change. Other key ingredients are about eHealth adoption, such as determinants of technology acceptance (Davis et al., 1989; Venkatesh et al., 2007; Venkatesh et al., 2012) (e.g., ease of use) or processes and mediators of adoption (Hirsch & Silverstone, 2003; May, 2006; May et al., 2007; Murray et al., 2010; Silverstone & Haddon, 1996) (e.g., objectification). In sum, the included studies highlighted participatory, user-centred, and iterative approaches with multiple perspectives about how to effectively influence the uptake of eHealth at several levels (e.g., from individual cognition to the elements of a macro-ergonomic work system). These ingredients and other insights (metaphors) of the included studies were compared and translated within and across studies. In the sections below, the included studies are mentioned by the first author's name in the text and their underlying approaches are named and referenced when applicable.

### Behaviour change

The effectiveness of eHealth systems in the included studies in terms of behaviour change was operationalised by their success in improving self-management behaviours. In this regard, the operationalisation of key ingredients could be better understood through the sociotechnical perspective which broadly conceptualizes self-management as a complex biopsychosocial process, as proposed by the systems engineering initiative for patient safety 2.0 (Holden et al., 2013) and the patient work lens for consumer-facing health (Valdez et al., 2015) model. Throughout the included studies, the proposed general solution was the provision of tailored, personalised, or timely support (Band et al., 2016), grounded in the potential of eHealth to deliver behaviour change techniques that can facilitate long-term sustained behaviour change (Duff et al., 2018).



Key ingredients were mostly informed by psychological theories such as social cognitive theory, which highlights determinants like self-efficacy, outcome expectancy, individual goals, and perceived impediments and facilitators (Bandura, 1977; Bandura, 1986; Bandura, 2004). Likewise, information, motivation, behavioural skills, and social opportunity were also parameters used by the selected studies to facilitate behaviour change, based on the behaviour change wheel (Michie, Atkins, et al., 2014; Michie et al., 2011) or the information, motivation, behavioural skills model (Fisher et al., 2003). Behaviour change was also proposed to be at play during the adoption of a technology according to the normalization process theory (May, 2006; May et al., 2007; Murray et al., 2010)—for example, to explain how patients or health care providers must integrate several behaviours into everyday life (interactional workability) or how patients must be able to adapt their self-care routines when required (reconfiguration). Finally, the review collected a long list of practical applications (translations of behaviour change techniques into intervention components) that showcased the similarity of current approaches to support self-management through remote monitoring technologies. For example, a familiarization phase (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) with the technology was an approach used by several studies. The most common features of the technologies included assessment, self-monitoring, feedback (during activity and after performance), behavioural change support (e.g., goal setting, promoting home exercising), and education (e.g., on disease management).

## Technology adoption

The effectiveness of eHealth systems in the included studies in terms of promoting technology adoption during the implementation process was operationalised mainly by the aim to create a fit between the system and the self-management routines of the patients.

Primarily, technology adoption was informed in the included studies by the recognition of a diversity of user experiences (Chantler et al., 2016), and the predominant strategy to undertake user-centred design (Humayoun et al., 2011; Matthew-Maich et al., 2016) to address this heterogeneity. Once again, the tailored, personalised, and timely support (Band et al., 2016) was the main driver during operationalisation. Specifically, the adaptation to the personal routines of patients (Villalba et al., 2009) was identified as a common idea across the included literature. In addition, the inclusion of a bidirectional service model (Baek et al., 2018) or blended care which entailed communication between health care providers and patients was also an important theme across the included studies. This was in part because the sense of connection to a support team that a system provides to a patient could act as a key motivator for the use of the technology (Chantler et al., 2016). Guidelines for health care providers to offer patient-centred support within a remote care context were applied by one of the included studies (Bradbury et al., 2017).

Remarkably, two major challenges of technology adoption were also identified. First, the technology knowledge gap (literacy) between younger and older generations (Duff et al., 2018). Second, the inertia of disengagement, which was proposed to be tackled by the establishment of design goals that promote rather than assume baseline levels of engagement (Srinivas et al., 2017). Technology adoption could also be assessed at multiple levels—for example, through a user interaction model (Villalba et al., 2009) that investigates the explicit and implicit interaction between the user and the technology or in terms of a multidimensional usability framework (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018). Notably, technology adoption could be explored through models such as the domestication of technology theory (Hirsch & Silverstone, 2003; Silverstone & Haddon, 1996), which describes the processes of acceptance, rejection, and use of technology by its users (Chantler et al., 2016). Likewise, the unified theory of acceptance and use of technology and the technology acceptance model were other models of adoption that offered determinants such as behavioural intention, performance and effort expectancy, experience, and price value (Davis et al., 1989; Venkatesh et al., 2007; Venkatesh et al., 2012).

Finally, the key insights for building a minimum viable product (e.g., value propositions), derived from the business model canvas, were also interpreted as key ingredients to enable the desired adoption during implementation of the technology (Athilingam, Jenkins, et al., 2018).

## Health-related outcomes

The paths to health improvement of the eHealth systems in the included studies were several. Overall, most of the listed ingredients could be categorised as engagement outcomes (e.g., continued use and high usability), behavioural outcomes (e.g., improved self-management), or health-related outcomes (e.g., reducing admissions or increasing quality of life). In these terms, the operationalisation of health-related outcomes in the selected studies focused notably on behaviour change as the indirect path to increase health, an approach often grounded in the behaviour change wheel and its capability, opportunity, motivation and behaviour model (Michie, Atkins, et al., 2014; Michie et al., 2011). For example, technologies were designed to include several intervention functions, such as enablement (increasing means and reducing barriers to perform the behaviour), education (increasing knowledge or understanding), and environmental restructuring (changing the physical or social context). Moreover, the sociotechnical perspective of the systems engineering initiative for patient safety 2.0 (Holden et al., 2013) was used by Srinivas et al. (2017) to broaden the understanding of the various components of an intervention (e.g., work processes) in relation to their impact on potential outcomes (proximal or distal, desirable or undesirable). An important challenge to improve health in the selected literature focused on hypertension was clinical inertia (McGillicuddy et al., 2012) (i.e., the failure to establish appropriate targets and escalate treatment to achieve treatment goals). Additionally, the accurate measurement of changes in key determinants (e.g., knowledge, as approached by Bartlett et al. (2014)) was also a possible methodological obstacle.

## Fit of key ingredients with holistic principles for research and development

Projects at the intersection of self-management, CVD, and eHealth have directly or indirectly applied holistic principles for research and development. Namely, the principle of eHealth as a participatory development process and the principle that eHealth development is intertwined with implementation have been explicitly endorsed in the included studies. On the other hand, the principle that eHealth development creates new infrastructures for improving health care, health, and well-being has been partially operationalised through the use of various frameworks but has remained unacknowledged as a key underlying theme. Similarly, the principle that eHealth requires continuous evaluation cycles has been indirectly addressed by a wide variety of aims and methods operationalised across many phases of the eHealth development process. Ultimately, the principle that eHealth development is coupled with persuasive design was unacknowledged across included studies, although varied and generic approaches to inform design were found.

## Development is a participatory process

The principle of participatory development has been widely operationalised as part of a fundamental integration of person-based approaches with theory and evidence (Band et al., 2017) and directly grounded in the concept of user involvement, which was promoted throughout the included literature to conform with the guidelines of the MRC (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013). Moreover, the participatory approach was complemented with a socioecological perspective to secure inclusion of a diversity of user experiences (Chantler et al., 2016) and multiple levels of the target group's ecosystem (as applied by Walsh, Moran, Cornelissen, Buys, Claes, et al. (2018)). The aims and methods for participatory development of the included studies have been extensively underpinned by user-centred design (Humayoun et al., 2011; Monk, 2000) and applied to the full extent of eHealth development phases (from planning to deployment) (Matthew-Maich et al., 2016; Valdez et al., 2015; Yardley, Ainsworth, et al., 2015; Yardley, Morrison, et al., 2015).

## Development creates new infrastructures for improving health care, health, and well-being

Initially, the principle that eHealth development creates new infrastructures for improving health care, health, and well-being was thought to be self-evident given the scope of the review (remote care). The established aims of researchers and developers in the selected studies endorsed this principle, such as providing tailored, personalised, and timely support (Band et al., 2016) or the unobtrusive remote delivery of system refinements (Triantafyllidis, Velardo, Chantler, et al., 2015).

Key contextual factors were also highlighted by the included studies, such as the facilitating conditions (perceptions of the resources and support available to perform a behaviour) defined by the unified theory of acceptance and use of technology model (Venkatesh et al., 2007; Venkatesh et al., 2012). In this regard, as posed by the behaviour change wheel (Michie, Atkins, et al., 2014; Michie et al., 2011), context can also include the policy categories surrounding technology-supported interventions (decisions made by authorities that help to support and enact an intervention). An early step to create an infrastructure can be to develop a program plan to describe the scope and sequence of intervention components, its required materials, and the protocols for implementation (as in intervention mapping) (Bartholomew, 2001).

In addition, the use of interdisciplinary methods (e.g., factorial or fractionated evaluation designs discussed by Walsh, Moran, Cornelissen, Buys, Claes, et al. (2018) and a socioecological perspective (Walsh, Moran, Cornelissen, Buys, Cornelis, et al., 2018) are approaches that can facilitate the understanding of eHealth infrastructures and ecosystems (i.e., identifying what works, who should be involved, and how in remote care support).

## Development is intertwined with implementation

An implementation focus such as the one promoted by the development and evaluation process for mHealth (Whittaker et al., 2012) was prominent across the selected literature, directly supporting this principle. However, the aims and methods to accomplish this were often vaguely and partially described. For example, business modelling (Blank & Dorf, 2012; Sreejesh, 2014) approaches have been used for research (Athilingam, Jenkins, et al., 2018), but only for an initial conceptualisation of the technology (a first concept of the solution that still requires validation, as defined by the iterative software design process (Villalba Mora et al., 2008). A highlighted example of development intertwined with implementation was the aim to provide remote delivery of system refinements as proposed in the iterative refinement and patient participatory approach (Triantafyllidis, Velardo, Chantler, et al., 2015). This approach intended to facilitate continuous system updates without the use of valuable human resources. For this principle, only formative research such as focus groups (Duff et al., 2018) and field studies (Bartlett et al., 2014) have been employed as methods that can be intertwined with the development process to understand and ideally increase the uptake of the technology.

## Development integrates theory, evidence, and participatory approaches for persuasive design

The term of persuasive design, prominent in the field of human-computer interaction, was completely omitted in the included literature. However, it was evident that the integration of theory-, evidence- and person-based approaches (Band et al., 2017) was used to increase persuasiveness. In other words, the selected studies implicitly set persuasiveness as part of their development aims—for example, by the proposed personalisation and tailoring (Chantler et al., 2016) of the intervention, the creation of habits in the use of a technology, or the leverage on the hedonic (fun, pleasure) (Duff et al., 2018) and automatic motivation (emotional reactions) of end users (Band et al., 2017; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018).

In this regard, theoretical approaches were often related to theoretical modelling, such as logic modelling (Band et al., 2017), while evidence was explored through preclinical or theoretical research (e.g., literature reviews) conforming to the MRC's guidelines (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013).

As mentioned before, participatory or person-based approaches were more often applied as part of user-centred design. Hence, this revised principle highlighted how the included studies coped with the challenge of knowledge translation across different areas of research and its application to a specific aim (i.e., integrating multidimensional ingredients that contribute to a common goal). To exemplify this, the aim for personalisation and tailoring was derived from evidence that prioritised 'the need to tailor...systems to user's capacity and preferences' (Chantler et al., 2016), rather than assuming these aspects as key principles to increase technology persuasiveness via the facilitation of task support (as proposed by the persuasive systems design model (Oinas-Kukkonen & Harjumaa, 2009)). One trade-off made apparent by this revised principle and example is that the identified approaches were not related to theory developed specifically for technology-based interventions, and therefore their application to this area seemed to be open to the interpretation of researchers and developers.

## Development requires continuous evaluation cycles

The requirement of continuous evaluation cycles in eHealth development revealed a contradiction within the included literature. The contradiction was outlined by the MRC's (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013) proposed stepwise development of complex interventions, as opposite to its own practical recommendation to undertake a parallel approach that can integrate stages with distinct aims into larger phases of development. For example, a large phase of development can include preclinical or theoretical research (e.g., understanding the users and their environment through literature reviews) (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013), early solution finding (e.g., discussing solutions with the target group as defined by the iterative design model (McGillicuddy et al., 2012)), and an initial theoretical conceptualisation (as defined by the development and evaluation process for mHealth (Whittaker et al., 2012)) or modelling of the eHealth technology and its components (e.g., deciding on the theoretical basis and proposing how an intervention could work) (Campbell et al., 2007; Craig et al., 2008; Craig et al., 2013).

In practical terms, evaluation cycles were often defined by either the choice of an agile (rapid and cyclical stages) or waterfall approach (long and sequential stages) to product development (Srinivas et al., 2017). This principle also highlighted the importance of integrating interdisciplinary methods (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) that accommodate to the planned evaluation cycles. In this regard, the creation of an evaluation plan (Bartholomew, 2001), where variables are defined in a measurable way in relation with the intervention objectives, methods, and strategies, seemed to be a key phase to bridge early design with formative evaluation processes of eHealth. To apply continuous evaluation cycles, the included studies made wide use of user-centred design methods (Humayoun et al., 2011; Monk, 2000) such as usability testing but also other frameworks such as realistic evaluation (Pawson et al., 1997), which is a theory-driven approach to evaluate the complexity of social programs (Bartlett et al., 2014).

## DISCUSSION

### Principal findings

The findings of this review confirm and exemplify the remarkable challenges posed by the multidisciplinary gap in the field of eHealth. Mainly, the review listed 43 multidisciplinary frameworks, models, theories, and guidelines that have informed interventions within the scope of eHealth applications to self-management of CVD.

Multidisciplinary approaches were often integrated and aimed to create a fit between users, the content of an intervention, and its context. The following sections summarise and assess the contributions of the principal findings with prior and related works.

### **Bridging the multidisciplinary gap in eHealth research and development**

In terms of development, the findings of this review place the integration of theory-, evidence- and participatory approaches to inform persuasive design as a newly generated overarching principle (Band et al., 2017). To do this, the studies often integrated knowledge from several disciplines, which in general has been argued as positive and desirable for eHealth (Pagliari, 2007). However, in terms of design, one downside from the selected studies was that the approaches considered were often constrained to behavioural or sociological perspectives that were not focused on increasing the use and uptake of technology. In terms of implementation, this review suggests the importance of interdisciplinary methods that integrate broad perspectives such as the socioecological, sociotechnical (Holden et al., 2013; Valdez et al., 2015), or business modelling (Blank & Dorf, 2012; Sreejesh, 2014) approaches.

Specifically, the importance of workflow for the success of eHealth interventions has also been observed in another review (Granja et al., 2018). Workflow can be defined as the way people interact with their work, the communication pathways, and other people (Granja et al., 2018). The inclusion of novel technological tools in the workflow of patients and health care providers was addressed in the reviewed studies through the lens of models such as the systems engineering initiative for patient safety 2.0 framework (Holden et al., 2013), or the domestication of technology theory (Hirsch & Silverstone, 2003; Silverstone & Haddon, 1996).

For evaluation of eHealth, the reviewed literature acknowledged the iterative nature of this process, but some of the identified approaches seemed to still be restrained by fixed stages of post development testing of effectiveness. It must be noted that these fixed research programs can hinder the adaptability of interventions to the dynamic and flexible reality of the patients (Greenhalgh, A'Court, et al., 2017). In this light, a previous review on the adoption of self-management solutions has also showed that a broad 'consideration of preconceived barriers and facilitators for adoption' might be too simplistic, because what is perceived as a barrier or facilitator for one individual could have the opposite effect for another (Harvey et al., 2015). To maximise adoption, it is therefore recommended to iteratively reevaluate key social, motivational, cultural, moral, and financial factors (Harvey et al., 2015). The continuous evaluation of these factors can be matched with participatory and user-centred principles

### **Challenge of reporting intervention content and design**

Overall, the findings of this review are in line with the general literature addressing several advantages to the use of theoretical frameworks for eHealth development and design and the different ways in which they can be operationalised (Hekler et al., 2013). However, the major challenge of adequate reporting of intervention design and content was also recognised (Srinivas et al., 2017; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018). The lack of specification of the underlying approaches and their operationalisation is still 'suspected to be an artefact of publishing conventions and space constraints, as much as if not more than the nature of actual research being performed' (Srinivas et al., 2017). All in all, the review included exemplary cases of publications with rich conceptual and descriptive data about eHealth development and design (Athilingam, Clochesy, et al., 2018; Band et al., 2017; Bartlett et al., 2014; Duff et al., 2018; Srinivas et al., 2017; Villalba et al., 2009; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018).

## Strengths and limitations

This is considered to be the first meta-ethnography focused on bridging knowledge from multidisciplinary fields of science to better understand and improve eHealth research and development approaches. The review made great efforts to follow a thorough, systematic, multilevel approach (Cruz-Martínez et al., 2019), adhere to recently developed guidelines (France, Cunningham, et al., 2019), and be informed by similar studies (Atkins et al., 2008; Borgnakke, 2017; Britten et al., 2002; Britten & Pope, 2012; Cahill et al., 2018; Campbell et al., 2011; Erasmus, 2014; France, Uny, et al., 2019; Malpass et al., 2009; Morton et al., 2017; Noblit & Hare, 1988; Siau & Long, 2005; Toye et al., 2013; Toye et al., 2014). Although the number of papers included was relatively low, meta-ethnography is a complex methodology and synthesis process that entails numerous challenges and limitations (Noyes et al., 2018). For this review, a main limitation in the search phase was that no efforts were made to contact the authors to request additional information on their studies. This would have added additional time constraints that were not seen as feasible. For the same reason, although reference tracking was originally planned (Cruz-Martínez et al., 2019), no further inclusions through this method were considered.

Although it was an exclusion criterion, it could arguably be seen as a limitation that some studies were excluded because they did not explicitly describe their underlying approaches. Including more papers could have arguably added new perspectives to the synthesis, but the added time to the interpretative task would have been too burdensome. In the translation phase, several concepts and themes required a high level of interpretation and study contextualisation acquired by rereading the articles several times and with different intentions (e.g., for data extraction, comparison, or verification) (Cahill et al., 2018). The main reviewer applied this approach, but co-reviewers followed a sequential approach focused on validation or identification of inconsistencies. Finally, it should also be noted that the key ingredients were sometimes extracted from the sources cited by the selected studies. Hence, the review could have missed updates and refined assumptions or principles. For example, the intervention mapping protocol has been continuously upgraded in comparison with the cited source of the selected studies (Kok et al., 2017).

## Conclusions

The multidisciplinary gap naturally constrains eHealth research and development to the structures and perspectives of discipline-specific frameworks that often miss key factors of the complex reality in health care. A holistic approach to the problem should consider multidisciplinary principles, such as those outlined by this review, to better define, structure, and report the underlying approaches to research and development of future eHealth interventions. The principles of the CeHRes roadmap mapped fairly well to what has been done in the selected literature. Positively, the use of participatory, user-centred design, and continuous evaluation cycles were commonly applied principles. On the contrary, less attention was given to the integration of implementation in the development process and implications of the new eHealth-based health care infrastructures as a whole. The integration of theory and evidence to inform (persuasive) design was an important principle that arose from the included studies, but the frameworks or models used to this purpose are not focused on creating a fit between human and technology. Overall, it is recommended that researchers and developers make explicit and concrete statements about their approaches to eHealth. For instance, once a thoughtful decision has been made on guiding frameworks, models, or theories, it would be useful to also underline the holistic principles that are considered valuable by the research team (e.g., will the approach consider existing evidence and theory or will it be solely guided by new data?). Unfortunately, there are no gold standards to report the content of eHealth interventions, beyond the CONSORT-EHEALTH checklist v.1.6 (Baker et al., 2010; Eysenbach, 2011), which is specific to trials, and even less so to report underlying guiding principles.

In the future, clearer operationalisation (and reporting) of guiding frameworks and theoretical models is seen as vital to advance such knowledge in the field, as better predictive theories could provide an answer to the question ‘what works, for whom, in what settings, to change what behaviours, and how?’ (Michie et al., 2017). By and large, both theory and evidence must converge to determine the most effective mechanisms for technology-supported interventions. To accomplish this and move beyond what can be learned from published literature, holistic approaches can integrate patient-centred studies with consolidated knowledge from expert-based approaches (e.g., via Delphi or other group decision-making methods) (Hsu & Sandford, 2007).

Finally, many questions still remain regarding the optimal use and advantages of specific frameworks or theories for eHealth development. Future reviews could aim to compare the effectiveness of theory-based eHealth interventions with those that do not make use of any. Moreover, more exploratory works are needed to understand how different frameworks or theories are more relevant or useful for specific settings and contexts (e.g., which types of theories or frameworks are better suited to inform remote care interventions and why?).

# Chapter 4

## Tailoring eHealth design to support the self-care needs of patients with cardiovascular diseases: A vignette survey experiment

**This chapter is based on the following publication:**

Cruz-Martínez, R. R., Wentzel, J., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (2021). Tailoring eHealth design to support the self-care needs of patients with cardiovascular diseases: a vignette survey experiment. *Behaviour & Information Technology*, 1-22. doi: 10.1080/0144929X.2021.1971764.



## ABSTRACT

**Background:** Self-care support is a key cornerstone of treatment for patients with a cardiovascular disease. The success of any supportive intervention requires adaptation to the distinct needs of individuals. This requirement also applies to eHealth interventions.

**Objective:** This study investigates how experts from multiple fields of science assess the potential success of different eHealth design strategies when matched to key self-care needs.

**Methods:** An online vignette survey experiment was conducted. Nine vignettes representing different combinations of self-care needs (maintenance, monitoring, management) and eHealth persuasive design strategies (primary task support, dialogue support, social support) were evaluated. In total, 118 experts from 18 different countries participated in the survey.

**Results:** Their evaluations show primary task support as a promising design strategy across all self-care needs. In contrast, dialogue support and social support showed more promise for specific self-care needs.

**Conclusions:** Above all, according to experts, the success of design strategies could be enhanced by (i) personalising the pacing of the intervention and (ii) tailoring the information to the literacy and culture of the person. Adding to that, self-care support should distinctly (iii) support the three self-care needs, be (iv) patient-centred, (v) support the collaboration with caregivers, and (vi) be aligned to the life goals and values of individuals.

## INTRODUCTION

### A vision of self-care: Part 4

The previous chapter showed there are gaps in the research and development taking place at the crossroads of eHealth, self-care, and CVD. Mainly, because researchers and developers often use discipline-specific theories, models, or frameworks which miss other key factors of the complex reality in CVD self-care and health care. Moreover, it was observed that researchers and developers do not always make explicit and concrete statements about their underlying approaches to eHealth (e.g., due to space constraints in scientific publishing). As a result, it could not always be established if or what decisions were made by research and development teams to guide the development or design of eHealth. To follow up on these results, it was decided to take a more direct approach in understanding how eHealth can be designed to specific cases of CVD self-care.

### Focus of the present chapter

The present chapter describes an expert-centred study that addressed the question: what are some of the most promising eHealth (persuasive) design strategies that can be tailored to the theory-based, key elements of self-care? The expert-centred study was conceived as a direct follow-up of the systematic literature review described in **Chapter 2** and **Chapter 3**. There was a necessity to go beyond what was found in published literature and that is why a decision was made to directly involve eHealth researchers and developers to express their choices when it comes to tailoring eHealth design to the case of CVD self-care support. Figure 4.1 recalls that three key needs or processes could be identified within self-care. Such key processes could be used to prompt the judgements and opinions of researchers and developers regarding the tailored design of eHealth for CVD self-care.

Figure 4.1. To go beyond what can be found in published literature, the judgements and opinions of researchers and developers of eHealth could be collected and analysed to better understand how to tailor support to the key needs of CVD self-care.

### The design of eHealth could be best tailored to key self-care needs:

**Self-care maintenance** entails the performance of behaviours to improve well-being, preserve health, or maintain physical and emotional stability. The goal is to preserve health and prevent symptom exacerbations. (Riegel et al., 2012, 2019)

**Self-care monitoring** refers to the process of routine, vigilant body monitoring, surveillance, or 'body listening'. The goal is recognition that a change has occurred. (Riegel et al., 2012, 2019)

**Self-care management** refers to the evaluation of changes in physical and emotional signs or symptoms to determine if action is needed. The goal is the effective treatment of symptoms. (Riegel et al., 2012, 2019)

## BACKGROUND LITERATURE

Cardiovascular disease (CVD) adds an alarming burden to health care systems worldwide (Roth et al., 2017). A key cornerstone of treatment that can lessen such burden is to support the self-care goals and behaviours of patients (Riegel, Moser, et al., 2017). To effectively support self-care, a strategy must consider the distinct needs of the individual, their most relevant goals, and key behaviours (Harvey et al., 2015; Tadas & Coyle, 2020). For example, the needs of a patient with a stable condition might centre on the goal of improving general health and well-being to minimise risks, which can be achieved through the performance of healthy behaviours such as going for a short walk every morning. The present study investigates how the design of technology-based interventions can be tailored to better support the varying self-care needs of patients. The approach of using technology to support health, well-being, and health care is better known by the concept of electronic health or eHealth (van Gemert-Pijnen, Kip, et al., 2018). The study proposed different eHealth design strategies to support distinct theory-based selfcare needs, and asked individuals with diverse professional backgrounds and expertise to evaluate their potential success (e.g., cardiologists, psychologists, and technology designers). The study follows the premise that multidisciplinary expert stakeholders play key roles in the process of eHealth development. In that regard, the present study aimed to take a ‘holistic’ view of eHealth development to capture many of the influencing factors that determine the success of eHealth (e.g., human, technological, and contextual factors) (van Gemert-Pijnen et al., 2011). Therefore, the views of experts were studied to better understand their diverse views and approaches to eHealth design when it comes to self-care support. To elaborate on this approach, the following sections introduce two overarching themes that inspired this study.

### Designing eHealth for self-care with theory

To better understand the needs of patients, it is important to understand self-care as a complex process involving multiple goals and behaviours. This paper uses the term self-care instead of self-management, self-regulation, or other related terms, adhering to the propositions of the Middle-Range Theory of Self-Care of Chronic Illness (Matarese et al., 2018; Riegel, Jaarsma, et al., 2019; Riegel et al., 2012). This theory posits that self-care entails key processes of health maintenance (e.g., to take a short walk every day), monitoring (e.g., to routinely measure blood pressure), and management (e.g., to decide if a perceived symptom is a reason to call the health care provider) (Riegel et al., 2012). This theory outlines the complexity of self-care because it explains how it can be influenced by multiple, reciprocally interacting factors such as the experience, motivation, and cultural beliefs of the patient (Riegel, Jaarsma, et al., 2019). The use of theory in self-care studies also contributes to the accumulation and curation of knowledge, thus facilitating progress towards the identification of the most promising components for self-care support (Cornet, Daley, et al., 2020; Jaarsma et al., 2020; Riegel, Dunbar, et al., 2019; Toukhsati et al., 2019).

The complexity of the individual self-care process makes it important to identify what support strategies work best, for whom, and why (Hekler et al., 2016; Jaarsma et al., 2020; Riegel, Dunbar, et al., 2019). The present study specifically investigates strategies that are embedded in eHealth design to support the self-care of patients with a CVD. There is already a lot of accumulated evidence that eHealth can support self-care of chronic conditions, including all types of CVD (Greenwood et al., 2017; Hanlon et al., 2017; Kebapci et al., 2020; Kim & Lee, 2017; Riegel, Moser, et al., 2017; Villarreal & Berbey-Alvarez, 2020). All in all, the promise of eHealth seems to rest on its ability to support patients while they are at their homes and communities. For instance, smartphone-based applications that seek to remotely support self-care of patients with heart failure or hypertension have been found to be feasible, acceptable, and effective interventions (Cajita et al., 2017; Chandler et al., 2019; Chantler et al., 2016; Foster, 2018; Triantafyllidis et al., 2019; Woods et al., 2019b).

To effectively support self-care, an eHealth technology can integrate multiple **design strategies**. The challenge of designing for self-care arises because multiple agents and their roles must be considered (e.g., patients, family members, informal caregivers, and health care professionals) (Cornet, Daley, et al., 2020). To put an example, design strategies can direct what type of content (e.g., information about the disease) and mode of presentation is employed (e.g., text or videos). Technology design models such as the Persuasive Systems Design (PSD) model can be used to select supportive design strategies (Oinas-Kukkonen & Harjumaa, 2009). The PSD model categorises design strategies that aim to increase a system's persuasiveness, meaning how much it can motivate its users to reach their goals (Oinas-Kukkonen & Harjumaa, 2009). For instance, patients who need to improve their general health and aim to do so by increasing physical activity could be supported by a planner to schedule daily exercise sessions (an example of what the PSD model calls primary task support). Alternatively, the same patients with the same need could be supported through the delivery of motivational messages to their phones (an example of what the PSD model calls dialogue support). Finally, the same patients could also be supported via the enrolment in an online support group with other individuals that share similar goals (an example of what the PSD model calls social support).

In practice, persuasive design strategies can be operationalised in many different ways in an eHealth technology. For instance, they can be tailored to target key psycho-behavioural determinants that potentially increase eHealth effectiveness (e.g., targeting an individual's motivation to change) (Oyebode et al., 2021; van Velsen et al., 2019). In studies of persuasive design, strategies have targeted specific determinants using theoretical frameworks such as self-determination theory (van Velsen et al., 2019) or the ARCS motivation model (Oyebode et al., 2021). In a similar way, it is plausible that different strategies could also have varying effects on the distinct processes of self-care that are proposed by the Middle-Range Theory of Self-Care of Chronic Illness (e.g., the same factor could act as a facilitator or a barrier, depending on the person, the need, and the context) (Harvey et al., 2015; Tadas & Coyle, 2020). Moreover, research has suggested that persuasive design strategies such as goal-setting, suggestions, or reminders are key components of eHealth interventions that aim to promote healthy lifestyles (Lentferink et al., 2017). However, in the context of CVD, no studies have yet explored how specific eHealth (persuasive) design strategies should actually be operationalised and tailored to the diverse and dynamic self-care processes to achieve optimal support.

## **Studying the tailoring of eHealth design through vignette survey experiments**

Several approaches that can be used to inform, guide, or operationalise the tailoring of eHealth design to the patients' characteristics can be identified in scientific publications. For instance, the use of theoretical models to inform or justify design choices, the creation of 'representative' user profiles to guide or reflect upon the design work, or the development of data-driven adaptive features to operationalise tailoring during implementation (Cruz-Martínez et al., 2018; Haldane et al., 2019; Mawson et al., 2016; Wais-Zechmann et al., 2018; Wildeboer et al., 2016). However, in the specific case of tailoring for CVD self-care, this type of information is still often lacking or left unclear in published reports. Case in point, a recent review of eHealth interventions within this scope showed that the vast majority of theoretical models used to inform their design was not suitable to capture all relevant factors (e.g., developers did not consider technology-driven models) (Cruz-Martínez et al., 2020). In general, detailed descriptions of the guiding design approaches were lacking, making it difficult to identify what type of knowledge informed, guided, or was used somehow to tailor an intervention (Cruz-Martínez et al., 2020). As noted before, the approaches that expert stakeholders adopt to inform, guide, or operationalise eHealth design matters because their choices can end up determining the success of an intervention.

Thus, here lies a gap in the case of CVD self-care, because previous works have not directly studied how or why specific eHealth design strategies could be successful at supporting some self-care needs, while being less promising for others. To bridge the aforementioned gap, it is important to identify how eHealth could be tailored to ensure an optimal match between different types of design features and the dynamic self-care needs of patients with a CVD. For example, to identify what influencing factors could be the most relevant for a patient with an outstanding maintenance need, and then select the eHealth design features that could best support them. To pursue that goal, one could consider developing contrasting versions of a particular eHealth intervention, then deliver each version to a suitable amount of individuals, and finally observe their outcomes before making an informed decision for the best tailoring approach. However, that could be a highly inefficient way to meet the goal, as it would take time and resources to develop and test multiple designs of the same intervention. Alternatively, to study the potential effect of eHealth design strategies on distinct self-care needs, and to go beyond what can be found in the literature, the present study proposes to form a multidisciplinary panel of experts that can directly tackle the gap and pursue the main goal (e.g., experts such as cardiologists, nurses, technology designers, or psychologists who conduct research on eHealth or use it in their professional practice to treat CVD).

Certainly, it must be noted that the views of experts can only provide a partial view on the matter, as it leaves out the perspectives of patients. However, the present work adopts a holistic view of eHealth that seeks to explore the views of all key stakeholders who are involved in the process of design and development (van Gemert-Pijnen et al., 2011). For that reason, the study holds the premise that systematically assessing the views of experts on the tailoring of eHealth design for self-care is a feasible and relevant step that can begin to bridge the observed gap in the published literature at the crossroads of self-care, CVD, and eHealth (Cruz-Martínez et al., 2020). That is, because published literature does not always clarify how eHealth researchers and developers underpin their design choices (e.g., in theory, empirical studies, or intuition). Nevertheless, expert stakeholders play important roles in determining how supportive strategies are matched to the needs of individuals in the target population. Thus, studying their views and decisions could provide a deeper understanding of how eHealth design can be tailored to best support self-care.

Importantly, when a panel of experts is involved, it is necessary to collect and analyse data in such a way that it derives valid and structured conclusions, rather than just a collection of multiple and diverse opinions. To this end, a vignette survey experiment was proposed as a suitable method. **Vignettes** are short, systematically varied descriptions of situations or persons (Atzmüller & Steiner, 2010). In a vignette experiment, respondents are confronted with vignettes that are composed of a (randomised) combination of different factors (which is why they are also called factorial survey experiments) (Atzmüller & Steiner, 2010; Auspurg & Hinz, 2015). The experimental approach aims to identify how each factor might causally affect individual responses to the contextualised, hypothetical settings depicted in the vignettes (Atzmüller & Steiner, 2010). The vignettes can be presented to respondents within the survey in many different forms, for example using keywords, narrative text, pictures, audio, or videos (Atzmüller & Steiner, 2010). The vignettes can also provide rich qualitative data because they generate reactions to stimuli that seeks to closely resemble realistic situations (Jackson et al., 2015). In short, this study proposes that a vignette survey experimental approach can facilitate the collection of key, contextualised information from experts, which will advance knowledge of how distinct eHealth design strategies can better match specific self-care needs of patients with a CVD.

## Aim

The present study aims to investigate how experts from multiple fields of science (such as medicine, psychology, or technology design) assess the potential success of eHealth design strategies when matched to the specific processes of self-care maintenance, monitoring, and management.

The multidisciplinary perspective is important to capture various dimensions of factors that are often missed by discipline-specific studies. The results of the study will provide practical knowledge on which eHealth design strategies are potentially more effective than others, and why. This practical knowledge will be used in future studies to design and test prototypes that are tailored to specific needs, relevant goals, and key behaviours. The main research questions of the study are:

(1) What eHealth design strategies are most promising (i.e., perceived to be successful), according to the views of experts, to support distinct self-care needs of patients with a CVD?

(2) According to the views of experts, what factors can explain the high or low promise (i.e., perceived success) of eHealth design strategies to support distinct self-care needs of patients with a CVD?

To assess the external validity of the results, an additional question was also of interest: how realistic are the cases depicted in the vignettes, according to experts from multiple fields of science? An advantage of vignette survey experiments is precisely that they aim to balance both internal and external validity (Auspurg & Hinz, 2015). Although it is not a main study question, providing an answer to it could help to establish the generalisability of the results.

## METHODS

### Study design

An online vignette survey experiment was conducted (Auspurg & Hinz, 2015). The survey collected both quantitative and qualitative data in parallel. Data were analysed separately at first but brought together at the discussion level to bridge all key findings of the study (Creswell & Clark, 2017; Fetters et al., 2013).

### Experimental factors and design

To answer the research questions, a factorial experimental design was used in order to establish how single factors and their levels, as depicted and systematically varied in the vignettes, causally affected individual responses (Atzmüller & Steiner, 2010). It must be emphasised that, in contrast to typical experiments of interventions in health care, vignette experiments use short, systematically varied descriptions of situations or persons (called vignettes) to elicit the beliefs, attitudes, or behaviours of respondents with respect to the scenarios presented within the survey (Steiner et al., 2017). Following that rationale, the factorial design of the present study included two factors, self-care needs and eHealth design strategies, with three levels each. The factor levels defining distinct self-care needs were based on the Middle-Range Theory of Self-Care of Chronic Illness (Riegel et al., 2012). The three levels were: maintenance, defined as the performance of behaviours to improve well-being, preserve health, or to maintain physical and emotional stability; monitoring, defined as the process of routine, vigilant body monitoring, surveillance, or ‘body listening’; and management, defined as the evaluation of changes in physical and emotional signs and symptoms to determine if action is needed (Riegel et al., 2012).

The factor levels defining different eHealth design strategies were based on the PSD model and previous studies on eHealth design (Oinas-Kukkonen & Harjumaa, 2009). The three levels used were: **primary task support**, defined as a persuasive design strategy that directly supports the user in carrying out a primary task; **dialogue support**, defined as a persuasive design strategy that implements computer–human dialogue in a manner that helps the user move towards the goal or target behaviour; and **social support**, defined as a persuasive design strategy that seeks to motivate the user by leveraging social influence (Oinas-Kukkonen & Harjumaa, 2009). These levels were chosen based on previous studies of eHealth design (Asbjørnsen et al., 2020; Lentferink et al., 2017; van Velsen et al., 2019) and because in the PSD model they are broad, easily distinguishable categories that can include more specific principles to persuade users into behaviour change.

For example, differentiating the previously defined categories could be easier and more relevant than differentiating ‘reminders’ from ‘suggestions’, both of which are specific principles placed under the dialogue support category. The factorial design resulting from the combination of these factors and levels delivers a population of 9 different vignettes ( $3 \times 3$  or  $3^2$ ). Figure 4.2 presents an overview of the nine vignettes, and Figure 4.3 in the next section presents an example of a vignette design and structure, as it appeared in the survey. For easier comparison, Appendix 1 as reported by Cruz-Martínez, Wentzel, Sanderman, et al. (2021) presents a full list of key study definitions used throughout the paper. Moreover, Appendix 2 also as reported by Cruz-Martínez, Wentzel, Sanderman, et al. (2021) provides the full textual summaries of each vignette.

## Vignette design

To provide valid answers to the research questions, each vignette in Figure 4.2 must accurately describe a hypothetical scenario aligned to the corresponding combination of factors. To accomplish that, in each vignette the selfcare need was represented with a short video that described the situation and self-care needs of an individual with a CVD (left in Figure 4.3). To complement the vignette, the persuasive design strategy was represented by a visual mock-up of an eHealth intervention (right in Figure 4.2).

Specific cardiovascular conditions were used to make each case more realistic and contextualised. For that, three different conditions were selected to represent each self-care need (left in Figure 4.2). Coronary heart disease was selected for the maintenance need, hypertension for the monitoring need, and heart failure for the management need. An overview of CVD self-care studies shows that these three conditions demand engagement in all self-care needs (Riegel, Moser, et al., 2017).

On the other hand, a **mock-up** was created to contextualise the presentation of key components for an eHealth intervention (right in Figure 4.2). Mock-ups are a way to provide medium-fidelity representations of a design, and can complement other forms of description such as text or diagrams (Burns, 2018). A smartphone app was chosen as the mode of delivery because it is often used in eHealth interventions that combine **monitoring technologies** and **coaching technologies** to promote healthier lifestyles, and several examples were known by the research team from periodic literature searches and a systematic review of eHealth interventions for CVD (Cruz-Martínez et al., 2019; Cruz-Martínez et al., 2020). In short, the mock-up mimicked a smartphone app, its interface and presented a visualisation of active technological devices and its key ingredients. To make sure the depictions of the self-care needs or design strategies were clear, each vignette was iteratively revised with input from researchers of the department of Psychology, Health and Technology of the University of Twente, who were not involved in the study.

Figure 4.2. Factorial combination ( $3^2$ ) for the vignette survey experiment.

Factor 1: Self-care need		
Factor 2: Persuasive system design	Vignette 1 <b>Maintenance</b> supported by primary task support	Vignette 4 <b>Monitoring</b> supported by primary task support
	Vignette 2 <b>Maintenance</b> supported by dialogue support	Vignette 5 <b>Monitoring</b> supported by dialogue support
	Vignette 3 <b>Maintenance</b> supported by social support	Vignette 6 <b>Monitoring</b> supported by social support
		Vignette 7 <b>Management</b> supported by primary task support
		Vignette 8 <b>Management</b> supported by dialogue support
		Vignette 9 <b>Management</b> supported by social support

## Survey design

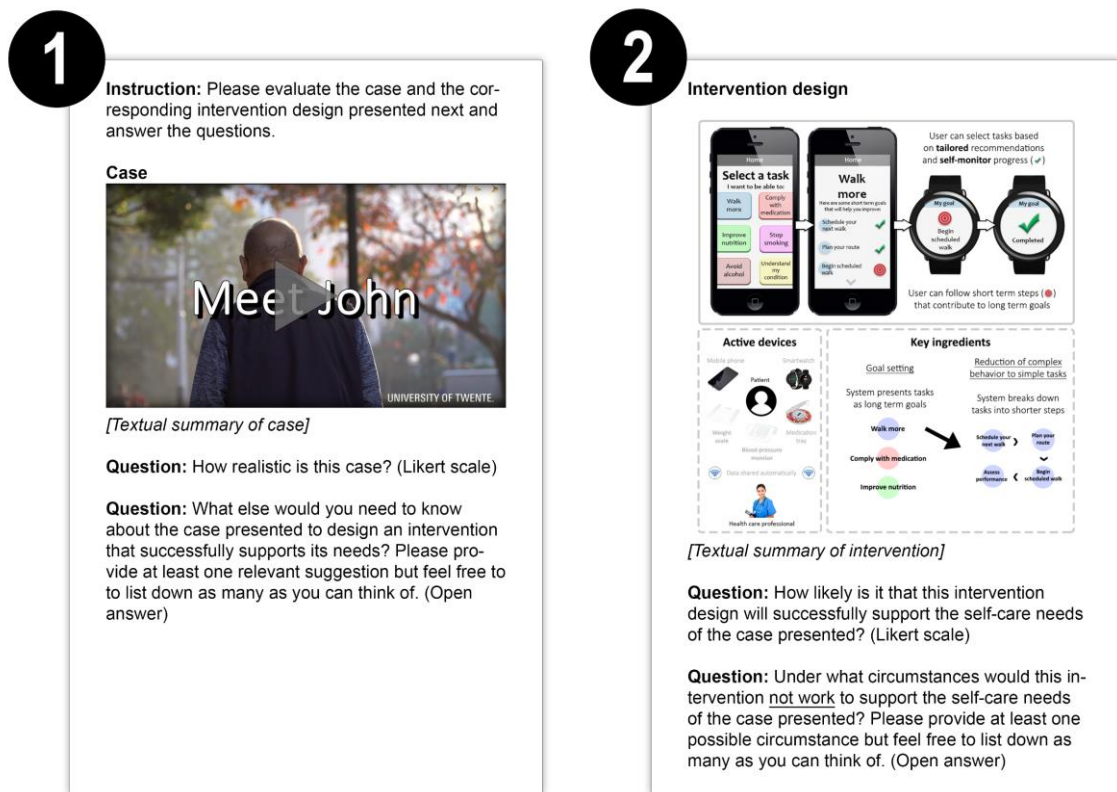
To answer both research questions, it was important to obtain sufficient assessments for all vignettes. However, principally to make it less burdensome and repetitive for respondents, the nine vignettes were divided into three different survey blocks. Dividing the survey into equally sized blocks (also called sets or decks) is a common technique of vignette survey experiments (Auspurg & Hinz, 2015). The survey was created using the Qualtrics software (Qualtrics, Provo, Utah, U.S.A.), and divided in three blocks. Earlier versions of the survey were also pilot tested with researchers not involved in the study. Appendix 3, as reported in Cruz-Martínez, Wentzel, Sanderman, et al. (2021), provides additional descriptions of each survey section and its content.

In accordance with the experimental approach, each respondent was randomised to one of the three different blocks. However, each block displayed the cases representing the self-care needs in the same order: first the maintenance need, then the monitoring need, and finally the management need. The main difference therefore was that each block presented a different mock-up of an eHealth design strategy as a solution to each case. The order was based on the propositions of the Middle-Range Theory of Self-Care of Chronic Illness, mainly by the argument that patients must lay a foundation on self-care maintenance first, and later build expertise in self-care monitoring and management (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012). Such theory-based order was preferred over total randomisation of vignettes across respondents, primarily because respondents could have been instinctively confused by the order in which vignettes are presented, or became highly aware of the aim of the study by having to rate two or more vignettes with repeated self-care needs or eHealth design strategies. Supporting this choice was evidence that shows order effects of vignettes are minimised when vignettes have a certain level of complexity (e.g., by video presentation rather than just a short text) (Auspurg & Jäckle, 2017).

As can be observed in Figure 4.3, for each vignette respondents were first presented with the self-care case video. They were then asked about how realistic the cases seemed to them. For that, they could answer via a 5-point Likert scale, ranging from ‘Extremely unrealistic’ to ‘Extremely realistic’. This was followed with an open-ended question asking about aspects of importance to design an intervention that successfully supports the case’s needs. In this way, respondents were primed to think about their own expertise and experience before presenting a mock-up. Next, respondents were presented with a mock-up and were asked about the likeliness to succeed of the eHealth intervention design to support the case’s self-care need. Respondents could also answer via a 5-point Likert scale, ranging from ‘Extremely unlikely’ to ‘Extremely likely’. After providing this rating, respondents were finally asked an open-ended question about the circumstances under which according to them the intervention would not work to support the self-care needs of the case presented.



Figure 4.3. Example of a single vignette, its design and structure in the survey experiment.



## Sample size and recruitment

The recruitment objective was to collect a minimum of 30 responses per vignette from experts and to randomise to each survey block to achieve balanced groups. Based on that objective, a minimum sample size of 100 participants was determined. Between January and April of 2020, 752 experts were invited to participate via e-mail. The list of potential participants was created by searching scientific publications, professional networking platforms (e.g., LinkedIn and ResearchGate), and websites of relevant institutions (e.g., directories of universities, medical associations, or research centres). Snowball sampling was also used, prompting those first invited to refer other experts. The survey was only accessible to individuals who received an invitation link via e-mail by the main researcher (RCM). In the case of referrals, their expertise and experience were checked before sending an invitation to participate. On top of that, the exit questions asked background information and an email for a potential follow-up. Although it was not possible to certify with a hundred percent confidence who was sitting behind the screen responding to the questions, the aforementioned steps were considered to provide sufficient confidence in the identity, expertise, and experience of the respondents (i.e., the pre-screening, the individual invitation links, and the exit questions).

As a selection criterion, **expertise** was defined as having cross-disciplinary or domain-specific knowledge in one of the key topics of the survey, which could include but not be limited to medical, behavioural, computer and informational systems engineering, design, human-technology interaction, human factors and ergonomics, and business or innovation. In addition, **experience** was defined as having led, participated, or consulted in projects of relevance to the topics of the survey. The projects could be related to academia, health care institutions, private industry, or policy-making. Ethical approval was obtained from the ethical committee of the Faculty of Behavioural, Management and Social sciences of the University of Twente (request number 191396).

## **Data analysis**

### **Quantitative data**

To answer the first research question, about the identification of the most promising eHealth design strategies to support specific self-care needs, it was hypothesised that vignette factor levels (the specific need or the design being presented) would have significant effects on the ratings, mainly by interactions between each other (e.g., that for the same case, different designs have higher or lower chances to be rated higher in the success scale). Quantitative data were entered into SPSS version 26 (IBM Corp., Armonk, New York, U.S.A.). Descriptive statistics (e.g., percentage distributions) and generalised linear mixed modeling (GLMM) were used due to the ordinal measurement level of the outcome variables and the hierarchical structure of the data (Garson, 2013; Heck et al., 2013). The dependent variables were the realism and success ratings given to the vignettes, while the independent variables were the vignette factors being rated. As an external validity check, the realism of each case presented was first examined. For this, it was expected that realism ratings would not differ between cases. For the GLMM of the success ratings, the five-point scale was collapsed into three categories because both the 'Extremely unlikely' and 'Extremely likely' categories had low counts (six, and three, respectively). For the GLMM of the realism ratings, the five-point scale was collapsed into four categories because the 'Extremely unrealistic' category had only three counts in total.

### **Qualitative data**

To answer the second research question, about the possible reasons argued by experts for the (lack of) perceived success of eHealth design strategies, qualitative data were analysed by RCM and JW with the thematic analysis method (Braun & Clarke, 2006). The thematic analysis could provide support to the answers of the first research question (e.g., why a strategy was seen as promising) or provide expanding or contrasting evidence (e.g., arguments for the potential of strategies despite being perceived as 'less successful'). To conduct the analysis, the data were exported to a Microsoft Excel 2016 workbook. The analysis consisted of four steps: (1) inductive pilot coding; (2) codebook-driven coding; (3) analysis and revision of coding results; and (4) searching and reviewing for themes.

The inductive coding pilot was performed independently by two reviewers (RCM and JW) on a small set of data extracts (i.e., individual responses to open ended questions), to become familiarised with the data. Next, RCM considered the results of the pilot and then proceeded to code all of the data to create an initial codebook, iteratively revising code labels and descriptions. The codebook resulting from RCM's full data coding was then used independently by JW, who could still suggest new codes or make notes when necessary. Once all data had been independently coded by both researchers using the codebook, RCM analysed the results and suggested revisions according to the levels of agreement reached. For instance, the highest priority of data extracts to revise were those with no agreements between reviewers despite multiple codes being proposed by one or both. A sub-set of these revisions were checked and approved by JW. At this stage it was judged that the qualitative data set had been analysed thoroughly and additional full dual reviewing was not deemed necessary. To finalise, RCM searched, reviewed, and defined the themes, receiving feedback from JW and JGP. The most salient codes by frequency and interpreted significance per vignette (case by design combinations) were taken as the basis for most themes.

## **RESULTS**

### **Characteristics of respondents**

Out of the 752 invited experts, 118 completed the survey (15.7% response rate). Respondents were from 18 countries in total.

The Netherlands (38.3%), the United Kingdom (10.3%) and the United States (8.4%) were the most common countries of origin. Most respondents categorised themselves as a ‘researcher’ (66.1%), rather than a ‘developer or implementer’ or a ‘health care professional or provider’. Table 4.1 presents an overview of the respondents’ expertise. Appendix 4, as reported by Cruz-Martínez, Wentzel, Sanderman, et al. (2021), provides more details about the respondents’ characteristics.

Table 4.1. Overview of respondents’ expertise.

Areas of expertise	Total (n)	Percentage (%)
<b>Medical sciences</b>		
Health sciences	41	34.8%
Nursing	25	21.2%
Medicine	16	13.6%
Technical medicine	3	2.5%
<b>Social sciences</b>		
Psychology	28	23.7%
Communication science	9	7.6%
Educational science	8	6.8%
Business and public administration	7	5.9%
Philosophy	2	1.7%
<b>Interdisciplinary sciences</b>		
Human-media interaction	15	12.7%
Human factors and ergonomics	13	11.0%
Biomedical engineering	9	7.6%
<b>Computer and engineering sciences</b>		
Computer and informational systems engineering	14	11.9%
<b>Other(s)</b>	16	13.6%

Notes: Respondents could select multiple ‘areas of expertise’, therefore percentages here do not add up to 100%. Sixteen respondents did not confirm or specify their expertise themselves via the exit questions of the survey, so their data are missing from the table.

## Quantitative results

In total, 329 ratings were collected about both the success and realism of vignettes. The goal was to collect three ratings per participant but 7.1% responses were missing (25 out of 354).

### Perceived success of eHealth design strategies

In answer to the first research question, about the identification of the most promising eHealth design strategies, the results show that some combinations of cases and designs did differ with each other. Figure 4.4 presents all percentage distributions of the success ratings per vignette. Figure 4.4 shows some noticeable differences in the ratings across vignettes. For instance, primary task support was more frequently rated as ‘very likely’ to succeed for both monitoring (V4) and management (V7) needs.

Similarly, dialogue support for a monitoring need (V5) was the highest rated combination. In contrast, the social support strategy was more frequently rated as ‘very unlikely’ to succeed for both monitoring (V6) and management (V9) needs. Dialogue support for a management need (V8) was also more frequently rated the same way. Interestingly, what Figure 4.4 also shows is that a large amount of experts settled for the ‘somewhat likely’ response option when rating the potential success of eHealth design strategies (from 48.6% for V8 up to 81.1% for V3). Table 4.2 presents an overview of the GLMM output of success ratings. Table 2 shows that some combinations of cases and designs did significantly differ with each other ( $F = 3.22$ ;  $p = .013$ ). Specifically, Table 4.2 reveals that, when compared to primary task support, social support was significantly less likely to be successful at supporting monitoring needs ( $OR = .167$ ; 95% CI .035–.801;  $p = .025$ ). Similarly, both dialogue ( $OR = .147$ ; 95% CI .028–.769;  $p = .023$ ) and social support ( $OR = .114$ ; 95% CI .024–.540;  $p = .006$ ) were significantly less likely to be successful at supporting management needs.

Figure 4.4. Percentage distribution of the success ratings per vignette (case x persuasive design strategy).

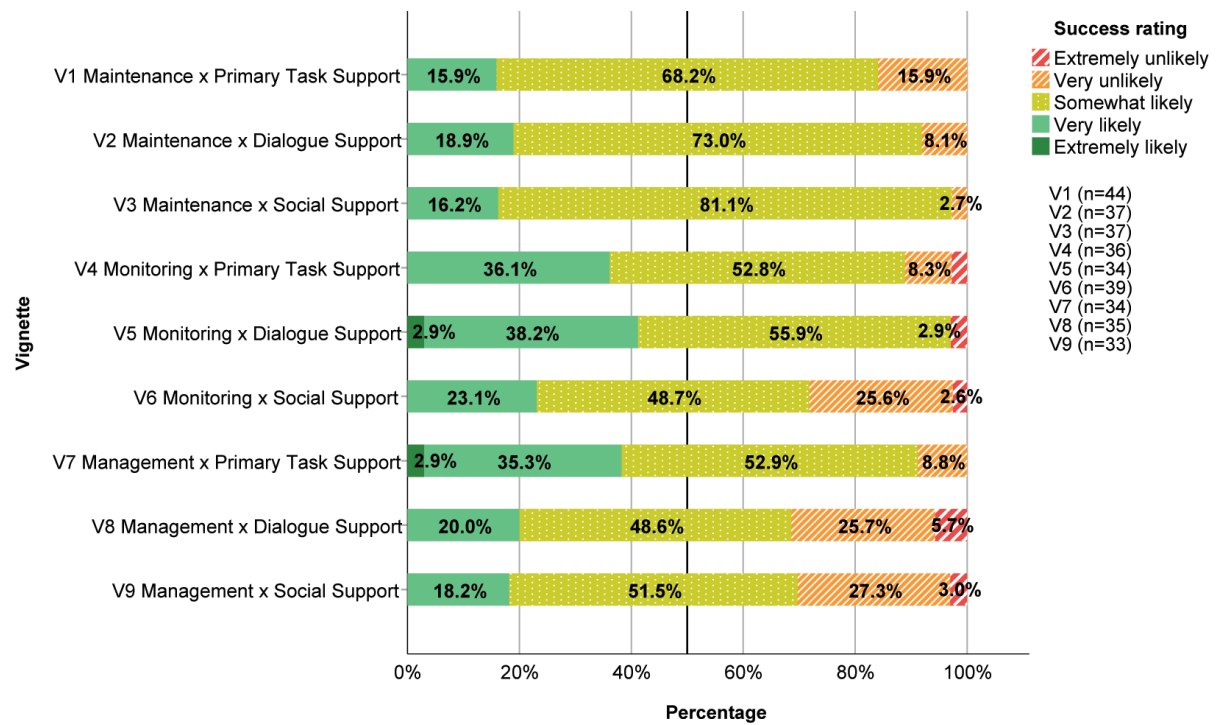


Table 4.2. Fixed coefficients in GLMM of success ratings.

Variables		Coefficient	SE	t	Sig.	OR	95% CI	
							Lower	Upper
Thresholds	0 (very or extremely unlikely)	-1.749	.3620	-4.831	<b>.000</b>	.174	.085	.355
	1 (somewhat likely)	1.796	.3604	4.983	<b>.000</b>	6.025	2.965	12.244
Management		1.204	.5277	2.283	<b>.023</b>	3.335	1.181	9.418
Monitoring		1.014	.5462	1.857	.064	2.758	.942	8.077
Social support		.576	.4337	1.327	.185	1.778	.757	4.174
Dialogue support		.404	.4813	.839	.402	1.498	.581	3.861
Management*Social support		-2.172	.7905	-2.747	<b>.006</b>	.114	.024	.540
Management*Dialogue support		-1.915	.8397	-2.280	<b>.023</b>	.147	.028	.769
Monitoring*Social support		-1.787	.7956	-2.247	<b>.025</b>	.167	.035	.801
Monitoring*Dialogue support		.113	.8175	.138	.891	1.119	.224	5.590

Notes: Case\*design fixed effect  $F=3.222$ ;  $p=.013$ ; probability distribution: multinomial; link function: cumulative logit. Statistically significant values highlighted in bold ( $p<.05$ ).

## Realism of the self-care cases

The self-care cases depicted in the vignettes were expected to be assessed as highly realistic by experts. However, the results show that this was not always the case. Figure 4.5 presents the percentage distribution of the realism ratings of cases and visualises how much, in comparison to the maintenance case, the monitoring and management cases were less frequently rated as being ‘very’ or ‘extremely’ realistic.

The observed difference was statistically significant ( $F=13.79$ ;  $p=.000$ ), as can be confirmed by the GLMM output of realism ratings shown in Table 4.3. Specifically, the monitoring ( $OR=.338$ ; 95% CI .195–.586;  $p=.000$ ) and management ( $OR=.325$ ; 95% CI .205–.516;  $p=.000$ ) case were significantly perceived to be less realistic when compared to the maintenance case.

Figure 4.5. Percentage distribution of the realism ratings of cases.

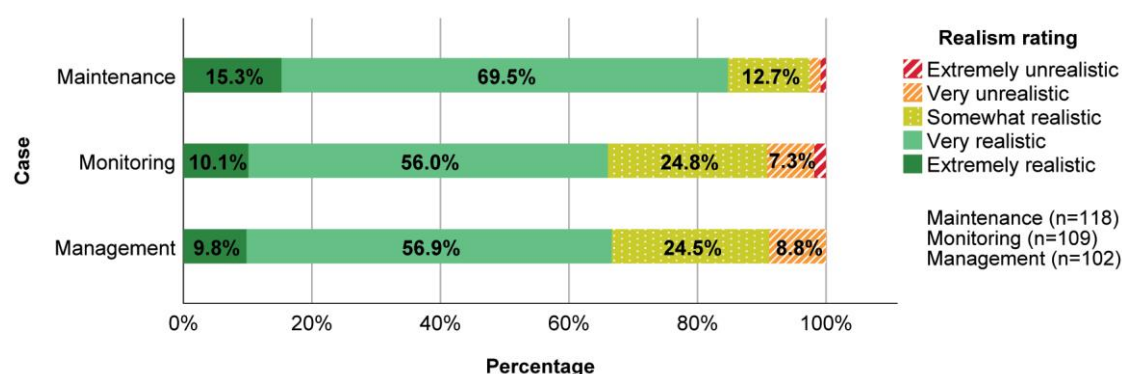


Table 4.3. Fixed coefficients in GLMM of realism ratings.

Case comparison	Coefficient	SE	t	Sig.	OR	95% CI	
Management (vs. Maintenance)	-1.124	.2351	-4.780	<b>.000</b>	.325	.205	.516
Monitoring (vs. Maintenance)	-1.084	.2793	-3.880	<b>.000</b>	.338	.195	.586

Notes:  $F=13.789$ ;  $p=.000$ ; probability distribution: multinomial; link function: cumulative logit. Statistically significant values highlighted in bold ( $p<.05$ ).

## Qualitative results

In answer to the second research question, about the arguments provided by experts to judge the potential (lack of) success of eHealth design strategies, the patterns of the qualitative data emphasised multiple approaches towards eHealth tailoring. At large, experts proposed how to tackle the multidimensional factors that can influence the potential success of design strategies for self-care support. Six major themes were identified:

- (1) Unraveling complexity to achieve patient centredness.
- (2) Addressing complexity by adjusting the pacing and simplicity of eHealth interventions.
- (3) Supporting persons and their circumstances, not just as patients.
- (4) Supporting collaboration between the patient and the health care team.
- (5) Targeting key objectives with eHealth support.
- (6) Fitting eHealth into self-care routines.

### Unraveling complexity to achieve patient centredness

According to experts, the success of any design strategy depended heavily on first conducting a holistic, thorough, patient-centred assessment. However, the list of influencing factors could be extensive, multidimensional, and naturally unknown to the health care provider or intervention designer. In practice, experts advised to collaboratively analyse key factors with the patient before considering any potential solutions. The primacy of patient-centredness was well described by the following quote:

*“To ensure the optimal personalisation of the intervention [we would seek to collect] baseline data around the subjects physical condition, mental health and current relevant behaviours, their attitudes to behaviour change and willingness to change, or to optimise each of the various behaviours and the barriers to those changes (i.e., how easy it is to improve behaviour or reach optimal behaviour for each indicator).” (eHealth developer with expertise on computer and informational systems engineering and neuroscience)*

Recurring views from experts suggested that the highest level of complexity in such an assessment comes with factors that are highly intertwined with each other. For instance, what was often referred to as the ‘social context and environment’ can be composed of several factors. The next quote exemplifies this for the maintenance case:

*“What is John’s family situation? Who makes the decisions on what to buy from the store? Who makes the foods John eats? Should the whole family be included in the intervention? Does John have any other conditions that we should be aware of? What is the education level of John? What kind of terminology should be used for him? In what kind of environment does John live in? Is it possible for him to, for example, take a walk in the neighbourhood or to go to a forest for a walk?” (eHealth researcher with expertise on communication science)*

Other important multifactorial aspects to consider were about the availability of technology, its acceptability as a potential solution to self-care needs, and finally, the capability of the patient to actually use it for that purpose. Similarly, the patient’s own previous experience in self-care was complex because it could englobe both favourable and unfavourable beliefs or attitudes towards intervention components.

### Addressing complexity by adjusting the pacing and simplicity of eHealth interventions

According to experts, the success of design strategies goes beyond simply matching problem A with solution B. What matters the most is to address the problem in the simplest, most meaningful way. To do this, experts highlighted the importance of attuning the pacing of the intervention to what better fits each patient according to their experiences, abilities, or attitudes. This idea is outlined by the next quote:

*“It comes down to what kind of patient is in front of you. In case of our own mHealth [mobile health] intervention, I can say that the majority of patients is cooperating without an issue. They learn about their disease and via that route, they manage to both improve their lifestyle and ask better questions to the physician. However, there are many patients who need (technology) support. This cannot be disregarded when starting an mHealth intervention.” (eHealth implementer with expertise on medicine)*

Experts emphasised that pacing does not apply only to the ability of using technology, but extends to the patient’s physical or mental state and current knowledge or skills in self-care. Therefore, tailoring also requires adaptation to the patient’s informational, learning, or reflective needs. This refers to what patients need to know, how they can better get to learn it, and how they prefer to reflect about it. For example, the following two experts envisioned two different directions in the provision of information for the management case:

*“I am not sure whether it is advantageous to know all side effects of medication. I know from experience that patients get very afraid about those side effects, leading to negative emotions, which in turn can affect the desired positive outcome of the intervention.” (eHealth researcher with expertise on communication science, human-media interaction, and psychology)*

*“I think a personal plan involves more than text messages can solve. An online ‘workbook’ with questions and assignments that help George to deal with his lack of knowledge on symptoms and guidelines and solutions for the necessary adjustments could be an extra intervention, and again with the guidance needed.” (eHealth researcher with expertise on health sciences, nursing, and philosophy)*

## Supporting persons and their circumstances, not just as patients

According to experts, despite the wide range of potential design strategies that can be considered, the starting point in offering support is clear: start where the patient chooses. In other words, when supporting self-care: prioritise the person over the patient. The next quote exemplifies this approach for the maintenance case:

*“What are concrete goals in regard of daily life which are hindered by his illness? For example, related to career, leisure, social interactions, etc. In my view, to be successful in goal achievement, these personal goals should be the starting point and determine what should be John’s medical and functional goals and subsequently the self-care tasks/activities John should perform to achieve these goals (medical and personal). For example, John wants to go on a world-trip. This requires John to be in relative good health, which can be achieved through performing self-care activities X, Y and Z.” (eHealth researcher with expertise on human-media interaction)*

Several experts reasoned that this approach to promote self-care must leverage on a person’s intrinsic motivation. Nevertheless, some experts also warned that behaviour change is not just about motivation. To help the person achieve their life goals, experts emphasised that all design strategies must be aware of the context or the person’s circumstances:

*“I think simplification of the complex behaviour is a good way to support self-care. However, one also needs to consider external factors as these are very much context dependent. For example, John, as an old man, may find it difficult and inconvenient to take a walk when it is raining outside. Hence, when breaking down the tasks into shorter steps, the system should be aware of the context.” (eHealth researcher with expertise on human-media interaction)*

## Supporting collaboration between the patient and the health care team

In the view of experts, the most successful strategies are those that facilitate (rather than seek to replace) the collaboration between a person and the health care team. However, experts in this study did not just prefer warm over cold care, but also emphasised that what is necessary is to provide health care professionals the right tools to support the self-care process. This challenge is noted by the following quote:

*“How are the data to be presented to the health care professional? Our research showed sharing is an important motivator but professionals do not want a constant stream of raw data and will not participate unless the data has been intelligently presented and transferred to them in a way that is congruent with other data such as hospital letters. I.e., they do not like having to log on to a website.” (eHealth researcher with expertise on health sciences and nursing)*

Design strategies that skip over the process of collaboration could overwhelm patients, especially for the interpretation of symptoms and the decisions about how and when to take action. On the other hand, several experts made the point that collaboration must still be driven by patient-centredness. The following quote highlights again this important requirement:

*“It is pretty clear in this case scenario what health care professionals think that the patient should do, and why. What I completely miss in this case scenario is the patient’s own intrinsic motivation. I therefore also miss any tool and/or strategy to explore and strengthen that intrinsic motivation.” (Expert on preventive cardiology)*

## Targeting key objectives with eHealth support

According to experts, while health care providers are indispensable, eHealth does have things to offer for self-care support. One of the key objectives that eHealth can help with is to increase the patient's health literacy. Bridging the knowledge-behaviour gap was a key challenge, as it could be for the maintenance case (e.g., understanding information about condition, medication, long-term effects). Another important objective for eHealth is to support the habituation to monitoring signals and symptoms. This is outlined for the monitoring case in the following quote:

*“Why not let technology work as it already does? The APIs [application programming interfaces] in the mobile systems take in the measurements automatically from internet-capable devices such as scales and blood pressure monitors and the system could simply show the ongoing trend and maybe the latest reading and show if there is a gap (e.g., if the user did not step on scales this week).” (eHealth researcher with expertise on human factors and ergonomics, and psychology)*

Beyond simply monitoring, experts also highlighted the importance of the provision of feedback, and its potential challenges. Three key objectives that eHealth design strategies could help with were identified in this area: to increase awareness, to facilitate sense-making, and to support emotional control (e.g., over anxiety or fear). Both primary task support and dialogue support were often endorsed as suitable persuasive strategies that could be applied to fulfil these objectives.

## Fitting eHealth into self-care routines

According to experts, overcomplicated and unnecessary design strategies would only hinder eHealth's uptake and fit in a person's life. However, doing this required more than just simplicity. Remarkably, several experts called for eHealth to be empathic, reassuring, and empowering.

In this regard, several experts suggested that eHealth design strategies must be personalised to reflect a person's internal narrative of his/her condition, for example by offering tailored messages. The following quote gives an example of this approach:

*“Jane's main problem is fear of [the consequences of her] condition and of information that might likely tell her that her condition is not improving. She needs to be empowered by the technology, not disabled by it. Technology is not always positive, unless [...] the interpretation of results is very easy and clear, [which might not occur] particularly if [the] technology breaks or is unreliable.” (eHealth researcher with expertise on health sciences and psychology)*

Experts in this study also endorsed tailored prompts to incentivise engagement and progress in self-care. The next quote outlines this method for the maintenance case:

*“Leaving the selection of the tasks to the patient may promote selection bias towards the easiest task for that particular patient. One possible example is the patient selecting the ‘walk more’ goal and never selecting ‘stop smoking’. Maybe forcing less preferred tasks from time to time could be more effective towards more relevant changes in the patient's lifestyle.” (eHealth researcher with expertise on computer and informational systems engineering)*



## DISCUSSION

The present study pursued the goal of understanding how to best tailor eHealth for self-care support by matching design strategies with the distinct needs of patients with a CVD. The goal was operationalised as two main research questions, which can be simplified as what works? And why does it work? When it comes to self-care support through eHealth.

The first research question sought to identify, from the view of experts, the most promising eHealth design strategies that can support specific self-care needs (i.e., under what context is a strategy most promising?). The results showed that primary task support was seen as a promising design strategy across different self-care needs. In contrast to that, while dialogue support was also promising for maintenance and monitoring needs, it was perceived to be less promising when supporting a management need. Moreover and notably, social support was perceived to be most promising only when supporting a maintenance self-care need. To characterise these findings, it must be noted that a large amount of experts settled for the 'somewhat likely' response option when rating the potential success of eHealth designs (see Figure 4.4). That observation highlights the importance of the answer obtained for the second research question of this study.

The second research question sought to integrate the arguments from experts about the potential success of eHealth design strategies when matched to specific self-care needs (i.e., why would a strategy work or not under that specific context?). The results relating to this question were represented by six major themes. These themes showed in general how the multidimensional, complex nature of self-care presents a remarkable challenge for eHealth design. In the following sections, the findings of the study are discussed along with related literature.

### **Promising eHealth design strategies to support distinct self-care needs**

#### **Primary task support**

As remarked above, the results suggest that primary task support could be a promising eHealth design strategy across different self-care needs of patients with a CVD. In light of the themes of the qualitative data, the promise of this strategy seems to rest on the potential simplification of the various tasks across different self-care goals (maintenance, monitoring, and management). Experts suggested how different operationalisation of primary task support could match the varying behaviours across the theory-based self-care processes. For example, by setting personally meaningful goals for self-care maintenance (e.g., to support engagement in physical activity), facilitating self-care monitoring through automatic measurements (e.g., to support symptoms monitoring), or lowering the threshold of communication with the health care team for self-care management (e.g., to support collaboration with clinicians).

Research from the perspective of end users supports the large and promising applicability of primary task support strategies that was noted by experts involved in the present study. For instance, research on how eHealth can support long-term weight control has shown that end users could benefit from direct support to their self-regulation skills (Asbjørnsen et al., 2020). Adding to that, primary task support principles within the PSD model such as 'reduction' (e.g., stepped, short term goals) or 'personalisation' (e.g., self-set goals) have been recognised as necessary components that can help achieve health outcomes (Lentferink et al., 2017). Likewise, literature with a clinical perspective argues that these types of components could also help promote the underlying principle that there must be a shared responsibility between health care providers and patients (Riegel, Jaarsma, et al., 2019; Tadas & Coyle, 2020).

In the present study, respondents with clinical expertise often emphasised the important balance between giving the patient the initiative while at the same time not leaving them completely alone in the process. In contrast to that, respondents with technical backgrounds rather emphasised the potential of eHealth to simplify or automatise tasks that could decrease the burden to the patient.

## Dialogue support

In turn, the dialogue support design strategy was seen as promising for maintenance and monitoring needs (or at least as much as primary task support), but less so for a management need. According to several experts, the most salient barrier for the success of dialogue support was actually the fragility of the person depicted in the management case, and not the design itself. For some experts this combination was even unrealistic because someone like George (the fictional person depicted in the management case) would not be left alone or even 'trusted' with only technology to manage his own condition.

Therefore, dialogue support seemed to be frequently judged by experts to be inadequate when the case at hand showed a dire need for more direct help and guidance to ensure the safety of the patient. These views made evident that another important objective for eHealth support was to minimise risks and contribute to ensure the patient's safety. The aforementioned insights aligns with research that has shown end users do appreciate dialogue support strategies such as receiving suggestions or reminders, as they could help them build confidence or motivation towards their goals (Oyebode et al., 2021). Furthermore, related literature also supports the important requirement – noted repeatedly by experts involved in the present study – that communications must be timely, context-aware, and customisable by end users (Vo et al., 2019). In that sense, the arguments in favour of dialogue support put forward by experts echoed the importance of underlying principles that eHealth developers and implementers should consider when aiming to support self-care. For example, on the principle of patient-centredness, which under this context meant to ensure that communications from the technology stay relevant to the patients' preferences and personal circumstances (e.g., literacy level and culture).

## Social support

In the case of the social support design strategy, its merit was strikingly judged by many experts to be lower for the monitoring and management needs (when compared to the maintenance need). First, it might not be surprising that this strategy fits well with maintenance needs, as the importance of social support has been identified in self-care studies (Fivecoat et al., 2018; Won & Son, 2016). Furthermore, there is evidence that individuals appreciate eHealth design strategies that aim to motivate them through social competition or compliments that they receive from others through digital means (van Velsen et al., 2019). However, those works have not distinguished between self-care processes as done by the present study (i.e., to identify if the aforementioned benefits apply to self-care monitoring and management tasks).

The results of the present study in fact suggest that the proposed operationalisation of the social support design strategy, as a chat function to facilitate peer support, was the main reason for the lower promise to support both the monitoring and management needs. For example, for the monitoring need, experts found it difficult to conceive how social support could promote or facilitate the corresponding behaviours such as to routinely measure blood pressure. Moreover, experts reasoned that this strategy entailed too many pitfalls when it came to support management needs. For example, potential risks caused by misinformation or lack of supervision over interactions between patients. Research on social support has supported the ambiguity of this type of strategy as signaled by the present study. For instance, social support has been noted to act as both an important facilitator or barrier for the adoption of self-care solutions (Harvey et al., 2015).

Extending on that, a meta-review of qualitative studies with patients supports the view that such strategies might only be appreciated by specific sub-groups (e.g., younger individuals) or work under specific circumstances (e.g., when there is social isolation) (Vo et al., 2019).

### **Tailoring eHealth design to the self-care needs of cardiovascular diseases**

Largely, for many of the multidisciplinary experts involved in this study the optimal eHealth design includes but goes beyond simply selecting a specific design strategy to support a targeted need. Instead, experts offered multiple recommendations through which eHealth could be optimally tailored to best support the complex and dynamic self-care processes in a way that accounts for the many influencing factors (see the qualitative data themes).

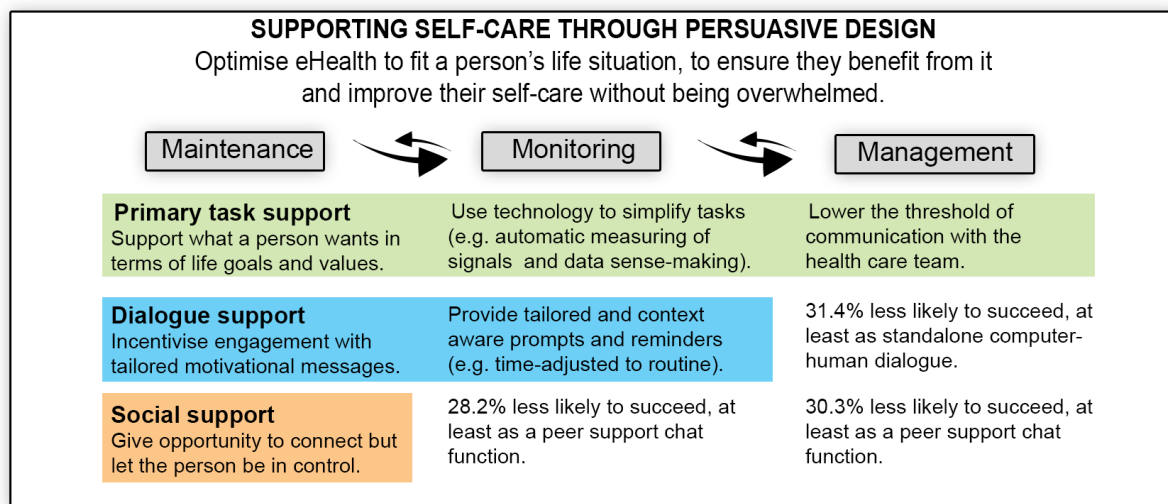
The most outstanding optimisation strategies collected by the present study are summarised in Figure 4.6 as a visual joint-display of both quantitative and qualitative insights. The figure outlines examples of how eHealth design can be optimised to match distinct self-care needs. It centres on instances where eHealth (persuasive) design strategies were found to be most or least promising, according to the assessments of multidisciplinary experts.

Figure 4.6 must be considered in light of the six major themes identified in the qualitative data, which provide an underlying context to the numerical ratings given by experts. Mainly, experts in this study highlighted that the key principles of patient-centredness and the need to support collaboration between the patient and the health care team must always guide the tailoring process. This aligns with research that endorses the importance of patient-centredness for self-care remote-support (Harst et al., 2019; Harst et al., 2020) and the collaboration between patients and health care providers (Nordfonn et al., 2019). Adding to that, experts pointed to many of the multidimensional factors that can increase the complexity of individual cases and thus hinder the potential success of any eHealth design strategy (e.g., availability of social support, comorbidities, attitudes and beliefs). This multifactorial, complex nature of self-care has been observed in previous works, especially in those that collect the experiences and perspectives of patients with CVD (Harst et al., 2020; Nordfonn et al., 2019; Vo et al., 2019).

Notably, several experts argued that an optimal eHealth design must ‘strive for simplicity’, which could be achievable by adjusting the pacing of the intervention and tailoring information to key factors such as literacy and culture (especially for dialogue support). Finally, experts suggested that eHealth is most optimally tailored when it targets problems where technology offers opportunities that other supportive solutions do not. For example, the availability of evidence-based knowledge about CVD and self-care via digital educational materials, the support for habituation to key healthy behaviours via prompts or reminders, or the facilitation of self-awareness and sense-making through self-monitoring and feedback.

Figure 4.6. Optimisation of eHealth persuasive design strategies to support self-care of patients with cardiovascular diseases, according to the views of experts.

**LEGEND:** Optimisation of   primary task support,   dialogue support, and   social support strategies.



## Strengths and limitations

Naturally, this study had its strengths and limitations. One strength is that researchers from multidisciplinary fields of science were actually included. However, a limitation in that respect was that most respondents self-identified as ‘researchers’ rather than ‘developers/implementers’ or ‘health care providers’, which means the views of the latter are underrepresented. Moreover, the general approach of the study to involve only experts and not end users naturally limits its findings to a partial view on the matter. Certainly, neither this nor any single study can provide definitive answers to the question of how to tailor eHealth design strategies for self-care. However, the findings of this study are argued to be important because they display how the diverse views of experts can have an impact in the design of eHealth for self-care. In that regard, while there are multiple publications that collect the experiences and attitudes of patients towards eHealth, how experts use that knowledge to inform eHealth design had been harder to find in the literature.

Regarding the use of vignettes, while their presentation was pre-tested, two patient cases depicted in them were perceived by some experts to be less realistic. For instance, as several experts debated the representativeness of the monitoring case. Although Jane’s case (the patient depicted in that case) was inspired by interventions focusing on titration of medication for patients with uncontrolled hypertension, the vignette did not make this clear (Band et al., 2017; Chandler et al., 2019). Because of this, the findings of the study must be considered in light of the specific operationalisation of factors used for the vignettes (e.g., the monitoring case presented as a patient with hypertension, or the social support strategy operationalised as a peer support chat function).

Additionally, it could be seen as a limitation that the data were collected through an online survey, making it impossible to be a hundred percent confident of the background of the respondents or their comprehension of the vignettes and survey questions. All of those aspects could have certainly influenced the results, and other methods with different aims could have led to different conclusions (e.g., a consensus-building Delphi study) (Wainwright et al., 2010). Finally, in terms of generalisability, it could be seen as a limitation that the study did not consider other categories or specific principles proposed by the PSD model (e.g., **system credibility support** such as third-party endorsements) or other promising approaches such as gamification (Radhakrishnan et al., 2019).

However, the context-based evaluations that took place in the present study attempted to be a representation of real-life scenarios, where design choices by eHealth developers must be made in light of the target behaviours, context of use, and many other influencing factors. In short, since the tailoring of eHealth design must always be context-specific, enacting that context is exactly what the present study attempted to achieve with the use of vignettes.

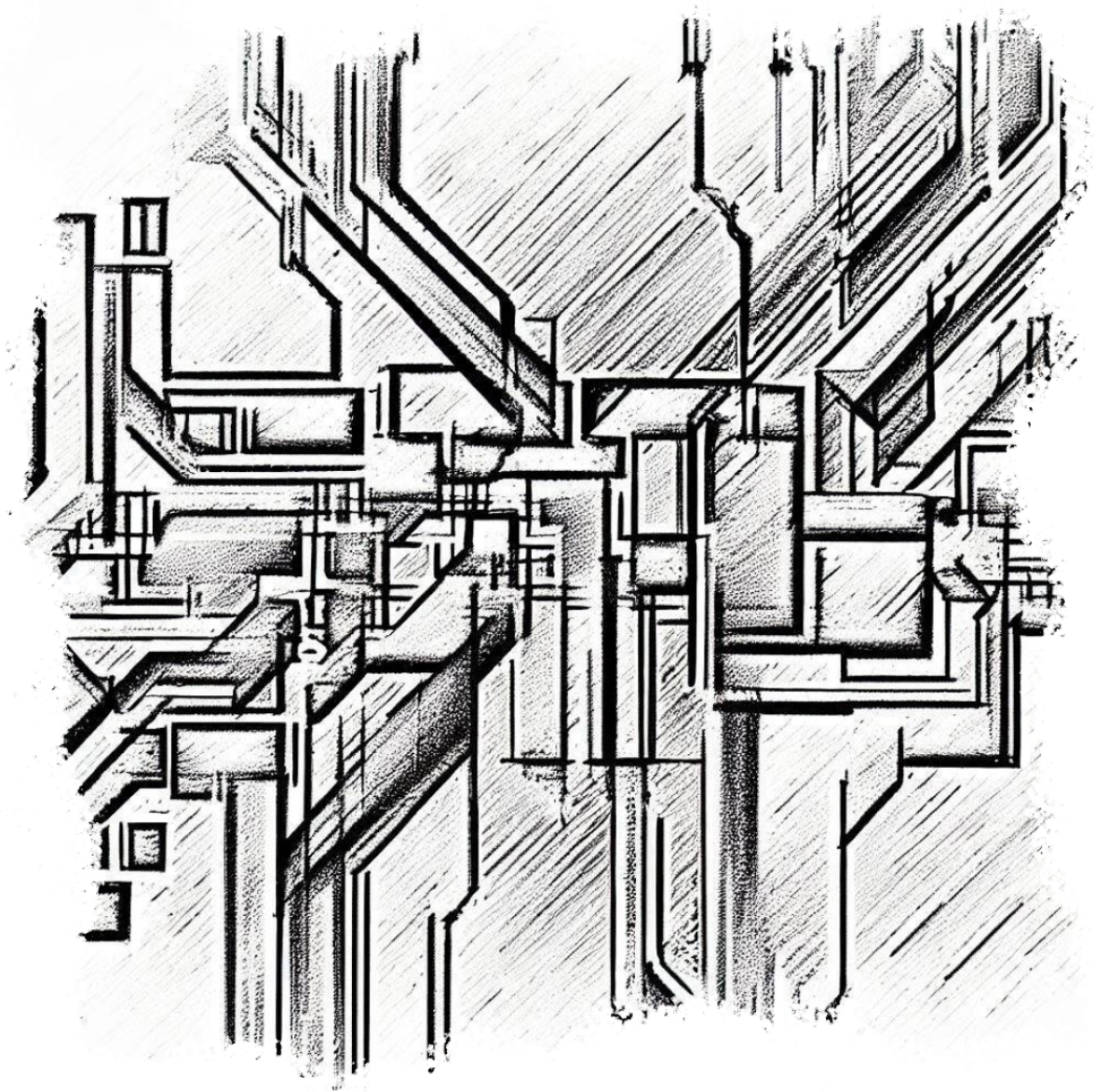
### **Future work and opportunities in eHealth design for self-care**

The findings of the present study add in to important ongoing discussions about eHealth design and development. While this study centred on the self-care needs as guiding determinants for tailoring, there are many other influencing factors that play a role as facilitators or barriers for self-care. Arguably, some factors such as motivation or social support have been extensively studied, while others such as personal values or cultural practices are influencing dimensions that require further exploration. For instance, there is already a body of knowledge about the roles of personal values among individuals with chronic conditions, but these works have not yet been translated to eHealth applications to self-care (Berry, Lim, et al., 2017b; Lim et al., 2019; Lim et al., 2017). Similarly, the influence of cultural factors has been studied in the specific context of CVD and selfcare (Osokpo & Riegel, 2019), and has been observed in investigations of eHealth persuasive design for other target behaviours, but nevertheless many questions remain (e.g., how to best tailor eHealth to cultural factors) (Orji et al., 2021). Understanding how these factors can inform eHealth design could significantly enhance the effectiveness of self-care supportive interventions. On the broadest view, the present study showed how theory can be used to create and propose potential design solutions (using vignettes) and how to collect not just opinions but contextualised and rich insights from experts with different backgrounds and areas of expertise (using a survey experiment). These contributions are important, because there is an ongoing debate about the usefulness of theory in the design and development of interventions (Hagger & Weed, 2019). It must be noted that, as used in this study, theory-based vignettes are different from other typical representations such as personas because they focus on distinguishing behavioural patterns or needs and not on representing ‘average’ users (LeRouge et al., 2013). In this regard, the research team will continue to study the use of vignettes as part of focused scenario-based testing for tailored (eHealth) interventions (Cornet, Daley, et al., 2020).

### **Conclusions**

The present study sought to identify the most promising eHealth design strategies that can support distinct self-care needs of individuals with a CVD. In that regard, the integrated views of experts from multiple scientific disciplines characterised primary task support as a promising support strategy for all theory-based self-care needs (maintenance, monitoring, and management). This type of support could be even seen as a prerequisite, as it could not only seek to simplify self-care tasks but also help ensure the safety of patients under the context of remote care. When compared to primary task support, social support was considered by experts to be less likely to succeed in supporting monitoring needs. Similarly, both dialogue and social support were less likely to succeed in supporting patients’ management needs. In practice, the findings of the present study suggest that eHealth design for self-care could benefit from a lean approach (i.e., ‘less is more’). The involvement of experts with diverse backgrounds and areas of expertise displayed various tailoring approaches to the multidimensional complexity of individual self-care processes. Principally, experts suggested that interventions must be simplified by personalising their pacing to the personal circumstances of each patient (e.g., their knowledge and skills) and by tailoring the information they provide to their preferences (e.g., their literacy and culture). Above all, the results of the study endorse the view that eHealth design must distinctly address all theory-based self-care needs (maintenance, monitoring, and management), while embracing patient-centredness (i.e., the alignment with the patients’ life personal goals and values) and facilitating the collaboration between patients and caregivers.

# **PART 2: DESIGN AND PROPOSITION OF THEORY-BASED AND VALUE SENSITIVE EHEALTH FEATURES**



# Chapter 5

## Toward value sensitive design of eHealth technologies to support self-management of cardiovascular diseases: Content analysis

**This chapter is based on the following publication:**

Cruz-Martínez, R. R., Wentzel, J., Bente, B. E., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (2021). Toward Value Sensitive Design of eHealth Technologies to Support Self-Management of Cardiovascular Diseases: Content Analysis. *JMIR Cardio*. 5(2), e31985. doi:10.2196/31985.



## ABSTRACT

**Background:** eHealth can revolutionise the way self-management support is offered to chronically ill individuals such as those with a cardiovascular disease (CVD). However, patients' fluctuating motivation to actually perform self-management is an important factor for which to account. Tailoring and personalising eHealth to fit with the values of individuals promises to be an effective motivational strategy. Nevertheless, how specific eHealth technologies and design features could potentially contribute to values of individuals with a CVD has not been explicitly studied before.

**Objective:** This study sought to connect a set of empirically validated, health-related values of individuals with a CVD with existing eHealth technologies and their design features. The study searched for potential connections between design features and values with the goal to advance knowledge about how eHealth technologies can actually be more meaningful and motivating for end users.

**Methods:** Undertaking a technical investigation that fits with the value sensitive design framework, a content analysis of existing eHealth technologies was conducted. We matched 11 empirically validated values of CVD patients with 70 design features from 10 eHealth technologies that were previously identified in a systematic review. The analysis consisted mainly of a deductive coding stage performed independently by 3 members of the study team. In addition, researchers and developers of 6 of the 10 reviewed technologies provided input about potential feature-value connections.

**Results:** In total, 98 connections were made between eHealth design features and patient values. This meant that some design features could contribute to multiple values. Importantly, some values were more often addressed than others. CVD patients' values most often addressed were related to (1) having or maintaining a healthy lifestyle, (2) having an overview of personal health data, (3) having reliable information and advice, (4) having extrinsic motivators to accomplish goals or health-related activities, and (5) receiving personalised care. In contrast, values less often addressed concerned (6) perceiving low thresholds to access health care, (7) receiving social support, (8) preserving a sense of autonomy over life, and (9) not feeling fear, anxiety, or insecurity about health. Last, 2 largely unaddressed values were related to (10) having confidence and self-efficacy in the treatment or ability to achieve goals and (11) desiring to be seen as a person rather than a patient.

**Conclusions:** Positively, existing eHealth technologies could be connected with CVD patients' values, largely through design features that relate to educational support, self-monitoring support, behaviour change support, feedback, and motivational incentives. Other design features such as reminders, prompts or cues, peer-based or expert-based human support, and general system personalisation were also connected with values but in narrower ways. In future studies, the inferred feature-value connections must be validated with empirical data from individuals with a CVD or similar chronic conditions.

## INTRODUCTION

### A vision of self-care: Part 5

The previous chapter described promising findings on the use of theory to describe and understand how technology can support self-care of CVD. Given the focus of the previous study, some experts involved in the online experiment provided a noteworthy remark. That is, that while their opinion matters, they would typically also seek to consider the perspective of the patient. What would a patient like Albert want? What seems more fitting from his perspective? Does he feel confident enough to comply with each recommendation? While the importance of the patient's perspective is not new, it did raise a relevant question that related to the focus of the present thesis. What theories, models, or frameworks exist that could help intervention developers, designers, and implementers better understand the perspectives and motivations of individuals? How can those theories and models actually contribute to the success of eHealth as a supportive intervention? What difference does it make, for eHealth and its success, to better understand Albert's motivations? The answers to these questions might seem obvious to some. However, have these questions also been addressed by the research and development conducted at the crossroads of eHealth, self-care, and CVD?

Having determined it as important to look at this topic with a theoretical lens, the present thesis focused at this stage on the concept of 'values.' The conceptualisation and operationalisation of this term was investigated under the context of study: CVD and self-care support. At the beginning, a broad framework such as Schwartz's (2012) refined theory of basic human values was considered to work with as a foundation. However, in light of the context-specific adoption of self-care theory, it was preferred to instead rely on the value sensitive design framework, which is itself specific to technology (Friedman et al., 2013). To accompany the use of this framework, a bottom-up approach to the understanding of values was also considered. That is, by using emerging findings from an empirical study focused on identifying the values of patients with a CVD. As illustrated by Figure 5.1, both empirical findings and theory were used to inform a new study under the scope of the present thesis.

Figure 5.1. Illustration of questions that could be answered through empirical or theoretical perspectives.



### Focus of the present chapter

The present chapter describes a study that sought to connect a set of empirically-validated values of individuals with a CVD with existing eHealth technologies and their design features. By adopting a technology-driven framework such as value sensitive design, and being informed also by empirical studies investigating the target population, the following work sought to identify potential connections that could inform eHealth development for self-care. In practice, the study once more aimed to exemplify how theory could inform the design of eHealth technologies. In this case, investigating how technology can be meaningful for its end users, enhancing engagement and thus its effectiveness.

## **BACKGROUND LITERATURE**

### **The promise of eHealth for self-management support**

Self-management can be broadly defined as an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, and lifestyle changes inherent in living with a chronic illness (Barlow et al., 2002). In 2005, the influential psychologist Albert Bandura (Bandura, 2005) characterised self-management as 'good medicine' and went even further, stating that 'if the huge benefits of these few habits were put into a pill, it would be declared a scientific milestone in the field of medicine.' Such a milestone would certainly lead to a much-needed reduction of the alarming burden on health care systems worldwide caused by the increasing amount of chronically ill individuals, many of them with a cardiovascular disease (CVD) (Roth et al., 2017).

Obviously, there is not yet—and perhaps there will never be—a 'pill' that prompts individuals to actively engage in the maintenance, monitoring, and management of their own health. The reality is much more challenging, as performing self-management entails the enactment of multiple behaviours and a continuous confrontation with barriers and competing interests (Riegel, Moser, et al., 2017). For example, stroke survivors can be overwhelmed by the physical and cognitive efforts required by rehabilitation programs and by other sudden changes to their lifestyles, leading them to feel as if they have 'lost control' over their life.

Although not a 'pill,' the use of digital technologies to support health, well-being, and health care holds high promise. Such an approach is better known by the term of electronic health or eHealth (van Gemert-Pijnen, Kip, et al., 2018). Specifically, technologies such as smartphone applications and internet-enabled monitoring devices have been proposed as tools that can support self-management (Greenwood et al., 2017; Hanlon et al., 2017). Among other things, eHealth promises to facilitate tasks and provide personalised information, feedback, or cues to action. eHealth technologies have, in fact, already shown positive results in terms of supporting patients in the management of chronic conditions, including CVD (Greenwood et al., 2017; Hanlon et al., 2017; Jonkman et al., 2017; Kebapci et al., 2020; Kim & Lee, 2017; Pfaeffli Dale et al., 2016; Triantafyllidis et al., 2019; Villarreal & Berbey-Alvarez, 2020).

### **Realising the promise of eHealth through value sensitive design**

Despite their promising results and recognised potential, eHealth technologies that aim to support self-management have come across multiple challenges. One of the most important obstacles is the fluctuating motivation of individuals to actually perform self-management (Kebapci et al., 2020; Kim & Lee, 2017). As a result, when motivation is low, eHealth technologies can become an added burden (Harvey et al., 2015). To overcome that barrier, multiple calls have been made to design eHealth in a way that better aligns with the underlying needs of individuals (Greenwood et al., 2017; Hanlon et al., 2017; Kim & Lee, 2017; Van Velsen et al., 2013). One key proposal is that eHealth technologies should be personalised in a way that taps into a more powerful source of motivation: values. To realise this, eHealth technologies should be designed in a way that strengthens patients' values and fulfils their needs. For instance, patients who highly value social interactions could be motivated through eHealth features that facilitate communication with peers, friends, or the health care team.

In fact, the need to meet patient values through the design of technologies has led to the development of novel methodologies and theoretical approaches. One of these approaches is value sensitive design, which serves as both a theoretical and methodological framework that seeks to integrate values into design work (Friedman et al., 2013).

The **value sensitive design framework** ensures that the design of technologies accounts for values in a principled and comprehensive manner, through integrative and iterative methodologies that include conceptual, empirical, and technical investigations (Friedman et al., 2013). Conceptual investigations can focus on the philosophical analysis and specification of value constructs (e.g., the value of ‘feeling in control’ or the value of ‘feeling supported by others’). Meanwhile, technical investigations can take the analysis further and design technologies using the identified values as assessment criteria (e.g., how do wearable technologies meet the value of ‘feeling in control over life?’). Finally, empirical investigations can evaluate the process of a particular design or context use (e.g., a formative evaluation of technologies to assess if and how they contribute to patient values).

## Conceptualising values for eHealth design

In the value sensitive design framework, a **value** refers to ‘what a person or group of people considers important in life’ (Friedman et al., 2013). In eHealth, this could translate to a life ideal or important interest, related to health or well-being, that individuals could pursue or meet with the help of technologies (Van Velsen et al., 2013). This paper uses the terms ‘values’ and ‘patient values’ interchangeably. Moreover, this paper uses the term ‘connection’ to refer to a potentially positive relationship between a specific technology—or one of its design features—and a patient’s value that leads to an increase or maintenance of motivation (e.g., a self-monitoring feature might be ‘connected’ to the value of ‘feeling safe and stable’). Other terms used in scientific works talk about how technologies or design can ‘contribute,’ ‘meet,’ ‘support,’ or ‘honour’ values. These verbs are all understood to refer to the same relationship.

As mentioned before, incorporating values into technologies can entail multiple integrative and iterative steps. For instance, value specification precedes value sensitive design. Value specification is the identification of the most important values for stakeholders of eHealth (e.g., end users such as individuals with a CVD) (Kip & van Gemert-Pijnen, 2018). Holistic approaches to eHealth development and design, such as the one promoted by the Center for eHealth Research (CeHRes) Roadmap (van Gemert-Pijnen et al., 2011), stress the importance of identifying the diverse and often conflicting values and concerns that different stakeholders have (e.g., what does a patient value in health and life and thus expect to be helped with through eHealth?). This raises a fundamental question: What values must be considered to design effective support for the values of individuals with a CVD? A previous investigation by authors of this study directly addressed this question (Bente et al., 2021). Concretely, an interview study integrated a list of 11 values of patients with a CVD (Bente et al., 2021). Then, as a follow-up study, the list of values was revised and empirically validated through a survey with members of a patient association in the Netherlands, constituted by individuals who have attended or are still attending a cardiac rehabilitation program (Bente et al., 2021). Therefore, there are already available data establishing a set of potential values of importance for individuals diagnosed with a CVD.

## Connecting values with eHealth technologies and design features

Importantly, the value sensitive design framework also presupposes that a given technology is more suitable for certain activities and more readily supports certain values, while rendering others more difficult to realise (Friedman et al., 2013). Therefore, it suggests that it all depends on the ‘features’ or ‘properties’ that people design into technologies. In this study, the term ‘design feature’ is used to define any clearly identifiable property of a technology that serves a specific function and is proposed to help achieve an overarching aim. Given such a definition, design features could be functional or visual properties, underlying technical mechanisms, as well as recognisable ‘building blocks’ such as behaviour change techniques (Michie et al., 2015) and persuasive design strategies (Oinas-Kukkonen & Harjumaa, 2009). Furthermore, this study defines an eHealth technology as a (set of) technological instrument(s), such as a mobile app, that is specifically developed to support well-being, health, or health care (van Gemert-Pijnen, Kip, et al., 2018).

In contrast, an eHealth intervention is defined as the full package and procedures that describe how a specific eHealth technology intervenes to support well-being, health, or health care (van Gemert-Pijnen, Kip, et al., 2018). The former concept is favoured because the focus of this study is design features of technologies that are at different stages of development (e.g., from high-fidelity prototypes to systems that have already been implemented and evaluated).

In light of the aforementioned information and given the numerous examples of eHealth technologies that exist, it is plausible that several values have already been met by their design features. However, to the best of our knowledge, the connection between specific design features and patient values has not been directly investigated in previous studies. Therefore, it is necessary to advance the understanding about how technologies can best support the values of individuals. This knowledge can be uncovered through what the value sensitive design framework calls ‘technical investigations,’ which are studies that focus on how existing technological properties and underlying mechanisms support or hinder values (Friedman et al., 2013). In this way, technical investigations could help advance knowledge about what works, for whom, and why in terms of CVD self-management (Michie et al., 2017). Consequently, evidence on the most effective technological properties and mechanisms could be translated into practical guidelines for the development and design of future eHealth technologies.

As empirical knowledge about the values of individuals with a CVD already exists, what is needed is a set of technologies that can be investigated with the aforementioned aim in mind. To that end, the outcomes of a recent systematic review that identified and analysed multiple eHealth technologies for CVD self-management could be used (Cruz-Martínez et al., 2019; Cruz-Martínez et al., 2020). The review analysed technologies with sufficient and substantial information about their objectives and design (i.e., their design features). Thus, information about the design features of existing eHealth technologies is also readily available for the purposes of this investigation.

## **Aim**

This study sought to connect a set of empirically validated values of patients diagnosed with a CVD with existing eHealth technologies and their design features. By doing so, the findings of the study aimed to be a foundation for new hypothetical assumptions that contribute to value sensitive eHealth design and that could be validated in future empirical studies. Content analysis is proposed as a suitable method to meet this aim because it allows making replicable and valid inferences from texts or other meaningful matter to the contexts of their use (Krippendorff, 2004). As a scientific tool, content analysis can provide new insights, increase the understanding of particular phenomena, or inform practical actions (Krippendorff, 2004). In short, content analysis offers a sound and verifiable method that can connect patient values with multiple and distinguishable eHealth design features. Following what has been issued in the previous sections, this research follows a patient-centred design approach to focus on the main drivers of patients’ needs and concerns: their values. The research question is: What eHealth design features can be connected with the values of patients with a CVD?

## **METHODS**

### **Overview**

To meet the study aims, the research team conducted a content analysis (Krippendorff, 2004). The content analysis consisted of 3 stages: preparation, organisation, and analysis and reporting (Elo et al., 2014). The main researcher (RRCM) conducted the preparation stage by collecting and setting up the data to analyse the eHealth design features (Elo et al., 2014). Next, 3 researchers (RRCM, JW, and BEB) performed the organisation stage independently by deductively coding the data (Elo et al., 2014).

Finally, all researchers contributed to the reporting stage, consisting of displaying the results according to the selected approach and categorisation scheme (Elo et al., 2014).

## **Preparation**

The preparation stage aimed to identify design features of existing eHealth technologies and to describe them in a format that facilitated their analysis. To identify eHealth design features for the study, RRCM revised and expanded the data extracted about 10 eHealth technologies during a previous literature systematic review (Cruz-Martínez et al., 2019; Cruz-Martínez et al., 2020). Additionally, RRCM searched for newer publications of all technologies through reference tracking of the included papers. Importantly, RRCM extracted both descriptive and contextual information about each eHealth design feature. Descriptive information could be a clear textual description of the design feature (e.g., what it does or intends to do according to the publication) and a figure or picture of it (when available). In contrast, contextual information could be the name of technologies, their main characteristics, their target group, and any specific objectives. RRCM integrated all descriptive and contextual information about each eHealth design feature in separate Microsoft PowerPoint slides. For example, the Engage mobile application included 5 design features (Srinivas et al., 2017): log, hint/facts, goal, progress report, and deck of cards.

At this stage, RRCM noticed and began to group the design features of different technologies according to their similar characteristics or functions. For example, the 'log' feature of the Engage technology (Srinivas et al., 2017) is similar to the 'assessment' feature of the HeartMapp (Athilingam, Clochesy, et al., 2018) technology, in the sense that they both facilitate self-reporting of symptoms and other self-management behaviours. The researchers finally agreed on the final grouping of design features at the analysis and reporting stages (as described in the following sections). In this way, both descriptive and contextual information facilitated a better comprehension of eHealth design and its features. In total, the study analysed 70 design features from 10 different CVD eHealth technologies. Multimedia Appendix 1, as reported in Cruz-Martínez, Wentzel, Sanderman, et al. (2021), presents a detailed overview of the included technologies and their design features.

## **Organisation**

The organisation stage aimed to connect a list of 11 empirically validated patient values to the eHealth design features by means of deductive coding. A usability study and a follow-up survey study generated and validated the list of values (Bente et al., 2021). The first study consisted of 10 interviews within the context of patients' usability tests with the online BENEFIT Personal Health Platform, which aims to support the adoption and maintenance of healthy lifestyles (Bente et al., 2021). The second study distributed an online survey to panel members of Harteraad, a Dutch patient association for cardiac diseases (in total, the survey had 710 respondents) (Bente et al., 2021). In this survey, the respondents rated the values identified in the first study according to their importance for themselves, which aimed to estimate relevance and generalisability of the values in a larger population. To prepare the codebook for this study, BEB and JW translated the list of values from the Dutch language into English. Table 5.1 presents the list of values in their final form as the codebook for this study.

Table 5.1. Codebook with list of patient values and their definitions.

Number	Value label	Value definition
1	To have confidence and self-efficacy in treatment and ability to achieve goals	Having confidence in the doctors and the treatment they prescribe or having the feeling that patients are capable of following the treatment plan or have the ability to achieve their goals
2	To be seen as a person rather than a patient	Not constantly feeling that they are a patient with a disease but also still being able to be a human without their illness
3	To not feel fear, anxiousness, or insecurity about their health	Not having to worry about their physical condition, being provided coping strategies or information that helps them feel safe or less anxious
4	To preserve a sense of autonomy over their life	Having a feeling of being in control of their life (e.g., being able to make their own decisions)
5	To receive social support	Feeling heard, supported, and understood by the people that surround them (e.g., family and friends) and having the feeling that they have somewhere or someone to go to when they need a sympathetic ear (e.g., via a virtual coach or a chat)
6	To have or maintain a healthy lifestyle	Maintaining or changing their lifestyle in such a way that new incidents are prevented and they (re)gain health
7	To have an overview of personal health data	Having a central source where they have insight into their personal health data or condition (e.g., measured values or any insights into physical and mental well-being and health)
8	To perceive low thresholds to access health care	Being helped or treated quickly and easily, at a health care organisation or at home; being facilitated to manage their own disease and take action
9	To be extrinsically motivated to accomplish goals or activities (related to health/lifestyle)	Being extrinsically motivated to do or accomplish things, such as their treatment or activities for a healthy lifestyle (e.g., via social pressure)
10	To have reliable information and advice	Having understandable, relevant information and advice that is scientifically proven and recommended by the clinical team (i.e., evidence-based information)
11	To receive personalised care	Receiving a personal approach in which their opinion and preferences are taken into account (e.g., personalisation or tailoring of treatment choices or features)

RRCM, BEB, and JW independently performed the coding of the eHealth design features. All coders are experts in eHealth research and development, having overall conducted various studies focused on eHealth design and evaluation involving multiple stakeholders' perspectives (e.g., end users such as patients or expert stakeholders such as health care providers). The researchers first conducted a pilot of the coding using design features of a technology that was not included in the systematic review (Woods et al., 2019a; Woods et al., 2019b). Minor adjustments were made to the codebook based on the resulting discrepancies.

During coding, each researcher could characterise the connection between a specific design feature and a patient value as follows: (1) 'Yes,' if the design feature directly and clearly accomplishes or contributes to a value; (2) 'Maybe,' if the design feature accomplishes or contributes to a value only indirectly or if the information is unclear; and (3) 'No,' if the design feature clearly does not accomplish or contribute to a value.

In addition to the deductive coding stage, RRCM invited authors of publications related to the included technologies via email to fill in a self-assessment form that asked about the relationship between their technology and the list of patient values. The self-assessment form posed 2 questions: (1) 'Do you consider that your intervention accomplishes or contributes to any of the patient values listed below?' and (2) 'When applicable, can you specify which feature or part of the intervention you consider seeks to accomplish or contribute to the corresponding patient value?' Finally, respondents could also freely state if other patient values outside the list provided were considered targets of the technology.

In this way, it was expected that authors could link their technology and one or multiple design features to one of the values in the codebook. Multimedia Appendix 2, as reported in Cruz-Martínez, Wentzel, Sanderman, et al. (2021), presents the self-assessment form that authors were invited to fill in. During the coding stage, the research team was blinded to any self-assessment sent by the researchers or developers of technologies.

## **Analysis and reporting**

To analyse the results, simple agreements (percent agreements) and the interrater reliability resulting from the deductive coding were calculated. Krippendorff alpha (KALPHA) was used as the measure of interrater reliability because, among other things, it takes into account the expected disagreement and not only the observed disagreement (Krippendorff, 2004, 2011). Values of KALPHA range from 0 to 1, where 0 is perfect disagreement and 1 is perfect agreement. Although it depends on the context, an alpha >0.80 is usually ideal, and a minimum level of acceptance is typically 0.667 (Krippendorff, 2004).

Although independent coding performed by the research team led the search for potential connections, the input received from researchers and developers of technologies could support the identification when full agreement was not achieved. Therefore, the positive identification of a potential connection had to meet 1 of 2 criteria. The first and main criterion was to have full agreement on a connection among the 3 coders (i.e., 3 out of 3 agreed on a feature-value connection). However, a potential connection was also recorded when the input by researchers and developers of technologies suggested it, as long as there was also partial agreement between coders (i.e., 2 out of 3 agreed independently on a feature-value connection).

To report the results, the connections were first summarised at the level of the technologies. This first summary is reported because it is important to understand—and later to discuss—the surrounding context of the design features, which could have a relationship with their potential connections with patient values (e.g., the intended goals of technologies that led design choices).

Next, the design features that were connected with values were grouped according to their objectives and functionalities (e.g., grouping different design features that relate to ‘self-monitoring’ support, as with the previously mentioned ‘log’ and ‘assessment’ design features).

By grouping specific design features according to their common characteristics, it was easier to identify potential differences in their design and their potential connections to values. For example, 2 different self-monitoring support design features could still be distinct enough that one could potentially contribute directly and clearly to a value while another one does so indirectly. This meant that some types of design features could entail both direct and indirect pathways toward a value. When relevant, some outstanding design features were textually described (e.g., features that contributed to largely unaddressed values).

## **RESULTS**

### **Deductive coding**

In total, 70 design features from 10 different eHealth technologies were used for the content analysis (see Multimedia Appendix 1 in Cruz-Martínez, Wentzel, Sanderman, et al. (2021) for the full overview). To recall, each design feature was coded according to its potential connection with 11 different values (as ‘Yes,’ ‘Maybe,’ or ‘No’). Table 5.2 presents a summary of the percent agreements that resulted from the independent deductive coding.



As can be observed in Table 5.2, 41 direct and clear connections between design features and patient values were identified in this way (i.e., the ones with full agreement on ‘Yes’). In addition, 4 pairings were characterised as indirect or unclear (i.e., the ones with full agreement on ‘Maybe’).

Table 5.2. Summary of percent agreements from deductive coding of 70 eHealth design features according to the potential connection with 11 different patient values, resulting in 770 possible connections between a design feature and a patient value.

Level of agreement	Results, n (%)
Connections with <i>full</i> agreement (i.e., 3 out of 3)	502 (65.2)
<b>Responses for connections with <i>full</i> agreement (i.e., 3 out of 3)</b>	
Yes	41 (8.2)
Maybe	4 (0.8)
No	457 (91.0)
Connections with <i>partial</i> agreements (i.e., 2 out of 3)	209 (27.1)
<b>Responses for connections with <i>partial</i> agreements (i.e., 2 out of 3)</b>	
Yes	48 (23.0)
Maybe	10 (4.8)
No	151 (72.2)
Null agreement (i.e., 0 out of 3)	59 (7.7)

The KALPHA coefficient for all data was 0.4536 (95% CI 0.4087-0.4978), which is low, as 0.667 is typically the minimum acceptable level (Krippendorff, 2004). KALPHA was computed using an ordinal measurement level that treated the potential connection between a design feature and a patient value as increasing from ‘No’ (0) to ‘Maybe’ (1) and ‘Yes’ (2). At the start, as can be seen in Table 5.2, 44 connections (41 ‘Yes’ and 4 ‘Maybe’) were identified through deductive coding. However, after integrating the input of researchers and designers of the reviewed technologies, the inferred connections between eHealth design features and patient values increased up to a total of 98 connections. Of the 45 researchers invited to complete the form, 6 individuals returned it (6 more also responded but redirected the request to a co-author who ultimately responded).

Each form received related to a different technology; therefore, input was received for 6 of the 10 reviewed technologies: Engage (Srinivas et al., 2017), HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam et al., 2016; Di Sano et al., 2015), HOME BP (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018), PATHway (Triantafyllidis et al., 2018; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018), SMART-PSMS (Bartlett et al., 2014; Burns et al., 2010; Mawson et al., 2016; Mawson et al., 2014; Parker, Mawson, Mountain, Nasr, Davies, et al., 2014; Parker, Mawson, Mountain, Nasr, & Zheng, 2014), and SUPPORT-HF (Chantler et al., 2016; Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015; Triantafyllidis, Velardo, Shah, et al., 2015). For the remaining technologies, the authors either declined the invitation or did not respond after several reminders: MedFit (Duff et al., 2018; Kuklyte et al., 2017; Prabhu et al., 2018), MyHeart (Villalba et al., 2009; Villalba Mora et al., 2007; Villalba Mora et al., 2008), SMASH (Chandler et al., 2019; Davidson et al., 2015; McGillicuddy, Gregoski, et al., 2013; McGillicuddy, Weiland, et al., 2013; McGillicuddy et al., 2012; Sieverdes et al., 2013), and Mock-Up by Baek et al (Baek et al., 2018).

## Contributions of existing eHealth technologies to patient values

The design features reviewed in this study were not created in isolation. Their surrounding context was an overarching eHealth technology with specific goals that led design choices. Because such context is important, it is also relevant—although not the focus of the study—to report the identified connections between eHealth technologies and patient values. The 98 connections suggest that some of the values are addressed by a majority of the 10 eHealth technologies. For instance, all of the technologies were connected with the patient value of ‘having or maintaining a healthy lifestyle.’

Similarly, the following values were connected with 8 different technologies: ‘having an overview of personal health data,’ ‘having reliable information and advice,’ ‘being extrinsically motivated,’ and ‘receiving personalised care.’ Less frequently, the ‘perceiving low thresholds to access health care’ value was connected with 6 different technologies.

In contrast, other values connected with only a minority of the reviewed eHealth technologies. For instance, only 3 of 10 technologies were connected with the patient value of ‘receiving social support’: PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018), MedFit (Duff et al., 2018; Kuklyte et al., 2017; Prabhu et al., 2018), and HOME BP (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018). Likewise, only 3 different technologies were connected with the patient value of ‘not feeling fear, anxiousness, or insecurity about health’: SMASH (Chandler et al., 2019; McGillicuddy et al., 2012), HOME BP (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018), and SUPPORT-HF (Chantler et al., 2016; Triantafyllidis, Velardo, Chantler, et al., 2015). Only 2 technologies were connected with the patient value of ‘preserving a sense of autonomy’: Engage (Srinivas et al., 2017) and the SMART PSMS (Mawson et al., 2016; Mawson et al., 2014). Only the ‘On-screen positive reinforcement’ design feature of the PATHway technology was connected with the patient value of ‘having confidence and self-efficacy in the treatment and the ability to achieve goals’ (Triantafyllidis et al., 2018; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018). Similarly, only the ‘culturally-attuned motivational and reinforcement SMS messages’ design feature of the SMASH technology was connected with the patient value of ‘being seen as a person rather than a patient’ (Davidson et al., 2015; McGillicuddy et al., 2012; Sieverdes et al., 2013).

## **Contributions of eHealth design features to patient values**

The eHealth design features could be grouped according to their similar objectives and functionalities (i.e., what they aim to do and how they try to do it). In total, the analysis identified 13 distinguishable ‘types’ of design features: educational support, self-monitoring support, behavioural assessment support, behavioural planning support, behavioural performance support, feedback on monitored data, feedback during behaviour performance, motivational incentives, prompts or cues, reminders, peer-based support, expert-based support, and the personalisation of the system’s design features. Textbox 5.1 presents descriptions and examples of the types of eHealth design features.

- **Educational support:** Features that enable the patients to access educational materials on various topics (e.g., the ‘Heart Failure (HF) Info’ feature of HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam et al., 2016; Di Sano et al., 2015)); educational information could be presented with text, audio, or videos.
- **Self-monitoring support:** Features that facilitate the patient’s monitoring of various types of data (e.g., the ‘log’ feature of Engage (Srinivas et al., 2017)), for instance, monitoring symptoms, weight, or self-management behaviours.
- **Behavioural planning support:** Features that facilitate selection and action-planning of health maintenance behaviours (e.g., the ‘goal’ feature of Engage (Srinivas et al., 2017)), for instance, to decide when and how to exercise based on long-term goals that were either self-set or agreed upon with health care providers.
- **Behavioural performance support:** Features that provide information, guidance, or support for the actual performance of health maintenance behaviours (e.g., the ‘exercise’ feature of MedFit (Duff et al., 2018; Kuklyte et al., 2017; Prabhu et al., 2018)), for instance, an animated deep breathing practice or a list of guided exercise classes; the features can include real-time feedback or self-evaluation options (e.g., rating performance or intensity).
- **Behavioural assessment support:** Features that assess a patient’s readiness to change a selected behaviour (e.g., PATHway’s ‘behavioural change assessment’ and ‘good habits visualisation’ (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)); they can lead to a visual display of risk factors or recommended priorities for behaviour change.
- **Feedback on monitored data:** Features that present graphs, charts, or written reports of a patient’s data over time (e.g., ‘statistics/stats’ feature of HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam et al., 2016; Di Sano et al., 2015)); the data can be about symptoms, behaviours, or the progress toward a desired performance.
- **Feedback during behaviour performance:** Features that provide real-time feedback during the performance of health maintenance behaviours (e.g., the ‘on-screen positive reinforcement’ feature of PATHway (Triantafyllidis et al., 2018; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)), for instance, to incentivise the correct execution of physical rehabilitation exercises.
- **Motivational incentives:** Features that incentivise engagement with the technology by using metaphors such as ‘missions,’ ‘medals,’ or ‘cards’ (e.g., the ‘deck of cards’ feature of Engage (Srinivas et al., 2017)); they can be personalised according to a prescribed treatment, self-set goals, or automatic analyses of data collected.
- **Cues:** Features that provide prompts or cue to actions (e.g., the ‘behaviour change notifications’ feature of PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)); they are directed to specific behaviours and can be personalised to a patient’s preferences.
- **Reminders:** Features that provide reminders to facilitate adherence to medication (e.g., the ‘medication tray reminder signals’ of SMASH (McGillicuddy, Gregoski, et al., 2013; McGillicuddy, Weiland, et al., 2013; McGillicuddy et al., 2012)); they can include the demand of an action or a request for additional input such as a reason for not conducting the behaviour (e.g., report the intake of medication as prescribed or a reason for skipping it).
- **Peer-based human support:** Features that facilitate interaction with peers (e.g., the ‘multiplayer class’ feature of PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)), for instance, through online platforms that allow data comparison between individuals or make it possible to plan activities with others.
- **Expert-based human support:** Features that focus on the interaction or involvement of health care providers (e.g., the ‘contact’ feature of SUPPORT-HF (Chantler et al., 2016; Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015)); they can include a communication channel with an expert or support team and be linked to a clinical team module or a back-end alarm system that prompts interaction.
- **System personalisation features:** Features that aim to (de-)activate the system’s modules based on individual needs (e.g., the ‘remote system refinements and features activation’ feature of SUPPORT-HF (Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015)); personalisation can occur at the initial introduction of the technology or as a response to the evolving situation of the individual.

The results of the content analysis revealed that different (types of) design features from existing eHealth technologies could be connected with values of patients with a CVD. Figure 5.2 and Figure 5.3 present overviews of how the different types of eHealth design features connected with one or more patient values. Both figures summarise the cases where at least one specific design feature connected with a value and mark whether that connection was inferred to be direct or indirect. To recall, a direct connection referred to a clear and potentially positive relationship between a design feature and a patient value, leading to an increase or maintenance of motivation for self-management. In contrast, an indirect connection referred to an instance where the positive relationship required some assumptions to be made on behalf of the research team (e.g., because information about a design feature's functionality was unclear or unavailable). Moreover, both figures also show that, in some cases, design features within the same category could have different connections (i.e., one direct and another indirect).

Figure 5.2. Overview of the types of eHealth design features that were most frequently connected with values of patients with a cardiovascular disease.

Types of eHealth design features	Patient values				
	To have or maintain a healthy lifestyle	To have an overview of personal health data	To have reliable information and advice	To be extrinsically motivated to accomplish goals or activities (related to health/lifestyle)	To receive personalised care
Educational support	Indirect (1)/Direct (2)		Direct (9)		Direct (1)
Self-monitoring support	Indirect (1)/Direct (5)	Indirect (1)/Direct (1)	Direct (3)		
Behavioural planning support	Direct (4)			Indirect (1)	Indirect (1)/Direct (3)
Behavioural performance support	Direct (5)				Direct (1)
Behavioural assessment support	Indirect (1)	Direct (1)			
Feedback on monitored data	Indirect (2)/Direct (1)	Direct (8)	Direct (1)		
Feedback during behaviour performance	Direct (2)	Direct (3)			
Motivational incentives	Indirect (4)	Direct (1)		Indirect (1)/Direct (2)	Direct (1)
Cues				Direct (4)	Direct (1)
Reminders	Indirect (1)/Direct (1)			Direct (2)	Direct (1)
Human peer-based support				Direct (1)	
Human expert-based support					
System personalisation					Indirect (1)/Direct (1)
<b>Total amount of connected features:</b>	30	15	13	11	11

<b>Legend:</b>	Direct	eHealth design feature(s) could directly and clearly contribute to the patient value.
	Indirect	eHealth design feature(s) could contribute to the patient value but only indirectly.
	Indirect/Direct	eHealth design feature(s) could contribute to the patient value both directly and indirectly.

Figure 5.3. Overview of the types of eHealth design features that were least frequently connected with values of patients with a cardiovascular disease.

Types of eHealth design features	Patient values					
	To perceive low thresholds to access health care	To receive social support	To preserve a sense of autonomy over their life	To not feel fear, anxiousness, or insecurity about their health	To have confidence and self-efficacy in treatment and the ability to achieve goals	To be seen as a person rather than a patient
Educational support				Indirect (1)/Direct (1)		
Self-monitoring support	Indirect (1)		Indirect (1)			
Behavioural planning support			Direct (2)			
Behavioural performance support						
Behavioural assessment support						
Feedback on monitored data					Direct (1)	
Feedback during behaviour performance						Direct (1)
Motivational incentives						Direct (1)
Cues						
Reminders						
Human peer-based support		Direct (3)				
Human expert-based support	Indirect (2)/Direct (3)	Direct (1)		Indirect (1)		
System personalisation						
Total amount of connected features:	6	4	3	3	1	1

Direct	eHealth design feature(s) could directly and clearly contribute to the patient value.
Indirect	eHealth design feature(s) could contribute to the patient value but only indirectly.
Indirect/Direct	eHealth design feature(s) could contribute to the patient value both directly and indirectly.

Figure 5.2 summarises the patient values most frequently connected with the eHealth design features analysed in this study. As can be seen in Figure 5.2, five of the eleven patient values were extensively connected with multiple design features with distinct characteristics and objectives. An apparent exception is the ‘to have reliable information and advice’ value, which was connected with 3 types of design features (educational support, self-monitoring support, and feedback on monitored data). However, even in that case, the total amount of specific design features was relatively high (13 in total).

Beyond frequencies, Figure 5.2 also visualises potential clusters of design feature types in relation to patient values. For instance, several features providing feedback on monitored data connected with the value of ‘having an overview of personal health data.’ Likewise, motivational incentives, cues, and reminders most frequently connected with the value of ‘being extrinsically motivated.’

In contrast to the aforementioned results, Figure 5.3 summarises the patient values least frequently connected with the eHealth design features analysed in this study. Figure 5.3 shows that, for the remaining 6 patient values, the amount of connected design features is fewer, also varying less in their functionalities or objectives. In comparison with Figure 5.2, the values presented in Figure 5.3 connected only, at most, with 2 different types of eHealth design features. Beyond mere frequencies, Figure 5.3 shows that both human peer-based and expert-based support clustered toward a couple of the values in Figure 5.3. Namely, the values of ‘perceiving low thresholds to access health care’ (5 specific features) and ‘receiving social support’ (4 specific features). The rest of the values in Figure 5.3, however, connected only to a maximum of 2 specific features. Finally, the values of ‘having confidence and self-efficacy’ and ‘being seen as a person rather than a patient’ connected only with a single feature each.

## DISCUSSION

### Principal findings

This study sought an answer to the research question ‘what eHealth design features can be connected with the values of patients with a CVD?’

To approach an answer, the study explored potential connections between 11 empirically validated values of patients diagnosed with a CVD and 70 design features of 10 existing eHealth technologies that aim to support this population. In total, 98 connections—both direct and indirect—were inferred between the design features and the values included in the analysis. On the one hand, some design features connected with multiple values. On the other hand, some values were less frequently connected, with a couple remaining largely unaddressed.

Principally, the results of the study show that design features of existing eHealth technologies could already be connected with values of individuals with a CVD. The findings add up to the general literature about value sensitive studies of chronically ill populations and the design of self-management eHealth solutions. The connections between design features and values inferred by this study are still hypothetical, but the knowledge generated can be used to suggest new approaches for the development of personalised and tailored eHealth. The following discussion centres on the arguments that underlie outstanding cases among the 98 inferred connections, as well as some of their potential applications to the design of eHealth for self-management support.

## **Inferred connections between eHealth design features and patient values**

### **Supporting patients who value ‘a healthy lifestyle’**

It comes arguably without surprise that the most frequently connected patient value was ‘to have or maintain a healthy lifestyle’ (see Figure 5.2). Design features such as goal setting, suggestions, or reminders have been identified as key components of eHealth technologies that aim to promote healthy lifestyles (Lentferink et al., 2017). Figure 5.2 reflects a similar variety in the types of eHealth design features connected with this value (e.g., all forms of behavioural support). Outstandingly, design features related to behavioural planning support, behavioural performance support, and the provision of feedback during behaviour performance directly connected with this value. However, the analysis identified only 2 examples of real-time feedback features during performance.

Specifically, the ‘on-screen positive reinforcement’ feature of PATHway (Triantafyllidis et al., 2018; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) and the ‘upper-limb rehabilitation’ feature of the SMART PSMS stroke module (Parker, Mawson, Mountain, Nasr, & Zheng, 2014). Similarly, the PATHway ‘behavioural change assessment’ feature stood out as a way to potentially and indirectly honour this value (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018). The aforementioned features could represent untapped design opportunities to support individuals who highly value the maintenance of a healthy lifestyle (full details and references to specific features can be found in Multimedia Appendix 1, reported in Cruz-Martínez, Wentzel, Sanderman, et al. (2021)).

### **Supporting patients who value ‘an overview of personal health data’**

The study also connected several eHealth design features with the value of ‘having an overview of personal health data’ (Figure 5.2). These included all types of feedback provision but also self-monitoring support, behavioural assessment support, and even motivational incentives. That the agreed connections went beyond the ‘typical’ feedback features (e.g., statistics charts) could arguably hint toward ways to resolve the challenges reported by patients for the sense-making of their health data (Mamykina et al., 2015; Morton et al., 2017). Sense-making is considered the explicit and effortful approach of individuals to analytically engage with a situation, in order to construct explanations that allow them to select appropriate actions (Mamykina et al., 2015). For example, the ‘good habits visualisation’ feature of PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) is a behavioural assessment feature that not only delivers an overview of data but also suggests areas that need to be improved.

Similarly, the self-monitoring features connected with this value included a follow-up overview of monitored data. Specifically, the ‘self-management’ feature in the mock-up by Baek et al. (2018) directly provides an overview of data, while the ‘log’ feature of Engage (Srinivas et al., 2017) indirectly does so by requiring a few actions to access one. The ‘walking re-education and foot placement’ feature of the SMART PSMS stroke module is the single motivational incentive feature connected with this value (Mawson et al., 2014; Parker, Mawson, Mountain, Nasr, Davies, et al., 2014). The overview provided by this feature emphasises a feeling of progress and reward (Parker, Mawson, Mountain, Nasr, Davies, et al., 2014). Studies from the sense-making perspective support the notion that data-driven features can engage patients in different ways, by providing external motivational incentives, facilitating goal setting, or, in a lesser degree, allowing open exploration of their health data (ideally triggering sense-making) (Mamykina et al., 2017; Turchioe et al., 2019).

### Supporting patients who value ‘reliable information and advice’

Unsurprisingly, multiple educational support features connected with the value of ‘having reliable information and advice’ (Figure 5.2). Additionally, self-monitoring and monitored data feedback features connected with this value by guiding correct monitoring procedures and providing quick practical advice. For example, the ‘assessment’ feature of HeartMapp goes beyond just self-monitoring support by classifying patients according to safety levels and delivering behavioural actions (Athilingam, Clochesy, et al., 2018). Importantly, some features connected also with other less frequently addressed values, such as ‘not feeling fear, anxiety, or insecurity’ or ‘having confidence and self-efficacy.’ The struggles of patients in their transition from hospital-based care to self-managing at home are widely acknowledged (Nordfonn et al., 2019). The ability to access reliable information and advice during and after this transition could underlie the aforementioned feature-value connections but also a relation between patient values.

### Supporting patients who value ‘extrinsic motivation’

The study also connected multiple eHealth design features with the value of ‘being extrinsically motivated to accomplish goals or activities related to healthy lifestyles’ (Figure 5.2). Cues, reminders, peer-based support, and motivational incentives directly connected with this value. These connections could be supported by the available evidence on the positive effects of social support (Fivecoat et al., 2018) and of features that prompt immediate behavioural action (Vo et al., 2019), remind patients about key activities (Woods et al., 2019b), or aim to motivate self-management in general (Chandler et al., 2019; van Velsen et al., 2019). In this regard, the ‘culturally-attuned motivational and reinforcement SMS messages’ of the SMASH technology stood out because it also directly connected with other values, including the least frequently addressed value of ‘being perceived as a person rather than a patient’ (Chandler et al., 2019; Davidson et al., 2015; McGillicuddy et al., 2012). Finally, the ‘goal’ feature of Engage was the only behavioural planning feature indirectly connected with the ‘extrinsic motivation’ value (Srinivas et al., 2017). The argument for the indirect connection is its integration with the ‘deck of cards’ motivational feature (Srinivas et al., 2017).

### Supporting patients who value ‘personalised care’

As with the previous cases, the study connected several eHealth features with the value of ‘receiving personalised care’ (Figure 5.2). These included educational support features; behavioural planning and performance support; and motivational incentives, cues, and reminders. As an example, the ‘optional lifestyle changes’ educational feature of HOME BP allows patients to personally request additional content (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018). Alternatively, the ‘exercise’ feature of MedFit automatically updates the list of guided exercise classes based on the evaluation of classes performed earlier (Duff et al., 2018; Kuklyte et al., 2017; Prabhu et al., 2018). Outstandingly, 2 overarching system personalisation features connected with this value.

On the one hand, the ‘my stroke’ feature of the SMART PSMS permitted the customisation of the system during its deployment, with the involvement of both the patient and health care provider (Mawson et al., 2016; Mawson et al., 2014). On the other hand, the ‘remote system refinements and features activation’ of SUPPORT-HF connected indirectly because the personalisation seemed to be exclusively controlled by clinicians (Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015). Both features exemplify what appear to be still untapped opportunities in terms of modular customisation of eHealth technologies for individual cases.

### Supporting patients who value ‘low thresholds to health care’

In contrast to the previous values, only 5 human expert-based support features and a single self-monitoring support feature connected with the value of ‘perceiving low thresholds to access health care’ (Figure 5.3). The connections with expert-based support features align with literature highlighting the irreplaceable role of health care providers, especially when it comes to remote support (Morton et al., 2017; Tadas & Coyle, 2020). In this regard, front-end support features permitting the patients to trigger, request, or receive advice from professionals connected directly with this value. For example, the ‘contact’ feature of SUPPORT-HF allows patients to contact the support team (Chantler et al., 2016; Rahimi et al., 2015; Triantafyllidis, Velardo, Shah, et al., 2015). In comparison, back-end features exclusively available to health care providers connected only indirectly, for example, the ‘clinical team module’ of the HeartMapp application (Di Sano et al., 2015). Standing on its own, the ‘today’s exercise’ self-monitoring feature of the SMART PSMS stroke module also connected indirectly with this value (Mawson et al., 2016; Parker, Mawson, Mountain, Nasr, Davies, et al., 2014). This specific connection was argued on the integration of a preliminary check of symptoms and mood, which, if necessary, prompts patients to call the hospital for assistance before initiating exercises (Mawson et al., 2016; Parker, Mawson, Mountain, Nasr, Davies, et al., 2014).

### Supporting patients who value ‘social support’

Expectedly, 3 peer-based support features connected with the value of ‘receiving social support’ (Figure 5.3). PATHway’s ‘multiplayer class’ and ‘calendar for events/exercise’ features (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) as well as MedFit’s ‘social interaction’ feature connected directly with this value (Duff et al., 2018; Kuklyte et al., 2017; Prabhu et al., 2018). Perhaps more surprising in this case is that the expert-based ‘behavioural support (via health care provider)’ feature of HOME BP connected with this value (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018). This feature gives patients the option to request face-to-face or telephone-based behavioural support for self-monitoring and lifestyle modifications (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018). The underlying argument for this connection was the implementation of a training protocol for caregivers called ‘congratulate, ask, reassure, encourage’ or CARE (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018). Although patients’ families and peers are typically the expected sources of social support, a recent study acknowledged that health care providers can also play significant roles in this regard (Won & Son, 2016).

### Supporting patients who value ‘a sense of autonomy’

This study only connected 3 eHealth design features with the value of ‘preserving a sense of autonomy’ (Figure 5.3). The ‘goal’ feature of Engage (Srinivas et al., 2017) and the ‘my exercises’ feature of the SMART PSMS stroke module (Mawson et al., 2016; Mawson et al., 2014) connected directly by allowing patients to create their own self-management action plans.



Indirectly connected, Engage's 'log' self-monitoring feature allows patients to select and record the performance of activities based on a predetermined set of recommended actions (Srinivas et al., 2017). Supporting this connection, recent works ascertained how the support for autonomy can also promote the patients' individual responsibility for their own care (Tadas & Coyle, 2020; Vo et al., 2019). The aforementioned features exemplify how eHealth might be able to promote autonomy, that is, by providing options and thus avoiding fixed or generic recommendations for self-management.

### Supporting patients who value 'not feeling fear, anxiety, or insecurity'

The study directly connected only 1 eHealth design feature with the value of 'not feeling fear, anxiousness, or insecurity about health' and 2 more indirectly (Figure 5.3). The 'education about medication titration' feature of HOME BP connected directly because it addressed potential concerns about the side effects of medication (Band et al., 2017; Band et al., 2016; Bradbury et al., 2017; Bradbury et al., 2018; Morton et al., 2018). The 'how to keep healthy' educational feature of SUPPORT-HF connected indirectly by its presentation of videos depicting other patients' stories (Chantler et al., 2016; Triantafyllidis, Velardo, Chantler, et al., 2015). The 'clinical inertia alarms (to health care providers)' feature of SMASH (Chandler et al., 2019; McGillicuddy et al., 2012) also connected indirectly. In this regard, a study has reported how awareness of such links with health professionals can generate feelings of safety in patients (Middlemass et al., 2017). The small amount of features connected with this value is worrying in consideration of the feelings of fear, anxiety, and hopelessness that are commonly reported by patients with a CVD (Greenhalgh, A'Court, et al., 2017; Nordfonn et al., 2019). Therefore, it seems important that future eHealth technologies aim to assist the patient's control over these emotions.

Although not reviewed by this study, there are some design examples that go beyond those already mentioned, such as feedback during behaviour performance based on optimal training zones identified through heart rate monitoring (e.g., during cycling (Geurts et al., 2016)).

### Supporting patients who value 'confidence in treatment and for goal achievement'

The 'on-screen positive reinforcement' of PATHway is the only feature connected with the value of 'having confidence and self-efficacy in the treatment and the ability to achieve goals' (Triantafyllidis et al., 2018; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018) (Figure 5.3). This specific finding could represent an important gap in eHealth design, as self-efficacy is known to be a key influencing factor for self-management behaviours (Huygens et al., 2017; Riegel, Dickson, et al., 2017). Future eHealth technologies could attempt to integrate principles of evidence-based approaches such as motivational interviewing (Vellone et al., 2017). Alternatively, it could be explored why previous design approaches seem to fall short in boosting self-efficacy, that is, because a recent scoping review of digital games aiming to support CVD self-management concluded that they failed to improve the self-efficacy of patients (Radhakrishnan et al., 2019).

### Supporting patients who value 'being seen as a person rather than a patient'

Finally, this study connected only the 'culturally-attuned motivational and reinforcement SMS messages' feature of SMASH with the value of 'being seen as a person rather than a patient' (Davidson et al., 2015; McGillicuddy et al., 2012) (Figure 5.3). This feature delivers motivational and reinforcement messages tailored to the patient's values, beliefs, and short- or long-term life goals (Sieverdes et al., 2013). This is arguably an important yet challenging objective for value sensitive design. The shift from hospital- to home-based care could be accompanied by a change in perspective about how individuals are treated. Novel eHealth design approaches could take into consideration recent studies that explored ways to identify, elicit, and communicate about the values of individuals with multiple chronic conditions (Berry, Lim, et al., 2017a; Berry, Lim, et al., 2017b; Berry, Lim, Hartzler, Hirsch, Wagner, et al., 2017; Berry et al., 2019).

## **Applications and challenges of value sensitive eHealth design for self-management**

The potential connections described in the previous sections represent only a first step toward a value sensitive approach to the design of eHealth for CVD self-management support. Operationalising value sensitive design will certainly require more than making one-to-one connections between features and values, mainly because self-management is a naturalistic, dynamic, and complex decision-making process (Riegel et al., 2012; Riegel, Moser, et al., 2017). Self-management entails distinct and often conflicting goals (Riegel et al., 2012) (e.g., health goals vs personal life goals (Cornet et al., 2018; Cornet, Daley, et al., 2020)), intricate interactions between different actors (e.g., patients, families, caregivers (Cornet, Daley, et al., 2020; Holden et al., 2015)), and many influencing factors (e.g., skill, motivation, confidence (Riegel et al., 2012)). eHealth must aim to facilitate self-management processes, whether it is by delivering only key information, allowing care customisation, or addressing person-specific barriers (Cornet, Daley, et al., 2020).

Moreover, studies involving patients with multiple chronic conditions have also shown the challenges in the identification and conceptualisation of their values (Lim et al., 2019; Lim et al., 2017). For example, a study has shown that values can be explicitly or implicitly stated by patients, be also in conflict in with each other, and extend across several conceptual domains (Lim et al., 2017). Therefore, value sensitive design is in itself a complex approach and cannot be expected to account for all the challenges ascribed to eHealth self-management solutions. However, its importance lies in the premise that it aims to maximise the patients' motivation to engage in their own care.

Some of its methodological challenges are worth discussing: first, the required methods for the elicitation and translation of values to eHealth design; second, the strategies to simultaneously personalise eHealth to both self-management needs and patient values; third, the underlying research and development approaches through which the aforementioned challenges can be tackled.

### **Elicitation and translation of values to design as a collaborative task**

The elicitation and translation of values to eHealth design is a task that demands the involvement of multiple stakeholders, including health care providers, patients, and their families (Berry, Lim, et al., 2017a; Berry, Lim, et al., 2017b). The findings of this study represent only hypothetical connections that must be validated in consideration of the key elements of a patient's work system (i.e., the persons, tasks, tools, and surrounding contexts) (Holden et al., 2015). For example, studies involving informal (family) caregivers report the feelings of stress and anxiety caused by a patient's discharge from a hospital (Blair et al., 2014). Both patients and caregivers alike expressed the need for more involvement of health care providers in this follow-up process (Blair et al., 2014). Although this study identified features that connect with similar values such as 'having reliable information and advice,' it is unclear if the conceptualisation accurately expresses the interests and needs of informal caregivers. It is necessary to validate all observed connections with the actors that become implicit participants by eHealth design (e.g., expert-based support features imply the involvement of clinicians and nurses). At early stages of eHealth development, human-centred (Burns, 2018) or holistic approaches to eHealth (van Gemert-Pijnen et al., 2011) could be instrumental for the elicitation and translation of patient values (i.e., a consideration of perspectives from diverse stakeholders and scientific disciplines).

### **Personalising eHealth design to self-management needs and patient values**

The 98 connections suggest different ways in which eHealth design could be personalised to keep patients motivated and engaged in self-management. However, in naturalistic settings, it is necessary to consider many more influencing factors before settling for a personalisation strategy.

For example, older adult patients, a majority in chronically ill populations, often experience cognitive decline (Vaughan Dickson et al., 2011), have to deal with comorbidities (Dickson et al., 2013), and might require training in the use of technologies (Kim & Lee, 2017). For these patients, traditional educational strategies tend to be ineffective (Vaughan Dickson et al., 2011) while high levels of comorbidity decrease their self-efficacy. This study suggests design choices such as providing feedback during self-management performance or those argued before as capable to support sense-making. In short, it could be hypothesised that older adult patients who highly value ‘feeling confident’ will benefit more from features sensitised to such value. This requirement also makes apparent that overarching remote system personalisation features are vital for proper and on-the-go personalisation to individual cases (e.g., as done by the SMART PSMS (Mawson et al., 2016; Mawson et al., 2014) or the SUPPORT-HF intervention (Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015)).

## **Research and development approaches to aid value sensitive design**

To ensure its successful operationalisation, value sensitive design must be integrated with both existing and novel approaches of eHealth research and development. On the one hand, value sensitive design aims to sensitise researchers and developers to value-centred work, from theory to practice and vice versa (Hendry et al., 2021). On the other hand, what is also needed are underlying approaches that guide the actual design processes of value sensitive technologies. In eHealth, user- or human-centred frameworks stand out as widely accepted practices for development (Burns, 2018).

However, the practical challenges and pitfalls of these approaches are seldomly reported in published literature (Cornet, Toscos, et al., 2020). Challenges can come in formative, design, and evaluation stages or as recurrent processes (Cornet, Toscos, et al., 2020). On top of that, to validate value sensitive eHealth, it will be necessary to test the differences in actual effectiveness trials. Methodologies such as the Multiphase Optimisation Strategy (MOST) could be most suitable [98]. MOST’s fundamental idea is that interventions should be optimised to meet specific criteria before conducting a large-scale randomised control trial (Collins, 2018). Given the motivational aim of value sensitive design, eHealth technologies could be optimised based on multiple criteria of self-management engagement or its health-related outcomes.

## **Future work**

Future studies in the area of value sensitive eHealth design should seek to explore and confirm the connections made by this study. Primarily, studies could pursue further validation of the value conceptualisations in CVD populations. If validated, future studies could then seek the integration of other values identified in similar populations (e.g., other chronic conditions such as diabetes or chronic obstructive pulmonary disease). Similarly, future studies could revise or expand the categorisation of eHealth design features proposed by this study (i.e., according to what they aim to do or how they try to do it) (Cruz-Martínez et al., 2020). Certainly, design work is and should always be context-specific, and so the operationalisation of design features even for similar objectives might never be exactly the same. However, by refining value conceptualisations and by clustering specific design features within identifiable categories, new hypotheses and guidelines could be tested in order to advance value sensitive design across different eHealth applications and contexts.

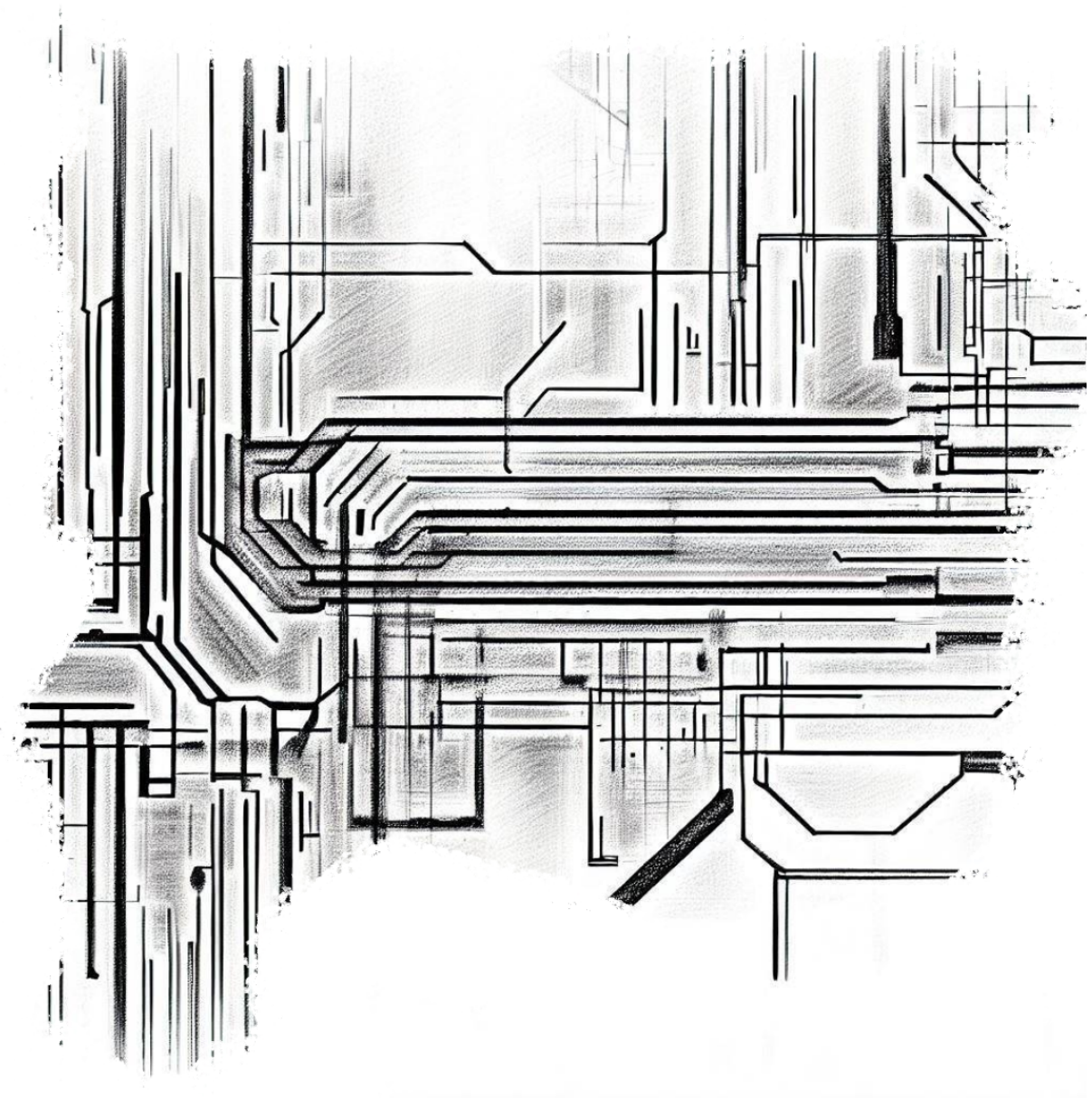
## **Strengths and limitations**

The hypothetical connections identified by this study can be debated from multiple perspectives. For instance, there is a number of caveats that concern the clarity and reliability of the inferred connections. To recall, the connections are the result of combining a content analysis performed by the authors of this study with the input received from researchers and designers of 6 of the 10 reviewed technologies.

On the one hand, the deductive coding of the content analysis shows that all 3 raters agreed most of the time (65.2%, see Table 5.2). Additionally, one-third of the time, 2 of 3 raters agreed (27.1%), and for 7.7% of the total pairings, there was no agreement at all. On the other hand, the KALPHA coefficient for all data was low (0.4536; 95% CI 0.4087-0.4978). However, it must be considered that KALPHA is a strict coefficient that accounts for the expected disagreement and not only the observed disagreement (Krippendorff, 2004, 2011). Therefore, the measure punishes when agreements were not achieved by the challenging, interpretative task of linking design features—described as best as possible with the available information—and a set of values, which are, by definition, subjective. Despite this, the hypothetical connections brought forward by the study must also be valued in light of the aims of the study, namely that it was not the objective to immediately agree on a characterisation of values and their potential contributions. In fact, the reliability and lack of agreement were deemed relatively negligible given that the next objective of the project is to validate the presumed connections with individuals in the target group. Thus, the most obvious limitation that the study confronts is that all inferences are still hypothetical and expert-based. In other words, the connections between design features and values must continue to be tested, refined, and generalised.

## **Conclusions**

This study identified 98 connections between design features of existing eHealth technologies and a set of empirically validated values of individuals living with a CVD. Although existing eHealth technologies were already found to have design features that could align well with patient values, some values were not frequently addressed. These results shed light on the importance of value sensitive design for future eHealth technologies. By and large, what this study adds are explicit and specific design hypotheses for future study that still require validation but, nevertheless, promise to advance the uptake and effectiveness of eHealth self-management support for individuals with a CVD.



# Chapter 6

## **Designing eHealth to support the self-care of patients with cardiovascular diseases: Proposition of theory-based and value sensitive prototypical features**

**This chapter is based on the following work:**

Cruz-Martínez, R. R., Wentzel, J., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (*Preprint*). Designing eHealth to support the self-care of patients with cardiovascular diseases: Proposition of theory-based and value sensitive prototypical features.

## ABSTRACT

**Background:** Cardiovascular disease (CVD) is a major cause of premature death and chronic disability worldwide. To stop the worsening of the health care crisis caused by CVD, the promotion and support for self-care is essential. Because patients need to be informed and advised remotely, eHealth interventions are one of the most promising solutions for sustainable self-care support. To improve the acceptability, uptake, and effectiveness of remote self-care support, theory-based and value sensitive design are promising approaches to inform eHealth design and its development process.

**Objective:** The present study aims to showcase how self-care theory and a value sensitive approach can inform and guide the design of eHealth to support patients with a CVD. The objective is to explicitly integrate the assumptions and propositions of the middle-range theory of self-care of chronic illness in the design of eHealth. The second objective is to outline design hypotheses and design requirements for the value sensitive design of eHealth to CVD patient values.

**Methods:** The first phase of the present study entailed theoretical and design work aiming to create mock-ups of 'prototypical' eHealth design features, defined as characteristics and functions of eHealth typically integrated or even essential for CVD self-care support. Mock-ups of these features were created in Figma, a cloud-based design tool, and linked to self-care theory and design hypotheses and requirements for value sensitive design.

**Results:** The study generated a first iteration of mock ups representing prototypical eHealth design features for the remote support of CVD self-care. In total, thirty-two prototypical eHealth design features are proposed and organised across eight overarching categories. The thirty-two features are theory-based and hypothesised to be fitting for known values of patients with a CVD, assuming that they meet the specified design requirements. Importantly, all of the features can be linked back to characteristics of technologies previously reported in scientific literature.

**Conclusions:** While the prototypical eHealth design features are a product of theoretical, conceptual, and design work, it is important to seek their validation in future research. In a subsequent phase, the mock-ups and their theoretical foundations are intended to be validated with stakeholders. The goal will be to collect quantitative and qualitative data to accept, reject, or reform a sub-set of the proposed hypotheses and requirements. Key stakeholders are CVD patients, informal caregivers, health care professionals, and eHealth developers and designers. Proposed methods to collect data, some of which have already been tested, include online surveys, individual interviews, and group feedback sessions.

**Keywords:** eHealth; self-care; cardiovascular diseases; value sensitive design; theory; prototyping

# INTRODUCTION

## A vision of self-care: Part 6

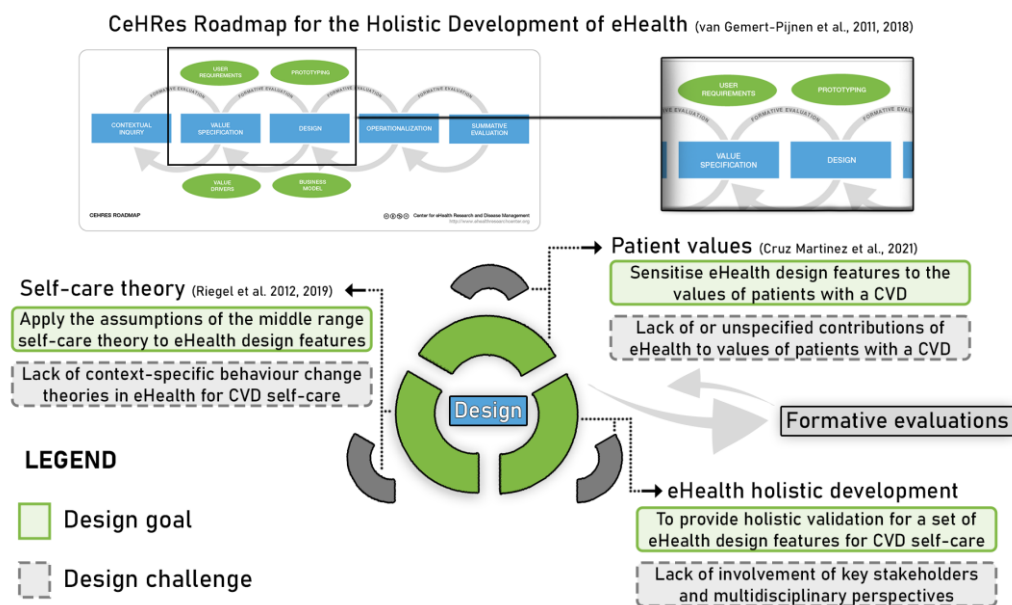
To recall, **Chapter 1** introduced and described the fictional case of Albert, depicting with it an optimistic vision of how eHealth could effectively support the self-care of individuals. To help realise that vision, the present thesis chose to investigate how technology can be designed and developed through the lens of different (theoretical) perspectives. At first, several perspectives and approaches were identified, although their influence on eHealth design and development was not always clear. To explicitly make theoretical connections and descriptions under the case of study, the works composing the present thesis adopted the middle-range self-care theory, the persuasive systems design model, and the value sensitive design framework. All of these, with the clear goal of informing eHealth design and development.

It is fair to ask, what could these theories and models signify in the end for cases like Albert's? In theory, a proper understanding of self-care allows designers, developers, and implementers to deploy a support system that can adapt to the specific behavioural needs of Albert. Understanding what Albert needs to do to maintain his health and well-being, demands also that key factors of the context are taken into account. In theory, a *persuasive* support system can facilitate Albert's behaviour change journey. It can, for instance, make use of social support features to motivate self-care maintenance behaviours. However, in the end it is still Albert's journeys to make. In theory, a *value sensitive* support system is adaptable to Albert's reality, as it reflects and honours his own perspectives and needs, rather than imposing fixed recommendations and mandates for self-care.

## Focus of the present chapter

There is already empirical evidence supporting the propositions of the self-care theory, on persuasive systems, and on value sensitive design. However, there are not yet examples to be found of how these (or similar) approaches can be integrated under a holistic approach for eHealth design and development. As illustrated in Figure 6.1, the present chapter seeks to make the first steps towards this holistic approach. Specifically, in the study hereby described: *theoretical*, *design*, and *prototyping* works are situated within the 'value specification' and 'design' stages of eHealth development.

Figure 6.1. Illustration of a holistic approach to eHealth design to support CVD self-care.





## BACKGROUND LITERATURE

### Understanding self-care of patients with a cardiovascular disease

Cardiovascular disease (CVD) is a major cause of premature death and chronic disability worldwide (Roth et al., 2017). The prevention and management of CVD poses an alarming burden to health care systems, and is expected to worsen due to an aging population, increase of risk factors, and the prevalence of other chronic conditions (Riegel, Moser, et al., 2017). To stop the worsening of the health care crisis caused by CVD, the promotion and support for self-care is essential.

To support self-care most effectively, it seems necessary to have a complete understanding of its behavioural processes and influencing factors. However, interventions aiming to support self-care do not always meet this step. For instance, a systematic review of literature at the crossroads of CVD, self-care support, and eHealth found that none of the included studies used a theory to define self-care as the specific target for behaviour change (Cruz-Martínez et al., 2020) (see **Chapter 3**). As a direct response to that study, a middle-range theory of self-care of chronic illness (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012) was adopted and used in an online survey experimental study to investigate how the precepts of that theory could inform eHealth design (Cruz-Martínez, Wentzel, Sanderman, et al., 2021) (see **Chapter 4**).

According to the middle-range theory adopted in that study, self-care can be generally defined as a process whereby individuals and their families maintain health through health-promoting practices and managing illness (Riegel, Moser, et al., 2017). Specifically, self-care actually involves distinct processes and goals which can in turn be influenced by multiple factors and involve different actors even beyond individuals and their families (e.g., health care professionals informing and guiding patient's lifestyle changes). To exemplify, a patient's decision to take a healthy walk outside could be influenced by their habits, physical capability, the weather conditions, or the motivation to follow their doctor's recommendations. According to the middle-range theory of self-care of chronic illness, self-care is understood to involve three core elements: self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012).

**Self-care maintenance** entails the performance of behaviours to improve well-being, preserve health, or to maintain physical and emotional stability (Riegel et al., 2012). For example, when a patient engages in physical activity to maintain or lose weight. In turn, **self-care monitoring** refers to the process of routine, vigilant body monitoring, surveillance, or 'body listening' (Riegel et al., 2012). For example, when a patient completes a symptoms checklist at key moments of the day. Finally, **self-care management** refers to the evaluation of changes in physical and emotional signs or symptoms to determine if action is needed (Riegel et al., 2012). For example, when a patient reacts to a symptom exacerbation by promptly contacting health care providers and following their recommendations. For interested readers, it is useful to know that the terminology used by this theory has also been informed by conceptual analyses, supporting the argument that self-care can encompass other concepts such as self-management (Matarese et al., 2018).

In addition to the specification of core elements, the middle-range self-care theory puts forward multiple assumptions and propositions that suggest self-care is a complex, dynamic, and subjective decision-making process (Riegel et al., 2012). Supporting this notion, various elements of this theory have been extensively studied and validated in the context of CVD and other chronic conditions (Fivecoat et al., 2018; Jaarsma et al., 2017; Lee & Riegel, 2018; Osokpo & Riegel, 2019; Riegel, Dickson, et al., 2017; Riegel, Moser, et al., 2017).

Currently, one of the most important tasks on the research agenda is the need to advance practical knowledge on how to apply the theoretical understanding of self-care to the development and design of interventions aiming to support it (Jaarsma et al., 2020; Riegel, Dunbar, et al., 2019). The premise is that a comprehensive understanding of self-care could help developers and designers create more effective and efficient interventions. In conclusion, despite the availability of a solid theoretical foundation for self-care, its adoption in the field of eHealth is still lacking. To that end, the present paper builds onto previous studies with the aim to facilitate the design of theory based eHealth interventions to support self-care of patients.

### **The potential of eHealth for home-based, remote self-care support**

In light of the added burden caused by CVD to health care systems, interventions providing self-care support should not only improve the lives of patients but also try to save or simplify the use of health care resources. To accomplish that, the provision of self-care support faces a fundamental challenge. That is, the fact that self-care mostly occurs outside clinical settings, given that self-care entails individuals living their own lives, pursuing their personal goals, and on top of that managing their health or (risk of) illness. In numbers, one estimate is that of the 8760 hours in a year, patients are spending only around 10 hours (0.1%) with their health care providers (Riegel, Moser, et al., 2017). As can be understood, this can leave individuals with limited motivation and energy to engage in self-care. Therefore, self-care support must be delivered to individuals while they are at their homes and communities. In order for interventions to be successful they have to fit in and work effectively under that reality.

Because patients need to be informed and advised remotely, technology-based interventions are one of the most promising solutions for sustainable self-care support. The use of technology to support health, well-being, and health care is known by the concept of *electronic health* or *eHealth* (van Gemert-Pijnen, Kip, et al., 2018). In fact, multiple reviews already endorse the potential of eHealth to support the self-care of patients with chronic conditions, including CVD (Greenwood et al., 2017; Hanlon et al., 2017; Kebapci et al., 2020; Kim & Lee, 2017; Villarreal & Berbey-Alvarez, 2020). All in all, the promise of eHealth for remote self-care support rests on features that facilitate real-time monitoring of symptoms and the provision of personalised and timely behavioural coaching and feedback (Kim & Lee, 2017; Riegel, Moser, et al., 2017). Adding up to the health benefits, studies have shown that both patients and health care providers can accept and endorse eHealth as a form of support (e.g., because it provides much needed day-by-day assistance for patients dealing with behavioural and psychosocial consequences of their conditions) (Feller et al., 2020; Middlemass et al., 2017; Vo et al., 2019; Walkden et al., 2019; Woods et al., 2019b).

### **Challenges in the design of eHealth for remote self-care support**

The development, implementation, and evaluation of eHealth entails many challenges and pitfalls (Michie et al., 2017). Two of these challenges stand out within the context of remote self-care support, as they must be tackled during the early design phases of eHealth. One is related to the use of theory and the other is akin to the concept of engagement. The first challenge refers to the lack of clarity about the operationalisation of theoretical constructs and mechanisms that are or should be informing eHealth development and design (Michie et al., 2017; Moller et al., 2017). For instance, the characterisation of existing interventions and their features, modes of delivery, and context of use are often lacking in detail (Michie et al., 2017). As mentioned before, in the case of CVD a recent systematic review of eHealth technologies focused on self-care support noted the same lack of clarity and detail on how researchers and developers underpin their design choices (e.g., in theory, empirical studies, or mere expert intuition) (Cruz-Martínez et al., 2020).

The added value of theories for the development and design of health care interventions is that they can contribute to the accumulation, curation, and dissemination of knowledge about what works, when, and how (Hekler et al., 2013; Hekler et al., 2016; Moller et al., 2017; Riley et al., 2011).

However, given the current state of affairs, the usefulness of theory-based interventions in real-world settings has been under debate (Hagger & Weed, 2019). Therefore, more transparency, clarity, and general methods are needed that can guide and eventually validate the value of scientific knowledge and theories for design work.

Then comes the second challenge, which is the low engagement to eHealth that is frequently observed among end users (Michie et al., 2017). Low engagement is often related to the scarce personalisation or tailoring of interventions, which can lead to disparities by leaving some individuals at risk (Michie et al., 2017). Similarly, the fluctuating motivation of individuals to engage in healthy and illness-managing behaviours is one of the key obstacles to overcome (Kebapci et al., 2020; Kim & Lee, 2017). To address this challenge, one of the proposed solutions is to design eHealth in a way that better aligns to the underlying interests and needs of individuals (Hanlon et al., 2017; Kim & Lee, 2017; Van Velsen et al., 2013). The premise here is that if patients see their personal values reflected in the design of eHealth, they might be more motivated to embrace it as a medium to engage in self-care.

In eHealth development, the concept of ‘value’ can be used to refer to any ideal or interest that an individual could pursue or meet with the help of technology (Cruz-Martínez, Wentzel, Bente, et al., 2021). However, conceptualising and integrating values into eHealth design is not a straightforward task, as multiple approaches exist with varying scopes. For instance, value sensitive design is a theoretical and a methodological framework that explicitly seeks to integrate values into technology design work (e.g., values such as privacy, autonomy, or trust) (Friedman et al., 2013). This approach has not yet been extensively applied at the crossroads of eHealth, self-care, and CVD, but given its promise, it might be able to make meaningful contributions to the design of more effective and efficient interventions.

## **Using self-care theory and value sensitive design for holistic eHealth development**

In light of the above, it can be argued that eHealth technologies—including those designed to remotely support the self-care of patients with a CVD—often still struggle to provide a clear and transparent theoretical foundation. In practice, this could end up hindering their chances to understand and leverage on the motivations of individuals to engage in self-care, or on the stakes of other actors involved in the provision of support (e.g., informal caregivers and health care professionals). In consequence, the lack of proper understanding limits the accumulation of knowledge and thus the potential effectiveness of future eHealth interventions. Nevertheless, as presented before, there already exist theories and frameworks that could be used to guide and potentially improve the design of eHealth for self-care support.

To tackle the aforementioned challenges, a holistic approach to the development, implementation, and evaluation of eHealth is recommended (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). To this end, the CeHRes roadmap is a guideline for holistic eHealth development that integrates multiple frameworks and is mainly grounded in persuasive technology design (van Gemert-Pijnen, Kelders, et al., 2018), human-centred design (Burns, 2018), and business modelling (Nieuwenhuis, 2018). The holistic view promoted by the roadmap recognises the importance of the whole as well as the interdependence of its parts. This means that the interaction and reciprocal influence between contextual, technological, and human factors must be emphasised early and often during eHealth development and design.

In practice, striving for a holistic view demands the involvement of multiple and diverse stakeholders in the process of eHealth development and design (i.e., people or groups of people who affect or are affected by an eHealth technology). As shown before, there are in fact many contextual, technological, and human factors to consider in the process of home-based eHealth self-care support for CVD: *How to best support the distinct core elements of self-care? How to align technology with the patients’ values? What would (novel) requirements of value sensitive eHealth mean for the work processes and roles of stakeholders?*

The holistic view of the CeHRes roadmap must be complemented with theories that fit and describe the context of interest. For the case at hand, the middle-range self-care theory (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012) could be used to address the aforementioned theory-based design challenge, by providing a comprehensive understanding of self-care, its behavioural processes and influencing factors. A proper and context-specific conceptualisation of the target behaviour(s) is one of the main advantages of using self-care theory for eHealth design (e.g., to focus the tailoring of eHealth on the core elements of self-care). For instance, the previously mentioned online survey experimental study assessed the potential success of persuasive design strategies when matched to the distinct theory-based self-care needs (Cruz-Martínez, Wentzel, Sanderman, et al., 2021). The study concluded that eHealth design features resembling primary task support are promising support strategies across all core elements of self-care (maintenance, monitoring, and management). Therefore, primary task support could be a prerequisite, as it can simplify self-care tasks but also ensure the safety of patients. The findings of that study suggested that, compared to primary task support, social support strategies could be less likely to succeed in supporting self-care monitoring (Cruz-Martínez, Wentzel, Sanderman, et al., 2021). Similarly, the findings suggested that, compared to primary task support, both dialogue support and social support strategies could be less likely to succeed in supporting self-care management needs (Cruz-Martínez, Wentzel, Sanderman, et al., 2021).

Adding to the contributions of self-care theory in the process of holistic eHealth development, the value sensitive design framework could help address the aforementioned engagement design challenge, by ensuring eHealth can tap on more powerful motivational sources of individuals (i.e., their personal values), while also keeping the stakes or interests of other key actors into consideration. Value sensitive design could be used to ensure that the design of technology accounts for the values of patients. To realise that, this framework prescribes the use of integrative and iterative methodologies that include conceptual, empirical, and technical investigations (Friedman et al., 2013). For instance, as described in **Chapter 5**, a previous study undertook a value sensitive approach to match the design features of existing eHealth technologies with a set of empirically-validated CVD patient values (Cruz-Martínez, Wentzel, Bente, et al., 2021).

Specifically, 70 design features from 10 eHealth technologies were analysed and connected to a set of 11 values. In total, the study identified 98 potential connections between eHealth design features and the patient values included in the analysis (Cruz-Martínez, Wentzel, Bente, et al., 2021). Importantly, the findings of that study suggested that some eHealth design features could be connected to multiple patient values, but also that some values could be less frequently honoured by existing eHealth technologies (Cruz-Martínez, Wentzel, Bente, et al., 2021). To emphasise, in the study it became evident that not all patient values were always accommodated in eHealth design. In fact, the matchmaking process also suggested that values are often not placed centrally during design (but rather often driven by technological innovation or the requirements of health care professionals). In order to effectively support self care, the present paper endorses that eHealth developers should strive to design for patient values, and seeks to support that process. Contrary to recurrent practices, it is the patient needs and their values and not the main care activities of professionals that should dictate the design and development of interventions.

## **Aim**

The present study aims to showcase how the design of eHealth can be informed and guided by self-care theory and a value sensitive approach to support the cases of patients with a CVD. Such an approach is novel because it has been scarcely reported in previous literature at the crossroads of CVD, self-care, and eHealth (Cruz-Martínez et al., 2020). The first goal of the study is to integrate the assumptions and propositions of the middle-range self-care theory in the design of eHealth. The second goal is to propose and advance the validation of hypotheses and requirements detailing how eHealth, or its design features, could honour CVD patient values.

To be clear, the present study uses and focuses on the term ‘**eHealth design feature**’ to refer to any clearly identifiable property of a technology that serves a specific function and is proposed to help achieve an overarching aim for health, well-being, or health care. This definition is primarily based on the description of technological ‘features or properties’ by the value sensitive design framework (Friedman et al., 2013). According to the study’s definition, eHealth design features could be functional or visual properties, underlying technical mechanisms, as well as recognisable ‘intervention building blocks’ such as behaviour change techniques (Michie et al., 2011) and persuasive design principles (Oinas-Kukkonen & Harjuma, 2009).

The overarching research questions of the study are:

- How can self-care theory inform the development process of eHealth design features?
- How can a value sensitive approach inform the development process of eHealth, to meet the values of patients with a CVD?

By approaching an answer to these questions, the present study aims to promote approaches to eHealth design that comprehensively adapt to the complex nature of self-care, and that directly aim to keep patients with a CVD engaged in that process by tapping on the motivational power of their values.

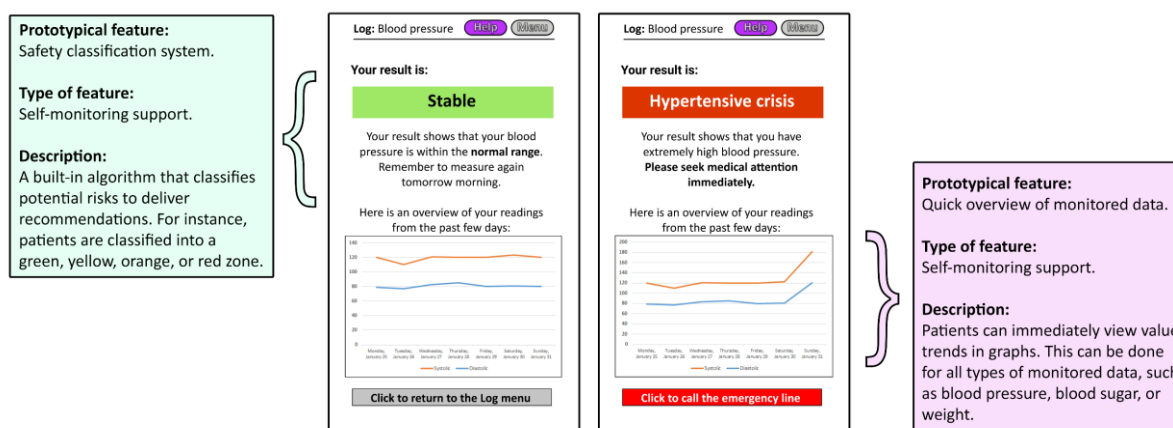
## METHODS

To accomplish its aim and goals, the present study combines knowledge accumulated by previous works on the value sensitive design of CVD eHealth applications with the assumptions and propositions of self-care theory. Therefore, the present study focused on theoretical and design work that used theory and key empirical findings to propose an initial set of **prototypical eHealth design features**.

### Prototypical eHealth design features

The term ‘**prototypical**’ means to emphasise that the *eHealth design features* proposed by the present study are representations of characteristics and functions typically integrated, maybe even essential, to eHealth technologies providing remote CVD self-care support. As such, the features are in most cases replications of those from existing interventions. To illustrate this approach, Figure 6.2 presents a ‘mock-up’ showcasing the design of two prototypical eHealth features. **Mock-ups** are low-fidelity, visual representations of a design that can accompany textual or other forms of description (Burns, 2018). In this case, Figure 6.2 shows self-monitoring support features that have been observed in existing interventions. To give a few examples, such features exist in the HeartMapp (Di Sano et al., 2015) or Care4myHeart (Woods et al., 2019b) mobile applications, the Home and Online Management and Evaluation of Blood Pressure intervention (Band et al., 2017), and the SMART Personalised Self-Management System (Parker, Mawson, Mountain, Nasr, & Zheng, 2014).

Figure 6.2. Mock-ups representing two ‘prototypical’ eHealth design features for CVD self-care support.



The present study aimed to deliver a first iteration of mock-ups representing prototypical eHealth design features. Previous studies conducted by the authors have collected and thoroughly revised the characteristics and underlying development assumptions of eHealth technologies aiming to support CVD self-care (Cruz-Martínez et al., 2020; Cruz-Martínez, Wentzel, Sanderman, et al., 2021). The technologies revised in those studies served as the basis for the identification of thirty-two prototypical eHealth design features (i.e., features that tend to appear across multiple eHealth applications to CVD self-care). The resulting mock-ups are presented in the results, but the present section seeks to clarify the theoretical and design process that led to those representations. Throughout the theoretical and design work, RCM revised the mock-ups and their underlying design hypotheses and requirements based on feedback from the rest of the research team (JW, LGP, RS).

## Design hypotheses and design requirements

Importantly, this phase of the study linked the prototypical features to explicit ‘design hypotheses’, which is a concept adopted from the work of Hekler et al. (2013) where, among other things, the gap between theory and concrete design guidelines was already attempted to be bridged. A **design hypothesis** outlines a set of assumptions about how an eHealth technology, or its specific features, can affect the user’s behaviour or cognition (Hekler et al., 2013). Under that rationale, the theoretical work of the present study entailed the translation of assumptions and propositions from the middle-range self-care theory (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012) and key findings of previous works focused on patient values (Cruz-Martínez, Wentzel, Bente, et al., 2021) into design hypotheses and design requirements underlying the proposed eHealth design features. To clarify, while a ‘design hypothesis’ is a scientific proposition about how eHealth affects behaviour or cognition, a ‘**design requirement**’ states what exactly is required from the technology with respect to matters like software, hardware, content, and visuals (Kip & van Gemert-Pijnen, 2018).

## Theoretical work

The explicit specification of design hypotheses and requirements is necessary because, while the middle-range theory describes influencing mechanisms and processes of self-care (Riegel et al., 2012), it is not within its scope to provide assumptions or predictions about how eHealth can be an effective mode of support. Likewise, the hypotheses on value sensitive design came mainly from a content analysis of existing eHealth applications to CVD self-care (Cruz-Martínez, Wentzel, Bente, et al., 2021). Table 6.1 presents a worked example of the translation of theoretical or empirically-grounded assumptions and propositions into design hypotheses and design requirements for eHealth design.

As can be seen in Table 6.1, design requirements can also be broken down into categories. Some possible types of requirements are: **content requirements**, **usability and user experience requirements**, **functional and modality requirements**, **service requirement**, and **organisational requirements** (Kip & van Gemert-Pijnen, 2018). As can be appreciated so far, the theoretical and design work during phase one entailed the explicit definition of a lot of key concepts and terms.

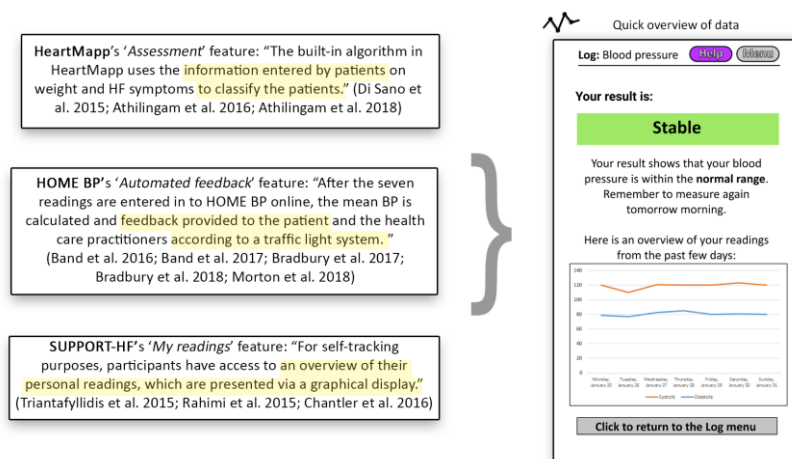
## Design work

The main researcher (RCM) used Figma (*Figma - the collaborative interface design tool*), a cloud-based design tool, to create and iteratively refine the mock-ups. The first step in designing the mock-ups was to represent the 70 design features from 10 eHealth technologies that had been previously identified in a systematic review and subsequently revised in a content analysis study (Cruz-Martínez et al., 2020; Cruz-Martínez, Wentzel, Bente, et al., 2021). Figure 6.3 illustrates how the one of the prototypical eHealth design feature integrates characteristics of features from three eHealth technologies that have been described in scientific publications.

Table 6.1. Worked example of how theoretical or empirical assumptions or propositions translate into hypotheses and requirements for the design of eHealth for CVD self-care support.

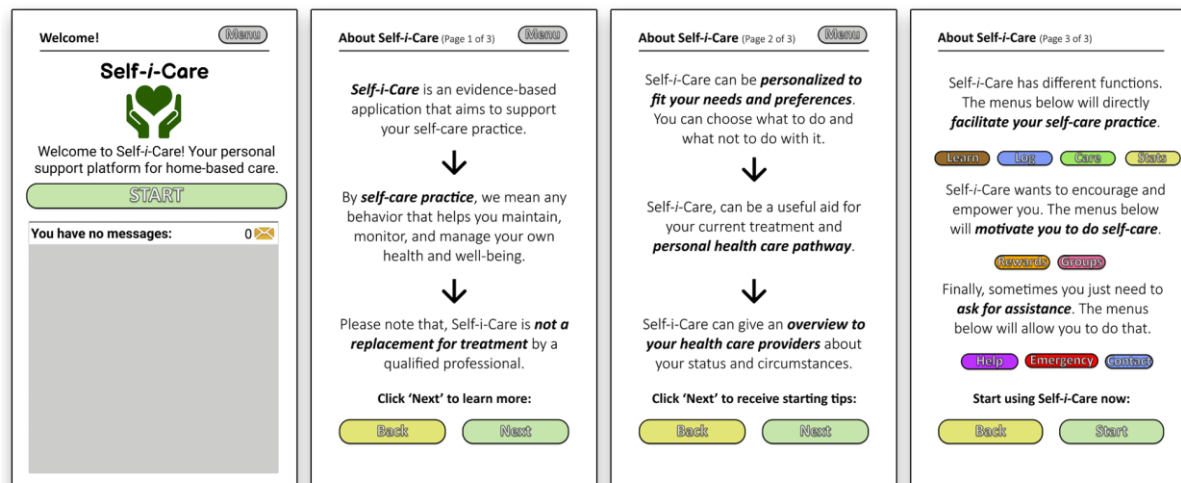
Assumption or proposition	Design hypothesis	Design requirement
<b>Self-care theory</b>		
Self-care monitoring is necessary for effective self-care management, because to make a decision a symptom change must first be noticed and evaluated (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012).	eHealth self-care support is more effective when it helps individuals achieve mastery in self-care monitoring (e.g., through simplification of tasks, aid with sense-making, or context-aware prompts and reminders (Cruz-Martínez, Wentzel, Sanderman, et al., 2021)).	<i>Usability and user experience requirement:</i> eHealth self-care support must facilitate mastery of self-care monitoring as a prerequisite for effective self-care management (e.g., with features such as those in Figure 6.2).
<b>Value sensitive design</b>		
Individuals with a CVD tend to value <i>having an overview of their personal health data</i> (Bente et al., 2021)	Individuals feel their value is honoured through eHealth design features that provide <i>self-monitoring</i> , leading to an overview of their health data (Cruz-Martínez, Wentzel, Bente, et al., 2021) (e.g., such as those in Figure 6.2).	<i>Content requirement:</i> The technology must provide a simple overview of monitored data that immediately follows the logging of a value (e.g., to visualise the new value compared to a trend or threshold).
Individuals with a CVD tend to value <i>perceiving low thresholds to access health care</i> (Bente et al., 2021)	Individuals feel their value is honoured through eHealth design features that provide <i>self-monitoring</i> , leading to the identification of potential risks and, when necessary, prompt the clinical team to intervene (Cruz-Martínez, Wentzel, Bente, et al., 2021) (e.g., such as those in Figure 6.2).	<i>Functional and modality requirement:</i> The technology must provide an underlying mechanism to identify potential risks and give safety recommendations to the user, such as by following a traffic light rating system on symptoms monitoring (green, yellow, orange, red).

Figure 6.3. Mock-up of prototypical eHealth design feature, illustrating how its design relates to descriptions of other features as reported in scientific publications.



The second step in designing the mock-ups was to create a testable (low-fidelity) prototype. To be clear, a **prototype** is an initial, raw visual representation of a technology. Prototypes are simplified versions of a final end product, which can be tested with users and others stakeholders to identify issues or necessary changes (Kip & van Gemert-Pijnen, 2018). In the elaboration of the prototype, the main researcher designed menus and transitions to connect each of the thirty-two prototypical design features. Figure 6.4 illustrates the introductory menu for 'Self-i-Care', the name given to the low-fidelity prototype. The prototype can be accessed and interacted via Figma (Cruz-Martinez, 2023). The design work ended when the team had an overview of the first set of mock-ups, with their underlying hypotheses and requirements.

Figure 6.4. Mock-up of introductory menu for 'Self-i-Care', a low-fidelity prototype for CVD self-care support.



## RESULTS

### Prototypical eHealth design features to support CVD self-care

To recall, the study aimed to generate a first iteration of mock ups representing prototypical eHealth design features to remotely support the self-care of patients with a CVD. As a result, thirty-two prototypical eHealth design features have been designed and provided with a theoretical foundation on self-care theory and a value sensitive approach. To facilitate their presentation in this section, the features are organised across twelve categories, and introduced with their representative mock-ups and a general description of their distinctive traits.



It is important to consider that all of the features can be linked back to characteristics of technologies previously reported in scientific literature. To begin with the presentation, **Table 6.2** lists the twelve categories with their corresponding description and examples from eHealth interventions as described in scientific publications. The set of categories was first generated in a previous study that analysed 70 eHealth design features (see **Chapter 5**).

Table 6.2. (Part 1) Categorisation of eHealth design features to support self-care of patients with a CVD. Adapted from Cruz-Martínez, Wentzel, Bente, et al. (2021).

Category	Description	Examples
Educational support	eHealth design features that enable a patient to access educational information on various topics. Educational information can be presented in multiple formats such as text, audio, or videos	'Heart Failure Info' feature of HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam et al., 2016; Di Sano et al., 2015)
Self-monitoring support	eHealth design features that facilitate a patient's monitoring of various types of data. For instance, monitoring symptoms, weight, or self-care behaviours	'Log' feature of Engage (Srinivas et al., 2017)
Behavioural assessment support	eHealth design features that assess a patient's readiness to change a selected behaviour. They can lead to a visual display of risk factors or recommended priorities for behaviour change	PATHway's 'behavioural change assessment' and 'good habits visualisation' (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)
Behavioural planning support	eHealth design features that facilitate action-planning of self-care behaviours. For instance, to decide when and how to exercise based on long-term goals that were either self-set or agreed upon collaboratively with health care providers	'Goal' feature of Engage (Srinivas et al., 2017)
Behavioural performance support	eHealth design features that provide guidance or support during the performance of self-care behaviours. For instance, an animation to guide a deep breathing practice. They can integrate real-time feedback or be followed up by (self-)evaluations (e.g., rating one's own performance or perceived workout intensity)	'Exercise' feature of MedFit (Duff et al., 2018; Kuklyte et al., 2017; Prabhu et al., 2018)

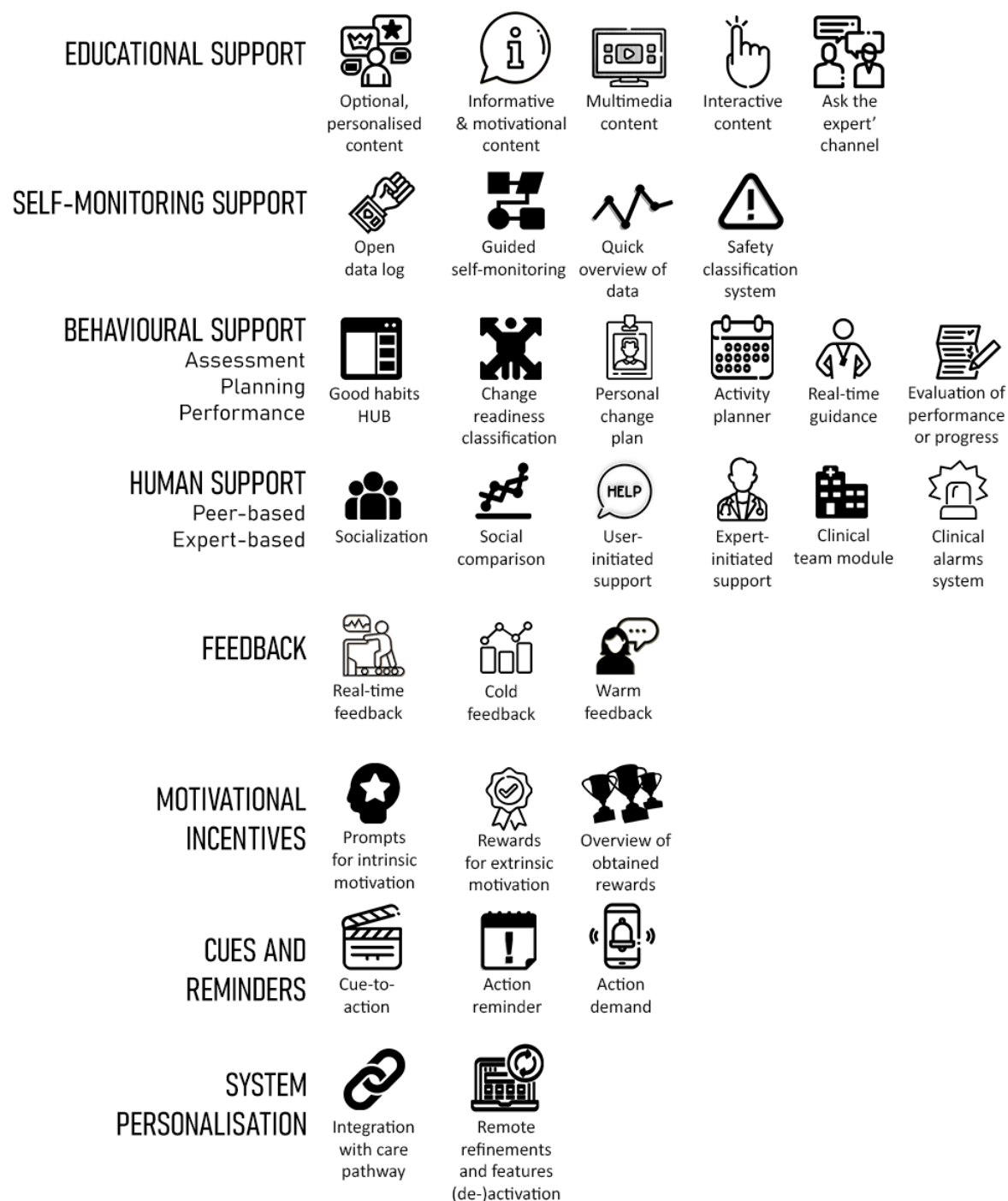
Table 6.2. (Part 2) Categorisation of eHealth design features to support self-care of patients with a CVD. Adapted from Cruz-Martínez, Wentzel, Bente, et al. (2021)

Category	Description	Examples
Feedback	eHealth design features that provide feedback on monitored data or tracked behaviour. For instance, via graphs, charts, or written reports about symptoms, behaviours, or the progress towards a goal. Alternatively, feedback can be provided in <i>real-time</i> during the performance of self-care maintenance behaviours	'Statistics/stats' feature of HeartMapp (Athilingam, Clochesy, et al., 2018; Athilingam et al., 2016; Di Sano et al., 2015), or the 'on-screen positive reinforcement' feature of PATHway (Triantafyllidis et al., 2018; Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)
Motivational incentives	eHealth design features that incentivise the engagement with the technology by using metaphors such as 'missions', 'medals', or 'cards'. They can be personalised according to a prescribed treatment, self-set goals, or automatic analyses of monitored data	'Deck of cards' feature of Engage (Srinivas et al., 2017)
Cues	eHealth design features that provide prompts or cues-to-action. They are directed to specific behaviours and can be personalised to a patient's preferences or circumstances	'Behaviour change notifications' feature of PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)
Reminders	eHealth design features that aim to facilitate adherence to self-care behaviours. They can include the demand of an action or a request for additional input such as a reason for not conducting the behaviour (e.g., report the intake of medication as prescribed or a reason for skipping it)	'Medication tray reminder signals' of SMASH (McGillicuddy, Gregoski, et al., 2013; McGillicuddy, Weiland, et al., 2013; McGillicuddy et al., 2012)
Peer-based human support	eHealth design features that facilitate interaction with peers. For instance, an online platform that allows data comparison between individuals or makes it possible to plan activities with others	'Multiplayer class' feature of PATHway (Walsh, Moran, Cornelissen, Buys, Claes, et al., 2018)
Expert-based human support	eHealth design features that facilitate the interaction or collaboration with health care providers. For instance, a communication channel with an expert or support team. They can be linked to a clinical team module or a back-end alarm system that prompts interaction	'Contact' feature of SUPPORT-HF (Chantler et al., 2016; Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015)
System personalisation	eHealth design features that aim to (de-)activate the system's modules to create a better fit with a patient's needs, preferences, or circumstances. Personalisation can occur during the introduction of the technology, or as a response to the evolving situation or circumstances of the patient	'Remote system refinements and features activation' feature of SUPPORT-HF (Rahimi et al., 2015; Triantafyllidis, Velardo, Chantler, et al., 2015)

Before finally proceeding to describe each feature, Figure 6.5 provides an illustrative overview of the resulting thirty-two prototypical eHealth design features. In Figure 6.5, the features are organised across the twelve categories and represented with distinctive labels and icons.

To be noted, the categories in Figure 6.5 do not aim to be exhaustive, but rather descriptive of what has been observed in previous studies. Moreover, they are certainly often not stand-alone features, but rather integrated with others in eHealth design. In this section the potential integration will also be exemplified, especially in terms of how they can best meet patient values.

Figure 6.5. Thirty-two theory-based prototypical eHealth design features to support CVD self-care and patient values.

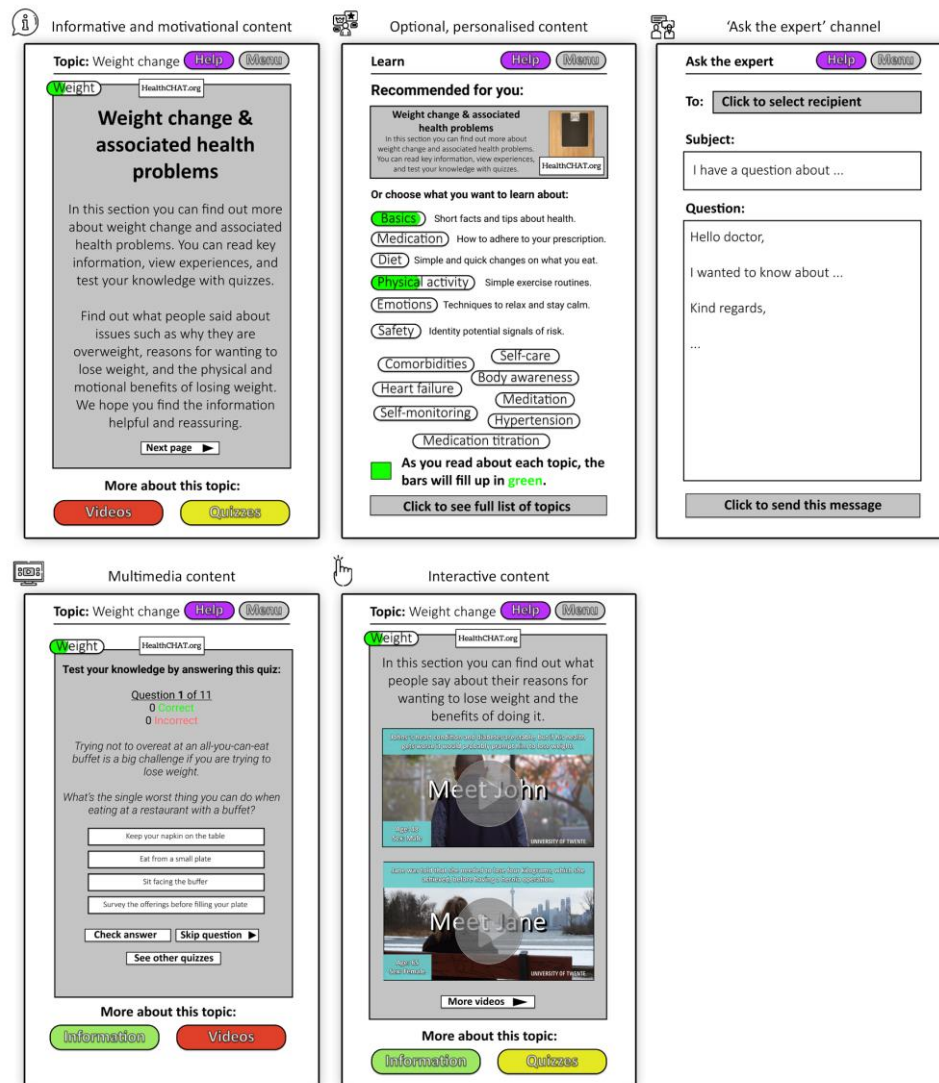


## Educational support

Figure 6.6 presents the mock-ups of prototypical **educational support features**. These features mainly differ in how educational content is presented to the end user. For instance, prototypical features provide educational content that is *optional and personalised*, as well as *informative and motivational*. Additionally, other prototypical features for educational support go beyond the provision of textual information and can include *multimedia* or *interactive* content (e.g., videos to prompt self-reflection or quizzes to enhance learning).

Finally, another prototypical feature is the availability of a communication channel with health care providers or with any other actor supporting learning (e.g., via an ‘ask the expert’ channel). This last feature typically aims to clarify information or misunderstandings about educational content related to disease symptoms or self-care practices.

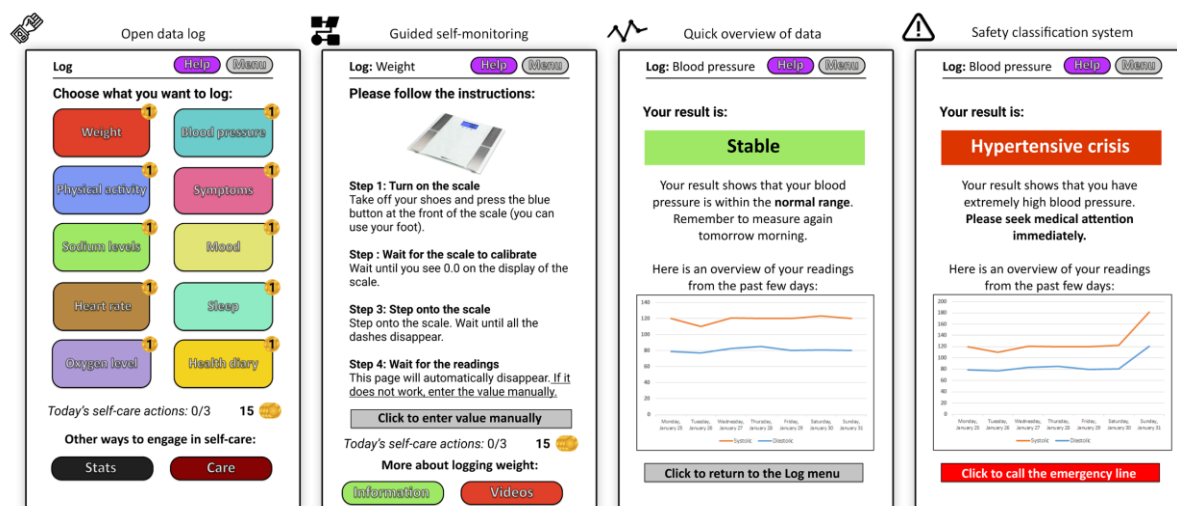
Figure 6.6. Prototypical eHealth design features for *educational support* of CVD self-care.



## Self-monitoring support

Figure 6.7 presents the mock-ups of prototypical **self-monitoring support features**. These features mainly differ in the extent to which self-monitoring is supported or complemented. For instance, a prototypical feature is to give control to the end users for what they monitor and when (e.g., via an ‘open data log’). Additionally, a prototypical feature is to facilitate *guided self-monitoring* (i.e., tunnelled, step-by-step guidance). This feature typically automatises monitoring with internet-enabled sensors, but can also guide the manual entry of data. Finally, other prototypical features are the provision of a *quick overview of monitored data* that immediately follows monitoring, and the output display of an underlying *safety classification system* (e.g., a traffic light system to signal potential risks). Arguably, these two features could also be categorised as ‘feedback’ and not just ‘self-monitoring support’. However, their main aim is to round up self-care monitoring, by ensuring the safety of the patients and thereby lessening fears or anxieties caused by symptoms.

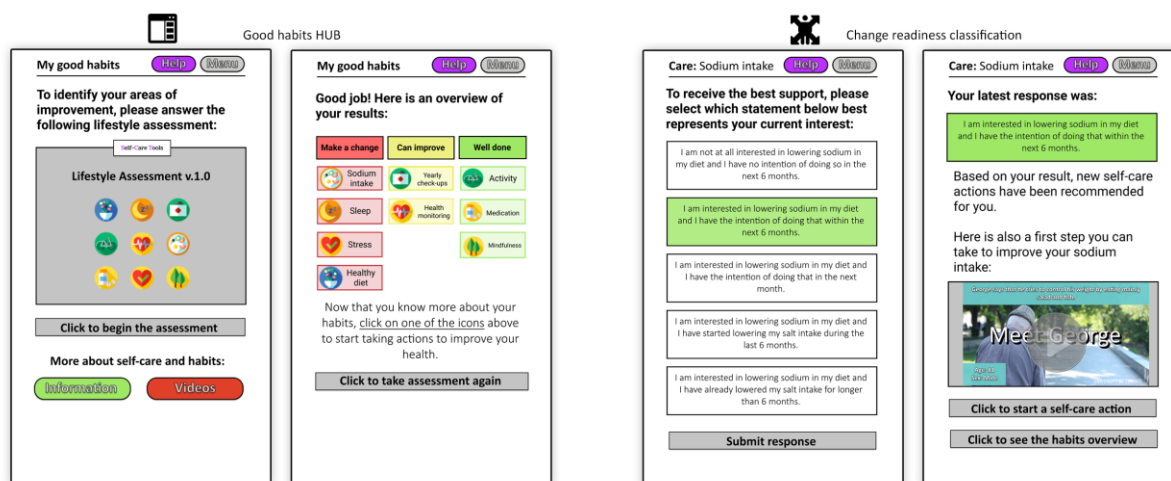
Figure 6.7. Prototypical eHealth design features for *self-monitoring support* of CVD self-care.



## Behavioural assessment support features

Figure 6.8 presents the mock-ups of prototypical **behavioural assessment support features**. As a subset of behavioural support, the features in this category differ mainly in their approach to motivate or facilitate behaviour change. The *good habits HUB* feature centres on the assessment of lifestyle habits (e.g., using validated questionnaires to identify habits that need improvement). The *change readiness classification* feature focuses on assessing the *behavioural readiness* of conducts that have already been determined as important targets of change. By a combination of assessment features such as these two, the system delivers recommendations for self-care behaviours to improve (e.g., prioritising medication intake due to its impact on health and the patient's behavioural change readiness).

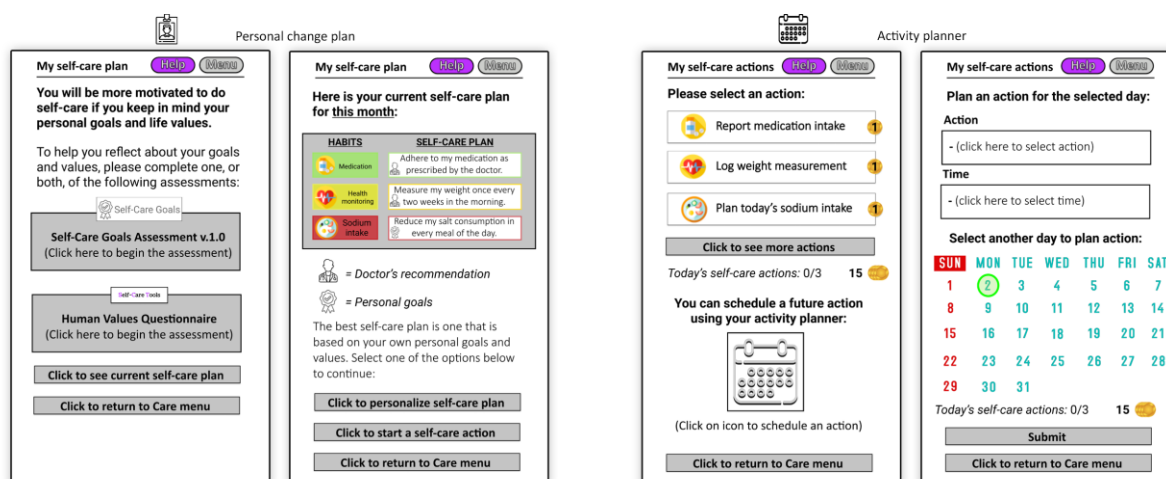
Figure 6.8. Prototypical eHealth design features for *behavioural assessment support* of CVD self-care.



## Behavioural planning support

Figure 6.9 presents the mock-ups of prototypical **behavioural planning support features**. As a subset of behavioural support, the features in this category seek to motivate or facilitate behaviour change by enabling implementation intentions or action-planning for self-care. The *personal change plan* feature gives the patient the ability to set up or personalise a general behavioural change plan (e.g., to determine specific target behaviours). The *activity planner* feature serves the more specific purpose of scheduling self-care activities (e.g., exercise sessions).

Figure 6.9. Prototypical eHealth design features for *behavioural planning* support of CVD self-care.



## Behavioural performance support

Figure 6.10 presents the mock-ups of prototypical **behavioural performance support features**. As a subset of behavioural support, the features in this category seek to directly motivate or facilitate behaviour change *during* the actual performance of self-care behaviours. The *real-time guidance* feature provides information or advice that aims to facilitate the achievement of a desired performance (e.g., reaching a step goal or the correct execution of exercises). The *evaluation of the performance or progress* centres on a short but often detailed overview of the performance achieved during a self-care session (e.g., comparing current with past and best performances).

## Feedback

Figure 6.11 presents the mock-ups of prototypical **feedback features**. *Real-time feedback* is a prototypical feature that directly supports self-care maintenance behaviours (e.g., displaying the amount of steps taken during a walk). The distinction of this feature with *real-time guidance* as behavioural support will be discussed later on. *Cold feedback* is also a feature of many eHealth CVD self-care applications, typically operationalised as graphs or charts displaying various types of monitored data. This feature is labelled as 'cold' because typically there is no further assistance for the patient on how to make sense of the data. In contrast, *warm feedback* is the one provided by humans, such as health care professionals or informal caregivers. As suggested before, feedback can often be a complement of other features, but in most cases feedback itself comes in the aforementioned forms. The prototypical features related to feedback can usually be distinguished by answering the question: *when, how, or by whom* is feedback provided?

Figure 6.10. Prototypical eHealth design features for behavioural performance support of CVD self-care.

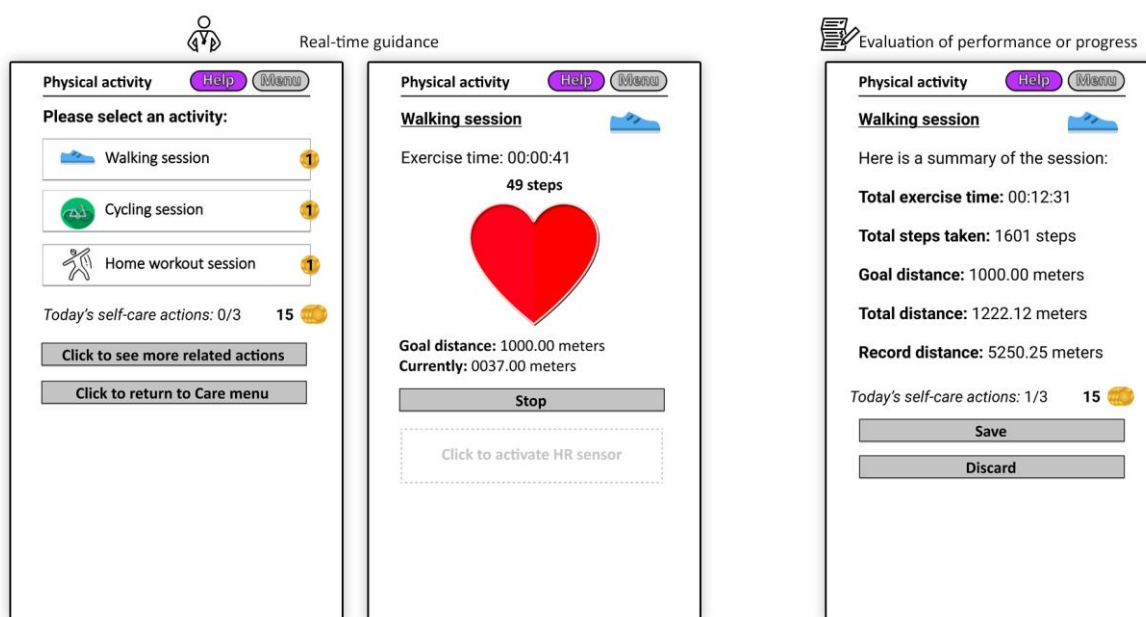
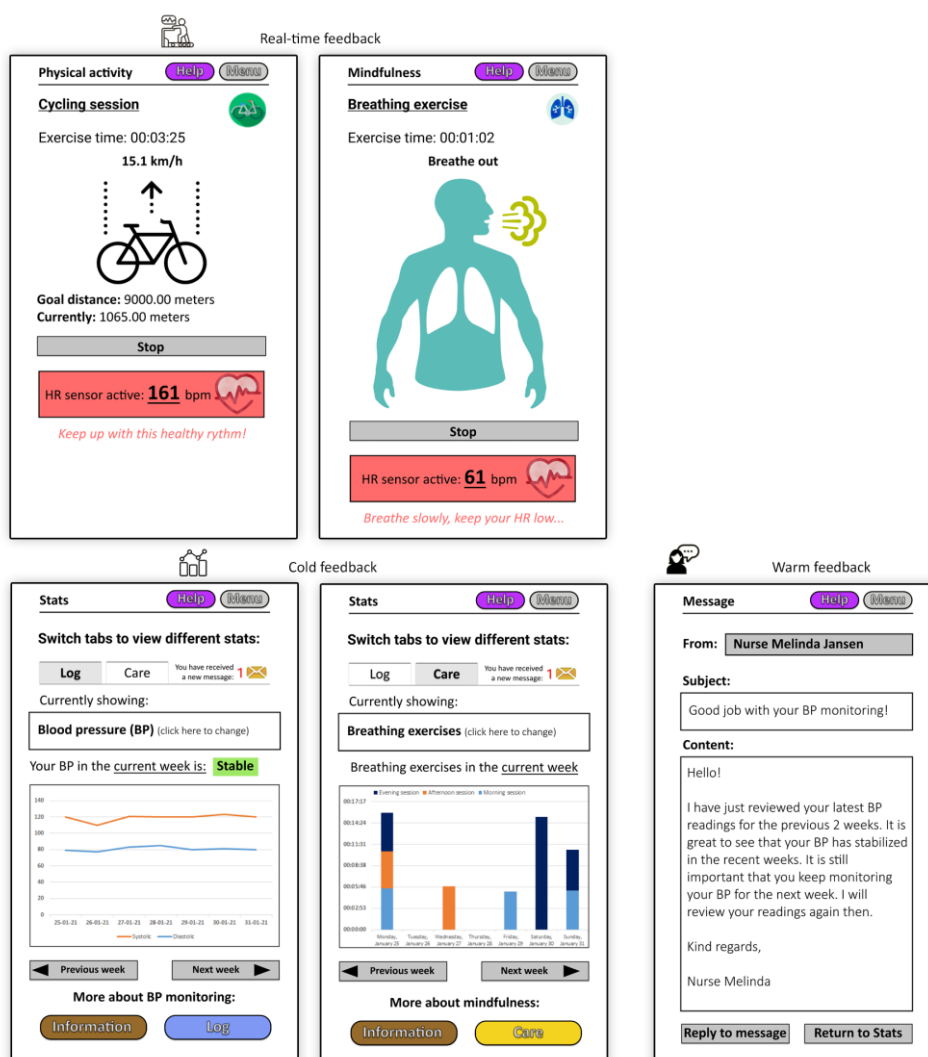


Figure 6.11. Prototypical eHealth design features for the provision of feedback for CVD self-care.

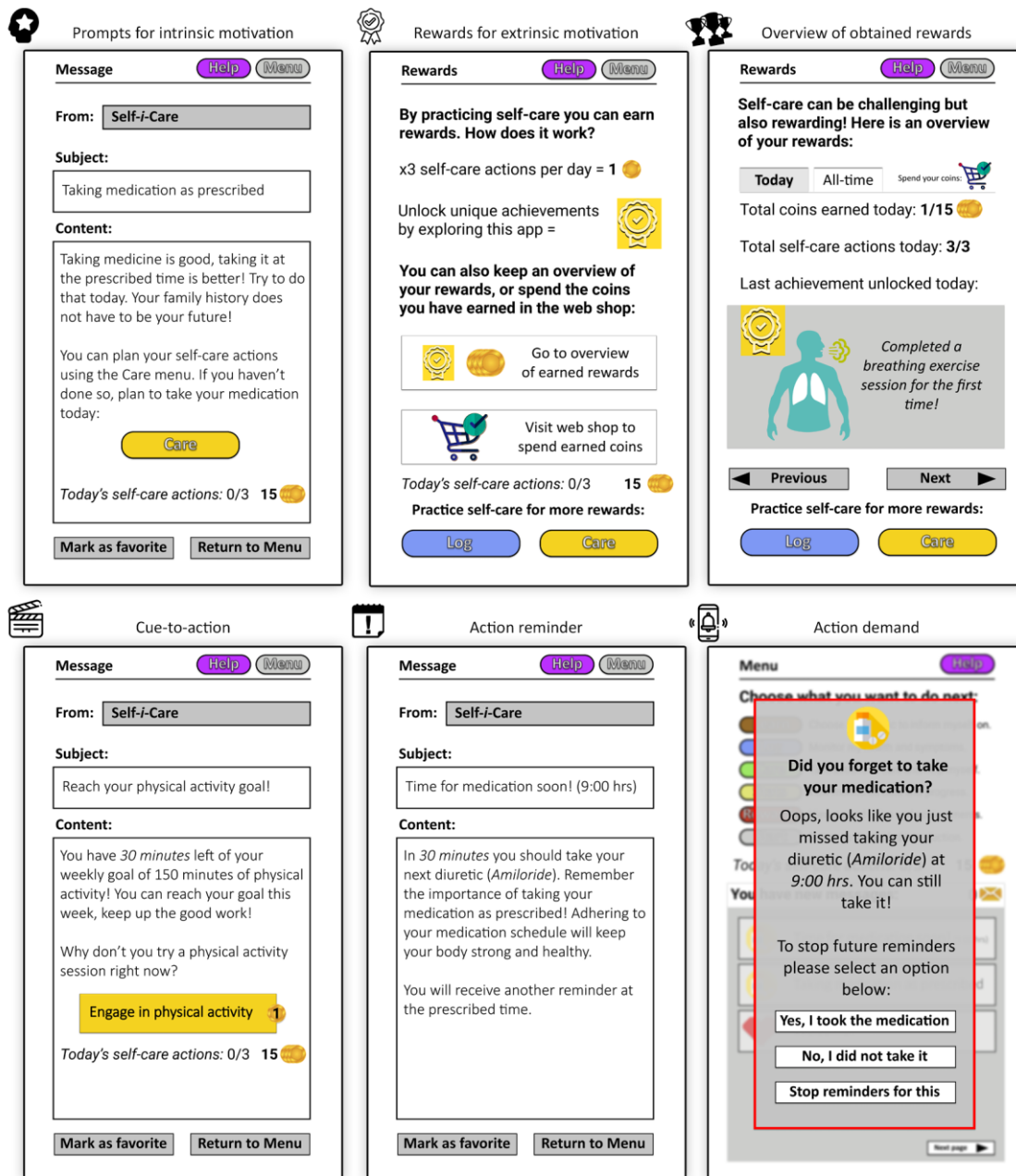




## Motivational incentives, cues, and reminders

Figure 6.12 presents the mock-ups of two related but fairly distinguishable categories of prototypical features: **motivational incentives** and **cues** or **reminders**. Arguably, these could be labelled together as different types of ‘prompts’ or ‘notifications’, depending on what they try to achieve.

Figure 6.12. Prototypical eHealth design features for the provision of *motivational incentives, cues, or reminders* for CVD self-care.



Regarding incentives, a prototypical feature is to provide *rewards for extrinsic motivation* (e.g., goods that can be earned by accumulating virtual points). In contrast, another prototypical feature is to deliver *prompts for intrinsic motivation* (e.g., motivational messages tailored to the values or beliefs of a person). This feature is potentially more difficult to execute as it entails, among other things, first identifying what the key intrinsic motivations of each user are.



Finally, providing an overview of *obtained rewards* is a prototypical feature that aims to evoke a sense of progression, regardless if the rewards are material or perceived (e.g., virtual achievements). Regarding cues and reminders, a prototypical feature is the provision of *cue-to-actions*, aimed at enacting self-care in the short term (e.g., context-aware cues to interrupt sitting). Lastly, two types of reminders can be distinguished: an *action reminder* and an *action demand*. The first one simply reminds the user to perform a certain behaviour, while the second one continues to prompt the user until an action is taken or reported (e.g., continuous reminders until an electronic medication tray is opened).

## Peer-based support

Figure 6.13 presents the mock-ups for prototypical **peer-based human support features**. One prototypical feature is to facilitate *socialisation* (e.g., via online group exercise sessions). Alternatively, peer-based support can also enable *social comparison* (e.g., comparing one's self-care performance with other users). Despite the 'peer' label, these prototypical features can also involve informal caregivers such as family members or community actors.

Figure 6.13. Prototypical eHealth design features for human, peer-based support of CVD self-care.



## Expert-based support

Figure 6.14 presents the mock-ups of prototypical **expert-based human support features**. Here, a first distinction is made between *user-initiated* and *expert-initiated* support. The former can, for instance, simply entail a button to call an emergency line. In contrast, expert-initiated support can range from text message recommendations from health care providers, to more direct forms of interaction (e.g., video calls). In this category there are two 'back-end' prototypical features: a *clinical team module* and a *clinical alarm system*. These two features are prototypical because they involve and ideally facilitate the provision of remote support provided by health care professionals. Typically, these features allow clinicians to monitor a patient's status, for instance, in case of symptom exacerbation or to monitor medication adherence.

## System personalisation

Figure 6.15 presents two prototypical features under the **system personalisation** category. They both involve a modular personalisation of the eHealth technology to the characteristics and circumstances of the patient. The *integration with care pathway* is a prototypical feature that aims to introduce and fit eHealth support into the existing care program of the person. This feature ideally entails an assisted introduction to the technology (e.g., by a trained caregiver). Finally, the ability to perform *remote refinements and features (de-)activation* to the system allows caregivers to personalise an intervention from a distance.

In this way, patients might not feel overwhelmed by the system and could rather perceive it as useful and relevant for their needs (e.g., because unnecessary features are disabled).

Figure 6.14. Prototypical eHealth design features for human, expert-based support of CVD self-care.

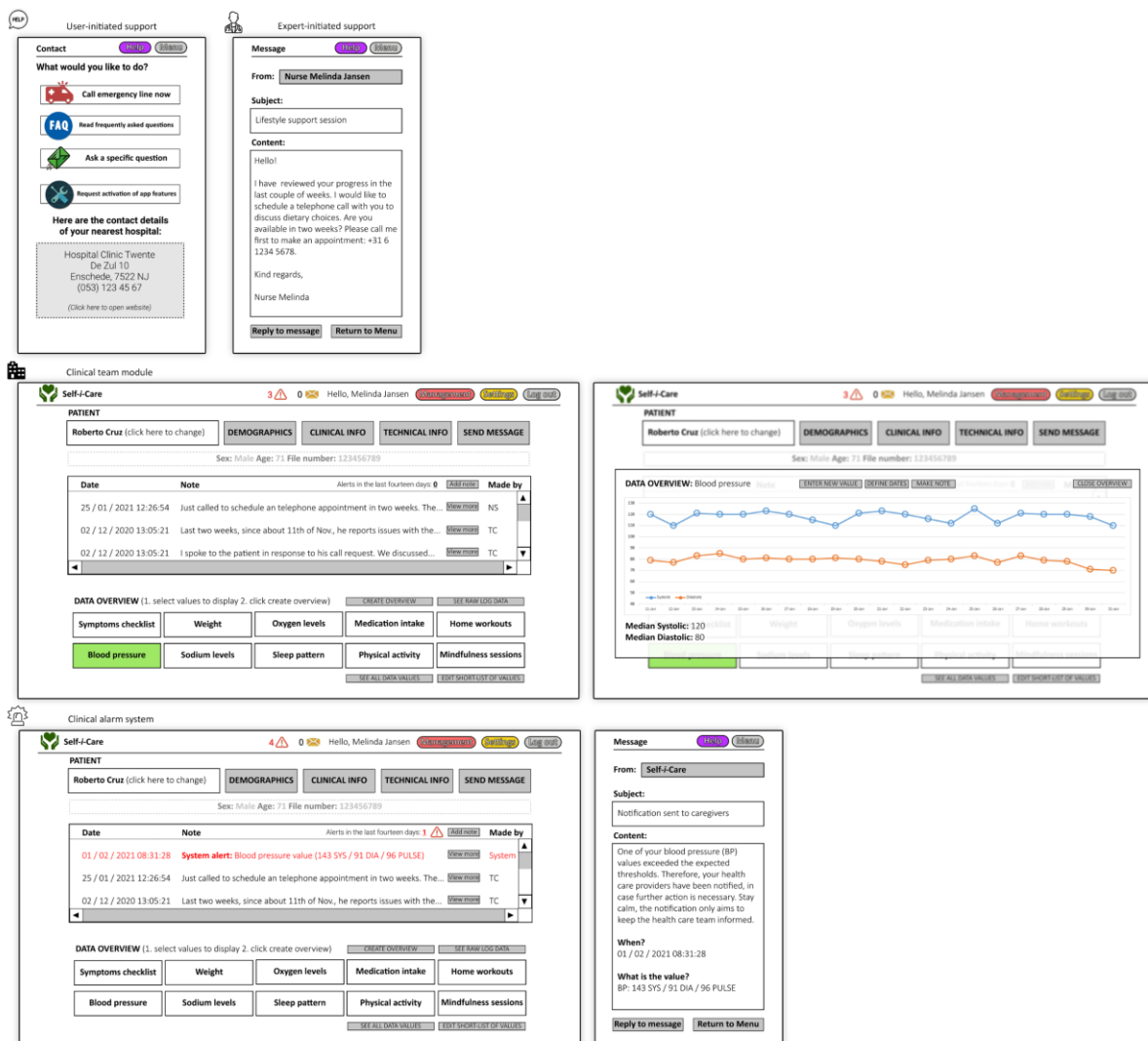
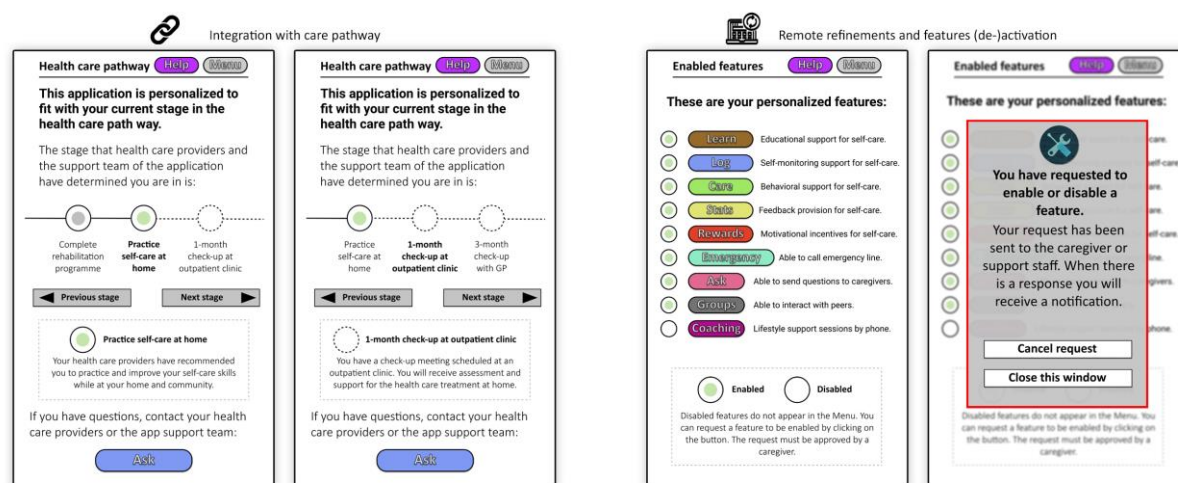


Figure 6.15. Prototypical eHealth design features for system personalisation in CVD self-care support.



## Design hypotheses for eHealth self-care support

The present study led to the specification of design hypotheses for eHealth self-care support that can be connected to the prototypical eHealth design features which have been previously described. The first set of design hypotheses partake from the assumptions and propositions of the middle-range theory of self-care of chronic illness from Riegel et al. (2012, 2019). Table 6.3 presents the assumptions and propositions of this self-care theory and redefines them to design hypotheses for eHealth self-care support. In addition, seeking to increase the potential effectiveness of eHealth self-care support, the present study outlined design hypotheses adopting a value sensitive approach. Table 6.4 presents the design hypotheses for value sensitive eHealth self-care support, which are based primarily on the work of Cruz-Martinez et al. 2021 (see **Chapter 5**). It should be noted that the theoretical assumptions and values presented in Table 6.4 have been derived from empirical studies including patients diagnosed with a CVD, thus further validation is still needed for populations with other chronic conditions.

## Design requirements for eHealth self-care support

The design hypotheses are not specific guidelines about how technology should be developed, in terms of choices for software, hardware, content, or visuals. To facilitate that step, the present study also resulted in the specification of design requirements for eHealth self-care support. The requirements are categorised as *general*, meaning those directly aligned with the proposed design hypotheses, or *specific*, meaning those directly aligned to each of the prototypical eHealth design features presented in this study. Textbox 6.1 presents the general design requirements for eHealth self-care support, based as mentioned before on the design hypotheses outlined in the present study. Table 6.5 presents the specific design requirements for each of the prototypical design features described in this study.

## Integrating design hypotheses, requirements, and features in eHealth design

In total, Table 6.3 and Table 6.4 integrate four theoretical assumptions (labelled as A1-A4 in the tables), three derived from the self-care theory and one from the value sensitive design framework. Similarly, Table 6.3 and Table 6.4 together present eighteen theoretical propositions (labelled as P1-P18 in the tables), seven which are derived from self-care theory and eleven derived from a previous study analysing empirically-validated values of patients with a CVD. As a result of the above, Table 6.3 and Table 6.4 contain twenty-two design hypotheses for eHealth self-care support. To recall, a *design hypothesis* was defined as a set of assumptions about how eHealth technology, or its specific features, can affect the user's behaviour or cognition.

In contrast, design requirements state what exactly is required from the technology with respect to matters like software, hardware, content, and visuals. Figure 6.16 illustrates the integration of design hypotheses, requirements, and features by presenting an intervention logic model at the individual level. To be clear, in health promotion programs, an intervention's logic model of change seeks to show the change that is needed to prevent, reduce, or manage a health problem, and it includes the methods or practical applications (e.g., behavioural change techniques or eHealth design features) and the proposed mechanisms of change (Bartholomew Eldredge, 2016).

Table 6.3. Design hypotheses for eHealth self-care support, based on the Middle-Range Theory of Self-Care of Chronic Illness from Riegel et al. (2012, 2019)

Theoretical assumptions and propositions	Design hypotheses for eHealth self-care support
(A1) There are differences between general self-care and illness-specific self-care, mainly in the factors that can influence the process.	(H1) eHealth self-care support can influence an individual's <i>experience, skill, motivation, cultural beliefs and values, confidence, habits, functional and cognitive abilities, support from others, or access to care</i> .
(A2) Self-care is a decision-making process, thus requiring the ability to focus attention, think, and use one's memory or learning capacity.	(H2) eHealth self-care support is less effective in individuals with limited <i>attention and memory</i> capacity (e.g., individuals with dementia).
(A3) Self-care for patients with multiple conditions might be conflicting when self-care is considered separately.	(H3) eHealth self-care support is less effective in individuals with <i>multiple chronic conditions</i> , if their self-care is considered separately (e.g., only a sub-set of self-care needs are addressed).
(P1) There are core similarities in self-care across different illnesses.	(H4) eHealth self-care support for health <i>maintenance, monitoring, and management</i> can be effective for individuals across a diverse range of chronic conditions.
(P2) Previous experiences with self-care increase self-care performance (i.e., self-care processes can be learned).	(H5) eHealth self-care support is more effective for individuals with previous experiences in self-care, whether as patient or caregiver.
(P3) Self-care mastery comes through purposive and reflective engagement, which can be learned.	(H6) eHealth self-care support is more effective when it helps individuals to engage in purposive and reflective self-care.
(P4) Misunderstandings, misconceptions, and lack of knowledge hinder self-care, which captures the importance of professional support.	(H7) eHealth self-care support is more effective when it helps individuals to deal with misunderstandings, misconceptions, and lack of knowledge.
(P5) Mastery of self-care maintenance precedes mastery of self-care management, because decision-making adds complexity.	(H8) eHealth self-care support is more effective when it helps individuals achieve high skill in self-care maintenance.
(P6) Self-care monitoring is necessary for effective self-care management, because to make a decision a symptom change must first be noticed and evaluated.	(H9) eHealth self-care support is more effective when it helps individuals achieve high skill in self-care monitoring.
(P7) Individuals who perform evidence-based self-care will obtain better outcomes than those who do not.	(H10) eHealth self-care support is more effective when it helps individuals perform evidence-based self-care.

Abbreviations: A = theoretical assumption; P = theoretical proposition; H = design hypothesis

Table 6.4. Design hypotheses for value sensitive eHealth self-care support (based primarily on the work by Cruz-Martinez et al. 2021)

Theoretical assumptions and propositions	Design hypotheses for eHealth self-care support
(A4) Individuals who perceive their values are honoured become more engaged to technology and its goals.	(H11) eHealth self-care support is more effective when individuals feel their values are honoured by the technology or intervention.
(P8) Individuals with a CVD tend to value having confidence and self-efficacy in their treatment and ability to achieve their goals.	(H12) Individuals feel their value is honoured through eHealth design features that provide <i>real-time feedback</i> during the performance of treatment or goal-oriented tasks.
(P9) Individuals with a CVD tend to value being seen as a person rather than a patient.	(H13) Individuals feel their value is honoured through eHealth design features that provide <i>motivational incentives</i> tailored to their personal beliefs or circumstances that are not illness-related.
(P10) Individuals with a CVD tend to value not feeling fear, anxiousness, or insecurity about their health.	(H14) Individuals feel their value is honoured through eHealth design features that provide <i>educational support</i> and <i>human expert-based support</i> , aiming to decrease fear, anxiety or insecurity.
(P11) Individuals with a CVD tend to value preserving a sense of autonomy over their life.	(H15) Individuals feel their value is honoured through eHealth design features that facilitate <i>self-monitoring</i> and <i>behavioural planning support</i> , giving them autonomy to decide what to do and when.
(P12) Individuals with a CVD tend to value receiving social support.	(H16) Individuals feel their value is honoured through eHealth design features that facilitate <i>human support</i> , whether <i>peer-based</i> and <i>expert-based</i> .
(P13) Individuals with a CVD tend to value having or maintaining a healthy lifestyle.	(H17) Individuals feel their value is honoured through eHealth design features that aim to facilitate having or maintaining a healthy lifestyle. For instance, by <i>educational support</i> , <i>self-monitoring</i> , <i>behavioural support</i> (assessment, planning, or performance), <i>feedback</i> , <i>motivational incentives</i> , or <i>reminders</i> .
(P14) Individuals with a CVD tend to value having an overview of personal health data.	(H18) Individuals feel their value is honoured through eHealth design features that provide an overview of their health data. For instance, through <i>self-monitoring</i> , <i>behavioural assessment support</i> , <i>feedback</i> , or <i>motivational incentives</i> .
(P15) Individuals with a CVD tend to value perceiving low thresholds to access health care.	(H19) Individuals feel their value is honoured through eHealth design features that facilitate any form of <i>human expert-based support</i> . Including, for instance, when <i>self-monitoring</i> leads to the identification of potential risks and prompts the clinical team to intervene.
(P16) Individuals with a CVD tend to value being extrinsically motivated to accomplish goals or activities related to their health or lifestyle.	(H20) Individuals feel their value is honoured through eHealth design features that provide <i>human peer-based support</i> , <i>behavioural planning support</i> , <i>cues</i> , <i>reminders</i> , or <i>motivational incentives</i> for self-care.
(P17) Individuals with a CVD tend to value having reliable information and advice.	(H21) Individuals feel their value is honoured through eHealth design features that provide <i>educational support</i> , <i>self-monitoring</i> , or <i>feedback</i> .
(P18) Individuals with a CVD tend to value receiving personalised care.	(H22) Individuals feel their value is honoured through eHealth design features that provide personalised content. For instance, through <i>educational support</i> , <i>behavioural support</i> (planning or during performance), <i>cues</i> , <i>reminders</i> , or <i>motivational incentives</i> when tailored to their personal circumstances.

Abbreviations: A = theoretical assumption; P = theoretical proposition; H = design hypothesis.

Textbox 6.1. General design requirements for eHealth self-care support, based on the design hypotheses outlined in present study. Abbreviation: R = design requirement.

- (R1) eHealth self-care support must be tailored to the personal and contextual circumstances of individuals, including their specific chronic condition(s) and abilities to focus attention, use their memory, and learn.
- (R2) eHealth self-care support must facilitate purposeful and reflective self-care learning experiences.
- (R3) eHealth self-care support must facilitate the relationship between patients and health care providers.
- (R4) eHealth self-care support must facilitate mastery of self-care maintenance and self-care monitoring before promoting mastery of self-care management.
- (R5) eHealth self-care support must facilitate evidence-based self-care.
- (R6) eHealth self-care support must be personalised to values of individuals in order to keep them motivated and engaged.

Table 6.5. (Part 1 of 3) Design requirements of prototypical eHealth design features for CVD self-care support.

Prototypical feature	Requirement and description
<b>Educational support</b>	
Optional, personalised content	<i>Content requirement:</i> The technology must provide access to educational content about various health related topics. Access must be optional but must highlight potentially relevant materials for the user.
Informative and motivational content	<i>Content requirement:</i> The technology must provide a wide range of educational content about health and self-care. Information must be presented with an empowering and motivational communication style.
Multimedia content	<i>Content requirement:</i> The technology must provide educational content with different modes of presentation, such as text, audio, and videos.
Interactive content	<i>Content requirement:</i> The technology must provide educational content that is interactive and aims to enhance learning.
‘Ask the expert’ channel	<i>Service requirement:</i> The technology must provide a communication channel to forward questions about educational content to health care professionals or informal caregivers.
<b>Self-monitoring</b>	
Open data log	<i>Functional and modality requirement:</i> The technology must facilitate the manual or automatic monitoring of health or self-care data, such as clinically-relevant parameters (e.g., weight), presence of symptoms, or the performance of self-care behaviours.
Guided self-monitoring	<i>Content requirement:</i> The technology must provide introductory or supportive guidance on how to correctly undertake self-care monitoring, especially in the case of clinically-relevant parameters (e.g., blood pressure).
Quick overview of monitored data	<i>Content requirement:</i> The technology must provide a simple overview of monitored data that immediately follows the logging of a value (e.g., to visualise the new value compared to a trend or threshold).
Safety classification system	<i>Functional and modality requirement:</i> The technology must provide an underlying mechanism to identify potential risks and give safety recommendations to the user, such as by following a traffic light rating system on symptoms monitoring (green, yellow, orange, red).
<b>Behavioural assessment support</b>	
Good habits HUB	<i>Content requirement:</i> The technology must provide an assessment of lifestyle habits which is followed by a display of behavioural recommendations (e.g., ‘well done’, ‘room for improvement’, ‘make a change’).
Change readiness classification system	<i>Functional and modality requirement:</i> The technology must provide a method to identify the psychological change readiness for different self-care behaviours (e.g., by applying the stages of change model to deliver behavioural recommendations).

Table 6.5. (Part 2 of 3) Design requirements of prototypical eHealth design features for value sensitive CVD self-care support.

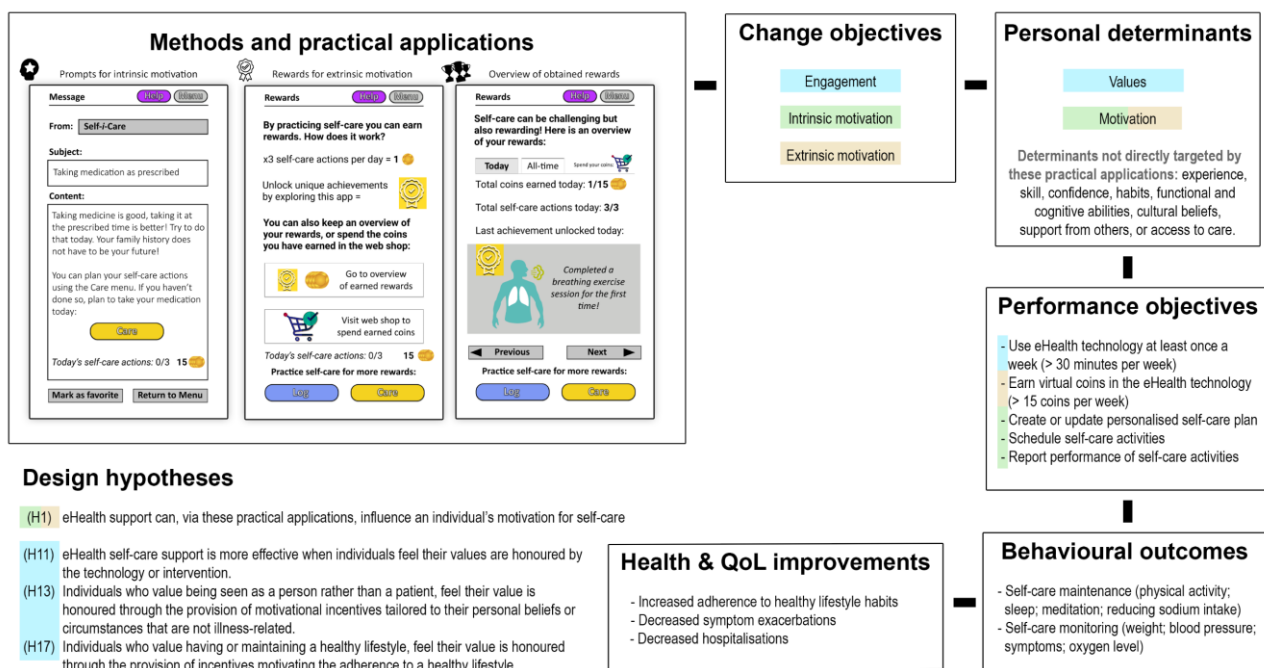
Prototypical feature	Type of requirement and description
<b>Behavioural planning support</b>	
Personal change plan	<i>Content requirement:</i> The technology must facilitate an integration of the clinical prescriptions and treatment with self-set life goals, subsequently linking them to suitable support features or content (e.g., a library of exercise programs or breathing control trainings for self-care maintenance).
Activity planner	<i>Content requirement:</i> The technology must facilitate the scheduling of daily self-care activities in a calendar, which can be linked to clinical prescriptions, treatment, or life goals. The user can mark when a planned activity has been realised.
<b>Behavioural performance support</b>	
Real-time guidance	<i>Functional and modality requirement:</i> The technology must provide guidance in real-time during the performance of self-care maintenance behaviours (e.g., guiding videos of instructors demonstrating each workout in an exercise session).
Evaluation of performance or progress	<i>Content requirement:</i> The system must provide an evaluation or an overview of progress on recently performed self-care maintenance behaviours (e.g., show steps taken in a day and compare them with standard recommendations).
<b>Feedback</b>	
Real-time feedback	<i>Functional and modality requirement:</i> The technology must provide feedback in real-time during the performance of self-care maintenance behaviours (e.g., an avatar that reacts to the correct execution of motion-tracked exercise movements).
Cold feedback	<i>Content requirement:</i> The technology must provide statistical overviews of monitored data over time, to distinguish trends or salient values via graphs, charts, or a textual summaries (e.g., daily step counts over a whole month).
Warm feedback	<i>Service requirement:</i> The technology must facilitate that users can receive feedback from health care professionals or informal caregivers based on the monitored data (e.g., in case changes to treatment or medication are necessary).
<b>Motivational incentives</b>	
Prompts for intrinsic motivation	<i>Usability and user experience requirement:</i> The technology must deliver personalised prompts or cues that specifically appeal to the user's values, beliefs, or life goals (e.g., culturally-attuned text messages).
Rewards for extrinsic motivation	<i>Usability and user experience requirement:</i> The technology must facilitate to the user the acquisition of (perceived) rewards through the performance of relevant self-care behaviours (e.g., virtual coins earned by exercising or daily self-monitoring).
Overview of obtained rewards	<i>Content requirement:</i> The technology must provide an overview of obtained rewards that reflects progress achieved over time (e.g., the number of virtual coins or medals obtained in the last month).
<b>Cues and reminders</b>	
Cue-to-action	<i>Functional and modality requirement:</i> The technology must deliver personalised prompts or cues that ask the user to perform specific self-care behaviours in the short term (e.g., notification to interrupt prolonged sitting periods).

Table 6.5. (Part 3 of 3) Design requirements of prototypical eHealth design features for value sensitive CVD self-care support.

Prototypical feature	Type of requirement and description
<b>Cues and reminders</b>	
Action reminder	<i>Functional and modality requirement:</i> The technology must deliver personalised prompts or cues that specifically remind the user to perform self-care behaviours (e.g., a reminder to take medication).
Action demand	<i>Functional and modality requirement:</i> The technology must deliver continuous prompts until a self-care behaviour is performed or an action is taken by the user (e.g., to open an electronic medication tray or to report the reason for missing intake).
<b>Peer-based support</b>	
Socialisation	<i>Functional and modality requirement:</i> The technology must facilitate tools to socialise with peers before, during, or after the performance of self-care behaviours (e.g., to participate in a virtual group exercise class).
Social comparison	<i>Content requirement:</i> The technology must provide a way to compare the performance of self-care behaviours with peers (e.g., to view one's position in a ranked list of steps taken in a week).
<b>Expert-based support</b>	
User-initiated support	<i>Service requirement:</i> The technology must allow the user to initiate contact with a health care professional or informal caregiver (e.g., to chat with a specialist to request additional support).
Expert-initiated support	<i>Service requirement:</i> The technology must allow the user to receive recommendations or additional advice from health care professionals or informal caregivers (e.g., an inbox to receive written messages).
Clinical team module	<i>Organisational requirement:</i> The technology must include a module for health care professionals, to display information about one or multiple users (e.g., to review their prescribed treatment, visualise monitored data, or deliver recommendations remotely). The technology introduces or makes the end user aware of this feature.
Clinical alarms system	<i>Functional and modality requirement:</i> The technology must deliver notifications to the health care professionals or informal caregivers when a user's monitored data values or trend reaches a determine threshold (e.g., to signal potential risks). The system introduces or makes the end user aware of this feature.
<b>System personalisation</b>	
Integration with care pathway	<i>Organisational requirement:</i> The technology must be integrated with the user's care pathway, including other treatments or forms of support (e.g., introducing the system at the end of a cardiac rehabilitation program).
Remote system refinements and features (de-)activation	<i>Functional and modality requirement:</i> The technology can be personalised to the user's needs and circumstance through the (de-)activation of features or modules (e.g., to disable notifications in order to avoid irrelevant prompts for the end user). Requests for modular personalisation can be initiated by either end users, health care professionals, or informal caregivers.



Figure 6.16. Intervention logic model, exemplifying the integration of design hypotheses, requirements, and features in eHealth design.



## DISCUSSION

The present study aimed to showcase how self-care theory and a value sensitive approach can inform and guide the design of eHealth to support the self-care of patients with a CVD. The study focused on theoretical and design work, aiming to answer the following research questions: *How can self-care theory inform the development process of eHealth design features? How can a value sensitive approach inform the development process of eHealth, to meet the values of patients with a CVD?*

The study led to the development of thirty-two mock-ups that represent the objectives and characteristics of prototypical eHealth design features for CVD self-care support. These features are considered to be typically integrated, and often essential, in eHealth technologies within the context under study. An answer to the first research question was given by means of the mock-ups, the low-fidelity prototype, and the specification of design hypotheses and requirements based on self-care theory. Similarly, an answer to the second research question was provided via the specification of design hypotheses and requirements based on the value sensitive framework. Furthermore, the results of the study have been described in thorough detail, including the presentation of a logic model to exemplify the integration of the key theoretical and design elements.

The debate on the usefulness of theory-based interventions in real-world settings seems to still be ongoing (Hagger & Weed, 2019). The present study sought to lay foundations and provide examples that inspire and facilitate the specification and analysis of behavioural self-care theory in eHealth studies. Beyond the previous work of the authors, other systematic reviews have also showed that eHealth applications to support self-care of CVD lack a theoretical foundation (only 10 out of 28 articles used a theoretical framework) (Delva et al., 2021). Although there are good examples to be found in terms of theory-based specification—for instance, see Hong et al. (2021)—the literature at the crossroads of eHealth, self-care and CVD seems to still need proper adoption of self-care theory. Even more, the exploration of value sensitive approaches in this context is largely ignored.

To the advantage of the field, the available tools for theoretical and design work are plenty. The present study showed that multiple (visual and textual) representations can be used to describe theoretical connections between key constructs, some of which can or must even be debated at the theoretical level. The concepts and terms used by the present study, although informed by empirical studies, do not constitute a closed theory. Implicitly, the paper seeks to highlight the value of conceptual work in psychology, a practice that is quite often undervalued, yet of great importance (Machado & Silva, 2007). To exemplify the relevance of conceptual analysis, it is sufficient to consider the importance of defining the target behaviour: is it *self-care* or *self-management*? what does one or the other exactly entail? (Matarese et al., 2018; Van de Velde et al., 2019). In one way, the present study has made an argument in favor of the middle-range of self-care theory, which is considered the most advanced and detailed theoretical foundation for the target and population of interest (Riegel, Dunbar, et al., 2019; Riegel, Jaarsma, et al., 2019; Riegel et al., 2012; Riegel et al., 2022).

## **Future work**

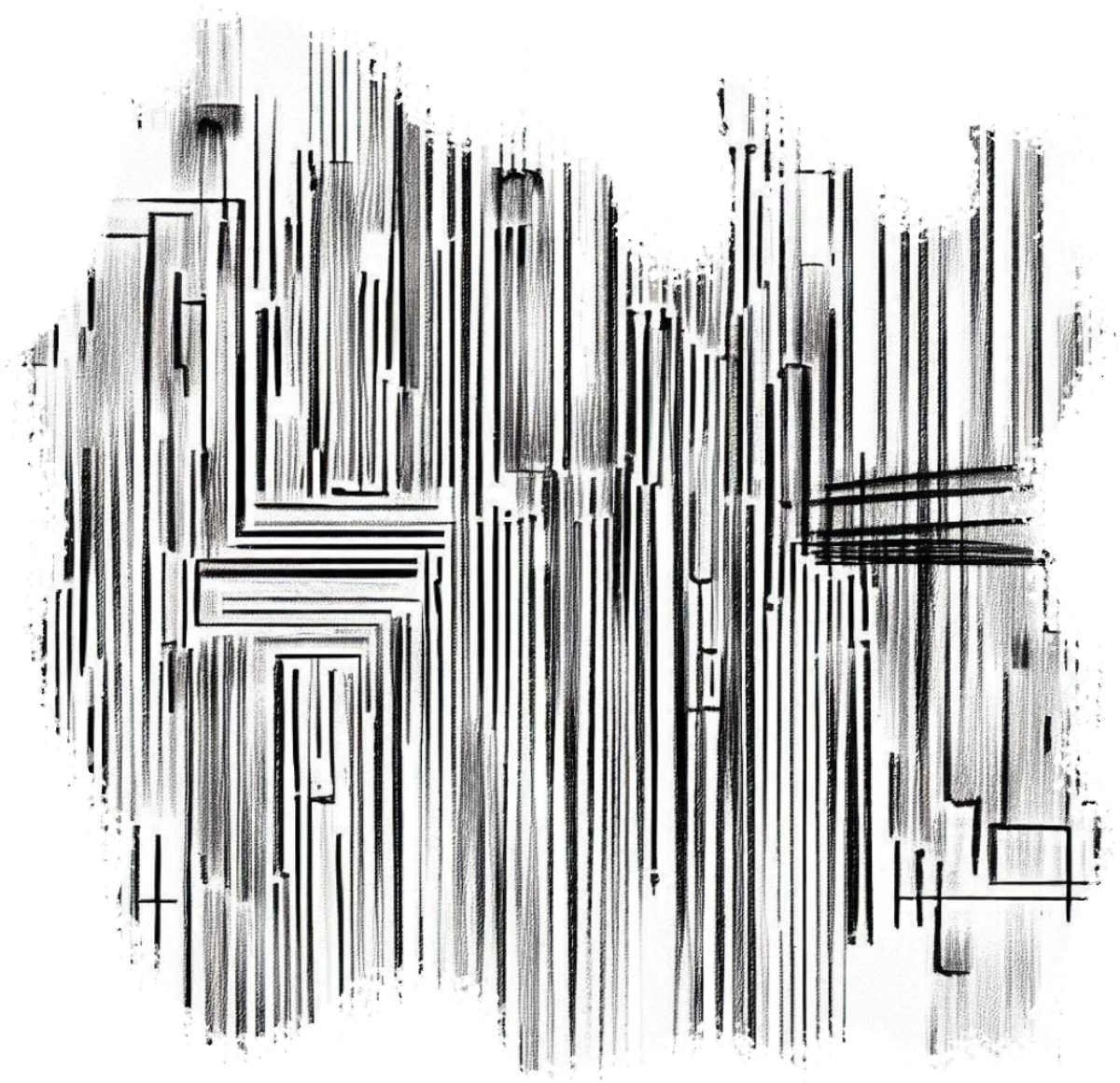
To validate the propositions of the present study a second phase is necessary, entailing iterative evaluations with key stakeholders to refine the proposed features. The findings of future evaluations can lead to the acceptance, rejection, or reformation of the specified hypotheses and requirements. Such an evaluation phase can focus on a sub-set of the proposed eHealth design features generated in this study. Importantly, evaluations should involve diverse key stakeholders of eHealth applications for CVD self-care (e.g., end users as well as experts such as cardiologists or technology designers). The diverse perceptions, judgements, and attitudes of stakeholders are important to advance the theoretical, design, and prototyping work, resulting in new iterations and revisions of the propositions (e.g., to better understand not only how eHealth can align with patients values but also what that would entail for other stakeholders in the care process). Proposed evaluation methods are online surveys, individual interviews, and group feedback sessions.

## **Limitations**

While the strengths of the study have been discussed above, the limitations are perhaps self-evident. Theoretical and design work at the level of the present study (i.e., low-fidelity) requires (many) more stages of iterative development and evaluation. In the course of the present study, evaluation tasks have been undertaken but the data remains to be analysed. Therefore, the findings of the study are limited to the clarity of its concepts, terms, and prototypical representativeness of eHealth design features, and the perceived value of the design hypotheses and requirements that have been specified.

## **Conclusion**

All in all, the present study showed that it is possible to provide theoretical and conceptual clarity for eHealth design with a dual-purpose: effectively supporting self-care and honouring the values of individuals. By providing a strong theoretical foundation, eHealth interventions should irremediably improve over time, simply by progressively learning more about what works and what doesn't. The prototypical eHealth design features described in the present study are a product of thorough theoretical, conceptual, and design work. Nevertheless, it is important to seek their validation in future research. The mock-ups and their theoretical foundations must be validated with stakeholders (CVD patients, informal caregivers, health care professionals, and eHealth developers and designers). Only then will theory be allowed to show its value, and fulfil its promise of advancing knowledge and its application in real-world settings.



# Chapter 7

## General discussion

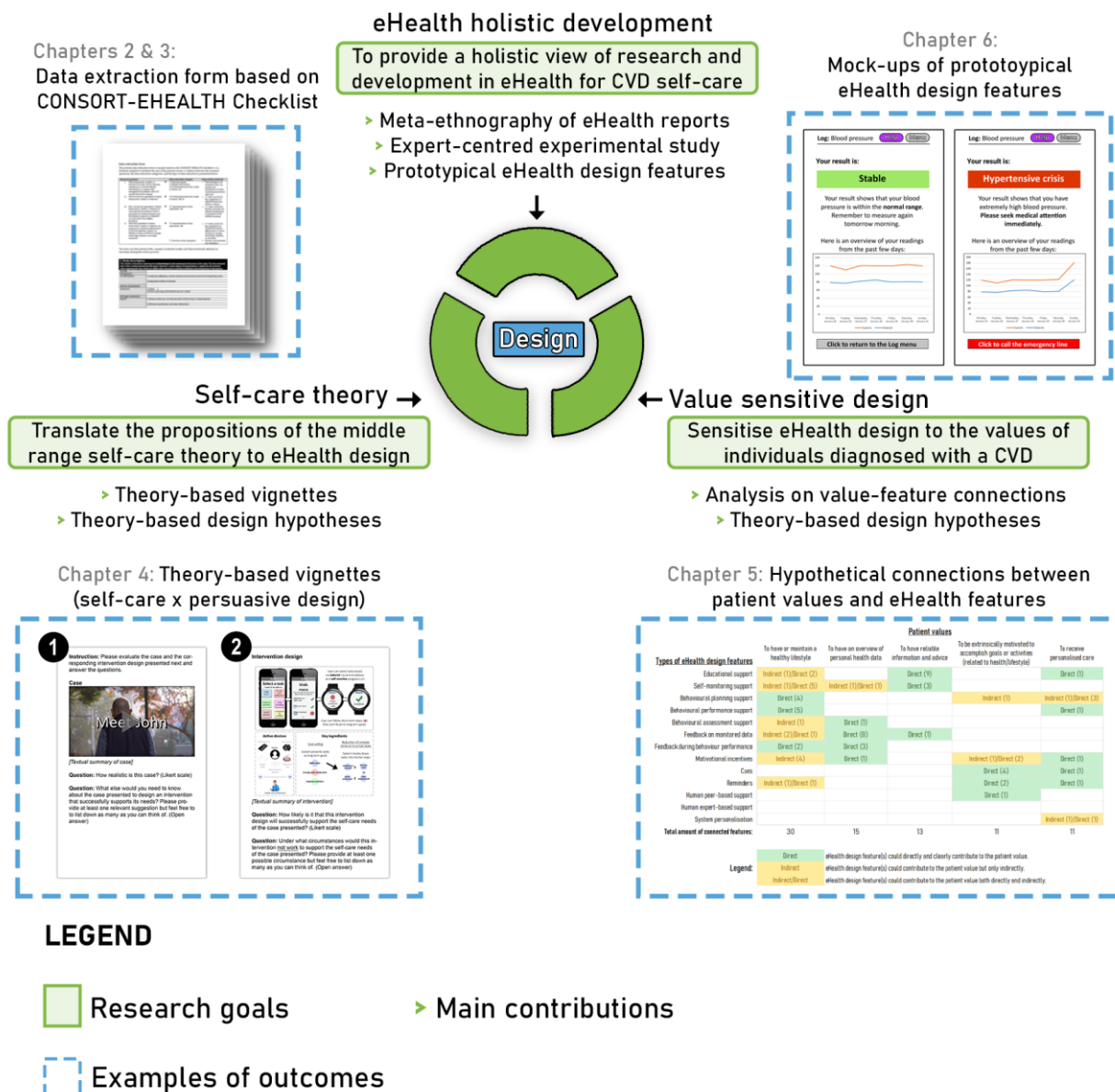
## INTRODUCTION

The present thesis aimed to advance theory-based research and development at the crossroads of eHealth, self-care support, and cardiovascular diseases (CVDs). To accomplish that, the work strived to achieve a holistic view on the matter, conducting several studies that collected and integrated views of different stakeholders across multiples dimensions. In practice, the goal was to accumulate, revise, and refine scientific knowledge in order to promote better research and development practices of eHealth technologies.

## SUMMARY OF FINDINGS

Figure 7.1 presents an illustrative overview of the main contributions of the present thesis. At large, the holistic approach to eHealth converged in the adoption and exploration of two theoretical frameworks in the research process: the middle-range theory of self-care of chronic illness (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012), and the value sensitive design framework (Friedman et al., 2013). The following sections summarise the key findings of the present thesis, and highlights practical tools as ‘key insights’ that guided the translation of theory to design.

Figure 7.1. Illustrative overview of the main contributions of the present thesis. Abbreviations: CVD = Cardiovascular disease



## The use of theory for the research and development of eHealth

The first part of the thesis described studies focused on the revision of theory and expert-based knowledge. The first step consisted in developing a protocol that could thoroughly analyse not just the characteristics, but also the underlying, theoretical foundations of eHealth interventions and technologies that had been reported in scientific publications (**Chapter 2**). To that end, the meta-ethnography method was adopted, promoting a holistic and detailed revision of scientific reports, and focused on the translation and synthesis of key concepts and ideas found in different studies and contexts. By means of highly-detailed data extraction forms, data comparison matrices, conceptual networks, and bibliometric analyses, the protocol exemplified how to approach the study of eHealth, without losing a grip on its multidisciplinary and thus multidimensional nature. The results of the meta-ethnographic systematic literature review suggested a general lack of information in published studies about their operationalisation of theory for eHealth development (**Chapter 3**). In that regard, it was even more striking that, within the scope under study, comprehensive use of *behavioural theories* for self-care was not identified in any of the reviewed interventions and technologies. Arguably, the lack of specification on the use of theory could be ‘suspected to be an artefact of publishing conventions and space constraints, as much as if not more than the nature of actual research being performed’ (Srinivas et al., 2017). However, the literature review study did find multiple exemplary cases containing rich conceptual and descriptive information about the operationalisation of theory for eHealth research and development.

**Advancing theory-based research and development | Key insight #1 | Data extraction form in a systematic review of eHealth interventions:** The data extraction form based on the CONSORT-EHEALTH checklist (Baker et al., 2010; Eysenbach, 2011) proved to be an effective tool for the identification of key components of eHealth interventions, as well as the revision of implicit or explicit design choices. The form, inspired by the thoroughness of the meta-ethnography method, can guide and prompt researchers to conduct an investigation of scientific and practical knowledge that is not always clearly communicated in published literature.

## Integrating self-care theory in eHealth design

The first part of the thesis culminates with the description of a study that adopted self-care and technology design theories in an expert-centred study, to explicitly revise and analyse their promise for eHealth design and its potential success. Therefore, this study undertook a more direct approach, asking researchers and developers of eHealth about their judgements and opinions regarding the tailoring of an intervention design to key self-care needs (**Chapter 4**). In that online experimental setting, relations were drawn and tested between a middle-range self-care theory (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012) and persuasive system design principles (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjuma, 2009). To meet its goal, the experimental study developed and made use of theory-based vignettes, which are short, contextual descriptions of persons and situations (e.g., a patient with CVD in need of self-care support). Similarly, to describe key design choices in eHealth design, the study developed and used mock-ups, which are representations that can complement other forms of description such as text or diagrams. The study results in the identification of promising design strategies for specific theory-based self-care needs (self-care maintenance, self-care monitoring, and self-care management). For example, the potential success of ‘primary task support’ seemed to extent to all self-care needs, while ‘social support’ was considered by experts to be less likely to succeed when supporting self-care monitoring.

**Advancing theory-based research and development | Key insight #2 | Theory-based vignettes:** Vignettes facilitated the communication and discussion of theory-based design choices between eHealth researchers, developers, and implementers. Moreover, vignettes can work as input for early (online) experiments where theoretical assumptions and propositions can be tested among stakeholders without significant burden in terms of costs or development time.



At that stage, new propositions for the success of theory-based, tailored eHealth design features could begin to be generated. To explore ways of bridging the observed gap in the use of behavioural theories for self-care, subsequent studies described in the present thesis adopted the middle-range self-care theory when theory-based design for self-care was the goal. While the study provided an in-depth analysis of expert-centred perspectives, its findings also highlighted the necessity to look at the other side. Yes, you can have clear behavioural assumptions about individuals, and propositions of how an intervention and its features could serve and benefit them. However, in practice and when it comes to self-care: which perspective should most prominently inform design, development and implementation? The health care providers', or the patients', or both? And how can that focus be properly enabled?

## **Aligning eHealth to the values of individuals in need of self-care support**

As just suggested above, another important theoretical gap was revealed in the course of the previous studies, which referred to the need for a proper understanding on the *patient*—or some would rather say—the *person perspective*. Consequently, this led to question the ability of technology to acknowledge, reflect on, and honour that perspective. To recall, this is important not just because of the perceived existence of a theoretical gap but also because of its implications in real-life settings. First, the burden of CVD, as represented often by the increased workload and costs in health care systems, can be lessened by the provision of effective self-care support. Second, effective self-care support must take place in the naturalistic setting of individuals, their homes and communities. In consequence, the promise of eHealth as an effective approach for self-care support lies precisely on the premise that it can be well-aligned with the lifestyles and needs of individuals.

The second part of the thesis tackled this gap by studying and later adopting the value sensitive design framework (**Chapter 5**). In this framework, a value refers to 'what a person or group of people considers important in life' (Friedman et al., 2013). Therefore, a follow-up study described in the present thesis investigated value-based design as a complementary and important approach for the development of tailored self-care support for CVD via eHealth. Namely, a content analysis connected the empirically-validated values of CVD patients with a set of design features that had been identified in existing eHealth interventions. To be specific, the study explored potential connections between 11 empirically-validated values of patients, and 70 design features of 10 existing eHealth technologies. As a result, 98 potential connections were inferred. Notably, while some design features could be connected with multiple values, some values were also considered to be less frequently addressed in eHealth design, with two specific cases remaining largely unaddressed. The most representative example was on the value of 'being seen as a person rather than a patient', which touched upon the basis for such a study. In that case, only one eHealth design feature—out of seventy that had been analysed—was considered to be honouring such a value (motivational incentives tailored to a person's culture and beliefs). At large, the study found value sensitive design to be a promising framework for eHealth design. However, its use in the design and development of eHealth for self-care support had also not been identified in existing interventions and technologies. Although it was not the focus of the present thesis, it is hard to argue against the idea that value sensitive design entails still a lot of unexplored promise for the field, as was observed at least within the scope of CVD self-care support.

**Advancing theory-based research and development | Key insight #3 | Content analysis of eHealth interventions through a value sensitive lens:** The content analysis method was used to draw hypothetical connections between design features of eHealth interventions and empirically-validated values of end users. In that way, a content analysis of existing interventions can serve as a tool for theory-building, as a bridge between conceptual work (e.g., identifying and defining values) and design work (e.g., identifying if existing technologies honour specific values). Under the scope of the value sensitive design framework (Friedman et al., 2013), this aligns with the propositions of 'technical investigations' that aim to use identified values as assessment criteria for the both the design and evaluation of technologies.

## Using theory in eHealth design for self-care support of CVD

The second part of the thesis sought to integrate the key findings of previous studies to culminate the work with the proposition of theory-based (prototypical) eHealth features for CVD self-care. The term ‘prototypical’ was chosen to note that the proposed eHealth design features are representations of characteristics and functions typically integrated, and maybe even essential, to eHealth technologies aiming for self-care support in CVD. Thus, in this phase the research focused, even more than the previous studies, in theoretical and design work. Specifically, the final study of this thesis aimed to showcase how the design of eHealth could be informed by self-care theory and value sensitive design to support individuals with a CVD (**Chapter 6**). The result of the study was the proposition of thirty-two prototypical eHealth design features, represented by mock-ups and accessible also via a low-fidelity prototype (Cruz-Martinez, 2023). More importantly, the eHealth design features were informed and explicitly connected to a theoretical foundation combining self-care theory and a value sensitive approach. The theoretical underlying consisted of design hypotheses and design requirements, therefore serving a practical purpose for the development of eHealth self-care support.

**Advancing theory-based research and development | Key insight #4 | Mock-ups as representations of theory-based design hypotheses:** Mock-ups and prototypes were used to accompany the proposition of design hypotheses for eHealth self-care support in CVD. While theories provide specification to key constructs and mechanisms for behaviour change and technology adoption, their operationalisation for design can be visualised—and therefore more easily discussed with stakeholders—by means of low- and hi-fidelity representations.

## LIMITATIONS AND STRENGTHS OF THE RESEARCH

As can be expected, the works in the present thesis entail both limitations and strengths meriting discussion. A notable limitation that spans across several of the described studies, is the lack of further validation on the theoretical propositions and assumptions that have been generated. Although in most cases the propositions were often based (indirectly) on empirical findings (e.g., studies described in scientific literature), the theorisation process must ideally be interlinked with iterative rounds of validation and refinement of precepts. However, the thesis explicitly meant to focus on the theoretical basis of interventions, and the goal was indeed to generate propositions that would prompt revision and discussion in future (empirical) studies. Moreover, the works presented in this thesis focused on the practical methods and tools that facilitated theory-building (generation and revision), since that was precisely observed as a challenge in the literature at the crossroads of eHealth, CVD, and self-care. In other words, the thesis focused on promoting theory-based work but also on guiding and exemplifying its performance. Thus, the validation of findings is not always expected to take place within scientific research, but the validity will also be measured in terms of the practical usefulness of the propositions and outputs of this thesis for eHealth researchers and developers.

Similarly, another notable limitation relates to the low- and medium-fidelity representations of eHealth that the works in this thesis frequently employed. Conceptual, visual, and textual descriptions often accompanied mock-ups or prototypes to represent eHealth interventions and its key features. The fidelity of these representations does not come close to the conditions of real-life settings, especially when trying to capture and analyse the interactions between end users and technology. Nevertheless, such (design) tools are often employed in research as part of formative evaluation within the development process, and are useful from early (pre-)design stages (Van Velsen et al., 2013). Naturally, it is also an economical choice, since it would be costly to prepare and analyse complete, operational designs of the same eHealth intervention (or a minimum viable product). When that is possible, the results are of course very conclusive, and frameworks to guide such approaches already exist (e.g., see the MOST from Collins (2018)). The purpose of this thesis was not to advance a specific intervention throughout all stages of development and optimisation of its effectiveness, but rather to portray and analyse the key choices that can be made in eHealth design by the use of theory.



Most evidently and meriting discussion is also the fact that the studies conducted under the present thesis lacked in most cases a direct involvement of key stakeholders: individuals within the target group. Although the scope of the thesis rested on achieving an overarching perspective, it was still the plan to adhere to the holistic approach by also involving individuals with a CVD. Such plans were difficult to realise in the end, and thus no such investigations or findings can be reported so far. Nevertheless, as stressed before, the main strength of this thesis is its focus on investigating the use of behavioural, self-care theory for the development and design of eHealth interventions. The use—or at best the clear and transparent report in the use—of these type of theories was largely as lacking in the observed literature, and therefore constituted a remarkable gap in research needing to be addressed. The work described in the thesis went beyond the behavioural field, to include also the value sensitive framework stemming from the field of computer science. While the thesis eventually focused on two theoretical frameworks, at multiple points the research done touched upon theories and frameworks from multiple fields of science. Numerous theoretical models and frameworks do exist, but the findings of the present thesis presume that these might have remained largely unacknowledged in research and development of eHealth. Thus, while the focus of this thesis in a specific case of study and its context can be considered a strength, its findings seek to create value by leading, or rather inspiring, the exploration, revision, and application of theories in other relevant contexts of application for eHealth.

## **IMPLICATIONS FOR THEORY**

### **Tailoring eHealth with behavioural, self-care theory**

The most salient contribution of the present thesis is its use of self-care theory to analyse and inform the design and development of eHealth. In consideration of the literature reviewed throughout this project, the case remained that research and development of eHealth occurs often without a clear foundation, especially on the target of behaviour change and its influencing mechanisms. That is surprising, considering the acknowledge and growing necessity to attend the burden of chronic diseases, and the relatively new paradigm shifting the focus towards patient-centred interventions. In that regard, the present thesis extensively analysed the assumptions and propositions of self-care theory under the light of eHealth and its design and development challenges. The findings can lead to more effective tailoring and personalisation of interventions, striving away from the ‘one-size-fits-all’ packages. Moreover, the findings provide a more dynamic framework for design based on more precise understanding of behavioural change at the individual level. For example, through the middle-range self-care theory it is made possible to envision how an individual advances on the learning process of self-care, first obtaining mastery in self-care maintenance, then self-care monitoring, and finally in self-care management. That is not an evolution that was explicitly recognised by (the lack of) others frameworks and their conceptualisations.

### **Personalising eHealth with value-based design**

While self-care theory can assist interventions with the tailoring in terms of behaviour change, the research described in this thesis also emphasised the need for personalisation in eHealth. Personalisation has already been studied as a prominent design goal in the eHealth development. However, the focus on values as the factors informing personalisation did not seem to be highly considered. This could arguably be understood, in consideration of the challenges of conceptualising and defining values. In the present study, such challenges were tackled by choosing to adopt empirically-validated values from the specific population of interest. Doing so, facilitated also the subsequent integration with the value sensitive design framework, which carried a compatible definition of values and sought their explicitly application in technology design. The findings of the present thesis found that value sensitive design offers a high promise for eHealth, mainly when it comes to engagement as a design goal. At this stage, the overarching thesis for value sensitive design became self-evident: the motivation and conduct of individuals is largely influenced by the things they consider most important in life and, if technology is able to acknowledge and honour those values, it is more likely to be adopted and thus to meet its intended purpose.

Personalisation at the level of superficial preferences and ‘A or B’ choices does not tap on underlying motivations such as those implied in the conceptualisation of values. The present thesis showcased that the value sensitive design framework should be explored by future eHealth design studies. This recommendation rests on the assumption that technology must fit the life of individuals, especially when self-care support is the goal—as without engagement of the end user, the supportive technology will hardly meet its purpose.

## **Psychological theories and conceptual research in eHealth development**

The findings of this thesis also give merit to the value of theoretical and conceptual research in psychology. Specifically, in consideration of its contribution to the multidisciplinary field of eHealth. For instance, by making a case for the analysis of key concepts, a task that is not typically seen in the development processes of technology. The present thesis insisted on the importance of specifying key constructs, especially those related to the targeted behaviour change.

The thesis argued that conceptual differences leads to different or incomplete understanding of a phenomenon (e.g., self-management versus self-regulation versus self-care). Consequently, when translated to practice, incomplete understanding could lead to design choices that hinder the impact or effectiveness of interventions. Considering the work performed under this thesis, it is worth noting that the self-care theory adopted in it originated in the field of nursing and not psychology. However, its assumptions and propositions are centred on behavioural constructs and its precepts are connected to a range of multidimensional, contextual factors that enhance its comprehensiveness. Beyond its origin, such a theory was adopted because the research and development of eHealth that was observed in the literature seemed to often—and at the best—rely on theories that did not offer specific explanations and predictions for the targeted behaviours. It is worth noting that this issue often did not lie with the theory or its original proponents, but rather in how the propositions were adopted and referred to within eHealth studies to justify design and development choices.

To give an example, the use of the self-determination motivational theory seemed to be fragmentally used in part of the screened literature, focusing only on a subset of the macro theory (e.g., on the basic psychological needs). To give another example, it also occurred when screening reports of interventions that a whole design was justified in the concept of self-efficacy, while ignoring other key interdependent constructs. The present thesis explored these theoretical and conceptual gaps within the context of CVD self-care as a case of study. In the process, new questions arose at the same level, which remain yet to be addressed. The thesis argues for the fact that new studies tackling those questions do not require the collection of any empirical data, but rather the identification and analysis of existing interventions and their theoretical foundations. The work is conceptual in nature, and the objective might seem daunting, but to give context-specific answers the task could be constrained to case studies of interest, which are plenty in the vast and rapidly-evolving field of eHealth.

## **Multidisciplinary research and development demands cross-disciplinary theories**

The present thesis recognised from the get-go the multidisciplinary of eHealth. However, its focus and findings sought to distinguish and make a case for cross-disciplinarity. Not far from its emergence Pagliari (2007) and others made a case in favour of multidisciplinary approaches in eHealth. Nowadays, it is easy to observe this at the level of eHealth projects and teams, frequently involving multiple disciplines in their composition.

Thus, multidisciplinary can also be observed in the process, as in the collaboration taking place between the various experts throughout development. As just stated, the present thesis sought to focus on cross-disciplinary knowledge and practices. In contrast to the above, cross-disciplinarity emphasises a shared understanding that runs through diverse fields and areas of study. The thesis exemplified this by investigating the integration of behavioural, medical, and technological perspectives for design. Through its findings, the thesis argued that the growth of eHealth research did not seem to be accompanied by fitting theories aligning with this cross-disciplinary need.

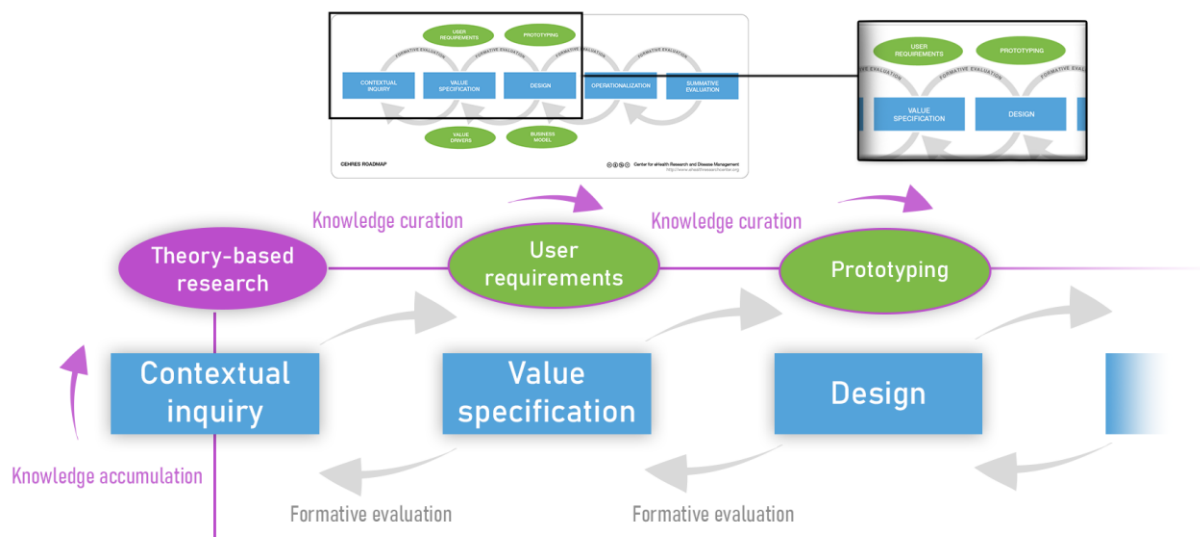
Inferring from what was observed in the case study, the thesis points out to the fact that fitting theories do exist, but more often than not they remain unacknowledged at worst, and disconnected from each other at best. Understandable, if it is reasoned that interconnection between theories had not been a goal in early eHealth studies, driven perhaps by a push for innovation. The present thesis referred often to its case study as the ‘crossroads’ between eHealth, self-care, and CVD. At that specific point, the interconnection of theories from different fields seemed to be lagging. By investigating this issue, the present thesis also acknowledged on the numerous challenges when building such connections. Mainly, the fact that disciplines speak their own language and work naturally towards the their own focused objects of study.

To breach that gap, the present work noted the appearance and embraced theories that have the potential to meet each other. The dissertation sought to facilitate that meeting, to achieve that cross-disciplinary connection. For instance, by exploring potential interconnections between self-care theory and persuasive design, and later on with value sensitive design.

## IMPLICATIONS FOR PRACTICE

The present thesis focused on theory-based work, partaking from the overarching, holistic approach to eHealth research and development of the CeHRes roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011). Based on the findings and lessons learned, the work done by this thesis can contribute back to the principles of the CeHRes roadmap by noting the potential role of theory-based research in the process of holistic eHealth development. As illustrated by Figure 7.2, knowledge accumulation and curation are important scientific outcomes that are arguably intrinsic—but not always explicitly acknowledged—in the first stages of the roadmap: contextual inquiry, value specification (at the end user’s level), and design. While knowledge dissemination is not depicted in this figure, all of these outcomes can be obtained from eHealth projects, if theory-based research is incorporated (and hence, valued) as an important and intrinsic part of the development process.

Figure 7.2. Illustrated process of knowledge accumulation and curation, depicted in alignment with the stages and activities of the CeHRes roadmap (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011).



## Multidisciplinary development teams

The present thesis sought to achieve a holistic view on its case of study by taking into consideration different scientific and pragmatical perspectives on eHealth research and development. Achieving effective collaboration between different specialists is a complicated task in itself and was not the focus of this thesis. However, the thesis did point out to an underlying and perhaps more ambitious goal: achieving a shared understanding of phenomena. The different representations generated by the studies of this thesis strived to accomplish that goal.

Mainly, by promoting a shared understanding in early (pre-)design stages of eHealth by means of concepts, mock-ups, prototypes, vignettes, and other forms of knowledge representation. Even when multidisciplinary is lacking in a team, the thesis exemplified means through which expert-based knowledge can be collected and revised. For instance, through online survey experiments or literature reviews focused on that level, collecting and analysing judgements and decision-making from multiple perspectives.

Within that multidisciplinary, the role of psychological expertise has already been highlighted. To recall, given the inherent goal of behaviour change in eHealth, the findings of this thesis pointed towards the need for adoption of structured theories with sufficient and fitting specification of key constructs. Furthermore, the findings of this thesis deemed equally important to establish and clarify the relation between the underlying theoretical constructs and other practical elements of an intervention. For example, for the case that an eHealth design feature must be accompanied with fitting rationale and specification on *what* it is seeking to change, *how* it is predicted to change it, *when*, *how much*, and so on.

Understandably, the debate on the usefulness of theory-based interventions is arguably still ongoing (Hagger & Weed, 2019). There does not seem to be a conclusion yet, because there is not enough data on which to make an assessment. It must be the role of the sciences involved, such as psychology—or scientists and psychologists in a multidisciplinary team—to connect theory-based constructs to (key) components of eHealth interventions and their features, to enable proper evaluation of the success, as well as to facilitate knowledge accumulation and curation in the multidisciplinary field.

### **Dynamic, adaptive interventions**

The findings of the present thesis suggest that the adoption of fitting theories opens up opportunities for more advanced tailoring and personalisation of eHealth interventions. This is important, because protocol for treatments with eHealth as the mode of delivery should be dynamic and adaptable to the complexity of behaviour change (Hekler et al., 2016; Larsen et al., 2017). This includes the notion that potential on eHealth's adaptability redefines the thresholds or indicators to measure success. For instance, as presented in this thesis, the implication of value sensitive design entails that the self-care goals must be personalised and intervention engagement driven by the core values of individuals. An individual who values social support will only feel success if the technology enables or facilitates the fulfilment of that need. Importantly, the dynamic understanding entails embracing time as one of the key factors. That is, clearly aligning with the fact that behaviour change occurs throughout time. This approach has led to the emergence of studies of 'just-in-time adaptive interventions' and within the scope of eHealth and CVD, promising examples commence to appear (Etminani et al., 2021; Golbus et al., 2021).

A promising area of application is support in secondary disease prevention of CVD, as it is the case for cardiac rehabilitation for patients with coronary artery disease and heart failure (Scherrenberg et al., 2021). For these patients, a comprehensive, lifelong cardiac rehabilitation program is necessary, and through adaptive techniques an eHealth system could serve multiple individuals while accounting for their heterogeneity. Examples of adaptive applications for secondary prevention of CVD already exist, such as the 'Back-on-Bike (BoB) Mobile Cycling' app that provides technology-supported rehabilitation (while also aiming to influence psychological states such as reducing fear and anxiety, while increasing motivation) (Geurts et al., 2016). All in all, while many of the novel approaches are often more data-driven than theory-based, the interconnection between these two seems more possible than ever before.

### **Description of eHealth interventions in published literature**

The present thesis showcased extensive and thorough efforts striving to identify and understand the theoretical foundations of eHealth interventions. At times, the task had to rely on high levels of interpretation, due to the lack of clarity in published reports.

If there is one argument to be made by this thesis, is that there is an enormous necessity to ensure proper specification of key components of interventions, including the connections between underlying theoretical assumptions and practical applications translated to design. It is comprehensible that sufficient clarity is not always achieved, but it should be concerning that unclarity occurs more often than not. Future eHealth studies that report on research and development processes should be more common and equally valued, as they provide means for knowledge accumulation and curation. For instance, clear and standardised reporting can facilitate further and most innovative advancements in behavioural science, such as the specification and codification of theoretical concepts into computer-readable ontologies (Larsen et al., 2017). Consequently, as stated by Norris et al. (2020): ‘As machine-readable representations of knowledge, these ontologies provide a framework for applying Artificial Intelligence to synthesising and interpreting evidence.’ (pg 13).

The synthesis of evidence by the use of machine learning and natural language processing methods shows a lot of promise, and it might even be a necessity with the rapidly growing body of evidence in health-related interventions (Marshall et al., 2020). In the context of self-care support, a checklist such as the template for intervention description and replication (TIDieR) (Hoffmann et al., 2014) has been recommended (Riegel et al., 2022). In the present thesis, the CONSORT-EHEALTH checklist v.1.6 (Baker et al., 2010; Eysenbach, 2011), although specific to experimental studies, was adapted for that purpose. That has shown, that even if there are not yet gold standards for the reporting of eHealth interventions and their characteristics, there are means that make it possible to have meaningful and useful descriptions.

## MAIN RECOMMENDATIONS

By and large, the present thesis highly recommends that future eHealth research and development should start with theory, whether it is at least acknowledged, or ideally fully adopted. Theoretical work at early stages should focus, for instance, on the identification and comparison of theoretical frameworks and their propositions. On the other hand, if an intervention already exists, it is still of equal importance to explore and specify its key features, to learn about what worked and how in terms of behaviour change. Again, theoretical and conceptual work can be conducted to identify and extract those theoretical implications.

Within the scope of self-care and CVD, the works composing this thesis also provided more specific recommendations for research and development, some of which have already been discussed. Regarding methodology, eHealth studies are recommended to adopt holistic approaches that seek to integrate patient-centred studies with consolidated knowledge from expert-based approaches. This recommendation has been recently echoed within the context of the case study (Riegel et al., 2022).

Moreover, eHealth studies should explicitly aim to converge theory and evidence when determining the most effective mechanisms for effective support (**Chapter 3** and **Chapter 4**). This could enable a transition that partakes from multidisciplinary, but moves towards cross-disciplinary perspectives: a shared understanding. Finally, eHealth studies should aim to establish clear connections between their theoretical assumptions on target behaviours and the proposed design solutions for change (**Chapter 3** and **Chapter 6**). Promising frameworks that were directly analysed—and thus recommended—in this thesis are the middle-range theory of self-care of chronic illness (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012), the persuasive design systems model (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjumaa, 2009), and the value sensitive design framework (Friedman et al., 2013; Hendry et al., 2021) (see **Chapter 4**, **Chapter 5**, and **Chapter 6**). Nevertheless, other frameworks were also identified but not directly explored, such as macro ergonomic frameworks (Holden et al., 2013; Holden et al., 2015) and sense-making models (Mamykina et al., 2015).

In the area of value-based design, relevant approaches also exist, such as Schwartz's (2012) refined theory of basic human values or theory-building empirical works on populations with chronic conditions (Berry, Lim, et al., 2017b; Lim et al., 2019; Lim et al., 2017). Such frameworks and models merit exploration, as they are emerging within or near the multidisciplinary field of eHealth.

Finally, as has already been stressed, the reports of eHealth studies should provide a clear identification and operationalisation of their guiding theories, models, and frameworks, as only then will it be possible to optimise the accumulation and curation of knowledge in this field of study (**Chapter 2** and **Chapter 3**).

## **FINAL CONCLUSION**

Self-care is good medicine, but there is not yet a pill for it (Bandura, 2005)—and likely there will never be. eHealth promises to be an effective mode of delivery for self-care support, but to achieve that goal some fundamental steps still need to be made. The present thesis undertook a holistic approach to the study of eHealth research and development, focusing down on the scope of self-care support for CVDs. The goal was to accumulate and refine scientific knowledge in order to seek the improvement of eHealth research and development practices. The present work sought to identify theories, models, or frameworks that had been used to develop, implement, or evaluate eHealth interventions, and it did so extensively. Specific theories were also adopted and revised in detail, interconnecting them within the context of a case study to arrive at cross-disciplinary perspectives. The thesis also sought to identify promising eHealth design strategies that were theory-based, and fitting with self-care as a target behaviour. In that regard, multiple eHealth design strategies were identified and described, inspired by existing interventions but based as well on technology-focused frameworks for persuasive or value sensitive design. The thesis strived to facilitate some of the steps that needed to be made, often forward, looking ahead at innovations in the field such as multiphase optimisation or just-in-time adaptations. However, steps also needed to be made backwards, to identify the assumptions that started it all and clarify or revise propositions that needed so. At large, the field of eHealth seems to require both types of steps, moving forward and backwards if it aims to meet its promise for self-care and health promotion.

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# Glossary

**behavioural assessment support:** Term used by the present thesis to categorise eHealth design features that assess a patient's readiness to change a selected behaviour. They can lead to a visual display of risk factors or recommended priorities for behaviour change. **Chapter 6** provides example representations of these features.

**behavioural performance support:** Term used by the present thesis to categorise eHealth design features that provide guidance or support *during* the performance of self-care behaviours. For instance, an animation to guide a deep breathing practice. They can integrate real-time feedback or be followed up by (self-)evaluations (e.g., rating one's own performance or perceived workout intensity). **Chapter 6** provides example representations of these features.

**behavioural planning support:** Term used by the present thesis to categorise eHealth design features that facilitate action-planning of self-care behaviours. For instance, to decide when and how to exercise based on long-term goals that were either self-set or agreed upon collaboratively with health care providers. **Chapter 6** provides example representations of these features.

**bibliometric analysis:** Refers in general to the use of methods that seek to analyse the relationship or communication patterns in (scientific) literature (Knutas et al., 2015). Communication is typically measured through citation analysis, at the level of different authors or their publications. Networks or other graph representations can be derived from these analyses.

**business modelling:** Term used by the present thesis to refer to recognised principle for the holistic development of eHealth, in line with the CeHRes roadmap. It is defined as how an organisation creates, delivers and captures values. It can be a conceptual and analytical framework to discuss the added values of an eHealth intervention. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**cardiovascular diseases:** Class of different illnesses that relate to the heart or blood vessels, such as hypertension, heart failure, stroke, coronary artery disease, peripheral artery disease, or atrial fibrillation. In 2019, CVDs caused around 17,9 million deaths, representing 32% of all global deaths (World Health Organization, 2020a).

**coaching technologies:** Term used by the present thesis to refer to eHealth technologies that provide feedback, guidance, or recommendations to the patients. Coaching technologies are often designed as web-based, mobile, or wearable apps.

**co-citation analysis:** Refers to a measure in citation analysis used to determine a degree of relationship or communication between two publications. Co-citation occurs when two separate publications reference a third one in common.

**content requirements:** In the context of eHealth design and development, these type of requirements state what information the technology should present to the user (e.g., information about the symptoms of a specific condition) (Kip & van Gemert-Pijnen, 2018).

**cues:** Term used by the present thesis to categorise eHealth design features that provide prompts or cues-to-action. They are directed to specific behaviours and can be personalised to a patient's preferences or circumstances. **Chapter 6** provides example representations of these features.

**design hypothesis:** Term adopted by the present thesis to outline a set of assumptions about how an eHealth technology (or a specific design feature) can affect the user's behaviour or cognition (Hekler et al., 2013). For instance, in **Chapter 6** design hypotheses are proposed to outline how 'prototypical' eHealth design features can meet the values of CVD patients to motivate and support self-care.

**design strategies:** Term used by the present thesis to refer in general to the different potential approaches that can be taken in eHealth design to meet an intended goal. Design strategies can direct what type of content and mode of presentation is employed. Moreover, even design strategies working under the same principle can be operationalised in many different ways. In

**dialogue support:** Persuasive design strategy that implements computer-human dialogue in a manner that helps the user move towards the goal or target behaviour (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjumaa, 2009). In **Chapter 4**, this principle was operationalised and examined as a potential eHealth design strategy in the context of CVD self-care support.

**educational support:** Term used by the present thesis to categorise eHealth design features that enable a patient to access educational information on various topics. Educational information can be presented in multiple formats such as text, audio, or videos. **Chapter 6** provides example representations of these features.

**eHealth:** Broadly refers to the use of technology to support health, well-being, and health care (van Gemert-Pijnen, Kip, et al., 2018).

**eHealth design feature:** Term used by the present thesis to refer to any clearly identifiable property of a technology that serves a specific function and is proposed to help achieve an overarching aim for health, well-being, or health care. This definition is primarily based on the description of technological 'features or properties' by the value sensitive design framework (Friedman et al., 2013). According to this definition, eHealth design features could be functional or visual properties, underlying technical mechanisms, as well as recognisable 'intervention building blocks' such as behaviour change techniques (Michie et al., 2011) and persuasive design strategies (Oinas-Kukkonen & Harjumaa, 2009).

**eHealth development:** Refers to an *iterative process* of development of eHealth, entailing activities for pre-design, design, implementation and evaluation.

**eHealth development as intertwined with implementation:** Term used by the present thesis to refer to recognised principle for the holistic development of eHealth, in line with the CeHRes roadmap. It refers to the inclusion in the development process of activities that are undertaken to realise the adoption, dissemination and long-term use of a product in its intended context. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**eHealth evaluation:** Term used by the present thesis to refer to formative evaluation or summative evaluation of eHealth. In short, *formative evaluation* englobes the activities throughout the entire development process that provide ongoing information on how to improve. In contrast, *summative evaluation* is the development phase which studies the impact and uptake of the technology. These related concepts were operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**eHealth evaluation entailing continuous (product evaluation) cycles:** Term used by the present thesis to refer to recognised principle for the holistic development of eHealth, in line with the CeHRes roadmap. It refers to the employment of iterative design methodologies based on a cyclic process of needs assessment, prototyping, testing, analysing and refining a product, during which changes and refinements are made to the product based on the results of the most recent iteration of a design. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**eHealth implementation:** refers *exclusively* to activities that are undertaken to realise the adoption, dissemination and long-term use of a product in its intended context.

**eHealth intervention:** Refers to an eHealth technology specifically focused on intervening in an existing context by changing behaviour and/or cognitions (van Gemert-Pijnen, Kip, et al., 2018).

**eHealth technology:** Refers to the actual technological instrument via which health, well-being and health care are supported, often refers to information or communication technologies (van Gemert-Pijnen, Kip, et al., 2018).

**experience:** In the context of eHealth design and development, experience had to be defined as part of the selection criteria for the online survey study (**Chapter 4**). The present thesis defined experience as having led, participated, or consulted in projects of relevance in one of the key domains addressed by the survey. The projects could be related to academia, health care institutions, private industry, or policy-making.

**expert-based human support:** Term used by the present thesis to categorise eHealth design features that facilitate the interaction or collaboration with health care providers. For instance, a communication channel with an expert or support team. They can be linked to a clinical team module or a back-end alarm system that prompts interaction. **Chapter 6** provides example representations of these features.

**expertise:** In the context of eHealth design and development, expertise had to be defined as part of the selection criteria for the online survey study (**Chapter 4**). The present thesis defined expertise as having cross-disciplinary or domain-specific knowledge in one of the key domains. These domains could include but not be limited to medical, behavioural, computer and informational sciences, engineering, design, human-technology interaction, human factors and ergonomics, and business or innovation.

**feedback:** Term used by the present thesis to categorise eHealth design features that provide feedback on monitored data or tracked behaviour. For instance, via graphs, charts, or written reports about symptoms, behaviours, or the progress towards a goal. Alternatively, feedback can be provided in *real-time* during the performance of self-care maintenance behaviours. **Chapter 6** provides example representations of these features.

**formative evaluation of eHealth:** Encompasses the activities throughout the entire development process that provide ongoing information on how to improve the development process, outcomes of activities and eHealth technology. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.



**framework:** Term used by the present thesis to refer to an extensive set of principles, such as assumptions, constructs, quality criteria, and ideas that can guide eHealth research and development. It can also contain strategies such as guidelines, design heuristics, and methods to assist on a staged, phased, or time oriented process. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**functional and modality requirements:** In the context of eHealth design and development, these type of requirements specify technical features and prescribe the kind of technology and operating systems that might be required. They are mainly focused on the programmer's point of view. For example, it might be a requirement that an eHealth intervention should be deliverable on both Apple and Android systems (Kip & van Gemert-Pijnen, 2018).

**health care systems:** Term used by the present thesis to refer to the organisational level that encompasses institutions, resources, and health care workers (e.g., general practitioners, and specialised nurses). In the present thesis, the complexity of such systems is also considered in the recommendation for a holistic approach to eHealth research and development. This is itself based on the notion that patient care be so fragmented into different specialities, that there is a similar need to maintain a holistic view of the patient (Covvey, 2018).

**holistic:** Term used by the present thesis to refer to an underlying approach of eHealth research and development that emphasises the importance of the whole and the interdependence of its parts. In practice, this notion endorses multidisciplinary, participatory development and continuous evaluation cycles in eHealth, as exemplified by the CeHRes roadmap and its principles (Kip & van Gemert-Pijnen, 2018; van Gemert-Pijnen et al., 2011).

**human or user-centred design:** Term used by the present thesis to refer to recognised principle for the holistic development of eHealth, in line with the CeHRes roadmap. It is defined as a framework that aims to develop solutions to problems by involving the human perspectives in all steps of the process, via observing the problem within context, brainstorming, conceptualising, developing and implementing the solution. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**intervention outcomes:** Term used by the present thesis to refer to a key feature or element of an eHealth intervention or technology. Refers to the target outcomes of an intervention that directly or indirectly have an impact on the health or well-being of the target group. For example, changes in health parameters (e.g., blood pressure control), risk factors (e.g., weight), or performance of self-care or healthy behaviours (e.g., physical activity levels).

**key elements or features of interventions:** Terms used by the present thesis to generally refer to clearly identifiable characteristics of eHealth interventions. They can refer to psychological, behavioural, technological, or contextual factors, and describe both constructs or processes. For example, a theoretical principle under which design is underpinned, or a practical application of that principle reflected in the front-end design of technology. In **Chapter 2** and **Chapter 3**, the systematic literature review used the term 'key ingredients' to refer to the same concept.

**key metaphors:** Term used in a meta-ethnography to refer to phrases, ideas, concepts, perspectives, organisers, or themes that emerged in a reviewed study (Noblit & Hare, 1988). In **Chapter 2** and **Chapter 3**, the meta-ethnography review distinguished between primary and secondary key metaphors. Primary key metaphors were the key ingredients of frameworks, models, or theories operationalised by the authors of a reviewed study. Secondary key metaphors were—as traditionally defined in meta-ethnographies—remarkable phrases, concepts, ideas or perspectives by the authors of a study, but not apparently derived from a structured underlying framework, model, or theory.

**line-of-argument synthesis:** Term used in a meta-ethnography review to refer to the third type of relation after reciprocal and refutational analysis. It is defined as a new storyline or overarching explanation of a phenomenon (France, Uny, et al., 2019).

**middle-range theory of self-care of chronic illness:** Theory that generally defines self-care as a process whereby individuals and their families maintain health through health-promoting practices and managing illness (Riegel, Moser, et al., 2017). The theory proposes how self-care can be distinguished by three core elements: self-care maintenance, self-care monitoring, and self-care management (Riegel, Jaarsma, et al., 2019; Riegel et al., 2012).

**mock-up:** Medium-fidelity representation of a technology's design via elements such as colours, fonts, texts, images and logos. These elements can be presented via wireframes or another form of presentation and integrated as part of a low- or mid-fidelity prototype (e.g. to show or simulate the structure of a design or the interaction with it) (Burns, 2018). In **Chapter 4** and **Chapter 6**, mock-ups are used to represent eHealth design strategies and features.

**model:** Term used by the present thesis to refer to a simplified representation of a reality, hypothesis, theory, or knowledge. It can contain a set of concepts, statements, or both that specify how constructs relate to each other. It can be both 'precise and quantified' or 'imprecise and qualitative'. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**monitoring technologies:** Term used by the present thesis to refer to eHealth technologies that allow the user to collect health-related data and often also share the patient's data with a health care team. Examples of monitoring technologies are internet-enabled blood pressure monitors and weight scales.

**motivational incentives:** Term used by the present thesis to categorise eHealth design features that incentivise the engagement with the technology by using metaphors such as 'missions', 'medals', or 'cards'. They can be personalised according to a prescribed treatment, self-set goals, or automatic analyses of monitored data. **Chapter 6** provides example representations of these features.

**noncommunicable chronic diseases:** Proposes how self-care can be defined and distinguished by three core elements: self-care maintenance, self-care monitoring, and self-care management (Riegel et al., 2012).

**organisational requirements:** In the context of eHealth design and development, these type of requirements concern the integration of the technology into the organisational structure and working routines. They are mainly aimed at managers. For example, it might be a requirement to allocate time in nurses' schedules so they are available to answer questions from end users about the eHealth intervention (Kip & van Gemert-Pijnen, 2018).

**parameters for effectiveness of behaviour change methods:** Term used by the present thesis to refer to a key feature or element of an eHealth intervention or technology. As defined by Peters, de Bruin and Crutzen (2015, p.3): “Parameters for effectiveness are the characteristics that a practical application[, of a behaviour change method,] must manifest for it to accurately reflect the theoretical method. When these parameters are lost in translation from method to application, effective behaviour change is undermined and may even result in counterproductive effects. Evidence for the existence of such parameters can range from theoretical to meta-analytical.”

**participatory development:** Term used by the present thesis to refer to a what was understood as a principle for the holistic development of eHealth, in line with the CeHRes roadmap. Defined as a structural cooperation of eHealth developers with potential end users and other stakeholders during its development. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**peer-based human support:** Term used by the present thesis to categorise eHealth design features that facilitate interaction with peers. For instance, an online platform that allows data comparison between individuals or makes it possible to plan activities with others. **Chapter 6** provides example representations of these features.

**persuasive systems design:** Term used by the present thesis to refer to a recognised principle for the holistic development of eHealth, in line with the CeHRes roadmap. It refers to designing technology that aims to reinforce, change, shape or influence behaviour and attitudes by being compelling and without being coercive or deceptive. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**. Persuasive systems are themselves defined as a computerised software or information systems designed to reinforce, change or shape attitudes or behaviours or both without using coercion or deception (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjumaa, 2009).

**practical applications of behaviour change methods:** Term used by the present thesis to refer to a key feature or element of an eHealth intervention or technology. As defined by Peters, de Bruin and Crutzen (2015, p.3): “Practical applications are the translations of theoretical methods of behaviour change to practical intervention elements. Applications are by definition specific, ideally tailored to populations, intervention contexts and behavioural domains.”

**primary task support:** Persuasive design systems principle that seeks to directly supports the user in carrying out a primary task (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjumaa, 2009). In **Chapter 4**, this principle was operationalised and examined as a potential eHealth design strategy in the context of CVD self-care support.

**profiling mechanisms:** Term used by the present thesis to refer to a key feature or element of an eHealth intervention or technology. Defined as elements employed to adapt an eHealth intervention to the characteristics of an individual or cohort (e.g., motivation levels as measured in a pre-test).

**prototype:** An initial, raw visual representation of a technology. It is meant to show a simplified version of the final end product, which can be tested with users and others stakeholders to identify issues or necessary changes (Kip & van Gemert-Pijnen, 2018). In **Chapter 6**, a prototype for CVD self-care support was created to integrate a set of proposed eHealth design features.

**prototypical eHealth design features:** Term used by the present thesis to refer to eHealth design features argued to be typically integrated, maybe even essential, to eHealth technologies and interventions within a specific context. In **Chapter 6**, prototypical eHealth design features are represented via mock-ups and a prototype, which are specific to the context of remote self-care support for patients with a CVD.

**reciprocal translation:** Term used in a meta-ethnography review to describe the process of identifying or generating metaphors which can better enable holistic accounts of phenomena (Noblit & Hare, 1988).

**refutational translation:** Term used in a meta-ethnography review to describe the process of giving explicit attention to identifying the incongruities and inconsistencies in the data (France, Uny, et al., 2019).

**reminders:** Term used by the present thesis to categorise eHealth design features that aim to facilitate adherence to self-care behaviours. They can include the demand of an action or a request for additional input such as a reason for not conducting the behaviour (e.g., report the intake of medication as prescribed or a reason for skipping it). **Chapter 6** provides example representations of these features.

**requirement:** Describes what a technology should do, what data it should store or retrieve, what content it should display, and what kind of user experience it should provide. A requirement can be elicited from multiple sources, like stakeholders, literature, legal documents, or technical constraints. Some possible types of requirements are: content requirements, usability and user experience requirements, functional and modality requirements, service requirements, and organizational requirements (Kip & van Gemert-Pijnen, 2018).

**self-care:** As defined by the middle-range theory of self-care, it refers to the process whereby individuals and their families maintain health through health-promoting practices and managing illness (Riegel, Moser, et al., 2017).

**self-care maintenance:** Refers to the performance of behaviours to improve well-being, preserve health, or to maintain physical and emotional stability (Riegel et al., 2012). The goal of maintenance is to preserve health and prevent symptom exacerbations (Riegel, Jaarsma, et al., 2019).

**self-care management:** Refers to the evaluation of changes in physical and emotional signs or symptoms to determine if action is needed (Riegel et al., 2012). The goal of management is the effective treatment of symptoms (Riegel, Jaarsma, et al., 2019).

**self-care monitoring:** Refers to the process of routine, vigilant body monitoring, surveillance, or 'body listening' (Riegel et al., 2012). The goal of monitoring is recognition that a change has occurred (Riegel, Jaarsma, et al., 2019).

**self-regulation:** Refers to the various processes involved in how individuals set and pursue their goals (Vancouver & Day, 2005). The goal of management is the effective treatment of symptoms (Riegel, Jaarsma, et al., 2019).

**self-management:** In health care settings where it is most-often used, it refers to an individual's ability to manage the symptoms, treatment, physical and psychosocial consequences, as well as the lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002).

**self-monitoring support:** Term used by the present thesis to categorise eHealth design features that facilitate a patient's monitoring of various types of data. For instance, monitoring symptoms, weight, or self-care behaviours. **Chapter 6** provides example representations of these features.

**service requirement:** In the context of eHealth design and development, these type of requirements state the best way to organise the services that support the technology. They are mainly relevant for managers who make decisions on matters like marketing or user support. For example, it might be a requirement to have a 24-hour helpdesk in case end users face problems with a technology (Kip & van Gemert-Pijnen, 2018).

**social support:** Persuasive design strategy that seeks to motivate the user by leveraging social influence (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjumaa, 2009). In **Chapter 4**, this principle was operationalised and examined as a potential eHealth design strategy in the context of CVD self-care support.

**snowballing:** Refers to the use of reference lists or citations of studies to identify additional relevant publications. It is a common method to accompany database searches in systematic literature reviews (Badampudi et al., 2015). It is referred to as backward snowballing when it uses the reference list of a relevant publication (going 'back' to previous works referred to in that paper). It is referred to as forward snowballing when it uses the citations of a relevant publication (going 'forward' to newer works citing the current paper).

**summative evaluation of eHealth:** Refers to the eHealth development phase which studies the influence and role of the technology on health, the context, behaviour and stakeholder perspective via evaluations of impact and uptake of the technology. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**system credibility support:** Persuasive design strategy that emphasises the expertise behind a system (Oinas-Kukkonen, 2013; Oinas-Kukkonen & Harjumaa, 2009). In **Chapter 4**, this principle was considered a prerequisite of all interventions (i.e., trust in novel eHealth remote support systems is a known important factor). Therefore, this was not operationalised as an eHealth design strategy to test in the online experimental study.

**system personalisation:** Term used by the present thesis to categorise eHealth design features that aim to (de-)activate the system's modules to create a better fit with a patient's needs, preferences, or circumstances. Personalisation can occur during the introduction of the technology, or as a response to the evolving situation or circumstances of the patient. **Chapter 6** provides example representations of these features.

**technology adoption:** Term used by the present thesis to refer to a key feature or element of an eHealth intervention or technology. It refers to those features that aim to increase the engagement, use, adherence, uptake or adoption of the technology. For example, the use of profiling mechanisms, defined as elements that are employed to adapt an eHealth intervention to the characteristics of an individual or cohort (e.g., motivation levels as measured in a pre-test).

**telehealth:** Term used by the present thesis to refer to a form of eHealth focused on remote communication between patients and their caregiver, including also typically remote monitoring of symptoms. In this form of eHealth, the caregiver is usually in the lead.

**theory:** Term used by the present thesis to refer to a set of concepts and/or statements with specification of how phenomena relate to each other. Theory provides an organizing description of a system that accounts for what is known, and explains and predicts phenomena. This concept was operationalised for purposes of the systematic literature review, which methodology is described in **Chapter 2**.

**topic modelling:** Refers to the use of (statistical) methods to identify overarching topics describing a collection of documents. For example, in **Chapter 2** and **Chapter 3** of the present thesis, topic modelling was used as part of the bibliometric analysis to identify common logical topics relevant studies based on their keywords and abstracts.

**usability and user experience requirements:** In the context of eHealth design and development, these type of requirements concern the user perspective and specify the interface and interaction design of the technology (Kip & van Gemert-Pijnen, 2018).

**value:** Term used by the present thesis to refer to any ideal or interest of an individual, which could be pursued or met with the help of technology (Van Velsen et al., 2013). Values can be translated to more technical, concrete requirements for the design of an eHealth technology. In **Chapter 5** and **Chapter 6**, values of patients with a CVD are examined in relation to specific eHealth design features.

**value sensitive design framework:** Theoretical and methodological framework that seeks to integrate values into design work (Friedman et al., 2013). The framework aims to ensure that the design of technologies accounts for values in a principled and comprehensive manner, through integrative and iterative methodologies that include conceptual, empirical, and technical investigations.

**vignettes:** Short, systematically varied descriptions of situations or persons (Atzmüller & Steiner, 2010). In a vignette experiment, such as the one described in **Chapter 4**, respondents are confronted with vignettes that are composed of a (randomised) combination of different factors (which is why they are also called factorial survey experiments) (Atzmüller & Steiner, 2010; Auspurg & Hinz, 2015).



# Summary

The present thesis adopts a holistic approach for the study of eHealth research and development under the scope of self-care support for cardiovascular diseases (CVDs). The thesis revises the contemporary use of frameworks, models, and theories for research and development, identifies promising theory-based approaches to eHealth design, and proposes eHealth features that are based on self-care theory and technology design models.

## INTRODUCTION

**Chapter 1** contains the general introduction. This chapter introduces the specific case of study for the thesis: the alarming burden caused by chronic cardiovascular diseases to health care systems worldwide. In a nutshell, the alarm is raised by the increasing demand in the provision of care for patients with noncommunicable chronic conditions, particularly those with cardiovascular diseases. To alleviate this burden, it is deemed necessary to support health care models that motivate individuals to take an active role and assume responsibility in their own self-care.

**Self-care**, as defined by the middle-range theory of self-care of chronic illness, is the process whereby individuals and their families maintain health through health-promoting practices and managing illness. Self-care can be further specified by its three core elements: self-care maintenance, self-care monitoring, and self-care management. To effectively support self-care, interventions must not only improve the lives of patients but must also ensure that no burden is added to health care workers and systems. Taking this into account, technology-based interventions are one of the most promising solutions for the provision of self-care support. **eHealth** is a concept that englobes the use of technology to support health, well-being, and health care. eHealth uses information and communication (digital) technologies such as smartphones, wearable sensors, or internet-enabled health monitoring devices such as blood pressure monitors, to form a support system that can be personalised and tailored to the needs of individuals in a target group.

While the promise of eHealth is high, its development, implementation, and evaluation entails many challenges and pitfalls. For instance, the pace and efficiency of its development, the engagement of end users with digital interventions, the use of theory in design, the evaluation of effectiveness and cost-effectiveness, as well as the surrounding regulations, including ethics and information governance. The present thesis focused primarily on one of the aforementioned challenges: the theoretical foundation of eHealth for its development and design. This choice partakes from the dogma that the use of solid, scientific theories in intervention development contribute to the accumulation, curation, and dissemination of knowledge about what works, when, and how. As such, the use of theory can have a fundamental role in the development of behavioural, evidence-based interventions. A theoretical foundation for eHealth in the context of self-care support would facilitate the identification of the most effective features or characteristics of technology. At a granular level, it could advance understanding of how different design strategies work best, for whom, and under what circumstances.

The research composing this thesis adopted a holistic approach guided by the principles of the **CeHRes roadmap**. In this manner, the thesis sought to accumulate knowledge and practical perspectives from different stakeholders and lenses, to analyse and integrate them in an overarching understanding. Through the holistic approach, the end goal of research and development is to account for all of the key factors that will most likely ensure the uptake and success of eHealth. Derived from this and under the context of eHealth, self-care, and CVD, the research questions addressed by the thesis are:



1. What and how have theories, models, or frameworks been used to develop, implement, or evaluate eHealth interventions?
2. What are some of the most promising eHealth (persuasive) design strategies that can be tailored to the theory-based, key elements of self-care?
3. What eHealth design features honour or can be connected to the values of patients (i.e., their health-related ideals and interests)?
4. What and how can theory-based eHealth design features, or combinations thereof, meet the values of patients in order to best support their self-care?

The rest of the thesis is divided in two main parts, each composed by multiple chapters. The first part of the thesis presents two studies that focused on the *revision of theory- and expert-based knowledge* within the scope of eHealth applications for CVD self-care. The second part presents two more studies that dived into the *design and proposition of theory-based and value sensitive eHealth features*.

## **PART 1: REVISION OF THEORY- AND EXPERT-BASED KNOWLEDGE**

**Chapter 2** describes the underlying methods used to synthesise, in a systematic literature review, a holistic view on multidimensional contexts and factors as derived from scientific theories, models, and frameworks, which were reported in published literature as the basis for the development of existing eHealth projects, interventions, and technologies.

A protocol for a systematic literature review was developed by adopting the **meta-ethnography** approach as the basis. Meta-ethnography is a suitable method because it aims to achieve a holistic interpretation of a given topic. An exhaustive systematic search was conducted to find published studies at the crossroads of eHealth, CVD, and self-care. Furthermore, the protocol guided complex, iterative and highly-analytical interpretative phases of knowledge synthesis. Precisely, the main difference between a meta-ethnographic review and other systematic reviews lie in its synthesis approach. In a meta-ethnography, the context in which findings emerge is preserved. For the case at hand, the context of interest concerns the various research disciplines at the crossroads of eHealth, CVDs, and self-care. This would not have been possible by aggregative methodologies or purely descriptive approaches.

The protocol also describes how several tools (Covidence, ATLAS.ti, and Microsoft Office) were employed to conduct a thorough systematic qualitative evidence synthesis, as demanded by the meta-ethnography approach. To highlight, several steps not unique to meta-ethnography were also applied (quality appraisal, data comparison matrix, and bibliometric analysis) to provide clarity and depth to the analysis and synthesis. The results aimed to show how the meta-ethnography method could contribute to overcoming the challenges derived from the multidisciplinary and rapidly evolving nature of eHealth research and development.

**Chapter 3** presents the results of the meta-ethnography review, which aimed at understanding the distinct approaches in the development of eHealth interventions for CVD. The findings of this review support and exemplify the numerous possibilities in the use of frameworks, models, and theories to guide research and development of eHealth.

Specifically, the review identified 43 multidisciplinary frameworks, models, theories, and guidelines that have informed interventions within the scope of eHealth support for self-care of CVD. The review found that multidisciplinary approaches were often integrated with each other, and aimed to create a fit between users, the content of an intervention, and its context. However, the review also noted a lack of specification of the underlying approaches in terms of their operationalisation for eHealth development and design.

The meta-ethnography also used the principles of the CeHRes roadmap to analyse the selected literature and the key components of the reviewed interventions. On the one hand, the use of participatory, user-centred design, and continuous evaluation cycles were commonly applied principles. On the other hand, less attention was given to the integration of implementation in the development process and to account for the implications of the new eHealth-based health care infrastructures as a whole.

**Chapter 4** describes a vignette survey experiment that investigated how experts from multiple fields of science assess, in an online experimental setting, the potential success of different eHealth design strategies when matched to key self-care needs. The survey revealed that experts from multiple scientific disciplines characterised primary task support as a promising support strategy for all theory-based selfcare needs (maintenance, monitoring, and management). Primary task support was predominantly seen as a prerequisite, as it could not only seek to simplify self-care tasks but also help ensure the safety of patients under the context of remote care. When compared to primary task support, social support was considered by experts to be less likely to succeed when supporting monitoring needs. Similarly, both dialogue and social support were less likely to succeed when supporting patients' management needs.

The surveyed experts also suggested various eHealth personalisation and tailoring approaches for self-care. Principally, they suggested that interventions must be simplified by personalising their pacing to the personal circumstances of each patient (e.g., their knowledge and skills) and by tailoring the information they provide to their preferences (e.g., their literacy and culture). In general, patient-centredness was seen as fundamental (i.e., the alignment with the patients' life personal goals and values), together with support for the objective of facilitating collaboration between patients and caregivers.

## **PART 2: DESIGN AND PROPOSITION OF THEORY-BASED AND VALUE SENSITIVE EHEALTH FEATURES**

**Chapter 5** describes a study that sought to connect a set of empirically validated values of individuals with a CVD with existing eHealth technologies and their design features. The study searched for potential connections between design features and values with the goal to advance knowledge about how eHealth technologies can be more meaningful and motivating for end users. As a result, the study identified 98 connections between design features of existing eHealth technologies and a set of empirically validated values of individuals living with a CVD.

On the one hand, some design features were connected with multiple values. On the other hand, some values were less frequently connected, with a couple remaining largely unaddressed. These results shed light on the importance of value sensitive design for future eHealth technologies. As an example of a frequently connected value, the value of *'having or maintaining a healthy lifestyle'* was linked to design features related to behavioural planning support, behavioural performance support, and the provision of feedback during behaviour performance. On the contrary, as an example of a largely unaddressed value, the value of *'being seen as a person rather than a patient'* was only linked to a single design feature that delivers culturally-attuned motivational and reinforcement messages to end users. By and large, this study contributed to the formulation and revision of explicit and specific design hypotheses for value-sensitive eHealth self-care support.

**Chapter 6** describes a theoretical and design study that aims to showcase how self-care theory and a value sensitive approach can inform and guide the design of eHealth to support patients with a CVD. As a result, thirty-two *'prototypical'* eHealth design features were created and provided with a theoretical foundation on self-care theory and a value sensitive approach. The features are considered to be *'prototypical'* because they are typically integrated, and often deemed essential, in eHealth technologies aiming to support self-care of CVD.

The design features were organised across twelve categories, and represented through mock-ups and a general description of their distinctive traits. The mock-ups were also integrated in a low-fidelity prototype. Importantly, the specification of design hypotheses and requirements for each feature were based on self-care theory and the value sensitive framework. Finally, a logic model was presented to exemplify the integration of all key theoretical and design elements.

## CONCLUSION

**Chapter 7** contains the general discussion. This chapter reviews the implications that can be derived from the multiple studies composing the thesis. Importantly, the goal of the thesis to advance theory-based research and development of eHealth is discussed in the light of the strengths and limitations of the research findings. At large, the holistic approach to eHealth that led the research converged in the adoption and exploration of two theoretical frameworks in the research process: the middle-range theory of self-care of chronic illness and the value sensitive design framework. In a similar fashion, the process of knowledge revision, curation, and generation prompted the development and application of various tools and methods for the translation of theory into design, and vice versa. For instance, the meta-ethnography review entailed the development of a data extraction form based on the CONSORT-EHEALTH checklist. This form enabled the identification of key components of eHealth interventions, as well as the revision of their implicit and explicit design choices. On the other end, design representation tools such as vignettes and mock-ups were repeatedly used in the studies to depict theory-based assumptions and propositions for eHealth self-care support. These design tools could be used to evaluate the theory-based design hypotheses (as in the survey online experiment) as well as to express new propositions for eHealth design and development (as done via the prototypical design features).

In conclusion, the present thesis achieved its goal to identify theories, models, or frameworks that had been used to develop, implement, or evaluate interventions at the crossroads of eHealth, self-care, and CVD. By adopting and revising promising theories, the research successfully interconnected relevant constructs within the context of study. That is, the research identified promising eHealth design strategies that were theory-based and fitting with self-care as the target for behaviour change. The eHealth design strategies were primarily based and inspired by existing interventions but were also influenced by technology-focused frameworks for persuasive and value sensitive design. Although the work performed in the present thesis is largely conceptual and theoretical, its findings endorse and exemplify the vision that future eHealth research and development should start with theory and be continuously paired with it. At the very least, theory should be clearly acknowledged and detailed when used, but ideally, theory should be fully and comprehensively adopted as part of holistic eHealth development, evaluation, and implementation.

# Samenvatting (Summary in Dutch)

Dit proefschrift hanteert een holistische benadering voor de studie van eHealth onderzoek en ontwikkeling in het kader van zelfzorgondersteuning voor hart- en vaatziekten (*cardiovascular diseases* in het Engels, afgekort als *CVD's*). Het proefschrift herzielt het hedendaagse gebruik van kaders, modellen en theorieën voor onderzoek en ontwikkeling, identificeert veelbelovende theorie gebaseerde benaderingen voor eHealth ontwerp en stelt eHealth kenmerken voor die gebaseerd zijn op zelfzorgtheorie en technologie ontwerpmodellen.

## INTRODUCTIE

**Hoofdstuk 1** bevat de algemene inleiding. Dit hoofdstuk introduceert de specifieke casus van het proefschrift: de alarmerende belasting van de gezondheidszorg wereldwijd door chronische hart- en vaatziekten. Kort gezegd wordt de alarmbel geluid door de toenemende vraag naar zorg voor patiënten met niet-overdraagbare chronische aandoeningen, met name hart- en vaatziekten. Om deze last te verlichten, wordt het noodzakelijk geacht om gezondheidszorgmodellen te ondersteunen die individuen motiveren om een actieve rol te spelen en verantwoordelijkheid te nemen voor hun eigen zelfzorg.

**Zelfzorg** (*self-care* in het Engels), zoals gedefinieerd door de middle-range theorie van zelfzorg van chronische ziekte, is het proces waarbij individuen en hun families hun gezondheid behouden door middel van gezondheidsbevorderende praktijken en het beheren van ziekte. Zelfzorg kan verder gespecificeerd worden aan de hand van drie kernelementen: zelfzorgonderhoud, zelfzorgmonitoring en zelfzorgmanagement. Om zelfzorg effectief te ondersteunen, moeten interventies niet alleen het leven van patiënten verbeteren, maar er ook voor zorgen dat gezondheidswerkers en -systemen niet extra belast worden. Met dit in het achterhoofd zijn interventies op basis van technologie een van de meest veelbelovende oplossingen voor het bieden van zelfzorgondersteuning. **eHealth** is een concept dat het gebruik van technologie ter ondersteuning van gezondheid, welzijn en gezondheidszorg omvat. eHealth maakt gebruik van informatie- en communicatietechnologieën (digitale technologieën) zoals smartphones, draagbare sensoren of gezondheidsmonitoring apparaten met internetfunctionaliteit, zoals bloeddrukmeters, om een ondersteuningssysteem te vormen dat kan worden gepersonaliseerd en afgestemd op de behoeften van individuen in een doelgroep.

Hoewel de belofte van eHealth groot is, brengt de ontwikkeling, implementatie en evaluatie ervan veel uitdagingen en valkuilen met zich mee. Bijvoorbeeld het tempo en de efficiëntie van de ontwikkeling, de betrokkenheid van eindgebruikers bij digitale interventies, het gebruik van theorie in het ontwerp, de evaluatie van effectiviteit en kosteneffectiviteit, evenals de omringende regelgeving, waaronder ethiek en informatiebeheer. Dit proefschrift richt zich primair op een van de bovengenoemde uitdagingen: de theoretische onderbouwing van eHealth voor de ontwikkeling en het ontwerp ervan. Deze keuze komt voort uit het dogma dat het gebruik van solide, wetenschappelijke theorieën bij de ontwikkeling van interventies bijdraagt aan de accumulatie, curatie en verspreiding van kennis over wat werkt, wanneer en hoe. Als zodanig kan het gebruik van theorie een fundamentele rol spelen bij de ontwikkeling van gedragsgerichte, *evidence-based* interventies. Een theoretische basis voor eHealth in de context van zelfzorgondersteuning zou de identificatie van de meest effectieve kenmerken of eigenschappen van technologie vergemakkelijken. Op een meer gedetailleerd niveau zou het meer inzicht kunnen geven in hoe verschillende ontwerpstrategieën het beste werken, voor wie en onder welke omstandigheden.

Het onderzoek gebruikte ook de principes van de **CeHRes-roadmap** om de ontwikkeling van bestaande eHealth-interventies te analyseren. Dus het doel van dit onderzoek was om kennis en praktische perspectieven van verschillende belanghebbenden en lenzen te verzamelen, te analyseren en te integreren in een overkoepelend begrip. Door de holistische benadering is het einddoel van onderzoek en ontwikkeling om rekening te houden met alle sleutelfactoren die hoogstwaarschijnlijk zullen zorgen voor de invoering en het succes van eHealth. Hiervan afgeleid en in de context van eHealth, zelfzorg en CVD, zijn de onderzoeksvragen die in dit proefschrift aan de orde komen:

1. Wat en hoe zijn theorieën, modellen of kaders gebruikt om eHealth interventies te ontwikkelen, implementeren of evalueren?
2. Wat zijn enkele van de meest veelbelovende eHealth (*persuasive*) ontwerpstrategieën die kunnen worden afgestemd op de op theorie gebaseerde, belangrijkste elementen van zelfzorg?
3. Welke eHealth ontwerpkenmerken eren of kunnen verbonden worden met de waarden van patiënten (d.w.z. hun gezondheidsgerelateerde idealen en interesses)?
4. Wat en hoe kunnen op theorie gebaseerde eHealth ontwerpkenmerken, of combinaties daarvan, voldoen aan de waarden van patiënten om hun zelfzorg zo goed mogelijk te ondersteunen?

De rest van het proefschrift is verdeeld in twee hoofddelen, elk bestaande uit meerdere hoofdstukken. Het eerste deel van het proefschrift presenteert twee studies die zich richtten op de *herziening van theorie- en expertgebaseerde kennis* in het kader van eHealth toepassingen voor CVD zelfzorg. Het tweede deel presenteert nog twee studies die zich richtten op het *ontwerp en de propositie van theorie gebaseerde en waardegevoelige eHealth functies*.

## DEEL 1: HERZIENING VAN OP THEORIE EN EXPERTS GEBASEERDE KENNIS

**Hoofdstuk 2** beschrijft de onderliggende methoden die zijn gebruikt om, in een systematisch literatuuronderzoek, een holistische visie te synthetiseren op multidimensionale contexten en factoren zoals afgeleid uit wetenschappelijke theorieën, modellen en kaders, die werden gerapporteerd in gepubliceerde literatuur als basis voor de ontwikkeling van bestaande eHealth projecten, interventies en technologieën.

Er werd een protocol voor een systematisch literatuuronderzoek ontwikkeld door de **meta-ethnografie** benadering als basis te nemen. Meta-ethnografie is een geschikte methode omdat het gericht is op een holistische interpretatie van een bepaald onderwerp. Er werd een uitgebreide systematische zoekactie uitgevoerd om gepubliceerde studies te vinden op het kruispunt van eHealth, CVD en zelfzorg. Bovendien leidde het protocol complexe, iteratieve en zeer analytische interpretatiefasen van kennissynthese. Het belangrijkste verschil tussen een meta-ethnografische review en andere systematische reviews is de synthesebenadering. Een meta-ethnografie behoudt de context waarin de bevindingen tot stand komen. In dit geval betreft de context de verschillende onderzoeksdisciplines op het kruispunt van eHealth, CVD's en zelfzorg. Dit zou niet mogelijk zijn geweest met aggregatieve methodologieën of puur beschrijvende benaderingen.

Het protocol beschrijft ook hoe verschillende hulpmiddelen (Covidence, ATLAS.ti en Microsoft Office) werden gebruikt om een grondige systematische kwalitatieve onderzoekssynthese uit te voeren, zoals de meta-ethnografie vereist. Er werden ook verschillende stappen toegepast die niet uniek zijn voor meta-ethnografie (kwaliteitsbeoordeling, vergelijkingsmatrix en bibliometrische analyse) om de analyse en synthese helderheid en diepgang te geven. De resultaten waren erop gericht aan te tonen hoe de meta-ethnografie methode zou kunnen bijdragen aan het overwinnen van de uitdagingen die voortkomen uit de multidisciplinaire en snel evoluerende vak van eHealth onderzoek en ontwikkeling.

**Hoofdstuk 3** presenteert de resultaten van de meta-ethnografie review, die gericht was op het begrijpen van de verschillende benaderingen in de ontwikkeling van eHealth interventies voor CVD. De bevindingen van deze review ondersteunen en illustreren de vele mogelijkheden in het gebruik van kaders, modellen en theorieën om onderzoek en ontwikkeling van eHealth te sturen.

De review identificeerde 43 multidisciplinaire kaders, modellen, theorieën en richtlijnen die interventies binnen het bereik van eHealth ondersteuning voor zelfzorg van CVD hebben geleid. Uit het onderzoek bleek dat multidisciplinaire benaderingen vaak met elkaar geïntegreerd waren en gericht waren op het creëren van een samenhang tussen gebruikers, de inhoud van een interventie en de context. De review constateerde echter ook een gebrek aan specificatie van de onderliggende benaderingen in termen van hun operationalisering voor de ontwikkeling en het ontwerp van eHealth.

De meta-ethnografie maakte ook gebruik van de principes van het *CeHRes-roadmap* om de geselecteerde literatuur en de belangrijkste componenten van de onderzochte interventies te analyseren. Enerzijds waren het gebruik van participatief, gebruikersgericht ontwerp en continue evaluatiecycli algemeen toegepaste principes. Anderzijds werd er minder aandacht besteed aan de integratie van de implementatie in het ontwikkelingsproces en aan de implicaties van de nieuwe op eHealth gebaseerde gezondheidszorginfrastructuren als geheel.

**Hoofdstuk 4** beschrijft een vignetten enquête-experiment dat onderzocht hoe experts uit verschillende wetenschapsgebieden, in een online experimentele setting, het potentiële succes van verschillende eHealth ontwerpstrategieën beoordelen wanneer deze gekoppeld worden aan belangrijke zelfzorgbehoeften. Uit het onderzoek bleek dat experts uit verschillende wetenschappelijke disciplines *primaire taakondersteuning* karakteriseren als een veelbelovende ondersteuningsstrategie voor alle op theorie gebaseerde zelfzorgbehoeften (zelfzorgonderhoud, zelfzorgmonitoring en zelfzorgmanagement). *Primaire taakondersteuning* werd overwegend gezien als een eerste vereiste, omdat het niet alleen zelfzorgtaken kon vereenvoudigen, maar ook de veiligheid van patiënten kon helpen garanderen in de context van zorg op afstand. In vergelijking met *primaire taakondersteuning* was *sociale ondersteuning* volgens de experts minder succesvol bij het ondersteunen van zelfzorgmonitoring. Evenzo hadden zowel *dialogoog* als *sociale ondersteuning* minder kans van slagen bij het ondersteunen van de zelfzorgmanagement van patiënten.

De ondervraagde deskundigen stelden ook verschillende eHealth personaliserings- en afstemmingsbenaderingen voor zelfzorg voor. Ze suggereerden vooral dat interventies vereenvoudigd moeten worden door het tempo aan te passen aan de persoonlijke omstandigheden van elke patiënt (bv. hun kennis en vaardigheden) en door de informatie die ze verstrekken af te stemmen op hun voorkeuren (bv. hun geletterdheid en cultuur). In het algemeen werd patiëntgerichtheid als fundamenteel gezien (d.w.z. het afstemmen op de persoonlijke doelen en waarden van de patiënt), samen met steun voor de doelstelling om de samenwerking tussen patiënten en zorgverleners te vergemakkelijken.

## **DEEL 2: ONTWERP EN VOORSTEL VAN OP THEORIE GEBASEERDE EN WAARDEGEVOELIGE E-HEALTH KENMERKEN**

**Hoofdstuk 5** beschrijft een onderzoek waarin werd geprobeerd een reeks empirisch gevalideerde waarden van mensen met een CVD te koppelen aan bestaande eHealth technologieën en hun ontwerpkenmerken. Het onderzoek zocht naar potentiële verbanden tussen ontwerpkenmerken en waarden met het doel om meer kennis te vergaren over hoe eHealth-technologieën zinvoller en motiverender kunnen zijn voor eindgebruikers. Als resultaat identificeerde het onderzoek 98 verbanden tussen ontwerpkenmerken van bestaande eHealth technologieën en een reeks empirisch gevalideerde waarden van mensen met een CVD.

Eenzijds waren sommige ontwerpkenmerken verbonden met meerdere waarden. Aan de andere kant waren sommige waarden minder vaak verbonden, en bleven er twee grotendeels genegeerd. Deze resultaten werpen licht op het belang van waardegevoelig ontwerp voor toekomstige eHealth technologieën. Als voorbeeld van een vaak verbonden waarde werd de waarde *'een gezonde levensstijl hebben of behouden'* gekoppeld aan ontwerpkenmerken met betrekking tot ondersteuning van gedragsplanning, ondersteuning van gedragsprestaties en het geven van feedback tijdens het uitvoeren van gedrag. De waarde *'gezien worden als een persoon in plaats van een patiënt'* werd daarentegen, als voorbeeld van een grotendeels onaangeroerde waarde, slechts gekoppeld aan één ontwerpkenmerk dat cultureel afgestemde motiverende en versterkende boodschappen levert aan eindgebruikers. Over het algemeen heeft dit onderzoek bijgedragen aan de formulering en herziening van expliciete en specifieke ontwerphypothesen voor waardegevoelige eHealth zelfzorgondersteuning.

**Hoofdstuk 6** beschrijft een theoretisch en ontwerpend onderzoek met als doel te laten zien hoe de zelfzorgtheorie en een waardegevoelige benadering het ontwerp van eHealth kunnen informeren en begeleiden om patiënten met een CVD te ondersteunen. Als resultaat werden tweeëndertig *'prototypische'* eHealth ontwerpkenmerken gecreëerd en voorzien van een theoretische kader op basis van zelfzorgtheorie en een waardegevoelige benadering. De kenmerken worden als *'prototypisch'* beschouwd omdat ze typisch geïntegreerd zijn, en vaak als essentieel worden beschouwd, in eHealth technologieën die gericht zijn op het ondersteunen van zelfzorg bij CVD.

De ontwerpkenmerken werden verdeeld over twaalf categorieën en weergegeven door middel van mock-ups en een algemene beschrijving van hun onderscheidende kenmerken. De *mock-ups* werden ook geïntegreerd in een *low-fidelity* prototype. Belangrijk is dat de specificatie van ontwerphypothesen en vereisten voor elk kenmerk gebaseerd waren op de zelfzorgtheorie en het waardegevoelige kader. Tot slot werd er een logisch model gepresenteerd om de integratie van alle belangrijke theoretische en ontwerpelementen te illustreren.

## CONCLUSIE

**Hoofdstuk 7** bevat de algemene discussie. Dit hoofdstuk geeft een overzicht van de implicaties die kunnen worden afgeleid uit de verschillende onderzoeken van dit proefschrift. Belangrijk is dat het doel van het proefschrift om theorie gebaseerd onderzoek en ontwikkeling van eHealth te bevorderen wordt besproken in het licht van de sterke punten en beperkingen van de onderzoeksbevindingen. De holistische benadering van eHealth die het onderzoek leidde, convergeerde in de toepassing en verkenning van twee theoretische kaders in het onderzoeksproces: de middle-range theorie van zelfzorg bij chronische ziekten en het waardegevoelige ontwerpkader. Op een vergelijkbare manier leidde het proces van kennisrevisie, curatie en -generatie tot de ontwikkeling en toepassing van verschillende instrumenten en methoden voor de vertaling van theorie naar ontwerp, en andersom. De meta-ethnografie review leidde bijvoorbeeld tot de ontwikkeling van een data extractie formulier gebaseerd op de *CONSORT-EHEALTH checklist*. Met dit formulier konden de belangrijkste componenten van eHealth interventies worden geïdentificeerd en hun impliciete en expliciete ontwerpkeuzes worden herzien. Aan de andere kant werden in de onderzoeken herhaaldelijk ontwerprepresentatiehulpmiddelen zoals *vignetten* en *mock-ups* gebruikt om op theorie gebaseerde aannames en proposities voor eHealth zelfzorgondersteuning weer te geven. Deze ontwerphulpmiddelen konden worden gebruikt om de op theorie gebaseerde ontwerphypothesen te evalueren (zoals in het online onderzoeksexperiment) en om nieuwe voorstellen voor het ontwerp en de ontwikkeling van eHealth uit te drukken (zoals via de prototypische ontwerpkenmerken).

Concluderend het doel om theorieën, modellen of kaders te identificeren die zijn gebruikt voor het ontwikkelen van interventies op het kruispunt van eHealth, zelfzorg en CVD is bereikt. Door veelbelovende theorieën over te nemen en te herzien, slaagde het onderzoek erin relevante constructen binnen de onderzoekscontext met elkaar te verbinden. Dat wil zeggen, het onderzoek identificeerde veelbelovende eHealth ontwerpstrategieën die theorie gebaseerd waren en pasten bij zelfzorg als doel voor gedragsverandering. De eHealth ontwerpstrategieën waren voornamelijk gebaseerd en geïnspireerd op bestaande interventies, maar werden ook beïnvloed door technologiegerichte kaders voor persuasief en waardegevoelig ontwerp. Hoewel het werk in dit proefschrift grotendeels conceptueel en theoretisch is, onderschrijven en illustreren de bevindingen de visie dat toekomstig eHealth onderzoek en ontwikkeling moet beginnen met theorie en daar voortdurend aan gekoppeld moet worden. Op zijn minst moet de theorie duidelijk worden erkend en gedetailleerd wanneer deze wordt gebruikt, maar idealiter moet de theorie volledig en uitgebreid worden toegepast als onderdeel van holistische eHealth ontwikkeling, evaluatie en implementatie.





# Publications and other output

## Main output

- Cruz-Martínez, R. R., Noort, P. D., Asbjørnsen, R. A., van Niekerk, J. M., Wentzel, J., Sanderman, R., & van Gemert-Pijnen, L. (2019). Frameworks, Models, and Theories Used in Electronic Health Research and Development to Support Self-Management of Cardiovascular Diseases Through Remote Monitoring Technologies: Protocol for a Meta-ethnography Review. *JMIR Res Protoc*, 8(7), e13334. doi:10.2196/13334.
- Cruz-Martínez, R. R., Wentzel, J., Asbjørnsen, R. A., Noort, P. D., van Niekerk, J. M., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (2020). Supporting Self-Management of Cardiovascular Diseases Through Remote Monitoring Technologies: Meta-ethnography Review of Frameworks, Models, and Theories Used in Research and Development. *J Med Internet Res*, 22(5), e16157. doi:10.2196/16157.
- Cruz-Martínez, R. R., Wentzel, J., Sanderman, R., & van Gemert-Pijnen, J. E. W. C. (2021). Tailoring eHealth design to support the self-care needs of patients with cardiovascular diseases: a vignette survey experiment. *Behaviour & Information Technology*, 1-22. doi: 10.1080/0144929X.2021.1971764.
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- Cruz Martinez, R., Sieverink, F., Wesselink, R., & van Gemert-Pijnen, L. (2018). Towards Data-Driven Persuasive Coaching in a Heart Failure Telemonitoring Technology. In F. Sieverink, R. Klaassen, R. van Delden, J. Wenzel, L. van Gemert-Pijnen, D. Heylen, & H. Oinas-Kukkonen (Eds.), *Proceedings of the Sixth International Workshop on Behavior Change Support Systems: Co-located with the 13th International Conference on Persuasive Technology (PERSUASIVE 2018)* (pp. 60-75). (CEUR Workshop Proceedings; Vol. 2102). CEUR. <http://ceur-ws.org/Vol-2102/>
- Cruz-Martínez, R. R., Wentzel, J., Sanderman, R., & Gemert-Pijnen, J. E. W. C. (2020). *Work In Progress: Matching Persuasive Design with Self-Management Needs of Patients with Cardiovascular Diseases - Preliminary Results of A Survey Vignette Experiment*. Poster presented the 15th International Conference on Persuasive Technology, PERSUASIVE 2020. [http://ceur-ws.org/Vol-2629/3\\_poster\\_cruz.pdf](http://ceur-ws.org/Vol-2629/3_poster_cruz.pdf)
- Cruz-Martínez, R. R., Wentzel, J., Sanderman, R., & Gemert-Pijnen, J. E. W. C. (2020). *Towards development guidelines for eHealth interventions that support self-management of cardiovascular diseases: A holistic, theory-based, and cross-cultural approach*. Doctoral consortium at the 15th International Conference on Persuasive Technology, PERSUASIVE 2020.

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Pieterse, M., Kip, H., & Cruz-Martínez, R. R. (2018). The complexity of eHealth implementation: A theoretical and practical perspective. In *eHealth Research, Theory and Development* (pp. 247-270). Routledge.

## Unpublished research work

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Nesvarova, M. (2022). *'I enjoy activism very much. Maybe too much'*. Interview article by U-Today. <https://www.utoday.nl/PhD-stories/72326/i-enjoy-activism-very-much-maybe-too-much>

# About the author



**Photo:** Frans Nikkels (Nikkels Fotografie)

Roberto was born on April 20<sup>th</sup> 1990 in Monterrey, Nuevo León, México. **In 2012**, he obtained his bachelor degree in psychology, with a specialisation in social psychology, at the Autonomous University of Nuevo León. Roberto followed his studies by pursuing a master degree in sports psychology at the same university. In that period, he participated in an international student exchange program, spending six months at the University of Málaga in Spain. In Málaga he followed various courses that were part of the master of physical activity and sports research. **In 2014**, after returning to

México and having obtained his master degree with an honorific mention, Roberto worked for two years as a sport psychologist for the State Institute of Physical Culture and Sports of Nuevo León. In the first semester of 2016, Roberto also performed as a guest lecturer in his alma mater and in the Autonomous University of Yucatán.

**In August 2016**, Roberto achieved one of his personal goals: to depart from México in order to dedicate himself to the study of self-regulation and eHealth. Roberto arrived in the Netherlands and the University of Twente, taking part and graduating cum laude from the master of science in psychology, with a specialisation in health psychology & technology. During these studies, he performed as a student assistant at the Department of Psychology, Health & Technology, supporting the editing and publication of the book *'eHealth Research, Theory and Development: A Multi-Disciplinary Approach'* (2018).

**In November 2017**, Roberto began his PhD project funded by the Mexican National Council for Humanities, Science, and Technology (CONAHCYT, in Spanish). Early in his days as a PhD candidate, he joined the board of the PhD Network of the University of Twente (P-NUT). Roberto served as a board member of P-NUT for three years, including acting as the elected president in 2019. **In January 2022**, having exhausted his PhD scholarship and a three-months' extension, Roberto began to work for the University of Twente as an information specialist embedded in the faculty of Behavioural, Management, and Social sciences (BMS), and as a member of the central support team for open-access publishing. Continuing with his activism, he was elected as a member of the University Council (URaad) in September 2022, for a period of two years.

Roberto describes himself not as a scientist, but an academic, and—more quietly—as an aspiring writer. He is determined to dedicate his professional life to the understanding of human behaviour and, more specifically, to the study of individual performance. Roberto is deeply interested in how we as individuals proceed on setting, pursuing, and achieving our personal goals. To fulfil his mission, Roberto is focused on learning as much as he can about the key elements and dynamics of self-regulation. At the same time, he wishes to make the understanding of self-regulatory practices more accessible and actionable for the general public. Roberto likes to do this by presenting and writing about how we, as individuals and as society, can recognise our natural potential and maximise our performance. One day, if he is able to attune his own self-regulatory skills, Roberto dreams of writing a book about his learnings of human performance. In the end, he wants his work to inspire and prepare younger academics so that they can continue to advance our knowledge of human performance, and the art of self-regulation, for the generations to come.

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One day in the summer of 2017, I remember to be sitting in the lobby of the Cubicus building, ruminating about my soon-to-begin PhD project in my soon-to-be workplace. As it was usual for me at the time, I was daydreaming about the end goal. More precisely, I was imagining what my acknowledgement speech would be when I obtained my PhD degree. I did not really care to plan the research yet. Neither did I really think about any of the challenges to come. My mind was skipping to the very end: my acknowledgement speech. Throughout the years, I often came back to think of that moment, developing and replaying bits and pieces. Despite the constant daydreaming, I never wrote down a single word of that speech anywhere, until now. Because I don't actually know if I get to deliver a speech at all, I chose to finally write it down in the following paragraph. You should picture me standing in front of a small crowd filled with colleagues, friends, and family. I raise my right arm and point with my index finger at the crowd, as I begin:

*'You, are not normal. This, is not normal. It is not normal for someone to be able to choose their purpose in life, and find it so easy to advance towards it. It is not normal for someone to go abroad, far from their birthplace, and feel so welcomed and at home. It is not normal for someone to find so many inspiring and curious characters gathered in one, single community. It is not normal to feel extremely safe and comfortable every day in your surrounding environment. It is not normal to find a working atmosphere where work-life balance is highly appreciated. It is not normal to cycle to work in a priority lane and, practically in a straight, completely flat line. It is—obviously—not normal to take two extra years to finish your PhD dissertation, and find more support and understanding than pressure and harsh-judgement. I could go on with examples, but I hope my point comes across. My point is: you, are not normal; and this, what has happened to me, is not normal either. You might think or find some of these things to be normal, but you are wrong. We are privileged. I am privileged. I am privileged of being here, of having experienced what I did. And I am very honest when I say that, I consider myself privileged because I had the opportunity to meet and share many great moments with you all. Even those here who don't suspect it, trust me, I have watched, learned from, and imitated you. Thank you for being here, and I look forward to more abnormal experiences with you.'*

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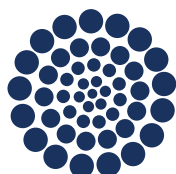


Self-care can be defined as the process whereby individuals and their families maintain health through health-promoting practices and managing illness. Self-care entails many different behaviours, such as exercising, body listening or symptom monitoring, and decision-making processes such as choosing to call a doctor.

In 2005, the influential psychologist Albert Bandura characterised self-care as ‘good medicine’. He went even further, and stated that ‘if the huge benefits of these few habits were put into a pill, it would be declared a scientific milestone in the field of medicine.’

Certainly, reaching such a milestone would lead to a much needed reduction of the alarming burden on health care systems world-wide. This alarm is caused by the increasing amount of chronically ill individuals, many of them with a cardiovascular disease.

The use of digital technologies to support health, well-being, and health care holds high promise. Such an approach is better known by the term of electronic health or eHealth. eHealth promises to facilitate tasks, provide personalised information, feedback, and cues to action. Could eHealth become a self-care ‘pill’ to effectively support those who need it the most?



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