# HeartMan: (Self-)Managing Chronic Heart Failure

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**Abstract.** In this position paper, we report on preliminary results from the human-centered design process in the HeartMan project. The goal of the HeartMan project is to develop and test self-management technology for patients suffering from chronic heart failure (CHF). The human-centered design process within the project aimed to develop and test a mobile app for CHF patients, focusing on therapy adherence concerning medication intake, physical activity, nutrition, and mental support. Initial user testing revealed different attitudes and habits that affected the perception of the "self-management" approach of the technology. Specifically, test users showed a variety of behaviours in which they (unconsciously) tended to delegate responsibility to either formal carers (the cardiologist) or informal carers. In this paper, we describe how the patients' existing attitudes and behaviours impact their initial perception of the technology during user tests. In a later phase, the clinical trial will show how the HeartMan technology impacts these attitudes and habits in the longer term.

**Keywords:** Healthcare, Self-Management, Chronic Heart Failure, Human-Centered Design.



## 1 Introduction

While evolutions in healthcare raise life expectancy, increasing age also results in a rising prevalence of chronic diseases. In order to prevent or manage chronic diseases, a healthy lifestyle is required. This is also the case for chronic heart failure (CHF) patients: they need to adhere to a complex therapeutic regimen. For example, patients have to take several types of medication at specific times, are advised to engage in appropriate physical activity, and need to take into account specific dietary advice. Not adhering to medication intake or dietary advice might endanger the patient.

Technology can be used to provide people with data about their own behaviour. Personalized feedback can make people more aware of their behaviour, allowing them to improve or maintain a healthy lifestyle. As such, self-management is an attractive approach for patient empowerment [4], allowing patients to take control of their disease, and allowing hospitals to save resources as patients become less dependent on caregivers [5]. In this paper, we describe test users' initial response to the HeartMan self-management technology, and how existing attitudes and behaviour influence these patients' perception of the system.



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## 2 HeartMan

The core of the HeartMan system is a mobile application connected to a wristband measuring the patients' vital functions, including heart rate monitoring and variability, activity monitoring, galvanic skin response and skin temperature. The information gathered about the patients' health and activity is processed by mathematical models that can predict under which conditions the patient's health or wellbeing is likely to get worse. When such conditions are detected by the sensors, the application will search for actions the patient can take in order to prevent such worsening.

In addition to the measurements and the predictive technology, cognitive behavioural therapy is used to help patients change life-long habits, such as changing dietary habits, or (a lack of) physical activity. The HeartMan system offers a series of mental exercises and simple practical exercises that can change the patient's mindset.

The combination of tracking health data, predictive modelling of the patients' health, and cognitive behavioural therapy makes the HeartMan system a technology that allows for self-monitoring of various therapeutic aspects.

## 3 Human-Centered Design and Self-Management

### 3.1 General

Self-management technology has been discussed widely, both in medical and in Human-Computer Interaction (HCI) literature. During the development of self-management technologies several barriers and opportunities for the sustainable use of technologies have already been identified. Examples include the work on diabetes self-management by Maniam et al. [3], discussing factors for technology acceptance including financial and privacy aspects, and the work of Doyle et al. [1], emphasizing the importance of education and goal-setting. Grönvall and Verdezoto [2] have emphasized the role of the care network in the use and uptake of self-monitoring technology. In this position paper, we take a similar perspective: we discuss the perception of self-monitoring, related to the role of other stakeholders in the care network (especially professional carers and the primary informal caregiver).

### 3.2 Human-Centered Design in HeartMan

As self-management in healthcare puts the responsibility of adherence with patients, it is highly important to design self-management technology that is accepted by the patients and that has the desired effects. To ensure high acceptance and effectiveness, we implemented an extensive human-centered design process in which we designed and evaluated the HeartMan technology. After this process, the resulting technology will be tested by patients in a clinical trial (in the latter half of 2018). Before discussing preliminary results from the design process, we first discuss the human-centered design and evaluation process that has been implemented.



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**Diary Studies and Interviews.** In order to investigate the users' everyday lives, including their specific needs, two studies were carried out in Belgium and in Italy. The first study was a diary study, in which CHF patients kept a diary containing 10 assignments for a period of 10 to 14 days. The second study was an interview study. In this study, CHF patients participated in semi-structured interviews that were conducted at their homes.

The purpose of the diary study was twofold. First, the study allowed participants to gather data in their own environment and at their own pace, without being affected by the presence of a researcher. The diary study did not focus on specific single tasks but rather on a range of everyday activities and habits. General themes included specific patient characteristics, the patients' experience, disease management, and their social network. These diaries allowed for a structured data collection within the participants' own context. Second, the study sensitized participants with regard to the topics that were discussed in the subsequent interviews. As interviews often focus on topics that people do not think about very often (such as the emotional experience of their disease), it can be hard for interview participants to express themselves. As such, the assignments in the diary were intended to make participants think about these topics before the interview, to make them aware of their own experiences, as this would help them to talk about their world of experience during the interviews.

The interview study dealt with the same topics as the diaries did and aimed to understand participants' world of experience, problems and needs into more depth. As the interviews were carried out in two countries and by 4 researchers, an interview protocol was used in which the diary assignments served as a guide for the interview.

**Iterative Design.** Based on the diary studies and interviews, initial designs of the HeartMan application were made. The designs incorporated specific functionalities resulting from the user studies described above. For instance, the designs take into account specific needs concerning lifestyle advice (coping with CHF in various ways) and disease management (providing educational material and administrative support, e.g. for doctor's appointments). These designs were iteratively tested and refined. In three iterations, user testing was performed on increasingly realistic and interactive mock-ups and prototypes.

The first iteration focused on information structure and individual screen designs mock-ups of the patients' smartphone app. This mock-up was combined with scenarios of use illustrating how a fictitious patient could use the different functionalities of the app. The paper prototype mock-ups were evaluated with 9 patients in Belgium and 11 patients in Italy, as well as with 10 caregivers in Belgium and 5 caregivers in Italy.

The second iteration was based on a redesign of the feedback received during the first round of evaluations. The prototype was redesigned, and tested as a fully interactive mock-up of the patient app. In this round, the interactive mock-up was tested by 11 patients in Belgium, and 10 in Italy.

A final testing iteration was performed with the functional Android app (see Figure 1), using fictional scenarios instead of live tracking of the patients' health data. This evaluation was performed with 9 patients in Belgium and 9 in Italy.



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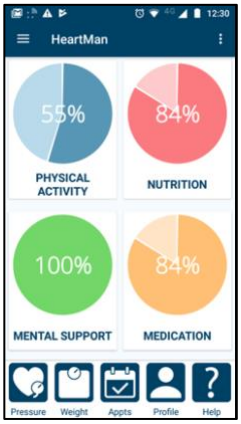


**Fig. 1.** Screenshot of the final app design (home page). The screen shows the four areas HeartMan concentrates on: physical activity, nutrition, mental support, and medication.

## 4 Preliminary Results: Perception of Self-Management

In this section, we present preliminary results from the human-centered design process leading up to the clinical trial of the HeartMan system. We will focus on the patients' perception of the HeartMan system, and the benefits it can bring for them. We point out how for some patients, the perceived benefits were different from the intended system benefits, and how the dynamics between patient and primary carer played a role in using the HeartMan system.

### 4.1 Self-Management and the Primary Carer

In the HeartMan system, the smartphone is the primary device patients use to monitor their health, their medication adherence, and other parameters. As such, the HeartMan system was clearly conceived as a self-management system: the patient can interact with the system to enter health data (blood pressure, weight), and receives questionnaires and reminders concerning nutrition and medication. Next to the patient app, the HeartMan system also provides a carer's app, which provides similar information for informal carers, but does not provide the patient-specific interactivity (e.g. entering blood pressure values, completing questionnaires).

However, during user research, it has become increasingly apparent that in some cases, it is the patient's primary carer (often the partner) who takes charge of managing the disease. Often, partners are responsible for administrative tasks, (making appointments, collecting prescriptions), preparing medication, and taking into account dietary advice. Many participants acknowledged the central role of their partner in managing their heart condition in the interviews:

> Interview participant 6: "*I think, as a patient, if you get lots of support from your partner, everything is much easier to cope with.*"



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Interviewer: "*And it sounds like you have that support, right?*"
P6: "*I won the lottery there.*"
P6's partner: "*He doesn't care much. Medication too, if I don't set that out for him, and if I don't check if he took his medication, they'll be there in the morning you know.*"

These observations confirm prior work stating that sometimes, control is delegated to someone close to the monitored person [2]. However, our observations show that this relation has profound effects on the use of the technology itself. Even during short user testing sessions, several partners accompanying the patients took a very active role in the user test, commenting on the scenarios, and even taking the place of the patient, assuming the role of the primary user. In these cases, the patients' role was often reduced to confirming what the partner said, and making some suggestions.

While the purpose of user testing was, of course, to test the app with CHF patients, the observations described above point towards an interesting dynamic. The HeartMan app was designed to be a *self*-monitoring app for CHF patients. However, existing dynamics between patients and their partners/informal carers suggest that it can be expected that in some cases, the HeartMan app will be used most by the primary carers, instead of the patients. As such, these observations show that in some cases, the technology confirms existing behaviour and social dynamics, rather than changing the patients' behaviour. The clinical trial will provide more details about to what extent the technology will become part of existing power relations between partners, or play a role in *empowering* patients themselves.

### 4.2 Self-Management and Remote Monitoring

User test round 3, participant 7: "*The most interesting aspect is that data is transferred to the hospital, and them monitoring my data remotely.*"

While the primary goal of the HeartMan system is self-management of CHF, relevant data (heart rate, blood pressure) is also sent to the hospital. These detailed data provide clinicians with more detailed information about their patients, which can contribute to fine-tuning the patients' treatment during regular follow-up visits. While self-management was clearly stressed during user tests as the primary goal of the system, mentioning data sharing with hospitals had an important effect. For some patients, the perceived benefit of the HeartMan app was primarily the data sharing with the hospital. As such, the self-management app was perceived as a remote monitoring app. For these patients, the main goal was reassurance: data sharing with the hospital meant that they would be tracked closely.

This perception has two main implications. First, for the setup of the clinical trial: it became apparent that when contacting patients for the clinical trial, it is important to clarify the distinction between a self-management app, and a monitoring or emergency app. Especially the latter includes the expectation that the patient is monitored 24/7, and that in case of an emergency, caregivers will be notified automatically. The HeartMan system, as a self-monitoring system, does not include such functionality. Second, the emphasis on remote monitoring shows how empowerment is not



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necessarily high on the patients' own agenda. Instead of perceiving the HeartMan system as a technology for patients to take control of their own disease, the main perceived benefit of the system is often related to remote monitoring, rather than self-management. While the system intends to empower patients, the patients' existing attitudes and perception of the system emphasize their dependence on the doctor's expertise. Rather than empowering patients as actors in their own care, this confirms patients in their existing attitude, in a more passive role, subject to the professional caregivers' treatment.

## 5 Conclusion

While the HeartMan system is intended as a self-management technology, the human-centered design process has made clear that even during short user tests, the technology is quickly inscribed into the patients' personal situation and habits. In some cases, this link with existing relations between patient, informal carers, and healthcare professionals creates a situation in which the technology is appropriated as a tool that reinforces existing power relations, rather than activating and empowering patients. As such, the preliminary results from the HeartMan human-centered design process have highlighted the tension between the designers' intentions (self-monitoring and empowerment) and existing behaviours and attitudes (delegating control and responsibility) as important challenges for the design and adoption of self-management technology.

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