Perceptions and experiences of health care professionals on the use of eHealth technology in daily practice.

Qualitative research on the Personal Health Record e-Vita.

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Abstract

Chronic obstructive pulmonary disease (COPD) is a chronic respiratory disease characterized by a decline in lung function over time and accompanied by various symptoms. The goals of treating patients with COPD are to decrease disease-related complaints, improve exercise performance and disease-related quality of life, and to reduce the future burden of disease. eHealth can play an important role in disease management, by increasing the self-management of patients. e-Vita developed a Personal Health Record (PHR) in order to increase quality of care. Most research so far has focused on the patient's perspective of PHRs, but the adoption and implementation of PHRs in health care systems has broad implication for health care providers and delivery systems. Therefore, the goal of this research is to identify the perceptions and experiences of nurse practitioners in the Netherlands on the use and implementation of e-Vita COPD eHealth systems.

Qualitative research was carried out by conducting semi-structured in-depth interviews with nurse practitioners from participating practices, including questions about: general tasks of nurse practitioners, the introduction of e-Vita within the practice, the value of e-Vita in the treatment of COPD patients, (dis)advantages of the use and deployment of e-Vita, and the future of PHRs in health care. In total, eight COPD nurse practitioners participated in the interviews. Results showed that nurse practitioners did not used the e-Vita platform often, and experience several barriers when they do. System incompatibility, lack of patient-reported information, usability problems, or forgetting to check the platform were mentioned as reasons for non-use of the PHR e-Vita. Nurse practitioners see an important role for PHRs in the future, but indicated the need for personal consultation as well.

It was also decided upon to conduct interviews with five COPD patients of general practices because of the fact they are also users who eventually have to work with a PHR and have expectations regarding the use of PHRs in the future. In semi-structured in-depth interviews, questions were asked about: support and guidance, online activities, and the future of PHRs in health care. Patients do not see an important role for PHRs in future, and personal contact with nurse practitioners is highly appreciated.

In conclusion, the system of the PHR e-Vita is not being used to its full potential. A need remains for strategies to improve outcomes, while eHealth technologies have proven their potential, there is still a need for human-centered design when developing new technologies. Nevertheless, nurse practitioners see the potential of using e-Vita, provided that e-Vita

increases in value by adding new features. Future research should combine health professionals' perspectives and patients' perspectives in order to increase this value even further.

Abstract (Dutch)

Chronische obstructieve longziekte (COPD) is een chronische respiratoire ziekte, gekenmerkt door een daling van de longfunctie die gepaard gaat met verschillende symptomen. Het doel van de behandeling van patiënten met COPD is om ziekte-gerelateerde klachten te verminderen, verbeteren van de prestaties met leefstijlverbeteringen en de ziekte-gerelateerde kwaliteit van leven, en de toekomstige lasten van ziekte te verminderen. eHealth kan een belangrijke rol spelen in het beheersen van de ziekte teneinde zelfmanagement van de patiënt te stimuleren.

E-Vita heeft een Personal Health Record (PHR) ontwikkeld om de kwaliteit van de zorg verder te verbeteren. Het meeste onderzoek is gericht op patiënten perspectief, maar de adoptie en implementatie van PHR's heeft ook veel invloed op het werk van medewerkers in de gezondheidszorg en de werkprocessen. Daarom is het doel van dit onderzoek om de percepties en ervaringen te identificeren van praktijkverpleegkundigen in Nederland aangaande het gebruik en de implementatie van PHR e-Vita COPD.

Kwalitatief onderzoek werd uitgevoerd door het uitvoeren van semi-gestructureerde diepte-interviews met praktijkverpleegkundigen van de deelnemende praktijken met vragen over: algemene taken van de praktijkverpleegkundige, de invoering van e-Vita binnen de praktijk, de waarde van e-Vita in de behandeling van COPD patiënten, voor- en nadelen van het gebruik van e-Vita en de toekomst van eHealth in de gezondheidszorg. In totaal hebben acht praktijkverpleegkundigen deelgenomen aan de interviews. Resultaten toonden aan dat praktijkverpleegkundigen het e-Vita-platform niet vaak hebben gebruikt, en verschillende belemmeringen hebben ervaren bij het gebruik. Systeem incompatibiliteit, gebrek aan patiënten-informatie, gebruikersproblemen of vergeten het platform te raadplegen, werden genoemd als redenen voor het niet gebruiken van de PHR e-Vita. Praktijkverpleegkundigen zien een belangrijke rol in de toekomst voor het gebruik van PHR's maar de behoefte aan een persoonlijk gesprek met de patiënt blijft bestaan. Ook werden er interviews gehouden met vijf COPD-patiënten van (niet deelnemende) praktijken vanwege het feit dat ze een toekomstige gebruiker van een PHR kunnen worden. In semi-gestructureerde diepte-interviews werden vragen gesteld over: ondersteuning en begeleiding bij COPD, online activiteiten en de toekomst van PHR's in de gezondheidszorg. Patiënten zien geen belangrijke rol weggelegd voor een PHR en persoonlijk contact met de praktijkverpleegkundige wordt zeer gewaardeerd.

Kortom, het potentieel van de PHR e-Vita wordt niet volledig benut. Er blijft behoefte aan strategieën om de resultaten te verbeteren. Desalniettemin zien praktijkverpleegkundigen potentieel in e-Vita mits nieuwe functies worden toegevoegd met persuasieve elementen.

EHealth-technologie heeft zijn potentieel in zijn algemeenheid bewezen maar er is sterk behoefte aan een mens-gecentreerd ontwerp bij het ontwikkelen van een nieuwe toepassing. Toekomstig onderzoek zou het professionele perspectief van de gezondheidsfunctionaris moeten combineren met het patiëntenperspectief om het potentieel zo optimaal mogelijk te kunnen benutten.

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1. Introduction

1.1 Chronic obstructive pulmonary disease (COPD)

Chronic obstructive pulmonary disease (COPD) is a chronic respiratory disease characterized by a decline in lung function over time and accompanied by various symptoms. In particular, these symptoms are chronic bronchitis, shortness of breath especially during physical activities, wheezing, chest tightness, having to clear the throat first thing in the morning due to excess mucus in the lungs, a chronic cough that produces sputum, frequent respiratory infections, lack of energy, and unintended weight loss (in later stages). These symptoms slowly worsen over time. People with COPD are also likely to experience episodes called 'exacerbations', during which their symptoms become worse than their usual day-to-day levels and which persist for at least several days. The disease leads to a loss of well-being for patients and affects their quality of life. Chronic illnesses are meaningful to individuals and expensive to society. On the basis of the burden of disease, COPD forms an enormous threat to public health in the Netherlands (www.CBS.nl, 28 December 2015). It is associated with a significant economic burden including hospitalization, work absence, and disability. On 1 January 2007, there were 276,100 people with COPD in the Netherlands: 15.5 per 1000 women and 18.3 per 1000 men (www.nationaalkompas.nl, 28 December 2015). Figure 1 shows the difference in prevalence within men and woman after the age of 60. After this age, men are diagnosed with COPD much more than women.

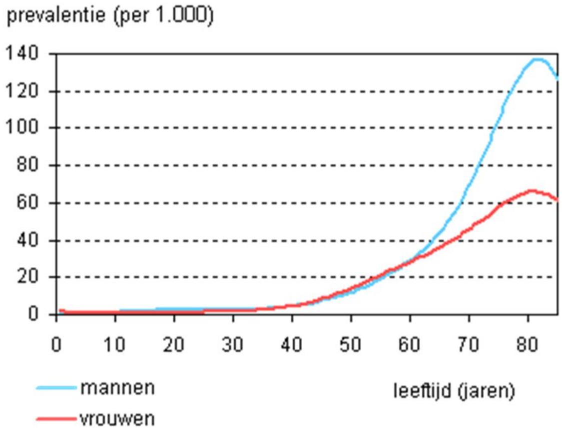


Figure 1: Point prevalence (per 1000) of COPD on 1 January 2007 by age and gender (www.nationaalkompas.nl), (mannen: men; vrouwen: women; leeftijd (jaren): age (years)).

Current data show that COPD mortality is increasing, and by 2020 COPD is predicted to be the third-leading cause of death worldwide (Rycroft, 2012). In the Dutch general population, three of every 1000 people are diagnosed with COPD per year. The incidence increases rapidly with age and is higher in men than in women. One in eight men and one in 12 women, despite being COPD free at the age of 40, will develop COPD during their later life. Mortality rates differ substantially between COPD patients and non-COPD subjects of the same age, underlining the burden of this disease (Afonso, Verhamme, Sturkenboom & Brusselle, 2011). Because of the potentially significant savings in health care costs, more emphasis is being placed on cost-effective health care. Therefore nursing care for patients with COPD is moving from outpatient clinics into primary care settings and, particularly, into their homes. However, with the rising prevalence of COPD and a growing recognition of the long lasting, comprehensive and complex healthcare needs of people with COPD and their families, primary health care providers face the challenge of restructuring their practices as well (Jónsdóttir, 2008).

Most healthcare providers follow nationally recognized standards for taking care of COPD patients. The members of the Nederlands Huisartsen Genootschap (NHG: national general practitioner association) follow the NHG-guidelines for diagnosing, treating and monitoring COPD (www.nhg.org/standaarden/volledig/nhg-standaard-copd, 28 December 2015). The goal of treating patients with COPD is to decrease disease-related complaints, improve exercise performance and disease-related quality of life, and to reduce the future burden of the disease (e.g. normalize the decline in lung function, prevent exacerbations, and delay or prevent disability and mortality). General practitioners (GPs) counsel and treat most of patients with mild or moderate disease burdens. In some primary care practices, the care of patients with COPD is delivered within a care chain as an integrated care program with other health care providers, such as lung specialists, COPD nurse practitioners, physiotherapists and dieticians. In consultation with the patient, individual treatment goals are discussed and adopted, based on general treatment goals. The health-related goals of the patient are determined in an individual care plan, along with agreements on the frequency of progress monitoring, medication use, lifestyle change, policy at exacerbations, and any agreements with other health care providers. Some concerns, such as giving information, help quitting smoking, spirometry, inhalation and medication instructions and monitoring the use of medication, can be delegated to a nurse practitioner specialized in COPD treatment. The inhalation instruction can also be performed by the pharmacist.

1.2 Self-management and COPD

The definition of self-management according to Barlow, Wright, Sheasby, Turner & Hainsworth (2002) is as follows: “Self-management refers to the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life. Thus, a dynamic and continuous process of self-regulation is established”.

As mentioned, the symptoms of COPD slowly worsen over the years. This leads to loss of well-being for these patients and affects their quality of life. A change of life-style is important for the prevention or treatment of COPD. Patients should not only take their medication and adhere to general principles but they are also responsible for measuring their weight, blood pressure and heart rate to provide health care givers insight into the course of the disease. Patients should be more physically active, quit smoking, and eat more healthily. Self-management of COPD also includes behavior to sufficient cope with limitations caused by the disease, compliance with inhaled medication, paying attention to changes in the severity of the disease, adequate inhalation technique, and self-adjustment of the medication in case of exacerbations. Overall, Barlow et al. (2002) stated that compared to no intervention, self-management approaches can potentially provide benefits for patients, mainly in terms of knowledge, behavior, self-efficacy and some aspects of health status. Self-management plays a significant role in the treatment of chronic COPD patients (Barlow et al., 2002). Self-management is particularly significant for COPD patients who experience greater physical health losses and who are dealing with greater depressive symptoms, compared to patients with diabetes or cardiovascular disease. Interventions that improve self-management abilities may counteract a decline in physical health and an increase in depressive symptoms (Cramm & Nieboer, 2012). Self-management is independently associated with disease-specific quality of life for COPD (Zwerink et al., 2014, Benzo, Abascal-Bolado & Dulohery, 2015). The significant self-management domains for COPD are investment in behaviors and self-efficacy. Age and lung function are not significantly associated with self-management abilities for COPD. Self-management reduces hospital admissions of patients with stable COPD. However, its role immediately after post-acute exacerbation (AE) is unclear (Harrison, Janaudis-Ferreira, Brooks, Desveaux & Goldstein 2015).

Debate on the most effective content in self-management is ongoing (Zwerink et al., 2014, Harrison et al., 2015), but essential patient skills for successful self-management include problem solving, decision making, resource utilization, forming a partnership between themselves and their healthcare provider, taking action, and self-tailoring (Lorig, 2003). Even so, self-management training is becoming more and more important in the treatment of COPD because a change of lifestyle is important to prevent the disease from getting worse. Self-management training teaches patients the skills and behaviors they need to successfully manage their disease. The patient becomes an active participant in their treatment. Ideally, self-management training should be aimed at sustained behavioral change. To bring about this behavioral change the patient needs self-efficacy. Self-efficacy is seen as patients' confidence that they can effectively manage their health, and has been recognized as a powerful factor in inducing new behaviors (Bandura 1977; Lorig 2003). Self-efficacy can be strengthened through skills mastery, modelling, interpretation of symptoms and social persuasion (Lorig, 2003).

Technology can play an important role in supporting and developing these competences. For example, the 'It's LiFe!' monitoring-and-feedback-tool embedded in the Self-Management Support Program (SSP) attempts to stimulate physical activity in people with COPD or type 2 diabetes who are treated in primary care. The combination of counseling and this tool has proven an effective way to stimulate physical activity (Van der Weegen et al., 2015). Another example is an eHealth portal for patients in a bariatric surgery program. The portal includes patient information, self-management tools, and communication features for online dialog with peers and health care providers at the bariatric surgery clinic. Health care professionals can observe the writings and revelations of patients, thereby capturing patient challenges and acting to implement measures. Interacting with patients through the portal can prevent dropouts and the deterioration of the health of patients (Das, Faxvaag & Svanæs, 2015).

1.3 eHealth technology

Information and communication technology in healthcare (eHealth) has multiple definitions without scientific agreement. E-health can be described according to the definition of Eysenbach (2001):

> "E-health is an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology".

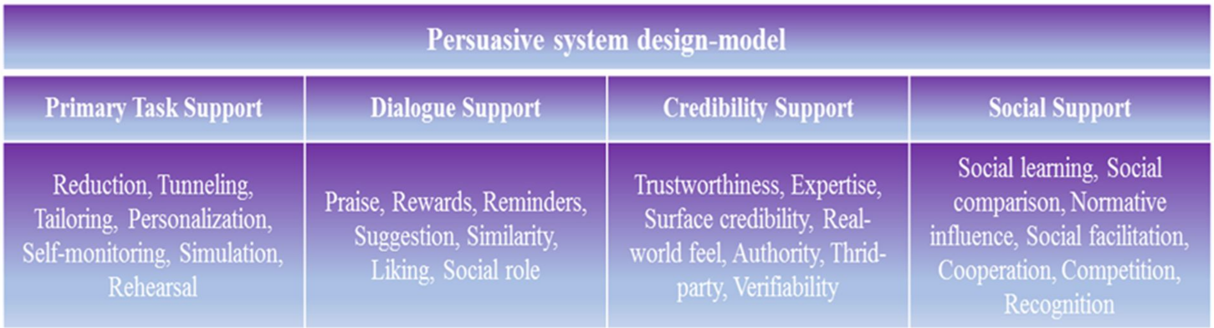
This definition covers a wide range of applications; eHealth is basically described as the use of information and communication technologies, internet technology in particular, to support or improve health and health care, without restricting it to a particular group of users or specific disease (van Gemert-Pijnen, Nijland, van Limburg, Ossebaard, Kelders & Eysenbach, 2011). This information and communication technology can refer to internet technologies such as informative websites, interactive health applications (e-consultation, online communities, online decision-making AIDs and tailored health education programs), online health portals and electronic patient records. But eHealth can also refer to mobile health programs for communication (serious gaming to stimulate movement or 3-dimensional applications for extra stimulation to treat anxiety disorders, demotics (electronic tools for the home such as sensors for fall prevention) and robotics (deployment of robots to support an operation) (van Gemert-Pijnen et al., 2011).

EHealth provides possibilities for meeting the requirements of self-management; supporting patients by providing online information, education, and diagnoses; supporting treatment choices; monitoring their disease, for example by keeping track of readings (telemonitoring); and providing contact with peers (peer-to-peer support) (van Gemert-Pijnen et al., 2011). Furthermore, the use of eHealth interventions has the potential to assist patients in self-managing their conditions with individually tailored education and action plans, and also by providing support for patients to monitor and interpret their own physiological data (Hardinge et al., 2015). Patients may in this way carry out for themselves certain tasks related to their own care, for example checking blood glucose values or monitoring health plans. Partly because the patient will be better informed, he will search by himself for information about the disease and his own condition, but also the contact between patient and health care provider will be intensified, and this will offer opportunities for health care providers to coordinate care (van Gemert-Pijnen et al., 2011).

1.3.1 Persuasive technology

Persuasive technology plays a major role in self-management systems. It is designed to change the attitudes or behaviors of users through persuasion and social influence, and can make interventions more successful (Fogg, 2003; Oinas-Kukkonen & Harjumaa, 2009). According to Oinas-Kukkonen and Harjumaa (2009) persuasive systems are “computerized software or information systems designed to reinforce, change or shape attitudes or behaviors or both without using coercion or deception”. The technology is developing rapidly and has been widely used in various fields including health.

Via persuasive techniques, eHealth technologies can be designed to motivate patients to engage in self-management (Oinas-Kukkonen & Harjumaa, 2009). The prevention or treatment of COPD (partly) depends on a changed lifestyle, and persuasive technology can play an important role in this as well. The integration of persuasive technology and self-management can therefore support chronic patients in forming healthy attitudes, behaviors and habits, which can strengthen the flexibility of patients and thus improve the efficiency of self-management (Jie et al., 2015). Persuasion implies a voluntary change of behavior or attitude (Oinas-Kukkonen & Harjumaa, 2009). Via persuasive techniques, eHealth technologies can be designed to motivate patients to engage in self-management. Oinas-Kukkonen & Harjumaa (2009) developed the Persuasive System Design model (PSD-model), see Figure 2.



Persuasive system design-model

Primary Task Support	Dialogue Support	Credibility Support	Social Support
Reduction, Tunneling, Tailoring, Personalization, Self-monitoring, Simulation, Rehearsal	Praise, Rewards, Reminders, Suggestion, Similarity, Liking, Social role	Trustworthiness, Expertise, Surface credibility, Real-world feel, Authority, Thrid-party, Verifiability	Social learning, Social comparison, Normative influence, Social facilitation, Cooperation, Competition, Recognition

Figure 2: PSD-model, Oinas-Kukkonen, 2009

This model classifies system features of the technology as primary task support (the system supports the user in carrying out their primary task), dialogue support (the system supports the interaction between the user and system to stimulate desired behavior), system credibility (the system is credible), and social support (the system provides social support). The PSD-model is a theoretical framework for developing and evaluating persuasive systems as well as describing what kind of content and software functionality may be found in the final product (Oinas-Kukkonen & Harjumaa, 2009). eHealth technologies mainly use primary task support. An example of primary task support is tailoring: customizing the system to the needs of the user and using it, for example, for personalized feedback. As for the use of items for dialogue support or social support, this appears to be mainly used for reminders and social facilitation, such as peer-to-peer support (Kelders, Kok, Ossebaard & Van Gemert-Pijnen, 2012).

To develop an intervention at the 'design' phase, the values and (functional) requirements of the stakeholders can be translated into communicative (persuasive) and technical requirements for prototypes (van Gemert-Pijnen et al., 2011). The PSD-model can also be of use while creating the prototype, for example to persuade the end users to use their medication correctly (Oinas-Kukkonen & Harjumaa, 2009). Potential persuasive technology features are text messages, interaction or virtual coaching, tailoring, and personalization with different levels of value. Oinas-Kukkonen and Harjumaa (2009) give the example of the Nike+ running system, which comprises a pair of running shoes with a built-in pocket for a running sensor, an mp3 player or a sport band, and a web service [Nike+ 2008]. The sensor tracks running information and sends data to a device. While running, the user can hear summary feedback such as pace, time, distance, and calories burned. After running, the user can download the training information to the web service and see the full run data. The Nike+ system supports the complexity of planning the exercises by suggesting training programs based on the runner's goals. It is also possible to personalize the system by enabling the one's name and picture to be added to the screen, and self-monitoring is applied by providing possibilities of tracking the running information. The computer-human dialogue is supported by praise and rewards. To put it briefly, this running system contains all the elements of the Persuasive System Design model (PSD-model). This model classifies system features of the technology as primary task support (training programs), dialogue support (summary feedback), system credibility (training information) and social support (run data on the web). Other striking examples of persuasive techniques are the heart rate monitor, which presents its user's heart rate and the duration of their exercise, or mobile phone applications which present users' daily step counts (Oinas-Kukkonen & Harjumaa, 2009).

1.4 Development of eHealth technology

There are numerous aspects to the development of a Personal Health Record (PHR) which makes the intervention finally successful and easy to diffuse. For the development of eHealth technology, a holistic approach can be used (Van Gemert-Pijnen et al., 2011). This means that the emphasis is on the importance of the whole and its separate parts. The involvement of both the user and the other parties involved, such as investors, decision makers, insurers, and board members, is desirable in order to increase the implementation of eHealth Technology (Van Gemert-Pijnen et al., 2011). Developing eHealth technology can be undertaken in different ways. User- or human-centered design is an approach in which, starting from the initial phase, systematic and continuous feedback is given to the potential users (Van Velsen, Wentzel, van Gemert-Pijnen, 2013). A practical model which uses a holistic method for developing new eHealth technologies, improving existing technologies, and evaluating and implementing eHealth in healthcare is the CeHRes Roadmap (Abbr. Center for eHealth Research & Disease Management) (van Gemert-Pijnen et al., 2011), see Figure 3.

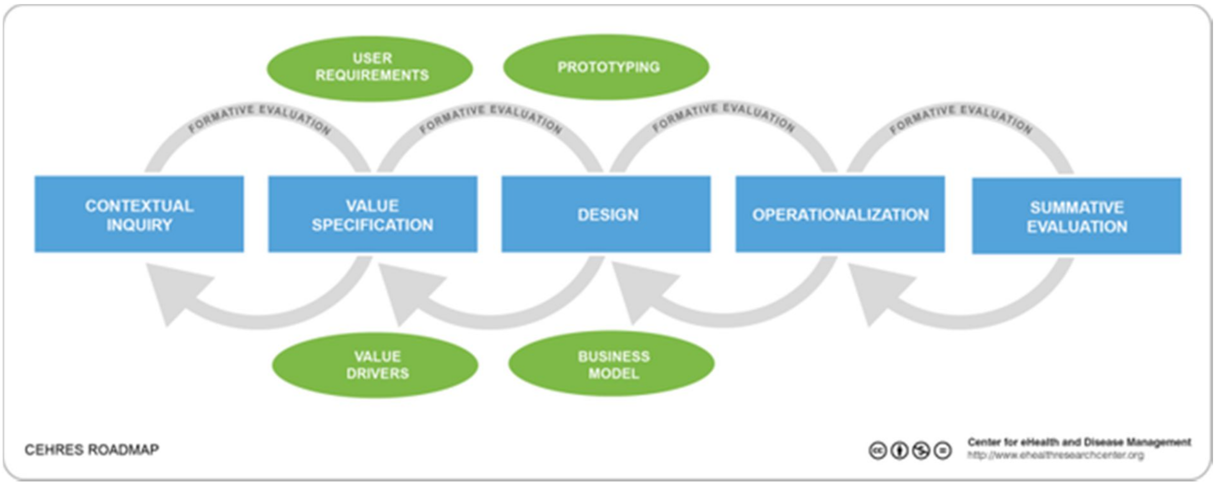


Figure 3: CeHRes Roadmap, http://www.ehealthresearchcenter.org/wiki/index.php/CeHRes_Roadmap, June 11th, 2016

The CeHRes Roadmap can be used to help plan, coordinate and execute the involved development process of eHealth. It leads to a holistic research and development approach and consists of five main phases: contextual inquiry, value specification, design, operationalization and summative evaluation at the end of a process and after each phase in the process. During the first phase, the design team wants to understand who the future users will be and what the problem is, and also consider the strengths and weaknesses in the current health care process (van Velsen et al., 2012). The second phase consists of determining what the different users and stakeholders find important, which they do through user identification, risk analyses and interviews. Between the second and third phase, the ‘early design’ phase, the needs and requirements of the user group will be translated to personas and possible use-case scenarios. Personas are hypothetical ‘archetypes’ of end-users (van Gemert-Pijnen et al., 2011) and are intended as a brief summary of end-users, presented by the biography of a person. Use-case scenarios are used to describe the interaction between the product or system and the people who use it in practice (Grudin & Pruitt, 2002). Interview quotes and the personas are also the input for the use-case scenarios, and thus the use-case scenarios are based upon these things (Lerouge, Ma, Sneha & Tolle, 2013). In the use-case scenarios the goals, motivations, actions and reactions of the users are also mentioned (Grudin & Pruitt, 2002). The use-case scenarios can be used as a base for developing the prototype, by investigating what the system needs to provide to fulfill the user requirements.

1.4.1 Implementation and diffusion of innovations

Whether an eHealth intervention is successful also depends on its implementation and the extent of its use. Gee, Greenwood, Paterniti, Ward & Miller (2015) have explored three aspects that influence the rate of diffusion of innovations within an organization: perceptions of the innovation, the features of the individuals who may adopt the change, and contextual and decision-making factors within the organization. Gee et al. (2015) examined theory and research on the dissemination of innovations and have suggested applications of that theory to health care. Based on this concept, there are seven recommendations for health care managers who want to stimulate the rate of diffusion of innovations within their organizations: find sound innovations, find and support ‘innovators’, invest in ‘early adopters’, make early adopter activity observable, trust and enable reinvention, create slack for change, and lead by example (Berwick, 2003). Furthermore the validated Chronic Care Model (CCM), see Figure 4, improves health outcomes for people with chronic conditions when systematically implemented (Gee et al., 2015). The Chronic Care Model (CCM) is a framework that illustrates a complete approach to caring for the chronically ill that supports increased functional and clinical outcomes.

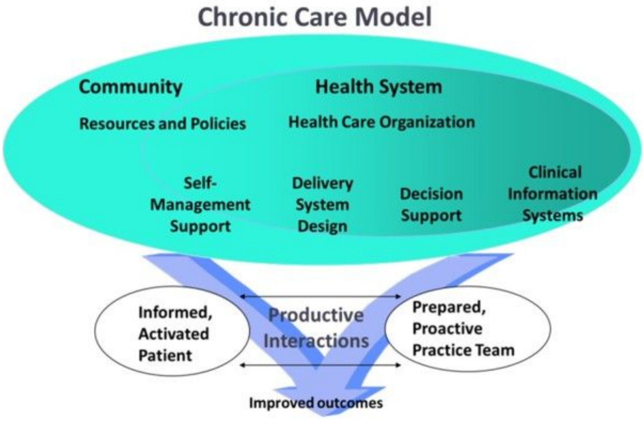


Figure 4: Chronic Care Model Developed by the MacColl Institute, ©ACP-JSIM Journals and Books

The model includes six key interdependent components: community resources, health system support, self-management support, delivery system design, decision support, and clinical information systems. Since the development of the original CCM, several information management, communication, and technology advancements have been made. The CCM places chronic care both in the context of the community where the person will receive health care services, and with the health systems involved in that care. The CCM highlights the importance of "Self-Management Support", giving patients the knowledge, confidence, and skills for self-management of their condition. According to Gee et al. (2015) there is evidence demonstrating that eHealth tools can further strengthen and enhance the already successful CCM. According to Gee et al. (2015) the literature suggests an additional improvement to the CCM extension of the support element 'eHealth Education' (Figure 5). The eHealth enhanced CCM framework contains the terms 'data', 'information', 'knowledge', and 'wisdom'.

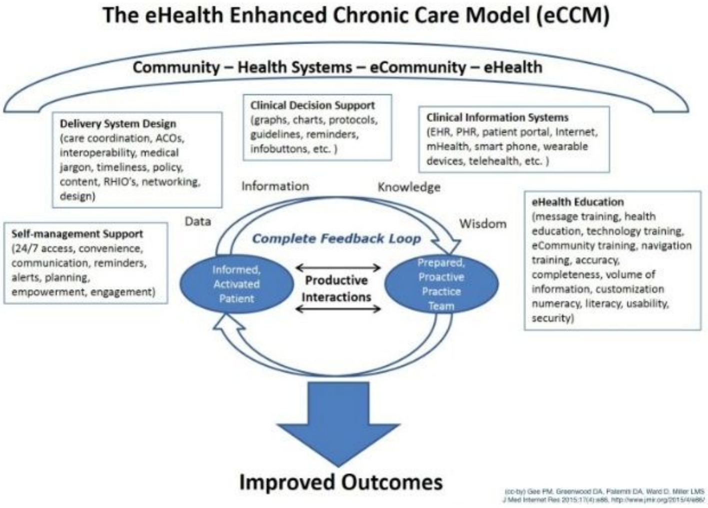


Figure 5: eHealth Enhanced Chronic Care Model. Created by Gee et al. (2015). Adapted from The Chronic Care Model (see Figure X).

Concerning the diffusion of innovation, Rogers (2003) identified the five elements that are most likely to influence the adoption of innovation: (1) relative advantage; the more value or benefit that is anticipated from adoption of the innovation relative to current practice, the more rapidly it will diffuse; (2) compatibility; the ability of an innovation to coexist with technologies and social patterns already in place improves the prospects for adoption/diffusion; (3) pace of innovation/reinvention; innovations that are general, not specialized, not very complex, and are process-oriented often get reinvented to a larger extent than innovations which are not; (4) trial ability; the ability to try out an innovation without total commitment and with minimal investment improves the prospects for adoption and diffusion; and (5) observability; the extent to which potential adopters can witness the adoption of an innovation by others improves its prospects for diffusion. Cain & Mittman (2002) present the basics of innovation diffusion by describing ten critical dynamics of the process: relative advantage; trial ability; observability; communication channels; homophile groups; pace of innovation/reinvention;

norms, roles and social networks; opinion leaders; compatibility; and infrastructure. Significant forecasters are relative advantage and complexity, which decide whether or not an eHealth technology will be accepted. These aspects indicate that a technology is used less thoroughly when a patient does not recognize the added value (relative advantage), or when use of the technology is difficult (Kelders et al., 2012).

Next to the previously described benefits of self-management and a PHR for COPD patients, research shows that eHealth solutions, such as secure online portals, do create new chances for better quality health care but much depend on the organizational infrastructure and the health care professionals providing them (Das et al., 2015). Until now, the advantages for health care professionals have received limited attention and the overall adoption of eHealth solutions remains low. Das et al. (2015) have presented professionals who reported on organizational problems and personal limitations related to online communication with patients. Health care professionals need guidelines and education about how to handle, prioritize, communicate with, and facilitate patients online. Also Nazi (2013) indicated four implications for health care professionals beyond the usually reported obstacles of privacy and security. First, the health care professional is responsible for introducing the PHR to a patient and the use of the PHR tools. Second, adequate training and training opportunities for health care professionals should be available for PHRs to be adopted and used successfully. Third, the effective support and improvement of health care by technology must take into account that the technology has to fit into existing healthcare processes. And fourth, increased use of PHRs may lead to increased workloads for healthcare professionals. As mentioned earlier, eHealth systems are more than just static repositories for patient data. They combine data, knowledge, and software tools that help patients to become active participants in their own care. However, supporting evidence for specific benefits and an appropriate business model for PHR adoption are limited (Tang, Ash, Bates, Overhage & Sands, 2006). Patients must understand and accept their roles and responsibilities related to their own health care, but health care providers will also need to develop another way of thinking and more confidence in patients. It is possible that self-management and a PHR will threaten the control, autonomy, and authority of (some) health care providers, given traditional provider–patient roles (Tang et al., 2006, Archer, Fevrier-Thomas, Lokker, McKibbon & Straus, 2011).

1.5 Personal Health Record

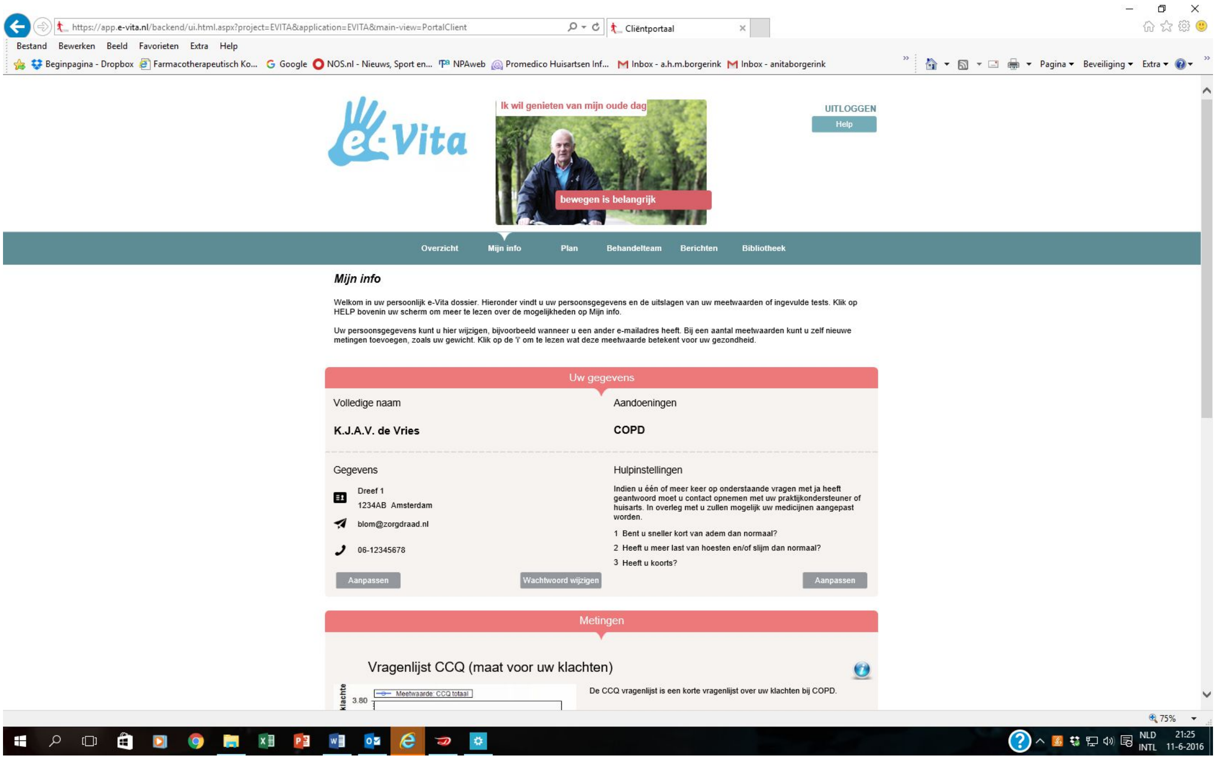
An example of an eHealth technology is the Personal Health Record (PHR). As no universally agreed definition of an electronic PHR exists, it has been described as “an electronic application through which individuals can access, manage and share their health information in a private, secure and confidential environment” (Pagliari, Detmer & Singleton, 2007). There are a number of different fundamental designs for PHRs: electronic versions include internet-based portals or computer-based applications used by health care providers, or PHRs can be installed on isolated personal computers or in internet-based portal services with which only the user enters and maintains personal health data. Then, personal health record systems are more than just static repositories for patient data. They combine data, knowledge, and software tools that help patients to become active participants in their own care (Das et al., 2015). PHRs have the potential to empower patients in the self-management of chronic diseases, which should lead to improved outcomes. There are no studies on PHRs for COPD-patients, but according to Tenforde, Jain & Hickner (2011) PHR use, although not intensity of use, is associated with improved diabetes quality measure profiles. To optimize the importance, the next-generation of PHRs must be designed to involve patients in daily diabetes self-management. When PHRs are integrated with electronic health record systems, they provide greater benefits than stand-alone systems would for consumers (Tang et al., 2006). A PHR includes health information managed by an individual. An individual can create a low profile functional PHR using a commercially available (web-based) application or a high profile alternative which allows patients to view their own health information stored in their health care provider record, the electronic health record (EHR).

One of the most important benefits of PHRs is that they give the patient greater access to all health information, data, and knowledge. Information can be customized and patients can use this to improve their health and manage their diseases. Nevertheless, patients must understand and accept their roles and responsibilities related to their own health care. A PHR will only be useful if the patient understands the importance of maintaining health-related documentation and activities and coordinating them with health care providers, but the traditional provider-patient roles will also change. It will require a different mindset and levels of trust from both parties (Tang et al., 2006, Archer et al., 2011).

Nevertheless, eHealth interventions may play a role in delivering health support along with providing the opportunity to monitor symptoms and physiological variables. Home-based, unassisted, daily use of the eHealth platform is feasible and acceptable to people with COPD for reporting daily symptoms and medicine use, and for measuring physiological variables such as pulse rates and oxygen saturation. These findings provide evidence for integrating telehealth interventions with clinical care pathways (Hardinge et al., 2015).

1.5.1 Personal Health Record e-Vita

The online health platform e-Vita is an example of a Personal Health Record for people with a chronic disease, see Figure 6 (www.e-vita.nl, 28 December 2015). With the use of e-Vita, patients can learn to cope with their disease in order to improve their quality of life. The platform is intended for use by people who suffer from type 2 diabetes mellitus, COPD or chronic heart failure (CHF). The PHR e-Vita is an initiative of the Dutch foundation Care Within Reach (in Dutch: Zorg Binnen Bereik), an investment collaboration between Philips and Achmea, a Dutch health insurance company.



Mijn info

Welkom in uw persoonlijk e-Vita dossier. Hieronder vindt u uw persoonsgegevens en de uitslagen van uw meetwaarden of ingevulde tests. Klik op HELP bovenin uw scherm om meer te lezen over de mogelijkheden op Mijn info.

Uw persoonsgegevens kunt u hier wijzigen, bijvoorbeeld wanneer u een ander e-mailadres heeft. Bij een aantal meetwaarden kunt u zelf nieuwe metingen toevoegen, zoals uw gewicht. Klik op de 'i' om te lezen wat deze meetwaarde betekent voor uw gezondheid.

Uw gegevens

Volledige naam
K.J.A.V. de Vries

Aandoeningen
COPD

Gegevens
Dreef 1
1234AB Amsterdam
blom@zorgdraad.nl
06-12345678

Hulpinstellingen

Indien u één of meer keer op onderstaande vragen met ja heeft geantwoord moet u contact opnemen met uw praktijkondersteuner of huisarts. In overleg met u zullen mogelijk uw medicijnen aangepast worden.

1 Bent u sneller kort van adem dan normaal?
2 Heeft u meer last van hoesten en/of slijm dan normaal?
3 Heeft u koorts?

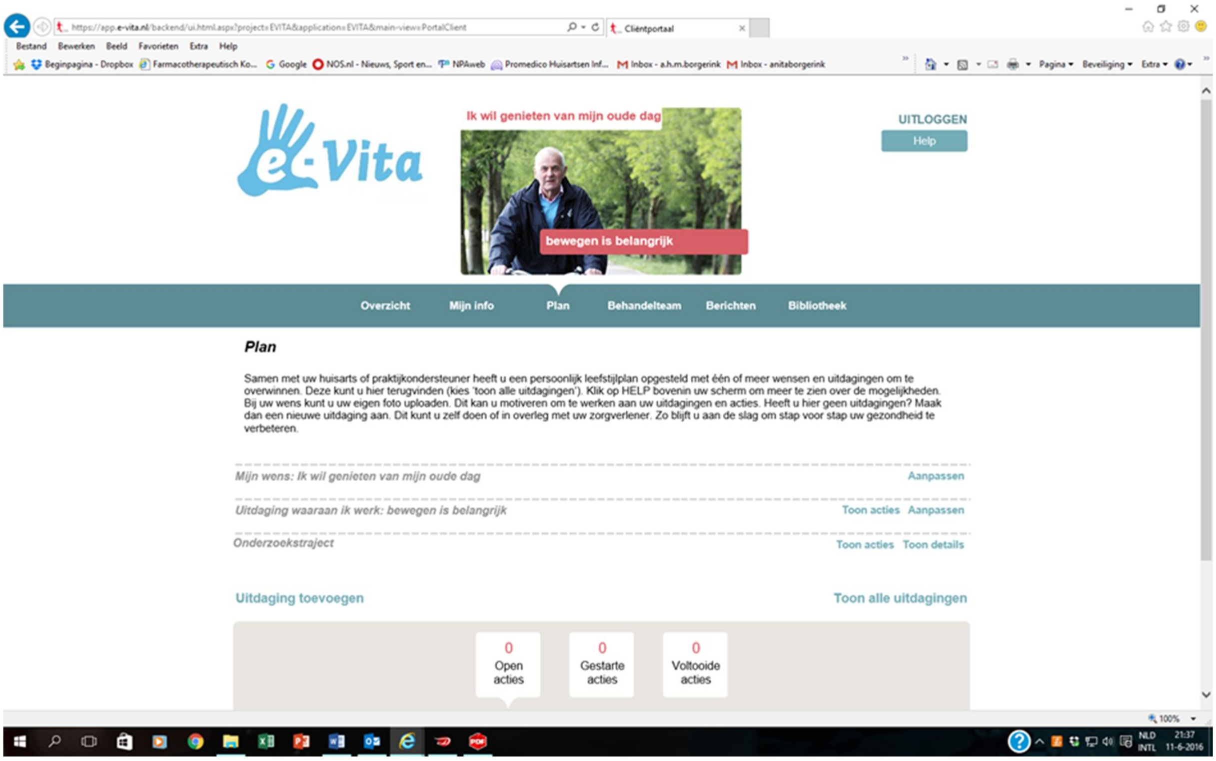
Metingen

Vragenlijst CCQ (maat voor uw klachten)

De CCQ vragenlijst is een korte vragenlijst over uw klachten bij COPD.

Figure 6: screenshot personal file e-Vita

With the interactive healthcare platform e-Vita, people with chronic illnesses can actively cope with their conditions, so they get a more pleasant life. The e-Vita COPD platform supports COPD patients with working on their personal learning goals (see Figure 7), which they have established during consultation with their health care providers.



Plan

Samen met uw huisarts of praktijkondersteuner heeft u een persoonlijk leefstijlplan opgesteld met één of meer wensen en uitdagingen om te overwinnen. Deze kunt u hier terugvinden (kies 'toon alle uitdagingen'). Klik op HELP bovenin uw scherm om meer te zien over de mogelijkheden. Bij uw wens kunt u uw eigen foto uploaden. Dit kan u motiveren om te werken aan uw uitdagingen en acties. Heeft u hier geen uitdagingen? Maak dan een nieuwe uitdaging aan. Dit kunt u zelf doen of in overleg met uw zorgverlener. Zo blijft u aan de slag om stap voor stap uw gezondheid te verbeteren.

Mijn wens: Ik wil genieten van mijn oude dag

Uitdaging waaraan ik werk: bewegen is belangrijk

Onderzoekstraject

Figure 7: screenshot health plan patient

Furthermore, e-Vita offers the patient the possibility to work with targeted education and (links to) online support programs and local initiatives. In addition, the patient has access to their own test results to monitor their symptoms' progress (including the CCQ test: a short health questionnaire for patients with COPD, pulmonary emphysema or chronic bronchitis, the purpose which is the periodic measurement of the state of health of patients with symptoms due to these diseases). There is a special module incorporated for exacerbation. The patient can give their nurse practitioner information about the progress of their learning goals and their symptoms' progression. Through the portal, the health care provider can also make ready the CCQ in preparation for the next consultation. The patient is actively addressed about their own responsibilities, and the health care provider is prepared. e-Vita provides the opportunity for communication between patient and health care provider. The goal of this COPD e-Vita study is to explore and how the PHR can affect the quality of life, self-care, hospitalization, and survival of people who suffer from COPD. Eight general practices in the Netherlands participated in this research pilot for COPD e-Vita.

1.6 Summary and research question

COPD is a high frequency chronic respiratory disease. eHealth can play an important role in the treatment and self-management training of patients. e-Vita has developed a system that combines a PHR and optimal health care for the patient. PHRs primarily focus on COPD-patients, but the use of PHRs also have a great effect on the work of health care professionals and the work processes in health care. The successful use of a PHR is only partially due to the patient. The role of the health care provider in implementing PHRs is also very important. Therefore, the following research question was developed to identify the perceptions and experiences of COPD nurse practitioners and COPD patients alike, regarding the use and implementation of e-Vita in practices:

“What are the perceptions and experiences of health care providers on the implementation and use of PHR e-Vita COPD in different practices in the Netherlands?”

Sub questions:

- How have COPD nurse practitioners embedded the PHR e-Vita in their daily care routines?
- What were the perceived and expected barriers and facilitators while embedding the PHR e-Vita in daily care routines, according to COPD nurse practitioners?
- What are the nurse practitioners’ experiences using PHR e-Vita in the care process?
- What are the expectations of COPD nurse practitioners and patients regarding the use of technology for the support of self-management in future?

2 Methods

2.1 Design

In order to answer the research questions, a qualitative study was conducted with semi-structured in-depth interviews with COPD nurse practitioners at the participating practices. To answer the research question about the expectations of patients regarding the use of technology for the support of self-management in the future, COPD patients from general practices, who are not participating in e-Vita, were interviewed (also with semi-structured in-depth interviews).

2.2 Participants

Eight different practices in the Netherlands, all affiliated with e-Vita, were approached to participate in the interview study. It was decided upon to conduct the interviews with COPD nurse practitioners because of their direct involvement in the treatment of COPD patients and the e-Vita project. They provide information to patients about their disease, the possible need to change their lifestyle and habits, and they are involved in spirometry and the control of medication. COPD nurse practitioners are the first point of contact for patients when questions arise. In addition, COPD nurse practitioners have access to the electronic patient record and are closely connected with the other health care providers.

An e-mail was sent to the nurse practitioners with an explanation of the research, the purpose and topics of the interview, and the rights of the participants, and asking whether they wanted to participate in the research. The e-mail was sent about two weeks before the interviews took place (Appendix 1, in Dutch).

Interviews with five COPD patients from general practices were also conducted, because of the fact they are also users who will eventually have to work with PHRs and have expectations regarding the use of PHRs in the future. The patients were invited to participate in the interview study by their nurse practitioners. After one week the participants received a telephone call and they were asked if they had questions about the research, the purpose and topics of the interview, or the rights of the participants, and asked whether they wanted to participate in the research.

In the construction of both interviews, schedule topics were taken from the literature and the practical experiences of other researchers concerning the project e-Vita.

2.3 Procedure

The interview schedule for the nurse practitioners was sent before the interview took place, so that they could prepare to answer the questions. On the agreed date, the participants were called for a telephone interview or were visited by the researcher. Telephone calls was made in a quiet room with no distractions for either researcher and participant, and interviews took place in a consulting room in the practice. Preceding the interviews the participant was informed of the purpose of the study and their right at any time to stop participating. It was explained that the information from the interview would only be used for the purposes of research and that confidentiality is guaranteed. After giving informed consent (Appendix 2, in Dutch), the participants were asked if they agreed. Then the interview began, in which the interview schedule was used. An audio recording was made of each interview. The interview lasted on average 60 minutes. The same procedure was followed for the patients. These interviews lasted on average 20 minutes. The study protocol was submitted to the Ethics Committee (EC) of the Faculty of Behavioral Sciences of the University of Twente and assessed as non-complicit according to the Law of Medical Research (in Dutch: Wet Medisch-wetenschappelijk Onderzoek).

2.4 Material

The interviews were semi-structured based on an interview schedule. The interview schedule (Appendix 3, in Dutch) for the nurse practitioners consisted of five parts. Questions were asked regarding the following themes: general tasks of COPD nurse practitioners, the introduction of e-Vita within the practice, the value of e-Vita in the treatment of COPD patients, (dis)advantages of the use and deployment of e-Vita, and the future of health care given the emergence of new technologies such as e-Vita. The interview schedule (Appendix 4, in Dutch) for the COPD-patient consisted of four parts. Questions were asked regarding the following themes: general data, support and guidance in their disease, online activities, and the future of health care given the emergence of new technologies such as an online health platform.

The interview schedule consisted mainly of open questions, after each of which the interviewer often requested more information or an explanation. In order to obtain as much information as possible, the interviewer used verbal encouragement ("hm", "yes") and continued to ask about the answers to the open questions ("can you tell a bit more about that?", "how do you mean that?", "can you give an example of that?") (Baarda et al., 2013). In addition, general information was asked for, namely working experience, and the number of colleagues and COPD patients in treatment.

2.5 Data-analysis

The audio recordings of the interviews are anonymously transcribed verbatim. The interview transcripts were analyzed by one coder. At first, each relevant quote was attributed to a variable. Subsequently, per variable inductive analysis was applied to search for categories and themes, until no new codes were found (Baarda et al., 2013). After that, all of the transcripts were read through completely again to make sure all the information therein was used, and determine whether the categories were a good representation of the information that the participants had given. Unclear quotes were discussed with an external second coder until consensus was reached.

3 Results

3.1 Description of participants

In total, eight different COPD nurse practitioners participated in the interviews, all female. All of the nurse practitioners (n=8) have relevant diplomas and have had their refresh courses during the last two years. They have an average of 6.25 years of working experience as a COPD nurse practitioner. In their work, the participants (n=8) use the national guidelines ('NHG-standard') or custom-made protocols based on the national guidelines. Two of the participants work at home care organizations (n=2), six participants work at health care centers with several practices, or in solitary medical practices (n=6). The practices have an average of 120 COPD patients in care, of whom on average nine are included in e-Vita.

Five patients also participated in interviews, one woman (n=1) and four men (n=4). For clarity, the patients are referred to as 'patients' instead of 'participants'. Their average age is 66 years. All patients were diagnosed with COPD between two and 19 years ago. The level of education of the patients is high school or vocational school. The patients all use a computer or tablet nearly every day. They use it to perform various tasks such as e-mail, word processing, banking, and getting information from the internet, including occasionally seeking information about their health or disease.

3.2 Personal Health Record E-Vita

All participants (n=8) were introduced to the PHR e-Vita by their general practitioner or another official in their practice, and heard about e-Vita for the first time between one and a half and two years ago.

3.2.1 Motivation to participate in PHR e-Vita

All participants (n=8) were motivated to take part in e-Vita. Motivation can be divided into extrinsic and intrinsic motivation. Extrinsic motivation refers to behavior that is driven by external rewards, such as money, fame, grades, and praise. This type of motivation originates outside the individual, as opposed to intrinsic motivation, which arises inside the individual. Intrinsic motivation refers to behavior that is driven by internal rewards. In other words, the motivation to engage in a behavior arises from within the individual because it is intrinsically rewarding. This contrasts with extrinsic motivation, which involves engaging in a behavior in order to earn external rewards or avoid punishments (Deci & Ryan, 2002). Table 1 shows an overview of motivations for participating in PHR e-Vita. Eight participants (n=8) showed an intrinsic motivation: they would like to participate in order to improve their professional behavior. Seven participants (n=7) showed extrinsic motivation. The practice in which they work was driven to adopt e-Vita to improve their integrated care process and the benefits for the patient. One participant (n=1) had no idea if there was an extrinsic motivation.

Table 1

Motivation to participate in e-Vita (n=8)

Motivation	**n=**	**Quotation**
Intrinsic	8	I also find it kind of fun to participate in surveys to get another view.
Extrinsic	7	Because they [the practice] got money for it. The insurers say than if you join, doing research, there you can get extra money. If you can show you participate in a survey, then this was of course COPD, but we have a nice group of patients which we can investigate, so we thought that this would deliver us an increase of quality of care too, but it's not just for the money, but if it is offered then it is also fine if it [the PHR] can deliver what's promised.
Unknown	1	No idea.

3.2.2 Training to use PHR e-Vita

All participants (n=8) attended an information meeting and introduction training that was given at each participating practice before the start of the e-Vita project. Table 2a and 2b shows an overview of the positive and negative experiences with the training. Six participants (n=6) were positive about the training and the instruction on the job, and found the content useful in practice. In the instruction on the job they got to know the software and the use of the PHR. Two or three part days of training focused on learning how to motivate patients to participate in e-Vita and get to know the software (n=5). One of the eight participants (n=1) felt secure working with e-Vita after the training and instruction on the job. Most of the participants (n=7) indicated they felt insecure working with e-Vita after training and instruction. Two participants (n=2) mentioned difficulties in use of the software because of the relatively small number of patients that use the PHR. One participant mentioned:

> “I think that also comes because you don't do it every day, there is sometimes a long time between and then you have to look up how does it go again, or ask a colleague how it works again, so it's not something you do every day during work, and then it disappears again into the background.”

Three participants (n=3) were negative about the training and did not feel they had a comprehensive grasp on the software. Two participants (n=2) found the instruction on the job unhelpful.

Table 2a

Training to use PHR e-Vita (n=8)

Positive experiences	n=	Quotation
Personal supportive instruction on the job	6	There was a lot of enthusiasm and then someone came along with us on the practice to view, well this is how it works, so you can login and if you can provide and the patient than the software is more lively. The training was very exciting but somewhat vague because we could not exactly see what was expected of us, but then when she came on the practice personally, that added some.
Inspiring and motivating training	5	The training sessions were very enthusiastic, there were several researchers and anyone who took part in the e-Vita project who gave that training, who were all very inspiring and that motivated you to get started.
Secure working with e-Vita	1	I thought it was not difficult software, you could pretty easily describe the patients in it, and certainly the first time with the book beside you, but it was easy software for that matter.

Table 2b

Training to use PHR e-Vita (n=8)

Negative experiences	n=	Quotation
Insecure working with e-Vita	7	No idea how I had to work so we sat with the manual next to it with the patient, we settled it step by step. So it was and then the patient also had enough of it, no matter how positively you started it, at some point you notice your own frustration.
Vague content of the training	3	I do know that it was vague for everyone then, also for my colleagues, how do we fill it in, how does it work, people who are on such a website and have to login, it was very though to add something. And then that forum was not yet up to date, it was not yet ready, a few things still had to be adjusted, so we could not see it yet, it was still vague what exactly we had to do and what was expected of us.
Insufficient instruction on the job	2	I think that is done remotely, I do not know it, actually that's gone through the ICT Department and someone was here with us to guide us through the program. We received our login codes by mail and she has been here to see if we could cope with it but then the software was also not yet completely launched, that was started in December and we started somewhere in January.

3.2.3 Introduction of patients to PHR e-Vita

Table 3 shows manners of introduction of patients to e-Vita. Half of the participants (n=4) indicated that the introduction of e-Vita to the patients was initiated by themselves. The other half of the participants (n=4) told the introduction was done by employees of e-Vita. Five of the participants (n=5) indicated that selection criteria were based on age (not too old or outmoded), care burden, and care refusal. Two participants (n=2) applied no selection criteria due to the fact that in their opinion a person's willingness to participate does not depend on age or other issues. One participant (n=1) did not know if there were selection criteria applied.

Table 3

Introduction patients to e-Vita (n=8)

Introduction e-Vita	n=	Quotation
Introduction by nurse practitioner	4	We also had a small sheet of information and I discussed that with patients and I tried to get them there, that it was an extra support, that it was not a replacement of my contact with them, because that is sometimes the objection that people may have, but that it is an extra support and that the patients, above all the work of themselves, that they also can give a boost to get the right things to be able to do and thereby dealing with COPD could be better or easier.
Introduction by e-Vita	4	I believe they were called by the employees of e-Vita, what I understood is that they have looked at which patients they had approached by telephone and who had to be motivated by us and then they were called by e-Vita or agreed with it and then we had a consultation time in which they could plan the people. We got an email 'we have found someone' and the patient comes on that day at that time and then they received from e-Vita the package at home. Yes, they were approached by the employees of e-Vita.
Selection criteria applied	5	The GP has looked whether these patients can be accessed and not this one. Old patients, patients with terminal care, patients who refuse care, who in any case refuse care and so on, they were not approached.
Non selection criteria applied	2	Actually I discussed it with everyone because you cannot judge from the outside, one 80-year-old is not the other, so I cannot judge in advance if anyone there will or will not be interested, so I have actually asked everyone who I had contact with.
Unknown if selection criteria were applied	1	I wouldn't know.

3.2.4 Integrating e-Vita in the care process

Table 4 shows which modules of the PHR e-Vita were used by the nurse practitioners. Four participants (n=4) indicated that they use e-Vita in their consultations but four participants (n=4) mentioned the use of e-Vita was minimal. Several modules of the platform were mentioned as used by participants or patients. Half of the participants (n=4) reported that (some of) their patients filled in CCQs or other questionnaires for the purpose of the project e-Vita. Also used was the possibility of filling in patients' own health goals (n=3), which provides the opportunity for the patient to promote self-management. Also, according to the participants (n=2) the patients searched for information on the linked information website and watched movies on the e-Vita platform (n=2). Two participants (n=2) used the email function in e-Vita. Finally, half of the participants (n=4) mentioned they barely use e-Vita because of the fact their patients were not motivated to use it, like this participant:

> "I also called the patient and asked what the reason is, what are the restrictions, well sometimes you get then to be told it had gone badly with them, that they stayed in the hospital for example, it was not on their mind. Others had sometimes just forgotten it or had no time to spend on it."

Table 4

Used modules of e-Vita in care process (n=8)

Modules	n =	Quotation
Use of CCQ / questionnaires	4	My job was to fill in questionnaires for those patients and to provide information to the extent of what I could give and what I knew.
Use of action plan / health goals	3	What we were going to look at with the people now was the weather and they wanted to go cycling, well then make it a goal of that and try to motivate them. Try to fill it in, make the goal not too high, as it should also be feasible and that we are good that way, or smoking, some people wanted to quit smoking, well make this a goal.
Use of library	2	The plan with goals and we have supplemented the library very much by ourselves and there is a movie about inhaler use submitted.
Use of instruction movies	2	Movies of 'Longfonds' with a very nice explanation of inhalation use and respiratory protectors and bronchodilators, which I try to inform the patient via e-Vita.
Use of email	2	But then we got this all of a sudden by e-mail I believe, somehow we were informed.
No modules of e-Vita used	4	They came to me in consultation after half a year, then it was 'oh yeah' I had to do some filling out, actually I have not looked at it yet and then we have here in this office the wishes and challenges filled in, well then they were enthusiastic, but of course if they were at home, as long as they have no symptoms they do not use the PHR.

Table 5 shows the experiences of participants with the integration of e-Vita in care processes, and support while working with e-Vita. Participants (n=6) experienced not much support in their use of e-Vita in daily practice. Participants reported that they often indicated that the project is poorly run, questions were not answered, no mid-term evaluations were planned and there were too few patients to make it successful. In the participants' opinions, they talked with too few patients.

Despite this, two participants (n=2) experienced enough support with e-Vita. They could call or email, and also helped the patient to use e-Vita. Half of the participants (n=4) integrated e-Vita in their consultation. They talked with the patient about their health plan, which was filled in in e-Vita, and/or made the patient aware of the instruction movies.

Table 5

Integration e-Vita in care process (n=8)

	n=	Quotation
No support of integration or (intervening) project-evaluation	6	I don't know if that is the intention or should I do more actively, I heard nothing about it and have not been informed, there is also no really mid-term review with the question how are we doing, what can we improve. No actually, we would get a mid-term review in May, and then you hear there not so much of a hurry, it bleeds a bit to death and then you think how hard should I try with the project if I continue, the patient does not give as much cooperation, I myself do not fully support those movies, I had my doubts.
Supporting the nurse practitioner using e-Vita	2	That was a home visit to speak to another together to see if we still have one colleague, that was pretty much our point of contact within the team, and we could ask questions to the help desk.
Integration of e-Vita in consultation	4	So we have launched an action plan with the participants and we refer for information, also say search in the library and people get CCQs sent regularly anyway, which they then have to fill in and there are also inhalation protocols on there that you refer to.

3.2.5 Perceived barriers and advantages when using e-Vita

After implementation of the PHR e-Vita there were several factors which hindered the progress of the project. Table 6 shows the perceived barriers and advantages. Most of the participants (n=6) mentioned technological shortcomings of the software as a barrier to adequate use of e-Vita. Participants assess the e-Vita platform as slow and unclear. These participants indicated that the helpdesk was not easily accessible and unresponsive to help questions. According to participants, patients did not receive an account or could not use the account. The impossibility of dialogue support and of receiving messages from the platform was mentioned as a disadvantage. Participants indicated that the system did not support the interaction between the user and system, so-called ‘human computer dialogue support’. There was no interaction between participants and patients via digital means or adding a personal note, nor between participants and the e-Vita helpdesk. Participants forgot to look at the e-Vita platform because it was not integrated into their work routines and no e-mail alerts were received. Furthermore, most of the participants (n=6) indicated they did not experience any project support about e-Vita or what to do next in the project.

Also, the participants (n=3) indicated that it is inefficient to use the e-Vita platform because of incompatibility between the e-Vita platform and their other electronic patient records. E-Vita is not integrated with other software, which causes extra work for participants. With the advent of e-Vita, the participants are obligated to work with multiple systems that they perceived as non-practical and labor-intensive. Also the possibility of monitoring a time horizon for only one goal was indicated as a limitation, because the participants or the patients want to adjust the next goal after finishing the first one. Patients could not adjust their successes or share them. Also, the childish instruction movies on e-Vita were mentioned as a restriction. The information on the e-Vita platform was often incomplete, inaccurate or not even registered at all.

Three participants (n=3) had patients in practice who did not use the PHR e-Vita after all. Two participants (n=2) stated they had too few participants so they usually have too little contact with the patients to communicate effectively about e-Vita.

Table 6

Perceived barriers for using e-Vita (n=8)

Perceived barriers	n =	Quotation
Technological shortcomings of software	6	Also last week I happened to be with somebody and there was the password missing and then I can click on the handler's side ‘send new password ' and then comes that usually within 1 or 2 minutes, but there was now nothing at all, then you are to wait and then try one more time, but the email with the new password did not come in and then I stopped after a quarter of an hour. I also see that the program is not beneficial and at best cumbersome, the information is minimal and the potential minimum, the interaction in the program is also minimal.
Insufficient project support from e-Vita	6	I didn’t know very well what was meant, what was especially asked of us, create a profile for the patients and we knew what we had to do with it, we thought e-Vita will do something with it. We had done what we had to do for our sense and that was it, because we heard very little of e-Vita how to go further, do we have to do something with it.
Incompatibility systems	3	We must keep track of two systems, which is time consuming, it is not possible to have a link to another system, with Medicom and e-Vita at the same time, but it was now really and and, that's just time consuming.
Patient does not use e-Vita	3	Maybe that's also my job, maybe I should do what with it, but I don't think so, it all feels a bit of nothing, I don't feel like going looking there each day, but maybe one time per month having a look at what I can still improve and how can I improve. I also told this to the patient and then they are often also excited but in practice they still do not use it.
Few participants, not much contact nurse practitioner – patient	2	So you speak about it with the patient especially during the consultation, but those patients who are so stable, they come like once a year. Yes, once or twice per year, one time for control and one time for Spirometry, one time to two times per year and most come once a year.

Although the e-Vita platform is not used much in daily care routines, some benefits were also mentioned by the participants. Table 7 shows the advantages mentioned. With the e-Vita platform, patients can expand the self-management of their disease (n=6). Also, patients can search for information on the linked information website, and it is possible to maintain their health goals, which provides the opportunity for the patient to increase responsibility, awareness, and promote self-management. Third, and linked to this, participants (n=3) see the advantage that this increased awareness and self-management leads to reduced workloads in practice.

Table 7

Perceived advantages when using e-Vita (n=8)

Perceived advantages when using e-Vita	**n =**	**Quotation**
Facilitating goal setting and providing information	6	Awareness of their own goals and then get on with it in a different way and because they also have to fill in things there, it often works better on paper than when it's just in their head. And it's a way they still can do things independently and read about disease and health. Or watch instruction movies. So this increases their ability to cope with it.
Reduced workload nurse practitioner	3	For the patient it is an advantage because then it gives less exacerbations and the patient is much more aware and that is also much better, so less medication and that sort of thing and to me as health care provider means that I don't have to see them more often than once a year.

3.3 Future of eHealth in health care

3.3.1 E-Health and the position of nurse practitioner

Questions were asked about e-health and its relation to the future role and function of nurse practitioners. Table 8 shows the results. All participants (n=8) mentioned the development of ‘blended care’, where regular face-to-face consultations are combined with interventions such as online chat, video calls, e-consultations, online treatment modules and online access to the personal health record. Next, most of the participants (n=6) indicated that an important role of theirs, which will remain in future, is stimulating self-management with patients so patients can be in control when it comes to their disease. Finally, four participants mentioned coaching patients in the management of their diseases, which is part of their role now and in their opinion will continue to be so in the future, to function as a “sort of threat” (n=4).

Table 8

E-Health and future role and function of nurse practitioner (n=8)

e-Health	n =	Quotation
Blended care, combination of personal contact for general observation patient and mail or e-consult	8	We see the difference already with telemonitoring. Surely this is not the same, to have contact via Facetime for example, the connection is often not quite good, it is difficult to have a good conversation via Skype or Facetime, does matter I think. And face to face just with the patient himself, you see more, you signal more, people are more at ease, they show more of themselves.
Nurse practitioner facilitating disease management and lifestyle using eHealth technologies	6	Though they have the COPD damage now, if the right technology can be a tool for this group of patients and they can with self-management increase awareness and increase a healthy lifestyle, then it will run again easier. It will perhaps not even be 20 years, I think the next 10 years will be spicy yet, because now when I look at the group of 50 and 60 year olds, then there are quite a lot of people who have already stopped smoking too.
Nurse practitioner coaching the patient in disease and health awareness, personal coach	4	Because I always think that personal contact is also important. Sometimes a patient may not be aware of certain things, that maybe he would have to do differently and he will not change it when you only have digital guidance. For example, the can skip the information about the importance of moving, because they think 'I move enough', or think it is not important, so therefore they would perhaps still miss that.

3.3.2 Future developments in health care, perspective nurse practitioner

Finally, questions were asked to participants about the future developments in eHealth related to COPD, seen from the perspective of nurse practitioners. (See Table 9). All participants (n=8) indicated that they expect that their work will more or less change with the advent of health platforms such as e-Vita, or other health technologies.

Self-management will play a more prominent role especially when it comes to lifestyle factors (n=3). Linked to that, a few participants (n=2) indicated they think the need of patients for information about their diseases and health will increase. Patients will become accustomed to looking up lots of information about their diseases stored in one place. Also, participants (n=2) indicated that due to digital care the possibility or need will arise for interaction between participants and patients via digital means or, adding a personal note, using webcams to check someone's health condition instead of a personal consult. Finally, one participant mentioned the (further) development of integrated care supported by compatible eHealth technologies (n=1).

Table 9

Future developments in eHealth related to COPD chronic care (n=8)

Future development	n =	Quotation
Stimulating self-management prominent role	3	Increase focus on self-management, but not that the care is very different in practice, what you can see is that you're no longer so much looking at the statistics and to results, but to how the patient feels.
Patients wants more information about disease and health	2	Well I think people nowadays go look up, they are much more at home with the GP or practice nurse and then they get at the information and then they go right home look up what do I have exactly, what does COPD or asthma means, what can I do with it, yes what does it mean. So I guess we already can take advantage of this and it really adds something. Yes, apart from what sort of forum, if you just introduce some more patients and can create and offer new information, yes I think this could improve the care.
Prominent role for digital care in treatment because of travel time and finances health care	2	Guidance by distance, that is really the future. I now go to the customer's home, I have my travel time, I am an hour away and I have again the next appointment. I have a very large work area, so I have very much time to travel. I think we will have more distance care and then to support this a program like e-Vita, that is the future, even though I would find that very regrettable, but I do think that is the future, because what we do is actually not affordable in the long term, I think.
Integrated care supported by compatible eHealth systems	1	At the moment we are working with the clinical pathway COPD. For the patient it is important that all the health care providers and anyone around him, that they cooperate with each other. That is also about communication between themselves and reporting about care. What you in practice always encounter is that we all have different systems, so you can now not enter other systems.

3.3.3 PHR and the patient in future, perspective patient

No patient (n=5) had expectations about an online health platform. They never really thought about having a Patient Health Record and think they will not need one in future, like this patient:

> “No, if I have something I go to the doctor or the nurse practitioner or I go to the hospital, I can find my way very well.”

Although all patients (n=5) think technology will play a greater role in health care in future, they were not able to describe what shape it would take. The question also remains who has to pay for eHealth interventions, the health care provider, the government or the patient:

> “I'm afraid that if it at some point is going to be too technical, that it just again will be blocked by our ministers, etc., that they would not pay for it. That is a possibility. Because there are more of those things, they invent everything in the medical field, of course, but that is at one point blocked again because it is just too expensive. Then why they invented it in the first place, I think.”

Table 10 shows their opinion about the importance of personal contact in health care. Patients all (n=5) have the opinion that despite developments in eHealth technology and the use of e-mail, Facetime, and so on, personal contact between nurse practitioner and patient stays very important. Two participants (n=2), however, added to this that it can be useful occasionally to send a mail also, in the case the patient still has questions after a consultation.

Table 10

Personal contact between nurse practitioner and patient (n=5)

Personal contact between nurse practitioner and patient	**n =**	**Quotation**
Personal contact may be less but particularly medically important	5	There are things that you can ask through the mail, which I find that I also need to be able to, but personal contact is very important. The health care provider should also be able to see me and assess me.
Online contact can be useful as a supplement	2	It is also easy if you ask a question by mail between consultations occasionally. Yes, then you do not claim the time of the healthcare provider.

4 Discussion

The goal of this study was to identify the perceptions and experiences of COPD nurse practitioners from eight different general practices in primary care in the Netherlands regarding the implementation and use of the PHR e-Vita for patients with COPD. Alongside this was the goal of identifying the expectations of both COPD nurse practitioners and COPD patients regarding the use of eHealth and/or PHRs in the future.

4.1 Implementation and use of PHR e-Vita

The nurse practitioners indicated they received a training before e-Vita was implemented in their clinics, during which attention was paid to motivating patients to use PHR e-Vita, but nevertheless felt insecure working with e-Vita. Linked to this, most of the nurse practitioners indicated that they experienced usability problems while using the e-Vita platform. No differences in working context and amount of included patients were found. The nurse practitioners experienced login problems, the use of the software was difficult, and the content unsatisfactory, which influenced its use and adoption. These findings are supported by Van Gemert-Pijnen et al. (2011) who state that many eHealth technologies are not successful in realizing workable innovations in health care practices. One of the reasons for this is that the development of eHealth technology often neglects the required close cooperation of technology and human characteristics. Also when nurse practitioners used the e-Vita platform, the information that the patients were supposed to provide the platform was lacking. Consequently, the nurse practitioners perceived the relevance (Nazi, 2013) and added value (Cain & Mittman, 2002) of using e-Vita as low.

Results showed that incompatibility plays an important role in the adoption of the PHR e-Vita. The lack of integration between e-Vita and other systems, and the fact that using e-Vita took too much time during a consultation were seen as major barriers to its use. In a review study by Archer et al. (2011) it was also found that PHRs and electronic medical record systems (EMRs) should be linked for the successful use of PHRs. When adopting a new technology, it is important that existing technologies cluster with the innovation (Gee et al., 2015). Using new technologies can lead to frustrations and also appears to be time consuming (Van Gemert-Pijnen et al., 2011). Furthermore, results showed that the nurse practitioners did not receive much support when using e-Vita and did not experience much involvement in the project. According to Van Gemert-Pijnen et al. (2011) when introducing eHealth technologies into the health care system, successful implementation requires precise coordination and communication among health care professionals and patients.

The aforementioned obstacles can be reduced through the process of development, implementation, and diffusion of e-Vita. The majority of the problems show that end-users (nurse practitioners and patients) were minimally involved. Most of the modules are not used, or only half-used, and are used by only half of the end-users. Therefore, when developing and implementing eHealth technology in the future there is an absolute need for human-centered design of the software. According to Van Gemert-Pijnen et al. (2011), different stakeholders (health care professionals, technology providers, financiers, and patients) should be consulted in the design, development, implementation and evaluation. This is to ensure that the system meets the needs and desires of users, and that most of the arising problems are detected, and hopefully addressed, at early stage.

The results also indicated that the diffusion of the PHR e-Vita is rather low. Only barely half of the participants have used e-Vita in practice, the other half not at all. The factor that influenced this diffusion, from the view of the participants, was that there was no support for integrating the system into daily practice, nor ongoing project evaluations to keep the project going. Consequently, the awareness of the possible value of e-Vita is low and this reduces its diffusion. Archer et al. (2011) also found that adoption issues among health care providers include new workflow demands and inadequate technology literacy, which can reduce its diffusion and later use. To increase the diffusion of PHRs in the future, it is therefore useful to guide health care providers in integrating the system into their daily routines. This is possible by developing new working procedures to integrate the use of PHRs in consultation. Furthermore, it could be useful to engage a sort of super user, who are colleague nurse practitioners who already effectively use the PHR in daily practice and who have a lot of knowledge of the system and the integration of a PHR in care. These super users are easily approachable and observability will increase, whereby the diffusion of this innovation would be more likely to be successful (Nazi, 2013, Sieverink et. al, 2014).

4.2 Future of PHR in health care

The perceived barriers mentioned affected the implementation and use of e-Vita. Subsequently, challenges arise from this research that must be taken into account in future research.

First, the PHR e-Vita is an eHealth application. The objective of e-Vita is to help people to manage their diseases and increase self-management by patients. Successful self-management includes the capacity of the patient to monitor their condition and to effect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life. Through reading information on websites, the patient can increase his knowledge but the health care provider does not know if the patient really reads the information or understands it. This lack of interaction is an example of e-Vita failing to use persuasive elements to encourage or motivate the use of the PHR. The comments which nurse practitioners gave about this were classified by the PSD model (Oinas-Kukkonen & Harjumaa, 2009). The most comments were given about primary task support (such as the possibility of monitoring and clear layout or structure) and dialogue support (such as getting reminders and compliments, for example smileys). This enables stimulating elements that can promote the use of e-Vita. Also, embedding peer support, such as social networks, and group participation, may be important for changing patient behavior (Kahn, Aulakh & Bosworth, 2009). Embedding new features in the e-Vita system, such as the aforementioned interaction with the system and the ability to contact the health care provider and peers over the internet, should stimulate the self-management of patients. Future research should investigate whether these features in e-Vita actually lead to increased self-management.

Another point of interest is that nurse practitioners and patients both claimed that, even with the advent of e-Vita, a need for blended care still exists. Both see regular face-to-face consultations as very important because of the personal contact between patient and health care provider for general and medical observation. Signals are easier to be seen and the relationship is judged as more personal by the patient. This implies that the system e-Vita alone is not able to provide suitable quality chronic care, and does not seem to work for the health care provider or to the benefit of their patients. As a result, the PHR e-Vita faced adoption problems. Participants indicated the lack of interaction in e-Vita between health care provider and patient, and no persuasiveness in the system. In order to complement the system with the most effective features, elements from the PSD-model, for example, could be used (Oinas-Kukkonen & Harjumaa, 2009). Nevertheless, research is needed to determine how patients adopt technology, when are they motivated to take part in a PHR and to continue using a PHR. In the future, patients' perspectives about the PHR e-Vita must be taken into account as well.

Next to that, the interviewed patients indicated there is not so much need for a PHR which supports self-management. These patients now use the support of health care providers in monitoring their condition and they find this sufficient. The reason for having no need for a PHR is maybe that the group of interviewed patients have been familiar with a chronic condition for several years. This fact is reflected in the research of Nadarajah et al. (2011) in which the users who were most active were patients who had been familiar with diabetes for several years and were well regulated. The less motivated and relatively less healthy patients can benefit more from a PHR such as e-Vita, because they have a larger care need and demand than patients who already are well regulated and relatively healthy. Further research should focus on which type of COPD patient a PHR has the most impact on and therefore is the most effective for.

4.2.1 Limitations of this research

A positive point of this study is that it opted for qualitative research with an interview instead of quantitative research, such as a questionnaire. Because the largest part of the interview were open questions, it could collect richer information than a questionnaire could with associated response scales. This has the positive outcome that individual objectives, expectations and experiences in relation to the participants, both nurse practitioners and patients, could be identified.

The research also has some limitations. The sample of eight nurse practitioners and five COPD patients is small and therefore may not be representative for all nurse practitioners who participated in e-Vita and COPD patients; this thus limits the generalizability of these results. As a result, there is insufficient representation of the factors that make up the population of nurse practitioners and patients from the care programs that actually exist. For a more comprehensive impression of the experiences and goals it would have been valuable to get a larger sample. However, given the relatively small number of available participants, since the PHR e-Vita was a pilot-project, this was not possible.

In addition, during the current research only one coder has been active in analyzing the transcripts. As a result, there was no room for discussion about the categories found. There is a chance that an analysis with multiple coders would have other categories as an outcome.

4.3 Future

E-Vita includes aspects which patients need to support them in successful self-management. Patients can learn about their disease and monitor their own health, and it provides opportunities for the improvement of their lifestyle. With this research a first step has been made in examining the usability and persuasiveness of the system, and with that the added value of using e-Vita for the self-management of patients with a chronic condition. The results from this research have shown that more research is needed about adherence among patients who use e-Vita as a support instrument in self-management. It should be examined how e-Vita can be better integrated and implemented in primary care by facilitating more interaction and cooperation between patient and healthcare provider. It is also important to examine which factors influence the (non-)use of a PHR like e-Vita. Therefore, more detailed user profiles (age, educational level, need to belong, internet usage and persuasivity) of intended users within the care programs for COPD disease must be analyzed. But above all, it should first be considered whether an intervention such as a PHR is the most appropriate solution given the target group.

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Appendix A: Invitation interview

29 januari 2016

Geachte heer, mevrouw,

Uw huisartsenpraktijk is een van de deelnemende praktijken aan het e-Vita COPD-onderzoek. Daarmee draagt u bij aan een nieuwe aanpak van zorgverlening voor patiënten met COPD via een zorgplatform.

Het onderzoek
Uw mening is van groot belang bij het optimaliseren van de patiëntzorg, daarom willen we u graag een aantal vragen stellen. Deze vragen maken deel uit van het onderzoek van het Center for eHealth and Wellbeing Research van de Universiteit Twente, dat wordt uitgevoerd in opdracht van de Stichting Zorg Binnen Bereik en in samenwerking met Saltro en Evean.
Deze analyse is al gebeurd voor patiënten met diabetes type 2 en chronisch hartfalen. Door zowel kwalitatieve als kwantitatieve gegevens te verzamelen, willen wij antwoord krijgen op de volgende onderzoeksvragen:

1. Hoe wordt een zorgplatform voor patiënten met COPD op de lange termijn gebruikt door zowel patiënten als zorgverleners?
2. Door wie wordt een zorgplatform voor patiënten met COPD gebruikt?
3. Hoe gebruiksvriendelijk is een zorgplatform voor patiënten met COPD en hoe wordt het door de verschillende gebruikers gewaardeerd?
4. Hoe integreert een zorgplatform met de bestaande zorgpaden voor patiënten met COPD?

Het interview
Om meer inzicht te krijgen in welke factoren van belang zijn voor het gebruik van een zorgplatform binnen de dagelijkse (huisartsen)praktijk, nodigen wij u van harte uit om deel te nemen aan een interviewstudie. Tijdens dit interview komen onder andere de volgende onderwerpen aan bod:

- De introductie van een zorgplatform in uw praktijk
- De waarde van een zorgplatform voor u en uw patiënten
- Wat zijn de voor- en nadelen bij het inzetten van een zorgplatform
- De manier waarop een zorgplatform in de toekomst van belang kan zijn voor de huisartsenzorg voor patiënten met COPD

Wat vragen we van u?
Het doel van dit interview is de factoren in kaart te brengen die van invloed zijn geweest op de implementatie van e-Vita COPD. De resultaten van het interview worden gebruikt voor de verbetering van de inzet en de dienstverlening door e-Vita. Op deze manier kunnen wij e-Vita laten uitgroeien tot een waardevolle ondersteuning van de zorg voor patiënten met diabetes type 2, COPD of chronisch hartfalen. Ook wanneer u weinig gebruik maakt van een zorgplatform zoals e-Vita, is uw mening van groot belang voor ons!

Het interview kost ongeveer een uur van uw tijd. U hoeft zich niet voor te bereiden. Wij komen naar u toe op een moment dat het u uitkomt, bij voorkeur in de maand februari. Tijdens het interview worden geluidsopnames gemaakt. Wij benadrukken dat uw anonimiteit wordt gewaarborgd en dat uw gegevens nooit zonder uw toestemming aan derden wordt verspreid. Ook is uw deelname geheel vrijwillig en kunt u zonder opgaaf van redenen weigeren mee te doen aan het onderzoek. U kunt uw deelname op elk moment afbreken en binnen 24 uur na afronden van het interview aangeven dat uw gegevens niet voor het onderzoek gebruikt worden. Dit blijft ten allen tijde zonder nadelige gevolgen, ook voor uw deelname aan het onderzoek van Saltro of Evean. Als dank ontvangt u een cadeaubon van 50 euro voor uw medewerking, of kunt u er voor kiezen om dit bedrag door ons te laten schenken aan een door u gekozen goed doel.

Vragen over het onderzoek of interview
Wanneer u vragen heeft over het hierboven omschreven onderzoek van de Universiteit Twente, of wanneer u zelf alvast een afspraak wilt maken voor een interview, kunt u contact opnemen met een van de onderzoekers van de Universiteit Twente, Anita Borgerink, a.h.m.borgerink@student.utwente.nl, tel: 06-53428896.

Voor eventuele klachten over dit onderzoek kunt u zich wenden tot de secretaris van de Commissie Ethiek van de faculteit Gedragswetenschappen van de Universiteit Twente, mevrouw drs. J. Rademaker (telefoon: 053–4894059, j.rademaker@utwente.nl, Postbus 217, 7500 AE Enschede).

Binnenkort nemen wij telefonisch contact met u op over dit onderzoek. Wij hopen van harte op uw medewerking!

Met vriendelijke groet, mede namens de projectorganisatie e-Vita,

Anita Borgerink
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Floor Sieverink Msc
Prof.Dr. Lisette van Gemert-Pijnen
Center for eHealth and Wellbeing Research, Universiteit Twente

Appendix B: Informed consent

Toestemmingsverklaringformulier (informed consent)

Titel onderzoek: e-Vita COPD-onderzoek

Verantwoordelijke onderzoeker: Dr. L.M.A. Braakman-Jansen, Universiteit Twente

In te vullen door de deelnemer

Ik verklaar op een voor mij duidelijke wijze te zijn ingelicht over de aard, methode, doel en de risico's en belasting van het onderzoek. Ik weet dat de gegevens en resultaten van het onderzoek alleen anoniem en vertrouwelijk aan derden bekend gemaakt zullen worden. Mijn vragen zijn naar tevredenheid beantwoord.

Ik begrijp dat film-, foto, en videomateriaal of bewerking daarvan uitsluitend voor analyse en/of wetenschappelijke presentaties zal worden gebruikt.

Ik stem geheel vrijwillig in met deelname aan dit onderzoek. Ik behoud me daarbij het recht voor om op elk moment zonder opgaaf van redenen mijn deelname aan dit onderzoek te beëindigen.

Naam deelnemer: …………………………………………………………………………..

Datum: …………… Handtekening deelnemer: …...………………………………….

In te vullen door de uitvoerende onderzoeker

Ik heb een mondelinge en schriftelijke toelichting gegeven op het onderzoek. Ik zal resterende vragen over het onderzoek naar vermogen beantwoorden. De deelnemer zal van een eventuele voortijdige beëindiging van deelname aan dit onderzoek geen nadelige gevolgen ondervinden.

Naam onderzoeker: Anita Borgerink

Datum: …………… Handtekening onderzoeker: ...………………………………….

Appendix C: Interview schedule nurse practitioner

Algemeen

1. Hoe lang werkt u als praktijkondersteuner COPD/Astma?
2. Hoeveel medewerkers zijn er binnen deze praktijk?
3. Welke nascholing heeft u de afgelopen twee jaren gevolgd?
4. Hoeveel COPD-patiënten zijn er onder controle in deze praktijk?
   a. Hoeveel COPD-patiënten zijn geïncludeerd in het e-Vita project?
   b. Hoeveel geïncludeerde COPD-patiënten ziet u per week?
5. Welke protocollen worden er gebruikt?

E-Vita

6. Hoe hoorde u voor de eerste keer over e-Vita?
   a. Van wie hoorde u de eerste keer over e-Vita?
   b. Op welke manier?
   c. Hoe lang geleden was dat?
7. Waarom doet uw praktijk mee aan het onderzoek naar e-Vita?
   a. Weet u wat de motivatie "van uw praktijk" was om een online gezondheidsplatform in te zetten voor COPD-patiënten?
   b. Wat is uw persoonlijke motivatie als professional om gebruik te maken van een online gezondheidsplatform als e-Vita?
8. Kunt u iets vertellen over de training die u of uw collega's hebben gevolgd (of gaan volgen) rond het gebruik van e-Vita?
   a. Wat is er besproken?
   b. Op welke manier is de training gedaan? Door middel van een bijeenkomst / online / 1 op 1? Door wie werd u getraind?
   c. Hoeveel tijd nam de training in beslag? Hoe vaak bent u getraind? Waar vond die training plaats?
   d. Kon u na de training aan de slag met e-Vita?
9. Op welke manier introduceert u e-Vita platform bij uw patiënten?
   a. (Hoe) maakt u een selectie van mogelijke participanten?
   b. (Hoe) spoort u ze aan om e-Vita te gaan en blijven gebruiken?

Gebruik en implementatie

10. Hoe gebruikt u e-Vita bij de controles voor patiënten met COPD?
    a. Welke onderdelen van e-Vita gebruikt u binnen de behandeling?
    b. Op welk moment in de behandeling?
    c. Hoe lang bent u daar dan mee bezig?
    d. Wat zijn hierbij uw taken en verantwoordelijkheden?
    e. Wat zijn de taken en verantwoordelijkheden van de patiënt?
    f. Hoe begeleidt u patiënten bij het gebruik van e-Vita, als ze bijvoorbeeld tegen moeilijkheden aanlopen?
    g. Hoe wordt u zelf begeleidt bij vragen of problemen die problemen opleveren voor de behandeling?
11. Wat zijn volgens u de voordelen van e-Vita ten opzichte van bestaande traditionele zorg?
    a. Welke onderdelen van e-Vita zorgen voor dit voordeel?
    b. Voor wie is het een voordeel? Bestaat er ook een voordeel voor de zorgverlener (voor u dus)?
    c. Wat zijn volgens u de nadelen van e-Vita?
12. Wat ging goed bij het implementeren van e-Vita binnen uw praktijk?
13. Wat ging minder goed bij het implementeren van e-Vita binnen uw praktijk?
14. Het doel van e-Vita is om patiënten beter om te leren gaan met hun aandoening. Sluit e-Vita volgens u aan bij dit doel?
15. Sluit e-Vita aan bij uw eigen wensen en behoeften als praktijkondersteuner?
    a. Welke onderdelen mist u nog bij e-Vita?

Toekomstige ontwikkelingen

16. Hoe verandert de zorg voor COPD patiënten in de toekomst, denkt u?
17. Hoe denkt u dat technologie en zelfmanagement daar een rol in spelen?
18. Blijft face-to-face contact met de patiënt belangrijk?
19. Wat betekent dat voor uw rol als zorgverlener?

Afsluiting

20. Zijn er gebeurtenissen of onderwerpen die wij nog niet hebben besproken, maar die volgens u wel belangrijk zijn?

Appendix D: Interview schedule patient

Algemeen

Ik wil graag beginnen met het stellen van wat algemene vragen aan u.

1. *Geslacht: m / v*
2. Hoe oud bent u: ____
3. Wat is uw opleidingsniveau: *LBO / MBO / HBO / Univ*.
4. Hoe lang geleden kreeg u de diagnose COPD? ____ *jaar*
5. Woont u alleen of met anderen: *met/zonder partner; met/zonder kinderen*
6. Werk/ pensioen/ uitkering?

Ondersteuning en begeleiding

7. Hoe ziet uw dagelijks leven met COPD eruit?
8. Welke beperkingen ervaart u door uw ziekte?
9. Als u kijkt naar de beperkingen nu en drie jaar geleden, zit daar verschil tussen?
10. Wat doet u als uw klachten verergeren?
11. Kunt u meer vertellen over de begeleiding die u krijgt in het kader van uw ziekte? *(directe patiëntenzorg, educatie van de patiënt, inhalatiecontrole- en uitleg, het onderzoeken van de longfunctie d.m.v. spirometrie, voorlichting geven, zelfmanagement aanleren)*
12. Hoe vaak heeft u contact met de COPD verpleegkundige? ______*x per jaar*
13. Hoe vaak heeft u contact met een arts (of andere functionaris)? _______ *x per jaar*
14. Wat vindt u goed aan de begeleiding? (*per functionaris*)
15. Wat kan beter of mist u in de begeleiding? (*per functionaris*)
16. Wie vraagt u om hulp als u een vraag of probleem hebt in verband met uw gezondheid of ziekte? *(ook mogelijkheden als sociaal netwerk, patiëntenvereniging, forum, internetsites,……)*

Online activiteiten

17. Gebruikt u wel eens een computer of tablet?
    Hoeveel uur per week? Waarvoor? Privé/werk?
18. Gebruikt u wel eens een computer of tablet voor zaken die met uw gezondheid of ziekte te maken hebben?

a) Zo nee, waarom niet?

b) Zo ja, waar voor?

19. Weet u waar u online informatie en advies kunt krijgen over uw gezondheid of ziekte? *(bv. Mijngezondheidsplatform; Longfonds; LongAlliantieNederland, zorgverzekeraar)*

Toekomstige ontwikkelingen

20. Hoe verandert de zorg voor COPD patiënten in de toekomst, denkt u?

    a. Wat vindt u van een online health platform?

    Bijvoorbeeld website met alles over COPD, behandeling van COPD, leven met COPD, uw eigen EPD met medische informatie, een forum etc. maar ook: vragen stellen aan de zorgverlener, zelf gegevens bijhouden, online recepten aanvragen etc.

21. Hoe denkt u dat technologie en zelfmanagement daar een rol in spelen?

22. Blijft persoonlijk contact tussen u als patiënt en de zorgverlener belangrijk?

    a. Zou u minder vaak persoonlijk contact hebben als er een online mogelijkheid zou zijn?

    b. Wat betekent dat voor de rol van zorgverlener?

    c. Wat betekent dat voor de rol van u als patiënt?

23. Wie moet een platform aanbieden/financieren? *Zorgverzekeraar, overheid,….*

Afsluiting

24. Zijn er gebeurtenissen of onderwerpen die wij nog niet hebben besproken, maar die volgens u wel belangrijk zijn?