



Participatory development of a persuasive eHealth tool to support COPD self-management

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Abstract

Background. Self-management in chronic obstructive pulmonary disease (COPD) is important since it increases quality of life and thus reduces health service costs. The patient can be supported in this through eHealth, and social support from both informal caregiver and healthcare professional. Based on this idea, the self-management platform Emma was developed by Medicine Men. However, limited attention was paid to increasing psychological motivation to support behavioral change. Therefore, the aim of this study was to participatory increase the persuasiveness of Emma.

Methods. The CeHRes Roadmap and the Persuasive System Design (PSD) model were used for the development and evaluation. The study was divided into three stages; (1) Stakeholders, current situation and values; (2) Prototype design, requirements and development; and (3) Evaluation. Eight COPD patients (52-70 years) from the Bravis Hospital participated, together with three informal caregivers and four healthcare professionals. Participants were interviewed, invited for a co-creation session and completed an online evaluation in each stage respectively. The interviews and co-creation session were audio-recorded, transcribed verbatim and analyzed by an iterative process, which combined deductive and inductive coding.

Results. In stage 1, Medicine Men and users were selected as important stakeholders and the context was described. Three requirements were identified: a measure for oxygen saturation (Self-monitoring), support for patients in reaching their goal (Reminder) and a mobile application for the informal caregiver (Social Facilitation). In Stage 2 the prototypes were developed based on the requirements and design principles from the PSD model. A majority of stakeholder preferred the Reminder, and additional requirements were identified. In Stage 3 the Reminder was implemented and evaluated. Based on primarily experiences, patients indicated the tool persuaded them into changing their behavior, and therefore being effective in supporting self-management.

Conclusion. We showed that Dialogue and Primary Task support were needed in persuading COPD patients into increasing their self-management. A non-invasive Reminder tool seemed indeed effective in changing patients' behavior. Including multiple stakeholders and an extensive and systematic contextual inquiry are recommended.

Keywords: Participatory development; persuasive design; eHealth technology; self-management; chronic obstructive pulmonary disease

Samenvatting

Achtergrond. Zelfmanagement bij chronische obstructieve longziekte (COPD) is belangrijk omdat het de levenskwaliteit vergroot en daardoor de kosten van de gezondheidszorg vermindert. De patiënt kan hierbij worden ondersteund door eHealth en door sociale support van zowel de mantelzorger als zorgprofessional. Op basis van dit idee is het zelfmanagement platform Emma ontwikkeld door Medicine Men. Er is echter weinig aandacht besteed aan het ondersteunen van psychologische motivatie voor gedragsverandering. Daarom was het doel van deze studie om gezamenlijk de persuasiviteit van Emma te verhogen.

Methoden. De CeHRes Roadmap en het Persuasive System Design (PSD) model werden gebruikt voor de ontwikkeling en evaluatie. De studie was in drie fasen verdeeld; (1) Belanghebbenden, huidige situatie en waarden; (2) Prototype ontwerp, eisen en ontwikkeling; En (3) evaluatie. Acht COPD-patiënten (52-70 jaar) van het Bravis ziekenhuis hebben deelgenomen, samen met drie mantelzorger en vier zorgprofessionals. Deelnemers werden geïnterviewd, uitgenodigd voor een co-creatie-sessie en voltooiden een digitale evaluatie in elk stadium respectievelijk. De interviews en co-creatie sessie werden opgenomen, getranscribeerd en geanalyseerd via een iteratief proces, welke deductieve en inductieve codering combineerde.

Resultaten. In Fase 1 werden Medicine Men en gebruikers geselecteerd als belangrijke belanghebbenden en de context werd beschreven. Er zijn drie vereisten vastgesteld: een saturatiemeter (Zelfbewaking), ondersteuning voor patiënten bij het bereiken van hun doel (Herinnering) en een applicatie voor de mantelzorger (Samenwerking). In Fase 2 werden de prototypes ontwikkeld op basis van de eisen en ontwerpbeginselen van het PSD-model. Een meerderheid van de belanghebbende gaf de voorkeur aan de Herinnering, aanvullende eisen werden tevens geïdentificeerd. Deze tool werd ontwikkeld en geïmplementeerd. In Fase 3 werd de tool geavaleerd. Gebaseerd voorlopige ervaringen, gaven patiënten aan dat de tool overtuigde om hun gedrag te veranderen en dus effectief bleek te zijn bij het ondersteunen van zelf management.

Conclusie. We hebben laten zien dat dialoog- en primaire taakondersteuning nodig waren om COPD-patiënten te overtuigen hun zelfmanagement te versterken. Een niet-invasieve Reminder-tool leek inderdaad effectief om hun gedrag te veranderen. Het betrekken van meerdere belanghebbenden en een uitgebreid en systematisch contextueel onderzoek worden aanbevolen.

Trefwoorden: Gezamenlijke ontwikkeling; persuasief design; eHealth technologie; zelfmanagement; chronische obstructieve longziekte

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Introduction

COPD Self-Management

Chronic diseases affect an increasing number of people every year worldwide (Willis & Royne, 2017). According to the Nivel (2016) 8.2 million people in the Netherlands have at least one chronic disease, which is about half of the Dutch population. Despite the vast knowledge and significant number of interventions designed to prevent chronic diseases, it still remains the leading cause of illness, disability, and death (Willis & Royne, 2017). One such group of chronic diseases is chronic obstructive pulmonary disease (COPD), including chronic bronchitis and emphysema (GOLD, 2017). COPD is characterized by persistent respiratory symptoms and airflow limitation, due to airway and/or alveolar abnormalities, usually caused by smoking (GOLD, 2017). It is important to focus on COPD since it is a major health problem; prevalence and mortality rates are increasing worldwide. In the Netherlands alone, more than 607.000 people are diagnosed with COPD and numbers are rising (Nivel, 2016). However, this chronic disease is treatable according to the Global initiative for chronic Obstructive Lung Disease (GOLD, 2017). Therefore, interventions to decrease the mortality rates of COPD are required.

The main response from policy makers, health providers and healthcare professionals towards COPD so far has been to promote greater self-management (Department of Health, 2012). This is based on the finding that COPD self-management helps to slow down disease progression and reduces the need for unscheduled acute admissions, thereby increasing health-related quality of life and reducing health service costs (Alwashmi et al., 2016; Department of Health, 2012). Self-management refers to the important role people with COPD and other chronic diseases have in dealing with their condition. This single role can be further divided into three management tasks (Schulman-Green et al., 2012). The first task is medical management, which includes monitoring fluctuations. This is important since fluctuations in three vital signs (pulse rate, oxygen saturation, and respiratory rate) are predictive of exacerbation events, a worsening of dyspnea, cough, and sputum production (Bonten, Kasteleyn, Taube, & Chavannes, 2016; Shah, Velardo, Farmer, & Tarassenko, 2017). The second task is behavioral management, which includes adapting an active lifestyle. This is important since physical activity slows the decline of lung function, reduces the frequency of exacerbations and hospitalization, reduces

the risk or progression of co-morbidities, and improves health-related quality of life (Hartman, Boezen, de Greef, Bossenbroek, & ten Hacken, 2010; Maltais, 2013). The third task is emotional management, which includes processing emotions that arise from having COPD. This is important since depression is common in patients with COPD, and in turn interferes with medical and behavioral management (Yohannes, Hann, & Sibbald, 2011). Hence, in line with the aforementioned view, patients with COPD who adequately self-manage their chronic disease might indeed have an increased health-related quality of life and reduce health service costs (Department of Health, 2012).

Social Support and eHealth

Although self-management is beneficial for patients, they are confronted with various barriers like dyspnea, fatigue and muscle weakness, making it difficult to actually change their behavior (Janssen, Spruit, Uszko-lencer, & Wouters, 2011). Therefore, the question arises whether COPD patients require social support in self-managing their chronic disease. The World Health Organization defines social support as being both ‘emotional and practical support characterizing good social relations’ (Wilkinson & Marmot, 2003). Research shows indeed that social support is an important factor for improving self-management behaviors (Ungar et al., 2016). One source of social support are informal caregivers. They are of major importance for patients with COPD, since the majority of home care is provided by family and friends instead of healthcare professionals (Hasson et al., 2008). Research with COPD patients shows for example that social support from informal caregivers is essential in increasing physical activity (Barber, 2013), and improves adherence to medical recommendations (Trivedi, Bryson, Udris, & Au, 2012). But also a good patient–professional partnership appears to be beneficial for self-management. Suggesting also that healthcare professionals play an important role in supporting patients to change self-management behaviors associated with COPD (Fu, Yu, McNichol, Marczewski, & Jose Closs, 2016). Thus for the patient to successfully self-manage their COPD, social support from both informal caregiver and healthcare professional is needed.

One way of supporting social support and self-management is through eHealth. eHealth refers to health services and information delivered or enhanced through the internet and

related technologies (Eysenbach, 2001), such as wearables and mobile phones. Currently most eHealth interventions for COPD focus on improving self-management by only supporting the patient. This is done in two different ways. First, wearables are able to monitoring fluctuations through a pulse oximeter, which offer the possibility for early identification of exacerbations and allow the patient and healthcare professional to intervene successfully (Buul, Kasteleyn, Chavannes, & Taube, 2016). Second, mobile phones can to support physical activity in COPD patients. An example is of a tool embedded in a counseling protocol that used a pedometer and mobile app to monitor and motivate COPD patients to increase their physical activity in daily life (Weegen, 2015). Thus eHealth has the potential to support both medical and physical self-management, namely by decreasing exacerbations and increasing physical activity. However, social support is not yet incorporated in these eHealth interventions. So there seems to be a discrepancy between studies on social support and current interventions regarding the way of supporting COPD self-management. This discrepancy between tools found in literature and tools being implemented, was also found in a recent literature review of current eHealth applications for COPD self-management. More specific, results mentioned the following five tools; feedback, e-coaching, personalized education, social networking tool, and psychological motivation to support behavioral change (Sobnath et al., 2017). Hence, to successfully support COPD self-management, an eHealth intervention is needed which does incorporate aforementioned tools and thereby supports social support.

Online Platform for COPD Self-Management: Emma

An example of an eHealth intervention for chronic disease management which aims to offer an overall solution for self-management is the online platform Emma, which is currently being developed by Medicine Men, a start-up company founded in 2012. For this they make use of agile design, an approach which advocates the development of technology with a small team of experts and customers, and the rapid development of prototypical versions of the eHealth technology which are evaluated and redesigned (Hekler et al., 2016). The ultimate goal of Emma is to help patients better self-manage their COPD and decrease the number of exacerbations by 25% per year. In addition, Emma can also be used by patients with other chronic conditions in

which self-management is important, like the Human Immunodeficiency Virus (HIV). The platform Emma exists of a website, a mobile application (app), and a smartwatch app (see Figure 1). Via that Emma is able to collect different types of health data and monitor one's health. In the case of COPD, most important is the level of physical activity. By monitoring one's health, the system itself, but also the informal caregiver can provide feedback on patients' behavior. Moreover, this insight gives healthcare professionals the opportunity to provide e-coaching and to give personalized education. The platform can also be used as a social networking tool for communication between patient, informal caregiver and healthcare professional. Thus Emma is a unique platform since it already incorporates four out of five tools which were found to be missing in many other eHealth applications for COPD self-management (Sobnath et al., 2017).

What has received less attention is how to increase psychological motivation to support behavioral change. That it is important to focus on this tool, is in line with the view of Oinas-Kukkonen regarding the importance of health behavior Change Support Systems (hBCSSs) which are defined as: 'an information system designed to form, alter or reinforce attitudes, behaviors or an act of complying without using deception, coercion or inducements' (Oinas-Kukkonen, 2010). HBCCSs might be especially important in the case of COPD because adherence rates to self-management interventions tend to be as low as 32% (Søgaard et al., 2016). Hence, a tool is needed which increases motivation to support behavioral change.



Figure 1. The Emma platform

The CeHRes Roadmap

According to many studies, persuasive features play an important role in the acceptance of a hBCSS and in the intention to continue using the system (Kelders, 2012). Persuasive technology is defined as technology that is designed to change attitudes or behaviors of the users through persuasion and social influence, but not through coercion (Oinas-kukkonen & Harjumaa, 2009). However, persuasive technology itself might not be enough; technology needs to fit the requirements of the user in order to be successful and sustainable. The key is to involve stakeholders, the ones who affect or are affected by eHealth technologies, in every stage from problem definition to the technology's evaluation (van Gemert-Pijnen et al., 2011). This might be especially the case for COPD patients because of their general low socioeconomic status (Søgaard et al., 2016), which is associated with suboptimal chronic disease self-management (Kanervisto, Vasankari, & Laitinen, 2011). Thus it is important to combine both persuasive design and participatory development.

A framework which combines both was developed by the Centre for eHealth and Wellbeing Research (CeHRes) of the University of Twente; the CeHRes Roadmap (van Gemert-Pijnen et al., 2011). The Roadmap guides eHealth technology developers, researchers and policy makers through the processes of problem definition to successful eHealth technology. The CeHRes Roadmap is based upon three underlying approaches which serve as the theoretical background, namely persuasive design, participatory development and business modelling. Persuasive design is incorporated through the Persuasive System Designs (PSD) model, which offers a framework for applying and evaluating persuasive technology (Oinas-kukkonen & Harjumaa, 2009). This framework is divided into four categories: Primary Task Support, Dialogue Support, Social Support and Credibility Support (see Figure 2). Primary task Support aims to assist the user in performing their primary task. Dialogue Support refers to the interaction between the system and the user, with the aim to keep the user active and motivated. Social Support refers to the opportunity to make use of social support facilitated by the system. Finally, Credibility Support is the belief users have about the trustworthiness of the system. The four categories are operationalized via twenty-eight design principles (see Figure 2).

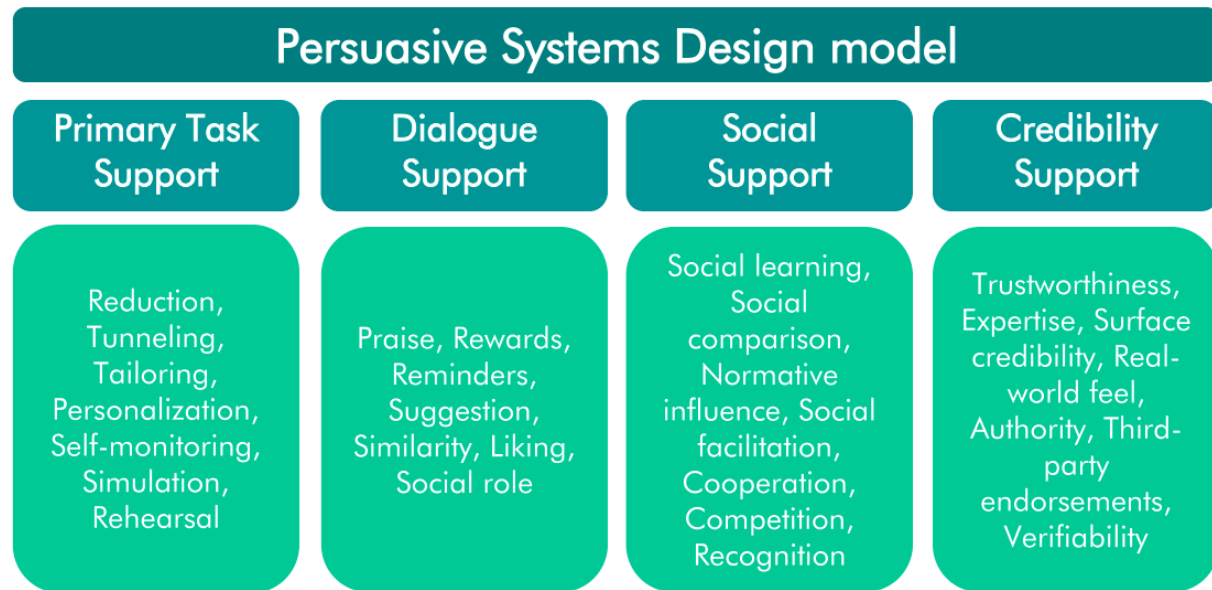


Figure 2. The Persuasive Systems Design model (Oinas-kukkonen & Harjumaa, 2009)

Business modeling refers to describing how the organization involved in the eHealth development creates, delivers and captures values. Business modeling plays an important part in the implementation, since it acts as the basis for discussion of value drivers with stakeholders and becomes the basis for further operationalization. Aside from the three underlying approaches, the Roadmap itself is divided into five intertwined phases and connecting cycles (see Figure 3). The aim of the Contextual Inquiry is to get an understanding of all stakeholders and their context, and analyze the strong and weak points of the current situation. In the Value Specification the aim is to determine which values both stakeholders deem important. These values are then translated into requirements. The aim of the Design is to develop a prototype version of the tool, based on the requirements. The Design is followed by Operationalization, in which the tool is introduced to users. The final step is the Summative Evaluation, in which is determined whether the added value was achieved and what the influence of the tool is. The connecting cycles represent the iterative formative evaluations, which are line with the method of agile design, and ensure that activities during a phase are related to the stakeholder perspective, the context, and outcomes of previous phases.

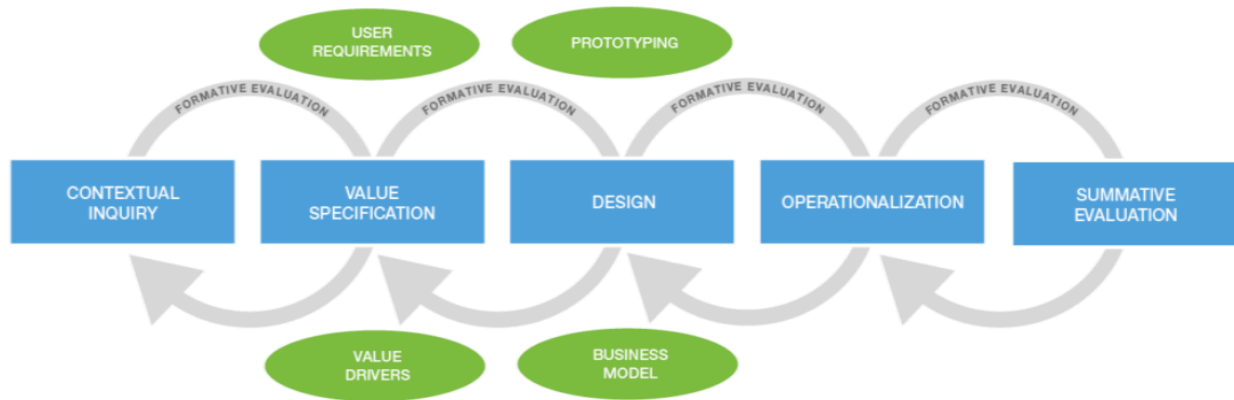


Figure 3. The CeHRes Roadmap (van Gemert-Pijnen et al., 2011)

Within this study, the PSD model will be used to identify in which category the persuasiveness of Emma is lacking and which design principle can be used to enhance behavioral change. The CeHRes Roadmap is used to guide through the processes of problem definition to a persuasive tool for Emma. Since the aim is to improve existing eHealth technology rather than design new technology, the focus will be on participatory development and persuasive design, and to a lesser extent on business modeling.

Research Questions

The aim of this study is to participatory increase the persuasiveness of Emma. The study is divided into three stages; (1) Stakeholders, current situation and values; (2) Prototype design, requirements and development; and (3) Evaluation. Within these stages the following research questions are answered:

1. Which key-stakeholders should be involved and what do they require in order to increase the persuasiveness of Emma?
2. What is the opinion of patients and informal caregivers regarding the prototypes?
3. What is the opinion of patients regarding the additional tool?

Stage 1. Stakeholders, Current Situation and Values

Methods of Stage 1

Stage 1 of this study reflects the Contextual Inquiry and Value Specification, the aim was to answer the following question: *‘Which key-stakeholders should be involved and what do they require in order to increase the persuasiveness of Emma?’* This stage was divided in three steps. Step 1 was to identify key-stakeholders, by desk research and unstructured interviews regarding their added value in this study. Step 2 was to describe the current situation, by analyzing the current platform Emma. Step 3 was to identify values from key-stakeholders by interviewing them, and translating these values into requirements while using the design principles.

Participants. Participants consisted of COPD patients, their informal caregivers and physiotherapists. HIV patients using a comparable version of Emma were also included in this study, since they might show similarities in usage and values regarding the persuasive elements, which might provide valuable insights for COPD patients. Furthermore, when usage and values were similar, the additional tool could also be implemented for and evaluated by HIV patients. All participants were already recruited and participate voluntary in one of two project teams aimed at developing and testing Emma; MyCOPD and METT (Met Emma Therapie Trouw; adherence with Emma). See Table 1 for an overview of all participants in per project and stage.

Table 1. Number of participants per project and stage

	MyCOPD			METT		
	P	IC	HP	P	IC	HP
Participants involved in the project	8	4	4	13	13	2
Participants involved in Stage 1	4	3	4	7	-	-
Participants involved in Stage 2	6	3	-	-	-	-
Participants involved in Stage 3	8	-	-	-	-	-

Note: P: Patient, IC: Informal caregiver, HP: Healthcare professional.

The project MyCOPD was in concordance with the Leids Univeristy Medical Center and the Bravis hospital in Roosendaal, a district general hospital in the Netherlands (385 beds). Recruitment of patients was done by a nurse of the hospital. Patients were eligible if they were interested in the study, owned an Android phone or tablet with WiFi access and were diagnosed

with COPD GOLD level three or four. The GOLD level indicates the severity of the COPD, ranging from one to four, with four being most severe (GOLD, 2017). All eight patients from the project participated in the study, see Table 2 for their characteristics. Only four patients were invited in this stage, since the other four were not using the full platform at the time of data collection. Three patients had an assigned informal caregiver, of which all were willing to participate, two being their partner (male) and one being their daughter. All informal caregivers were using the system for one week. Furthermore, two patients had one physiotherapist, and one patient had two physiotherapists, who were working with the platform. All physiotherapists (three female) were willing to participate, they were using the system for nine weeks on average (1–4 months).

Table 2. Characteristics and stage of study per patient from MyCOPD

	P1	P2	P3	P4	P5	P6	P7	P8
Age	64	52	55	65	67	62	70	68
Gender	F	F	F	M	M	F	M	F
GOLD level	3	4	3	3	4	3	3	3
Starting date	02-17	11-16	01-17	01-17	01-17	01-17	01-17	01-17
Stage study	1, 2, 3	1, 2, 3	1, 2, 3	1, 2, 3	2, 3	2, 3	3	3

The project METT with HIV patients was in concordance with the Emma hospital for children, part of the Amsterdam Medical Centre (AMC). Recruitment here was done by a physician assistant and researcher of the hospital. Patients were eligible if they were diagnosed with HIV, interested in the study, owned an Android phone or tablet with WiFi access, and were a maximum of 18 years of age. Seven patients (two female) were invited and participated in the study. Their average age was 14 years (10-17 years) and they were all diagnosed with HIV since birth. Patients were using the system for four months on average (3-6 months).

Procedure and materials. Participants received access to Emma platform and could use a Pebble smartwatch for free during the time of the pilot. All participants from MyCOPD were approached by phone and asked whether they were willing to participate in this study. All of the participants agreed and signed an informed consent form prior to participating (Appendix 1). Participants were then approached to set up an appointment for an interview, either by phone

or at the Bravis Hospital. A semi-structured interview schedule for each group of participants was created in concordance with Medicine Men. The schedules were largely based on the four categories of the PSD model, the category context was added. See for a description of each category and example questions Table 3, and for the complete interview schedules Appendix 2. The aim of the interview was to describe the context and identify where the persuasiveness of Emma was lacking according to its users. Interviews with the patients and physiotherapists took on average 45 minutes, interviews with informal caregivers took on average 20 minutes. With permission of participants, all interviews were audio-recorded. HIV patients from METT were already interviewed by a researcher from the AMC. Please note that all quotes used in this thesis were translated from Dutch to English, for original quotes see Appendix 3.

Table 3. Description per category and example questions for Stage 1

Category	Description	Example question
Context	Usage and relationships	Who is your IC and why?
Primary Task Support	Aim, impact and evaluation	Does the activity coach help you reaching your daily goals?
Dialogue Support	Dialogue between system and user	How do you experience the activity coach changing color?
Credibility Support	Reliability of the activity data	Do you think the activity information is correct?
Social support	Provided social support through Emma	What do you think of the involvement of your IC?

Note: Original questions were in Dutch.

Data-analysis. Participant dialogue from MyCOPD was transcribed verbatim by the researcher, using Express Scribe (version 6.04). To guarantee anonymity of the respondents, names and other personal information was anonymized. The data analysis was an iterative process, in which deductive- and inductive coding were combined. All transcripts from MyCOPD and METT were imported into the qualitative analysis software Atlas.ti (version 1.6.0). Data was analyzed separately for each group of participants. Relevant fragments were identified and classified through deductive coding, based on the four categories of the PSD model and the category Context (see Table 3). Subsequently, when it was meaningful to further categorize through inductive coding, a next level was added.

Results of Stage 1

Step 1. Identifying key-stakeholders.

Users: Patient, informal caregiver and healthcare professional. The first key-stakeholder was the user, whom could be divided into patient, informal caregiver and healthcare professional. The reason for including users as a key-stakeholder within this study was for them to use and evaluate the platform.

Medicine Men. The second key-stakeholder was Medicine Men, the company behind Emma. The task of Medicine Men within this study was to think along about the study plan and research questions, deliver technical support, and transform the prototype into an actual tool. The reason for including Medicine Men as a key-stakeholder concerned their ownership of Emma. Since they were financial responsible for the development, they had to permit and influence the changes being made.

Step 2. Describing the current situation.

Description of Emma: MyCOPD. Since the platform can be applied in a various number of ways, only the appliances of the platform relevant for the study are described. One appliance of the platform is used within MyCOPD. The first aim is to increase COPD patients' level of physical activity, and by that decreasing the number of exacerbations. The second aim is to predict future exacerbations. MyCOPD includes the Emma dashboard (website), Emma mobile app and Emma activity coach (smartwatch app, see Figure 4). On the Emma dashboard healthcare professionals can set a daily goal regarding the number of steps for each of the four parts of a day, including the percentage of allowed deviation. They can fill in a goal of their preference or use a suggested goal, which are based on patients' previous activity levels. Furthermore, patients, but also informal caregivers and healthcare professionals can Self-Monitor patients' activity levels. The dashboard also offers Social facilitation; patient, informal caregiver and healthcare professional can communicate with each other. Finally, healthcare professional can send a questionnaire to the patient. The Emma mobile app serves as a way to communicate between the Emma dashboard and Emma activity coach. The Emma activity coach looks like a battery and shows patients their daily goal and current level of physical activity. This

is measured by the number of steps, based on the build-in accelerometer. The activity coach will turn green if the current number of steps does not exceed daily boundaries. The color will change orange and next into red when the number of steps are too low or too high. Thus Emma uses Reduction to simplify the task of reaching daily activity goals. A recent update allows the informal caregiver to receive a text message or e-mail when the activity coach of the patient turned orange or red. However, it should be noted that we experienced the number of steps as incorrect when inactive.

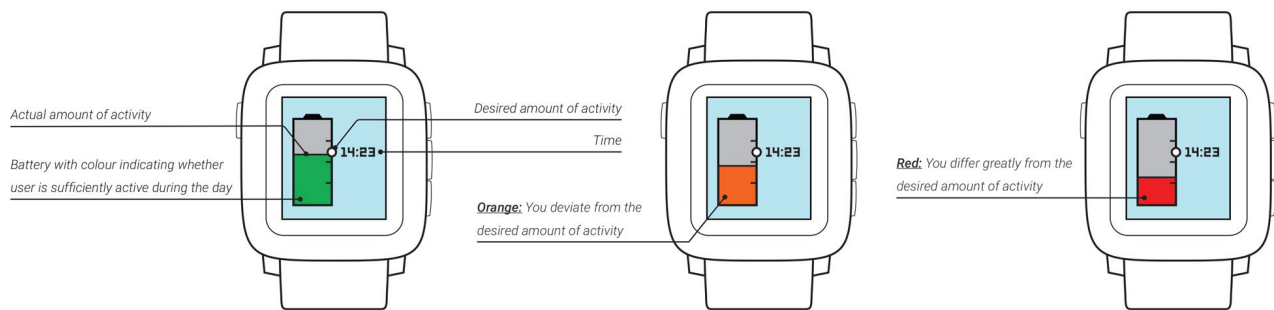


Figure 4. Emma activity coach for MyCOPD

Description of Emma: METT. A second appliance of the platform is used within METT. The aim is to make HIV patients more adherent to their medication, and therefore includes the Emma dashboard (website), Emma mobile app and Emma pill reminder (smartwatch app, see Figure 5). On the Emma dashboard patients, but also informal caregivers and healthcare professionals, can view results regarding adherence. The dashboard also offers Social facilitation; patient, informal caregiver and healthcare professional can communicate with each other.

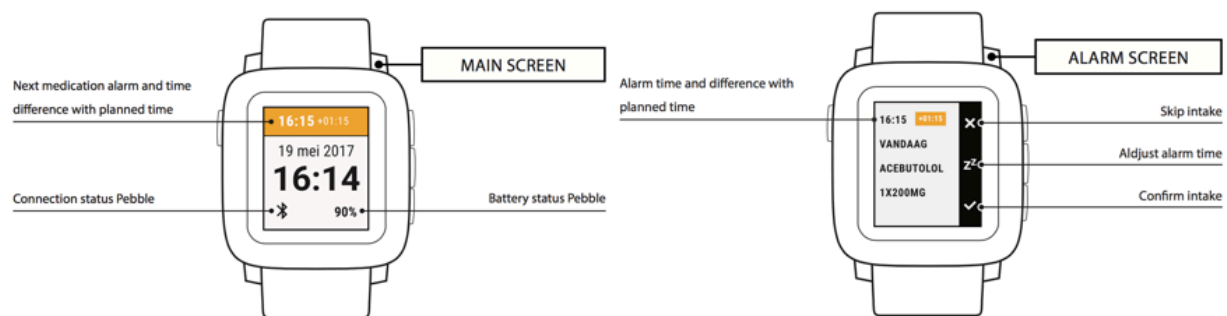


Figure 5. Emma pill reminder for METT

Within the Emma mobile app patients can view their agenda with future reminders for medication, and see an overview with history of alarms. The Emma pill reminder provides the actual alarm. Furthermore, informal caregivers and healthcare professionals can receive a text message or e-mail when the patient did not take their medication on time. This can be seen as a second form of Social facilitation. See Table 4 for an overview of the differences between both appliances of MyCOPD and METT regarding the aim, platform and persuasive elements.

Table 4. Differences in aim, platform, and persuasive elements between MyCOPD and METT

	MyCOPD	METT
Aim	1. Increasing level of physical activity 2. Predict future exacerbations	1. Increasing adherence to medication
Platform	Emma dashboard (website), Emma mobile app, Emma activity coach (smartwatch app)	Emma dashboard (website), Emma mobile app, Emma pill reminder (smartwatch app)
Persuasive elements	Reduction, self-monitoring, social facilitation	Reminder, social facilitation

Step 3. Identifying values

MyCOPD Users: Context. The Context describes the usage and mutual relationships.

Patient. All four interviewed COPD patients within MyCOPD were using the Emma activity coach, but not or barely the Emma app and dashboard. Patients looked at the Emma activity coach on their smartwatch at specific moments of the day, for example when they woke up. While the other two patients looked at the smartwatch when the activity coach appeared. Three patients have an informal caregiver, who provided social support. All patients indicated that they received feedback on their daily activities. However, they also indicated that they did not need additional social support; *"Yes that is not really necessary, because I have to do it myself. Yes, but they all say that you should walk more often, you have to do this more often. They are concerned"* (P1, F). All patients indicated that their informal caregiver was actively involved in the platform, for example by looking at their smartwatch or Emma app and giving feedback based on this. According to patients this was helpful to their informal caregiver; *"Yes, they are more comfortable because there is control, which is also nice for them. Also for non-caregivers. Yes, my son also likes it, yes, there is some kind of control for yourself, but also for*

them" (P1, F). Furthermore, all patients had one or two physiotherapists. Patients indicated they saw their physiotherapist two times a week to exercise in a group with other patients. One patient indicated that her physiotherapist was not involved in the platform and that she never had discussed her data. However, she did expect her physiotherapist to keep track of her data. The other three patients indicated that their physiotherapist was actively involved in the platform, by together looking at the data and setting activity goals.

Informal caregiver. All three informal caregivers indicated to help the patient by performing household activities. Before the patient was using the platform, two informal caregivers did not support the patient to be more active since the patient was stubborn. The other informal caregiver already supported the patient to be more active. All informal caregivers received access to the dashboard, but none of made use of this. Most gave no specific reason, although the absence of a computer was mentioned once. However, all informal caregivers did indicate to look at the smartwatch from the patient regularly; *"Yes, at least five or six times a day, and occasionally more. At the steps and the movement and, yes, I have to keep an eye on it" (IC3, M).* Because of Emma, informal caregivers supported the patient in two ways. Namely by discussing the data and giving feedback, and by planning activities for the next day. Although they did indicate it was up to the patient to act accordingly.

Healthcare professional. All four physiotherapists saw their patients two times a week, in which they performed exercises like walking and cycling. A training usually took one hour and was together with other patients. In most cases the Emma dashboard was used only a couple of times. Reasons given were the patient being sick or they started the treatment recently. One physiotherapist was using the platform actively, he looked once a week at the data and called the patient accordingly. Moreover, it was mentioned that the platform could be used to replace actual contact between him and the patient; *"If they are able to realize the training goals out of practice and I have a certain control, I think that would be fine too" (HP4, M).* The data was used as a way to provide feedback for the patient and adjusting training goals. The informal caregiver was mentioned once as an important source to support self-management behaviors.

MyCOPD Users: Persuasive elements

Primary Task Support. Primary Task Support described the reason for using Emma, how it impacts patients' physical activity level, and how more Primary Task Support could be provided.

Patient. All patients were using the platform to adjust their daily number of steps. Their aim varied somewhat, from becoming active and being able to perform certain activities with the grandchildren, to stop another exacerbation from happening. All patients indicated to change their activity levels based on the color of the activity coach. However, this was not always possible because of how they felt (e.g. tired). Noteworthy, half of the patients indicated that the activity coach indicated their physical state; *"Yes to me that's a tiring feeling, but also a sign of come on; we must go further and we must not sit still of course"* (P3, F). An oxygen saturation meter would be of an added value to all, in order to expand their Self-monitoring. A humidity and heartrate monitor were also mentioned once.

Informal caregiver. All informal caregivers indicated that Emma supported the patient in reaching their goal. Moreover, for one patient the platform took the fear of the patient away according to the informal caregiver; *"Then she can get out of the house more often, look, at one point she did not get out anymore. And then she also had the fears of course. Well now she is over the fear of course, because she is being watched"* (IC3, M). Two informal caregivers indicated they believe platform provided sufficient Self-monitoring tools. Only one caregiver provided a suggestion for improvement, regarding Self-monitoring; *"Uhm, yes, I do not know whether it is possible to measure it, you know, the oxygen or just what matters to her"* (IC1, F).

Healthcare professional. All four physiotherapists were using the platform to track the activity data of the patient at home and to predict an exacerbation. Their aim was to change the activity level of the patient and to prevent an exacerbation. They indeed agreed that the platform does change the behavior of the patient, and it was mentioned once that the platform successfully predicted an exacerbation. All physiotherapists thought that Self-monitoring was the source for the change of behavior; *"I think this tool can contribute to behavioral change. So, this works for a large proportion of patients, by experiencing direct control"* (HP2, F). A second way the platform influences the behavior was through simulation; *"I think people really get very aware of how much they are doing now and whether they actually reach their goals. That it's an*

additional incentive to get up and running again, yes" (HP1_1, F). All physiotherapists thought a weak point of the platform was the lack of Self-monitoring tools. The saturation meter was mentioned by all; they believed it would be certain an added value. Further Self-monitoring tools mentioned were a heart rate monitor, a measure of well-being, blood pressure, a measure of other activities like cycling, and the CCQ questionnaire.

Dialogue Support. Dialogue Support described dialogue initiated by the system.

Patient. Since there was no dialogue between the patient and the system, patients were asked how they felt about this. Three patients indicated they would like to receive support in the form of a Reminder when the activity coach changes color; *"I would like that, because now you are going to look every time what color it is" (P3, F).*

Informal caregiver. There was no dialogue between two informal caregivers and the system. Only one informal caregiver had received a notification of the activity level of the patient. The notification itself was clear to him and he would like to keep receiving them.

Healthcare professional. There was no dialogue between the platform and the healthcare professional.

Credibility Support. Credibility Support described the reliability of the activity data.

Patient. All patients indicated that they felt the provided data was trustworthy.

Informal caregiver. All informal caregivers thought the data was trustworthy and were convinced they number of steps reflected the reality.

Healthcare professional. Although physiotherapists found it rather difficult to check whether the information was trustworthy, they did believe so.

Social Support. Social Support described the support which is provided through Emma.

Patient. Although the dashboard offers users the possibility to communicate with their informal caregiver and healthcare professional, none of the patients made use of this function since they were not familiar with the possibility.

Informal caregiver. None of the informal caregivers used the communication tool. However, two indicated to look regularly at the Emma app of the patient and act upon.

Healthcare professional. None of the physiotherapists used the communication tool.

Results. Values which were mentioned by users more than once, were deemed important. This resulted in the value specification as seen in Table 5.

Table 5. Value Specification for MyCOPD

Category	Quote	Value	Valued by
Primary Task	"I would especially like to know the saturation, and especially the range in which the saturation has occurred, when someone takes multiple steps, right, a fair number of steps. The lower limit and the upper limit I would like to know, especially the lower limit" (HP3, M)	Monitoring oxygen saturation	P (N=4) IC (N=1) HP (N=4)
Dialogue Support	"Now you have to keep an eye on it yourself, I often watch my watch, but maybe there are people who do not and so you do not know" (P2, F)	Support reaching goal	P (N=4)
Social Support	"If I see that is going well, I can get in contact and then I can say so, maybe it motivates her" (IC1, F)	Access to health data	HP (N=2)

Note: P: Patient, IC: Informal caregiver, HP: Healthcare professional.

METT Users: Context. All thirteen interviewed HIV-patients within METT were using the platform as a pill reminder, with the aim to become and stay adherent to their medication. They are using both the Emma mobile and smartwatch app. Most patients indicated they were not that adherent before they started using the platform, i.e. forgetting to take the medication on time.

METT Users: Persuasive elements

Primary task support. All patients though the platform, and specific the Reminder, improved their adherence and that they were satisfied with the platform itself, although some mentioned it is a bit simple and it becomes boring after a while. Other weak points mentioned are technological issues, like turning off the vibration, charging, incorrect time, suddenly logging out without doing so, and the duration of the vibration as being too long.

Dialogue support. Patients received dialogue in the form of a Reminder from the platform. One patient mentioned specific that she liked the smartwatch giving the vibration, since she wears it all the time, in contrast to her mobile phone.

Credibility support. Only one weak point was mentioned regarding the trustworthiness; there was no possibility to make adaptations in the overview of previous medications, for

example when the patient took her medication but forgot to tick off, which resulted in an incorrect overview of adherence rates.

Social support. Although the dashboard offers patients the possibility to communicate with their informal caregiver and healthcare professional, none of the patients made use of this function since they were not familiar with the possibility. However, all patients had a parent who received a message when they did not take their medication on time. This form of Social facilitation was seen as fine or normal, and helpful in order to stay adherent.

Medicine Men. Based on previous conversations with patients and healthcare providers, Medicine Men identified multiple values. Most important making the platform more sustainable, both in the case of adherence and behavioral change, by adding a component which provides a motivational increase for all users. In specific, they did value the potential for the informal caregiver to play a more important role within the platform.

Requirements. Most important values from both users and Medicine Men were translated into requirements (see Table 6). A value was seen as important when at least two stakeholders mentioned it. Since the METT project deviated too much from MyCOPD regarding its usage, the focus was on MyCOPD. However, interesting is the finding the design principles Reminder and Social facilitation were seen as effective in reaching their primary task by HIV patients, and mentioned as lacking by COPD patients and their informal caregivers.

Table 6. Requirements per stakeholder and design principle

Value	Stakeholder	Requirement	Design Principle
Monitoring oxygen saturation	P, IC, HP	Adding a measure for oxygen saturation to the platform	Self-monitoring
Support reaching goal	P, MM	Adding a notification when the activity coach changes color	Reminder
Access to health data	IC, MM	Providing the informal caregiver with a mobile app	Social facilitation

Note: P: Patient, IC: Informal caregiver, HP: Healthcare professional, MM: Medicine Men.

Stage 2. Prototype Design, Requirements and Development

Methods of Stage 2

Stage 2 of this study reflects the Design, the aim was to answer the following question: *‘What is the opinion of patients and informal caregivers regarding the prototypes?’* This stage was divided in three steps. Step 1 was to design three prototypes, by using the requirements from the first stage. Step 2 was to identify additional requirements, by means of a co-creation. Step 3 was to develop the additional tool, by using the requirements from the previous step.

Participants. All eight patients and four informal caregivers from MyCOPD were invited, although three were not available. This resulted in an uptake of six patients (see Table 2 for characteristics) and three informal caregivers (one female). Two informal caregivers were using the system for three weeks, both participated in the first stage. One informal caregiver was not official assigned and had therefore not used the system.

Procedure and materials. The requirements from the first stage were translated in three prototypes and, in concordance with Medicine Men, visualized with a storyboard (see Appendix 4). The storyboards showed a sequence of images that clarified how the system interacts with a persona with COPD, and his caregiving son. During the co-creation session at the Bravis hospital in Roosendaal, each complete storyboard was first explained and evaluated by participants. Subsequently, each image was shown separately and specific questions were asked (see Appendix 4). For example: ‘Would you prefer to receive the notification by phone or smartwatch?’ After each question there was room for discussion. At the end, all stakeholders were asked which prototype had their preference, since only one prototype could be developed, because of time and money constraints, only one prototype could be developed. With permission of all participants, the session was recorded by audio and video software.

Data-analysis. Participant dialogue was transcribed using Express Scribe (version 6.04), and imported into the qualitative analysis software Atlas.ti (version 1.6.0). The data analysis was an iterative process, in which deductive- and inductive coding was combined. Relevant fragments were identified and classified through deductive coding, based on the four categories of the PSD model and the category Context (see Table 2). Subsequently, when it was meaningful to further categorize through inductive coding, a next level was added.

Results of Stage 2

Step 1. Designing the prototype. The value specification from the first stage resulted in three different prototypes and storyboard (see Appendix 4), all including multiple design principles (see Table 7).

Table 7. Persuasive features per prototype as shown in storyboard

Prototype	Design Principle	Category	Explanation
1	Self-monitoring	Primary Task Support	An oxygen saturation meter is connected to Emma and transmits the data
	Simulation	Primary Task Support	A graph displays the relation between oxygen saturation, activity levels and the CCQ
2	Reminder	Dialogue Support	Emma activity coach gives a vibration each time the activity coach changes color
	Praise	Dialogue Support	Emma activity coach gives a praise when the patient did reach their goal
	Suggestion	Dialogue Support	Emma activity coach gives a suggestion when the patient did not reach their goal
	Tailoring	Primary Task Support	The praise/suggestion is tailored on the activity levels of the patient
3	Social facilitation	Social Support	A mobile app for the informal caregiver shows the current health data of the patient
	Praise	Dialogue Support	IC can send a predefined praise when the patient did reach their goal
	Suggestion	Dialogue Support	IC can send a predefined suggestion when the patient did not reach their goal

Step 2. Identifying additional requirements.

Prototype 1: Self-monitoring. All patients had a positive attitude towards the prototype on oxygen saturation. Two patients indicated specific that they liked the idea of the vibration of the smartwatch to remind them to measure the oxygen saturation; *"Well, you see often, yes I have to measure again, uhm how is the oxygen saturation, and if you can give the signal, you can automatically measure the saturation once more"* (P2, F). All but two patients already had a saturation meter, independent from the platform. How often they used it differed per patient; some used it once daily, others three times a day or each time they were not feeling well. An important issue was the financial arrangement for the rather expensive oxygen saturation meter. Regarding the graph, patients agreed that it was interesting and clear. Two patients mentioned it was important that the graph remained simple. Other patients indicated it would be of an added value to add heartbeat and temperature.

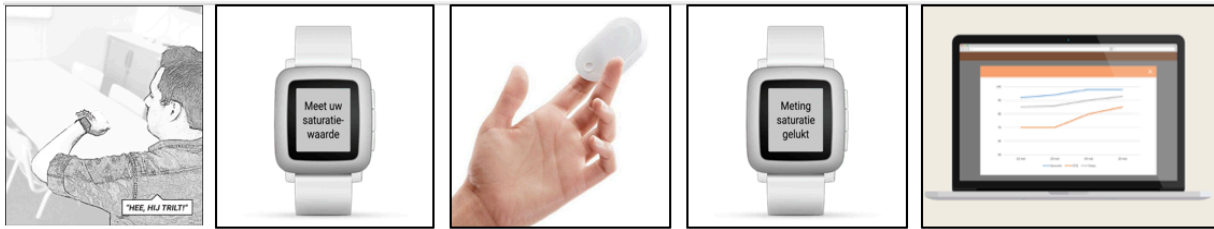


Figure 6. Miniature storyboard 1: Prototype Self-monitoring

Prototype 2: Reminder. All patients liked the idea of a vibration when the activity coach changed color, so they do not have to remember to look themselves. They indicated they wanted to receive it every time the activity coach changes color. However, patients reacted distinct to the persuasive message. Two patients believed there was no added value, since they knew what to do after the vibration. While three patients and one informal caregiver indicated that it would motivate them to adjust their activity levels; *"But sometimes you have to be motivated to do it I think. And that's what you say (P2) a message is able to motivate. Look, you have children at home of course, and they keep an eye on you, but if you're home alone, you're just lonely" (IC1, F)*. Most patients agreed that there should be the possibility to turn off the message, and that it would be of an added value to tailor it, for example by suggesting to go to the bakery. All patients agreed the tailored persuasive message was of no priority to them; the oxygen saturation meter was of a bigger additional value. Furthermore, patients thought that it would be a good idea to have the possibility to indicate why they did not reach their goal. Although all preferred again a simple design.



Figure 7. Miniature storyboard 2: Prototype Reminder

Prototype 3: Social facilitation. Patients and informal caregiver gave mixed reactions towards the last prototype on the mobile app of the informal caregiver. Two patients indicated that it would help them change their behavior, another patient was more reluctant; *"Well then*

he can call me, and then I say yes I'll do that, see you tonight bye. And then I think bye! Do you understand? Because then I think in my mind, I still have to do this, I still have to do that "(P2, F).

An important aspect was whether patient and informal caregiver lived together. When this was the case, all agreed that there was no added value of the prototype. According to one informal caregiver, an important aspect of the mobile app would be the privacy of the patient. Patients and informal caregivers further agreed that a notification itself was sufficient for them. Most informal caregivers and patients agreed with the idea to only receive a message when patients did not reach their goals. Patients and informal caregivers further thought that the possibility to send a predefined message was of an added value.

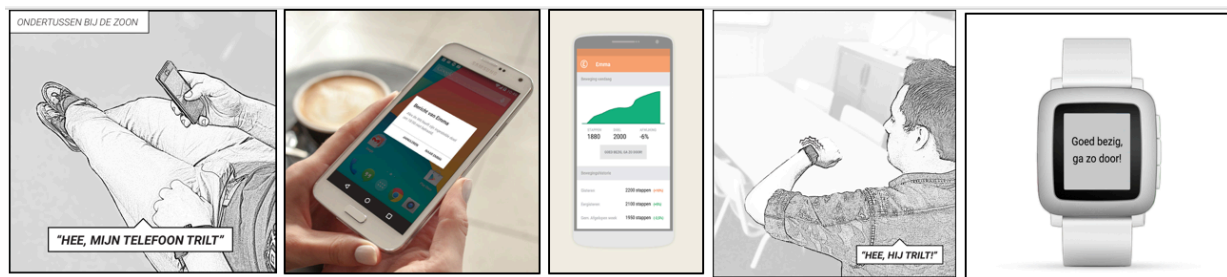


Figure 8. Miniature storyboard 3: Prototype Social facilitation

Results. To conclude, all identified additional requirements are shown in Table 8.

Table 8. Additional requirements per prototype based on co-creation session

Prototype	Requirement	Design Principle
1	Vibration through the smartwatch	Reminder
	Financial arrangement for oxygen saturation meter	-
	Simple design	Reduction
	Heartbeat and temperature in graph	Self-monitoring
2	Vibration when the activity coach changes color	Reminder
	Suggestion/praise combined with message	Suggestion/praise
	Possibility to turn message off	Personalisation
	Simple design	Reduction
3	No mobile app for the informal caregiver	-
	Message when activity coach changed into negative direction	Reminder
	Possibility to send predefined message	Social facilitation

Step 3. Development of the tool. See Figure 9 for the number of votes per prototype. Since the highest number of votes were given to prototype 2, and Medicine Men agreed, the Reminder was developed. The design was based on the aforementioned four requirements of this prototype. Every time the activity coach changes color, the smartwatch gives a vibration. This was combined with a timeframe of 20 seconds during which the activity coach is visible on the screen of the smartwatch. The persuasive message was not implemented since patient indicated it was of no priority and they preferred a simple design, for that the requirement to turn receiving the message off was not applicable.

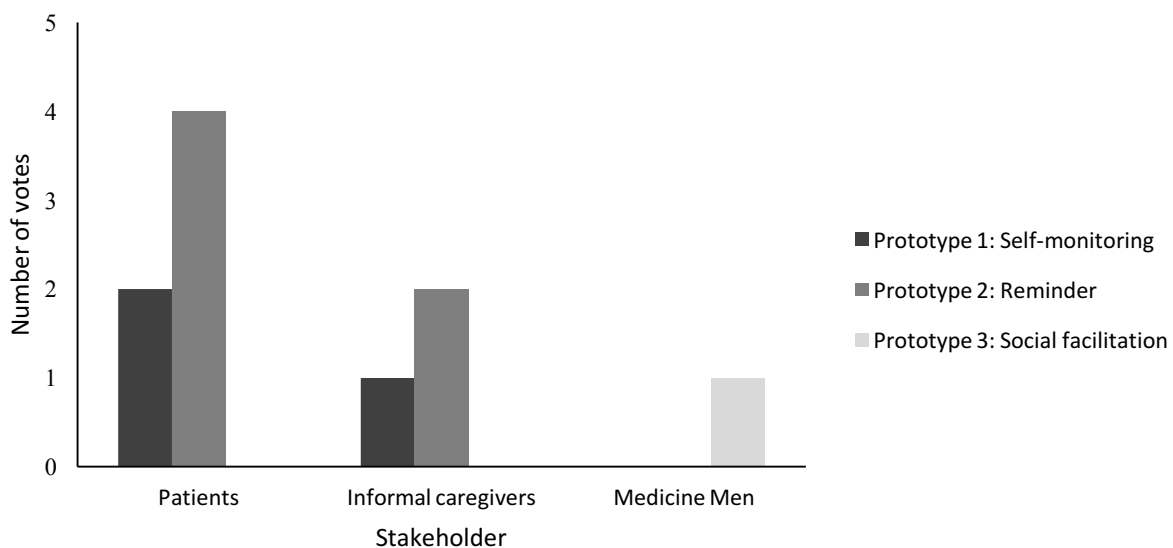


Figure 9. Number of votes for each prototype per stakeholder (N=10)

Stage 3. Evaluation

Methods of Stage 3

Stage 3 of this study reflects the Operationalization and Summative Evaluation, the aim was to answer the following question: *‘What is the opinion of patients regarding the additional tool?’* This was done by introducing the additional tool to patients, and an evaluation

Participants. All eight patients from MyCOPD were invited and participated in the third stage of this study (see Table 2 for characteristics). They were using the tool for 13 days on average (10-19 days).

Procedures and materials. All patients were using an older version of the Emma mobile app and received a notification through the Google Play Store to update. To make sure this went successfully, patients were called three or four days after the update. During the phone call, the additional tool was shortly explained, it was checked whether it was working and people were invited to participate in an online questionnaire within one week. The link to the questionnaire was sent by e-mail and consisted of fourteen questions regarding the usability, effectiveness and suggestions for improvement (see Appendix 5). The questionnaire was created in concordance with Medicine Men, and was partly based upon the PSD model. For example: 'Is the vibration helpful in reaching your goals?' There were nine open-questions, the other five questions could be answered on a 5-point Likert-scale ranging from 1 (very bad/not at all) to 5 (very good). The questionnaire took about five to ten minutes in order to complete.

Data-analysis. All analyses were carried out with IBM Statistical Product and Service Solutions Statistics for Mac (version 24.0). Descriptive statistics were calculated for all multiple choice questions. Since there were a limited number of open questions, and answers were short (< 10 words), no coding technique was used. Instead a summary of all answers was used to come to a conclusion.

Results of Stage 3

Users: Patient. During the evaluation, patients rated the tool positively with an average rating of 3.75 ($SD=1,75$, range 1-5). Patients responded on an open question that the Reminder kept them alert, kept an eye on them and that they knew how much they still had to do. Moreover, patients believed that the additional tool helped them in achieving their activity goals, with an average rating of 3.57 ($SD=1,81$, range 1-5). This was explained by patients seeing the tool as a memory aid. When the color changed, patients indeed reacted by adapting their activity levels accordingly. Most patients thought the duration and number of both vibrations per week were all right.

Discussion

In this study on a self-management tool for COPD patients, the aim was to participatory increase the persuasiveness of Emma. For this, we included users and Medicine Men as key-stakeholders. During the first stage, we found that more Primary Task Support through the design principle Self-monitoring, and more Dialogue Support through the design principle Reminder, were needed most in order to increase the persuasiveness of Emma, according to users. This is in concordance with literature, which argues that Self-monitoring and Reminders are among the most important beneficial persuasive features to improve self-management (Karppinen et al., 2016). During the second stage, patients indicated to prefer the Reminder over the Self-Monitoring tool. This finding can be largely explained by the fact that all users valued eHealth to be non-invasive. Which is in concordance with the rationale behind persuasive technology (Oinas-kukkonen & Harjumaa, 2009). During the third stage, patients indeed indicated the Reminder persuaded them into changing their behavior, based on their preliminary experiences, and was therefore being effective in increasing self-management. This is in concordance with results from the interviews with HIV patients, showing that the Reminder was supported their primary task. Additionally, several articles claim that reminders increase the effectiveness of an eHealth intervention by their impact on Primary Task Support (Karppinen et al., 2016; Oinas-kukkonen & Harjumaa, 2009). Thus our results suggest that a non-invasive Dialogue Support tool supports COPD self-management. In order to further increase the persuasiveness of Emma, it would be interesting to elaborate on Primary Task Support, by participatory developing a non-invasive tool for Self-monitoring.

An interesting aspect of this study was the discrepancy between expectations and the requirements from users regarding the additional value of Social Support, illustrating why it is important to use a participatory development approach with multiple stakeholders. Medicine Men expected Social Support to be an important issue for all users, based on their personal experiences. Also research showed that social support from both informal caregiver and healthcare professional was needed for the patient to successfully self-manage their COPD (Barber, 2013; Fu et al., 2016; Trivedi et al., 2012). However, this is not what the users themselves indicated. Patients indicated that they had no need for additional Social Support,

since they have to do it themselves after all. Also none of the informal caregivers indicated the desire to provide more or better Social Support through Emma. Moreover, during the second stage patients and informal caregivers were quite reluctant towards the Emma mobile app for informal caregivers, mainly because of the fact that patients had to change the behavior themselves. This finding is in concordance with an earlier study regarding the acceptability of different persuasive technology design principles for supporting and encouraging physical activity among COPD patients; they showed that the prototype application with Social Support was least popular and therefore least persuasive, compared to Dialogue and Primary Task Support (Bartlett, Webb, & Hawley, 2017). This raises the question whether the informal caregiver should be given the tools to provide Social Support through eHealth. The Home Sweet Home study, an observational, longitudinal study in patients with COPD and their resident loved ones provides some valuable insight (Nakken, 2017). They showed, among other things, that informal caregivers of patients with COPD have insufficient knowledge about COPD, and that resident relatives are often current smokers. Thus the informal caregiver might be unable and not motivated enough to provide Social Support through eHealth, when not persuaded sufficiently. For future research regarding the potential of Social Support, it would be interesting to focus on this discrepancy between informal caregivers' potential and pitfalls. For example, by tailoring or setting criteria for being an informal caregiver within eHealth.

Another interesting aspect concerns a difference in concept regarding Credibility Support. Before the start of the study we expected the credibility of the health data to be an important requirement, since we used the Emma activity coach ourselves and experienced the number of steps as being incorrect when being inactive. Although only research is available regarding the test-retest and validity of the walking speed, only a vigorous walking speeds showed a good accuracy (Sanders et al., 2016). Surprisingly, none of the patients or physiotherapists mentioned this aspect. For patients, this could be explained by the fact that they tend to have a low eHealth literacy, which is associated with a lack of motivation or literacy skills to evaluate the quality of the data (Chen, Lee, Straubhaar, Joseph, & Spence, 2014; Sogaard et al., 2016). For physiotherapists, this could be explained by the fact that they did not use the system themselves, and therefore relied on the information from the patient.

Furthermore, research shows that the credibility of the data describe both the concept of trust and accuracy, however it is yet unclear how they influence each other (Sbaffi & Rowley, 2017). Thus our findings suggest that patients and physiotherapists do trust the data of Emma, but take the accuracy of the data for granted. For future research it would be interesting to see how trust and accuracy influence each other, in the context of persuasive eHealth technology.

Limitations

Because Medicine Men makes use of agile design, we were provided with the possibility to directly implement the findings from the study in practice. This was of great added value for the users, since they directly profited from our findings. However, this agile design with rapid iterations also meant we had to deal with time limitations. This resulted in a rather incomplete and unsystematic contextual inquiry, leading to a conflicting value regarding the preferred prototype; during the second stage, users indicated they valued most the Reminder prototype, while Medicine Men preferred the Social Facilitation tool for informal caregivers. Therefore, the question arises, is it actually possible to combine both agile design and the CeHRes Roadmap? Research shows that the downside of agile design approaches is that they do not take the organization into account and hence, do not support the development of a business model (Iivari, Isomaki, & Pekkola, 2010). However, we do feel it is possible to combine both when a more extensive and systematic contextual inquiry is part of the study. For future research it would be interesting to focus on this balance.

Conclusion

By applying a participatory development approach, we showed that Dialogue and Primary Task support, but not Credibility or Social Support, were needed for COPD patients to increase their self-management. We thereby found that a non-invasive Reminder tool indeed persuaded patients into changing their self-management behavior, based on their preliminary experiences. We also showed how the CeHRes Roadmap could be used to improve existing eHealth technology, and recommend including multiple stakeholders, and combine agile design with an extensive and systematic contextual inquiry to reach its full potential.

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Appendix

Appendix 1. Toestemmingsformulier

Informatiebrief patiënt en mantelzorger

Titel: Het verbeteren van het systeem MijnCOPD

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan een onderzoek naar het verbeteren van het systeem MijnCOPD. MijnCOPD refereert naar zowel het platform Emma als het digitale Zorgpad van de LAN. U beslist zelf of u mee wilt doen. Wanneer u na het lezen nog vragen heeft kunt u terecht bij de onderzoekers. Verder op vindt u de contactgegevens. Het onderzoek wordt uitgevoerd door onderzoekers van de opleiding Psychologie aan de Universiteit Twente, de opleiding Gezondheidszorgtechnologie (Mens & Techniek) aan de Avans Hogeschool en het Bravis Ziekenhuis onder begeleiding van het bedrijf Medicine Men en het LUMC.

1. Wat is het doel van het onderzoek?

Graag zouden we meer inzicht krijgen in hoe u MijnCOPD ervaart en hoe deze verbeterd kan worden. Met uw input hopen wij het systeem in zijn geheel te kunnen verbeteren.

2. Hoe wordt het onderzoek uitgevoerd?

Het onderzoek zal bestaan uit verschillende interviews en een co-creatie sessie. Er zullen vragen aan u worden gesteld over uw mening en ervaringen met MijnCOPD. Het interview kan telefonisch of bij u thuis plaatsvinden, deze keuze wordt in overleg met u gemaakt. De co-creatie sessie zal plaatsvinden in het Bravis ziekenhuis in Roosendaal. Het interview zal opgenomen worden met geluidsapparatuur, de co-creatie zal worden opgenomen met geluids- en/of videoapparatuur.

3. Wat wordt er van u verwacht?

Wanneer u akkoord gaat met deelname kan u dit onderaan dit formulier aangeven. Indien van toepassing zal de onderzoeker contact met u opnemen voor het maken van een afspraak. Wanneer wij niets van u horen zullen wij telefonisch contact met u opnemen om te vragen of u wilt deelnemen.

4. Wat zijn mogelijke voor- en nadelen voor u van deelname aan dit onderzoek?

Voor de toekomst kan het onderzoek nuttige gegevens opleveren, om MijnCOPD in zijn geheel te verbeteren. Uiteindelijk kan deze informatie bijdragen aan het beter zelf-managen van

chronische ziekten. Een nadeel van deelname is dat u tijd moet vrijmaken om vragen te beantwoorden tijdens de interviews en de co-creatie sessie.

5. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u mee wilt doen aan het onderzoek. Deelname is geheel vrijwillig. Als u besluit om niet mee te doen, zal er niks veranderen in de huidige situatie. U hoeft ook niet te zeggen waarom u niet mee wilt doen. Als u wel mee wilt doen, kunt u zich op ieder moment bedenken en toch stoppen. Ook tijdens een interview of de co-creatie sessie is het mogelijk om te stoppen.

6. Wat gebeurt er met uw gegevens?

De volgende onderzoekers hebben toegang tot uw gegevens: M. F. Hofstede, L. L. Kramer en R. Voeten. Daarnaast hebben de medewerkers van Medicine Men na ondertekening van een geheimhoudingsverklaring toegang tot uw gegevens, met als doel het product te verbeteren. De interviews en de co-creatie sessie zullen worden opgenomen met video- en geluidsapparatuur. Aan de hand van deze opnames zullen beide worden uitgeschreven en geanalyseerd. Uw persoonlijke gegevens blijven te allen tijde anoniem, geslacht en leeftijd zullen wel bekend zijn. Daarnaast kunt u eventueel, wanneer u dat wilt, de onderzoeker vragen om uw interview in te zien en aan te passen, aan te vullen, te verwijderen of af te schermen. Gegevens van het interview worden samengevat en mogelijk gebruikt voor wetenschappelijke publicaties met letterlijke citaten uit het interview. Deze citaten zullen anoniem blijven.

7. Zijn er extra kosten/is er een vergoeding wanneer u besluit aan dit onderzoek mee te doen?
Voor uw deelname aan dit onderzoek wordt u niet betaald.

8. Wilt u verder nog iets weten?

Voor het stellen van vragen, maken van afspraken, en het inwinnen van meer informatie voor kunt u contact opnemen met de volgende onderzoekers:

M. F. Hofstede

Telefonisch contact op werkdagen via: 0620512408

E-mail: melanie@medicinemen.eu

L. L. Kramer

Telefonisch contact op werkdagen via: 0623412092

E-mail: lean@medicinemen.eu

Informatiebrief fysiotherapeut

Titel: Het verbeteren van het systeem MijnCOPD

Geachte heer/mevrouw,

Wij vragen u vriendelijk om mee te doen aan een onderzoek naar het verbeteren van het systeem MijnCOPD. MijnCOPD refereert naar zowel het platform Emma als het digitale Zorgpad van de LAN. U beslist zelf of u mee wilt doen. Wanneer u na het lezen nog vragen heeft kunt u terecht bij de onderzoekers. Verder op vindt u de contactgegevens. Het onderzoek wordt uitgevoerd door onderzoekers van de opleiding Psychologie aan de Universiteit Twente, de opleiding Gezondheidszorgtechnologie (Mens & Techniek) aan de Avans Hogeschool en het Bravis Ziekenhuis onder begeleiding van het bedrijf Medicine Men en het LUMC.

1. Wat is het doel van het onderzoek?

Graag zouden we meer inzicht krijgen in hoe u MijnCOPD ervaart en hoe deze verbeterd kan worden. Met uw input hopen wij het systeem in zijn geheel te kunnen verbeteren.

2. Hoe wordt het onderzoek uitgevoerd?

Het onderzoek zal bestaan uit in ieder geval 1 interview. Er zullen vragen aan u worden gesteld over uw mening en ervaringen met MijnCOPD. Het interview duurt maximaal drie kwartier en kan telefonisch ofwel in uw praktijk plaatsvinden. Het interview zal worden opgenomen met geluidsapparatuur.

3. Wat wordt er van u verwacht?

Wanneer u akkoord gaat met deelname kan u dit onderaan dit formulier aangeven. Indien van toepassing zal de onderzoeker contact met u opnemen voor het maken van een afspraak. Wanneer wij niets van u horen zullen wij telefonisch contact met u opnemen om te vragen of u wilt deelnemen.

4. Wat zijn mogelijke voor- en nadelen van deelname aan dit onderzoek?

Voor de toekomst kan het onderzoek nuttige gegevens opleveren, om MijnCOPD in zijn geheel te verbeteren. Uiteindelijk kan deze informatie bijdragen aan het beter begeleiden van chronisch zieke patiënten. Een nadeel van deelname is dat u tijd moet vrijmaken om vragen te beantwoorden tijdens het interview.

5. Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u mee wilt doen aan het onderzoek. Deelname is vrijwillig. Als u besluit om niet mee te doen, zal er niks veranderen in de huidige situatie. U hoeft ook niet te zeggen waarom u

niet mee wilt doen. Als u wel mee wilt doen, kunt u zich op ieder moment bedenken en toch stoppen. Ook tijdens het interview is het mogelijk om te stoppen.

6. Wat gebeurt er met uw gegevens?

De volgende onderzoekers hebben toegang tot uw gegevens: M. F. Hofstede, L. L. Kramer en R. Voeten. Daarnaast hebben de medewerkers van Medicine Men na ondertekening van een geheimhoudingsverklaring toegang tot uw gegevens, met als doel het product te verbeteren. De interviews en de co-creatie sessie zullen worden opgenomen met video- en geluidsapparatuur. Aan de hand van deze opnames zullen beide worden uitgeschreven en geanalyseerd. Uw persoonlijke gegevens blijven te allen tijde anoniem, geslacht en leeftijd zullen wel bekend zijn. Daarnaast kunt u eventueel, wanneer u dat wilt, de onderzoeker vragen om uw interview in te zien en aan te passen, aan te vullen, te verwijderen of af te schermen. Gegevens van het interview worden samengevat en mogelijk gebruikt voor wetenschappelijke publicaties met letterlijke citaten uit het interview. Deze citaten zullen anoniem blijven.

7. Zijn er extra kosten/is er een vergoeding wanneer u besluit aan dit onderzoek mee te doen? Voor uw deelname aan dit onderzoek wordt u niet betaald.

8. Wilt u verder nog iets weten?

Voor het stellen van vragen, maken van afspraken, en het inwinnen van meer informatie voor kunt u contact opnemen met de volgende onderzoekers:

M. F. Hofstede

Telefonisch contact op werkdagen via: 0620512408

E-mail: melanie@medicinemen.eu

L. L. Kramer

Telefonisch contact op werkdagen via: 0623412092

E-mail: lean@medicinemen.eu

Toestemmingsformulier

Ik heb de informatie voor deelname gelezen. Ik kon aanvullende vragen stellen indien nodig. Mijn vragen zijn voldoende beantwoord. Ik had voldoende tijd om te beslissen of ik wil meedoen of niet. Ik weet dat meedoen geheel vrijwillig is en dat ik op elk moment kan besluiten om toch niet mee te doen of te stoppen. Daarvoor hoef ik geen reden te geven. Het is mij bekend dat bepaalde personen mijn gegevens in kunnen zien. Ik geef toestemming om mijn gegevens te gebruiken voor de doeleinden die eerder genoemd zijn.

Ik neem deel aan dit onderzoek.

Naam proefpersoon: _____

Handtekening:

Datum:

Ik verklaar hierbij dat ik deze proefpersoon volledig heb geïnformeerd over het genoemde onderzoek. Wanneer er tijdens het onderzoek informatie bekend wordt die de toestemming van de proefpersoon zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker 1: _____

Handtekening:

Datum:

Naam onderzoeker 2: _____

Handtekening:

Datum:

Appendix 2. Interviewprotocol

Patiënt

Introductie:

Ten eerste bedankt voor u bereidheid om deel te nemen aan dit interview. Ik had gezien dat u het toestemmingsformulier heeft ingevuld, heeft u hier nog vragen over?

Het doel van dit interview is om na te gaan hoe u Emma en de inspanningscoach (MijnCOPD) gebruikt, hoe dit ervaart en vooral wat er verbeterd zou kunnen worden binnen de gehele interventie. Dus in het algemeen hoe kan MijnCOPD verder bijdragen aan het helpen omgaan van uw ziekte. Het interview zal ongeveer drie kwartier duren. Het gesprek zal worden opgenomen met een voicerecorder zodat wij deze op een later moment kunnen uitwerken.

Achtergrondinformatie (zelf invullen):

- Naam:
- Leeftijd:
- Geslacht:
- COPD fase:
- Hoe lang hij/zij MijnCOPD gebruikt:

Inmiddels gebruikt u ongeveer twee weken het batterijtje, ook wel de inspanningscoach genoemd.

Onderwerp: Inspanningscoach (20 min)

- Hoe gebruikt u inspanningscoach? Kunt u het gebruik gedurende een normale dag beschrijven?
 - Hoe vaak kijkt u naar het batterijtje op uw smartwatch?
 - Op welke momenten kijkt u naar het batterijtje?
- Hoe vaak denkt u dat het batterijtje oranje kleurde per week?
 - Hoe hebt u dat ervaren/geïnterpreteerd?
 - Wat u deed u toen?
- Hoe vaak denkt u dat het batterijtje rood kleurde per week?

- Hoe hebt u dat ervaren/geïnterpreteerd?
 - Wat deed u toen?
- In hoeverre schat u de bewegingsinformatie in als compleet?
- Denkt u dat de bewegingsinformatie klopt?
- Wat zijn voor u de redenen om de inspanningscoach te gebruiken?
 - Welk persoonlijk plan of doel wilt u behalen (niet aantal stappen)?
 - Welk doel wilt u behalen met de inspanningscoach?
- Wat zou er volgens u verbeterd kunnen worden aan de inspanningscoach?
 - Hoe zou dit u helpen?
 - Hoe zou dit eruit zien?
- Wat vindt u van de ingestelde dag doelen?
- Helpt de inspanningscoach bij het behalen van uw dag doelen?
- Wat zou u ervan vinden als u meldingen ontvangt wanneer de batterij van kleur veranderd?
 - Wanneer zou u een melding willen ontvangen (gelijk of per dagdeel)?
 - Hoe vaak zou u maximaal een melding willen ontvangen per dag, wanneer u zich niet aan de dagdeel doelen heeft gehouden?
 - Op welk apparaat zou u dit willen? (Horloge, smartphone)
 - Wat voor soort meldingen hebben uw voorkeur? (Trillen, SMS, e-mail, melding op scherm)

Onderwerp: MijnCOPD (10 min)

Graag zouden we willen beginnen met vragen hoe u MijnCOPD in zijn geheel gebruikt. Dit omvat dus ook het dashboard Emma en de Pebble applicatie op uw mobiele telefoon.

- Maakt u ook gebruik van het dashboard Emma?
 - Hoe vaak maakt u hier gebruik van?
 - Wanneer maakt u hier gebruik van?
 - Waarvoor gebruikt u dit?
 - Wat vindt u van het dashboard?

- Navigatie
 - Indeling
 - Overzicht
 - Hoeveelheid informatie
- Zouden er nog dingen aan toegevoegd of verbeterd kunnen worden?
- Maakt u ook gebruik van de Pebble applicatie?
 - Waarvoor gebruikt u dit?
 - Wat vindt u van de Pebble applicatie?
 - Grafieken
 - Overzicht
 - Hoeveelheid informatie
 - Zouden er nog dingen aan toegevoegd of verbeterd kunnen worden?
- Is er naast de eerder besproken verbeterpunten nog iets wat u mist en wat u zou kunnen helpen bij het managen van uw ziekte? Dit mag de inspanningscoach, het dashboard, de Pebble applicatie of iets geheel anders betreffen.
 - Hoe zou dit eruit moeten zien? En waarom?
 - Is er bepaalde informatie die u mist? (Vragenlijst, overzichten, andere apparaten)

Onderwerp: Relaties (15 min)

Graag zouden we nu wat meer vragen over hoe u MijnCOPD gebruikt in relatie tot uw mantelzorger en fysio.

Indien mantelzorger:

- Wie is uw mantelzorger en waarom?
- Hoe vaak ziet u uw mantelzorger?
- Woont de mantelzorger in de buurt?
- Hoe helpt de mantelzorger u bij uw ziekte?
- Houdt de mantelzorger zich op dit moment ook bezig met het systeem MijnCOPD?
 - Weet u wat hij/zij van MijnCOPD vindt?

- Wat vindt u van de betrokkenheid van uw mantelzorger binnen MijnCOPD?
- Wat vindt u hier goed aan gaan?
- Wat zou nog verbeterd kunnen worden?
- Wat zou u ervan vinden als uw mantelzorger met u meekijkt?

Indien geen mantelzorger:

- Wat is de reden dat u geen mantelzorger heeft aangewezen?
- Zou u dit alsnog willen?
- Indien u een mantelzorger zou hebben, zou u hem/haar bij het systeem willen betrekken?

- Hoe vaak ziet u de fysiotherapeut?
- Wat doet de fysiotherapeut met de inspanningscoach?
 - Wat vindt u hier positief aan?
- Hoe zou de fysiotherapeut u nog beter kunnen helpen binnen MijnCOPD?

Onderwerp: Overig

- Is er nog iets wat u kwijt wilt?

Bedankt voor uw tijd!

Mantelzorger

Introductie:

Het doel van dit interview is om na te gaan hoe u MijnCOPD gebruikt, wat u ervan vindt en vooral wat er verbeterd zou kunnen worden binnen de gehele interventie. MijnCOPD refereert naar het gehele systeem, dus zowel het horloge, als de applicatie en het dashboard. Dus in het algemeen hoe kan MijnCOPD verder bijdragen aan het bevorderen van zelf managen van de ziekte van uw naaste. Zoals afgesproken zal het interview 30 minuten duren. Het gesprek zal worden opgenomen met een voicerecorder zodat wij deze op een later moment kunnen uitwerken.

Achtergrondinformatie (zelf invullen):

- Naam:
- Leeftijd:
- Geslacht:
- Relatie met patiënt:

Onderwerp: Sociale steun

Graag zou ik eerst willen opgaan op de relatie tussen u en de patiënt, dus los van het systeem.

- Waarom bent u mantelzorger?
- Hoe lang bent u mantelzorger?
- Hoe vaak zien jullie elkaar?
 - o Spreken jullie elkaar daarnaast ook nog? (Telefonisch/chat)
- Kunt u beschrijven hoe u de patiënt helpt bij de ziekte bij de dagelijkse werkzaamheden?
- Kunt u beschrijven hoe u de patiënt helpt bij het omgaan met de ziekte?
 - o Motiveerde u voordat de patiënt het horloge kreeg hem/haar al om lichamelijk actief te blijven?
- Is er een manier waarop u de patiënt wellicht nog beter zou kunnen helpen?
 - o Heeft u hierbij hulp nodig?

Onderwerp: Mantelzorger

Ik kan mij voorstellen dat de ziekte van de patiënt op u persoonlijk ook invloed heeft.

- Op welke manier kan technologie u verder ondersteunen?

Onderwerp: MijnCOPD

We gaan nu verder in op hoe u gebruik maakt van het systeem MijnCOPD.

- Wat zijn voor u de redenen om MijnCOPD te gebruiken?
 - o Denkt u dat het systeem u helpt in het ondersteunen van de patiënt?
 - o Denkt u dat het systeem de patiënt helpt om meer of minder te bewegen op een dag?
- Zou u in het algemeen kunnen beschrijven hoe u MijnCOPD gebruikt gedurende de week?
- Wat vindt u van uw rol en taken als mantelzorger binnen MijnCOPD?
- Wat vindt u van het ontvangen van de meldingen wanneer de patiënt haar beweegdoelen niet heeft gehaald?
 - o Wat doet u na het ontvangen van een melding?
 - o Wat vindt u van de inhoud van de melding?
 - o Hoe vaak heeft u een melding ontvangen van het systeem afgelopen week?
 - Is dit te vaak of te weinig?
 - Zou de melding anders kunnen?
- Maakt u gebruik van het dashboard op de website van Emma? (Waarom niet)
 - o Hoe vaak kijkt u hiernaar?
 - o Wat doet u hiermee?
 - o Wat vindt u hiervan?
 - Welke filters gebruikt u?
 - Mist u nog filters?
 - Kunt u alle informatie vinden op het dashboard?
- Kijkt u mee op de applicatie Emma op de mobiele telefoon of het horloge van de patiënt?

- Hoe vaak kijkt u hiernaar?
 - Wat doet u hiermee?
 - Wat vindt u hiervan?
- Wat vindt u goed aan MijnCOPD?
- Wat zou er beter kunnen aan MijnCOPD?
 - Wat zou u verder willen met de verkregen data van MijnCOPD?
 - Hoe zou dit eruit zien?
- In hoeverre schat u de bewegingsinformatie in als compleet?
- Denkt u dat de bewegingsinformatie klopt?

Onderwerp: Overig

- Is er nog iets wat u kwijt wilt?

Bedankt voor uw tijd!

Fysiotherapeut

Introductie:

Het doel van dit interview is om na te gaan hoe u Emma en de inspanningscoach (MijnCOPD) gebruikt, hoe dit ervaart en vooral wat er verbeterd zou kunnen worden binnen de gehele interventie. Dus in het algemeen hoe kan MijnCOPD verder bijdragen aan het bevorderen van zelf managen van de ziekte voor de patiënt. Zoals afgesproken zal het interview 30 minuten duren. Het gesprek zal worden opgenomen met een voicerecorder zodat wij deze op een later moment kunnen uitwerken.

Achtergrondinformatie (zelf invullen):

- Naam:
- Geslacht:
- Praktijk:
- Hoe lang hij/zij MijnCOPD gebruikt:

Onderwerp: De behandeling (5 min)

Er zullen nu een aantal vragen gesteld worden die betrekking hebben op de behandeling die u de patiënt geeft, die gebruik maakt van MijnCOPD.

- Kunt u kort beschrijven hoe de behandeling met de patiënt eruitziet?
 - Hoe vaak ziet u de patiënt?
 - Is dit apart of in een groep sessie?
 - Wat is het doel van de behandeling?
 - Wat voor soort oefeningen doet u met de patiënt?
 - Is de behandeling redelijk gelijk bij andere patiënten?

Onderwerp: Huidige situatie (5 min)

We gaan nu verder of hoe u het systeem gebruikt in de praktijk.

- Hoe gebruikt u de beweegdata in MijnCOPD binnen de behandeling?
 - Kunt u ten voorbeeld een scenario beschrijven?

- Kijkt u ook met de patiënt naar de beweeggegevens? Zo ja, hoe gaat dit?
- Hoe vaak kijkt u naar de beweeggegevens?

Onderwerp: Evaluatie (20 min)

- Heeft u ervaring met soortgelijke systemen of eHealth?
- In hoeverre schat u de verkregen data in als compleet en correct?
- Wat is de toegevoegde waarde van MijnCOPD voor u?
 - In hoeverre voegt de inspanningscoach iets toe aan het spreekuur?
- Wat denkt u dat de toegevoegde waarde van MijnCOPD voor de patiënt is?
 - In hoeverre vindt u dat de inspanningscoach iets toe voegt aan de behandeling?
 - In hoeverre schat u in dat het de patiënt om zijn/haar gedrag te veranderen?
- Wat zou er nog verbeterd kunnen worden aan MijnCOPD om de patiënt beter te kunnen ondersteunen?
 - Hoe zou dit eruit moeten zien? En waarom?
 - Welke informatie, naast de beweegdata, zou u nog kunnen gebruiken?
 - Welke meetinstrumenten zouden volgens u iets kunnen toevoegen?
(Bijvoorbeeld: oxygen meter, weegschaal, bloeddrukmeter, dagboekje
vragenlijst: 6 MWD, CCQ, Rand-36, ziektelastmeter, FEV 1)
 - Wat zou u doen met deze gegevens?
 - Heeft u hier hulp bij nodig?
- Wat zou u ervan vinden dat u meldingen ontvangt wanneer de patiënt zich niet aan de beweegdoelen heeft gehouden? En hoe zou u dit willen ontvangen (hoe vaak, welk apparaat)?

Graag zouden we nu wat verder ingaan op specifiek het dashboard.

- Wat vindt u van het dashboard?
 - Wat vindt u goed aan het dashboard?
 - Wat zou er beter kunnen?
 - Aflezen

- Welke filters gebruikt u het meest?
 - Mist u nog filters?
- Duidelijkheid informatie
 - Wordt het aantal stappen duidelijk weergegeven in de grafieken?
 - Hoe zou dit beter kunnen?
- Beweegdata
 - Heeft u behoefte aan weekdoelen en/of dag doelen?
- Bij welke type patiënten zou dit programma nog meer ingezet kunnen worden?

Onderwerp: Overig

- Is er nog iets wat u kwijt wilt?

Bedankt voor uw tijd!

Appendix 3. Translated quotes used in thesis

Table 9. Original and translated quotes Stage 1: MyCOPD Context

Original quote	Translated quote
<i>"Ja dat hoeft eigenlijk niet, want ik moet het toch zelf doen. Ja maar ze zeggen allemaal wel van je moet vaker lopen, je moet vaker dit doen. Ze zijn wel bezorgd" (P1, F).</i>	<i>"Yes that is not really necessary, because I have to do it myself. Yes, but they all say that you should walk more often, you have to do this more often. They are concerned" (P1, F)</i>
<i>"Ja zij zijn geruster erop omdat er toch een controle in zit, dat is voor hun ook prettig. Ook voor de niet-mantelzorgers. Ja mijn zoon vindt dat ook prettiger, ja van goed er zit dan toch een soort controle achter, voor jezelf maar ook voor hun" (P1, F)</i>	<i>"Yes, they are more comfortable because there is control, which is also nice for them. Also for non-caregivers. Yes, my son also likes it, yes, there is some kind of control for yourself, but also for them" (P1, F)</i>
<i>"Ja toch wel een keer of vijf of zes op een dag hoor, en af en toe nog wat meer... Naar de stappen en de beweging en... ja ik moet het wel in de gaten houden" (IC3, M)</i>	<i>"Yes, at least five or six times a day, and occasionally more. At the steps and the movement and, yes, I have to keep an eye on it" (IC3, M)</i>
<i>"Dan kan ze meer het huis uit, kijk, op een gegeven moment kwam ze helemaal niet meer buiten En dan had ze ook de angsten natuurlijk. Nou is ze over de angst heen natuurlijk, omdat ze in de gaten wordt gehouden" (IC3, M)</i>	<i>"Then she can get out of the house more often, look, at one point she did not get out anymore. And then she also had the fears of course. Well, now she is over her fear of course, because she is being watched" (IC3, M)</i>
<i>"Als ze de beweegdoelen buiten de praktijk kunnen leren realiseren en ik heb er een bepaalde controle op dan vind ik dat ook prima zeg maar" (HP4, M)</i>	<i>"If they are able to realize the training goals out of practice and I have a certain control, I think that would be fine too" (HP4, M)</i>

Table 10. Original and translated quotes Stage 1: MyCOPD Persuasive elements

Original quote	Translated quote
<i>"Ja voor mij is dat een vermoeiend gevoel maar ook een teken van kom we moeten verder en we moeten niet blijven zitten natuurlijk" (P3, F)</i>	<i>"Yes to me that's a tiring feeling, but also a sign of come on; we must go further and we must not sit still of course" (P3, F).</i>
<i>"Uhm, ja ik weet niet of het te meten valt, weet je wel, de zuurstof ofzo gewoon wat voor haar belangrijk is" (IC1, F)</i>	<i>"Uhm, yes, I do not know whether it is possible to measure it, you know, the oxygen or just what matters to her" (IC1, F)</i>
<i>"Ik denk dat dit hulpmiddel wel kan bijdragen aan de gedragsverandering. Dus dat dit voor een groot deel van de patiënten wel werkt, doordat ze directer controle ervaren" (HP2, F)</i>	<i>"I think this tool can contribute to behavioral change. So, this works for a large proportion of patients, by experiencing direct control" (HP2, F).</i>
<i>"Ik denk dat mensen zich echt heel erg bewust worden van hoeveel ze nou doen en of ze inderdaad gestelde norm halen of niet. Dat het een extra stimulans is om op tijd op te staan en weer een rondje te gaan doen, ja" (HP1_1, F)</i>	<i>"I think people really get very aware of how much they are doing now and whether they actually reach their goals. That it's an additional incentive to get up and running again, yes" (HP1_1, F)</i>
<i>"Dat zou ik prettig vinden, want nou ga je eigenlijk ieder keer kijken van wat kleur is het" (P3, F)</i>	<i>"I would like that, because now you are going to look every time what color it is" (P3, F)</i>
<i>"Ik zou vooral de saturatie willen weten, en dan met name de range waarin de saturatie zich in heeft bevonden op het moment dat iemand meerdere stappen, he, een behoorlijk aantal stappen gaat maken. De ondergrens en de bovengrens zou ik willen weten, vooral de ondergrens." (HP3, M)</i>	<i>"I would especially like to know the saturation, and especially the range in which the saturation has occurred, when someone takes multiple steps, right, a fair number of steps. The lower limit and the upper limit I would like to know, especially the lower limit." (HP3, M)</i>
<i>"Nu moet je zelf het in de gaten houden zeg maar en ik kijk toch wel vaak op mijn horloge, maar er zijn misschien mensen die dat niet doen en dan heb je nog geen weet van" (P2, F)</i>	<i>"Now you have to keep an eye on it yourself, I often watch my watch, but maybe there are people who do not and so you do not know" (P2, F)</i>
<i>"Als ik zie dat het goed gaat kan ik dan ook contact opzoeken en dan kan ik het ook zeggen, misschien motiveert dat haar dan ook weer" (IC1, F)</i>	<i>"If I see that is going well, I can get in contact and then I can say so, maybe it motivates her" (IC1, F)</i>

Table 11. Original and translated quotes Stage 2

Original quote	Translated quote
<i>"Nou je ziet zo vaak van, ja moet ik weer gaan meten, uhm hoe is het zuurstofgehalte, en als je dan toch het signaal aan kan geven, dan kun je toch wel automatisch de saturatie een keer extra meten" (P2, F)</i>	<i>"Well, you see often, yes I have to measure again, uhm how is the oxygen saturation, and if you can give the signal, you can automatically measure the saturation once more" (P2, F)</i>
<i>"Maar soms moet je wel gemotiveerd worden om het te doen denk ik. En dat is wat jij zegt (P2) dat een berichtje wel kan motiveren. Kijk je hebt kinderen thuis natuurlijk en die blijven op je letten, maar als je alleen thuis bent, je bent maar alleen" (IC1, F)</i>	<i>"But sometimes you have to be motivated to do it I think. And that's what you say (P2) a message is able to motivate. Look, you have children at home of course, and they keep an eye on you, but if you're home alone, you're just lonely" (IC1, F)</i>
<i>"Nou dan kan hij me wel bellen, en dan zeg ik ja dat doe ik even, tot vanavond houdoe. En dan denk ik doe! Snap je? Want dan denk ik in mijn hoofd, ik moet dit nog doen, ik moet dat nog doen" (P2, F)</i>	<i>"Well then he can call me, and then I say yes I'll do that, see you tonight bye. And then I think bye! Do you understand? Because then I think in my mind, I still have to do this, I still have to do that" (P2, F)</i>

Appendix 4. Storyboards

Storyboard 1. Self-monitoring



Figure 10. Storyboard 1: Prototype Self-monitoring

Explanation Storyboard 1

Storyboard one shows the patient receiving a vibration from the Emma activity coach, with the message to measure oxygen saturation. After the measure is successful, the patient receives again a vibration indicating the data has successfully been transmitted to the Emma platform. Next the patient and the physiotherapist view together a graph on the Emma dashboard with three variables; oxygen saturation level, responses to the CCQ and the activity levels of the patient. This graph provides insight in the connection between those variables. So the patient becomes aware of the influence of activity on how he feels both subjective (CCQ) and objective (saturation). Moreover, the graph provides insight into when an exacerbation might happen.

Research questions storyboard 1

- 0.1 Wat vindt u van het idee?
- 0.2 Zou het u motiveren om meer/minder te bewegen?
- 2.1 Zou u de melding liever via het horloge of uw telefoon willen krijgen?
- 3.1 Hoe vaak per dag zou u de saturatie willen meten?
- 4.1 Zou u de resultaten van de meting liever via het horloge of uw telefoon willen laten verlopen?
- 5.1 Wat vindt u van de grafiek?
- 5.2 Hoe zou deze verbeterd kunnen worden?
- 5.3 Wat zou u kunnen helpen om meer inzage te krijgen in
- 6.1 Zou u de melding liever via het horloge of uw telefoon willen krijgen?
- 7.1 Zou u deze informatie met uw fysiotherapeut willen bespreken?

Storyboard 2. Reminder

Figure 11. Storyboard 2: Prototype Reminder

Explanation Storyboard 2

Storyboard two shows the patients receiving a vibration because the Emma activity coach turned orange. This vibration is combined with a persuasive and tailored suggestion, which further motivates the patient to change his behavior. After the patient is physical active, the smartwatch vibrates again, indicating that the Emma activity coach turned green again.

Research questions storyboard 2

0.1 Wat vindt u van het idee?

0.2 Zou het u motiveren om meer/minder te bewegen?

2.1 - Hoe vaak per dag zou u maximaal een trilling willen krijgen wanneer de batterij van kleur verandert?

3.1 Hoe vaak per dag zou u maximaal een berichtje willen ontvangen? Via het horloge of de telefoon?

3.2 Wat voor soort melding zou u motiveren om uw beweging aan te passen?

3.3 Heeft u een idee hoe het berichtje persoonlijk kan worden gemaakt?

3.4 Zou u de mogelijkheid willen om aan te geven waarom u het doel niet heeft behaald? Hoe zou dit eruit zien?

Storyboard 3. Social facilitation

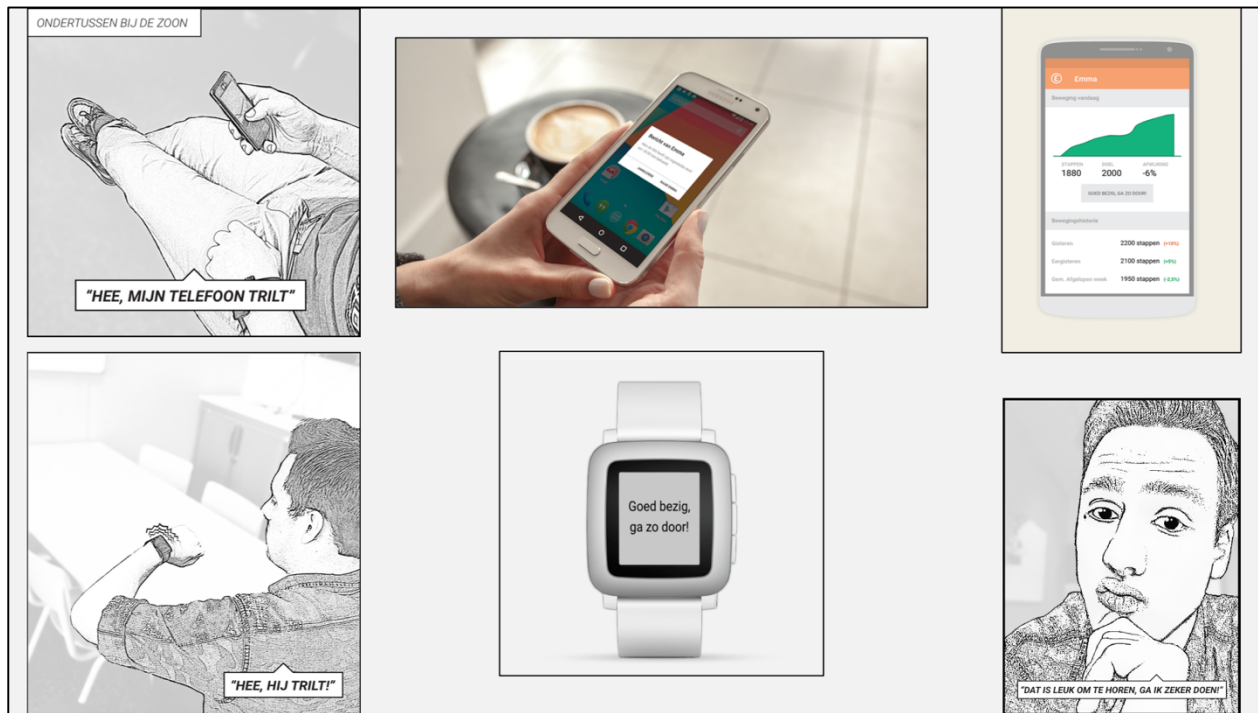


Figure 12. Storyboard 3: Prototype Social facilitation

Explanation Storyboard 3

Storyboard three shows the informal caregiver receiving a notification of his (new) Emma mobile app, indicating that the patient reached his activity goal. When clicking on the notification a screen appears with the current number of steps, goal, deviation and history. Moreover, after clicking on the praise (or suggestion) button, the patient receives a message on his smartwatch with this praise.

Research questions storyboard 3

0.1 Mantelzorger: Wat vindt u van het idee? Hoe zou u het gebruiken?

0.2 Patiënt: Wat vindt u van het idee? Denkt u dat het u motiveert om meer/minder te bewegen?

2.1 Ontvangt u liever een melding of een sms/e-mail?

3.1 Begrijpt u de informatie? Is deze duidelijk genoeg?

3.2 Is er nog meer informatie die u hier zou willen zien?

3.3 Zou u gebruik maken van de knop? Of zou u liever zelf een berichtje willen typen binnen de app?

3.4 De knop is een eigen idee, heeft u een suggestie hoe u binnen de app de patiënt zou kunnen motiveren?

5.1 Patiënt: Zou u deze melding liever via uw horloge of uw telefoon willen ontvangen?

Appendix 5. Online Questionnaire

Onderzoek MijnCOPD

Op basis van de bijeenkomst in het Bravis ziekenhuis is een trilling toegevoegd wanneer het batterijtje (de Emma activiteitencoach) op uw horloge van kleur verandert. Onderstaande 15 vragen gaan over deze trilling.

Het invullen van de vragenlijst duurt ongeveer 5 tot 10 minuten. Bij 'Your answer' kunt u uw antwoord intypen.

Voor vragen kunt u contact opnemen met:

- Lean kramer: lean@medicinemen.eu

1. Sinds wanneer ontvangt u een trilling bij het veranderen van de kleur van de batterij?

MM/DD

2. Wat vindt u van de trilling?

Zeer slecht (1) - Zeer goed (5)

3. Waarom?

4. In hoeverre helpt de trilling bij het behalen van uw bewegingsdoelen?

Totaal niet (1) – Zeer goed (5)

5. Waarom?

Onderstaande vragen gaan over de trilling wanneer de kleur verbeterd.

(Dus van rood naar groen)

6. Wat denkt u?

7. Wat doet u?

8. Wat vindt u van de duur van de trilling?

Te lang – Goed - Te kort

Onderstaande vragen gaan over de trilling wanneer de kleur verslechterd.

(Dus van groen naar rood)

9. Wat denkt u?

10. Wat doet u?

11. Wat vindt u van de duur van de trilling?

Te lang – Goed - Te kort

Onderstaande vragen gaan over de trilling in het algemeen.

12. Vindt u dat er voldoende verschil zit tussen beide trillingen?

Ja – Nee

13. Zou er volgens u een verschil moeten zijn? Waarom?

14. Wat vindt u van het aantal trillingen per week? Waarom?

15. Heeft u verdere opmerkingen of suggesties?