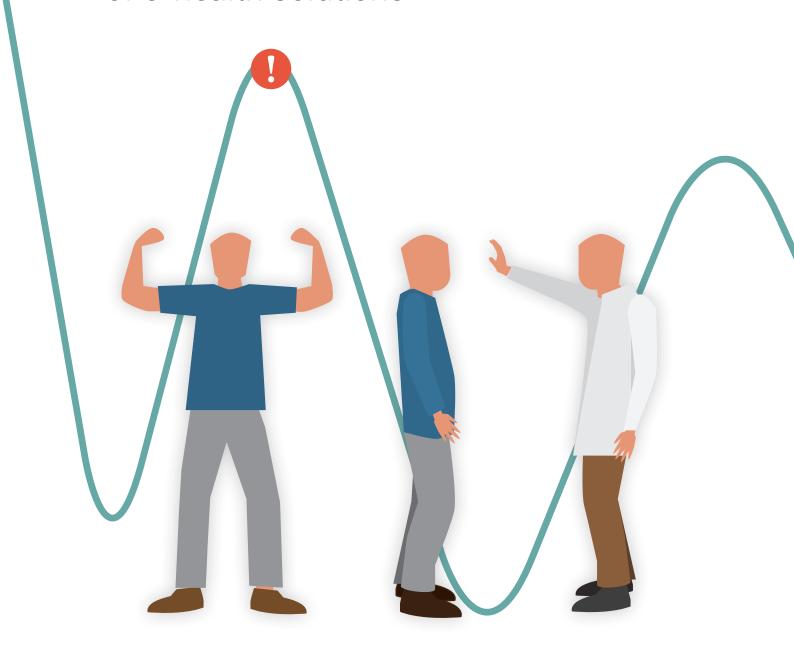
ENERGY MANAGEMENT OF COPD PATIENTS

Exploring the needs and criteria for support in self-management by means of e-health solutions



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Abstract

The number of people with chronic diseases is growing in The Netherlands. This growth leads to an increase of the healthcare cost. For example, costs for consults with different Health Care Professionals (HCPs), hospitalization and medication. To control or decrease the rising costs, patients are stimulated to use e-health solutions at home for self-management. These solutions aim to help the patient to manage their disease, develop a healthy lifestyle and prevent hospitalization.

COPD and energy management

One of these chronic diseases is COPD . COPD is a lung disease that causes damage in the patients lung, which results in energy and breathing problems. COPD patients often experience a decrease in their energy level, while the activities and goals in their life stay the same. So they have to find a new balance between their goals in daily life and their abilities, by changing their routine, habits and priorities. If a COPD patients struggles with finding this balance, they can follow a revalidation program, but once they are back home they are self-reliant again. The increasing developments of e-health solutions form an opportunity to support COPD patients with energy management back home after revalidation.

E-health and self-management

The management of energy can be seen as one of the self-management tasks for people with chronic diseases. With the developments in technology like smart watches with step counters and heartbeat monitors new opportunities arise to support the patient with these self-management tasks at home. A system that supports patients in self-management will be able to gather different types of relevant data, integrate this data so it becomes useful and display it to the users in a way they are able to reflect and learn.

Medicine Men

Medicine Men develops e-health solutions to support patients in self-management. Medicine Men focuses mainly on functional solutions for medication & treatment management and the communication with healthcare providers and caregivers. Medicine Men involves end users in the development of their solutions in order to create the right functionality. Medicine Men is less focused on the experience and feelings of the user. Therefore this project will focus on the experiences of COPD patients.

Focus of the project

This project focuses on exploring the needs, challenges of COPD patients in energy management. These needs and challenges will lead to a set of criteria that can be used by Medicine Men in development of e-health solutions to support COPD patient in energy management. The criteria will focus on creating a better the experience for the user.

Target group

COPD patients who experience difficulties with their energy management can be divided in two groups. The first group is afraid of spending too much energy after they experience a few days of fatigue or an exacerbation, therefore they don't move enough. The second group wants to continue their routine like they used to before they had COPD, since everything takes more energy they cross their upper limit often when they follow their old routine. This project is focused on the last group.

Revalidation

COPD patients who spend too much energy can learn to manage their energy in a revalidation program. During this program the patients stay at the revalidation center during the weekdays and have a structured program with for example physiotherapists, occupational therapists and psychologists. After the revalidation the patient has to actively apply the knowledge gained during the revalidation and has to change their habits and behavior at home. However this is a big challenge for COPD patients without the support from HCPs, in a non-controlled environment and with high expectations from friends, family and colleagues.

Data collection

A group of sixteen COPD patients was interviewed to explore the needs and challenges they face. In a

semi structured interview the patients were asked to complete a time line with their daily activities. Based on the time line they were asked about difficulties they experienced in daily life. The interviews were transcribed and analyzed with statement cards. It resulted in a set of nine challenges a COPD patient faces and two main needs.

Challenges for the patient

Based on interviews with COPD patient three main challenges for the patients were distinguished:

- Keep focus on energy level and act if needed
 Patients struggle to sense their energy regularly and do not always act even if they know they
 have to.
- Find a new applicable routine
 Patients have to find a new routine that fits their new energy level
- Put yourself in first place
 Can't always meet the expectations of others
 or help others and have to ask others more
 often to help them.

These challenges form opportunities for solutions to support the COPD patients in energy management.

Needs of the COPD patient

From a set of seven general needs, the two most important needs were selected for patients in managing their energy. is: to feel secure and autonomous.

Security

Patients with COPD want to feel secure and safe when they do daily activities, without being afraid of spending too much energy resulting a fatigue or an exacerbation. Feeling secure also means they want to feel comfortable in their daily routine and feel understood by others.

Autonomy

Patients with COPD want to feel autonomous like everyone else. Since their abilities are getting less, they are more depending on help from others. They want to feel in control of their own life, being able to decide what they spend their energy on and empowered to say no and ask help from others.

Needs for support

All the challenges of COPD patients lead to specific needs and needs for support. For example, the needs to feel in control over your body or the need to feel understood. The patients needs support to reach this desired situation and to create a balance between their goals and activities.

Criteria

A set of criteria was formulated based on the challenges, needs and needs for support of the patient. The criteria can be used to evaluate concepts developed by Medicine Men and to use as inspiration during ideation.

Testing the criteria

The criteria are tested by five designers who were asked to rate three different concepts with the criteria. The deviation in the rating by the designers in combination with the comments and questions they answered gave insights in the quality of the criteria. Based on the results of the test the criteria were revised

Integration in the design process

This project has resulted in a well evaluated set of criteria that can be used to develop e-health solutions for COPD patients to support them in energy management. The criteria and visuals with the challenges can be integrated in different stages of the design process. During the exploration phase the visuals with the challenges can be used to get familiar with the situation of the COPD patient. Afterwards COPD patients can be interviewed more targeted. During the ideation phase the criteria can be formulated as "How to ...? and function as starting point for a brainstorm. Finally, the criteria can be used to evaluate and improve concepts and create a pleasant experience for the COPD patient.

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INTRODUCTION

Assignment & approach

Background

Healthcare costs

In the Netherlands the number of people with chronic diseases is growing. This growth leads to an increase of the healthcare cost. For example, costs for consults with different Health Care Professionals (HCPs), hospitalization and medication. To control or decrease the rising costs, patients are stimulated to use e-health solutions at home for self-management. These solutions aim to help the patient to manage their disease, develop a healthy lifestyle and prevent hospitalization.

COPD and energy management

One of these chronic diseases is COPD. COPD is a lung disease that causes damage in the patients lung which result in energy and breathing problems. COPD has a big influence on patients' daily life (Bourbeau, 2009). They often experience a decrease in their energy level, while the activities and goals in their life stay the same. When a COPD patient spends too much energy, it leads to heavy fatigue or hospitalization. So they have to find a new balance between their goals in daily life and their abilities, by changing their routine, habits and priorities. If a COPD patients struggles with finding this balance, they can follow a revalidation program, but once they are back home they are self-reliant again and face a number of challenges. The increasing developments of e-health solutions form an opportunity to support COPD patients with energy management back home after revalidation.

Medicine Men

Medicine Men develops e-health solutions to support COPD patients (among other patients) in self-management. The main product is called Emma and helps patients with reminding to take their medication, gathering measurement like weight and blood pressure, filling out questionnaires about their condition and communication with caregivers and HCPs. The platform works with a website, mobile application and a smart watch app. Medicine Men developed a tool for COPD patients to monitor their steps with a smart watch. They believe the user should stay cen-

tral and in charge in all their solutions. Medicine Men involves patients in the development process to create the right functionality. However, they focus less on supporting the experience of the COPD patient and solutions to support patients in finding a balance between their daily life and energy use.

Assignment

COPD patients are one of the groups of chronically ill who have interest in self-management solutions that support them with their energy management. Medicine Men is one of the companies developing solutions in this field and has the knowledge and resources to build a solution that helps COPD patients with energy management. Little is known about the needs of support in energy management of these COPD patients and the corresponding criteria for an e-health solution that supports patients in energy management.

The goal of this project is to determine and explore the needs for support In this thesis the needs for support of COPD patient regarding energy management are explored and determined. These needs lead to a set of criteria to improve the experience of e-health solutions . This can be used by Medicine Men to develop solutions that support COPD patients with energy management.

Approach

The project is divided in three phases: preparation, exploration and integration (see figure 1.1). In the preparation phase literature research on COPD and self-management was executed. Besides, a few experts on COPD treatment and self-management in regard to energy use were interviewed. In the preparation phase also the company Medicine Men, their product Emma and the healthcare sector were explored. This led to the base for further research and the determination of the main challenge in energy management for COPD patients.

The second phase of the project, exploration, is focused on exploring the general needs of COPD patients in regard to energy management and the challenges they face in daily life. These challenges and needs are explored by interviewing COPD patients. Subsequently, the desired experiences of the COPD patients during daily activities are derived from their general needs and challenges (see figure 1.2). In the last phase integration, the insights about needs, challenges and desired experience are translated into criteria for solutions designed to support COPD patients in managing their energy. The criteria enable designers to integrate the gained knowledge into the design process. A test was performed with designers to validate the criteria. Three concepts that were created during the process of researching the patients needs, were rated with the criteria.

PREPARATION	EXPLORATION	INTEGRATION
Exploration of the topic of research	Collection of data, analyze results and visualize insights	Integrate insights into the design process
Literature research	Patient interviews	Define criteria
Desk research	Define needs & challenges	Test criteria
Expert interviews	Patient journey	Roadmap
	Interaction vision	

Figure 1.1 | Activities in different phases of the project

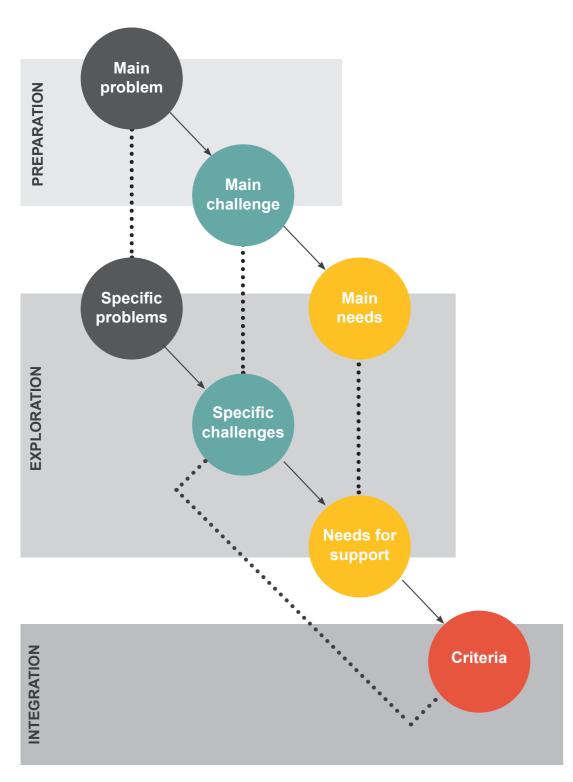


Figure 1.2 | Structure of the research and report

Glossary

COPD

Chronic Obstructive Pulmonary Disease

Self-management

In the context of healthcare used to describe the tasks of a patients in daily life to stay as healthy as possible

E-health

"E-health is the use of information and communication technologies (ICT) for health." (World Health Organization, eHealth, 2017).

Health Care Professional (HCP)

A person who is qualified and allow to provide care

Occupational therapist (Ergotherapeut in Dutch)

A health care professional who helps patients to carry out daily activities in a satisfying and healthy way.

Exacerbation

A sudden worsening of the COPD symptoms for a couple of days

II PREPARATION

In this chapter Medicine Men and their main product is described. Furthermore, COPD and the healthcare system around the COPD patient are explained, together with trends in healthcare. The need and challenges of self-management are explained and the basics of an e-health solution for self-management are described. Finally, the main problem and main challenge for COPD patients are determined.

2.1 Medicine Men

Medicine Men was founded in 2012 and develops medication management solutions. Their mission is "to develop, build and commercialise effective medication management solutions, using mobile devices and wearables".

The product developed by Medicine Men is called Emma (figure 2.1). Emma started with the aim to improve the therapy adherence of the user. The platform works on a mobile phone, a dashboard on a computer and the Pebble smart-watch. With these devices the user is able to set reminders and monitor his intake of medication.

Medicine Men has pivoted several times in the past years and changed the target group. The overall goal is to develop a patient centered self-management platform for people suffering from chronically diseases. Over the years different functionalities to support self-management were added. For example the possibility to collect and review measurement like high blood pressure and weight. As well as a communication system between the patient and caregivers and healthcare professionals. Medicine Men develops patient centered solutions. The needs of the patients form the basis for new functionality.

Currently Medicine man is particularly interested in creating a solution aimed on supporting COPD (Chronic Obstructive Pulmonary Disease) patients with self-management solutions.



Figure 2.2 | Smartwatch app by Medicine Men

The platform (including a smartwatch, mobile application and online dashboard) helps COPD patients to keep track of their steps during the day. Medicine Men developed a battery shaped visualization of the amount of steps and goal of that day on a smartwatch (figure 2.2). The color (green, orange or red) indicates if they are on track or of their goal. The goals are set for each part of the day. This is an important feature for COPD patients since the daily goal of regular step trackers not as flexible and includes too high daily step goals.

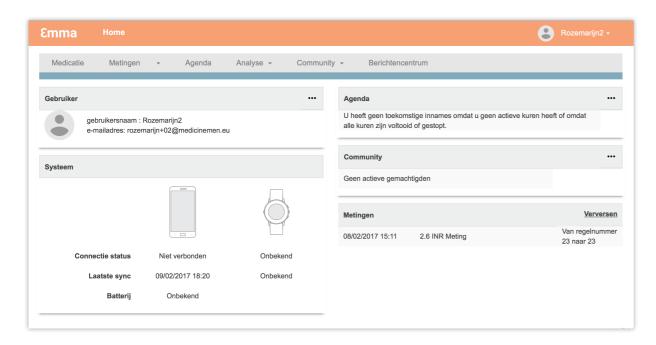


Figure 2.1 | Dashboard of Emma

2.2 Healthcare system

The Dutch healthcare system is divided in primary care (general practitioner, physiotherapist, dietitian) and secondary care (hospital care, specialists). The general practitioner is in most cases the first stop for patients and if needed the general practitioner refers them to another health care professional for further diagnosis or treatment. Figure 2.3 shows how the different healthcare professionals are situated around the patient.

Trends in healthcare

The healthcare system in The Netherlands is changing rapidly. There is an increase of elderly and chronically ill, causing a big increase of the healthcare costs (Idenburg & van Schaik, 2014). A way to reduce these costs is to minimize hospitalization, consults with healthcare professionals and

postpone the need to move to a nursing home. Therefore lots of e-health solutions are developed to support self-management and self-reliance of patients, so they need less direct care and stay more independent.

Another trend in healthcare is the focus on the situation and responsibilities of the patient. With shared discussion making, the patient is involved in finding the right (way of) treatment for his disease or in preventing other health issues (Idenburg, 2014). Related to this trend is the development of more tailored healthcare. So instead of a standard treatment for all COPD patients, the healthcare professionals look which treatment fits best to the patients behavior, personal situation and expectation.

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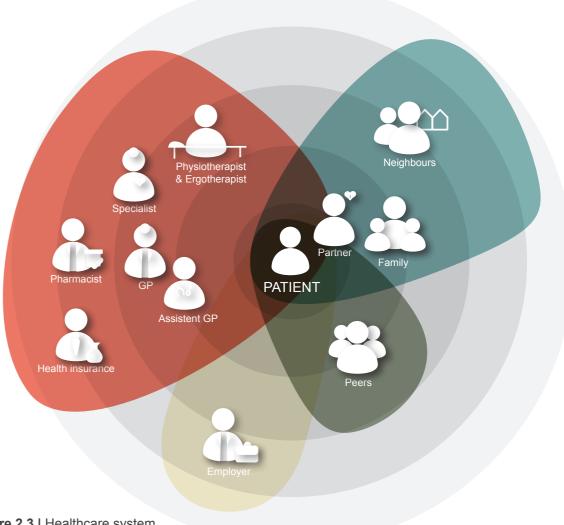


Figure 2.3 | Healthcare system

2.3 What is COPD?

COPD stands for Chronic Obstructive Pulmonary Disease and means that the lungs are damaged. It covers two lung diseases: Chronic bronchitis and Pulmonary emphysema. Chronic bronchitis is an inflammation of the bronchi (the branches in the lungs). This causes more mucus and makes breathing difficult. Pulmonary emphysema means the slowly increasing malfunction of lung blisters and causes stuffiness and fatigue. All COPD patients experience difficulties with breathing and daily activities will cost more energy.

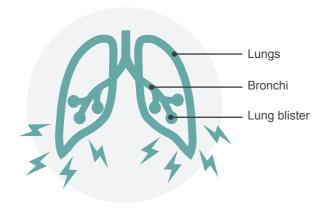


Figure 2.4 | Lung autonomy

There are four levels of COPD in the GOLD (Chronic Obstructive Lung Disease) classification approved by the World Health Organization. From COPD Gold 1, mild COPD, to COPD Gold 4, very severe COPD (COPD GOLD, 2017). In stage 1 patients might not notice they breath abnormally and cough a bit. In stage 4 they may need additional oxygen and have a reduced quality of life.

When symptoms, like short of breath, wheezing, mucus, headache or fatigue, increase it might indicate an exacerbation. In case of an exacerbation the patient needs to be hospitalized or take inflammatory inhibitors.

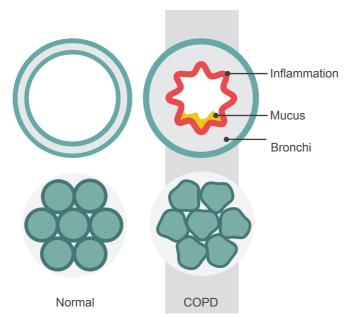


Figure 2.5 | Lung bronchi and blisters with and without COPD

COPD is a disease that can not be cured, but the decline can be slowed down by medication, managing movement/energy and by having a healthy lifestyle in general.

The Netherlands count over 600.000 COPD patients known to the GP. The number of female COPD patients has almost been doubled between 2000 and 2010. The number of male COPD patients remained roughly the same (COPD aantal bekend bij huisarts, 2017)

2.4 Self-management

Healthcare organizations in The Netherlands try to stimulate patients to take control over their own disease by performing self-management. One of the main reasons to do this is the increasing number of elderly and chronically ill, which comes at a high price. With the help of more self-management this increase of costs will be reduced by the increase of the independence of patients and the decrease in needs of healthcare.

In this project CBO's definition of self-management is used:

"Self-management is coping with a chronic condition (symptoms, treatment, physical, psychological and social consequences and corresponding changes in lifestyle) in a way the condition is optimally integrated in the patients life. Self-management means a chronically ill person can chose to which extent they keep control about their life and co-direct how the available healthcare is used to achieve or keep an optimal quality of life." (CBO, 2014)

People with chronic diseases benefit from self-management, since they have to cope with their condition daily for the rest of their life and health care professionals are not constantly present.

Self-management tasks and skills

Self-management for chronically ill patients exists of sets of different tasks related to medication management, role management and emotional management (Lorig & Holman, 2003). Some of the described skills are action planning, problem solving and resource utilization.

The ability and effort needed to perform these self-management tasks depends on a persons personality, knowledge and situation. For one person it might be easy, while others have to learn a lot and gain more confidence, before they can do certain self-management tasks.

Hibbard, Stockard, Mahoney, & Tusler (2004) have created a tool to determine which of the four levels of patient activation someone has by completing a short questionnaire. Figure 2.6 shows the different levels of activation from starting to take a role, to building knowledge & confidence, to taking action and finally maintaining behaviour. The level of patient activation from a patient can be improved by for example knowlegde and a supporting environment.



Figure 2.6 | Patient activation levels

Self-management barriers and support needs

A chronic disease has a big impact on the daily life of people and those around them. Patients have less physical abilities, have to take their medication every day, have to measure values or have to visit a healthcare professional regularly. Meanwhile they are trying to continue living the life they lived before this disease as much as possible. This can be a difficult balance to keep.

Van Houtum (2015) describes that this balance exist of three elements for chronic patients:

- 1. The goals a chronic patients sets;
- 2. The perceived burden of the disease
- 3. The resources a chronic patient has

The first element describes the goals someone has in (daily) life, for example working or activities with friends. The second element describes to which extend a patient perceives his disease as a burden and is a mental variable. The third element, resources, is the available knowledge and network the patient can rely on. When these three elements are out

of balance, there is a bigger need of support with self management.

Van Houtum (2015) also investigated the influence of the type of chronic disease, stage in chronic disease and stage in life on the self-management support needs. She found that patients with different chronic diseases have similar needs. The stage in the disease and the stage in life have much more influence on the support needs.



Figure 2.7 | Balance in needs for self-management support

Vosbergen, S, et al. (2013) and Boger, E., et al., (2015) both describe several barriers and needs that are important to self-management:

Knowlegde

One of the needs of (chronically) ill people is tailored knowledge about their condition. The type of knowledge they need, depends on their personal situation. Applicable knowledge about how to tackle little problems in daily life is really important for chronic patients. In addition it is important to be able to ask healthcare professionals questions to gain knowledge, but during a consult is can be difficult know what to ask.

Network

A possitive network of friends, family and peers to fall back on for practical as well as emotional issues is very important. But their network can also be a barrier when friends and family are overprotective.

Independence

An important goal for patients is to be independent. They want to be able to take care of themselves, without asking others for help.

Being me

Related to independence is the goal to express themselves. This may mean that they want to continue to work or being able to perform their hobbies.

Inability to prevent decline or repeating events
According to Boger, et al. (2015) patients often feel

unable to prevent decline or a repetition of an event. Some want to be able to understand the cause of the illness, so they can prevent progression in the future.

Implementation of self-management support

Self-management has to be executed by the patient himself. However, as Van Houtum (2015) also described there is a need for support in self-management on different levels.

In the Netherlands healthcare organizations often refer to The Chronic Care Model when talking about improvements in chronic health care (van Dis, Strijbis, & Spreeuwenberg, 2014). The Chronic Care Model is a model that described that chronic care is a collaboration between the healthcare professional and the patient. This model also includes self-management support.

Often this self-management support is described as support from healthcare professionals, for example by performing motivational interviewing. This is an important step in healthcare to focus more on the patients needs. However, besides the support from healthcare professionals there is also a big opportunity for e-health systems to support the patient in self-management.

A lot of research and companies have started to explore these opportunities, Medicine Men is one of them. Even though a lot of studies have been done and e-heath solutions have been developed, guidelines for developing an e-health solution for self-management support are not yet formulated.



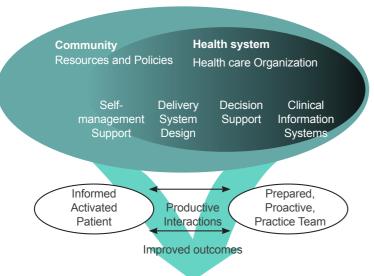


Figure 2.8 | Chronic Care Model (Developed by the MacColl Institute, ©ACP-JSIM)

2.5 E-health solution for support in self-management

In order to improve their self-management or energy management skills, patients have to reflect on their own actions and change their behavior based on the insights from the reflection. E-health has a number of qualities that are convenient to support patients in self-management and reflecting. In this paragraph the characteristics of e-health solutions for support in self-management are explained.

E-health is term used widely, but is defined in a lot of different ways (Rizo et al., 2005). The definition used in this report is the definition from the WHO: "E-health is the use of information and communication technologies (ICT) for health". (World Health Organization, eHealth, 2017).

E-health solutions are easily integrated in the daily life of patients. The solutions work with devices that are often well known by the user, like a mobile phone or a laptop. Or devices that are easily adapted by the user like step trackers and smart watches. These devices are always close to the user and therefore can support the user continuously and the devices are able to continuously measure relevant data. This leads to new insights and opportunities to give feedback to the user.

An disadvantage of these measurement is the possible low accuracy of the measurements. This has to be taken into account when developing a solution. However, since the solution will measure almost continuously the complete set of data will probably give very useful insights.

The main qualities of e-health solutions for support in self-management are:

- Continuously and automatically gather data
- Enable self-report by the patient
- Integrate data by comparing it to previous data and tailored setting
- Notify the user or others
- Visualize data
- Guide the user in reflection and decision making

Figure 2.9 shows these qualities in relation with the actions from the user. The user goes through a reflection circle that includes: do & self-report, reflect and decide & plan.

In the first phase the user performs his daily activities. Meanwhile the system measures the relevant data. The system will also enable the user to report data themselves (for example about his feelings).

The data, that is gathered by the system, will be integrated so it can reveal new insights. For example by comparing it with previous data or with settings by the user (for example a minimum amount of steps per day).

The insights from the data are shown to the user as visualized feedback. This feedback can be on the moment itself, for example by notifying the user. Or the feedback is given on a later moment in an overview, so the user can reflect on it. The system can help the user by guiding him thought the reflection.

Based on the reflection the user has to decide to change his actions or plan his actions differently in order to improve. The system can support the user in this stage by guiding him through the decision process and show the possible effects of a decision.

This circle can be applied multiple times in one e-health solution. For example once for direct feedback and reflection and once for weekly feedback an reflection.

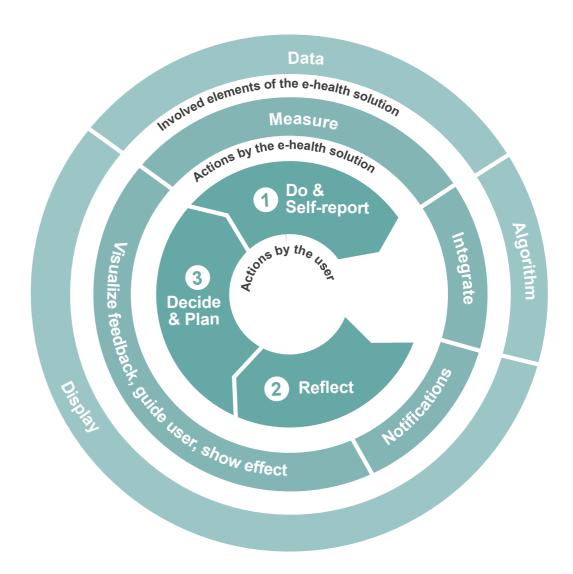


Figure 2.9 | Actions of the user and e-health solutions for self-management support

2.6 Course of a chronic condition

The experience and needs of a patient with a chronic condition (like COPD) changes during the course of the disease (van Houtum, 2015).

After analyzing interviews with COPD and thrombosis patients, four phases in the course of the disease are distinguished: Diagnosis, Revalidation, Adaptation and Acceptance (figure 2.10). In every phase the experience of the disease and the needs of the patient are different.

Diagnosis

In the run-up to diagnosis the patient often experiences unclear symptoms and goes to a doctor. Usually it includes several medical examinations before it is clear what the diagnosis is, what the impact is and what the treatment will be. This phase can be experienced as a roller-coaster with a lot of insecurity, questions and bad or good news. For the patients it is often insecure what will happen next or what they need to do next.

Revalidation

After the diagnosis and the determination of the treatment plan, the revalidation begins. The impact of the disease and the support during revalidation differs per condition. For COPD patients a revalidation program is not standard. Patients who are struggling with their energy, breathing, the acceptance or often have an exacerbation, can be redirected to a revalidation clinic. No matter the type of condition, the interviewees described it as a difficult period, with regular setbacks.

"Dat was overleven." – Husband P2 about the revalidation phase*

Adaptation

In the adaptation phase they have to get used to the decreased abilities of their body and find a way to continue normal life again. This means they have to find ways to do their normal daily activities differently and at another pace. They also have to accept that they can't do all the things they used to do be-

DIAGNOSIS REVALIDATION ADAPTATION ACCEPTATION Rollercoaster Mountain climbing Moving Resignation The rollercoaster of Get physically healthy Search for ways to Continue the found medical examination, again while rediscovercope with the diseas in routine while adapting insecurity and setback. ing the abilities of your daily life and find a new it slightly now an then, body and process what routine. with acceptance of the happened mentally. situation as final goal. **FOCUS AREA**

Figure 2.10 | The different phases in a chronic disease and how they are experienced

fore and say goodbye to work, hobbies or regular activities with friends.

"En langzamerhand kom je erachter dat je dat niet meer redt. Dus dan moet je langzamerhand afscheid nemen van een heleboel werkzaamheden en collega's, dus dan zit je continue met een rouwproces." – P4*

Acceptance

In the last phase, the acceptance phase, the patient has found a way to cope with their condition in daily life that fits their situation best. They now have to maintain and adjust this routine and balance, since life is always a subject of change. Besides, they have come close or have accepted their situation and the consequences it has, but that process of acceptance may take years.

"Daar ben ik echt al jaren mee bezig, van het actief alles zelf doen en heen en weer rennen, naar nu alles door anderen laten doen en kleine dingetjes die je zelf wilt doen echt in een slakkentempo moeten doen. Niet meer kunnen wandelen, niet meer kunnen fietsen. Ik denk dat ik er nog jaren voor nodig heb, voordat ik dat werkelijk geaccepteerd heb." - C6**

^{*} The quotes are a result from interviews with patients with a chronic disease (thrombosis, diabetes) from research done in earlier stages of the project.

^{**} The quotes are a result from interviews with COPD patients described in paragraph 3.1.

3.3 Challenges for chronically ill patients

As described before self-management is important for chronically ill people and they face different challenges in their self-management, like described by Lorig & Holman (2003): medication management, role management and emotional management. Based on over twenty interviews with chronically ill people, an adapted version of the challenges was made (figure 2.11).

Communication with healthcare professionals

Patients can be very tense or insecure when meeting with healthcare professionals. Talking about your health and body is very personal and changes in health may have an impact on your daily life. It can be hard to ask the right questions at the moment itself. Besides, during a consult you will hear a lot of new information, and terms you have never heard of. A healthcare professional will regularly ask about symptoms or other events that occurred in the past period. It can be hard to remember what hap-

pened when and in which context. This challenge is comparable with role management described by Lorig & Holman (2003).

Medication & treatment management

Chronically ill patients often have to take multiple medicines a day and they have to keep an eye on the development of their disease. It can be a challenge to integrate taking their medicines into their daily routine. Patient are not always aware of the reasons and effects of all the medication they take or the treatment they follow. Besides, they do not always know which treatment options they have.

Balance between daily life and disease

A chronic disease comes with a decrease in abilities. This often means the patients have to adapt their daily routine to their new abilities, while they rather want to continue their habits and routine like they used to. When a patient found a new convenient routine, he still has to keep on eye on short

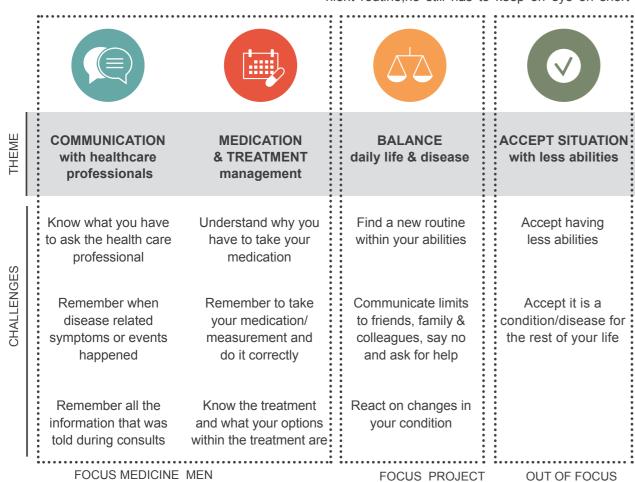


Figure 2.11 | The different themes of self-management for patient with a chonic disease

term or long term changes in his condition and react on those changes.

Not only the patients themselves have to get used to their new abilities, also their surrounding friends and family have to learn what the patients abilities are. It is difficult for the patient to communicate how they feel. Besides, it can be it can be difficult for those around them to always take the abilities of the COPD patient into account. Or the opposite, they are very worried and want to protect the COPD patient too much.

Accept the situation

Closely related to finding a balance is the challenge to accept the situation with less abilities. The patients are not able to do, what they used to do. That is difficult to accept for patients. Patients might have to stop doing a hobby, stop working or can't go out with friends without being knocked out the next day. Besides, patients depend more on others than they used to, for example because they can not do all the household activities anymore.

Focus Medicine Men

The focus of Medicine Men is mainly on the medication & treatment management. The first version of Emma was focused on increasing the medication adherence by reminding patients to take their medication. Later in the development of the platform more treatment management was included (for example measurement of high blood pressure). Communication with healthcare professionals is also included. Emma offers patients the opportunity to include healthcare professionals and caregivers in their community. By including them in the community the healthcare professionals have access to the data of the patient and can send and receive messages.

Focus project

The focus of this project is on 'Balance daily life & disease'. This area is new for Medicine Men, so research on this topic will result new insights and opportunities for Medicine Men.

The main challenge for COPD patient within the theme 'Balance daily life & disease' is the balance between their available energy and their activities. So within the theme 'Balance daily life & disease', the focus of this project is on balancing their energy and activities.

Conclusion

The increase in people with chronic diseases causes higher costs in healthcare. By improving the self-management skills of chronic patients they need less care and that will reduce the costs. E-health solutions are very suitable for supporting COPD patient in self-management.

Medicine Men develops E-health solutions for COPD patients and other chronic patients, but they do not have much experience with developing solution focused on the balance between daily life and a chronic disease. Or more specific with developing solutions for the main challenge for COPD patient within this theme: finding a balance between their new decreased energy level and their goals in daily life.

This challenge occurs in the adaptation phase of a chronic disease, when the patient has to adapt their behavior so it fits their new abilities.

Therefore this project focuses on the challenge of energy management for COPD patients.

Next

In the next chapter the main needs and more specific challenges a COPD patients faces in daily life are explored.

EXPLORATION

In this chapter the challenges and needs of COPD patients are explored in detail. Based on interviews with COPD patients two main needs in relation to energy management are identified. Furthermore nine challenges COPD patients face in daily life are determined and lead to a set of needs for support.

3.1 Approach exploration research

Goal of the research

The goal of the exploring research is to find out more about the challenges and needs of COPD patients. In the previous chapter the main problem, main challenge are identified: the COPD patient has a lower upper energy limit and has to learn how to stay between his upper and lower energy limit.

Based on interviews with sixteen COPD patients and three HCPs (two occupational therapist and one program manager COPD) the main needs, specific challenges and needs for support are determined.

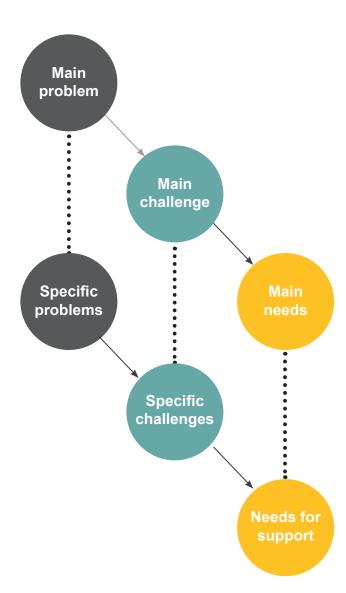


Figure 3.1 | Overview of interviews and test performed during the project

Method

Recruitment

The sixteen COPD patients and three HCPs are recruited at the revalidation clinic Revant (Revant, 2017). The choice to contact revalidation clinic Revant¹¹ in Breda was made because of earlier collaboration by Medicine Men with Revant.

In the week before the interviews flyers with information about the research and the interview were spread among the COPD patients. Some COPD patients indicated they wanted to participate in advance, others agreed to participate when they were approached on the day itself.

The only selection criterion, besides being a COPD patient, is some experience with smartphones. The reason for this criterion is the short test with concept ideas after the interview.

The participants

In total sixteen patients were interviewed. All the patients followed the revalidation program at Revant. The participants have COPD GOLD 2 till 4: six participants GOLD 2, six participants GOLD 3 and four participants GOLD 4. The division between men and women was equal: eight men and eight women. The range of the age of the participants was from 41 years old till 73 years old (See appendix A for a complete overview).

Interview

The participants were interviewed in a semi structured way. First the participants are asked about their activities on a normal day and write the activities down on a time line (see Appendix B). Next the participants are asked if and when they experienced problems dividing their energy. Based on their answers they are asked what they exactly struggle with, how they used to solve it and how they solve it now.

Test of concept ideas

In earlier stages the focus of the project was different (on high blood pressure and thrombosis). This part of the project is not included in this report. The patients interviewed in this stage also experienced problems with energy management. Combined with the experiences within Medicine Men with COPD patients and literature about COPD patients, there was already some knowledge available about energy management and COPD. Therefore the choice was made to combine the interview with the test of concept ideas. The goal of testing these concept ideas is to gain more insights in the needs of the patient and the right interaction styles.

The concept ideas are tested by presenting the participant a scenario supplemented with activities they mentioned earlier in the interview. They are asked how they would react in this situation. Next the concept idea is presented and they are asked how and if they would use and like the solution.

The direct results of the this test are not used in this report, however during the test participants told valuable information about their experiences. So this part of the test was handled similar to the interview part (also transcribed fully) and contributed to the insights described in this chapter.

The development of the concept ideas, the test setup and the results can be found in Appendix C.

Interviews experts

In an introductory meeting with the program manager of Revant the general procedure and information were discussed. The two occupational therapists were interviewed before and after the tests and concepts for solutions were discussed. A summary of the interviews with the experts can be found in Appendix D.

Processing the results

The interviews with the COPD patients were recoded with sound and video recording (with consent from the participants). The interviews were fully transcribed afterwards.

To make the data ready for analysis statement cards were used, a method to process and analyze the results from interviews (Sanders & Stappers, 2013). First all the interesting quotes were placed on the statement cards and a paraphrase of the issue in the quote was written above. To be able to trace the quotes a reference number for the participants was placed on the card as well. A few examples of the statement cards can be found in Appendix E.

Next the cards were printed and clustered based on the topic (see Figure 3.3). These topics formed the basis for the challenges and other insights described this chapter.

All the insights form this exploring research are described in the following paragraphs.

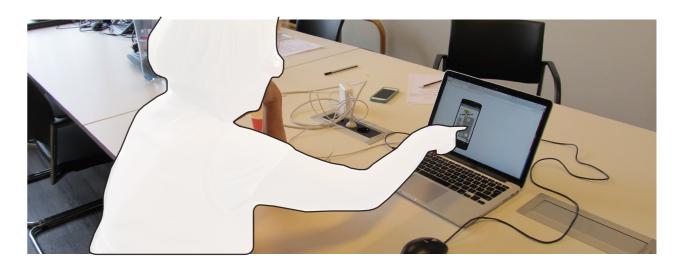


Figure 3.2 | One of the participants after the interview, during the test with the concept ideas.



Figure 3.3 | Clustering of the statement cards

3.2 Energy management of COPD patients

People with COPD often experience difficulties with the decrease in their physical abilities. Normal activities like cycling, vacuum cleaning, cooking or even taking a shower can be a really intense and cost a lot of energy for COPD patients. This can be seen as the main problem of in energy management for COPD patients.

In this process they have to discover the limits of their energy use. They have to make sure they don't spend too much energy, but also to move enough like everybody else. So they have to stay between their upper and lower energy limit (figure 3.4). These limits are different for every COPD patient and can even differ per moment for the same patient.



Figure 3.4 | The balance between the energy and activities

They have to find a new balance between their goals in daily life and their abilities, by changing their routine, habits and priorities (Boger et al., 2015; Heijmans et al., 2015; Townsend et al., 2006). Sometimes this means they have to stop working, can't do their hobby anymore or have to limit the amount of appointments with friends. In later stages of COPD household activities can also ask too much energy and have to be deputed to others around them.

The process of saying goodbye to meaning full activities can be compared with a the stages someone goes through in a mourning process.

COPD patients have to find new goals and adjust their expectations based on what is achievable. They have to find new ways to express themselves and try to stay as independent as possible. When patients move too much they are exhausted moments later and can be tired for up to several days. When it really escalates they have a so called exacerbation and have to be hospitalized.

The big challenge of energy management

COPD patients have stay between their upper and lower energy limit, in order to be able to live comfortable and happy as possible. To stay between those limits they have to change their habits and behavior. The main challenges the COPD patients face after revalidation are described in the paragraph 'challenges back home'.

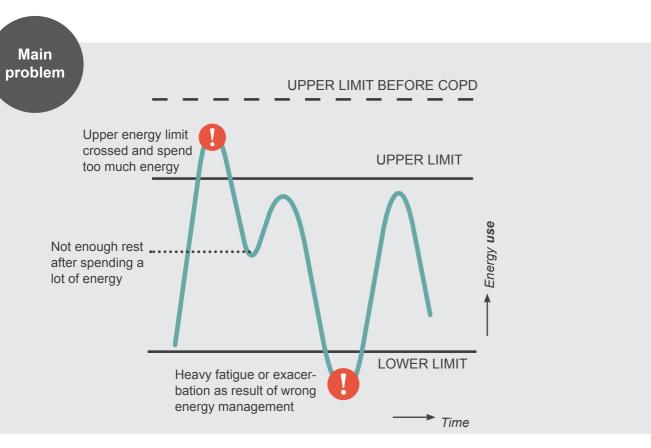


Figure 3.5| The upper and lower limit in energy use

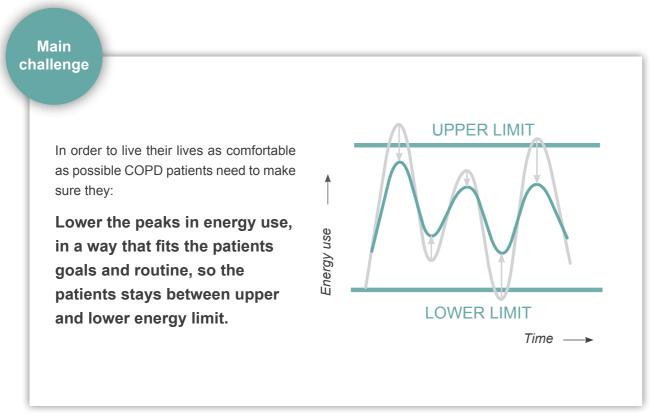


Figure 3.6| The main challenge of energy management for COPD patients

3.3 Target group

COPD patients, who experience difficulties with their energy management, can be roughly devided in two groups (figure 3.7):

- Patient who are scared to move too much after they experienced what happens when they spend too much energy. This group tends to avoid movement.
- Patient who want to continue their normal routine and have difficulties with spending less energy and taking enough breaks.

In this project the focus is on supporting COPD patients of the second group in finding a new routine without spending too much energy.

Level of COPD

The target group in this project is the group of people who have COPD with GOLD 2 or higher. COPD patients from GOLD 2 and up experience the consequences of having COPD and experience problems with their energy management. Patients with GOLD usually don't follow a revalidation program.

Returned home after revalidation for COPD

The target group consists of people who just returned home after revalidation and are in the adaptation phase. They experience problems with implementing the knowledge and tools they learned during revalidation into daily life.

Age between 45 and 75 years old

From the age of 45 upwards the group of COPD patients grows significant and keeps growing as the age increases. The age of 75 is chosen as the upper limit of the target group. From the age of 75 the percentage of people with digital skills decreases.

The focus of Medicine Men is on digital products and its digital elements are very applicable in self-management systems. So the group using these self-management solutions are preferably younger than 75 or have good digital skills.





Figure 3.7 | Patients who tend to avoid movement (at the top) and patients who continue there normal busy routine

Eager to live an active life and thus spend too much energy.

This project is focused on people who move too much and have difficulties to limit their energy use. Often these people used to have a very active life and are not ready to give up this active life. This makes it difficult for them to stay between their energy limits.

3.4 Situation before, during and after revalidation

COPD patients who struggle with disease related issues, like their energy balance or the acceptance of the disease, can be redirected to a revalidation program.

Situation before revalidation

Before the revalidation COPD patients who have an active lifestyle want to stay active. This means they pass their upper energy limit regularly and afterwards get exhausted or even an exacerbation. Their energy level is going up and down heavily and they often don't know why (figure 3.8).

Situation during revalidation

In the revalidation program the patients learn to manage their energy. They learn they have to take more breaks and move more slowly or in with a different way. Furthermore a part of the revalidation is about accepting their decline. During the ten week program they are supervised and stopped when they tend to pass their upper limit. Besides they have a fixed schedule so they are less temped to spend too much energy.

Situation at home after revalidation

Once patients are home they are not supported in managing their energy anymore and they have no supervision and fixed schedule at home, like they had in the revalidation clinic. COPD patients have to put all they have learned at the revalidation clinic into practice and try to find a suitable routine for at home. They have to answer questions like: Which route for walking near home fits my energy level and where can I sit down? How much energy does a visit from family or friends cost me? What can I do next to my daily tasks when I have a bad day?

Besides they are at home in an environment where not everybody understands their disease and people around them have expectations about joining activities or doing certain tasks. This results in relapses every now and then.

Focus project

There is not much support for the patients when they leave the clinic. At the revalidation clinic Revant the patients get a folder with leaflets and there is one 'return day' for evaluation after their revalidation. This despite the fact that the process of revalidation is not completed after the revalidation at the clinic and patients need support with the implementation of the knowledge and tools they gained during the revalidation.

Since it is impossible and undesirable to supervise a patient constantly, an self-management solution in combination with e-health seems to offer many promising opportunities.

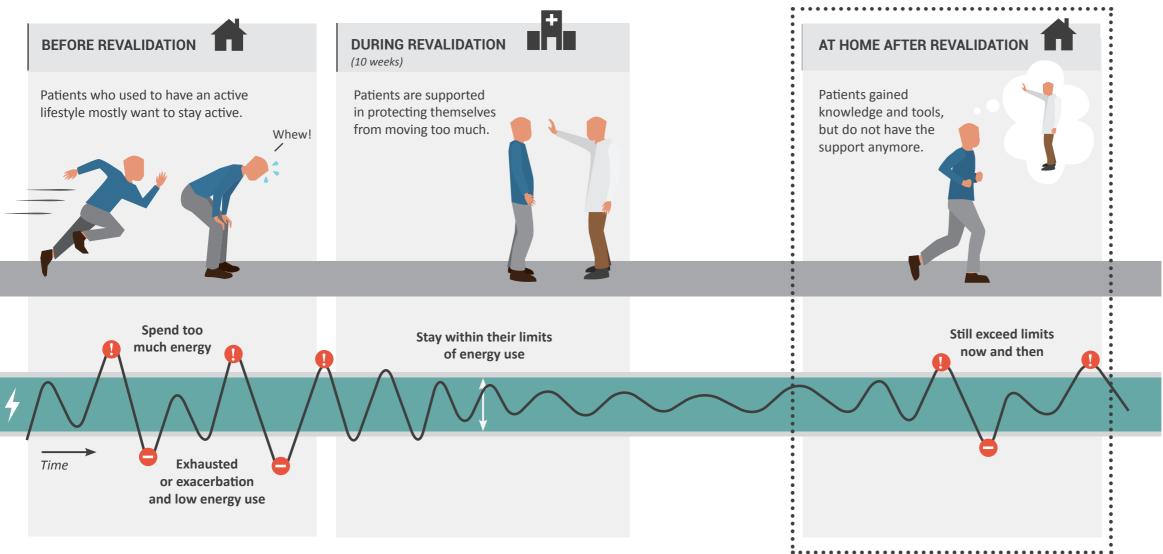


Figure 3.8 | Current situation energy management of COPD patients before, during and after revalidation

FOCUS AREA

3.5 Main needs

Based on the interviews two main needs of the COPD patient in regard to energy management where identified, with help from a cardset with seven needs created by Lenz, Diefenbach and Hassenzahl (2013).

Lenz, et al. (2013) created a set of need cards for designing interactive technology with seven needs in total: relatedness, competence, autonomy, security, popularity, meaning and stimulation. The needs *security* and *autonomy* apply most to COPD patients in relation to self-management. Based on the interviews these two needs are considered highly relevant for COPD patients struggling with their energy balance.



Figure 3.9 | Representation of autonomy

Autonomy

Autonomy is one of the two main needs of COPD patients that is challenged in their daily life. It is difficult to stay autonomous and live their life how they want to, since their physical abilities decrease and they have to accept their need for help with daily tasks. Besides, they get new obligations like take their medication, watch their energy use and symptoms, visit the physiotherapist and learn about their disease. Patients have to find a way to meet these obligations and accept some help, while they still feel independent, make their own choices and meet their goals. It is important for the design to support this need and not make it feel like another obligation without choices.

Autonomy includes among others: independence, liberty and self-reliance.



Figure 3.10 | Representation of security

Security

Autonomy is one of the two main needs of COPD patients that is challenged in their daily life. COPD patients experience a lot of insecurity. For example about the insecurity of the development of the disease. (What will I be able to do in a year?) But on daily basis they feel insecurity about their own abilities. They can feel fine on one moment, but feel bad an hour later. So they will never really know if they can do all they planned and it can feel insecure when doing activities spontaneously or without knowing how long or intense it will be. Therefore it is important to give the user the feeling of security that they will more or less know when they have to stop and that they are supported.

Security includes terms like: comfort, routine, clarity, structure and dependability

The balance between autonomy and security

The needs autonomy and security can interfere in sometimes. When a COPD patient wants maximum security when it comes to energy management, it means they have to let themselves monitor and guide by others. So the feeling of security is at the expense of their feeling of autonomy. The need for more autonomy or more security differs per person. So in a self-management solution a middle ground has to be found between these two or, even better, a flexible/tailored solution should be developed.

Another situation of interference between the feeling of autonomy and security occurs when a patient has to choose whether or not to join an intense activity that is highly valued by the patient. When the patient joins the activity, the patient will feel miserable afterwards or the next day and feel insecure. When the patient decides not to participate he will feel more secure, but affects their sense of autonomy.

The needs autonomy and security can also strengthen each other. When a patient feels secure and save to do something it can strengthen their feeling of autonomy. The feeling of security can remove barriers and empower patients.

3.6 Energy management issues before revalidation

Patients struggle with their energy management before revalidation (as described in paragraph 3.4) There are several reasons why COPD patients struggle with their energy. The following five issues are mentioned the most during the interviews with COPD patients. The quotes in the speech bubble are from the interviewees.

Keep the same routine as before COPD

One of the reasons is they want to keep the same routine as before they got COPD. They want to keep working or practicing their hobbies and are not prepared to eliminate some of their activities.

Push till the limit

COPD patients often go on till they really have no energy anymore. For example when they have done several activities in the morning and feel a bit tired, they won't cancel an intensive activity they have planned in the afternoon, but go on almost till they drop.

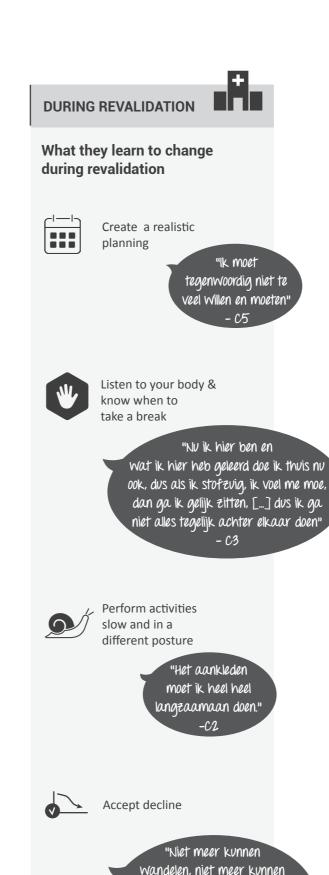
Want to finish a task

Another reason for spending too much energy mentioned by several patients was the urge to finish a task. For example during vacuum cleaning they wanted to finish it, even if they knew they actually should sit down for a minute in between.

Don't accept decline

As mentioned before it is really difficult for chronically ill people to accept they have this disease for the rest of their life. Especially when they have to give up activities they love. When a person has to give up activity after activity, it can hurt their self-esteem and feeling of Independence.





fietsen. Ik denk dat ik er nog

jaren voor nodig heb, voordat k dat werkelijk geaccepteerd

heb." - C6

Perform activities slow and in a different posture Besides taking enough breaks in time COPD patients learn to perform their activities slower and sometimes in a different posture. For example they practice making their bed in the right pace and with

energy.

Accept decline

During the revalidation the COPD patient are helped with accepting their decline by psychologists. This decline often involves losing a part of their independence and asking others for help. This is a process that can take years, but some important steps can be taken during the revalidation.

3.7 What COPD patients learn to change during revalidation

During the revalidation the COPD patients learn a lot about managing their energy. They are supervised by physiotherapists, occupational therapist, psychologists and others. They help them to realize what has to change and how they can change it.

Create a realistic planning

As described before, COPD patients often want to do more than they are able to. During revalidation they learn how to make a realistic planning. This is often done by metaphors like sugar bags or marbles. They learn their total amount of energy is x sugar bags and every activity costs them a certain amount of those sugar bags. They have to make sure they don't spend more sugar bags than their total amount of sugar bags or energy.

Listen to your body & know when to take a break

During the revalidation patients learn to take more breaks than they used to or feel to. For example one patient told she learned to put on a bathrobe after showering so she could take a break and dry herself after the little break. They also learn to listen to their body and pick up their body signals before they become exhausted.

the right posture. Some positions like bending over can make the breathing more difficult and cost more

3.8 Challenges back home



The real challenges for patients starts back home without the help of HCPs, a fixed structure and a safe environment.

They have to find a new applicable routine at home and learn to cope with expectations from others. Now they have the tools to manage their energy, but it is a challenge to change their habits and keep their focus on their energy management. Since the focus of this project is self-management after returning home from revalidation the challenges in this phase are further elaborated.

There are three main challenges identified: keep focus on energy level and act if needed, find a new applicable routine and put yourself in first place. Each of the three main challenges exists of three sub challenges. .

Keep focus on energy level and act if needed

COPD patients have to send their energy level frequently and start to recognize the symptoms of a low energy level. It can be difficult keep the focus on their energy, for example when they are doing something they really like and are in a flow. But only when they know they have are crossing their energy limit they will be able to act.

However, sometimes when a COPD patient knows their energy level is low, they will ignore it and continue. This can have multiple reasons. Some are mentioned before in the part about issues before revalidation: want to finish a task or just push themselves to the limit. Other reasons can be the pressure of others when they don't want to disappoint someone. (This last specific challenge is discussed under 'put yourself in first place'.)

Find a new applicable routine

COPD patients tend to, like everyone else, keep the same routine. It is very difficult to change this routine and behavior, but since their upper energy limit has lowered, they need to change.

To find and change their routine a COPD patient has to know how much energy different activities cost and how much acitivities they can do on a day. Next they have to find a way to create a routine that fits their life, but without high peaks of energy use.

Put yourself in first place

As a COPD patient you have to think about yourself first, before thinking about others. They cannot help others as much as they used to or join every time with a nice activity. So they have to say 'no' more often and clearly communicate their abilities. Besides, they will have to ask for help more often since they are often not able to do everything in and around the house themselves anymore.

On the next pages the specific challenges a patients faces are described in more detail. On the left the problem is described and in the column the

> Specific problems

Specific challenges





React on changes in energy level

Patients do not always react on a change in their energy level, even if they know they should.

The energy level of COPD patients can vary a lot by day or by hour. When their energy level drops, they have to change plans. It is tempting to continue and finish something

> "Het kan gebeuren dat ik lekker, na een korte nachtrust, opsta en dat ik me eigen prima voel en dan in ene keer boem. Dan komt de man met de hamer zea maar." - C4



Listen to your body and recognize symptoms

Because of the fluctuations in energy COPD patients have to be constantly conscious of their energy level and planning. So they need to learn to recognize the symptoms. It is inevitable someone forgets to focus on their energy level now and then, when they are in a flow.



Handle unfamiliar activities

In cases of unfamiliar activities it is even difficult to predict how much energy the activity will cost. Besides, unexpected events can happen.

> ""Ga maar naar de dierentvin, dat plan je niet in. Je kunt heel veel van tevoren bedenken maar je kunt niet alles bedenken. De eerste keer moet je naar een parkeerterrein, en dat is tig meter lopen, toen was ik al black out, toen was ik nog maar bij de kassa. - B4

Patients do not always recog-

nize a low energy level.

"Ja, Want het zijn altijd dezelfde valkvilen. Sommige dingen daar denk ik dan bij na, die doe je al zorgvuldig en daarbij let je op ademhaling. Maar er zijn valkvilen waar je gewoon, ownja." - 06

Patients experience problems with unexpected situation during unfamiliar activities



Find a new applicable routine

Patients want to continue the activities they used to do before they got COPD and overestimate their abilities



Create a realistic planning

They have to learn how much energy an activity costs and which activities they can do on one day, based on how they feel.

"Bijvoorbeeld als ik weet dat ik 's middags naar de stad wil gaan, [_] Dan doe ik 's morgens alles even rustig aan en dan kan ik 's middags de stap maken van even naar de stad." - C5



Find a way to do daily routine at ease

They have to apply the knowledge and

Some activities take to much energy, but the patient does not realize their might be other ways to do the activity tools they learned during revalidation at home, so move slowly, move in a different position and take more breaks. It can be difficult to apply this at home and to keep looking for solutions.

"Ja dat [koken] kost veel energie. [...] ik moet toch aan het aanrecht staan bij het eten klaarmaken. Dus nu zijn we op zoek naar een op bepaalde hoogte instelbare kruk, zodat ik kan zitten" - C2



- C I

"Nu is echt de knop om van

Patients do not take time to reflect or do not know how to reflect on their energy use



Learn from what went wrong in routine

Finding this new applicable routine is a process of trial and error. So it is important to learn from the errors and think of a better way to do it for the next time. But reflecting costs time and can be difficult to do and is easy to skip.



Put yourself in first place



Communicate energy level to others

Patients experience difficulties with explaining their energy level or the consequences of COPD on their daily life.

It is difficult for friends, family and colleagues the COPD patient to understand why they can do groceries one day, but are too tired to do groceries the next day.

> "Ja, niet alleen voor jezelf, maar ook om aan je omgeving te kunnen laten zien van joh het is op voor vandaag, Want dat wordt lang niet altijd begrepen," - C6



Say "no"

Patients experience difficulties with holding their boundaries and prioritize activities

Back home friends and family have expectations about what someone likes and does, based on the past. However now the COPD patients have less energy and when they are asked to join activities or to help others they have to make a choice and be able to say "no".

"Ik kon geen nee zeggen tegen niemand. [..] Maar dat leer ik nv ook en dat gaat tot nv toe goed. Ja nee zeggen is lastig, want het is een schoonzus die alles voor mij doet."

- C3



Ask and accept help from others

COPD patients have to ask others for help with tasks they are not able to do anymore. However, because patients want to stay independent and not be a burden for someone else it can be hard to ask for or accept help from others.

Patients hesitate to ask or accept help, because they do not want to be an burden for others

"Daar ben ik echt al jaren mee bezig, van het actief alles zelf doen en heen en weer rennen, naar nv alles door anderen laten doen"

- C 6

3.9 Needs for support

COPD patients want, like all people, live a happy and comfortable life. In regard to energy management this means feeling secure and autonomous. To achieve this, COPD patients have to control their energy and make sure they don't cross their energy limits. To achieve this the patients face some challenges like described before.

These challenges are barriers to achieve a desired situation by the patient (figure 3.11). This desired situation describes when the challenge is accomplished, through the eyes of the patient. This desired situation of the patient often go beyond staying between their energy limits and might be a reason they get intrinsically motivated. For example "I want to feel in control of my body". So the patient needs support with feeling in control of their body.

Each of the challenges described in the previous paragraph leads to a need for support.

Keep focus on energy level and act if needed

The desired situation in the eyes of the patient is when they are in control of their body and are content about how they spend their energy. During unexpected or unfamiliar situations they want to feel secure and supported.

To reach this desired situation they need support in sensing their energy level regularly and making a decision on how to respond to a changing level of energy. In case of unexpected or unfamiliar activities they need support in reminding to watch their energy level, in preparing unfamiliar activities and in preventing unexpected situations.

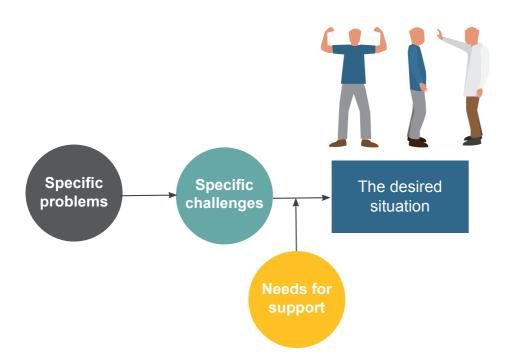


Figure 3.11 | The challenges and need for support between the current and desired situation

In the end the patient wants to feel satisfied about how they spend their energy. For example by spending a little energy in the morning, so there is energy left for a nice activity with family in the afternoon.

Find a new applicable routine

The desired situation for the patient is to feel secure during their daily activities and know what they can expect from themselves and others. So they need support in finding ways to spend less energy on energy consuming activities. The patient also need support in prioritizing and planning activities in order to feel secure about their schedule.

The patient also want to improve and stay motivated to improve. In order to do so they need support in reflecting in an easy, effective or even fun way.

Put yourself in first place

The desired situation for COPD patients is to feel understood by friends and family, feel empowered to hold their boundaries and feel free to say no or ask/accept help from others.

To reach this situation the patients need support in communicating about the impact of COPD and communicating their energy level at that moment. Furthermore they need help to prioritize their activities so they no when to say no and support in communicating this choice. When it comes to the help of others they need support in accepting they need the help from others, recognizing others are willing to help and reminding they can ask for help.

In figures 3.12a and 3.12b the problems, challenges and needs for support are visualized. Each of the challenges is visualized with a scenario of the challenge in daily life. The visual gives an overview of the situation of the patient and can be used in the design process to get a idea of the challenges a patient faces.

Figure 3.12a | Scenarios of challenges & needs for support

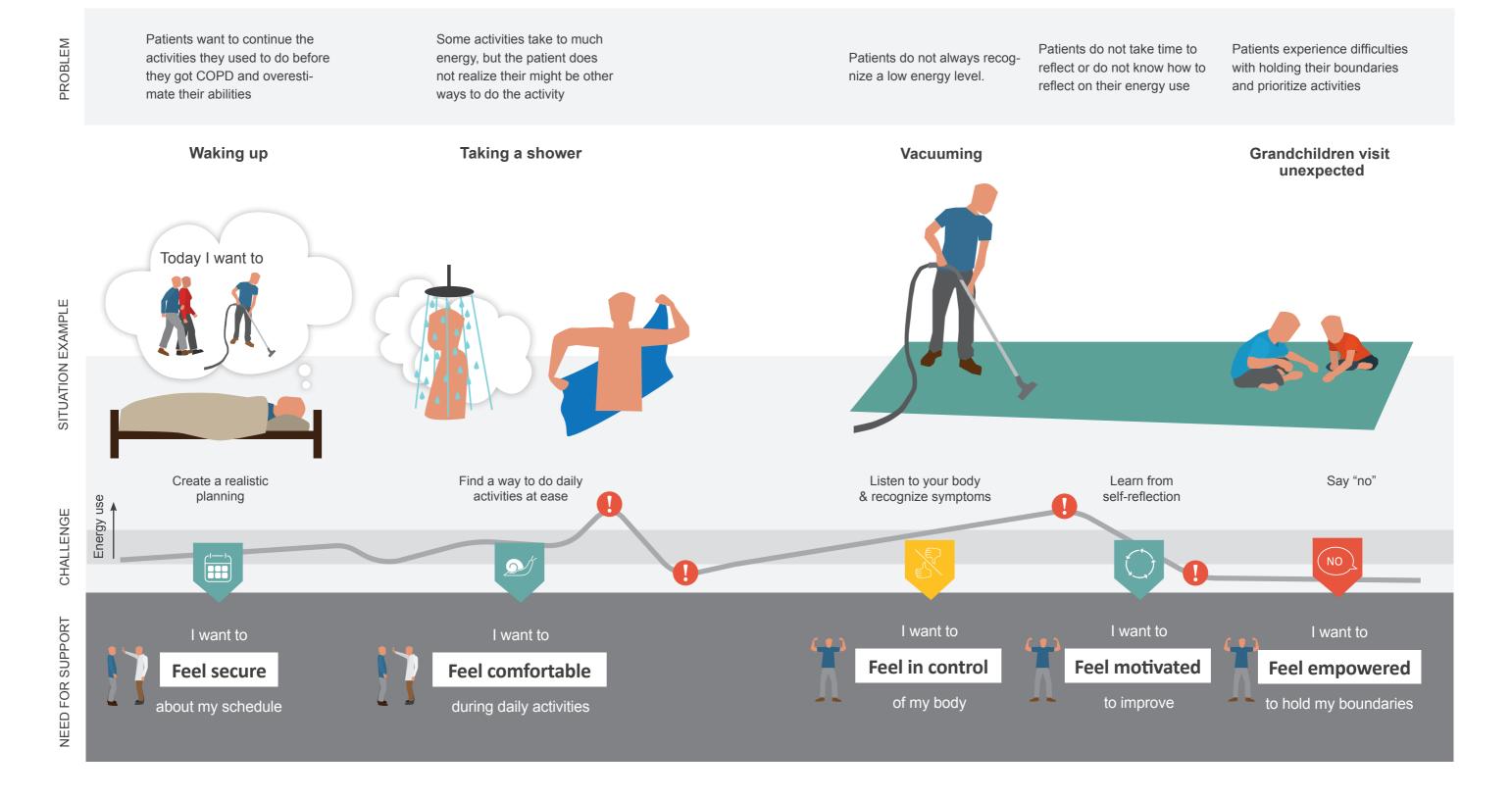
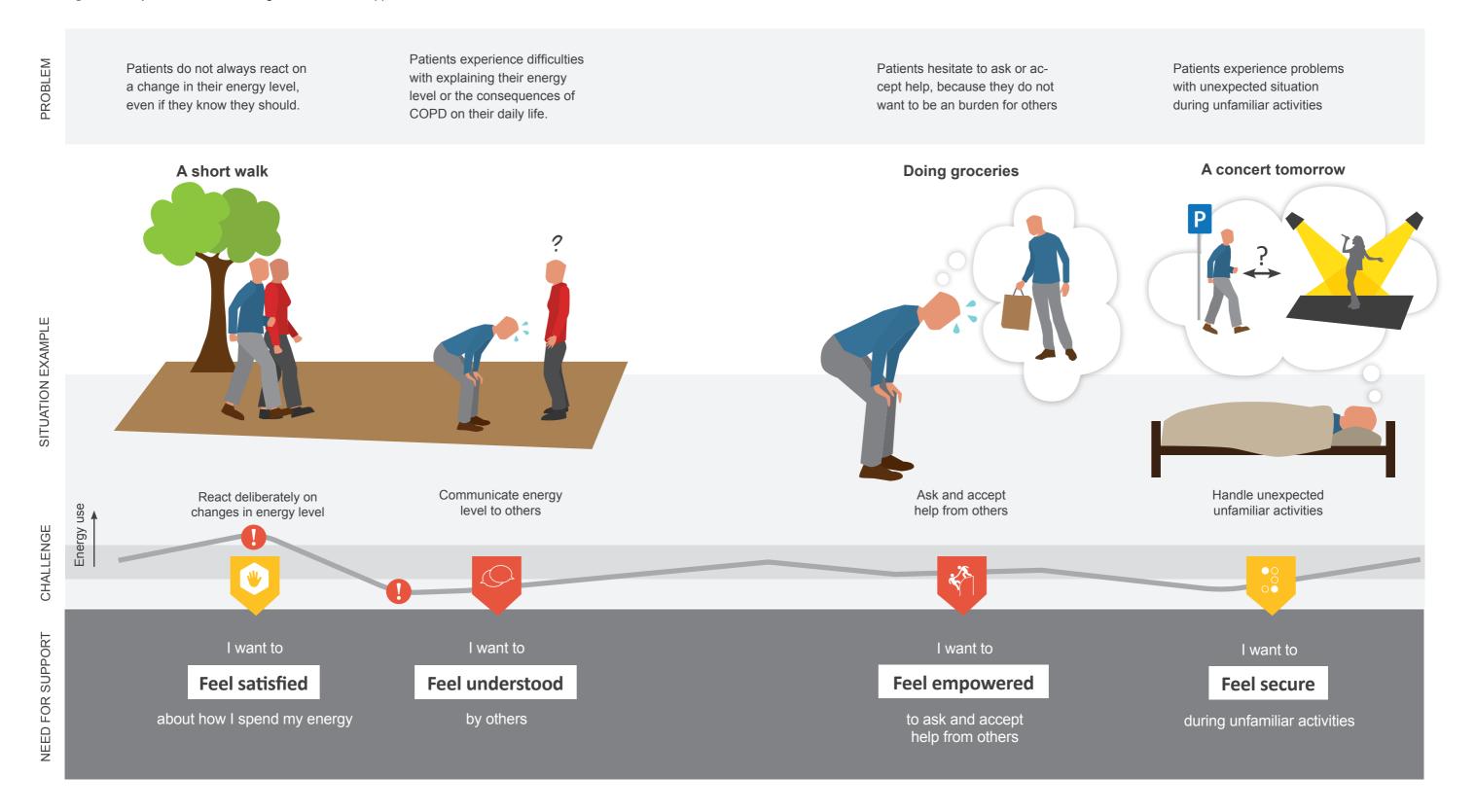


Figure 3.12b | Scenarios of challenges & needs for support



3.10 Interaction vision

The desired interaction between a self-mangement support solution and a COPD patient, shows a lot of similarities with rock-climbing. Therefore this interaction is chosen as the interaction vision to commucate the desired interaction between the solution and the patient.

The interaction shows so many similarities, because the whole situation is comparable. Rock-climbing can be a bit challenge, just like COPD patients can experience the management of their energy as a big challenge.

The belayer give the climber in a feeling of security and will protect the climber when she falls. Likewise, a COPD patients wants to feel secure about their energy level and support when they (are about to) spend too much energy.

The climber has the lead in this situation, she de-

cides where she goes and at what pace. A COPD patient is also in need of this autonomy and wants to keep control over their life, instead of being told what to do.

The belayer of the climber has the overview and is able to give the climber advise and suggestions, so the climber is able to continue. Likewise, a solution that support the COPD patient in energy management can gather and visualize information the patient can't see themselves. This information will help the COPD patient to continue and improve.

Finally, the climber is rewarded when they reach the top, with a nice view and the feeling of having accomplished something. To stay motivated a COPD patient also needs rewards and confirmation they are doing well.

Climbing a mountain while you are secured



Figure 3.13 | Interaction vision, climbing a mountain while you are secured

Conclusion

COPD causes a decrease in the maximum energy a COPD patient can use, without consequences. As a result of this decrease in energy COPD patient have to find a new balance between their activities in daily life and their energy level. COPD patient have two main needs when it comes to energy management, they want to feel secure and autonomous during their daily activities.

Patients can follow a revalidation program to learn how to manage their energy. However, once they are home they don't have the support from the revalidation clinic anymore and face number of challenges in reaching a balance. The three main groups of a total of nine challenges are:

- Keep focus on energy level and act if needed
- Find a new applicable routine
- Put yourself in first place

Based on the challenges the needs for support are formulated. These needs include feelings like: in control, empowered, secure and understood. Together with the interaction vision this gives a overview of the desired interactions between the user and the COPD patient.

Next

In the next chapter the needs for support are translated into criteria for e-health solutions that support patients in energy management.

IV INTEGRATION

In this chapter the challenges and needs of COPD patients are explored in detail. Based on interviews with COPD patients two main needs in relation to energy management are identified. Furthermore nine challenges COPD patients face in daily life are determined and lead to a set of needs for support.

4.1 Defining criteria

In order to enable designers to use the insights in the design process, a set of criteria is created based on the challenges for, and needs for support of the patient (see figure 4.1). The designer will be able to use the criteria to evaluate concepts as well as a source of inspiration.

The criteria are a combination of all the knowledge gained about the needs for support during the interviews and tests. Most criteria can be directly referred to one of the challenges and related need for support.

Other criteria relate more to the interaction style that is needed to support the COPD patient with energy management. For example "Give the user positive feedback & rewards when they are successful." is not focused on a specific need or challenge, but on how to keep the user motivated and engaged.

The criteria are divided into two groups based on the main needs: autonomy and security. The categories within the two group are formed by the feelings extracted from the needs of support (see figure 4.1). These feelings are all related to the main needs of the patient (autonomy and security), but address different challenges.

Figure 4.2 shows one example of the route from the problem and challenge to the final criterion. In table 4.1 the criteria are listed. The icons on the rights side of the criteria refer to the challenge that is addressed.

The set of criteria in table 4.1 is tested with five designers on three different concepts, see paragraph 4.2. The final criteria are explained in paragraph 4.4.

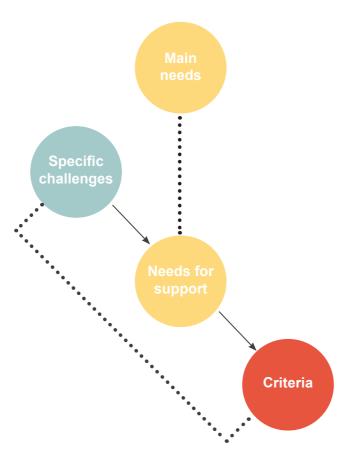


Figure 4.1 | Structure of the origin of the criteria

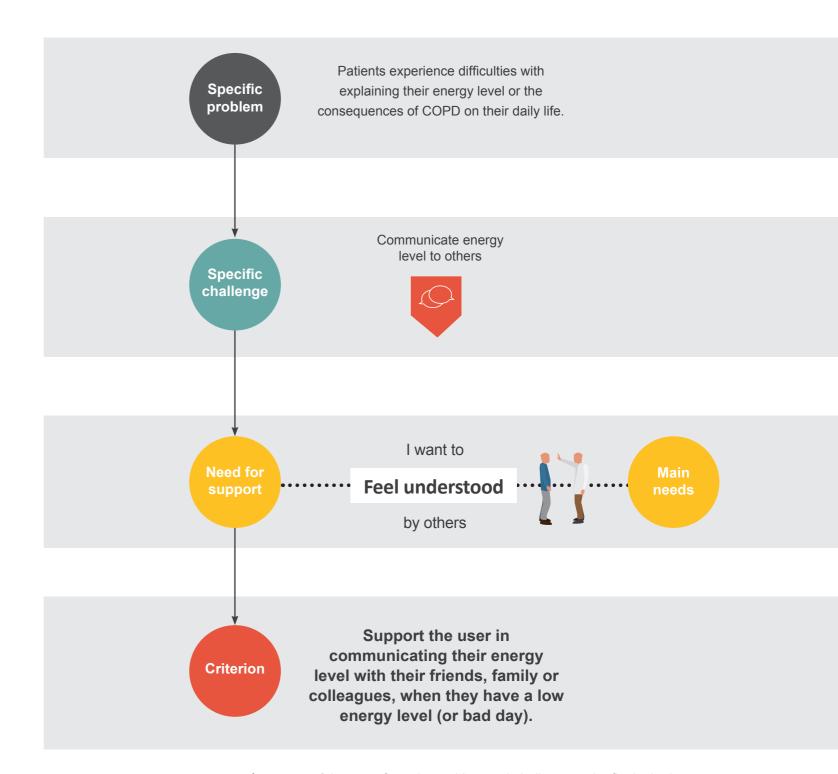


Figure 4.2 | Example of the route from the problem and challenge to the final criterion

Table 4.1 | First version of the criteria



Security

1. Let the user feel SECURE



1.1 Remind or warn the user when they spend too much energy.



1.2 Support in creating a realistic planning in early stages of use when they plan too much activities.



1.3 Enable the user to reach out for help or more support when they feel insecure.



1.4 Support in preventing unexpected situation when the user is in an unfamiliar situation.

2. Let the user feel UNDERSTOOD



2.1 Support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day).



2.2 Support the user in communicating the consequences of having COPD.

3. Let the user feel **COMFORTABLE**



3.1 Support the user in finding new ways to do activities, when an activity costs too much energy.



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3.2 Adapt to the users average level of energy and stage in disease.

Autonomy

4. Let the user feel **EMPOWERED**



4.1 Learn the user to listen to their body and sense/recognize their energy level.



4.2 Give the user insights about where in their daily routine they use (too) much energy.



- 4.3 Give the user insights in the relation between their energy level and their environment.
- 4.4 Learn the user to manage their energy in a way they can be independent of the solution when they master their energy.



4.5 Support the user in accepting or asking help from others, when they take too many responsibilities.



4.6 Support the user in holding their boundaries when they are asked to do more than they can or want to.

5. Let the user feel **IN CONTROL**



5.1 Support the user in taking a break in time.



5.2 Support the user in recognizing symptoms of a low energy level.



- 5.3 Give the user suggestions for interventions, but let them chose how to act when they spend too much energy.
- 5.4 Let the user decide the intensity of support by the system, based on their personal preferences and routine.

6. Let the user feel MOTIVATED



6.1 Give the user positive feedback & rewards when they are successful.

7. Let the user feel **SATISFIED**



7.1 Support the user in prioritizing activities when their goals in daily life are too high.

4.2 Testing the criteria

Method

The criteria are validated by comparing the rating of three different concepts by different designers. The deviations in the rating and the explanation of the designers show which criteria need to be revised.

The designers all rated the different concepts by means of the Harris Profile from '- -' till '+ +' (Boeijen, et al., 2010) and explained their choice. After evaluating the criteria the designers were asked to complete a short questionnaire.

The questionnaire asks the designers if the criteria are clear/unclear, too directive/vague, if they would leave out specific criteria or would add criteria and finally if they could design a solution for COPD patients with it that supports them in managing their energy.

The evaluation of the concepts with the criteria will tell if the criteria are clear and useful by comparing the rating of the different designers. The designers will rate the concepts similar or with minor deviations, if the criteria and concepts are clear. The questionnaire will give more insights about how the designers experienced working with the criteria. The form with the criteria and questionnaire can be found in appendix F.

The three concepts all try to support the COPD patient with energy management, but adress different needs and challenges. This ensures the concepts are rated differently on the same criterion and the criteria will be tested on their clarity and reliability.

- **Concept 1** is focused on supporting the patient in creating a realistic planning, reacting when they spend too much energy and reflecting on their activity.
- Concept 2 is focused on supporting the patient in recognizing and reporting their energy level and symptoms, communicating this energy level with others and reflecting on their energy level and energy use.
- Concept 3 is focused on supporting the patient in recognizing which activities and parts in their routine cost too much energy and supports them in changing their routine. Concept 3 as an additional function for support during unfamiliar activities.

The concepts are explained on the following pages. The concepts were presented in a similar way to the designers.

All the concept are visualized as mobile applications, but the functionality can be easily extended to a website or a wearable like a smart watch.







CONCEPT 1 Numbers tell the tale

This concept is focused on supporting the patient in creating a realistic planning, reacting when they spend too much energy and reflecting on their activity.



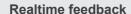
Dit kunt u doen:

Een activiteit niet doen

ACTIVITEITEN OK AANPASSEN

Plan

The user is supported in planning their energy over the day and week. He or she will be asked to enter their daily and weekly activities once at their first log in. These standard activities can always be edited. Every week the user will be asked to plan their additional activities, like visiting family, a walk with friends.



The user is at all times able to see how much steps they have taken and how this refers to their daily goals. Thereby the user is able to record steps for separate activities.

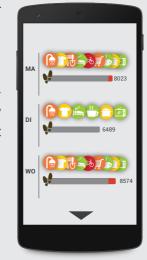
Warning

Next to the direct feedback in the form of battery, the user will get a warning message if needed. The message is send when the user is above his or her maximum intensity in steps/min, above their day part limit or above the maximum duration of their exertion in a row. It shows the message 'Take it easy', the reason why the message was send and some possible interventions they can do (slow down, take a break, postpone an activity or skip an activity).

Reflection

User are able to view an overview of their activities and energy use. The overview shows if they spend less or more energy than their upper limit and which activities they planned.





CONCEPT 2 Tell me







This concept is focused on supporting the patient in recognizing and reporting their energy level and symptoms, communicating this energy level with others and reflecting on their energy level and energy use.

Self-report energy

In the morning the user receives a message at a self-chosen moment. They are asked to indicate how they are feeling and are able to answer with a simple click. Additionally, they can add some notes if they want to. In the evening the user will receive a similar message with the question how they are feeling.

Self-report symptoms

When a user indicates they don't feel well, they are asked what doesn't feel well. The most common symptoms are shown in a visual way and can be selected easily.

Energie van Piet Het energie niveau van Piet is op dit moment laag. U helpt hem als u daar rekening mee houdt. OK

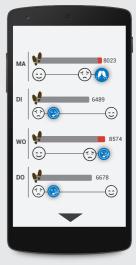
Share with others

A message is send to the people close the user when they indicate they have a low energy level. It is a very simple message that is not really disturbing for the receiver. It helps the user in communicating their energy level and preventing unexpected activities and having to say "no". With a simple message like this the user does not have to talk about their energy and disease so often.

Reflect

The user is able to see their total amount of steps per day together with their energy level and symptoms that they reported themselves.





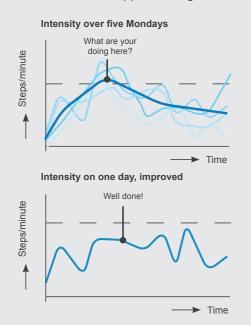






CONCEPT 3 Change your routine

This concept is focused on supporting the patient in recognizing which activities and parts in their routine cost too much energy and supports them in changing their routine. Concept 3 as an additional function for support during unfamiliar activities.



Measure deviations

By measuring the intensity of the movement of the users over several weeks, the moments of high energy use/intensity can be distinguished. For example every Tuesday morning the user babysits his grandchildren and spends a lot of energy. The application can show the user they spend that much energy every Tuesday morning and can ask what they are doing around that time. The application can support the user in finding a way to spread the energy use better. Besides, the application is able to see when the user improves and send a complement.

Change daily routine

The system determines where in their daily routine the user spends too much energy. At the end of a week the application notifies the user and support the user in planning more rest moments or activities that cost little energy in their daily routine. The application shows the activities the user does in one go and gives suggestions on which activities the user can do in between to create a moment of rest.



Hou mij extra in de gaten Voor minuten START ANNULEREN OK

Security button

Users have the opportunity to press the security button when they are in a situation that is unfamiliar or when they expect they will loose there focus on their energy level. When they press the button the system will send a reminder to watch their energy every half an hour and will warn them when they go towards their energy limit, instead of almost crossing it.



Results

The criteria are overall clear for the designers, but a few need improvement (the numbers are made bold in the text). A couple of criteria turned out to be unclear based on the results form the questionnaire and the deviations.

An overview of the evaluation of the concepts by the designers is shown in table 4.2. The table shows the spread of the ratings the designers gave: if the square is darker, more designer rated the similar. The last column shows the average standard deviation per criterion over the three concepts.

The five criterion with the biggest deviation (>0.7) are: **1.3**, **1.4**, **3.2**, **4.3** and **6.1**. The deviation of criterion 4.3 is significantly higher than all the others and is also mentioned by four designers as unclear. Four other criteria have a deviation between 0.6 and 0.7: 2.1, 2.2, **4.4** and **5.2** (the main criteria 2 and 6 are left out. .

Both the reasoning described by the designers for choosing the rating and the answers in the questionnaire clarify the deviations in the ratings. Table 4.3 shows the nine criteria with the largest average standard deviation and the most likely reason for this deviation. This can be either an unclear criterion, an unclear concept or one deviant rating.

In Apendix G all the results of the test can be found. The main results from the questionnaire are described below.

Would you leave out any criteria?

Two designers answered they would merge criteria, since they show similarities. One designer mentioned criterion **4.3** is quite similar to **4.1** and **4.2**, since they are all about insights in the patients energy use. An other designers mentioned the group of criteria **3** 'Let the user feel comfortable' is very similar to group **7** 'Let the user feel motivated' (with the criterion 'Give the user positive feedback & rewards when they are successful').

Did you miss any criteria?

The designers mentioned general usability and engagement criteria. One designer mentioned she

missed a criterion about supporting the user in recognizing they have accomplished something.

Are criteria pushing too much in a direction?

One designer mentioned the criteria in group 2 might be pushing towards a share function. An other designer mentioned criterion 1.2 (about creating a realistic planning) is "maybe not only about planning too much". This designer also mentioned criterion 4.6 (about holding boundaries when asked to help) might also applies when they want something themselves and have to hold boundaries.

All the designers indicated they would be able to design a solution to support COPD patients with their energy management with help of these criteria.

In the explanation the designers gave for the rating of a concept, more misinterpretations emerged. In criterion **2.2** (about communicating the consequences of having COPD) it is not evident what should be communicated. Criterion **3.1** (about finding new ways to do energy consuming activities) makes not clear it is about a different way to perform an energy consuming activity and not about changing the routine of several activities.

It is interesting to see the designers understood the needs of the user very well with help of a short explanation and the criteria, for example:

"No real way to prioritize, but still I think that the overview gives more support in feeling 'satisfied', than just responding when activities are too high. It is also nice to see what you have accomplished in a day!" Concept 1 and criterion 7.1 (Support the user in prioritizing activities when their goals in daily life are too high).

Furthermore they also recognized opportunities, for example:

Concept 1 and criterion 2.1 (Support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day)).

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"User can show battery or 'overview' to friends"

Table 4.2 | The evaluation of the three concepts by the designers

Concept 1	Concept 2	Concept 3	
+ ++	+ ++	+ ++	Average
SECURITY	SECURITY	SECURITY	deviation
1	1	1	0.183
1.1	1.1	1.1	0.298
1.2	1.2	1.2	0.332
1.3	1.3	1.3	0.812
1.4	1.4	1.4	0.793
2	2	2	0.611
2.1	2.1	2.1	0.698
2.2	2.2	2.2	0.697
3	3	3	0.332
3.1	3.1	3.1	0.548
3.2	3.2	3.2	0.745
AUTONOMY	AUTONOMY	AUTONOMY	
4	4	4	0.514
4.1	4.1	4.1	0.481
4.2	4.2	4.2	0.298
4.3	4.3	4.3	1.079
4.4	4.4	4.4	0.683
4.5	4.5	4.5	0.514
4.6	4.6	4.6	0.481
5	5	5	0.332
5.1	5.1	5.1	0.577
5.2	5.2	5.2	0.663
5.3	5.3	5.3	0.332
5.4	5.4	5.4	0.514
6	6	6	0.620
6.1	6.1	6.1	0.726
7	7	7	0.663
7.1	7.1	7.1	0.514
1 2 3 4 5 The number of designers who choose this rating.			

 Table 4.3 | The criteria with a high average standard deviation

Nr.	Criterion	Deviation	Mentioned by designers as unclear	Problem	
1.3	Enable the user to reach out for help or more support when they feel insecure.	0.812	2	It is not clear where the patients are insecure about. One participant understood this criterion only as support from people, not from a system.	
1.4	Support by preventing unexpected situations when they are in an unfamiliar situation.	0.793	2	The overall formulation of this criterion is unclear.	
2.1	Support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day).	0.698	0	The deviation in criteria 2.1 and 2.2 can be explained by the ambiguity of the concepts. Especially concept 1 was interpreted differently by the designers (some saw the op-	
2.2	Support the user in communicating the consequences of having COPD.	0.697	1	portunity in the concept to share a warning and reflection screen with others and gave the concept some points. While the other designers rated the concept low on these criteria). Criteria 2.2 was mentioned as unclear by one participant, because it is not clear what should be communicated.	
3.2	Adapt to the users average level of energy and stage in disease.	0.745	1	It is not clear what has to be adapted. Besides, the description of the concept was not clear enough about this topic.	
4.3	Giving the user insights in the relation between their energy level and their environment.	1.079	4	It is not clear what their environment means. Also the term insights is very broad in this criterion. However, the main reason for the big deviation is a different interpretation of th concepts by the designers.	
4.4	Learn the user to manage their energy in a way they can be independent of the solution when they master their energy.	0.683	2	The overall formulation of this criterion is unclear.	
5.2	Support the user in recognizing symptoms of a low energy level.	0.663	0	The somewhat higher deviation can be explained by one participant who rated concept 2 much lower than all the other designers.	
6.1	Give the user positive feedback & rewards when they are successful.	0.726	-3	Mentioned by 3 designer as clear . The reason for the deviation here, is clearly the different interpretations of the concepts by the designers.	

Concept 2 and criterion 6.1 (Give the user positive feedback & rewards when they are successful). "Symptoms/reasons for feeling good could be included"

Conclusion

Overall the criteria and concepts were well understood. The deviation in the rating with the criteria is small for most criteria. The explanations of their choices showed they understood the needs of the

user and saw the opportunities for improvement of the concepts. The test made also clear some criteria need improvement. The most substantial problems are ambiguities in the text. A small unreliability in the test was the ambiguity or incompleteness in the description of the concepts, but the explanations written by the designers indicated when the concept was not clear, instead of the criterion.

4.3 Changes in criteria

The criteria are changed based on the insights from the test. Some criteria only needed a minor textual adjustment. Other criteria are changed more thoroughly by merging them with other criteria, removing them entirely or moving them to an other category. In all categories the order of criteria has been In paragraph 4.4 the reasoning behind all the criteria changed to the order of importance.

In the following tables the changes are explained. The tables show the old and new version of the criteria. Criteria with a textual change are blue and the criteria with larger changes are orange.

is explained.

Table 4.4 | Overview of all the changes in the criteria

	Old criterion	New criterion	Explanation	
	1. Let the user feel SECURE			
	1.1 Remind or warn the user when they spend too much energy.	1.1.Remind or warn the user when they spend too much energy.	No change	
	1.2 Support in creating a realistic planning in early stages of use when they plan too much activities.	1.2 Support in creating a realistic planning, in early stages of use, when they plan too much activities.	No change	
• • • • • • • • • • • • • • • • • • • •	1.3 Enable the user to reach out for help or more support when they feel insecure.	1.4 Enable the user to reach out for help or more support by or via the system, when they feel insecure about their focus on their energy level or abilities.	Clarified it is about support from the system. Added the subject of their insecurity: their focus on their energy level or abilities.	
• • • • • • • • • • • • • • • • • • • •	1.4 Support in preventing unexpected situation when the user is in an unfamiliar situation.	1.3 Support in preparing unfamiliar activities to prevent unexpected situations and high energy use.	Added the part about <i>preparing and</i> activity in order prevent unexpected situations. Added high energy use as to clarify unexpected situations can lead to high energy use.	
	2. Let the user feel UNDERSTOOD			
0	2.1 Support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day).	2.1 Support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day).	No change	
	2.2 Support the user in communicating the consequences of having COPD.	2.2 Support the user in communicating the consequences of having COPD on their abilities en energy level in daily life	Added more explanation about the type consequences.	

Table 4.4 | Overview of all the changes in the criteria (continued)

Old criterion	New criterion	Explanation
3. Let the user feel COMFORTA	ABLE	
3.1 Support the user in finding ways to do activities, wher activity costs too much en	n an ways to perform energy co	on-
3.2 Adapt to the users average level of energy and stage disease.		vel that it is about the limits and goals
	3.3 Support the user in finding new routine without high egy peaks.	
4. Let the user feel EMPOWER	RED	
4.1 Learn the user to listen to to body and sense/recognized energy level.		level
4.2 Give the user insights about where in their daily routine use (too) much energy.		
4.3 Give the user insights in the relation between their ene level and their environment	rgy effect of their decisions at	the situation and which relation.
4.4 Learn the user to manage energy in a way they can lead dependent of the solution they master their energy.	oe in- user towards managing th	neir explicit. Ip
4.5 Support the user in accept or asking help from others when they take too many responsibilities.		
4.6 Support the user in holding their boundaries when the asked to do more than the can or want to.	y are their boundaries when the	ey are

Table 4.4 | Overview of all the changes in the criteria (continued)

	Old criterion	New criterion	Explanation
	5. Let the user feel IN CONTROL		
•	5.1 Support the user in taking a break in time.	5.1 Encourage the user to stop, take a break or slow down when it is needed.	Reformulated
	5.2 Support the user in recognizing symptoms of a low energy level.	Removed	Included in 4.1
V	5.3 Give the user suggestions for interventions, but let them chose how to act when they spend too much energy.	5.3 Give the user suggestions for interventions when they spend too much energy, but let them free in deciding how to continue.	Added when they spend too much energy in order to add more context
	5.4 Let the user decide the intensity of support by the system, based on their personal preferences and routine.	5. Let the user decide the intensity and moments of support by the system, based on their personal preferences and routine.	Added moments of support
	6. Let the user feel MOTIVATED		
0	6.1 Give the user positive feed- back & rewards when they are successful.	6.1 Give the user positive feed- back & rewards when they are successful.	No Change
/I—I\	7. Let the user feel SATISFIED	Removed	The category 'satisfied' is removed, since the criterion in this category matches the category 'in control'.
	5.4 Support the user in prioritizing activities when their goals concerning activities in daily life are too high.	5.4 Support the user in prioritizing activities when their goals concerning activities in daily life are too high.	Moved to 5.4

4.4 Final criteria

The final criteria are described in the following paragraphs per category. The criteria are ordered based on importance. The criteria are explained and supported with some additional information and advices.

Let the user feel secure

The user feels secure when they know what to expect or when they know they will be warned when it tends to go wrong. This leads to the four criteria in this category.

- 1.1 COPD patients have to discover their new energy limits and recognize they come close to the limit. In order to do so, it can help to warn them when they spend too much energy or to remind them to watch their energy. However, it is important that the COPD patient does not become dependent on these warning or reminders.
- 1.2 In order to know what to expect from themselves and others, patients need to make a realistic planning of their day. This means they have to know how much energy they have to spend and how much energy each of the activities costs. In such manner they know what they are able to do on one day. This support is mainly needed in the early stage when it is difficult for the patient to estimate their abilities.

It is important that the solution does not ask the users to plan every day into detail, this is contrary to their need of feeling autonomous. In addition, it is important to be able to adjust the planning to the fluctuations in energy. If not, the user will not be able to meet their planning when they have a bad day/ moment.

1.3 - When a COPD patient plans to do something they never did before, they have to guess how much energy it will cost. Based on the energy costs they have to decide if they can perform the activity. However, it is very difficult to estimate the amount of energy of an unfamiliar activity, since unexpected situations can occur. For example a long walk to the parking place or a lot of stairs.

1. Let the user feel SECURE



1.1.Remind or warn the user when they spend too much energy.



1.2 Support in creating a realistic planning, in early stages of use, when they plan too much activities.



1.3 Support in preparing unfamiliar activities to prevent unexpected situations and high energy use.



1.4 Enable the user to reach out for help or more support by or via the system, when they feel insecure about their focus on their energy level or abilities.

The COPD patient needs support in preparing an unfamiliar activity by gathering as much information as possible, to prevent unexpected situations that cost a lot of energy during the activity.

1.4 - In order to feel secure during for example unfamiliar activities the user has to be able to reach out for more support from the solution. This support can mean they are monitored more intensely or they are reminded more often to sense their energy level. This is mainly useful in a later stage, when the user has found a balance, but in some situations wants someone to keep an eye on them.

Let the user feel understood

The user feels understood when their friends, family and colleagues understand the consequences of COPD in daily life and the fluctuations in energy.

- 2.1 Because of the fluctuations in energy COPD patients are misunderstood when they can do something one day, but are too tired the next day. This is difficult to understand for the people around them. Therefore it is important to support users in communicating their energy level to their friends, family and colleagues.
- 2.2 For the same reason (as described at 2.1) the user has to be supported in communicating the consequences of COPD on their abilities and energy level. In order to create a general understanding of the situation from the COPD.

Let the user feel comfortable

The user feels comfortable when they can life their daily life without thinking too much about their energy level. To reach this comfort they need to find a routine that fits their new energy level.

- 3.1 Users have to know which activities or parts of their routine are energy consuming, in order to find a routine that fits their new energy level. A patient is not always able to recognize energy consuming activities, so they need support in recognizing them.
- 3.2 When a user knows which activities are energy consuming have to find a way to perform them with less energy. This may mean more moments of rest within one activity, perform the activity in a different position (for example sitting) or use devices to help.
- 3.3 Besides changing the activity, users can also change the sequence of activities in order to create a routine that fits their energy. This might mean they do not perform two energy consuming activities after each other, but for example drink a cup of tea in between. The user needs support in recognizing opportunities to lower their energy use.

2. Let the user feel UNDERSTOOD



2.1 Support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day).



2.2 Support the user in communicating the consequences of having COPD on their abilities en energy level in daily life

3. Let the user feel COMFORTABLE



3.1 Support the user in recognizing energy consuming activities or routines.



3.2 Support the user in finding new ways to perform energy consuming activities, so they are less energy consuming.



3.3 Support the user in finding a new routine without high energy peaks.

Let the user feel empowered

The user feels empowered when they feel capable of managing their energy themselves and are able to communicate their abilities and needs to others. -

- 4.1 The user needs to listen to their body and recognize symptoms of low energy in order to be able to manage their energy level without help.
- 4.2 The upper limit of the energy use of COPD patients differs a lot. So the limits and goals have to be adapted to the user. If not the user will not feel empowered to reach their goals or they within their limit.
- 4.3. It is difficult for users to say 'no' to others if they can not do or join something. Especially if they really want to do it. So the user needs support in holding their boundaries when they are asked to do or join something.
- 4.4. Users want to be autonomous, but sometimes this means they have to delegate tasks, in order to be able to keep doing other tasks. So they have to ask help from others. Asking for help can be difficult or even shameful, so they need support in asking for help or be reminded that they can ask for help.

4. Let the user feel EMPOWERED



4.1 Learn the user to listen to their body, sense their energy level en recognize symptoms of low energy.



4.2 Adapt the limits and goals in spending energy to the level of (desired) energy use of the user.



4.3 Support the user in holding their boundaries when they are asked to do more than they can or want to.



- 4.4 Support the user in accepting and asking help from others, when they take too many responsibilities.
- 4.5 The solution has to guide the user towards managing their energy without (much) help from the designed system.

4.5 - In the end the user has to be able to function without much help from the solution. When a COPD patient just left the revalidation clinic they need a lot of support in finding a new routine. But once they found that routine the intensity in use of the solution and support can be lowered step by step. However, the COPD patient should keep the ability to ask for support (see 1.4).

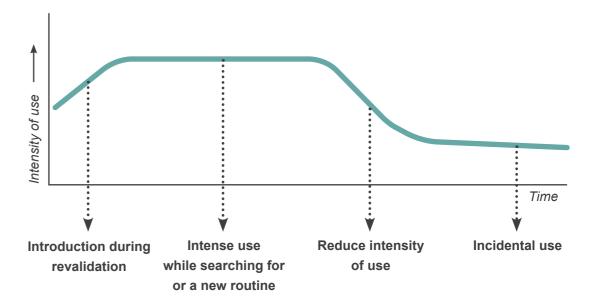


Figure x | Development in intensity of use

Let the user feel in control

The user feels empowered when they have the knowledge and tools to make the right decisions.

- 5.1 COPD patients do not always stop when they need to, even if they know they have to. Therefore they need to be encouraged to stop or take a break when they spend too much energy. However, the user has to stay in control. So if they don't want to stop and are aware of the consequences they should be able to.
- 5.2 In order to feel in control the COPD patient needs knowledge about the cause and effect of their actions.
- 5.3 When the user is notified to act, they have to know how to act. For example by stopping, taking a break or delegate a task. By giving the users suggestion the user knows what the options are and is still in control to decide what to do.
- 5.4 A COPD patient has to make choices in the activities they do, since they can not do everything they used to anymore. To feel in control of the activities they do and don't they need support in prioritizing their activities.
- 5.5 To let the user feel in control and comfortable the moments of interaction should be tailored to the routine and preferences of the user. Moments of interaction can be fixed recurring moments, for example a notification in the morning, or irregular moments based on the data the system receives. But also interactions initiated by the user or constant feedback for example on a display.

Let the user feel motivated

The user feel motivated when they feel they are in control and make progression.

6.1 - Next to all the suggestion and improvement the user needs some positive feedback and rewards when they are successful, in order to keep the user motivated.

5. Let the user feel IN CONTROL



5.1 Encourage the user to stop, take a break or slow down when it is needed.



5.2 Give the user insights in the effect of their decisions about and during activities, on their energy level.



5.3 Give the user suggestions for interventions when they spend too much energy, but let them free in deciding how to continue.



- 5.4 Support the user in prioritizing activities when their goals concerning activities in daily life are too high.
- 5.5 Let the user decide the intensity and moments of support by the system, based on their personal preferences and routine.

6. Let the user feel MOTIVATED



6.1 Give the user positive feedback & rewards when they are successful.

Implementation criteria in the design process

The criteria and visuals with insights in this project are meant to give Medicine Men and other design teams guidelines during the design process, in order to design an e-health solution for COPD patient and energy management. The criteria and interaction vision will support Medicine Men in creating the right experience for COPD patients in their designs. Elements of the criteria and visuals can be used in the exploration, ideation and naturally the evaluation phase.

Exploration

The visuals with insights can be used during the exploration phase of the design team. With the visuals they get a clear image of the main problem and needs of COPD patient sand specific challenges they meet. However, it is still very important for the team to talk to COPD patients and talk about specific challenges they meet in daily life and how they would like to feel.

Ideation

During the ideation the interaction vision, needs for support and the criteria can be used for inspiration. They help the designers to ask the right questions in order to come to a good solution. The interaction vision gives a sense of the aimed interaction. Both the needs for support and the criteria can be written as a 'How to' question to ideate on. For example: "How to let the user feel understood by others?" as a general question or ""How to support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day)?" as a more specific question.

Evaluation

Naturally, the criteria are meant for evaluating concepts. The criteria can be used with the Harris Profile to compare different concepts and evoke discussion. Since the criteria aim to solve different challenges the COPD patient faces, most concepts will meet all criteria. The criteria can be used to discover the strong points of one concept and the possibilities to combine these strong points with another concept.

The list with criteria is aimed at creating a solution that support the patient in their specific needs, to make them feel secure and autonomous. The list does not involve all possible criteria for an e-health solution for COPD patients. For example criteria aimed at usability of the solution and engagement with the solution are not fully present.

On the next page a roadmap is shown with the steps to implement the criteria in the design process. On the right page the visuals and related pages in this report that can guide the design team in these stages are shown.



1 EXPLORATION

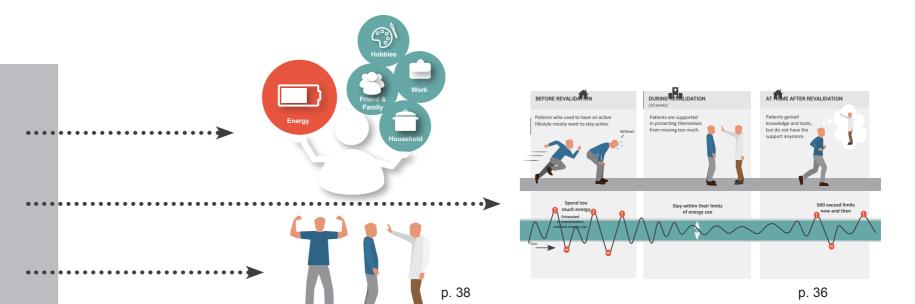
Explore the main challenge of energy management for COPD patient and the different stages with the chronic diseases and COPD

- What are the abilities of a COPD patient and the differences between patients?
- In which stage is your target group?

Explore the main needs of the patient

Explore the challenges and needs for support of patients

• Interview patients from your target group and find examples of the challenges (as described in the visual) in their life.



Today I want to Find a way to do daily activities all ease Find a way to do daily activities all ease I want to Feel secure acouting sale activities activities all ease I want to Feel montrol Gung daily activities Listen to your body A recognize symptom as of reflection Feel montrol Feel montrol Feel motivated to hold my bountaines

2 IDEATION

Use one challenge and need for support to design for

 Create an 'How to' question from the need for support. For example: "How to let the user feel understood by others?"

Use the interaction vision and two main needs to generate ideas with the right interactions

Use the criteria belonging to the challenge for more inspiration

• Create an 'How to' question from criteria. For example: "How to support the user in communicating their energy level with their friends, family or colleagues, when they have a low energy level (or bad day)?

4. Let the user feel EMPOWERED -- - + ++ 4.1 Learn the user to listen to their body, sense their energy level en recognize symptoms of low energy. 4.2 Adapt the daily limits and goals in spending energy to the level of (desired) energy use of the user. 4.3 Support the user in holding their

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3 EVALUATION

Use the criteria to evaluate and improve the concepts

- Evaluate the concept with the criteria following the Harris Profile.
- Discuss how the different concepts score
- Is it possible to combine the strong points of different concepts, for example if they are focused on solving different needs for support?

Test the concepts with COPD patients and use the criteria as a guidline. Dont' forget the test on general usability criteria and engagement as well.

boundaries when they are asked to do more than they can or want to.

4.4 Support the user in accepting and asking help from others, when they take too many responsibilities.

4.5 The solution has to guide the user towards managing their energy without (much) help from the designed system.

Conclusion

The list of criteria presented in this chapter are tested with five designers who all rated three concepts of mobile application to improve energy management for COPD patients. The results from the test show the criteria are helping the designers to understand the needs of the COPD patient. However, the designers need some background knowledge about COPD and the challenges of the COPD patient.

The test also showed some of the criteria where ambiguous, these criteria are revised and made more concrete

Conclusion and recommendations

Conclusion

Energy management is a serious challenge for COPD patients and it is important to support them at home after revalidation. e-health solutions have a number of qualities that are very suitable for the support of COPD patients after revalidation. e-health solutions are flexible and can be tailored to the needs of one patient. Besides, they can monitor and interact with the patient continuously.

The two main needs of COPD patients in regard to energy management are autonomy and security. COPD patients want to feel in control, empowered and motivated during their daily activities, but also secure, comfortable and satisfied.

The three main challenges they face in order to achieve these feelings while managing their energy are:

- Keep focus on energy level and act if needed
 Patients struggle to sense their energy regularly and do not always act even if they know they
 have to.
- Find a new applicable routine

 Patients have to find a new routine that fits their new energy level
- Put yourself in first place
 Can't always meet the expectations of others or help others and have to ask others more often to help them.

Based on the challenges and needs a list of criteria was created. All the identified challenges can be related to one or more criteria. And the criteria all address the needs autonomy or security.

This project has resulted in a well evaluated set of twenty criteria that can be used to develop e-health solutions for COPD patients to support them in energy management. The criteria support a design team during the development and evaluation of concepts. The criteria and visuals of the needs and challenges enable the designers to ask the right questions during the design process.

Recommendations

First of all the criteria are meant to be used in practice, this would be a great opportunity to test them in a design process. The criteria are tested on concepts, but not integrated in a design process from the start. In order to make insights about the challenges, needs and the criteria more tangible, they can be presented as a visual or, for example, developed as a card set.

The criteria are categorized by the needs of the COPD patient. The place of the criteria in these groups of needs can be argued. Some criteria address both autonomy and security. Besides, some of the categories are very similar and could be considered as one. It would be interesting to discuss the re-evaluate the categories in a group discussion.

The challenges, needs and criteria formulated in this project are based on experiences from COPD patients and meant for the period after revalidation. However, I expect they are also true for people with other chronic diseases, for example diabetes or heart failure. It would be advisable to explore to which extend the challenges and needs are similar.

Furthermore, it would be valuable to see if the criteria are also applicable to solutions for patients before the revalidation. It would be great if a solution created with the criteria could substitute a part of the ten-week revalidation program.

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