Personal Decision Support System
For Heart Failure Management

D2.2. User Requirements

Co-funded by the Horizon 2020
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## D2.2. User requirements

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Executive Summary

Deliverable D2.2 describes the results of the Belgian and Italian data collected within task T2.2.1. The goal of this task was to identify the problems, needs, wishes etc. of CHF patients, and to understand how their characteristics, their environment and their activities should be taken into account in the design of the HeartMan system.

In the first version of deliverable 2.2, the method of the research in Task 2.2.1. was described. In the second version the results of the Belgian user research were added, which contain rich and qualitative descriptions of the users as well as their context and activities. Also, an overview of user requirements regarding HeartMan was created. For the third and final version, the results of the Italian user research were added.
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1 Introduction

This deliverable describes the first research activities of the human-centred design approach in the HeartMan project. It is part of Task 2.2, which aims to involve end-users in the design process. Congestive heart failure (CHF) patients will be actively involved in gathering user requirements and the design process, taking part in both design and evaluation exercises.

More specifically, the work described in this report is part of Task 2.2.1, in which the users and the context of use were analysed. This task aimed to identify the problems, needs, wishes etc. of CHF patients, and to understand how their personal characteristics, their environment and their activities should be taken into account in the design of the HeartMan system.

In deliverable D2.2, we first describe the method of the research in Task 2.2.1. Afterwards, we present the results of the Belgian user research, which contain rich and qualitative descriptions of the users as well as their context and activities. Also, an overview of user requirements regarding HeartMan is included. Finally, we do a cross-check with the Italian user research to look for differences and similarities with the user requirements based on the Belgian data.
2 Methods

For the purpose of Task 2.2.1 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.

2.1 Materials

As both the diary study and the interview study were carried out in Belgium and in Italy, the research material was created by KUL in English and subsequently translated to Dutch (by KUL) and Italian (by UOR). This section will present the English material.

2.1.1 Diary study

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 purpose of Task 2.2.1 was to thoroughly understand the everyday lives of CHF patients, and as such it did not focus on specific single tasks but rather on a range of everyday activities. Therefore, doing observations, another typical method for early-stage human-centred design research, is not straightforward. Diaries with assignments covering many aspects of dealing with CHF on a daily basis 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 in human-centred design 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 diary assignments

The diary consisted of ten assignments. Each assignment will be briefly discussed below, including the goal. An overview of all assignments, their goals and the topics they address is given in Table 1. See Appendix A – Diary for the full version of the diary.
<table>
<thead>
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<th>Topic</th>
<th>Research goal</th>
<th>Title</th>
<th>Assignment</th>
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<tr>
<td>1 Patient characteristics</td>
<td>Map non-disease related personal characteristics in order to interpret the data</td>
<td>This is me</td>
<td>Answer several personal questions, similar to a friendship book.</td>
</tr>
<tr>
<td>2 Disease management</td>
<td>Map what patients need to do to manage their disease on a daily basis (monitor weight, take medication, exercises, ...)</td>
<td>A day in my life</td>
<td>Describe what an average day looks like.</td>
</tr>
<tr>
<td>3 Patient characteristics</td>
<td>Map use of digital technology</td>
<td>My digital technologies &amp; media</td>
<td>Indicate which digital technologies and media one uses, including frequency of use, ease of use, and purpose of use.</td>
</tr>
<tr>
<td>4 Patient experience</td>
<td>Understand what it means for patients to suffer from CHF</td>
<td>Letter</td>
<td>Write a letter of advice to a fellow-sufferer.</td>
</tr>
<tr>
<td>5 Patient experience</td>
<td>Understand what it means for patients to suffer from CHF</td>
<td>Associations</td>
<td>Write down as many words as possible that one associates with CHF.</td>
</tr>
<tr>
<td>6 Patient experience</td>
<td>Understand course of the disease over time in relation to patients’ personal life</td>
<td>Timeline</td>
<td>Mark medical events and personal life events on a timeline.</td>
</tr>
<tr>
<td>7 Patient experience</td>
<td>Understand impact of CHF on patients’ lives.</td>
<td>My tree</td>
<td>Mind map exercise to indicate which aspects of everyday life are affected by CHF.</td>
</tr>
<tr>
<td>8 Social network</td>
<td>Map patients’ social networks (including caregivers)</td>
<td>My social network</td>
<td>Indicate how close important family members, friends and caregivers are.</td>
</tr>
<tr>
<td>9 HeartMan expectations</td>
<td>Explore patients’ attitude towards mindfulness</td>
<td>Awareness exercise</td>
<td>Mindfulness exercise.</td>
</tr>
<tr>
<td>10 HeartMan expectations</td>
<td>Understand possible cognitive dissonances patients have</td>
<td>Costs &amp; benefits</td>
<td>List costs and benefits of following and not following the doctors’ advice.</td>
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Table 1 Overview of diary assignments

**Assignment 1: This is me**

**Goal:** Icebreaker; To gather contextual information about the participants to interpret their answers to other assignments;

Assignment 1 consisted of several boxes with short questions about participant’s personal characteristics that were not related to their heart condition. Resembling a spread in a friendship book, this assignment included the following questions:

- This is what I look like: ... (You can make a drawing, use a photograph, or describe yourself.)
- 'Home' for me means: ...
• My 'guilty pleasures': ... (Something you enjoy secretly, when nobody is watching you.)
• Things I like to do in my spare time: ...
• This is what I would bring to a deserted island: ...
• Three things that make me happy: ...
• and three things that I hate: ...
• My life motto: ... (Pick a motto that matches where you stand in life at home: what do you find important to feel good?)
• I also want to share this with the researchers: ... (Do you think we've forgotten to ask something important? Please tell us here.)

Assignment 2: A day in my life

Goal: To map what participants need to do to manage their heart condition on a daily basis.

Assignment 2 asked the participant to describe an average day in their life into as much detail as possible, paying special attention to anything that is related to their heart condition. As an example of the level of detail that was expected, a fictitious description of a day in the life of a school teacher was provided.

Assignment 3: My digital technologies & media

Goal: To understand participants’ technological literacy

As the HeartMan project focuses on technology to support disease management for CHF patients, it is important to understand these patients’ use of technology. Therefore, assignment 3 provides a list of several everyday digital technologies and media: analogue television, digital television, audio installation, computer/laptop, tablet/iPad, mobile phone, smartphone, portable music player, internet, digital games, smart watch, activity tracker. The participant indicated which of these technologies and media they use, how often they use it, how easy or difficult they find it to use, and for what purpose they use it.

Assignment 4: Letter

Goal: To understand the general patient experience of the participants.

In assignment 4 a fellow-sufferer was introduced to the participants. This was a person who was recently diagnosed with CHF and whose disease status is exactly the same as the participants’ when they were diagnosed. The participant was asked to write a letter of advice to this person, helping him deal with his condition and to be prepared of what’s lying ahead, starting from their own experiences.
Assignment 5: Associations

**Goal:** To understand the patient experience of a CHF patient in general.

For assignment 5, the participant was asked to list as many words that they associated with their heart condition. These could be positive or negative words, and the words could be directly related to their condition (such as physical aspects or emotional aspects), but also with other aspects related to activities of daily living or social life.

Assignment 6: Timeline

**Goal:** To understand participants’ health status and map the course of their heart condition over time.

Assignment 6 consisted of a timeline on a larger sheet of paper (A3), ranging from the participant’s diagnosis until today. The participant was asked to position blue and yellow stickers on the timeline, representing events related to their heart condition and important personal life events respectively. For each event, the participant wrote down what happened, and what the impact on their life was.

Assignment 7: My tree

**Goal:** To understand the impact of CHF on several aspects of the participants’ everyday life.

Similar to a mind map, assignment 7 asked the participant to draw a tree of which the branches represent different aspects of their life that may be affected by their heart condition. Based on an example representing the impact of having a broken leg, the participant could create main branches and smaller side branches.

Assignment 8: My social network

**Goal:** To map participants’ social networks.

Assignment 8 included a larger sheet of paper (A3) with concentric circles on it. The participant was asked to imagine that they represent the centre of the circle and was asked to indicate how close important family members, friends and caregivers are to them. Coloured stickers represented each of these categories of people, and participants wrote down the name of each person next to the stickers as well as their relationship to these persons.

Assignment 9: Awareness exercise

**Goal:** Explore participants’ experience with and attitude towards a mindfulness exercise.
Assignment 9 was an introduction to mindfulness, as the HeartMan system will include mindfulness exercises. The participant was asked to perform a classical mindfulness exercise and to write down their experiences with that exercise afterwards.

The exercise consisted of three steps: awareness, gathering and expansion. In the first step, the participant had to focus on their inner experience and notice their thoughts, feelings and bodily sensations. In the gathering step, the participant was asked to focus on their breathing, trying to let any thought, feeling and sensation pass by. In the final step, the participant expanded their focus to their entire body.

Assignment 10: Costs & benefits

Goal: To understand possible cognitive dissonances participants have with respect to therapy adherence.

The tenth and final exercise requested participants to think about how they deal with advice they receive from their doctors. They had to write down costs and benefits of both following and not following such advices. These costs and benefits may be representative of cognitive dissonances participants may hold regarding non-adherence.

2.1.2 Interview study

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 (see Appendix B – Interview protocol) in which the diary assignments served as a guide for the interview. Following a semi-structured interview approach, the interviewers asked additional questions as well as further explanations of the diary answers.

2.2 Procedure

2.2.1 Ethical approval

In Belgium, ethical approval was first obtained from KUL’s Sociaal Maatschappelijke Ethische Commissie (Social Societal Ethical Committee) or SMEC for both the diary study and interview study. The approval of the SMEC formed the basis to obtain approval from the ethical committees of the hospitals who recruited participants (AZ Maria Middelares Gent, UZ Gent and OLV Aalst).

In Italy, the San Camillo Hospital of Rieti, Azienda Ospedaliera Provinciale is involved for patient recruitment. The study protocol was submitted to the Ethical Committee of the San Camillo Forlanini Hospital in Rome for ethical approval. On June 20, informal approval of this committee was received and
as soon as the approval is formally confirmed, recruitment was started for the diary and interview study in Italy.

### 2.2.2 Recruitment

After screening eligibility from the medical records, participants were recruited by hospital employees in Belgium and Italy when CHF patients came by for a check-up or regular consultation. These patients were explained the purpose (based on the HeartMan brochure that was created in WP7, see D7.2) and nature of the study and were asked for permission to provide their contact details to the HeartMan researchers carrying out the study.

These HeartMan researchers contacted the patients who agreed to provide their contact details by phone, again explaining the purpose of the study, as well as its nature and procedure. Patients were subsequently asked if they would like to participate in the study.

Participants were assigned to either the diary only condition (n=5 in Belgium, n=3 in Italy), or to the diary & interview condition (n=14 in Belgium, n=15 in Italy). Originally, participants were to be randomly assigned to these conditions, but due to time constraints it was decided to finish the interviews as soon as possible by assigning the first fifteen patients who agreed to participate to the diary & interview condition.

### 2.2.3 Diary & interview procedures

With the participants in the diary & interview condition, the researchers immediately planned a date for an interview during the first phone contact. The interview was scheduled at least ten days after the participants would receive the diary by mail, as to provide ample time to make the assignments.

Participants in both conditions subsequently received the diary and an informed consent (two copies) form by mail. Participants in the diary only condition were asked to return the diary and one signed copy of the informed consent form in a stamped return envelope. Participants in the diary & interview condition would return the diary to the researchers during the interview.

The interviews took place at the participants’ homes. First, the researcher again explained the purpose of the HeartMan project and of the interview study. Then they walked the participant through the informed consent form of the interview study and asked if the participant had any further questions, after which both the researcher and the participant signed two copies of the informed consent form. Before starting the actual interview, the researcher asked whether the participant gave permission to make audio recordings of the interview. After starting the recording, the researcher followed the interview protocol (see Appendix B – Interview protocol).

During several of the interviews, the participants’ partners would be present too. Although the interviewers addressed the participants specifically,
several of the partners jumped in from time to time, and several participants actively involved their partners themselves.

### 2.2.4 Timing

The original timing of Task 2.2.1 aimed for data collection in April and May 2016 and analysis and reporting in June 2016. Unfortunately, several unforeseen events delayed the work in this task.

In Belgium, the ethical approval of the SMEC took longer than expected and was obtained on March 3\textsuperscript{rd} 2016. Unexpectedly, the Belgian hospitals who would recruit participants didn’t directly accept the ethical approval of the SMEC and requested additional approval from their own ethical boards, which was obtained throughout the month of May.

At the moment of writing this first version of D2.2, participant recruitment in Belgium was still ongoing. Twelve participants had finished both the diary study and the interview study, and eight participants were enrolled in the diary study. Another ten participants were still being recruited and included, for which especially women were sought for as the participant sample consisted of men only so far.

In Italy, UOR needed to recruit a researcher to carry out the research for Task 2.2. For this, an amendment had to be submitted to the EC, which was approved on May 18\textsuperscript{th}. As a result, an ethical approval could not be filed for before the end of May. Informal confirmation of ethical approval was obtained on June 21\textsuperscript{st}. As soon as this approval was conformed formally, recruitment immediately started here as well.

The result of this delay is that the first version of D2.2 did not contain any results yet, and the second version only presented the results of the Belgian study. In agreement with the consortium partners, it was therefore decided to slightly alter the procedure. Instead of presenting a complete analysis of the Italian data, we compared the requirements based on the Belgian data with the Italian data, and added this cross-check at the end of this deliverable.

### 2.3 Participants

#### 2.3.1 Criteria

The HeartMan Consortium agreed on a short list of criteria for participants:

- Ischemic heart failure patients
- NYHA classes II and III
- Reduced function (LVEF ≤ 40%)
- Stable outpatients: patients who had at least one hospitalization due to their HF once, who had no ischemic hospitalization in the last month and who have no planned surgical interventions (including heart transplantation)
- Renal insufficiency is not excluded, but patients on haemodialysis are excluded
• Atrial fibrillation is not excluded
• Patients already in home monitoring (defibrillator) or in any other particular disease management program are excluded
• Good cognitive functioning (based on patients’ files and clinicians’ knowledge of the patients)
• Sufficient knowledge of the Dutch/Italian language
• No formal age criterion
• No formal gender criterion, but strive for at least 1/3 women

2.3.2 Participant samples

In the Belgian study, twenty participants were included. Fourteen of them participated in both the diary study and the interview study, six of them only participated in the diary study. Only one of the twenty participants enrolled was female. Their ages ranged from 49 to 79 (mean = 65.7, SD = 8.2). In the Italian study, nineteen participants were recruited. Sixteen of them participated in both the diary and the interview study, three of them only participated in the diary study. In Italy, seven out of the nineteen participants enrolled was female. The ages of the participants ranged from 53 to 82 (mean = 74, SD = 8.05). All participants met the inclusion criteria as specified in section 2.3.1.

2.4 Analysis

Audio recordings of the interviews were transcribed and the participants’ diary entries were digitized (in text). To code these data, an initial codebook was created, based on the interview protocol (see Appendix B). One researcher used this initial codebook to do a preliminary coding of one interview, simultaneously adding missing codes to the codebook. A second researcher used this updated codebook to code another interview, again adding missing codes to the codebook. After that, all three (Belgian) researchers involved discussed and finalized the code book together to code all data (recoding the first two interview transcripts that were preliminary coded). During the final coding, the three researchers kept notes of codes that they felt should be changed (and of the data they assigned these codes to), and after coding all data, they again discussed the codebook and recoded the data for those codes they agreed to change in retrospect. This final codebook can be found in Appendix C.
3 Results: Rich and qualitative description of HeartMan Context of Use

As was explained above we first report the results of the Belgian study and, afterwards, present a cross-check with the Italian data. The results are structured according to the codebook (see Appendix C) that was described in section 2.2.3. For each main code, the main findings are described according to the sub codes (and sometimes sub-sub codes). The discussion of each main code is concluded with the user requirements that were derived from the insights, except for the main code ‘Patient experience’, for which the user requirements are organised per sub code.

To illustrate the findings, quotes from the interview transcripts are added in italics. The codes P[number] indicate the individual participants.

3.1 Patient Characteristics

3.1.1 Medical patient characteristics

Heart condition

The majority of the interview participants reported to have had one or more heart attacks. Often, a heart attack was the first indication of participants' heart failure condition. Also, almost all participants had some kind of surgical procedure due to their heart condition. These included open heart surgeries as well as routine heart procedures such as catheterizations, placements of stents, pacemakers and defibrillators, and bypass operations. Several participants reported to have had several of these procedures.

"I had a major heart attack in 2000. Five years later during a check-up, the cardiologist told me I had to stay in the hospital to get a bypass. So I had two bypasses. Two years later I had another small heart attack.” (P15)

"First your bypasses, then your extensions. We were already together back then. Then you had a heart attack when you were still working and then you got an open heart surgery and bypasses. Then, a few years later, you had another heart attack and they placed stents. Then a little while later you had yet another heart attack and then they gave you that defibrillator. Then you had a shock, that was when your heart stopped running for a moment because I had to call the ambulance then.” (P14)

Co-morbidity

In addition to their heart condition, the majority of the interview participants reported having additional health problems such as kidney deficiency, diabetes, lung diseases, and severe back pain. Others mentioned having undergone chemo therapy which led to a series of other inconveniences (e.g. digestive problems, lack of concentration). As a result of these co-morbidities, some patients mentioned having difficulties distinguishing which symptoms are caused by which disease.

"I’m also in a care trajectory for my kidneys. I take medication for that too because my kidney deficiency isn’t particularly severe. Some medication I’ve been taken for twenty years.” (P22)
Disease literacy

Fig. 1 The complete documentation about heart failure that patients receive from the hospital. Most patients know where it is located in the house but they do not use it very often.

Most patients seem to understand what is required in terms of lifestyle changes to deal with their heart condition, such as healthy eating habits (e.g. reducing salt intake and alcohol) and daily movement at a low intensity. For instance, some patients explained that salty nutrition in combination with large fluid intake (i.e., more than 1.5 litres) can result in water retention (e.g. in the lungs). Others explained that losing weight is required after being diagnosed with congestive heart failure, because being overweight puts too much stress on their heart. This knowledge was provided by doctors and other care givers and/or via brochures.
However, due to co-morbidities some patients perceive difficulties in distinguishing which symptoms are caused by which disease and which (contradictory) advice to adhere to (e.g. drinking enough water during chemotherapy vs. restricting fluid intake). This may result in a decrease in patients’ disease literacy.

Furthermore, as each interview progressed, the conversation revealed that most patients did not really understand all of the advice they had to follow, or could not name them. This leads us to the conclusion that disease literacy certainly could be improved.

“Yes, and by definition, if you lose weight that affects your body and your heart won’t have to work as hard etc.” (P7)

“Yes, yes. That was strongly, very strongly discouraged. But pure alcohol, of course, with that I mean brandy, whiskey, that kind of stuff. I don’t drink that anymore. That I don’t drink anymore.” (P7)

3.1.2 Patients’ technology use

The majority of the participants listen to the radio quite often. Reported uses are listening to music and the news. Some participants listen to the radio the entire day. Another medium that is heavily used is television. Although most participants report having a digital television, they rarely use the additional features that come with it (e.g. social functionalities, delayed viewing). Most participants use television to “watch TV” such as the news, sports, soaps and an occasional movie. Television was often cited as a medium they would not wish to be without. The same goes for the computer and/or tablet, used by the majority of the participants. Computers and the internet are used to check mails, to search for information and, to a lesser extent, for online banking, to read/watch the news, to book travel tickets, and to store/share photos. Despite these uses, most participants see themselves as light computer/internet users with rather limited digital skills (e.g. looking for information on the internet, texting friends/family). In case they experience a problem (e.g. a technical problem, difficulties transferring digital pictures to the computer, not being able to start their digital television), they usually rely on their family (e.g. grandson) or friends who are more tech-savvy to solve the problem.

A minority of the participants never or only rarely use a mobile phone. Those who use mobile phones, whether a smartphone or not, do so to call someone and/or to be reachable (e.g. in case of an emergency). Only half of the participants use their mobile phones to text friends and/or family. One participant has his medical file on his mobile phone via a dedicated application. It is sometimes unclear whether participants have their own mobile phone or share a device with their partner or spouse. Other types of technology mentioned during the interviews include activity trackers (two participants) and a device to measure blood pressure and heart rate sensors (one participant). Finally, some patients talked about their ICD and home monitoring system. Home monitoring systems are perceived as easy-to-use and provide participants with a sense of security, because the hospital will call them when something goes wrong.
"No, we only use our smartphone to make calls and to send messages. And as an agenda. I don’t have e-mail either." (P15)

Partner P1: "Yes, we have a mobile phone too."
Interviewer: "And what do you use it for, mainly?"
P1: "Only to be reachable."
Partner P1: "To make calls. We never send a message. If I send a message, I won’t get a reply. He’ll call if something is the matter, but he won’t send messages."

P1: "A normal phone is easier; I’ve never worked with a mobile phone."
Interviewer: "You’ve never worked with a mobile phone?"
P1: "Either I can’t turn it off, or I can’t make a phone call."
Interviewer: "And what is it that makes a normal phone easier for you?"
P1: "You just pick it up and you can communicate, and a button to turn it off, nothing difficult about that."

"I have a pedometer too. All very well to have one, but after two months you forget that you have it, and then you just forget about it." (P19)

During the interviews we used the diary as an elicitation tool. This means the dairy entries are used to stimulate our conversation with the participant. The diary itself however, contained a specific page to gather information about technology use. We asked participants to describe their technology use for Analogue TV, Digital TV, Audio installation, Internet, PC/Laptop, Tablet, Smartphone, Mobile and other. More specifically, we asked whether or not they used it, for what purpose, how frequently, and how easy they found it to use it. The overview can be seen in Table 2. As can be seen in the table, most participants use technology in general. However, their use is quite basic. Activities like looking up information and performing online banking operation point to utilitarian uses, while most other activities point toward entertainment or leisure use. What we also observe is that although seven participants have a smartphone, they do not make use of its added functionalities. The reported uses are calling and texting.

<table>
<thead>
<tr>
<th>No of participants</th>
<th>Technology</th>
<th>Use</th>
<th>Frequency of use (times/day)</th>
<th>Subjective ease-of-use (0 = I difficult; 10 = easy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5/19</td>
<td>Analog TV</td>
<td>Watch TV (in general), news, information</td>
<td>2.2</td>
<td>8.1</td>
</tr>
<tr>
<td>14/19</td>
<td>Digital TV</td>
<td>Watch TV (in general), news, movies, sports, soap, series</td>
<td>1.7</td>
<td>7.5</td>
</tr>
</tbody>
</table>
### 3.2 Disease management

#### 3.2.1 Administration

Oftentimes the patient’s partner does the administration, such as making appointments, collecting prescriptions and keeping the medical files up to date. An appointment with the cardiologist is usually made during the previous appointment, whereas other appointments (e.g. with a patient’s daily practitioner, physiotherapist, dietician) are initiated by the patient. Only one participant reported using a digital agenda and personalized notifications to keep track of his appointments and other tasks (e.g. getting prescriptions) related to his heart condition. In general, doing disease related administration is not regarded as especially difficult or complicated. However, this is mainly because in most cases the patient’s partner takes over the administrative tasks and/or implements strategies to make it easier for the patient to keep track of disease related administration.
3.2.2 Artifacts

Artefacts participants reported to use for disease management purposes include:

- Documentation about healthy food, such as what patients should eat with moderation (e.g. salt and fat), nutritional values, et cetera.
- Information brochures about congestive heart failure
- Information about the patient’s ICD, pacemaker and/or home monitoring system
- Documentation for cardiac rehabilitation, e.g. exercises (including maximum heart rates) that patients can perform
- Boxes to organize the patient’s medication (e.g. per moment of day for a whole week)
- Document listing the patient’s current medication
- A shared agenda (e.g. with the patient’s partner) to keep track of all the appointments with caregivers; typically, analogue
- A bulletin board or something similar to display sticky-notes with appointments, prescriptions, list with medication, etc. in a visible place in the patient’s home (e.g. kitchen)
- Notebook and/or digital file to keep track of different data (e.g. blood pressure, heart rate, weight)
- Home monitoring system, often placed in the patient’s bedroom (e.g. on the bedside cabinet)
- Cards with contact details (e.g. cardiologist, daily practitioner, contact person in case of an emergency), number medical file, health insurance information, etc.

"I follow everything perfectly. I put everything in a box once a week so that I know what to take. That’s much easier than having to collect your pills in the morning. Now I only have to open that box." (P14)

"Ah right, cards and documents, I always carry them with me. Much more interesting. You see, I have everything here with me. Here’s the card of the defibrillator with all information. A list with medication. My insurance card in case I need to be administered, that’s interesting. And if you are taken away with an ambulance for instance, they can quickly find it. The letter of the cardiologist is there too. Here’s a card with contact details in case of an emergency. Everything is in it, you see? My medical file number too." (P14)

P7: “Here it is, next to my identity card. It also includes the contact details of the doctor in the hospital, my GP.
Partner P7: “That card of the pacemaker should be in there too, but I still need to make a copy.”
Interviewer: “What’s the purpose of that card? That people know he has a pacemaker?”
Partner P7: “Not only that. If he is in an accident, they can see what kind of pacemaker he has so they can start working immediately.”
Participant: “They can see that as soon as they open my wallet, they can see everything you see?”

"I received very good information, documentation and booklets. The ones about exercise and training should still lie around here somewhere, with everything that’s possible. Now the cardiologist gave me brochures about implanting a defibrillator." (P22)
Fig. 2 A wallet dedicated to keeping all kinds of information: pacemaker card, diabetes card, ID...

Fig. 3 An organized box for medication with sub compartments for each day of the week
Fig. 4 A paper sheet showing the overview of all medication one participant is supposed to take at very specific times, in specific ways.
3.2.3 Support of family and friends

Many participants acknowledged the central role of their partner in managing their heart condition. In addition to mental support, the partner often implements dietary guidelines, arranges medication, makes appointments with caregivers when needed, and keeps track of administration. Practical support (e.g. doing groceries) was also experienced from other family members, such as children and brothers/sisters. Some participants mentioned experiencing much support from (some of) their neighbours (e.g. transport to the hospital, gardening). Finally, good friends and grandchildren were also mentioned as playing a crucial role in offering necessary distraction (e.g. phone call, quick visit).

P6: "I think, as a patient, if you get lots of support from your partner, everything is much easier to cope with."
Interviewer: "And it sounds like you have that support, right?"
P6: 'I won the lottery there.’’ (P6)

"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.” (P2)

"I’ll tell you, we were married for 14 days and I got a heart attack. If that had happened 14 days before our marriage, I wouldn’t have gotten married. Because I don’t want to do that, put someone up with an old person. But then, I wouldn’t have been here anymore now, because if I have to take care of going to the doctor and taking pills….” (P6)

3.2.4 Self-monitoring

Blood pressure and heart rate

Especially after being diagnosed with congestive heart failure or having undergone medical surgery, blood pressure and heart rate need to be measured on a daily basis. These data are written down in a notebook, in a brochure with information about CHF or in a digital file on the participants’ computer. After a while, the frequency of measurements diminishes to once every two weeks and/or when they consult their daily practitioner and cardiologist. A minority of the participants (2/14) reported that monitoring their blood pressure and heart rate made them more anxious, because they were constantly confronted with their heart condition and limitations. Those who received a home monitoring system or ICD no longer need to keep track of their heart rate because the devices do that for them.

P8: “If I’m in bed, I’m monitored from the hospital.”
Partner P8: "Yes, and if something’s wrong, they’ll call us.” (P8)

The cardiologist advised that my heart rate should stay below 125. Sometimes I would wear that during walks, but not anymore because my heart rate always stayed below 125. (P15)

"This week, during fitness, suddenly my heart rate was too high, and I said: that’s not right. Sometimes, those devices give incorrect information.” (P15)
"Blood pressure should be measured, but not every day anymore. I even have lists, because I used to keep track of everything. I have beautiful lists. The doctor said I didn’t need to do that anymore.” (P3)

**Diet**

Many participants reported having received documentation with dietary guidelines. This documentation is often actively used to do groceries and cook meals. Oftentimes, it is the participant’s partner who implements these guidelines into daily practice. Some participants mentioned having consulted a dietician shortly after being diagnosed with congestive heart failure or having undergone medical surgery. Typically, they were asked to write down everything they ate during one week. Based on these data they then received personalized advice from their dietician. Other strategies that were mentioned is choosing light products when doing groceries, not eating until you are full and accurately weighing food/fluids.

P15: “Fats and salt, I should reduce that, but my wife takes care of that. I went to a dietician too.”
Interviewer: “What does the dietician discuss with you?”
Partner P15: “We had to write down what he ate for a full week.”

“I had to keep track of a lot from the hospital. For example, whether I liked the food, how often I would go to the toilet. I wrote everything down so the doctor could have a look at it and we could discuss other things for a change.” (P3)

**Weight**

Especially in the period after being diagnosed with congestive heart failure the participants had to monitor their weight on a daily basis and, ideally, on the exact same moment every day. These data were usually written down in a notebook, information brochure or digital file on the participants’ computer. The doctor/specialist uses these data to evaluate the participant’s medical condition and detect potential water retention in the body. Once the participants’ medication was perfected, these daily measurements were no longer needed. From that moment on, most participants reported measuring their weight only once a week or once every two weeks and/or when they consult their daily practitioner and cardiologist. Apart from one exception, the participants did not report having difficulties monitoring their weight on a regular basis.

“Well, the GP said that it would be better for the check-up to do it [taking one’s weight] at the same time always. But I forget a lot too because I had a stroke. I don’t remember either. That’s why the GP said I don’t have to do it anymore, because I have my own problems. That’s why the doctor took over those tasks.” (P5)

“So that’s my first job in the morning [taking one’s weight]. However strange that may sound. Completely sober, but that’s the reason, to measure as correctly as possible. And yes, I keep track of it sometimes, if I remember to. And he [the doctor] knows he can get it, then I’ll e-mail it to him.” (P7)
Exercise

Participants monitor their exercise level in different ways. When following cardiac rehabilitation in the hospital, monitoring activities are taken over by physiotherapists who provide strict guidelines (e.g. about the intensity of the exercises). Some participants report having used/using an activity tracker to monitor their daily movement or a heart rate sensor to avoid being too active. An alternative strategy is listening carefully to one’s body. Two participants mentioned applying this tactic when working in the garden or going for a walk.

Interviewer: "Why did you buy a pedometer?"
Participant: "To keep track of my walks, and to see, well, because you need to take enough steps to exercise sufficiently." (P15)

"I’m a person who liked to be active, but now, yes…. Keep calm, you know, there are many things I’m not allowed to do anymore. And well, if I do those things anyway I’ll feel it half an hour or 45 minutes later, then I get tired. But that’s normal, if your motor isn’t running as it’s supposed to run." (P13)

Medication

Fig. 5 One participants showing all the medication.

Half of the participants mentioned that they prepare their medication for a whole week using drug boxes or little cups. Oftentimes it is the participant’s partner who does these preparations. The rationale for organizing medication this way is to avoid taking too much or too little medication, and not having to think about it during the day. The participants typically have to take a multitude of medicines, sometimes dosed differently according to the time of day. For most of them it took a while before the medication was adapted to their specific needs. For a minority of the participants, the medication still changes on a regular basis, for instance after having consulted their cardiologist or any other specialist. Other tactics that are used to keep track of medication is asking additional prescriptions (e.g. for a period of 6 months), carrying their personalized medication plan with
them at all times, applying a strict routine with regard to taking medicines (e.g. after breakfast and before brushing their teeth), and having a spare set with medication in the car. Despite these tactics, some participants perceive monitoring medication as a severe limitation to their daily activities (e.g. diuretics make it hard to go outdoors, which is discussed in more detail in the section on patient experience).

“I have a schedule. That would be something useful to implement! [laughs]
So, every morning I prepare my dosages for the whole day. I have a box with four sections. By now, I know it by heart. It has become a routine, but I always carry my schedule in the bag I keep my medication in.” (P7)

“When I go to the cardiologist, I ask for two prescriptions, when I go to the GP I ask for two so I have a back-up.” (P7)

**User requirements disease management**

To support patients in disease management, the HeartMan system could:

- Support patients in making appointments with caregivers
  - Remind patient when it’s time to make an appointment for a regular check-up with a caregiver
  - Remind patient when an appointment for a regular check-up is coming up
  - Provide a (printable) overview (e.g. agenda) of all appointments with caregivers
- Support patients and their spouses to do disease management together
  - Allow patient to give spouse access to the HeartMan system
- Support patients in remembering disease management tasks
  - Remind patient when he/she should perform a specific disease management tasks (taking into account patients’ agenda):
    - Request new medication prescriptions
    - Updating medical file
    - Measurements (blood pressure, heart rate, weight, food intake, exercise …)
- Improve patients’ disease literacy:
  - Educate patients on healthy eating behavior
  - Educate patients on their heart condition
  - Educate patients on the medical technological devices they use (e.g. IDC, pacemaker, defibrillator, …)
  - Provide an overview of a patient’s medication
- Support patients in adhering to dietary & exercise advice:
  - Provide strategies to adhere to dietary advice:
    - Grocery shopping strategies
    - Cooking strategies
    - Eating behavior strategies
    - Strategies for limiting intake of food/liquids
- Support patients in taking their medication in the right way, at the right time
  - Remind patient when it is time to take medication
  - Remind patient to bring medication when leaving the house
  - Support patient to organize medication to facilitate correct intake
• Provide strategies to create routines to facilitate correct intake
  • Support patients to monitor their condition
    o Allow patients to note and store health-related data, e.g.:
      ▪ Weight
      ▪ Blood pressure
      ▪ Heart rate
      ▪ Food intake
      ▪ Exercise
    o Import data collected by other devices, e.g. home monitoring systems, activity trackers, heart rate sensor
    o Allow patients to share self-monitoring data with caregivers
    o Prevent patients from becoming hyper-aware of their condition due to frequent self-monitoring, e.g. by automatic measurement
    o Support patients to pay attention to bodily signals that may indicate over-exercise or a physical problem
      ▪ Educate patients about bodily signals they should be aware of that might indicate a physical problem
      ▪ Advice patients about how to pay attention to bodily signals that indicate over-exercise
  • Monitor changes in patients’ condition (based on self-monitored data)
    o Warn patient in case changes may point to a problem that needs follow-up by a caregiver
    o Warn patient in case activity tracker data indicate they are going over their limits (e.g. high heart rate, engaging in physical activities for too long)
  • Support easy contacting caregivers
    o Provide an overview of contact details of important caregivers
    o Provide an easily accessible overview of the most important medical information of the patient (number medical file, insurance policy, …)

3.3 Advice & therapy adherence

3.3.1 Adherence

Most participants mentioned strategies to improve adherence. With regard to eating habits, one participant limits the amount of slices bread he eats and avoids getting chips around because he knows he cannot stop eating those. Other participants also mentioned not buying anything that is in conflict with their dietary advice. In order to restrict salt intake all members of one family join the patient in a reduced salt diet. This makes it a lot easier for the patient to stick to it. To flavour the food, they use more herbs. For the medication most participants distribute all their medication into cups, either for the day of for the whole week. Preparing their medication intake in advance, makes it easier to take the right amount. Information about what to take when is sometimes written on the cups, or on a notice board. Sometimes it is the spouse/partner who reminds the patient to take his/her medication. Limiting fluid intake is done by buying smaller cans or using smaller cups for coffee and tea.
Participants’ perceptions about their own adherence to the professional caregivers’ advice paint a complex picture. Some advice is followed to the letter; other advice is very difficult to adhere to according to the participants. Moreover, in order to make it easier to adhere to certain advice, it is sometimes adapted/adjusted to make it practical in everyday life. We call the latter “flexible adherence”.

Most participants claim that following some advice is easy. The respective advice, that is easy to adhere to, differs between participants: for some it is restricting salt, for others it is exercising. We have to note here too that although participants at first said that adherence in general was easy and that they followed the advice given by the doctor, we observed deviations from complete adherence later on in the interview when talking about specifics.

In many interviews participants talked about advice that was more difficult to adhere to. A particularly difficult advice to follow is to quit smoking. Furthermore, some patients have difficulties performing sufficient exercise each day. Some say it is difficult because they have really bad days due to CHF; others state that the winter period makes it more difficult for them to go outside for a walk. They sometimes forget to take their medication. Others explain that it is difficult to adjust their diet according to the dietitian’s recommendations, because it is quite a substantial change to what they are used to eat.
"No, I have the most problems with the accuracy of my diet. I like to each something... there needs to be a little bit of salt in it. I like to have a drink. By the way, would you like a pint (laughs)?" (P7)

Interviewer: "And can you always adhere to the advice to restrict your fluid intake?"
P2's partner: "difficult"
P2: "Yes"

Interviewer: "And what makes it difficult for you?"
P2's partner: "I say: when you are thirsty, you have to drink."
P2's partner: [laughs]
P2: "Yes, that is... I am also a diabetic. I have a dry mouth sometimes; then I will drink something."

59 excerpts from 13/14 patients indicate that they adhere to an advice, while 25 excerpts from 8/14 patients indicate the they do not adhere to an advice. In relation to this, we have 21 excerpts from 9/14 patients in which they adhere somewhat to the advice (flexible adherence). It is important to state that no great significance should be placed on such numbers in qualitative research. This is only mentioned in this case to point out that the majority of statements express adherence to the advice, and a minority non-adherence or flexible adherence. For the remainder, the categories adherence and non-adherence do not reveal new information that isn’t already present in more specific other categories such as adherence difficulty or adherence strategies for example.

Flexible adherence is prevalent among all participants. They adjust some of the very strict rules from the advice in order to make them more practical in everyday life. One thing that is also often mentioned is the fact that from time to time they need a little break in order to make their lives bearable. A typical example of flexible adherence is taking diuretics later during the day (when they should be taken in the morning), so they can more easily go out for groceries, visits etc. Because of the diuretics they have to go to the bathroom quite often; this makes it very difficult for them to leave their homes. By adjusting the timing of this particular medication, they make life a bit more practical.

Interviewer: "Then, the benefits and the downsides when you do not adhere to the advice.
P15: I would like to follow them. I do my very best but it shouldn’t go too far. I can’t do it 100%. I have even been in contact with people who adhere less than I do. I certainly try to follow 95%. If I don’t, I also mention it. I do not lie to the specialists. I like eating, but I’m not eating loads of food. I need to avoid salt and fats too."

Interviewer: "Other participants say that it is sometimes very difficult to go far outside the house due to the side effects of the diuretics.
P19: That’s the reason why I changed. I now take them in the evening so I am not inconvenienced during the day."

"The medication is put into little containers at the end of the day. At the start I had to take some medication at 8h and some at 10h, so yes that is difficult. That’s why I take medication twice a day: at 8h in the morning and at 20h in the evening. I keep to that schedule." (P19)

"I adhere to it but not every day, that’s important to note." (P2)
An important part of our results relates to the reasons why patients adhere or don’t adhere to the advice of the doctors. This section nuances and explains the previous section about adherence, flexible adherence and non-adherence. It becomes clear that adherence mostly is a continuum and cannot always be clearly defined as complete or non-adherence (from our qualitative approach in this study). For some, the trust in the doctor is so significant that they (say they) follow any advice they give, even though they do not completely understand the rationale behind it. Then, we made a distinction between situations in which the participants make up some kind of excuse for not following the advice, and situations in which they explicitly decide not to follow the advice.

“I can’t work with electrical devices anymore. On my fields there are (inaudible) every 5 feet that occasionally needs to be trimmed. I’m not allowed to do that anymore. I can’t operate an electrical saw anymore according to the professor. Even doing small chores here, I cannot bang a hammer anymore. I don’t see the relevance but if I can’t do it anymore, I can’t do it anymore.” (P13)

“My first 2 incidents were treated in UZ Ghent, but after that the professor changed hospitals, and I changed along. He asked me that question and I went along. After my heart surgery I have participated in a study. I still do that occasionally. The goal was to test a new machine.” (P15)

Another motivation (for adherence), is that their condition has become critical or they have recently experienced an important medical emergency. The gravity of the situation is recognised and therefore they start adhering to the advice. They know what will happen if they do not adhere to the advice.

P1’s partner: "Yes, but the main doctor had said something, about the heart transplant.”
P1: "We are not yet with our back against the wall, but I could perhaps [inaudible] last time I went, I had only quit smoking for 6 weeks, he says you are too early for a transplant, that the condition is not that bad yet.

Interviewer: “Is that a condition to get onto the [transplant] list?”
P1’s partner: “Yes”

Interviewer: "So that was a motivator to quit smoking?”
P1: “Yes, because you can’t go on like this.”

3.3.2 Changes in advice

Changes in advice are mainly carried out after a medical check-up or after an emergency. In the case of a medical check-up, several patient characteristics are measured, and, based on those measurements, the medication is adjusted. For this adjustment, caregivers also take into account side effects reported by their patients. Some of those side effects can be quite severe for certain patients, who then contact the caregiver or hospital immediately to report the problem.

"The advice is adjusted every time. The professors in Aalst send it to the GP after I receive the adjusted scheme. I also get a note to take home with me. The communication with the doctors is very good. Last time I had a lot of mucus and the doctors in Aalst said it did not originate from my lungs but from my heart. So they changed my medication.” (P3)
3.3.3 Content advice caregivers

Participants do not appear to monitor themselves in most cases. In only a small number of interviews it is mentioned. The act of explicitly monitoring themselves and keeping notes, is only reported by 1 participant.

"Weighing yourself, they ask me that every time. Do you remember? But yes, I still weigh myself. I can show it to you if you would like it, but it is not a lot. It’s only about a hundred numbers. How many is that, 365 for 10 years, that is probably around 3000 numbers? (P7)

Most participants report receiving the advice that they should exercise (moderately, not intensively). In most cases this advice is given by the cardiologist. In many cases the advice is specified: amount of steps to take each day, maximum heart rate during exercises. This is appreciated by the participants. One participant made a remark that the advice does not always contain an explanation of what will happen if they don’t exercise, or why it is important that they should exercise regularly.

"Yes, after my last operation they told me to walk 250 to 300 steps a day. I had to go outside for that." (P8)

"Now we are trying to work on that carefully because I cannot raise my heart rate above 120. Sometimes it goes from 100, 108 to 150, 160. I also experienced this on Monday, but I also had this in Roeselare. I had to do the exercises in Aalst, but after 4 minutes I had to stop immediately. (P1)

Advice on medication is discussed in most interviews. Participants receive a piece of paper that contains an overview of which medication they should take at what time, and how.

"Yes, I prepare it for a week in little containers to ensure I don’t forget any. Now, we also received a medication overview from the hospital. The children also know they shouldn’t touch it. Now, when I have to go to the hospital for a check-up, I get the paper." (P5)

In some cases, participants mention advice from caregivers concerning their activities of daily living: what they can’t do anymore, or what they should watch out for.

"Yes, that was the cause because he was always working using his equipment. That was the cause. Lifting weights higher than his heart is also not allowed anymore." (Partner P13)

"Yes, that is the limit, for example mowing the lawn is not allowed, working on my care is not allowed anymore. So everything I am allowed to do is nothing." (P6)

All participants reported getting advice concerning nutrition restrict fluid intake, not to eat too much fat, restrict drinks with sugar, salt intake, alcohol, chocolates and candy... In most cases the advice comes from the cardiologist; in some cases, participants are guided by a dietitian for a limited period of time. This kind of advice is given in consultations via conversations. All participants report receiving documentation about CHF in which this advice is explained.

Interviewer: "Did they also mention something about your diet?"
P22: "Yes, about healthy nutrition. I cook healthy, I watch it. An aid I use is using a lot of frozen vegetables and sometimes meals from Bofrost. They
deliver at home. You can use as much as you’d want. If you go to the store, you buy so much, but I’m only single.”

Interviewer: “Yes ok, and this information, did they explain it to you or did you receive it on paper?”
P6: “Yes, I received a note with general rules for heart patients. But I won’t start reading books or something. But anyway, at home they made sure that there was enough food I could eat. What I’m not allowed to eat, you won’t find at home. No chocolate and candy, because the children already say that they can’t find anything in the cupboards. Also because I cannot stop eating candy once I started.”

P1: “I can only drink 1,5 litres of fluids each day.”
Interviewer: “Maximally?”
P1: “Everything adds up: coffee, soup, lemonade. Sometimes I drink too much.”
Interviewer: “And those are the most important things, salt and fluid intake?”. P1’s partner: “Yes, because his heart has to pump to get all the fluids around.”

A smaller part of the participants reported advice concerning smoking, more specifically, that they should really quit smoking.

“They said: you have to quit smoking. It was difficult because I was a real smoker, I enjoyed a good cigar. After a lot of effort, I was able to quit and I can recommend it to everyone.” (P6)

3.3.4 Contradictory advice

In a number of cases we noted what seems to be contradictory advice, which can happen sometimes in cases of co-morbidity. CHF patients sometimes suffer from multiple conditions; each of those conditions requires a specific treatment. The treatment of one condition can sometimes be in complete opposition to the treatment of the other. Other conditions reported here are cancer, diabetes, lung problems, and kidney problems. Some participants have the impression that the specialists for the different conditions do not always consult each other to check for such issues. Sometimes the problems are caused by conflicting medication; sometimes the advice on fluid intake is the reason for the conflicting advice.

Interviewer: "Did you receive advice concerning fluid intake?"
P4: "No, it’s a bit ambiguous. According to the treatment I receive, I should drink a lot.”
Interviewer: "For the chemo?"
P4: "In order to get the chemo out of my body. You have to pee a lot in order to get rid of it. On the other hand, you can’t drink too much, maximally 1,5 liters in 24 hours.”
Interviewer: "For the heart failure?"
P4: "For the heart failure, yes.”

3.3.5 Own and peer advice

We were interested in what advice participants would give other people who had just have received a similar diagnosis. For this, we asked them to write a letter to a fictitious patient. For the most part, participants recommend following the advice of the doctor: taking the right medication, adjusting eating habits, following the medical rehabilitation program, avoiding
stressful situations, stopping smoking, having regular medical check-ups, and exercising at a moderate intensity.

"Cooperating with the hospitals etc., what I did. When they ask you to stop doing certain things, you really should. I did it and you can see the result. They sometimes tell me: our best customer is arriving. That's because I cooperate really well. I strictly adhere to the advice. It would be a lot easier for the doctors if everyone did so." (P5, in his letter of advice)

Our participants also shared their own experiences, perhaps to paint a picture of what to expect after a CHF diagnosis. On a somewhat similar topic, they try to encourage the person not to lose faith. One way they do this is by pointing out that the medical care they receive is excellent. Finally, they also recommend keeping a mobile phone at all times so they can alert the emergency services when something happens.

"If I can give some advice, always keep your mobile phone with you in case something happens. I have my phone with me 9 out of 10." (P4, in his letter of advice).

"I write back: a lot of courage and do not moan." (P3, in his letter of advice)

Requirements for advice & therapy adherence

In summary, in terms of adherence, the HeartMan system could:

- Repeat advice given by the cardiologist in small snippets, covering all types of advice.
- Provide reminder functionality.
- Provide specific advice and an indication of what kind of deviations are allowed if patients need to make compromises due to everyday practicality (temporarily).
- Provide tips on how to make adherence easier (such as how to use herbs and spices as alternatives for salt in food).
- Provide ideas on how to make monitoring easier for more difficult things such as limiting fluid intake.
- Remind participants from time to time about some concrete consequences of not following a certain advice.

In terms of monitoring, the HeartMan system could:

- Provide easy means to monitor each type of information required for proper adherence. Perhaps provide an indication of the importance of each type.
  - For physical efforts, provide a maximum heart rate.
  - For daily exercise, provide a number of steps to take.
  - For medication, monitor whether each type of medication is taken, and whether it is taken at the right time.
- Alert the necessary people if dangerous levels are reached or inform the patient to make an appointment with the doctor.
3.4 Relationship with caregivers

3.4.1 Frequency and nature of contact

The participants usually visit their cardiologist every three to six months for a regular check-up (emergency situations and/or medical interventions not included). These consultations typically include a follow-up of the medical condition, a data readout of the patient’s ICD (if they have one), evaluating medication and possible side effects, and providing prescriptions. Some participants consult multiple specialists (e.g. lung specialist) but at different times resulting in more visits to the hospital. For some participants, dividing appointments over multiple days is a deliberate strategy, because it increases their sense of security.

The majority of the participants visits their GP on a regular basis (i.e., once or twice a month) for blood tests, prescriptions or to discuss their medical situation. Some participants rely on their GP for general help and support, implying a bond of trust. Only a minority of the participants relies exclusively on their cardiologist and his/her team. Physiotherapists were mentioned as important for cardiac rehabilitation (e.g. to recover from a heart attack or a heart operation). Other caregivers include dieticians, psychologists and (home) nurses.

"Every three weeks I have to get blood drawn at the GP, that’s for the blood thinner, to check the status of my blood." (P1)

"Now it varies quite a lot. Normally we go every three months, but sometime it’s six months, sometimes it’s three. We do go to two doctors, one time to the doctor who placed the defibrillator, the other time to the heart specialist. We see each doctor every six months, but in the end there’s only three months between each visit, you see.“ (P13)

3.4.2 Satisfaction and trust

Only a minority of the participants reported being satisfied with the medical treatment they received when they first got hospitalized and/or were diagnosed with CHF. Half of the participants, however, reported the exact opposite. They increasingly distrusted their cardiologist and his/her team due to a faulty diagnosis, contradictory advice, a lack of transparency, insufficient communication with other specialists and/or the patients’ daily practitioner, a lack of genuine interest, too little information about their condition and its consequences, and a box mentality. These participants eventually went to another, more specialized hospital (e.g. after discussing their distrust and dissatisfaction with their daily practitioner). Most of these participants regret not having changed hospitals/specialists earlier, because they are pleased with the medical treatment they received since the change.

In general, the participants greatly value specialists and caregivers who know what they are doing but, at the same time, bear witness of an out-of-the-box mentality, are friendly, honest and reachable (e.g. over the phone), and share as much information as possible with other specialists in order to see the bigger picture and avoid contradictory advice.
"The doctors asked about my garden, they were really interested in me. We were once talking about the orchids in one of the doctors’ garden, they had a different colour than mine. He even showed pictures of the flowers in his garden. I like it when doctors really know you, that they know who you are. Then you also know their limits and capabilities." (P3)

Interviewer: “Who do you want to talk to, if you call to the hospital?”
Participant: “For me it’s important that I can talk to the cardiologist. If I don’t feel well, I call the cardiologist. That’s a person whom you trust and who listens to you.” (P8)

“Yes, that [medication] is changed regularly, but I especially regret that the different specialists don’t, or hardly communicate. They don’t discuss with the cardiologists or the diabetes specialists. Nobody discusses with each other but they keep adding medication.” (P8)

User requirements relationship caregivers

Based on the insights in participants’ relationships with caregivers, the HeartMan system could:

- Support remote monitoring patient’s condition by doctors/hospital
- Support multidisciplinary approach towards disease management
  - Advise patient on physical exercise (personalized)
  - Advise patient on diet (personalized)
  - Advise patient on psychological issues (personalized)
  - Advise patient on daily health care issues (personalized)
- Support trust relationship between patient and caregiver (e.g. the GP)
  - Allow patient to share information with caregivers
  - Allow caregivers to monitor & advice patient
- Support patients to deal with situations in which they don’t trust their caregivers
  - Allow patients to express doubt about diagnosis/apply for second opinion
  - Support patients in finding another caregiver
  - Support patients to demand their caregivers to be transparent
  - Support patients in dealing with contradictory advices
  - Support patients to demand their caregivers to share information to reach holistic, coherent advice
  - Support patients to demand their caregivers to provide personalized care (i.e. not only following standard rules and procedures)

3.5 Patient Experience

3.5.1 Important events

Almost all participants have gone through one or more major heart failure incidents, which they experienced as quite traumatic. Such incidents include emergency situations that require immediate medical treatment, such as a
heart attack or emergency surgery, as well as other medical events that made an impression on the participants.

"Yes, that first shock. That first one, that was my first heart attack you know." (P7)

The majority of the interview participants reported to have had one or more heart attacks. Often, a heart attack was the first indication of participants' heart failure condition. Also, almost all participants had some kind of surgical procedure due to their heart condition. These included open heart surgeries as well as routine heart procedures such as catheterizations, placements of stents, pacemakers and defibrillators, and bypass operations. Several participants reported to have had more than one of these procedures.

"Yes I first had a heart attack and about half an hour later I had another one. After that I had several catheterizations and stent implants. I've had that seven times in total." (P8)

Events related to participants' heart conditions that did not require immediate medical treatment included adjustments to pacemakers or defibrillators, water on the lungs and nutritional deficiencies (e.g. low kalium levels). Also, some participants indicated that they've felt at times that their pacemaker or defibrillator responded to a change in physical status.

"Yes yes, one morning it went off, he just had a cup of coffee in his hands, everything on the ground, it's a shock you get, right." (P2's partner)

Overall, we can conclude that for many participants it takes quite a long time to stabilize after a major heart incident. This is due to operations that are often necessary (e.g. to place stents or defibrillators or to create a bypass) and to the fact that it takes time to adjust the amount of medication. Also, patients sometimes need time to get used to the side effects. Another notable insight is the fact that some medical procedures (e.g. placing a defibrillator) do not only have a physical effect, but also make participants experience relief as it lowers their fears for another incident.

P10: "That was a difficult time. In 2011 I had my first heart attack. First they placed a stent and then a few weeks later I had open heart surgery. Interviewer: "And that was because the stent wasn't sufficient?" P10: "Not sufficient, they couldn't open up the other arteries anymore. And then they created a bypass." Interviewer: "OK, and did that make a difference?" P10: "Yes, I still had pain. After the stent I still had pain."

"The last time we had an emergency was when they connected the pacemaker to the wrong side of his heart. The pacemaker provided too much energy. That's why he lost consciousness so often. His left and right side don't go simultaneously, you know. The right side went 35 times while the left remained at 45." (P3's partner)
User requirements major medical events

In conclusion, the following user requirements can be derived for the HeartMan system from our insights in major medical events that happen to congestive heart failure patients:

The HeartMan system could:

- Support patients to recover from the traumatic experiences, both physically and mentally, related to major medical incidents
- Support patients in the stabilization process after major medical incidences, e.g.
  - Recovery from surgery
  - Adjustments to defibrillators, stents, pacemakers, ...
  - Adjustments to medication
  - Getting used to medication & side effects
- Support patients to deal with fear of another major medical incident
- Support patients to deal with (possibility that) defibrillator/pacemaker responds to change in physical status

3.5.2 Lifestyle changes

When asked about durable changes participants made regarding their lifestyles due to their heart condition, dietary changes, dedicated physical exercise and work-related changes were mentioned by several participants. Although most of these changes are discussed in more detail in the sections about advice and limitations & consequences, it is noticeable that for several participants the changes had a durable impact on their lifestyles. Several of them mentioned that they have a different relationship to food now, eating healthier than they used to. One participant even referred to this as the 'advantage' of his heart condition. Others mentioned that they actually started to enjoy doing fitness after following dedicated fitness programs for heart failure patients.

"The advantages. That I now pay more attention to what I'm eating and everything." (P1)

"And ehm, ... In summer I have enough work to do, but in winter I always go to the gym and I never did that before, fitness. But then with my heart went to the gym and a really started to enjoy that." (P10)

More negative major lifestyle changes include having to stop working and not being capable of doing physically demanding hobbies. Some participants also hinted at the fact that they had to lower the activity level of their lifestyle in general.

The doctors were very resolute because I had to immediately cut back my lifestyle from 140% to 80%." (P19)

User requirements lifestyle changes

User requirements that were drawn from insights on lifestyle changes include the following. The HeartMan system could:
• Support patients in making durable changes to their lifestyle, e.g. regarding
  o Nutrition
  o Exercise level
• Support patients in dealing with major changes to their lifestyle caused by their heart condition, e.g.
  o Stopping working
  o Not being able to do physically demanding activities
  o Turning down their activity level in general

3.5.3 Perceived status condition

Participants' subjective evaluation of the status of their heart condition at the moment of the interview varied. Several participants mentioned that they are feeling quite good, or that they were expecting to experience discomfort, which they did not. One of them mentioned that he has good and bad days though. Another participant stressed the fact that he does not consider himself to be ill at all, but that he does experience several limitations due to his heart condition.

"I am not ill; I’m just limited in everything that I have to do. But I’m not ill." (P6)

Several participants indicated that their condition seems to be deteriorating, and that they are seriously incapacitated, physically.

"I feel that it’s getting worse. I feel myself deteriorating and I find that hard to deal with." (P15)

User requirements perceived status condition

Related to perceived status condition, the following user requirements were identified. The HeartMan system could:

• Support patients in expectation management regarding their general condition
  o Educate patients about typical developments of their heart condition and their general physical and mental condition
  o Educate patients about realistic risks of specific deteriorations of their heart condition and their general physical and mental condition (personalized)
  o Educate patients about what is 'normal' for their status to experience
• Help patients understand whether they are having a bad day or whether their condition is consistently getting worse

3.5.4 Coping

In the interviews, several issues related with coping with one's heart condition surfaced. Immediately after being diagnosed as a heart failure patient, several participants struggle with fear and anxiety. For some of
them, this tended to dominate their overall mood and it took them quite some time to learn to cope, although fears and anxieties still pop up every now and then.

But I'm telling you, I have been mulling over it when I was in hospital. God, what's going to happen to me? You don't immediately think you're going to die, but still, what will the consequences be." (P10)

"Yes, somberness, some days it really occupies my mind you know, the problem and then you are.... You can feel it as soon as you wake up, at least I do. Really, and then you're preoccupied of course."

Interviewer: "How are you preoccupied?"

P10: "Well, sometimes... I just need to feel a tiny bit bad and I'm thinking: oh no, it's happening again. Or will it happen again, or something like that."

Others report difficulties accepting that they have become chronic patients. Some indicated that they were surprised that such a condition happened to them.

"But I'm telling you, the hardest part was in the early 1970s, when I heard it for the first time, a heart attack. That can't be! I never felt anything, I had people working for me and then just like that you're lying there, like an old sucker." (P6)

"And we were told, by the doctor who was treating him, that he has a very, very weak heart. And well, we couldn't believe it, because he really..., yes he always played soccer and all. (P1's partner).

Several issues that participants struggle with regarding the acceptance of their condition and the consequences thereof were discussed. For instance, participants indicated that they find it difficult to accept that they can't work anymore, or can't do some of the daily activities they used to do anymore, such as taking care of the house or garden, or that they have to live a less active lifestyle in general.

"We have a rather large piece of land, but the grass keeps growing you know. I can't mow it anymore. So I bought two sheep to graze. But there are thistles too, if you don't spray weed killer your land becomes a wilderness. Then there are about 40 pollard willows with branches that need to be cut back every five years. But I'm not allowed to do it anymore. My son does that now, but he only did half and now he has to drag around those heavy trimmings. Those are things that bother me you know. (P13)

Related to this is a feeling of being useless, and depending on others that some participants reported. They find it difficult to ask for help, or to accept the fact that they have had to give up some independence.

"It's difficult that I can't do that anymore on my own, that I need to ask for help. I'm not good at that." (P1)

"I've always been mobile. I had my car, she had hers. I could go wherever I wanted to go and now that's limited and that bothers me." (P6)

Several participants explicitly try to make the best of their situation, to accept their condition and its consequences and to make the best out of life. These participants try to put things into perspective and to focus on the good things in life they still have.

"What you have, you have, right? We don't complain about that." (P3's partner).
User requirements coping

In summary, in terms of coping, the HeartMan system could:

- Support patients to **cope with fears and anxiety** immediately after a major medical incident
  - Educate patients about realistic risks of recurring incidents
  - Support patients to understand bodily signals: are signals indicative of recurring incident or not?
- Support patients to **accept** the fact that they have a heart condition
  - Educate patients about realistic possible consequences (personalized) so that they know what to expect
  - Educate patients about fears and anxieties that they might experience now and then
  - Support patients in accepting that they have become chronic patients

3.5.5 Limitations and consequences

The participants experience many limitations and consequences as a result of their heart condition. Several of them specifically commented on the feeling of being restricted in their everyday activities due to their heart condition, especially regarding physical activities. This is also reflected in the association exercise in the diaries, in which participants noted down several words reflecting their limitations, most notably the words limitations, no sports and mobility.

"And the restrictions, that's important to me, that you are restricted in too many ways. You're not allowed to do this or that by the doctor, and this is something that makes you feel like you're put aside, and which makes you careful with everything you're doing." (P6)

"I've been denied many things." (P3)

Physical wellbeing

The participants mentioned several physical limitations and consequences of their heart condition. A much affected category of physical limitations has been labeled 'energy level' (see section below) and includes issues such as fatigue, shortness of breath, limited endurance/condition, etc. Due to these physical problems, several participants reported to have stopped doing physical activities they used to do, such as light sports and walking. The association exercise in the diary also reflects these limitations, given that the most frequently noted associations with physical wellbeing were related to fatigue and sleep.

"Yes, I did sports. Before my heart failure I played soccer and tennis, and I was an avid walker, but they had to come and pick me up recently, during a walk, I couldn't continue. This is something that I really regret. After the heart attacks I started walking again, but I can't anymore. (P8)

Another reason to stop engaging in physical activities is related to fear that something might go wrong. Quite a few participants, for instance, experience problems with balance and are afraid they might fall. Several
other physical problems were mentioned that participants considered to be related to their heart condition, such as the above-mentioned balance problems. Other issues include bad circulation, low body temperature, abnormal blood values, heart rhythm problems, and weight loss. Finally, the weather, or the temperature, is considered to be of an important influence on how participants feel. A few participants (3/14) indicated to feel much better in warm weather, e.g. because their body temperature is higher, or their general condition is better.

"I did give away my racing bikes; I couldn't cycle anymore because I had balance problems for a while." (P3)

"Circulation to my fingers is bad too, I practically always have cold fingers. Now, with this warm weather, this is not really a problem so I'm glad it's a bit warmer now." (P13)

Energy level

In terms of energy level, participants' physical wellbeing is heavily impacted both on a general level and regarding specific physical activities. To start with participants overall physical energy level, many report that they often feel tired in general, throughout the entire day (i.e. not related to a specific activity). In many diaries, participants indicate taking a nap in the afternoon (or to have a moment of rest). It happens often, for instance, that participants already feel tired when waking up in the morning. Also, many indicate that they get tired easily, not being able to keep doing what they're doing, even if this requires only the tiniest effort. In addition, shortness of breath and loss of strength are reported as well. Finally, several participants notice that they often experience 'off days', days when they have even less energy than they normally do.

P1’s partner: "Tired tired tired."
P1: "Tired."
P1’s partner: "He's always tired."

"There are days, I talked to the cardiologist about this, that I get up feeling tired, and then I keep feeling tired all day. Then I'm annoyed all day, lie in my chair all day. Trying to read but even that I can't do. And then everybody should leave me alone [laughs]. I have no explanation for it, I call those days my off days." (P7)

"And in the early days, it was a bag of concrete, concrete I'm telling you, concrete, picking it up from the street, throwing it on my shoulder, carrying it on the back, like it was nothing. And now, 20 kilos, I can't lift that anymore. Not even a watering can actually, what a difference, right?" (P4)

"If he has to walk even for just a little while, he's quickly out of breath, gasping." (P2’s partner)

Regarding participants' energy levels when doing specific activities, several participants indicated that they had to stop doing activities that they enjoyed doing. For some, this includes heavier activities such as home improvement or gardening, but one participant indicated that a short and very light activity such as taking mail out of the mailbox is sometimes too much for him. The majority of the participants indicated that they had to reduce their activities due to limited endurance. They still engage in these activities (mostly walking and gardening), but they shorten the duration or
distance, slow their pace, take more breaks, use special tools (e.g. electrical garden tools), refrain from heavy activities (e.g. lifting heavy objects), etc. One participant indicates that he finds it difficult to monitor his limits in this respect, he tends to keep doing an activity without stopping in time to rest.

"I'm sitting inside now, but otherwise I would be in the garden. Yes, pottering in my garden, working, I can't do that anymore." (P7)

Now, I also joined a walking club for heart patients. They have three groups who all walk different distances. On Saturday afternoons. For a while I've been able to do the one-hour walks, but I can't do that anymore. I could do it, but I can't keep up with the speed." (P19)

"Ehm, well yes, taking the garden as an example, I don't use the spade anymore because that's too heavy, you see. I have to sit on my knees, put plants into the soil, plant. Everything that requires me to sit bended over is too much, so I sit on my knees. I bought a special bench that makes it easier to get up etc. And I changed most of my tools for electrical appliances, so I have an electrical hoe, milling machine, etc. even that is too heavy," (P7)

Sleep

Several of the participants report suffering from sleeping problems. Sometimes, the diuretics participants take cause them to wake up frequently to go to the toilet. The most common problem, however, involves difficulties falling asleep. Most participants indicated that the cause of this problem is worrying. They tend to worry a lot about their heart condition, especially soon after the diagnosis, especially at night. One participant indicated that his worries were directly related to the fact that he had to monitor several aspects of his health (heart rate, blood pressure, ...), making him very much aware of having a heart condition. After stopping with this close monitoring, his sleeping problem improved significantly. Some participants take sleep medication, but many of them have an explicit aversion against such medications. They worry about addiction and don't like the side effects.

"Trouble falling asleep. If I don't fall asleep immediately, I might be awake all night." (P10)

"Constantly checking my pulse, is everything still all right? Does it still beat as it should? Because my heart always skips a beat. Now, see, now I go to bed and I fall asleep. In the hospital I got a notebook to keep track of everything, like pulse and blood pressure. But this made me think about it all the time, because I had low blood pressure quite frequently. And then I would think something would happen. (P13)

P10: "Now I take a sleeping pill occasionally. I could take one every day, but I won't."
Interviewer: "And why won't you?"
P10: "Because I'd get addicted [laughs]."

Medication/treatment

Heart failure patients generally take quite a lot of medications, up to 31 pills per day in our sample. Several participants indicated limitations and consequences related to their medication or treatment. They struggle with the amount of medication they are taking, but especially with side effects.
(for which they sometimes need additional medication). In particular, the side effects of diuretics were mentioned quite a lot.

"All those medicines, I find that, sometimes I don’t like to take them. All those pills. (P10)

Interviewer: "And the doctor has also adjusted your medication I see."

P13’s partner: "Those fourteen days have been hard on you, right? They had given him so many diuretics that he fainted.
P13: "I still take half a pill of those. After an hour I was completely drained."
P13’s partner: "I called the hospital again and the prof returned my call and said to stop taking one of the diuretic pills and to take half a pill of the other type. After five days it was supposed to get better."
P13: "Now my medication is perfect."

"I take diuretics. You take your diuretics in the morning and then it goes like …. [whistles]. Ask me about any shop or cafe or restaurant in Leuven and I’ll know where the restrooms are!" (P7)

Support family & friends

Most participants receive (and need) support from family and friends every now and then when it comes to physical activities. However, several participants indicated that they find it very difficult to ask for help. They don’t like it that they can’t do everything themselves anymore, and they worry that they are a burden.

"He can’t help out our children anymore. One bought a house, six months they’ve remodeled it, and they can’t ask their dad to help, you see." (P1’s partner)

Sex life

Although the topic wasn’t explicitly touched upon, two participants spontaneously mentioned the impact of their heart condition on their sex lives. Both indicate that they can’t really have sex with their wives anymore due to their heart condition, and that they regret this very much.

User requirements physical wellbeing

The user requirements that were identified regarding heart failure patients' physical wellbeing are divided in several categories:

Physical activities:

- Support patients in deciding whether they should engage in a physical activity:
  - Advice which activities a patient can and can’t do
  - Help patients predict when they can and can’t do an activity (e.g. taking into account the weather, recent/future activities, good/bad days...)
  - Advice how long a patient could do an activity
  - Advice suitable intensity for activities
  - Educate patient about realistic risks of engaging in an activity
• Advice patient how to do a **physical activity** safely (e.g. dealing with balance problems)
• Advice patients in adjusting a **physical activity** so that they can continue doing these, e.g. by:
  o Shortening durations
  o Shortening distances
  o Using lighter material
  o Lowering intensity
  o Using assistive tools
• Support patients to deal with **physical consequences of their condition**, e.g. by providing strategies to prevent/bear:
  o Circulation problems (cold hands and feet)
  o Heart rhythm problems
  o Bad circulation

**Exercise:**
• Support patients in **exercise** behavior that is suitable for their heart condition
  o Advice suitable exercise activities
  o Advice suitable moments to exercise (contextualization)
  o Monitor & coach patients during exercise
  o Monitor total 'amount' of exercise patient has engaged in & motivate patient to reach goal

**Fatigue:**
• Support patients to deal with **general fatigue**:
  o Help patients to recognize/predict off-days
  o Advice patients when to plan activities to prevent fatigue (e.g. by taking into account recent/future activities)
• Support patients to **monitor their limits** during (and between) activities to prevent over-tiredness, e.g. by reminding them to take a break or to stop

**Sleeping problems:**
• Support patients to overcome **sleeping problems**, especially not being able to fall asleep:
  o Provide exercises to avoid worrying

**Medication:**
• Support patients in deciding whether or not to use specific (sleeping) **medication**:
  o Educate patients about realistic risks (or lack thereof) of (sleeping) medication
• Support patients to deal with the specific **consequences of medication** (e.g. diuretics)
  o Advice about the most suitable time to take medication to avoid waking up frequently to go to the toilet
  o Provide information on location of nearest toilet
  o Advice to go to the toilet when there won’t be one around for a while
Support patients in dealing with **taking large amounts of medication**

Support patients with managing **side effects of medication**
- Educate patients about possible side effects
- Educate patients about realistic risks of side effects
- Advice patients to limit/prevent/deal with side effects

**Sex life:**

- Support patients' sex life
  - Help patients cope with impact of their condition on sex life
  - Educate patients about the impact of their condition on sex life
  - Support patients in deciding whether they should engage in sexual activities (see general requirement about engaging in physical activities above for details)

**Mental wellbeing**

Suffering from congestive heart failure may cause several limitations and consequences on a psychological or emotional level. In the interviews, the consequences that were brought up by the participants are related to their mood, to anxiety and worries (both their own and of their immediate social environment), to their cognitive functioning and to the support they receive from family and friends. Each of these categories of consequences is discussed in more detail below.

These categories also surfaced in the analyses of the association exercise in the diaries. In the words that participants used about their heart condition, several were related to emotional consequences. Most of these words are negative associations, including somberness, insecurity, restlessness, fear, worries, being a burden, depression, and difficult acceptance. A few positive associations were noted down as well: thankful, hope and putting things into perspective.

In the letter of advice participants were asked to write to a fictional fellow sufferer, by far the most frequent advice was related to mental wellbeing. Several participants tried to reassure the fellow sufferer by emphasizing that many anxieties and worries are unnecessary or refer to ways to lighten up his mood (which they assume will be low due to his heart condition, as was theirs).

"Try to go outside every day, so you'll forget you're having heart problems. Meet people, stay occupied." (P9, in his letter of advice)

**Mood**

Several participants reported suffering occasionally from somber, depressive or sad moods as a result of their heart condition. Some even mentioned that they, from time to time, wondered whether life is still worthwhile to them. Often, such moods are related to anxieties and worries participants have due to their heart condition (see section below), but sometimes it is difficult for participants to express the cause of their mood. Being confronted with one’s limitations and awareness of one’s own mortality are also mentioned as causes.
"I've only been having that since my heart attack. It will pass you know. There are moments that I'm thinking, it's not worthwhile to live anymore. That feeling does not last for days though; one day at the most." (P15)

"And also when you are somber, when you're having a bad day. But that's something I already feel when I get up in the morning. Then, ehm, if the day starts like that, then... If I'm lying awake at night, I often start worrying... Or it isn't worrying, but then I'm thinking and when you get up in the morning while you haven't slept... " (P10)

Also related to mood is the fact that several participants have a hard time accepting their condition and its consequences. They are still in the process to learn to live with their heart condition.

"You feel your level going down, you know. You feel that you're deteriorating and that is difficult for me sometimes. (P15)

Anxiety and worries

Several participants reported anxiety and specific worries related to their heart condition. What stands out here, is that it is difficult for participants to express what it is exactly that they worry about. Worrying is said several times to be a recurring problem for participants, sometimes causing sleeping problems. Often, however, participants do not indicate what it is they are mulling about. When asked specifically what worries participants, several vague terms are used to refer to an anxiety of new heart problems (e.g. another heart attack). Participants tend to beat about the bush by saying things like "he is always afraid something will happen" (partner of P6), "how long will things continue to go well" (P6), "well, I thought something was about to happen" (P13) or "if I have something on my left, I always directly think of my heart" (P15). These worries can get quite serious. One participant mentioned that he feels much better when his wife is at home: "Not as such in summer, but winter can be tough on me. Then everything is grey and dark, but things have gotten better since my wife has retired. When she's at home, I feel better. I'm calmer." (P8). His wife adds: "He's always afraid that something will happen."

Not all worries are directly related to serious heart problems, participants also mentioned to worry about their general health, the lasting consequences of their heart condition, and side effects of the medication.

"I was afraid because when I’m not feeling well, sometimes I... No, it won’t start again will it? I've had it once, when I had that mild heart attack a few years ago, I went to sleep and felt that something wasn't right. It all felt too familiar, just like when I had my first heart attack. Yes, my wife was pretty worried too then. (P15)

"That's why I don't go out much, or go somewhere because it happened a few times that I just fall and that's why I'm more and more afraid to go somewhere. It even keeps me from seeing my son or daughter." (P8)

Anxiety and worries environment

In general, the participants' environment (partners and children mostly) worry about similar things as the participants do themselves (e.g. new heart problems), and they too tend to be rather vague in their expressions.
about these worries. Several participants mention that their environment imposes certain requirements or restrictions on them, due to these worries. One participant's partner, for instance, won't allow him to be home alone. Whenever she is away from home (she travels quite a lot for her job), a family friend stays over, day and night. Another participant's partner always asks her husband to bring his mobile phone with him when he goes out for a walk. She also calls him frequently, to check if he is still all right. Two participants' partners don't like them to drive a car anymore (which they don't agree with).

"My wife is quite concerned. She always tells me to bring my cell phone. Sometimes I go cycling along the river Dender. A big river with a tow path that's very quiet, sometimes you don't see anyone there, so she's worried if I go cycling there. Even when I go to the woods she'll call me regularly." (P10)

"So now I'm staying with my daughter, and if I weren't here because our home remodeling, I would have had to come here or go to Antwerp. They don't like me being home alone." (P6)

"I'm allowed to drive, and I do drive, but my wife always says: there's always something there, you don't have to drive yourself." (P6)

When discussing the opportunities of wearable technology, one of the participants' partners suggested an alarm system, relating to her worry that something might happen when her husband is out on his own:

P13’s partner: "Would that have an alarm system?"
Interviewer: “Yes, that would be possible.”
P13’s partner: “Yes, that would be the most interesting. Yes, if someone would monitor and would be able to take action immediately. Something like that would be interesting.”
P13: "Well, I take my cell phone with me now...
P13’s partner: "But it would be interesting in case something would happen to you, that someone would be able to take action right away. If you fall in the street and nobody passes by, then you're just lying there, you know what I mean.

Cognitive consequences

Some participants reported cognitive issues that they relate to their heart condition. Two mention memory problems specifically, one participant's wife indicates that her husband has become less alert.

Interviewer: "You also mentioned that you sometimes have memory problems, is that related to your heart condition?"
P6: "Yes, that started when I had a heart attack, when they had to do CPR."

Support family & friends

Several participants experience emotional support from family and friends. Mostly, this concerns their partners or children, or very close friends, people participants can always rely on for help in any way. Emotional support can take many forms. Some participants are calmer, or feel safer when their partner is with them, for instance because they are afraid something will happen when they're alone, or because their partner can calm them down by trying to find a solution for an urgent problem. Others mention that the
close relationship they have with their spouse and/or children is very
important to them, for instance because they feel truly valued. Being able
to talk about confidential topics, or to blow off steam is also mentioned.
Both family (grandchildren especially) and close friends make participants
experience happy moments in difficult times. On the downside, having to
rely on family and friends makes some participants feel like they are a
burden.

"I became a family person, which I wasn’t. I like to be home when my
children are here. And what makes me feel good is that, when you grow
older, when being less able to follow, you automatically get less attention.
And when you tell them something, or you get heard, and people pay real
attention, that feels good. Being considered. Yes, that’s something I
frequently experience. (P7)

"Well, our house is an open house, everyone can come in. That’s always been
the case. We can talk about everything, except about my illnesses. Talking
about illnesses is almost exclusively for my wife." (P3)

P6: "My oldest daughter said to me: daddy, come to us, but I don’t want to
be a burden to others."
Interviewer: "And do you feel that you are a burden to them?"
P6: "Of course."

User requirements mental wellbeing
The user requirements that were identified in terms of patients' mental
wellbeing are as follows. The HeartMan system could:

- Support patients to cope with their loss of independence
- Support patients to cope with their experience of being restricted in
  their everyday lives
- Support patients to cope with somberness, depression, sad moods
  - Motivate patients to focus on what makes life worthwhile
  - Motivate patients to focus on what one still can do (instead of
    what one can’t do anymore)
- Support patients to cope with restlessness
- Support patients to improve feelings of insecurity
  - Alarm system to warn someone in case something happens when
    a patient is alone (incl. localization)
  - Automatic alarm system that warns someone when it detects
    inactivity (incl. localization)
- Support patients to cope with worries, fears, anxieties:
  - Support patients to estimate realistic risks
  - Provide strategies to deal with worries
  - Educate patients about realistic risks (personalized,
    contextualized)
  - Support patients to interpret bodily signals
  - Educate patients about possible lasting consequences of their
    heart condition (realistic risks)
- Support patients with their feeling of being a burden to others
- Support patients to prevent becoming hyper-aware of their
  condition (causing worries), e.g. as a result of monitoring their
  condition, e.g. by means of:
  - Automatic monitoring
Educating patients about normal value ranges that shouldn't cause concerns

Activities of daily living

Home maintenance & gardening

Many limitations related to home maintenance and gardening activities are caused by physical limitations, as have been discussed above in the section on physical wellbeing. Sometimes this means that participants can't do any home maintenance and gardening anymore. A few participants (3/14) indicate that they aren't allowed – by their doctors or partners – to do certain activities, e.g. on behalf of their doctors or partners. Others have need to cut down, take it easy and can do light activities only. Some of them have adjusted the way they carry out the activities, for instance by using different (e.g. electrical) tools (although some participants reported that they are not allowed to use electrical tools anymore, as they might interfere with their defibrillators). Others have to ask family and friends to help them out, especially when it comes to heavier tasks such as maintaining larger pieces of land and vegetable gardens, or home improvement.

P4: "And gardening, we have a garden where I grow vegetables, and a greenhouse. But I can't do anything really. I have tomato plants that should be planted, but I can't even plant them."
Interviewer: “Because you were so weak?”
P4: "So weak, that's really it. I can't stand on my feet very long you know."
"I have to help out in the vegetable garden because he can't do it anymore. It's too much for him, for example, to walk back and forth three times between one end of the garden and the other. Physically that's too much for him." (P3's partner)

Preparing meals

None of the participants reported limitations regarding preparing meals.

Personal care

None of the participants reported limitations regarding personal care (e.g. hygiene, getting dressed, ...).

Mobility

Several participants' mobility has been affected by their heart condition. Some can't drive a car anymore due to physical limitations (e.g. lack of endurance). They have to ask others to drive them or rely on other means of transport. Others can only drive shorter distances (even when someone else is driving), limiting their radius of action especially in terms of day trips and travel. This, too, is mostly related to physical limitations. Two participants indicated that their partners don't want them to drive anymore, while they see no problem in driving themselves. Cycling too can be a problem. Some participants don't cycle anymore due to physical limitations,
or only cycle short distances. One participant has bought an electrical bike so that he can still cycle.

"I don't drive anymore either. I don't dare to anymore. I always take the train. You have to adapt." (P3)

"Well, not being able to do much, being limited in your options. Mobility, again. I have to... We have friends in the south of France and we visit them for 3 days. My wife drives. That's 350 km. per day. Per day, right! Some people drive to Barcelona in one day. Ehm... Being tired, that's it." (P7)

Day trips & errands

Participants’ limitations related to leaving the house for day trips or errands are mostly related to physical limitations and side effects of medication. Again, participants' limited endurance causes them to make fewer day trips or to make adjustments (e.g. shorter trips, taking more breaks, ...). One participant also mentions that it is difficult to make plans because of the fact that he has good days and bad days, which are difficult to predict. Obviously, everyone has good days and bad days, but for patients who have little reserve, such as CHF patients, this is a much more influential issue.

"We used to do that quite often. Now we still do day trips in small groups. In August we're doing one. A small gathering of four, five people at the coast. We arrive by tram and then we continue on foot to the dike, and that part is becoming too heavy for me. Last year I did it, but halfway I needed to take a break on a terrace. This year I’ll take a taxi for sure so I can walk up the dike." (P22)

"We do more and more day trips. If I have a good day, we're off. But making reservations, we can't do that anymore." (P8).

Several participants complain about the side effects of especially their diuretics, which makes them go to the toilet very frequently, which affects their mobility and freedom during day trips. As a result, participants make sure they know where to find public toilets when they go somewhere.

P14: "Yes, that’s because of the pill. It’s a diuretic. Once, while on my way to work I got real sick and I had water in my lungs. I was immediately taken to the hospital, where they prescribed me the medication."

Interviewer: "That probably has quite some practical consequences, when you’re going somewhere?"  
P14: "It’s OK, there are many shops that have restrooms. Sometimes we go to a garden center and then I’ll stay in the car. JBC has nice restrooms, as do Colruyt and Dreamland. But some shops don’t. If we go into town we have our standard places to make a stop. Where we drink coffee then.

Travel

Some participants can’t really travel anymore, or choose not to travel. Those who do travel experience some consequences of their heart condition. Some worry that they will need medical care abroad (where they don’t speak the local language) and bringing along large amounts of medication can be a problem as well. As was discussed in the mobility section (see above), driving long distances can be a problem due to physical limitations, and some participants avoid destinations with warm climates.

"Benidorm is the best of all, you know, they speak Dutch there, they have a good hospital there. An acquaintance of ours needs kidney dialysis and goes
to Benidorm every year. The nurses even speak Dutch there. If something happens, you'll be alright there." (P14)

Interviewer: "But you do still go on holiday?"
Partner P2: "Yes, but only in Belgium, not abroad, because if something would happen to him, I won't take that risk." (P2)

Hobbies & other activities

Similar to the limitations reported in regard to the activities discussed above, several participants have had to stop doing hobbies and other activities, such as creative and cultural activities. This is mostly due to physical limitations, that keep participants from (e.g.) planning activities or travelling to a location, or that require them to adjust their activities (e.g. using lighter materials for sculpting). Cognitive limitations that participants ascribe to their heart condition may also affect hobbies such as reading.

"I help out with cycling races too, as a sign post. I was scheduled for tomorrow, but I called it off. That won't be possible." (P1)

"In sculpting too, I was working on pieces of marble, weighing about 40 kg. Now, that isn't very big yet, 40, 50 kg, but still, it's 40, 50 kg. Now I'm changing to lighter materials, you know. Like that sculpture in the closet over there, that's a recent one. That is, that weighs maybe not even one kg. Or half a kg." (P4)

User requirements activities of daily living:

In terms of activities of daily living, the following user requirements for the HeartMan system were derived:

- Support patients to ask help from others when they need this
  - Lower threshold to ask for help (patient)
  - Lower threshold to offer help (family/friends)
- Support patients to maintain/improve mobility
- Support patients to cope with (the consequences of) reduced mobility
- Educate patients regarding realistic risks of driving (a car)
- Educate patients about realistic holiday-related risks
  - Advice on quality & accessibility of local language
  - Advice on climate & prediction of patient's response to that (personalized)

Nutrition

The advice participants receive and their adherence to this advice have been discussed in the section on advice. This section focuses on the impact of the advices and participants' adherence has as well as on physical changes related to food intake as a result of congestive heart failure.

To start with the latter, several participants report suffering from changes in how their body responds to food. They have lower tolerances for (e.g.) coffee, preservatives, or respond badly to food cooked in restaurants. Also, some participants suffer from an occasional or a temporary lack of appetite. Although most participants seem to have accepted these physical changes, some do comment on the social impact, feeling ashamed that they respond badly to food, or feeling bad that people have to take their intolerances into
account. Another negative side effect involves not being able to eat out in a restaurant anymore, either because of intolerances or because they feel their dietary requirements will be too difficult for restaurants or cafes to take into account.

To deal with the physical changes and the food advice they are given, participants have implemented several behavioral changes. They (or their partners) prepare special meals (e.g. leaving out, reducing or replacing certain ingredients), or they bring along their own food on day trips or dinners with friends and family. Some participants pay constant attention to not to exceed fluid intake levels.

Having to follow so much nutrition advice is not considered easy. Several participants express irritation due to the many rules and restrictions imposed on them, especially regarding food they really enjoyed before their heart condition. Also, some don’t like the taste of their adjusted meals (mostly due to reduced salt levels). As was discussed in the section on adherence, several participants indicate to apply food rules with some flexibility, and some experience feelings of guilt as a result of this.

"I cook every day, because we can't go to a restaurant with his diet. If we go on a day trip, we bring sandwiches. I'll go into a cafe to get something for myself." (Partner P3)

"Always wondering, how much can I eat here, how much of that can I have, does it have salt, is it sweet, sugars, liquids. That you constantly have to worry, that it isn't easy to find something that's OK." (P4)

User requirements nutrition

The limitations and consequences that heart failure patients experience regarding nutrition have yielded the following user requirements for the HeartMan system:

- **Support patients in predicting how they will respond to a specific meal or type of food** (e.g. based on ingredients)
  - Educate patients on possible 'side effects'
  - Educate patients on realistic risks of side effects
- **Support patients to indicate to others (friends, family, restaurants) what exactly they can't eat**
  - Provide overview of ingredients patients can't eat (personalized)
  - Advice on alternative ingredients
  - Suggestions for recipes
- **Advice on special meals** (personalized)
  - Advice on replacing ingredients without losing flavor
  - Suggestions for recipes
  - Provide strategies that make it easier to adhere to nutrition rules
- **Support patients in flexibly applying nutrition rules**
  - Support patients to predict the consequences of incidental non-adherence
  - Advice when and to what extent non-adherence won't cause problems
D2.2 User Requirements

- Advice suitable moments to apply flexibility ("remember, you have a birthday too tomorrow, you might want to save your weekly exception until then")
- Support patients to monitor fluid intake

Work & financial impact

Suffering from congestive heart failure has several work-related and financial consequences. Half of the respondents indicated that they made serious adjustments (e.g. fewer hours or different job content) or had to stop working (e.g. by taking early retirement). Several participants feel like they were forced to stop working, either by their employer, or by their doctors or insurer. They would have preferred to keep on working. For some, it was physically impossible to keep working.

Besides being unhappy about having to stop working, several other consequences were reported, such as missing job satisfaction and one's feeling of independence, or feeling set aside. The loss of social contacts with colleagues was mentioned too.

"It's misery, that I lost my job." (P6)

"Here I had to stop working. A true disaster for me." (P3)

"I'd rather kept working... They didn't have suitable work for me anymore, and I got the feeling I wasn't welcome anymore. OK, I was probably welcome, but I felt it anyway. Of course I kept working, financially that was... Things didn't improve financially once I stayed at home." (P10)

"Giving up my job was incredibly hard for me. I was a chef, and I got tremendous satisfaction from my job. I almost couldn't do it. I had been home for a while and my employer's doctor called me in for a check-up and told me very specifically that it was over." (P8).

Not only does stopping with working have psychological consequences, it also has financial consequences. Several participants had to retire earlier than expected, leaving them with lower pensions than anticipated. Also related to financial impact, some participants mentioned that not all of their medications or treatments are reimbursed.

"I did have hospital insurance and all. But when you get heart failure, that insurance is effective from a month before you get ill until three months after. But a month before I was fine! And three months later I still had bills and the insurance also didn't cover the rehabilitation." (P10)

User requirements work & financial impact

In order to support heart failure patients to deal with the consequences of their condition related to work and finances, the following user requirements for the HeartMan system were identified:

- Advice patients on strategies to be able to keep working:
  - See user requirements for physical activities
  - Advice alternative job content
  - Advice alternative job hours
• Support patients in coping with the fact that they are not (fully) capable to work anymore
• Support patients in finding alternative activities to achieve 'job' satisfaction
• Educate patients regarding the (financial) consequences when they consider to stop working
• Support patients regarding possible reimbursement issues
  o Advice on reimbursement rules (personalized)
  o Suggest alternatives that are reimbursed (e.g. for medication, therapy, support, assistive tools, ....)
  o Suggest alternative types of insurance

Social impact

Social network

Several participants reported that their heart condition resulted in a decline in social contacts. Some had friends whom they never heard from after their diagnosis, which disappointed them. On the other hand, some participants also seem to avoid contacting friends themselves because they feel that they are not interesting for their friends anymore due to their heart condition. Others mention that they have a small number of very loyal friends who would do anything for them if needed. What is especially frequently mentioned in this respect is the fact that because participants stopped working they don't see their colleagues much anymore. Some also link their limited social contact to ageing rather than their heart condition.

As was mentioned earlier with regard to physical and mental wellbeing, participating in (social) activities is sometimes difficult for participants. They can't leave their home as easily anymore, or activities are simply too demanding. Some participants especially mention that social activities are overwhelming for them.

"Well, many friends, actually, if you're in a situation like mine, it's very superficial. They are there in good times, but in bad times, especially when the bad times last long, it isn't interesting anymore. Then they can't enjoy that man anymore, because, you know, he can't do anything anymore. That's the way I feel about it." (P4)

"I used to have my colleagues, right? I don't see my colleagues anymore." (P15)

"If the two grandchildren are here, it's busy you know. I can't handle that anymore. It's time they go home after a day." (P13)

On the positive side, a physical illness may also result in new friends. One participant in particular mentioned that getting to know fellow sufferers brought him new friends, and another participant got involved in patient organizations after her diagnosis. Finally, some participants also made new friends after their diagnoses. They met people during fitness training for instance, or fellow patients.

"Elly, for instance, is someone I met during rehabilitation. She has become a good friend." (P10)

"I've been the chairperson of the heart patients for a while." (P19)
Lack of understanding

One of the social problems several participants commented on is the lack of understanding for their situation. First of all, it happens frequently that people in the participants' surroundings simply don't believe that the participants experience so many consequences of their condition. A problem that is reported by several participants in this respect is the fact that a heart condition is an 'invisible disease'. Patients don't necessarily look ill (especially not on 'good days', which is when they use to see friends), so for their surroundings it is sometimes difficult to remember or to realize that they are suffering from a serious condition.

It is also reported that it is almost impossible for others to truly understand what it's like to suffer from a heart condition, or what impact such a condition has. Participants experience that it is hard to explain how they really feel, and some indicate that only very few people in their environment really understand what they are going through and what they can and can't do. For some participants it isn't easy to share with others what they experience either. They don't like to talk about their condition with anyone but their partner or they are afraid that friends will get bored of their complaining.

"One of the most important things, and I keep coming back to that, and perhaps the most important part of heart failure, the consequences of heart failure, is that you keep looking quite good. That is, they say I do and they say that of most patients. And that you don't feel like that at all. And you can't keep up. And you get the label of lazy bones, freeloader and ehm..." (P6)

"And often people don't believe you have that. That if you have a good day, they think: it's probably bluff or something." (P1)

"They can't understand at all! Very little. In my case, my cardiologist knows. My GP, even of him I doubt whether he understands. Two of my friends, they understand. I have one who comes over to take a walk with me every Sunday, and he adjusts his speed and makes the route shorter if I want to. Ehmm... My wife, but my children don't. They still think I can do much more than I show. It is the way it is." (P6)

User requirements social impact

To make it easier for CHF patients to deal with the possible impact on their social life of their heart condition, the HeartMan system could:

- Support patients in maintaining friendships:
  - Advice to reduce feeling of not being interesting to friends
  - Advice on staying in touch (taking initiative)

- Support patients in maintaining (or improving) their close relationships with family and friends:
  - Advice patients on sharing their experiences with family and friends
  - Advice patients to experience happy moments with family and friends

- Support patients in getting in touch with fellow sufferers
  - Provide platform for fellow sufferers to get in touch
2.2 User Requirements

- Advice participation in specific activities (personalized, contextualized)

- Support patients to **reassure family and friends**
  - Educate family/friends about realistic risks
  - Allow patients to alert someone when something happens
  - Allow patient monitoring in case something goes wrong when they're alone
  - Allow patient to let people know they're all right
  - Educate about possible side effects - expectation management
  - Suggest appropriate time to take medication to limit impact of side effects on daily activities, mobility, etc.

3.6 HeartMan expectations

3.6.1 Ideas to improve adherence

The interviews contained a number of suggestions which could help us improve adherence. An important insight is that most participants report receiving extensive documentation about their condition in the hospital. They also know where it is located in their home, but they very rarely make use of it. This leads us to question their disease literacy to some extent. An idea to improve adherence then is to regularly remind patients about certain aspects of CHF or consequences of non-adherence via the wearable solution. It is essential to make this very easy to use and readable.

*Interviewer*: "Did they provide some documentation?"
*P14*: "Yes, I received it, I have it upstairs."
*Interviewer*: "Do you still need it?"
*P14*: "Well, I don't like to get rid of it, but I'm not using it anymore. But some things I read some of it. It has helped me a lot, especially for nutrition."

*Interviewer*: "Did they provide you with any documentation or brochures? Do you still use them?"
*P15*: "We received them, but I'm not using it anymore. I know where they are in case I need them. I received a lot of brochures about the different kinds of cheese and meat that exist, and which ones are good and which ones aren't."

Sometimes participants realize and confirm that they could use a little encouragement to go outside and go for a little walk. Such reminders could be easily implemented.

*Interviewer*: "Yes, it was one of the things we will explore in the project. This was about mindfulness exercises."
*P7*: "But that could be useful, so there is a little bit more pressure to... that your machine says: you haven't carried out your exercises. If you've finished your exercises, you could then perhaps indicate so on the device."

One of the more difficult advice to adhere to is following a healthy diet. Practically, participants have some difficulties figuring out what they can eat in the supermarket. There is a lot of information on the packaging, but it is not easy to understand for lay people. An idea for the wearable could be to foresee some simple guidance to shopping for the right food in supermarkets. Supermarkets are designed for the general public, not for this particular target group. Furthermore, they are probably designed to sell a lot of products, not to sell healthy products in particular.
2.2 User Requirements

Interviewer: “So you shouldn’t check everything yourself.”

P4: “Yes, if you would like to find out [about food] they have all these very little numbers [on the packaging]. You need a magnifying glass to be able to read all that information. And then you still have to understand it.

Interviewer: “So it is yet another problem.”

P4: “Yes, I think so. We have learned something about how they organize and place food in the supermarket. I find that interesting.” (P4)

Restricting fluid intake is somewhat difficult. Monitoring is even more difficult. Similarly, offering practical tips on how to monitor fluid intake for everything they eat and drink, at home or on location, could make adherence/monitoring somewhat easier.

Interviewer: “That fluid restriction is difficult, but how do you know you have gone over the limit?”

P8: “I used to weigh all the food. Sometimes when I have to cough I drink water for it to pass.”

Although most participants report good adherence concerning medication, there are still some who forget to take the right medication at the right time. Also, many participants report some deviations, mainly due to the practical consequences of the diuretics, with regard to medication. Therefore, a smart pill box that monitors the exact intake, and reminds patients to take their medication at the right time, could increase adherence.

Interviewer: “And could such a smart device be able to help with that, with medication?”

Partner P2: “Yes, that would help, because I can tell you: if I do not look at it in the evening, he has taken them. I prepare them here in the morning, I place them here, then he takes the one from the morning, and those for in the evening he places here, on the fridge. But then he does not remember to take the ones for in the evening.”

P2: “Yes, from time to time I can forget.”

Partner P2: “Sometimes. But the worst of all is that the blood thinners are part of the evening medication, that results in a reaction. So sometimes his blood is too thick, because he forgot one.”

“Well, something like that I find … I can imagine that there are people who need a signal to remind them to take their medication, or who need to be reminded to go for a walk or to start meditating…” (P2)

Although there are some fitness centres or hospital programs that offer adapted exercise programs, an interesting feature could be to provide personalised advice as to the intensity of the exercises patients are allowed to conduct via the wearable. This way they are not restricted to the presence or absence of such specialized fitness programs, and they can apply it to any kind of exercise they would like.

Interviewer: “You would think that due to the aging of the population there would be more activities designed for the elderly.”

P15: “Yes, it exists, it’s called easy cycling. Then you do spinning, but at your own pace.”

3.6.2 Mindfulness

Overall, the mindfulness exercise we included in the diaries did not go well. That was probably to be expected since it required a lot of text to explain. While executing the different steps in the mindfulness exercise, they had to
close their eyes and not focus on the diary. This back and forth between diary and mindfulness made the exercise very difficult. Furthermore, some participants were simply not interested in doing mindfulness exercises. Finally, when describing their experiences with the exercise, some reported great difficulties in trying to describe their feelings. However, there were valuable responses by several participants. One participant had years of experience doing yoga and found it a great idea. He did not do the exercise that we prescribed exactly, but engaged in yoga exercises he was used to perform. Other participants cite that the breathing part is valuable. Some of them have gotten some instruction on how to perform breathing or relaxation exercises during medical rehabilitation in the hospital. Such exercises help them to relax – either regularly, or during sudden moments of stress (such as family discussions or arguing with grandchildren).

Interviewer: “Yes, we have added this to it. So, those 2 exercises, did you do those?”
P7: “Oh yes, those consciousness exercises. Those are… I do yoga since 1978 [laughs]. So I knew about these exercises and I know that they can be very useful. That is also partly covered in the rehabilitation program of the professor. You can look it up. Near the end they provide a very basic form of relaxation exercises. And yes, it works. You can become much more relax, which I assume has a good influence on your sleep. I do not exactly what is said here [in our diary], but it matches for 85 or 90 percent.”

Interviewer: “Did you find it difficult?”
P3: “No, it is just as you say, you have to expose yourself a bit and your feelings. That’s a big problem for him.

Interviewer: “What do you think when you perform such exercises on a regular basis? What would be the effect?”
P3: ”That you become an angel (laughing). I don’t know, I didn’t do it for very long.”
P3’s partner: “He read it 10 times and still had to think very hard about what he had to do.”

Interviewer: “Yes, that is one of the things we are exploring to see if those exercises can have a positive effect or not. We are seeing some mixed results.”
P8: “I have done some breathing exercises someday, by focusing on certain body parts. It worked perfect, but I was lying down then. I have tried this exercise 2 times but twice I had the feeling that I was about to fall. When I lie down it works.”

Interviewer: “Do your thoughts wander off? How did you experience the mindfulness exercise?”
P10: “Maybe I am doing it wrong. I tried 4 or 5 times but I can’t write down what I feel.”

Interviewers: “OK. And can you explain what exactly does not work?”
P10: “I can’t focus on those, how do I call it, sensations.”

3.6.3 Wearable technology

The wearable technology provides many opportunities for HeartMan. Here, we make a number of suggestions based on patients’ experiences reported in the diaries and interviews. A first one is that they have a lot of documents, cards and other information about their condition, their health insurance, their cardiologist, the presence of a pacemaker, the medication...
they are taking etc. that could be contained in the wearable. This way, all
information is immediately accessible in case of emergency.

P14: "I carry cards and documents with me. I find that much more
interesting. I have everything here. This is the card for the defibrillator. A list
with medication. A hospitalisation card from my insurance company in case I
am admitted. When you have to go into an ambulance, they can easily
access it. My medical file number is also in here."
Interviewer: "Who completed all of this? Is it a doctor?"
P14: "No, I have completed all of this and collected all information."
P14’s partner: "Because the problem arises when he can’t give the code for
his iPhone, then they still can perform an emergency call. Also, when you
lose your iPhone, they can see whose phone it is."

An alert function is also something all patients would very much appreciate.
Currently, they carry their mobile phone with them as much as possible,
especially because of such possible emergencies.

"If I can give some more advice, always carry your mobile phone with you in
case something happens. I have my phone with my 9 out of 10." (P14)

In the previous case the patients themselves would alert the emergency
services using the wearable. Many patients also would like to have some
kind of alert based on their bodily signals such as heart rate, in case it
detects something is wrong. Sometimes they feel something, of they feel
bad, but they don’t really know what is wrong with them. This would then
go into the direction of a diagnostic device, which is probably a step too far
for HeartMan. Some patients do not know their own physical limits and
perform too much physical work (for example in the garden). Therefore, an
alert could be activated when they are passing a certain threshold during
exercise.

P3: "When I’m working in the garden I can’t stop."
P3’s partner: "Last week he was working on the street and I was cleaning the
garden. We agree that we will stop working at 12h and we take an hour and
a half for lunch and then we continue. Also, he never has a hungry feeling.
That’s a big handicap. Sometimes he is just stubborn. The device should give
a signal that he should quit. To take over the role of the Gestapo. That’s how
I feel sometimes."

"This week in the gym, I suddenly reached a heart rate that was too high,
and I felt that it wasn’t right. So sometimes those machines do not relay the
right information. I have a pulse of 202 but I could feel that my heart wasn’t
going that fast. I joined spinning for a while. There my heart rate did go up
because you want to keep up with the group, with the rhythm. I told the
cardiologist about this and he said I should stop doing that." (P15)

Similar to alerts are reminders. For examples, participants noted they could
help remind them to take their medication or to perform meditation
exercises.

"Well, something like that I find, because that is one of the few things I’m
happy about, is that I don’t worry a lot about it but I can imagine that there
are people who need a signal for that, to take their medication, in order to be
stimulated to go for a walk or start meditating." (P7)
Some patients already take part in a home monitoring program in which they have special equipment at home that is able to measure and transmit important medical data to the hospital. Other patients, when talking about such functionality, are quite positive about it because they (or their partner) would worry less if someone is continuously watching over them.

Interviewer: “If you think about an emergency, what could be useful?”
P15’s partner: “That it could be connected to the hospital or the ER.”
P15: “Now, I think that some elderly use it already. They have such a device at home that is connected to the hospital.”

Regarding the look & feel of the wearable devices, in this case presented as a smartwatch prototype, participants note that it should not stand out too much. They would not like to be seen with a medical device. It should not be too large either. Furthermore, as they are a generation that still wears regular watches, they don’t see any problem wearing a smartwatch. Regarding functionality, some indicated that they would not like to have too much interaction possibilities on the device itself; the smartwatch should mainly register their data. Possible interaction could be offered on other platforms that are easier to interact with such as a computer or tablet.
"What I also find about the equipment is that it should be as simple as possible concerning size. It should be a big clunky thing, so they can see you from afar. So, something like that, like a watch, that’s ok. But not too outstanding.” (P4)

R1: "I think it goes in the right direction. I wouldn’t use it as a reading device, more as a registration device. But it should work automatically, and linked to an iPhone, a smartphone, a tablet of a computer.” (P7)

P13: "So it is also a watch?"
Interviewer: "Yes, look, here is a prototype.”
P13: I always wear a watch anyway so, yes, that would be convenient.

Which data should the devices capture, contain and share according to the participants in the study? The following types of data are mentioned: a step counter, measured bodily signals (heart rate, blood pressure, sleep patterns…), and medical information (contact details for their hospital/cardiologist, a pacemaker card, medication they are taking).

"Measuring blood pressure, heart rate, could best be connected to a monitor, for the wearer it would be simple. A step counter etc. could also be very convenient. Perhaps a GPS for people who suffer from dementia. You can do a lot with it. All medical information could be in there as well.” (P14)

User requirements based on HeartMan expectations

In summary, in terms of Ideas for Improved Adherence, the HeartMan system could:

- Provide more useful and brief snippets of information regarding advice that patients should follow, and present it from time to time.
- Provide reminder functionality to make sure patients adhere to each type of advice.
- Provide usable tips on how to get or buy healthy food.
- Provide smart pill boxes integrated in the HeartMan solution.
- Provide exercises that are adapted to the level of physical effort the patients can handle.
- Provide audio or video instructions for the mindfulness exercises
- Provide breathing exercises for people who are not comfortable with mindfulness exercises
- Provide a wearable that mainly monitors and interprets bodily signals.
- Provide a wearable that provides simple visualization of specific data.
- Provide more detailed information via other platforms (PC, laptop, tablet, smartphone)
- Provide a wearable that contains the most important health-related information about the patient for emergencies and travel.
- Provide alert and reminder functionality.
- Provide a not too big and not too noticeable wearable.
4 Results: Overview of HeartMan User Requirements

In this section, all user requirements that were identified in the description of HeartMan’s context of use (see section 3) are presented in a structured format. They are presented in three main categories: 1) HeartMan’s advice & interventions; 2) HeartMan’s disease management support and 3) Interaction with the HeartMan system.

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While reading this section, one should keep in mind that the user requirements presented here are only based on the user research. As such, the requirements only reflect the problems, needs and wishes of the participants of the research performed in T2.2.1. Ideas for requirements of the consortium, nor medical and technical requirements have not been taken into account yet.

Another thing to keep in mind while reading the overview of user requirements is the fact that all support, advice, interventions, information and exercises provided by the HeartMan system should be 1) personalized (adjusted to the specific situation of the individual user) and 2) contextualized (offered at a moment and in a format that allows immediate action). This is not repeated for every individual user requirement in the overview below.
4.1 Advice & interventions

4.1.1 Durable behavior changes needed to adopt a healthy lifestyle

- Support patients in making behavior changes towards a healthy lifestyle: healthy nutrition, sufficient exercise level, proper liquid intake, correct intake of medication and a good sleeping pattern
  - Educate patients about the changes their heart condition requires
  - Educate patients about the reasons why they need to make changes to their behavior
  - Educate patients on realistic risks of unhealthy lifestyle habits
  - Provide advice and interventions to support patients in making durable changes
  - Include advice and interventions suggested by patients’ specialists

- Support patients to adhere to advice and interventions
  - Present advice & interventions in an understandable and actionable way:
    - Support patients in setting SMART goals for each advice (specific, measurable, achievable, relevant, time bound) e.g.:
      - Provide only useful information about advice in brief snippets of information at a time
      - Adapt advice & interventions to the physical status of the patient and his/her current context
      - Provide advice and interventions only at suitable moments, when a patient can follow up immediately
  - Support patients to reach the goals they set for each advice:
    - Monitor & inform patients about their progress regarding the goals they set for each advice, e.g.:
      - monitor whether medication is taken, and whether it is taken at the right time (e.g. by means of smart pill box)
      - monitor level of physical activity throughout the day to assess whether this is within advised range (e.g. by means of activity tracker)
      - monitor level of physical activity during exercises
      - remind patient of their daily intake limits (e.g. of specific types of food/drinks) & inform them about the current status
    - Remind patients to adhere to each advice in case they don’t seem to meet their goals
  - Provide strategies, e.g. to facilitate adherence to advice & interventions, e.g.:
    - Grocery shopping strategies
    - Cooking strategies, e.g. advice on replacing ingredients (such as salt) without losing flavor
D2.2 User Requirements

- Eating behavior strategies, e.g. for limiting intake of food/liquid
- Suggestions for healthy recipes
  - Support patients in temporary adherence flexibility (i.e. non-adherence) to facilitate long-term adherence
    - Support patients to predict the consequences of incidental non-adherence
    - Give an indication of what kind of deviations are allowed if patients need to make compromises due to everyday practical situations
    - Advice when and to what extent non-adherence won't cause problems
    - Advice suitable moments to apply flexibility ("remember, you have a birthday too tomorrow, you might want to save your weekly exception until then")
  - Help patients deal with contradictory advice (e.g. provided by different specialists).

- Support patients in monitoring their lifestyle:
  - Allow patients to measure and store health-related data, e.g.:
    - Weight
    - Blood pressure
    - Heart rate
    - Food intake
    - Liquid intake
    - Exercise
  - Make measuring and storing health-related data easy for patients:
    - Automat monitoring as much as possible
      - Provide wearable technology for automatic monitoring
      - Import data collected by other devices, e.g. home monitoring systems, activity trackers, heart rate sensors
    - Remind patients to measure variables that need manual measurements at a suitable time
    - Provide strategies to make it easy to measure difficult-to-monitor variables, such as liquid intake
  - Inform patients about their status based on monitored data
    - Provide simple visualizations of monitored data
    - Support patients to monitor changes in their condition (based on self-monitored data)
      - Inform patients of changes in their health/condition
      - Warn patient in case changes may point to a problem that needs follow-up by a caregiver
      - Help patients understand whether they are just having a bad day or whether their condition is consistently getting worse
    - Prevent patients from becoming hyper-aware of their condition due to frequent self-monitoring
• by automatic measurement
• educate patients about normal value ranges that shouldn't cause concerns
• Allow patients to share self-monitoring data with others (family members, caregivers)
• Alarm others (e.g. partner, family members or hospital) in case measured data reach possibly fatal values

4.1.2 Achieve/maintain good quality of life given CHF limitations

Nutrition

• Support patients in deciding whether they should eat or drink something or not:
  o Support patients in predicting how they will respond to a specific meal or ingredient
    ▪ Educate patients on possible 'side effects' and provide realistic risk estimations
  o Support patients to indicate to others (friends, family, restaurants) what exactly they can't eat
    ▪ Provide overview of ingredients patients can't eat
    ▪ Suggestions for alternative ingredients
    ▪ Suggestions for recipes

Physical activity

• Support patients in deciding whether they should engage in a physical activity or not:
  o Provide advice about which activities a patient can and can't do
  o Support patients in predicting when they can and can't do an activity (e.g. taking into account the weather, recent/future activities, good/bad days,)
  o Support patients in recognizing/predicting off-days
• Provide advice about how to do a physical activity
  o Advice how long a patient should do an activity
  o Advice suitable intensity for activities
  o Educate patient about realistic risks of engaging in an activity
• Support patients in adjusting a physical activity so that they can continue doing these, e.g. by:
  o Shortening durations
  o Shortening distances
  o Using lighter material
  o Lowering intensity
  o Using assistive tools
• Monitor & support patients during physical activities:
  o Support patients in monitoring their limits
\begin{itemize}
    \item Warn patient in case they are about to go over their limits (e.g. high heart rate, engaging in physical activities for too long)
    \item Support patients to monitor their limits during activities and throughout the day to prevent over-tiredness, e.g. by reminding them to take a break or to stop
\end{itemize}

**Medication**

- Support patients in making decisions regarding medication:
  - Support patients in deciding whether to use specific (sleeping) medication or not:
    - Educate patients about realistic risks (or lack thereof) of taking certain medication (e.g. sleeping pills)
  - Support patients with managing side effects of medication
    - Educate patients about possible side effects and provide realistic risk estimations
    - Provide strategies to limit/prevent/deal with side effects
      - Suggest appropriate time to take medication to limit impact of side effects on daily activities, mobility, etc.
  - Support patients to deal with the specific consequences diuretics
    - Advice about the most suitable time to take diuretics, e.g.
      - to avoid waking up frequently to go to the toilet
      - to avoid frequent toilet visits during activities that don’t allow frequent toilet visits
    - Provide information on location of nearest toilet

**Sex life**

- Support patients in making decisions regarding sexual activities (see general requirement about engaging in physical activities above for details)
  - Educate patients about the impact of their condition on sex life and provide realistic risk estimation

**Work**

- Support patients in deciding whether they should work or not
  - Educate patients on the impact of their condition on their ability to work and provide realistic risk estimation
  - Educate patients regarding the (financial) consequences when they consider to stop working
- Support patients in adjusting their job so that they can continue to work:
  - Alternative job content
  - Alternative job hours
- Support patients in finding alternative activities to achieve 'job' satisfaction
Mobility

- Support patients in making mobility-related decisions:
  - Educate patients regarding realistic risks of driving (a car)
  - Educate patients about realistic holiday-related risks
    - Educate patients about quality & accessibility of local healthcare
    - Support patients in predicting their reaction to the local climate

Healthcare

- Support trust relationship between patient and caregiver (e.g. the GP):
  - Allow patient to share information with caregivers
  - Allow caregivers to monitor & advice patient
- Support patients to deal with situations in which they don’t trust their caregivers
  - Support patients in expressing doubts about diagnosis
  - Support patients to apply for second opinion
  - Support patients in finding another caregiver
  - Support patients to demand their caregivers to be transparent
  - Support patients to demand their caregivers to provide personalized care (i.e. not only following standard rules and procedures)
- Support patients in achieving multidisciplinary, holistic care:
  - Support patients in dealing with contradictory advices
  - Support patients to demand their caregivers to share information to reach holistic, coherent advice

4.1.3 Coping with (the consequences of) CHF

- Support patients in coping with their restrictions regarding activities of daily living:
  - Support patients to cope with the fact that they are not (fully) capable to work anymore
  - Support patients to cope with (the consequences of) reduced mobility
  - Support patients to cope with their reduced capability to do physically demanding activities
  - Support patients to cope with the fact that they have to tone down their activity level in general
  - Support patients to cope with impact of their condition on sex life

- Support patients in the stabilization process after major medical incidences, e.g.
  - Support patients to recover from surgery
2.2 User Requirements

- Support patients in understanding whether adjustments to defibrillators, stents, pacemakers, medication, ... are required
- Support patients in getting used to new medication & side effects
  - Educate patients about possible side effects

- Support patients to deal with the social consequences of their condition:
  - Support patients in maintaining friendships:
    - Support patients in reducing the feeling of not being interesting to friends
    - Support patients to stay in touch with others
  - Support patients in maintaining (or improving) their close relationships with family and friends:
    - Support patients in sharing their experiences with family and friends
    - Support patients to create happy moments with family and friends
  - Support patients to get in touch with fellow sufferers
    - Support patients in finding and contacting fellow sufferers
    - Suggest participation in specific activities
  - Support patients to ask for help when they need this
    - Lower threshold to ask for help (for patient)
    - Lower threshold to offer help (for family/friends)

- Support patients with expectation management regarding the evolution of their condition
  - Educate patients about possible side effects of CHF that they might experience
  - Educate patients about possible typical developments
    - of their heart condition
    - of their general physical condition
    - of their general mental condition
  - Educate patients about realistic risks of specific deteriorations
    - of their heart condition
    - of their general physical condition
    - of their general mental condition
  - Educate patients about possible lasting consequences of their heart condition and provide realistic risk estimations
  - Educate patients about what is 'normal' for them to experience given their current status
  - Prepare patients for the possibility that their defibrillator/pacemaker responds to change in physical status

- Support patients to deal with mental consequences of their condition:
  - Support patients to cope with their loss of independence
  - Support patients to cope with feeling restricted in their everyday lives
  - Support patients to cope with somberness, depression, sad moods
  - Motivate patients to focus on what makes life worthwhile
D2.2 User Requirements

- Motivate patients to focus on what they can still do (instead of what they can't do anymore)
- Support patients to cope with restlessness
- Support patients with their feeling of being a burden to others
- Support patients to accept the fact that they have a heart condition and that they have become chronic patients
- Support patients to cope with worries, fears, anxieties:
  - Educate patients about realistic risks
  - Provide strategies to deal with worries, fears, anxieties, e.g.
    - Provide exercises to avoid mulling at night
  - Support patients to interpret bodily signals: are signals indicative of a recurring incident or not?

- Support patients in feeling safe and secure:
  - Allow alarming in emergency situations:
    - Allow patients to (actively) alarm someone
    - Allow patients to activate physical activity and location monitoring & warning others in case something goes wrong when they're alone
  - Allow patients to let people know they're all right
  - Allow patients to share vital data with their doctors for monitoring

- Specific requirements for mindfulness exercises:
  - Provide audio or video instructions for mindfulness exercises
  - Provide breathing exercises for people who are not comfortable with mindfulness exercises

4.2 Disease management

- Support patients and their partners to do disease management together
  - Allow patient to give others access to the HeartMan system

4.2.1 Disease literacy

- Improve patients’ disease literacy:
  - Educate patients on healthy eating behavior
  - Educate patients on their heart condition
- Support patients to pay attention to bodily signals that may indicate over-exercise or a physical problem
  - Educate patients about the bodily signals they should be aware of that might indicate a physical problem
  - Provide strategies to create continuous awareness of bodily signals that indicate over-exercise or a physical problem
- Support patients with co-morbidity:
- Help patients understand causes of symptoms (which disease causes which symptoms?)

**4.2.2 Administration**

- Support patients in making appointments with caregivers
  - Remind patient when it’s time to make an appointment for a regular check-up with a caregiver
  - Remind patients when an appointment for a regular check-up is coming up
  - Provide a (printable) overview (e.g. agenda) of all appointments with caregivers
- Provide patients with an easily accessible overview of the most important medical information, that they can always carry with them (e.g. in a wearable) e.g.:
  - Numbers of medical files, insurance policies, ...
  - Medication
  - Medical devices (e.g. IDC, pacemaker, defibrillator, ...)
- Support patients in contacting caregivers
  - Provide an overview of contact details of important caregivers
- Support patients regarding possible reimbursement issues
  - Educate patients about reimbursement rules that apply to them
  - Suggest alternatives (e.g. for medication, therapy, support, assistive tools, ....) that are (fully) reimbursed
  - Suggest alternative types of insurance

**4.2.3 Medication**

- Support patients in taking their medication in the right way, at the right time
  - Remind patient when it is time to take medication
  - Remind patient to bring medication when leaving the house
  - Support patient to organize medication to facilitate correct intake (e.g. by means of digital pill box)
  - Provide strategies to create routines to facilitate correct intake
  - Support patients in dealing with taking large amounts of medication
- Remind patient when he/she should request new medication prescriptions

**4.3 Interaction**

- Be usable and accessible for patients with limited technological knowledge and skills
2.2 User Requirements

- Assume users don’t find/use additional functionalities on their own
- Assume users will need frequent support when using the HeartMan system
  - Provide more detailed information via more than one platform (PC, laptop, tablet, smartphone)
  - Provide large displays and large buttons
5 Results: Cross-check Italian data

In this section, we discuss the main differences and similarities between the Belgian and Italian data. For the analysis of the Italian data, we used the same procedure as for the Belgian data (i.e., semi-structured coding of fully transcribed interviews). Although there are some notable differences in terms of emphasis put on different requirements, no new requirements needed to be added based on the analysis of the Italian data.

5.1 Patients’ technology use

<table>
<thead>
<tr>
<th>No of participants</th>
<th>Technology</th>
<th>Use</th>
<th>Frequency of use (times/day)</th>
<th>Subjective ease-of-use (0 = I difficult; 10 = easy)</th>
</tr>
</thead>
<tbody>
<tr>
<td>3/15</td>
<td>Analog TV</td>
<td>Watch TV (in general), news, movies</td>
<td>1.7</td>
<td>5.8</td>
</tr>
<tr>
<td>13/15</td>
<td>Digital TV</td>
<td>Watch TV (in general), news, movies</td>
<td>1.7</td>
<td>5.7</td>
</tr>
<tr>
<td>4/15</td>
<td>Audio installation</td>
<td>Music, news</td>
<td>1.3</td>
<td>3.25</td>
</tr>
<tr>
<td>5/15</td>
<td>Internet</td>
<td>General, looking up information, news, mails, social media</td>
<td>1.25</td>
<td>7.0</td>
</tr>
<tr>
<td>5/15</td>
<td>PC/Laptop</td>
<td>News, mail, looking up information, internet, skype,</td>
<td>2.0</td>
<td>7.3</td>
</tr>
<tr>
<td>4/15</td>
<td>Tablet</td>
<td>Internet, learn, fun/leisure, look up information, social media</td>
<td>0.6</td>
<td>6.0</td>
</tr>
</tbody>
</table>
5.2 Therapy adherence and disease management

The reported therapy adherence is slightly higher in Italy, and participants experience less difficulties in managing their disease. Those participants that do experience problems in therapy adherence and disease management typically lack intrinsic motivation to improve their health. Most participants mention that it takes time to implement the required changes but after a while it becomes more or less a habit (e.g. measuring blood pressure in the morning, avoiding salty food, scheduling appointments with caregivers). A typical situation that can break the routine is when a patient feels anxious. This may, for instance, keep her/him from going for a walk to improve her/his overall endurance. Similar barriers were found among Belgian participants.

5.3 Support from relatives

The Italian participants are less dependent on their partner but often get more active support from their children. A minority relies heavily on their partner for disease management tasks such as making appointments with caregivers. A third of the participants mentioned they need no or only little help from relatives with regard to their disease. These patients typically have a positive mindset. Half of the patients rely on their children on a daily basis, both for practical and moral support. Especially the latter finding differs from the Belgian data, where only a minority mentioned receiving support from one of their children on a daily basis. This may be due to cultural differences, that is, the balance between individualism and the importance attributed to the family.
5.4 Mental support and Mindfulness

Whereas a majority of Belgian participants did not or only partly execute the awareness and Mindfulness exercises in the diary, most Italian participants executed the exercises. Whereas one participant mentioned becoming more anxious during these exercises (which is the exact opposite of what is aimed for with Mindfulness), the majority found it rather boring but would consider doing it on a regular basis if it would improve their condition and reduce feelings of anxiety. A minority of the participants had previous experiences with such exercises and see the value.

5.5 Overall mood and attitude

Half of the Italian participants mentioned that they are often anxious and restless due to their medical condition. These anxieties severely limit their daily activities. For instance, some participants mentioned that they do not wish to leave the house because they are afraid they will not get medical assistance in time if something goes wrong. Similar fears were noted among Belgian participants. Related to this, some participants explicitly mentioned they do not like to reflect on their condition and especially not on when it started. This makes them sad and even more anxious. A third of the participants do not experience such fears. They have a positive mindset and tend to focus on what they can still do rather than on what they cannot do anymore.

5.6 Expectations regarding Heartman

The expectations regarding the Heartman system (i.e., how it should support CHF patients in managing their disease and adhering to the prescribed therapy) are quite similar compared to the Belgian data. Since many of the patients do not use digital media often, they lack experience and skills, are afraid to make mistakes when interacting with a digital device and/or do not see any added value of wearables. Therefore, it is of utmost importance that the system is user friendly and not overly complex. In addition, the wearable should not be too big for aesthetic reasons. Suggested functions for the Heartman system are measuring blood pressure, taking away anxiety, automatic monitoring of physical activity and giving appropriate feedback (e.g., in a risky situation when certain thresholds are exceeded). These suggestions were already included in the requirements based on the Belgian data. From the Belgian and Italian data, we can conclude that the value of the Heartman system needs to be clear from the very start. A high perceived usefulness will have a positive impact on the ease of learning and, as such, on the ease of use of the system.
6 Contact Data

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Dear participant,

Thanks again for participating in our research for the HeartMan project! We highly appreciate your opinion and getting to know the patients for whom we are creating a solution in the project is of invaluable importance.

This first study of the HeartMan project is a so-called diary study. In this study, 60 people who suffer from congestive heart failure (30 in Belgium and 30 in Italy) will keep a diary. This allows us to understand what their lives look like and how we can employ new technology to help them to deal with their heart condition.

This diary consists of 10 assignments. You get about two weeks to make these assignments, and you can make them in any order you wish. Your answers to the assignments will be treated confidentially and anonymously. Only we, the KU Leuven researchers directly involved in the study, will know the names of the participants. Whenever we communicate about the results of this study, we will make sure to anonymize everything that you share with us.

If you have any questions during the study, please don’t hesitate to contact us!

Thanks again!

Kind regards,

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D2.2 User Requirements

This is me

In this assignment we ask you to tell us about yourself: Who are you? What drives you? This background information helps us to understand the other assignments.

You can answer as you prefer: in keywords, in sentences, drawings, collages, photos, ... Everything is possible! In case you'd rather not answer one of the questions you can of course leave that one open.

This is what I look like:
You can make a drawing, use a photograph, or describe yourself.

'Home' for me means:

Things I like to do in my spare time:

My 'guilty pleasures':
Something you enjoy secretly, when nobody is watching you.

This is what I would bring to a deserted island:

Three things that make me happy:

and three things that I hate:

I also want to share this with the researchers:
Do you think we've forgotten to ask something important? Please tell us here.

My life motto:
Pick a motto that matches where you stand in life at home: what do you find important to feel good?
D2.2 User Requirements

Example

A day in my life:

On a typical day I get up at 07:00. First, I take a shower, blow dry my hair and put some cream on my face. Then I get dressed (usually I decide what to wear the next day before I go to bed to save time) and go downstairs picking up the newspaper from the mailbox on my way to the kitchen.

In the kitchen the first thing I do is check on my coffee machine. Then I set the breakfast table. I normally eat two slices of bread, but sometimes I like to make some almonds instead. I also prepare lunch in the meanwhile; 4 sandwichs and a piece of fruit. During breakfast, I read the newspaper. Or actually I scan the headlines as I don’t have much time. Most days, I eat breakfast alone as my husband has recently retired and he likes to sleep in a lot.

When I’m finished eating I clear away my empty plate and mug andleave the table set for my husband. I put my lunch in a lunchbox and in my bag, I quickly brush my teeth in the kitchen sink and take my daily medication against high blood pressure. By this time, it usually is 08:00, time for me to leave for work.

I put on my coat, grab my bag and car keys, and go to the garage to start the car. I drive to work, which costs me about 20 minutes. Arriving at the school where I work (I’m a middle school teacher), I immediately go to my classroom to prepare for my first class. I spend the coffee break with my colleagues in the teachers’ room, chatting about our families, or our favourite teatives. I like to spend lunch outside, if weather allows, eating my sandwiches on a bench in the park behind the school. On most days, my first class ends at 13:00 and I’m home around 13:30.

Before I leave the school, I give my husband a quick kiss as he knows I’m on my way. I always wait for me with a fresh pot of tea and we discuss our days so far. After tea, I spend a couple of hours in my study preparing classes or checking students’ homework or tests. Until 20:00 I take my dog, Bonzo, for a long walk while my husband cooks dinner. Back home, he always reminds me to measure my blood pressure, which I have to do every day and note down for my GP. It’s important that I do that around the same time every day.

After dinner we wash the dishes and decide how to spend our evening. We like to work in our garden or to read in front of the fire. Or we watch some or an old time surfing the internet. Occasionally, we go to the cinema or babysit one of our grandchildren.

When I have an early class the next day, I prepare to go to bed around 22:00. I clean up a bit, put my work stuff in my bag, and if my blood pressure was rather high in the afternoon, I measure it again. Optionally, I brush my teeth, put undress, set my alarm clock and go to bed. I never read or watch TV in bed. I try to go to sleep immediately.

A day in my life

Below, describe an average day as detailed as possible, similar to the example on the left. Pay special attention to anything that is related to your heart condition. You may continue on the next page if you need more space.
### My digital technologies & media

Indicate which of the following digital technologies you use. Describe for each technology how often you use it, and how easy or difficult it is for you to use it. Technologies that you don't use may be left open.

<table>
<thead>
<tr>
<th>Technology</th>
<th>Use</th>
<th>Use Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analogue television</td>
<td>Use</td>
<td>About ... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Find it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>easy</td>
</tr>
<tr>
<td>Digital television</td>
<td>Use</td>
<td>About ... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Find it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>easy</td>
</tr>
<tr>
<td>Audio installation</td>
<td>Use</td>
<td>About ... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Find it</td>
</tr>
<tr>
<td></td>
<td></td>
<td>easy</td>
</tr>
</tbody>
</table>

*Cross out what isn't relevant
## D2.2 User Requirements

<table>
<thead>
<tr>
<th>Device</th>
<th>I use this for</th>
<th>I use this for</th>
</tr>
</thead>
<tbody>
<tr>
<td>Computer/laptop</td>
<td>I use this about .... times per day/week/month/year*</td>
<td>I use this about .... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
</tr>
<tr>
<td>Tablet/iPad</td>
<td>I use this for</td>
<td>I use this for</td>
</tr>
<tr>
<td></td>
<td>I use this about .... times per day/week/month/year*</td>
<td>I use this about .... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
</tr>
<tr>
<td>Mobile phone (not a smartphone)</td>
<td>I use this for</td>
<td>I use this for</td>
</tr>
<tr>
<td></td>
<td>I use this about .... times per day/week/month/year*</td>
<td>I use this about .... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
</tr>
<tr>
<td>Smartphone</td>
<td>I use this for</td>
<td>I use this for</td>
</tr>
<tr>
<td></td>
<td>I use this about .... times per day/week/month/year*</td>
<td>I use this about .... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
<td>I find it difficult + easy to use this (place an X on the line between difficult and easy)</td>
</tr>
</tbody>
</table>

* Cross out what isn’t relevant
### D2.2 User Requirements

<table>
<thead>
<tr>
<th>Activity tracker (e.g. a step counter, a FitBit, a smartphone app tracking your activity level)</th>
<th>I use this for</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I use this about ... times per day/week/month/year*</td>
</tr>
<tr>
<td></td>
<td>I find it easy to use this (place an X on the line between difficult and easy)</td>
</tr>
</tbody>
</table>

* Cross out what isn’t relevant

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**Letter**

In the envelope labeled with 'Letter' you will find a sheet of stationery.

Jules has recently been diagnosed with the same heart condition as you have. His condition is similar to yours when you were diagnosed. Write a letter to Jules, starting from your own experiences. Give him advice to help him deal with his condition and to be prepared for what’s lying ahead of him.
Association

Write down as many words that are related to your heart condition. These can be positive, neutral, and negative words. The words may be related to any aspect of your condition, such as physical aspects or emotional aspects, but also with aspects related to activities of daily living or your social life, or any other aspect you can think of.
Timeline

In the envelope labeled with 'Timeline' you will find a sheet of paper with a timeline printed on it, and some coloured stickers.

Mark the most important events in your life by placing a coloured sticker on the timeline. For each event, briefly write next to the sticker what happened, and what the impact of this event was on your life.

We provided stickers in two colours:

- Use blue stickers for events related to your heart condition (this could be events like hospitalisations, surgeries, changes in medication, major improvements or deteriorations of your condition, etc.)
- Use yellow stickers for important events related to your personal life (e.g. special birthdays, family events, a new hobby, ...)
D2.2 User Requirements

Draw a tree on the left page of which the main branches represent different aspects of your life that may be affected by your heart condition. These may include your diet, your energy level, your social life, your mood, your sleeping pattern, etc.

Each of these aspects can have several sub-aspects, e.g. foods you can’t eat anymore, or specific sleeping problems you have. Add these sub-aspects by creating smaller side branches.

Below you can find an example of a tree that someone started to show the impact of a broken leg. Don’t worry about how nice your tree looks. It would also be fine to make a very schematic tree, only showing the main and side branches.
My social network

In the envelope labeled with ‘Social network’ you will find a large sheet of paper and some coloured stickers. On this sheet, you see several circles. Imagine that you represent the inner circle.

- Place coloured stickers on the paper, each representing a person in your social network:
  - Use yellow stickers for family members
  - Use green stickers for friends, acquaintances, neighbours, etc.
  - Use blue stickers for caregivers (doctors, nurses, physical therapists, …)
- Place the stickers in such a way that people who are closer to you, are closer to the middle circles than people who are less close to you.
- Next to each sticker, write down the name of the person, and your relationship with them.
Tell us how you experienced the awareness exercise! Could an exercise like this one be meaningful to you? Why (not)?

Exercise

We're going to do the exercises described below. This will take about ten minutes. After doing the exercise, describe what you thought of it on the left page.

Preparation:
Read the entire assignment carefully first. Next, sit or stand up straight. If possible, close your eyes. Take your time to guide yourself through the following three steps.

Step 1: Awareness
Bring your awareness to your inner experience, focus on what you are experiencing right now:

- Which thoughts are going through your mind? Try not to resist these thoughts, but try to accept them by putting them into words.
- Which feelings do you have right now? Pay attention to possible uncomfortable or unpleasant feelings, accept their presence, and name them.
- Which bodily sensations do you have right now? Scan your body step-by-step to notice every sensation of tension.

Step 2: Gathering
Now bring your awareness to your breathing for a few minutes. Pay attention to the sensation of breathing in your abdomen, feel your abdomen expand when you breathe in, and go down when breathing out. Follow the stream of air going in and going out. Use your breathing to focus on the presence of your mind wandering, gently guide it back to your breathing.

Step 3: Expansion
Now expand your focus to your entire body, your posture, and your facial expression. When becoming aware of discomfort or tension, guide your attention to these by imagining that your breath streams to the place of discomfort or tension. Relax and open up while the air is streaming away from the discomfort or tension.

Try to take the expanded focus with you during the remainder of the day as good as you can.
Costs & benefits

You have probably been given lots of advices by your doctors and by other caregivers (e.g. about exercise, a healthy diet, ...). We can imagine that it isn't always easy to follow these advices.

Below, write a list of costs and benefits if you would seriously follow the doctor's advices:

Benefits | Costs
---|---

Below, write a list of costs and benefits if you would not follow the doctor's advices:

Benefits | Costs
---|---
Appendix B – Interview protocol

Let me start by thanking you in advance for meeting with me for this interview. Let me first tell you a little bit about myself. [INTRODUCE YOURSELF] I am a researcher from the University of Leuven and we...
Your experiences and opinions will help us to design a technological solution to make it easier to manage your chronic heart condition on a daily basis. At this time, I don't have a good view on what it means to live with congestive heart failure. Therefore, it is also important that we know, and through the remainder of the project, involve the patients themselves, people like yourself, in order to fully understand what it means to live with congestive heart failure. Without this information, it is impossible to design a solution that will work for you.
The results of this diary and interview study will be analysed and communicated to the partners in our project. We make sure that your identity cannot be revealed. Your identity or personal information are not of interest anyway since we draw conclusions based on the information of all the participants as a whole. The partners in our project are medical experts, and technical experts that will be involved in the making of the new technological solution.
This interview will last about one and a half hour. If you want to take a break, just say so! Let me now explain you the informed consent form.

Introduction (to build rapport)

1. How did it go with the diary? If you look back
   - Which assignments did you like the most? How so?
   - Which assignments did you find difficult to complete? Can you tell me why?
   - In the case you did not complete the assignments, why was that? What stopped you?
2. [DISCUSS SUB-ASSIGNMENT "This is me"]: We asked you to keep a diary. Let us go through the first pages.
   - Can you tell me about what you wrote [DISCUSS SUB-ASSIGNMENT "In my spare time I..."]?
   - Why would you bring that to a deserted island?
   - Can you tell me more about why you like/hate these three things?
3. [DISCUSS SUB-ASSIGNMENT "A day in my life"]. Can you take me through an average day in your life?
   - Which part or parts of the day do you like/dislike? Why is that?
   - How do other days sometimes differ?

My digital technologies & media

1. [DISCUSS ASSIGNMENT "My digital technology and media"]: We are investigating how to design a technological solution for people like you.
Therefore, it is important for us to understand how you use different technologies: TV, radio, etc. So, let us take a look at the next page.

- Can you show me which devices you use and what for?
- Is there any technology or device you couldn't live without? Why?
- Can you give me some examples in which you experienced problems with technology? What impact did it have on you?
- Would you describe yourself as a heavy or light technology user? How so?

**Patient Experience**

1. **[DISCUSS ASSIGNMENT "Letter"]** Another exercise we included in the diary, was the letter you would write to someone who was just diagnosed with the same condition. Let us take a look at that.
   - Can you tell me more about what you wrote to Jules?
   - Why did you mention these issues/experiences?

2. How did the doctors or nurses prepare you for managing your condition?
   - Did they provide you with any material, leaflets, documents or instructions at the time? [TAKE PHOTOS WITH PERMISSION] Could you show me? Do you make use of them? If so, how? If not, why not?

3. **[DISCUSS ASSIGNMENT "Associations"]** Let us now take a look at the words you associate with your condition
   - Tell me about what you wrote. Why did you write this?

4. **[DISCUSS ASSIGNMENT "Timeline"]** In a separate document we included a timeline for you to add more information about important events in your life. Could you guide me through your timeline?
   - Can you describe what changed for you after the diagnose had been made?

5. Could you describe a "recent" important event related to your disease (e.g. a hospital admission, new medication, emergency situation, ...)?
   - What started it? How did it evolve? What was the end results? How do you look back at this event?

6. How would you describe the status of your condition at this moment?

**Social network**

1. **[DISCUSS ASSIGNMENT "My social network"]** The following exercise focused on your social network.
   - Could you tell me more about the people you have indicated with the stickers?
• Which of these people are important to you with regard to your condition (not necessarily only the caregivers)? Why and how do they become important to you?
• Could you describe your contact with your caregivers? When do you see whom? Can you tell me more about those moments?
• Are there any people you don’t see any more, or significantly less than you used to? Which people don’t you see any more since you have acquired your condition? Why is this the case?

Disease management

As I said earlier, we will design wearable technology to help you manage your condition. Therefore, we would like to hear more about how you manage your condition.

1. The cardiologists in our project have already indicated that there is much to keep track of when managing your condition. Could you tell me about what issues you have to take into account, and how you try to adhere to these concrete advices?
   • How do you keep track of everything related to your disease? Monitoring, administration, planning, ... Can you show me how you do that?
   • Which medication do you have to take, when? [TAKE PHOTOS WITH PERMISSION]
   • How do you weigh yourself? How often do you do this?
   • How about blood pressure?
   • Do you have to watch what you eat? How do you keep track of this?
   • I guess that you also have some appointments with nurses, doctors and other caregivers. How do you arrange those? Who takes the initiative for these contacts? Do you receive any help from caregivers or other organizations to do this?

2. To what extent are you capable to adhere to all these issues with regard to your condition (e.g. registering all kinds of information, making appointments etc.)?

3. Which parts of keeping track of your disease do you find easy to do? Which are more difficult? Why?

4. Are there specific situations or moments when you find it difficult to keep track of your disease? Can you give me some recent examples? Why? When is this easier to do for you?

Therapy adherence

[DISCUSS ASSIGNMENT "Costs and benefits"]

1. What have your caregivers told you to do and not to do? Which are those advices? Could you discuss any advantages and disadvantages for both following the advice or not following the advice?
2. Which advices/rules/therapies do you find easy to fully adhere to? Which are hard? Why? When you do not adhere to an advice, how do you feel afterwards?
3. Are there any factors that influence whether you adhere to advices/rules/therapies or not? E.g. your mood, your physical wellbeing, people around you, specific situations? Something else?
4. How do you try to avoid not adhering to the advice? Could you think of anything else that would make it easier for you?

**Mindfulness**

[DISCUSS ASSIGNMENT "Awareness exercise"]
1. What did you think of this exercise? How did you experience it?
2. What do you think the effect of exercises like these would be if you’d do them regularly?
3. If you’d know that exercises like these would be good for your health, would you do them more often if you were given specific exercises? Why (not)?

**Attitude regarding wearable technology**

In our research project we will try to use wearable technology to help patients manage their condition. Let me show you an example of wearable technology. [SHOW the picture of the wearables]. These devices contain a number of sensors that can measure your heart rate, the amount of steps you have taken each day etc. Many devices are currently available, and are mainly used for sports. Cyclists for example can track each ride, and even receive training instructions. But there are also people who sit behind a desk all day at work, and they receive notifications to stand up and take a walk for example. A step counter then keeps track of their daily physical activities. They also exist in many forms: there are watches, belts, Band-Aids etc.

For our project we will go one step further and use it for medical purposes. In order to do that, we first need to understand the condition from a patient’s perspective. That is why we are here.

- If we were to provide you with a wearable to help you manage your condition, what should it do for you? How could it help or assist you?
Appendix C – Codebook

Disease management

Self- monitoring
- Weight
- Medication
- Exercise
- Heart rate
- Blood pressure
- Changes in condition
- Diet

Support family/friends

Medical checkup

Disease management artefacts

Capability to manage disease
- Easy to manage
- Hard to manage

Administration

Patient characteristics

- Technology
  - Type of technology
  - Reported use
  - Reported kills
  - Willingness to use
  - Reason/motivation
  - Preference
  - Frequency
- Medical
  - Disease literacy
  - Heart condition
  - Co-morbidity

Patient experience

- Important event
D2.2 User Requirements

- Emergency situation
- Other

- Lifestyle changes
- Limitations/consequences
  - Physical wellbeing
    - Energy level
    - Sleep
    - Support family/friends
  - Mental wellbeing
    - Mood
    - Anxiety
    - Support family/friends
  - Nutrition
  - Work
  - Activities of daily living
    - House hold
    - Preparing meals
    - Personal care
    - Other activities
    - Driving/mobility
  - Financial impact
  - Hobbies
  - Social impact
    - Lack of understanding
    - Planning/logistics
  - Sex life
    - Contact fellow sufferers
    - Perceived status condition
    - Coping

Advice

- Content advice caregivers
  - Nutrition
  - Exercise
  - Daily activities
  - Monitoring
  - Medication
D2.2 User Requirements

- Smoking
  - Own and peer advice
  - Changes in advice
  - Contradictory advice
  - Adherence
    - Reported adherence
      - Adherence
      - Non-adherence
      - Flexible adherence
      - Adherence difficulty
        - Easy
        - Hard
    - Reasons (non)adherence
      - Intentional non-adherence
      - Cognitive dissonance
      - Trust in doctor
    - Adherence strategies

Relationship with caregivers
- Role/nature of contact
- Moment of contact
- Frequency of contact
- Satisfaction
- Trust

HeartMan expectations
- Wearable technology
  - Look and feel
  - Which data
  - Alerts
  - Data sharing
  - Interpretation bodily signals
- Mindfulness
- Ideas to improve adherence