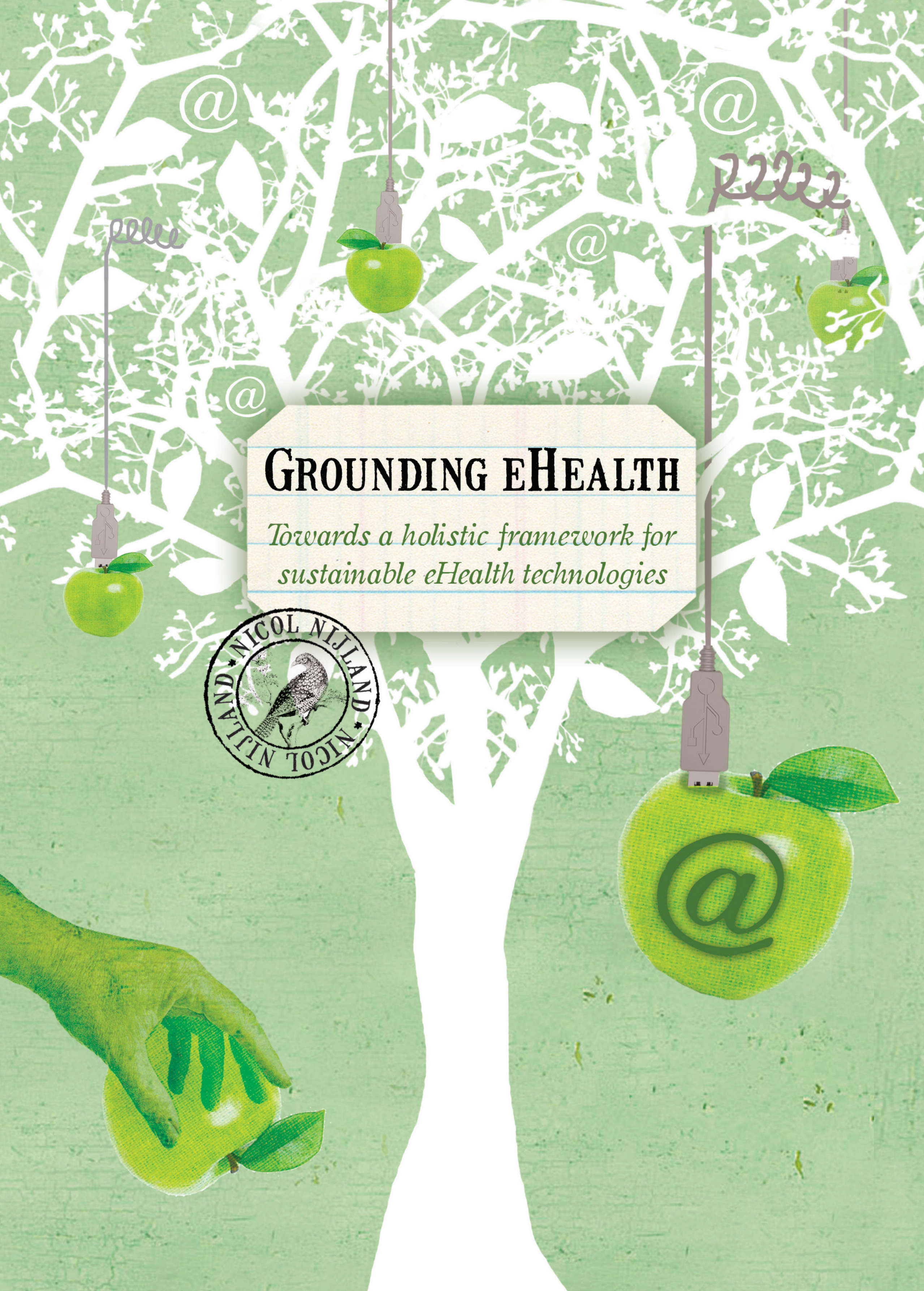

GROUNDING eHEALTH

Towards a holistic framework for sustainable eHealth technologies

NICOL NIJLAND

GROUNDING EHEALTH

TOWARDS A HOLISTIC FRAMEWORK FOR SUSTAINABLE EHEALTH TECHNOLOGIES

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PROEFSCHRIFT

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One of the cardinal characteristics of science is its cumulative character; the value of any single study is derived as much from how it fits with and expands on previous work as from the study's intrinsic properties. Although it is true that some studies receive more attention than others, this is typically because the pieces of the puzzle they solve (or the puzzles they introduce) are extremely important, not because the studies are solutions in and of themselves.

Cooper 1989, p.11

Cooper HM. Integrating research. A guide for literature reviews (2nd ed.). Newbury Park , CA: Sage Publications; 1989.

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Dankwoord (Acknowledgements in Dutch)

Chapter 1

Introduction

eHealth. A matter of facts

Your health comes first. This motto captures the essence of healthcare; providing care that is respective of and responsive to individual patient needs. The fact is that you will not be able to take this for granted in the future, and here are the reasons why.

> *The world's population is aging; the shift in the age structure of the world's population poses challenges to society, businesses, healthcare providers and policymakers to meet the needs of aging individuals.*

Population aging and its global implications have received considerable attention in industrialized countries, and awareness is growing in the rest of the world. The number of people worldwide aged 65 and older is estimated at 506 million as of mid-2008. By 2040, that number will hit 1.3 billion. So in 32 years, the proportion of older people will double to 14 percent of the total world population [1,2]. Moreover, the number of the world's "oldest old" (people aged 80 and over) is growing more rapidly than the older (65 and over) population as a whole. Improved health, increased access to health education, economic growth, and advances in medical science have all led to increased life expectancy. Long life is a sign of good health. In fact, the aging of the world's population, in both developing and developed countries, is an indicator of improving global health. Yet, this positive trend also brings its own special health challenges for the 21st century.

With the aging population comes an increase in the incidence and prevalence of age-related illnesses and chronic disease conditions, such as heart disease, diabetes, asthma, and co-morbidity [3,4]. As a result, it is expected that the total need for care will increase significantly in the coming years. Concomitant with the growing need for care is the limited growth of employment in healthcare, which exerts pressure on the healthcare system. Over the next 50 years, the number of elderly persons will continue to rise and the number of people of working age will decrease; the number of retiring workers each year will eventually exceed the number of new workers entering the labor market. This will increase pressure on the labor market for healthcare providers, for it will not be possible for the available healthcare personnel to keep up with the growing demand for healthcare services [5]. These prospects are predicted as the dominant forces that will drive healthcare in the future; a future in which we will be looking for ways to keep high quality healthcare accessible and affordable [6,7]. One of the ways in which the problems outlined above could be tackled is by deploying technology that would stimulate self-care, ease the burden on traditional healthcare and bring about innovation.

*More challenging types of healthcare systems and services are needed;
eHealth - the use of information and communication technology (ICT) to improve health systems performance - could be a promising means.*

Healthcare systems around the world face a significant challenge to create more convenient, effective, and efficient means for providing care and promoting health [6,8-11]. The introduction of the Internet has offered great opportunities to face the future challenges. It is a promising channel for increasing access to care and strengthening self-management skills [11-14] because web-based technology has the reach of a mass-medium, combined with the possibility for interactivity to tailor information specific to the individual [15].

The increased possibilities of supporting health through the use of technology has brought with it the concept of 'eHealth'. To put it briefly, 'eHealth' or 'electronic health' refers to all kinds of information and communication technology used for supporting healthcare and promoting a sense of well-being. The definition of eHealth has a very broad scope, which makes it difficult to define the concept [16]. The broadest, and most frequently quoted definition of eHealth since 2001, was formulated by Eysenbach [17]:

> *"eHealth 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 healthcare locally, regionally, and worldwide by using information and communication technology."*

Within eHealth a broad spectrum of technologies is used. These technologies include: *Internet technologies*, such as informational websites, *interactive health communication applications* (i.e., e-consultation, online communities, online health decision-support programs, tailored online health education programs), *online healthcare portals*, and *electronic health records*. It also includes *mobile health communication programs*, and other advanced technologies such as *virtual reality programs* (i.e., serious gaming to stimulate exercise or 3D-applications for the treatment of anxiety disorders), *home automation (domotics)*; sensor technology for independent living and remote monitoring, and *robotics*; the deployment of robots for assisting people with domestic tasks, or to perform surgery [18].

eHealth offers possibilities to strengthen the healthcare system by keeping high quality healthcare accessible and affordable in the future. eHealth has the potential to increase *access to care* [19] by making healthcare service delivery available at all times, in all places, in many forms and for everyone (equity). It enables patients to receive care whenever they require it and in the format in which they need it. This implies that the healthcare system must be responsive at all times, and access to care should be provided over the Internet, by phone, and by other means in addition to face-to-face visits. eHealth extends the scope of healthcare beyond its conventional boundaries by reducing the constraints on traditional healthcare service delivery. Internet support groups, for example, enable social networking for community guidance on emotional support between (isolated) individuals [20,21], and the threshold for taking up Internet-delivered therapeutic interventions will be very low i.e., in relation to the stigma associated with treatment, patients not having time, and/or not knowing where to go for services [22-24].

eHealth also offers opportunities to increase *efficiency* in healthcare, thereby decreasing *costs* [17]; for example, by avoiding duplicative or unnecessary diagnostic or therapeutic interventions through enhanced communication possibilities between healthcare establishments. As stated in the definition of eHealth above, introducing technology requires a new way of thinking about how to deliver healthcare that is supported by technology. Through technology, patients will have more access to healthcare and can communicate with other patients and caregivers about their symptoms and treatments. This can change the traditional healthcare delivery process; in fact, eHealth can be seen as the catalyst for changing healthcare. This would principally result from redistributing resources and shifting the skills of caregivers from the hospital environment into primary care. Providing more services in primary care, and ultimately in patients' homes, could reduce the overall cost of health services [25]. Teledermatology, for example, could provide opportunities for decreasing physical referrals to the hospital, and with that save costs for the healthcare insurer.

However, the ultimate challenge of eHealth is to encourage patient-centered care; providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions [6]. The use of information and communication technology (ICT) in healthcare opens up new avenues for patient-centered care that enable *evidence-based patient choice* and *empowerment*. Today's healthcare consumers are tired of routinely wasting time and money enduring long waits for appointments, struggling with inconvenient scheduling, and filling out duplicative forms. The new eHealth consumers are searching for *convenience, control and choice* [26-28]. They demand to be in control of their own health, or at least play a major role in it [29-31]. Pyper et al. [32] for example, found that the vast majority of patients would like to have access to their medical records. Making personal electronic records accessible to consumers over the Internet has the potential to improve patients' involvement in their own care, improve the health professional/patient relationship and improve access to healthcare services [32,33]. The switch from a role in which the patient is the passive recipient of healthcare services to an active role in which the patient is informed, has choices, and is involved in the decision-making process brings about structural changes in the traditional ways of healthcare delivery [9]. It encourages a new relationship between the patient and the healthcare professional; one that shifts more towards collaboration and partnership where decisions are made in a shared manner [6,26,28,34]. As such, eHealth offers a great opportunity for ensuring that patient values guide all clinical decisions.

Nowadays, eHealth is gaining ground in healthcare. All over the world eHealth is being increasingly introduced into the healthcare system for reasons of access, especially in the rural areas, and for increasing individual checks and balances [14,30,35-38]. Nevertheless, the ground is still weak. Despite the large number of eHealth projects to date and the positive outcomes of evaluation studies, the actual take-up of eHealth services is lower than expected [39].

The uptake of eHealth faces difficulties; questions remain about how eHealth can be sustainable and bring about measurable impact.

Many projects fail to survive beyond the pilot phase and studies that investigate the effectiveness of eHealth applications most often do not show any long-term effects. In general, three types of difficulties with the uptake of eHealth have emerged:

- *Slow diffusion:* the eHealth technology is not available for, or desired by, everyone (potential users do not have the resources (access), or the need, to use the technology) [15]
- *Low acceptance:* the eHealth technology is not satisfying (early adopters do not satisfy their needs) [7,40-43]
- *Low adherence*, also referred to as non-usage attrition: the eHealth technology is not used persistently (e.g., online therapy is not finished) [13,44]

During the last few years, several frameworks for the development process and a number of evaluation criteria have been introduced to increase the uptake of eHealth. Most frameworks are based on engineering models for the development of information systems (technical design focus). Well-known approaches include the Information Systems Success Model of DeLone and McLean [45,46], the Technology Acceptance Model [47-49], diffusion models and theories [50-53], and Human-Centered Design models [54-56]. These approaches all made great contributions to the usability of eHealth technologies, nevertheless, no single approach has emerged in the literature as being optimally effective in mutually addressing the problems with diffusion (access), acceptance, and adherence.

We believe that the current approaches should complement each other to make sure that the technology not only addresses the users' demands, but also the implementation requirements (infrastructure, resources, skills, and the organization of care). To achieve this, we advocate a holistic framework that addresses both the human factors (needs and requirements) and organizational factors (resources, and the organization of care) that are important for the adoption and implementation of eHealth technologies in daily practice.

Aim and scope of this thesis

This thesis first presents an explorative investigation into the factors that are critical for the development of sustainable eHealth technologies. Second, we synthesized the factors into a new holistic framework for the development of sustainable eHealth technologies.

The overall research questions of this thesis are:

(1) What factors hinder or foster the take-up of eHealth technologies? and

(2) What are the implications for design, implementation and evaluation?

To answer these questions, we evaluated eHealth technologies that were already developed and are currently in use. At the time of research no framework existed that could be used as a guide for our study. We therefore used the main principles for technology; that is, Human-Centered Design [54,55,57], and principles for implementing technology in healthcare, based on Rogers' diffusion theory [51,52].

We performed a variety of empirical case studies to investigate the factors underlying each of the problems encountered during the take-up of eHealth (slow diffusion, low acceptance, and low adherence). To this end, we evaluated various interactive health communication applications (IHCA) in primary care. These eHealth applications were at the time of research promising technologies, but the uptake of IHCAs in primary care faced difficulties. IHCAs were especially promising because of the opportunity they presented to facilitate healthcare processes such as the exchange of health information between patients and professionals via secure e-mail communication (e-consultation), for promoting positive health behaviors such as self-care [18], and also for efficiency improvements e.g., by replacing traditional healthcare with self-care support systems such as web-based triage. In our studies, we addressed both the quality of the technology (medium attributes), and the quality of healthcare delivery (the communication process) via technology. Moreover, we explored contextual factors that could have hindered the uptake of IHCAs. Indeed, IHCAs bring about substantial changes in the organization of healthcare; they require the healthcare professional to adapt to new ways of providing care which could create barriers to use such as increased workload or inconvenience because of the incompatibility of the new eHealth technology with existing technology. The study results serve as lessons learned and implications for (re)design; the input of a new framework.

Empirical case studies

Chapter 2: Factors influencing the diffusion of eHealth technologies

Chapter 2 explores the factors that can increase the use of e-consultation among patients with access to Internet but with no e-consultation experience (current non-users, but potential users). An online survey was conducted among non-users in order to assess the barriers they faced against using e-consultation, their demands regarding e-consultation and their motivation to use e-consultation. We investigated the motivating factors for using two types of e-consultation: (a) consulting a GP directly through secured email, and (b) consulting a GP through secured email with the intervention of a web-based triage system. We also identified the socio-demographic and health-related characteristics of non-users in order to find out how these factors affected e-consultation use.

Chapter 3: Factors influencing the acceptance of eHealth technologies

Chapter 3 consists of two supplemental studies. The aim of the first case study (chapter 3.1) was to determine the user-centered criteria for the successful application of various features for self-care, including a self-test, a free-text e-consultation service and a web-based triage system. In an effort to observe the problems that users experienced during use, we conducted scenario-based tests combined with in-depth interviews among 14 caregivers and 14 patients. We focused on the user-friendliness of the applications, the quality of care provided by the applications, and the implementation of the applications in practice.

The second case study (chapter 3.2) elaborates on the findings of the former chapter. The study presented here, takes a closer look at the functioning of web-based triage. Via a retrospective analysis we investigated the type of complaints that were submitted and the kind of advice provided by the web-based triage system. A prospective analysis was used to investigate the users' compliance with the advice provided and the factors that promoted compliance.

Chapter 4: Factors influencing adherence to eHealth technologies

The aim of the case study presented in chapter 4 was, therefore, to gain a greater insight into the factors that influence the long-term use of a web-based application (including e-consultation) for supporting the self-care of patients with Diabetes Mellitus type II. The actual use of the web application was registered via log-files over a 2-year period to determine how patients use the web application over a sustained period of time and to explore what system features are most meaningful to the patients. Patient characteristics were assessed in order to assess the differences between highly active (hardcore) users and low/inactive users of the web application (user profiles). It was hypothesized that patients with a greater need for care are more inclined to engage with the web application.

eHealth framework development

Chapter 5: Towards a holistic framework for the development of sustainable eHealth technologies

In chapter 5 we present the key principles for the development of sustainable eHealth technologies. These principles lay the foundation for a holistic framework to advance the development of sustainable eHealth technologies that are human-centered and represent value for all stakeholders. The framework is based on the findings of our empirical research on the use of eHealth technologies in practice, complemented by the insights derived from a narrative review of current frameworks for the development and evaluation of eHealth.

In the second part of this chapter the results of both the practice-based research and the narrative review are converted into a guideline to perform sustainable eHealth innovations. The guideline is intended for eHealth developers and researchers and will be made available via a web 2.0 platform, eHealthWiki.org, to stimulate collaboration and knowledge sharing.

Chapter 6: Conclusions and discussion

A reflection of the major findings and conclusions of the studies reported in this thesis are discussed in chapter 6. The implications for the development of eHealth technologies and future research efforts are described.

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Chapter 2

Increasing the use of eHealth technologies for supporting self-care among potential users

Based on: Nijland N, van Gemert-Pijnen JE, Boer H, Steehouder MF, Seydel ER. Increasing the use of e-consultation in primary care: results of an online survey among non-users of e-consultation. International Journal of Medical Informatics 2009;78(10):688-703.
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Abstract

Objective: To identify factors that can enhance the use of e-consultation in primary care. We investigated the barriers, demands and motivations regarding e-consultation among patients with no e-consultation experience (non-users).

Methods: We used an online survey to gather data. Via online banners on 26 different websites of patient organizations we recruited primary care patients with chronic complaints, an important target group for e-consultation. A regression analysis was performed to identify the main drivers for e-consultation use among patients with no e-consultation experience.

Results: In total, 1706 patients started to fill out the survey. Of these patients 90% had no prior e-consultation experience. The most prominent reasons for non-use of e-consultation were: not being aware of the existence of the service, the preference to see a doctor and e-consultation not being provided by a GP. Patients were motivated to use e-consultation, because e-consultation makes it possible to contact a GP at any time and because it enabled patients to ask additional questions after a visit to the doctor. The use of a web-based triage application for computer-generated advice was popular among patients desiring to determine the need to see a doctor and for purposes of self-care. The patients' motivations to use e-consultation strongly depended on demands being satisfied such as getting a quick response. When looking at socio-demographic and health-related characteristics it turned out that certain patient groups - the elderly, the less-educated individuals, the chronic medication users and the frequent GP visitors - were more motivated than other patient groups to use e-consultation services, but were also more demanding. The less-educated patients, for example, more strongly demanded instructions regarding e-consultation use than the highly educated patients.

Conclusions: In order to foster the use of e-consultation in primary care both GPs and non-users must be informed about the possibilities and consequences of e-consultation through tailored education and instruction. We must also take into account patient profiles and their specific demands regarding e-consultation. Special attention should be paid to patients who can benefit the most from e-consultation while also facing the greatest chance of being excluded from the service. As health care continues to evolve towards amore patient-centred approach, we expect that patient expectations and demands will be a major force in driving the adoption of e-consultation.

Introduction

These days the use of the Internet as a source for health information has increased substantially [1-4]. Therefore, we could expect that secured systems for online asynchronous patient-caregiver communication, such as e-consultation, would be incorporated into medical practice. However, the use of e-consultation remains relatively low [1,3,5-7]. This seems rather paradoxical since e-consultation has many potential benefits such as:

- *Increased access to care;* Patients can ask questions from any place and at any time, anonymous consultation is possible for sensitive questions and the service facilitates a second opinion [8-10].
- *Increased self-management support for individuals with significant medical problems;* e-consultation use can empower patients' self-control skills and strengthen their autonomy, especially when the service is used as part of a disease-management program for monitoring chronic diseases [11-15].
- *Reduced costs* while maintaining the same or achieving better quality of care [11,15]. This means that e-consultation can respond to an increasing demand for care in the aging society, provided that e-consultation will be widely used.

The main purpose of this study was to identify factors that can increase the use of e-consultation among non-users: patients with access to Internet, but with no prior e-consultation experience. We carried out an online survey among non-users in order to assess their *barriers* towards e-consultation, their *demands* regarding e-consultation and their *motivations* to use e-consultation. We investigated the motivations for using two types of e-consultation, which are being provided in the Netherlands: (a) *direct e-consultation*: consulting a GP through secured email, and (b) *indirect e-consultation*: consulting a GP through secured email with intervention of a web-based triage system.

The systems for direct and indirect e-consultation have been described in more detail in a previous study [16]. Web-based triage systems for e-consultation have been developed to prevent unnecessary visits to the doctor by promoting self-care advice. Web-based triage systems consist of a symptom-driven question-and-answer system for filtering urgent complaints. Patients have to label their health complaint either on alphabetically ordered lists or on a virtual body. Subsequently, they have to run through the questions and answers related to the identified problem. In the event of urgent symptoms the web-based triage application generates advice to visit a doctor. In the event of non-urgent issues it generates a tailored self-care advice. Through this study we hoped to assess whether patients are motivated to use such e-consultation services.

We also identified socio-demographic and health-related characteristics of non-users in order to find out how these factors affect e-consultation use. Therefore, we assessed barriers, demands and motivations regarding e-consultation of different patient groups, to know:

- *Patient groups that could benefit especially from e-consultation because of their increasing demand for care* such as elderly patients, frequent GP visitors, chronic medication users, because Internet users with more medical problems may have a more frequent need to use e-consultation [3].
- *Patient groups that have a significant chance of being left behind* such as less educated patients, because Internet users with lower levels of education were less inclined to use e-consultation than Internet users with higher levels of education [3,6].

Methods

Survey instrument

We used an online survey to assess the factors that can enhance e-consultation use among Dutch primary care patients who have Internet access, but lack experience with e-consultation. The survey covered 7 main topics and contained a total of 45 items. Topic 1 asked whether patients had experience with e-consultation (Yes/No). Topics 2-6 consisted of multiple statements, which could be answered on a 5-point scale ranging from strongly disagree (1) to strongly agree (5). The statements were based on previous studies about barriers and motivations regarding the use of e-consultation in primary care among early adopters [8-11,17-24] and referred to aspects with significant impact on e-consultation use, such as convenience, self-control, self-management of care and the use of different formats for self-control. Topic 2 (seven statements) examined possible barriers to using e-consultation. Topic 3 (ten statements) assessed patients' demands regarding e-consultation. Topic 4 (seven statements) identified motivations for using e-consultation. Topics 5 (seven statements) and 6 (eight statements) assessed the motivation for using two types of e-consultation: direct e-consultation and indirect e-consultation. Topic 7 closed the survey by asking patients' socio-demographic and health-related characteristics, such as gender, age, education level, chronic use of medication and frequency of seeing a GP. Respondents could skip questions. The survey was pre-tested by patients recruited through the Dutch Federation of Patients and Consumer Organizations.

Recruitment of study participants

In this study we collaborated with the Dutch Federation of Patients and Consumer Organizations. We focused on patients with various chronic complaints of different origins. Chronic patients with basic Internet skills, who have visited health-related websites, are a primary target group for e-consultation. We recruited participants through banners on frequently visited websites of 26 well-trusted patient organizations, all member organizations of the Dutch Federation of Patients and Consumer Organizations. For example, the National Federation of Cancer Patients, the COPD Patient Association, the Dutch Diabetes Association, the Cardiovascular Diseases Association, the Dutch Muscular Diseases Federation, Association of Patients in Mental Health Care, the Skin Diseases Federation, the Dutch Association for Patients with Hearing Problems. By clicking on a banner patients were automatically linked to the online survey, which was available for a period of eleven weeks. This enabled us to focus on the motivations of people with chronic complaints, an important target group for e-consultation. Eligible patients were at least 18 years old.

Data analysis

Statistical analyses were performed using SPSS version 13.0. Standard descriptive statistics were performed and mean sum scores were computed for all constructs (see Appendix A). Internal consistency of all constructs was satisfactory (Chronbach's $\alpha = .64$) to high (Chronbach's $\alpha = .84$). *F*-tests were used to identify significant differences between independent variables of interest. Linear regression models were used to predict the dependent variable 'motivation for using e-consultation' (mean score of questions 4-6, Chronbach's $\alpha = .86$). Independent predictors included: barriers towards e-consultation, demands regarding e-consultation and socio-demographic and health-related characteristics, such as age, education level, medication use and frequency of seeing a GP. Two-tailed significance was considered at the $p < .05$ level.

Results

Study participants

Of the total sample (N=1,706), 163 patients (9.6%) had experience with e-consultation. Of the remaining 1,543 patients (90.4%) who had no prior e-consultation experience, only 1,066 patients were eligible for the analysis. We excluded the patients who had filled out only 1 question. The N varies, because patients could skip questions. In this study we describe the results of the 1,066 patients with no e-consultation experience. Table 1 shows that most patients were female (62.4%) and frequent visitors of GPs (70.2%). The mean age was 49 years old (SD = 13.5) and half of the patients were highly educated (50.9%).

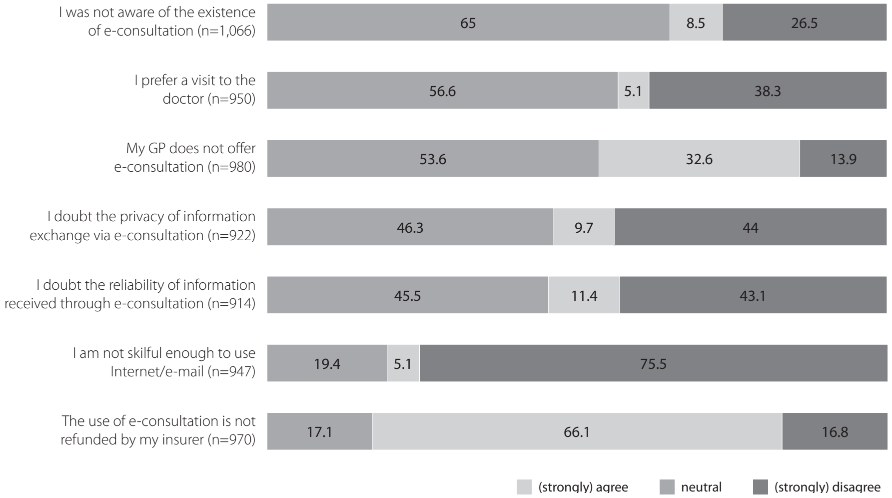
Table 1. Characteristics of patients (N = 1,066)

Characteristics	n	%
Age (*n* = 713)		
18-35	105	14.7
36-50	264	37.0
51-65	245	34.4
65-75	72	10.1
75-84	27	3.8
Gender (*n* = 713)		
Male	268	37.6
Female	445	62.4
Education level (*n* = 713)		
Low (primary/secondary school graduate)	43	6.0
Medium (high school graduate)	307	43.1
High (college graduate)	363	50.9
Chronic use of medication (*n* = 665)		
No chronic use	321	48.3
Chronic use	344	51.7
Frequency of GP visits (*n* = 708)		
Infrequent (less than once every 6 months)	211	29.8
Frequent (once every 6 months or more)	497	70.2

Barriers towards e-consultation

Figure 1 shows the reasons for the non-use of e-consultation. Of all the presented reasons the most prominent ones were: not being aware of the existence of e-consultation services (65%), the preference to see a doctor (56.6%) and limited access to e-consultation services, because 53.6% of the patients stated that their GP did not provide e-consultation. Computer or Internet skills were not expected to be a problem. In addition, 66.1% did not know whether the use of e-consultation is refunded by their insurer.

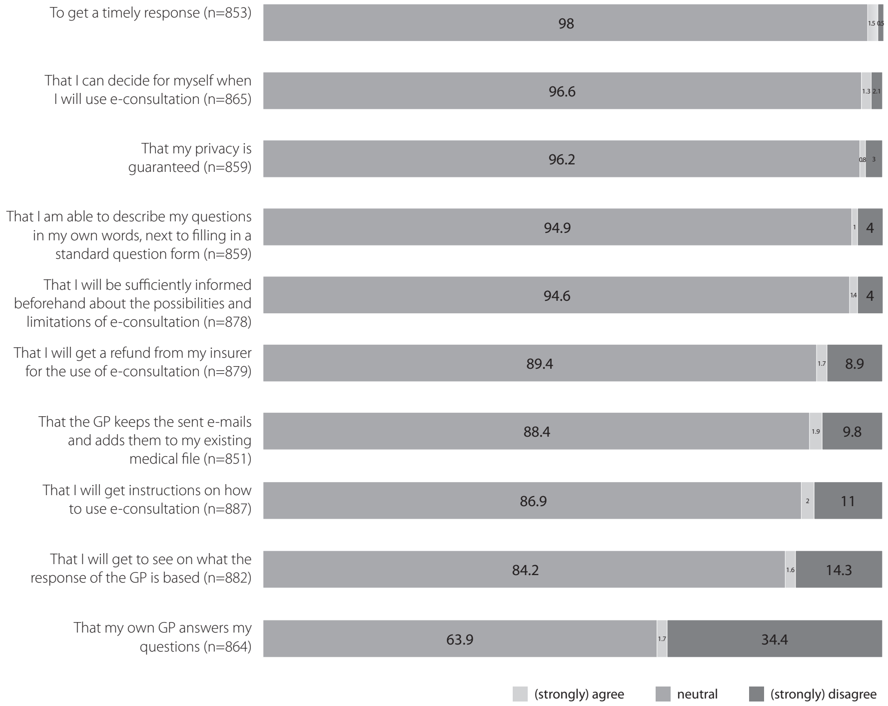
Figure 1. Barriers towards e-consultation (%)



Demands regarding e-consultation

Figure 2 presents the patients' demands regarding e-consultation. The top priority was getting a quick response (98%), but all other demands were almost equally important to the patients. Fewer patients (63.9%) agreed with the statement 'I find it important that my own GP answers my question'.

Figure 2. Demands regarding e-consultation (%)



Motivations for using e-consultation

Overall, the patients were fairly willing to use e-consultation given the high agreement on the presented statements (Figure 3). Of all the presented reasons to use e-consultation, the ability to contact a GP regardless of time (92%) and place (81.3%) and the possibility to formulate questions undisturbed (86.3%), were most appealing to the patients. These factors seemed to matter more than reducing office visits or travelling time.

We also asked the patients about their motivations for using two types of e-consultation, which are being provided in the Netherlands: direct e-consultation (consulting a GP through secured email) and indirect e-consultation (consulting a GP through secured email with intervention of a triage mechanism for advice on whether it is necessary to see a doctor and for self-care advice). Motivations for using direct e-consultation are presented in Figure 4. The possibility to ask additional questions after a visit to the doctor (88.2%) and the possibility to ask questions about medication use (78.4%) were most appealing to patients. Getting advice on how to handle a health problem and asking questions about the costs and payment of treatments were less of a motivation to use e-consultation (55.6%).

Figure 5 presents the motivations for using indirect e-consultation. Agreement on the statements was fairly high overall. We found that indirect e-consultation would be particularly useful for determining whether a visit to the GP is necessary (87.8%), for self-care advice (83.7%) and for uncertainty reduction e.g., knowing what is up and what to do (80.3%). The need to use indirect e-consultation for asking questions anonymously was rather divided. About 47% favoured anonymous communication against 41% who did not feel the need.

Figure 3. Motivations for using e-consultation in general (%)

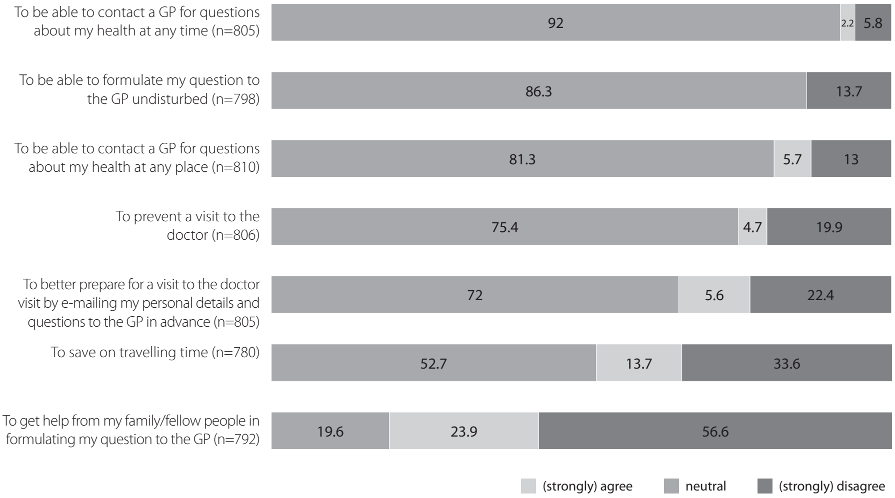


Figure 4. Motivations for using direct e-consultation (%)

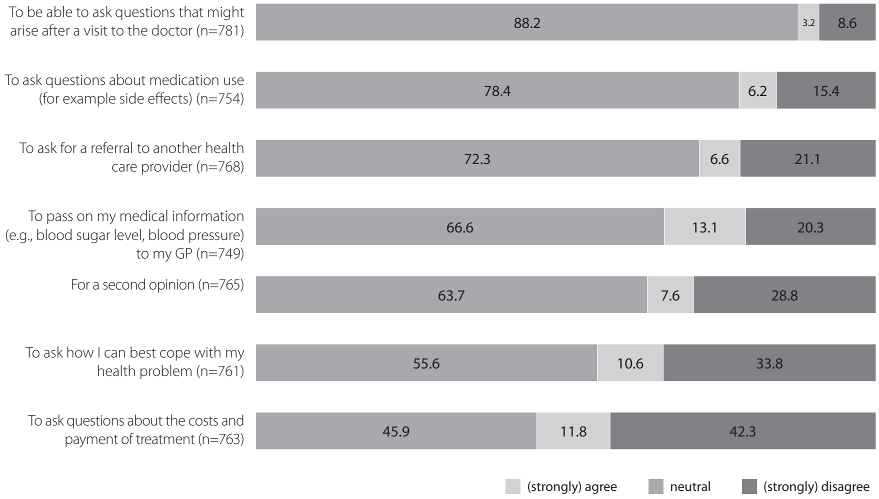
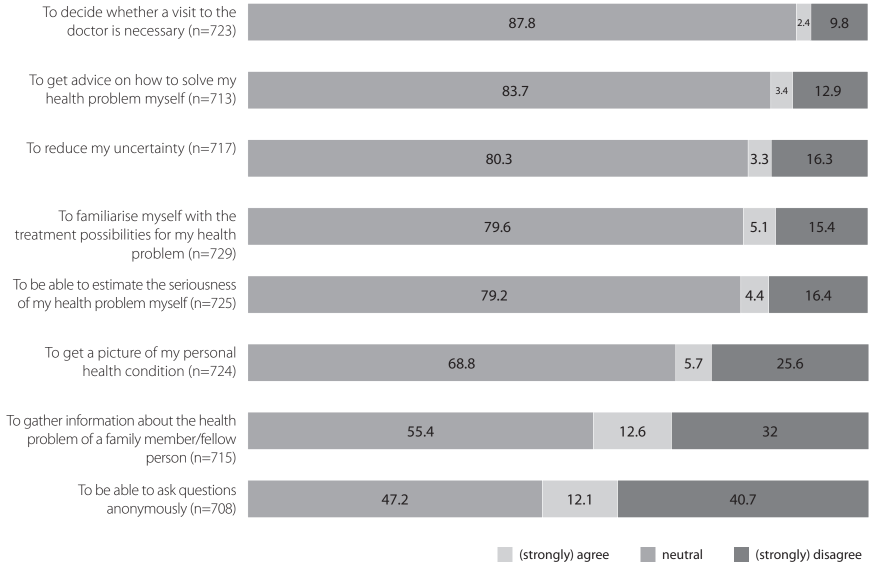


Figure 5. Motivations for using indirect e-consultation (%)



Main drivers for e-consultation

Regression analysis (Table 2) showed that the motivation for using e-consultation was highly correlated with patients' characteristics and their demands regarding e-consultation. The motivation for using e-consultation increased as more demands were satisfied such as getting a timely response. Of all patient characteristics, education level and age were the strongest predictors of the motivations for using e-consultation. The less-educated and elderly patients seemed more strongly motivated to use the service than the more highly educated and younger patients.

Table 2. Bivariate correlations and regression analyses: predictors associated with 'motivations for using e-consultation'

Predictors for motivations for using e-consultation	Univariate Correlation	Multivariate Beta coefficient
Age (*n* = 713)	.13**	.08*
Education level (*n* = 713)	-.19***	-.13**
Chronic use of medication (*n* = 665)	.05	-.01
Frequency of GP visits (*n* = 708)	.03	-.04
Barriers towards e-consultation (*n* = 824)	.07	-.09*
Demands regarding e-consultation (*n* = 827)	.43***	.42***

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

Patient characteristics and constructs (F (6; 664) = 27.9, $p < .001$) ($R^2 = .46$)

Specific items of construct Demands (F (9; 785) = 21.7, $p < .001$) ($R^2 = .45$)

Comparison of patient groups on barriers, demands and motivations regarding e-consultation

We compared distinct patient groups regarding age, education level, chronic use of medication and frequency of GP visits. Table 3 gives an overview of the distinguished patient groups. We focused on the patient groups that have a greater change of being left behind or that could benefit especially from e-consultation because of their increasing demand for care. These target groups are marked in the table.

Table 3. Distinguished patient groups (N = 1,066)

Patient characteristics		n	%
Age (*n* = 713)	18-49 years	369	51.8
	50-84 years*	344	48.2
Education level (*n* = 713)	Low/medium (primary/secondary/high school graduate)*	350	49.1
	High (college graduate)	363	50.9
Chronic use of medication (*n* = 665)	No chronic use	321	48.3
	Chronic use*	344	51.7
Frequency of GP visits (*n* = 708)	Infrequent (less than once every half year)	211	29.8
	Frequent (once every half year or more)*	497	70.2

* Target groups

Comparison of patient groups on perceived barriers towards e-consultation

The target patient groups perceived significantly more barriers towards e-consultation use than the other groups (see Table 3 for distinguished patient groups). Table 4 shows that compared to younger patients, the elderly appeared to have lower Internet skills and greater concerns about the costs of using e-consultation. Compared to more highly educated patients, the less-educated patients seemed to have lower Internet skills, were less aware of the existence of e-consultation services and had more doubts about the reliability and privacy of information exchanged via e-consultation. Face-to-face contact was preferred more strongly by the chronic medication users than by the patients without chronic conditions. The frequent GP visitors had a stronger preference to visit a doctor than the less frequent GP visitors.

Comparison of patient groups on demands regarding e-consultation

It turned out that the target patient groups had a greater number of demands regarding e-consultation than other patient groups (Table 5). The elderly patients had stronger demands, especially with regard to obtaining evidence-based answers from their caregivers. The less-educated patients more greatly preferred to receive instructions about e-consultation use, to receive information about the possibilities and restrictions of e-consultation and to use e-consultation free of charge. The chronic medication users had a greater desire to obtain an answer from their own GP and to have their e-consultation stored in their medical record. Frequent GP visitors preferred, over less-frequent GP visitors, to be informed about the possibilities and restrictions of e-consultation.

Comparison of patient groups on motivations to use e-consultation

We found significant differences between the patient groups with regard to their motivation to use e-consultation. The elderly patients, the less-educated patients and the chronic medication users were significantly more motivated to use e-consultation than their counterparts (Table 6). The elderly patients had a greater desire to use e-consultation in order to get help from their family/fellow people when formulating their health questions, to better prepare for a visit to the doctor by sending information in advance and to formulate their questions without disturbance. The less-educated patients were more motivated to use e-consultation to contact their GP from any place, to get help from their family/fellow people when formulating their health questions and to ask questions undisturbed. The chronic medication users were significantly more motivated to use e-consultation in order to prepare for a visit to the doctor by sending information about their health problems in advance, pass on their medical data (such as blood pressure and blood sugar levels) and to ask questions about their medications (such as side effects).

We also compared the patient groups regarding their motivations to use two types of e-consultation: direct e-consultation and indirect e-consultation with intervention of a web-based triage feature for determining the urgency of a health problem. The results on direct e-consultation showed that the elderly and less-educated patients were significantly more motivated (Table 7). E-consultation enables them to ask questions about the costs and payment of a treatment and to ask advice about certain health problems. The chronic medication users were also more motivated to use e-consultation, especially to pass on their medical data.

The results on indirect e-consultation (Table 8) indicated that the less-educated patients were more motivated than the more highly educated patients to use a web-based triage application, especially for uncertainty reduction.

Table 4. Comparison of patient groups on perceived barriers towards e-consultation

	Age		Education level		Medication use		Frequency of GP visits	
	<50	≥50	High	Low/medium	No	Yes	Infrequent	Frequent
Construct and items - Mean (SD)	($n = 369$)	($n = 342$)	($n = 361$)	($n = 349$)	($n = 319$)	($n = 343$)	($n = 210$)	($n = 495$)
Barriers towards e-consultation[a]	*2.63 (0.85)*	*2.96 (0.89)* ***	*2.54 (0.84)*	*3.05 (0.86)* ***	*2.68 (0.84)*	*2.86 (0.91)* **	*2.61 (0.87)*	*2.86 (0.89)* *
a. I was not aware of the existence of e-consultation	3.47 (1.56)	3.83 (1.34)**	3.42 (1.61)	3.87 (1.29)***	3.61 (1.54)	3.63 (1.44)	3.61 (1.59)	3.65 (1.42)
b. my GP does not offer e-consultation	3.83 (1.18)	3.84 (1.10)	3.92 (1.20)	3.75 (1.09)	3.73 (1.21)	3.90 (1.10)	3.65 (1.21)	3.91 (1.12)**
c. I am not skilful enough to use Internet/email	1.40 (0.85)	2.14 (1.38)***	1.43 (0.94)	2.07 (1.33)***	1.61 (1.12)	1.80 (1.20)*	1.67 (1.17)	1.75 (1.17)
d. the use of e-consultation is not refunded by my insurer	2.84 (0.97)	3.09 (0.93)***	2.84 (1.04)	3.08 (0.85)*	2.90 (0.94)	3.00 (0.97)	2.96 (1.03)	2.94 (0.92)
e. I prefer a visit to the doctor	3.08 (1.41)	3.30 (1.36)*	3.02 (1.39)	3.34 (1.37)**	3.02 (1.38)	3.31 (1.39)**	2.81 (1.39)	3.32 (1.36)***
f. I doubt the reliability of information received through e-consultation	2.83 (1.41)	2.93 (1.35)	2.63 (1.38)	3.17 (1.32)***	2.79 (1.36)	2.96 (1.39)	2.71 (1.37)	2.96 (1.38)*
g. I doubt the privacy of information exchange via e-consultation	2.86 (1.45)	3.04 (1.38)	2.70 (1.41)	3.24 (1.39)***	2.93 (1.43)	2.95 (1.42)	2.85 (1.44)	2.99 (1.41)

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

[a] To this day you have not used e-consultation. To what extent do the factors mentioned below play an important role in not using e-consultation?

Age: (F (1; 710) = 24.3, $p < .001$), Education level: (F (1; 709) = 64.3, $p < .001$), Chronic use of medication: (F (1; 661) = 7.2, $p < .01$), Frequency of GP visits: (F (1; 704) = 11.4, $p < .01$)

Table 5. Comparison of patient groups on demands regarding e-consultation

	Age		Education level		Medication use		Frequency of GP visits	
Construct and items - Mean (SD)	<50 ($n = 369$)	≥50 ($n = 344$)	High ($n = 363$)	Low/medium ($n = 350$)	No ($n = 321$)	Yes ($n = 344$)	Infrequent ($n = 211$)	Frequent ($n = 497$)
Demands regarding e-consultation[a]	*4.41 (0.47)*	*4.50 (.43)* *	*4.35 (0.47)*	*4.56 (0.42)* ***	*4.40 (0.47)*	*4.50 (0.44)* **	*4.35 (0.47)*	*4.50 (0.45)* ***
a. that I will get instructions on how to use e-consultation	4.04 (1.17)	4.29 (0.94)**	3.89 (1.20)	4.45 (0.82)***	4.09 (1.13)	4.20 (1.04)	3.97 (1.21)	4.24 (1.00)**
b. that I will be sufficiently informed in advance about the possibilities and limitations of e-consultation	4.43 (0.82)	4.55 (0.65)*	4.36 (0.81)	4.64 (0.64)***	4.47 (0.76)	4.50 (0.75)	4.33 (0.84)	4.56 (0.69)***
c. that I receive a refund from my insurer for the use of e-consultation	4.33 (0.93)	4.36 (0.95)	4.20 (1.03)	4.49 (0.81)***	4.27 (0.99)	4.44 (0.87)*	4.26 (1.02)	4.38 (0.91)
d. that I will get to see on what the response of the GP is based[b]	3.96 (1.17)	4.27 (0.97)***	4.02 (1.12)	4.20 (1.06)*	4.03 (1.11)	4.19 (1.04)	3.99 (1.15)	4.15 (1.07)
e. that I can decide for myself when I will use e-consultation	4.59 (0.66)	4.67 (0.56)	4.57 (0.66)	4.69 (0.55)**	4.63 (0.66)	4.62 (0.58)	4.58 (0.70)	4.65 (0.58)
f. that my own GP answers my questions	3.51 (1.40)	3.63 (1.36)	3.52 (1.36)	3.60 (1.41)	3.43 (1.41)	3.75 (1.34)**	3.33 (1.45)	3.67 (1.34)**
g. that I am able to describe my questions in my own words next to filling in a standard question form	4.53 (0.76)	4.52 (0.71)	4.44 (0.81)	4.60 (0.65)**	4.48 (0.77)	4.58 (0.68)	4.48 (0.76)	4.54 (0.73)
h. to get a timely response	4.74 (0.47)	4.71 (0.51)	4.68 (0.53)	4.77 (0.44)*	4.72 (0.48)	4.74 (0.49)	4.71 (0.51)	4.73 (0.49)
i. that the GP keeps the sent emails and adds them to my existing medical file	4.30 (0.98)	4.37 (0.95)	4.27 (0.99)	4.39 (0.97)	4.21 (1.04)	4.42 (0.90)**	4.17 (1.09)	4.40 (0.91)**
j. that privacy is guaranteed	4.77 (0.55)	4.69 (0.69)	4.68 (0.67)	4.78 (0.58)	4.70 (0.64)	4.77 (0.57)	4.68 (0.68)	4.75 (0.61)

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

[a] What is important to you when using e-consultation?

[b] for example by a reference to scientific sources and interesting websites

Age: (F (1; 712) = 6.3, $p < .05$) , Education level: (F (1; 712) = 40.2, $p < .001$) , Chronic use of medication: (F (1; 664) = 7.7, $p < .01$) , Frequency of GP visits: (F (1; 707) = 14.8, $p < .001$)

Table 6. Comparison of patient groups on motivations to use e-consultation in general

	Age		Education level		Medication use		Frequency of GP visits	
Construct and items - Mean (SD)	<50 (n = 369)	≥50 (n = 344)	High (n = 363)	Low/medium (n = 350)	No (n = 321)	Yes (n = 344)	Infrequent (n = 211)	Frequent (n = 497)
Motivations to use e-consultation in general [a]	*3.51 (0.76)*	*3.76 (0.68)* ***	*3.50 (0.73)*	*3.78 (0.72)* ***	*3.55 (0.74)*	*3.69 (0.72)* *	*3.56 (0.75)*	*3.66 (0.72)*
a. to get help from my family/fellow people in formulating my question to the GP	2.07 (1.16)	2.58 (1.17)***	2.16 (1.18)	2.48 (1.19)***	2.24 (1.18)	2.34 (1.17)	2.23 (1.23)	2.33 (1.16)
b. to be able to contact a GP for questions about my health at any place[b]	3.92 (1.12)	4.02 (1.01)	3.82 (1.13)	4.14 (0.96)***	3.95 (1.02)	3.98 (1.10)	3.95 (1.09)	3.99 (1.06)
c. to prevent a visit to the doctor	4.02 (1.21)	3.83 (1.22)*	3.96 (1.18)	3.90 (1.25)	3.99 (1.20)	3.86 (1.24)	4.12 (1.13)	3.86 (1.25)**
d. to better prepare for a visit to the doctor by emailing my personal details and questions in advance	3.59 (1.27)	3.93 (1.14)***	3.64 (1.24)	3.87 (1.19)*	3.55 (1.27)	3.91 (1.17)***	3.64 (1.28)	3.79 (1.21)
e. to be able to contact a GP for questions about my health at any time	4.46 (0.83)	4.42 (0.84)	4.35 (0.91)	4.54 (0.74)**	4.42 (0.81)	4.44 (0.87)	4.48 (0.83)	4.42 (0.84)
f. to save on travelling time	3.33 (1.43)	3.32 (1.26)	3.38 (1.35)	3.27 (1.36)	3.38 (1.35)	3.29 (1.36)	3.44 (1.37)	3.28 (1.35)
g. to be able to formulate my question to the GP undisturbed	4.26 (1.38)	4.71 (0.90)***	4.30 (1.34)	4.67 (0.97)***	4.32 (1.32)	4.60 (1.07)**	4.30 (1.37)	4.55 (1.10)*

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

[a] Why would you like to use e-consultation?

[b] on holiday, at home, in the hospital

Age: (F (1;712) = 21.8, $p < .001$), Education level: (F (1;712) = 27.8, $p < .001$), Chronic use of medication: (F (1;664) = 6.2, $p < .01$)

Table 7. Comparison of patient groups on motivations to use direct e-consultation

	Age		Education level		Medication use		Frequency of GP visits	
Construct and items - Mean (SD)	<50 (*n* = 369)	≥50 (*n* = 344)	High (*n* = 363)	Low/medium (*n* = 350)	No (*n* = 321)	Yes (*n* = 344)	Infrequent (*n* = 211)	Frequent (*n* = 497)
Motivations to use direct e-consultation [a]	*3.68 (0.67)*	*3.86 (0.67)* ***	*3.68 (0.69)*	*3.88 (0.65)* ***	*3.70 (0.65)*	*3.81 (0.70)* *	*3.75 (0.69)*	*3.78 (0.67)*
a. to be able to ask questions that might arise after a visit to the doctor	4.13 (0.97)	4.16 (0.85)	4.06 (0.93)	4.25 (0.89)**	4.11 (0.94)	4.17 (0.90)	4.06 (1.00)	4.19 (0.87)
b. for a second opinion	3.38 (1.32)	3.63 (1.13)*	3.40 (1.27)	3.63 (1.18)	3.50 (1.27)	3.49 (1.21)	3.49 (1.28)	3.50 (1.21)
c. to ask questions about the costs and payment of a treatment	2.82 (1.28)	3.19 (1.20)***	2.84 (1.26)	3.19 (1.24)***	3.03 (1.26)	2.99 (1.23)	3.00 (1.29)	3.00 (1.25)
d. to ask for a referral to another health care provider	3.62 (1.21)	3.82 (1.09)*	3.62 (1.19)	3.82 (1.12)*	3.73 (1.13)	3.72 (1.16)	3.70 (1.15)	3.72 (1.16)
e. to ask how I can best cope with my health problem	3.06 (1.30)	3.52 (1.17)***	3.03 (1.26)	3.57 (1.21)***	3.15 (1.28)	3.38 (1.24)*	3.23 (1.27)	3.32 (1.25)
f. to pass on my medical information (e.g., blood sugar level, blood pressure) to my GP	3.62 (1.17)	3.78 (1.05)	3.62 (1.14)	3.78 (1.09)	3.53 (1.15)	3.85 (1.06)***	3.58 (1.13)	3.74 (1.11)
g. to ask questions about medication use (for example side effects)	3.79 (1.15)	4.00 (0.97)*	3.77 (1.12)	4.02 (1.00)**	3.75 (1.10)	4.02 (1.02)**	3.70 (1.09)	3.97 (1.04)**

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

[a] For which purposes would you like to use direct e-consultation?

Age: (F (1; 712) = 12.8, $p < .001$), Education level: (F (1; 712) = 16.1, $p < .001$), Chronic use of medication: (F (1; 664) = 4.3, $p < .05$)

Table 8. Comparison of patient groups on motivations to use indirect e-consultation

	Age		Education level		Medication use		Frequency of GP visits	
Construct and items - Mean (SD)	<50 (n = 367)	≥50 (n = 344)	High (n = 363)	Low/medium (n = 348)	No (n = 321)	Yes (n = 344)	Infrequent (n = 211)	Frequent (n = 497)
Motivations to use indirect e-consultation [a]	*3.79 (0.90)*	*3.88 (0.78)*	*3.74 (0.92)*	*3.95 (0.75)* **	*3.85 (0.86)*	*3.82 (0.85)*	*3.83 (0.89)*	*3.84 (0.83)*
a. to familiarise myself with the treatment possibilities for my health problem	3.83 (1.14)	3.98 (1.05)	3.87 (1.14)	3.95 (1.05)	3.91 (1.09)	3.92 (1.09)	3.92 (1.11)	3.89 (1.10)
b. to get a picture of my personal health condition	3.43 (1.33)	3.73 (1.14)**	3.50 (1.29)	3.67 (1.21)	3.62 (1.25)	3.53 (1.26)	3.62 (1.30)	3.55 (1.23)
c. to gather information about the health problem of a family member/fellow person	3.38 (1.31)	3.15 (1.23)*	3.22 (1.33)	3.33 (1.22)	3.37 (1.27)*	3.15 (1.28)	3.23 (1.30)	3.29 (1.27)
d. to be able to estimate the seriousness of my health problem myself	3.87 (1.18)	3.89 (1.15)	3.78 (1.24)	3.99 (1.06)*	3.91 (1.13)	3.85 (1.20)	3.91 (1.19)	3.87 (1.15)
e. to get advice on how I might be able to solve my health problem myself	3.97 (1.09)	4.07 (.96)	3.97 (1.09)	4.09 (0.96)	4.06 (1.03)	3.95 (1.05)	4.06 (1.05)	4.01 (1.02)
f. to reduce my uncertainty	3.84 (1.17)	3.93 (1.06)	3.69 (1.19)	4.10 (0.99)***	3.87 (1.14)	3.90 (1.10)	3.84 (1.13)	3.91 (1.11)
g. to decide whether a visit to the doctor is necessary	4.15 (1.07)	4.24 (0.90)	4.08 (1.07)	4.33 (0.87)*	4.19 (1.00)	4.19 (1.01)	4.14 (1.06)	4.23 (0.95)
h. to be able to ask questions anonymously	3.23 (1.41)	2.95 (1.35)*	2.95 (1.39)	3.29 (1.36)*	3.18 (1.39)	3.03 (1.39)	3.12 (1.42)	3.09 (1.38)

Note. * $p < .05$, ** $p < .01$, *** $p < .001$

[a] For which purposes would you like to use indirect e-consultation?

Education level: (F (1; 710) = 10.9, $p = .001$)

Discussion

These days e-consultation provides more advanced services, such as web-based triage features for decision-making assistance and for promoting patient self-care [16]. Therefore, we would expect that e-consultation would be widespread in today's technological age. However, this is not the case. About 90% of our total sample (N = 1,706) had never encountered e-consultation. In this study we aimed to identify factors that can increase the use of e-consultation in primary care. With an online survey, we investigated the barriers, demands and motivations regarding e-consultation of patients with no prior e-consultation experience (non-users).

The results of our study showed that 70% of our study population, patients with no e-consultation experience (N = 1,066), were frequent GP visitors. E-consultation may be especially beneficial for these patients with a higher demand for care, because it can help them decide whether it is necessary to see a doctor and teach them self-care techniques in order to prevent unnecessary encounters [8,9,16]. This is an important reason to foster the use of e-consultation services in primary care.

The most prominent barriers towards e-consultation were: unawareness of the existence of e-consultation, e-consultation not being provided by a GP and the preference to see a doctor. Education and examination of user expectations can provide a solution for these barriers, for both patients and caregivers alike. Patients are dependent on a GPs' provision of e-consultation. Therefore, it is important to advise caregivers on the mutual benefits of e-consultation, its consequences and implementation into regular practice. It is also important for GPs to ask their patients about e-consultation, since patients are unlikely to request electronic GP access, simply because they are unaware of the option. Besides, non-users of e-consultation may have no clear ideas or assumptions about the benefits and disadvantages of e-consultation.

Next to the perceived barriers we gathered information about non-users' motivations and demands regarding e-consultation. We provided patients with statements based on prior research among e-consultation users [8-11,17-23]. These statements expressed the advantages of e-consultation such as being able to ask follow-up questions after a visit to the doctor, to ask questions about medication use, to pass on medical data (e.g., blood glucose) and to get decision-support on whether it is necessary to see a doctor. Overall, our results demonstrated that non-users were fairly motivated to use e-consultation for these purposes, but only under certain conditions. Patients attached great importance to a timely response and a guarantee on privacy. These results are comparable with other studies among early adopters of e-consultation [20,22,24], which gives us the impression that today's non-users do not differ from early adopters in their motivations to use e-consultation. Non-users and early adopters both, for example, expressed the desire for a primary evaluation of a medical problem, including advice as to the necessity of seeing a doctor [24].

Our study also revealed that certain patient groups, such as less-educated patients, elderly patients and chronic users of medication were especially motivated to use e-consultation, but also perceived many barriers towards e-consultation. The elderly patients, for example, perceived a stronger lack of Internet skills than younger patients and the less educated patients were less aware of the existence of e-consultation than the more highly educated patients. These results are consistent with the literature in the conclusion that socio-demographic and health-related factors influence the use of online patient-caregiver communication [3,4,25,26].

Overall, our findings on e-consultation are comparable with studies about online patient-provider communication in Europe and the United States [3,4]. Although there has been an increase in online communications regarding health-related issues since 2005 [26], the impact of e-consultation on the healthcare delivery system and its services is rather low. The potentials of e-consultation exist in enhancing its accessibility and in optimizing the features for self-care. Increasing the use of e-consultation requires a proactive approach, not only from healthcare professionals, but also from governmental agencies on a policy level [27-29].

Limitations of this study

There are a number of limitations of this study. Non-users might have a limited view on the possibilities of e-consultation for self-care. Because of this, we used statements to gain insight into their motivations for using e-consultation in our survey. These statements were based on findings of previous studies and are thus directive in nature. However, we could only give general directions for the design and implementation of e-consultation in primary care.

Future research could focus on the motivations of early adopters in comparison to the motivations of non-users and a user-centred approach will be necessary in order to transform the general directions into specific requirements that can be taken up in designing e-consultation applications [30].

Another limitation is that we did not reflect on the motivations, demands, or barriers of patients without access to a computer or Internet or patients with GPs without e-consultation services. The study was directed solely at Internet users, because this population has the potential to use e-consultation in the near future.

Conclusions

The findings of this study demonstrate that the use of e-consultation will not increase through efforts to change the attitudes of patients or health care providers, since many non-users liked the possibilities of e-consultation and were thus motivated to use e-consultation. Increase in use will rather occur through solving existing barriers among non-users [16,31] and through addressing patients' demands, preferences and skills when developing e-consultation systems [16,20,32,33]. Educational and informational deficits can be handled by informing end-users about the possibilities and consequences of e-consultation via tailored education and instructions. Moreover, we must take into account patient profiles; special attention should be paid to patients who can benefit the most from e-consultation, while also facing the greatest chance of being excluded from the service. As health care continues to evolve towards a more patient-centered approach, we expect that patient expectations and demands will be a major force in driving the use of electronic communication.

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Appendix A. Constructs and items of the online survey

Barriers towards e-consultation (Chronbach's $\alpha = .66$*)*

Survey question: To this day you have not used e-consultation. To what extent do the factors mentioned below play an important role in not using e-consultation?

a. I was not aware of the existence of e-consultation.
b. my GP does not offer e-consultation
c. I am not skilful enough to use Internet/email
d. the use of e-consultation is not refunded by my insurer
e. I prefer a visit to the doctor
f. I doubt the reliability of information received through e-consultation
g. I doubt the privacy of information exchange via e-consultation

Demands regarding e-consultation (Chronbach's $\alpha = .74$*)*

Survey question: What is important to you when using e-consultation? (I find it important…)

a. that I will get instructions on how to use e-consultation
b. that I will be sufficiently informed in advance about the possibilities and limitations of e-consultation
c. that I receive a refund from my insurer for the use of e-consultation
d. that I will get to see on what the response of the GP is based (for example by a reference to scientific sources and interesting websites)
e. that I can decide for myself when I will use e-consultation
f. that my own GP answers my questions
g. that I am able to describe my questions in my own words next to filling in a standard question form
h. to get a timely response
i. that the GP keeps the sent emails and adds them to my existing medical file
j. that privacy is guaranteed

Motivation for using e-consultation in general (Chronbach's $\alpha = .64$*)*

Survey question: Why would you like to use e-consultation?

a. to get help from my family/fellow people in formulating my question to the GP
b. to be able to contact a GP for questions about my health at any place (on holiday, at home, in the hospital)
c. to prevent a visit to the doctor
d. to better prepare for a visit to the doctor by emailing my personal details and questions to the GP in advance
e. to be able to contact a GP for questions about my health at any time
f. to save on travelling time
g. to be able to formulate my question to the GP undisturbed

Motivation for using direct e-consultation (Chronbach's $\alpha = .73$)

Survey question: For which purposes would you like to use direct e-consultation?

a. to be able to ask questions that might arise after a visit to the doctor
b. for a second opinion
c. to ask questions about the costs and payment of a treatment
d. to ask for a referral to another health care provider
e. to ask how I can best cope with my health problem
f. to pass on my medical information (e.g., blood sugar level, blood pressure) to my GP
g. to ask questions about medication use (for example side effects)

Motivation for using indirect e-consultation (Chronbach's $\alpha = .84$)

Survey question: For which purposes would you like to use indirect e-consultation?

a. to familiarise myself with the treatment possibilities for my health problem
b. to get a picture of my personal health condition
c. to gather information about the health problem of a family member/fellow person
d. to be able to estimate the seriousness of my health problem myself
e. to get advice on how I might be able to solve my health problem myself
f. to reduce my uncertainty
g. to decide whether a visit to the doctor is necessary
h. to be able to ask questions anonymously

Chapter 3

Problems encountered by early adopters when using eHealth technologies for supporting self-care

Chapter 3.1 is based on: Nijland N, van Gemert-Pijnen JEWC, Boer H, Steehouder MF, Seydel ER. Evaluation of internet-based technology for supporting self-care: problems encountered by patients and caregivers when using self-care applications. Journal of Medical Internet Research 2008;10(2):e13.
doi:10.2196/jmir.957

Chapter 3.2 is based on: Nijland N, Cranen K, Boer H, van Gemert-Pijnen JE, Seydel ER. Patient use and compliance with medical advice delivered by a web-based triage system in primary care. Journal of Telemedicine and Telecare 2010;16(1):8-11.
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Chapter 3.1

Abstract

Background: Prior studies have shown that many patients are interested in web-based technology that enables them to control their own care. As a result, innovative eHealth services are evolving rapidly, including self-assessment tools and secure patient-caregiver email communication. It is interesting to explore how these technologies can be used for supporting self-care.

Objective: The aim of this study was to determine user-centered criteria for successful application of web-based technology used in primary care for supporting self-care.

Methods: We conducted scenario-based tests combined with in-depth interviews among 14 caregivers and 14 patients/consumers to describe the use of various self-care applications and the accompanying user problems. We focused on the user-friendliness of the applications, the quality of care provided by the applications, and the implementation of the applications in practice.

Results: Problems with the user-friendliness of the self-care applications concerned inadequate navigation structures and search options and lack of feedback features. Patients want to retrieve health information with as little effort as possible; however, the navigation and search functionalities of the applications appeared incapable of handling patients' health complaints efficiently. Among caregivers, the lack of feedback and documentation possibilities caused inconvenience. Caregivers wanted to know how patients acted on their advice, but the applications did not offer an adequate feedback feature. Quality of care problems were mainly related to insufficient tailoring of information to patients' needs and to efficiency problems. Patients expected personalized advice to control their state of health, but the applications failed to deliver this. Language (semantics) also appeared as an obstacle to providing appropriate and useful self-care advice. Caregivers doubted the reliability of the computer-generated information and the efficiency and effectiveness of secure email consultation. Legal or ethical issues with respect to possible misuse of email consultation also caused concerns. Implementation problems were mainly experienced by caregivers due to unclear policy on email consultation and the lack of training for email consultations.

Conclusions: Patients' and caregivers' expectations did not correspond with their experiences of the use of the web-based applications for self-care. Patients thought that the applications would support them in solving their health problems. Caregivers were more reserved about the applications because of medico-legal concerns about misuse. However, the applications failed to support self-care because eHealth is more than just a technological intervention. The design of the applications should include a way of thinking about how to deliver health care with the aid of technology. The most powerful application for self-care was secure email consultation, combined with a suitable triage mechanism to empower patients' self-awareness. Future research should focus on the effectiveness of such web-based triage mechanisms for medical complaints and on the development of interactive features to enhance patients' self-care.

Introduction

Web-based technology has become increasingly important for promoting access to care and self-care management [1-3]. Particularly, systems that combine high-quality information with interactive components for self-assessment, decision support, or behavior change have the potential to reduce costs while maintaining the same or achieving better quality of care [2,4]. This means that technology can respond to an increasing demand for care in the aging society.

What has become widely accepted is the value of web-based technology to deliver health care irrespective of time and place, and the enhanced access to care for people from underserved areas [1,3]. Notwithstanding the better services, a relevant question is whether these web-based applications can support patients or consumers in controlling their own health behavior, and secondly, whether they can facilitate the quality of health care.

Recognizing that patients are interested in managing their own health, the industry is exploring ways of encouraging them to be more in control of their own health and health care [5]. Initially, health care innovations were mainly market-driven products delivering information that may not benefit patients. Currently, innovative web-based technologies in health care that have interactive components, such as an 'ask the doctor service' (via secure email consultation) [1] and self-tests, are evolving rapidly [6]. The use of the Internet is no longer restricted to information retrieval but enables patients to manage their own health proficiently and at their own convenience by means of such interactive components for self-care.

When self-care is the focus of web-based technology, we need to evaluate more thoroughly what people can do with the self-care applications. How do they evaluate their own health condition with self-assessment tools, what do they feel and think while communicating with a system about their ailment, and what do they expect from computer-generated self-care advice? A qualitative evaluation study is thus needed to achieve insight into the process of consulting web-based applications for medical support and to determine which health care functions can be delegated to web-based health care systems [2].

To date, evaluations that take user perspectives into account as well as the appropriateness and meaningfulness of interactive components to support self-care are scarce [2,7]. The aim of this study was to determine user-centered criteria for successful application of web-based technology for supporting self-care. To this end, we evaluated the use of three web-based applications in primary care that have various features for self-care (e.g., self-test, web-based triage) and electronic patient-caregiver communication (free text or question-and-answer form).

In wanting to observe the contribution of various interactive components to support self-care, we focused on the user-friendliness of the applications [2,3,8,9], the quality of care provided by the applications [2,10], and the implementation of the applications in practice [11].

Methods

Description of web-based applications for self-care

We evaluated three commonly used web-based primary care applications in the Netherlands: Medicinfo (M) [12], Praktijkinfo (P) [13], and Dokterdokter (D) [14]. These certified applications are based on ISO 9000:2000 standards [15] and use encrypted software for secure exchange of information. Users have to log on with a user ID and password. Patients have free access to all three applications.

The applications have multiple components for self-care so as to appeal to a wide range of users, thus underlining that patients will differ in their needs for self-care. In all three applications, patients can search for self-care information about their health complaint by means of a digital medical encyclopedia with alphabetically ordered lists or online health brochures. Two applications, M and D, provide self-care tools that can be used for various purposes: obtaining information about the possible causes of a health complaint, and checking the necessity of a doctor's visit and getting (self-care) advice for non-urgent health complaints.

For the first purpose, application M provides a so-called Symptom Scan. This self-test consists of a questionnaire about specific health symptoms and generates a bar chart showing the probabilities of medical causes for a certain disease or injury. For the second purpose, M and D provide a web-based triage function that consists of a symptom-driven question-and-answer system for filtering urgent complaints and for providing fully automated diagnosis and advice. The web-based triage is intended to prevent unnecessary visits to the doctor. Patients have to label their health complaint either on alphabetically ordered lists (M) or on a virtual body (D). Subsequently, they have to run through the questions and answers related to the identified problem. In the event of urgent symptoms, the triage application generates advice to visit a doctor. In the event of non-urgent issues, it generates tailored self-care advice.

All three applications offer the possibility of secure email communication between patient and caregiver. The P and D applications provide online encounters between patient and general practitioner (GP) but require a pre-existing relationship. Patients of M can consult 28 specific health experts anonymously. With M and P, patients can consult a caregiver in their own words (free text). With D, patients first have to run through a question-and-answer system (web-based triage) before being able to pose their question in their own words. Questions have to be answered within 24 hours, and caregivers receive a reimbursement for each web consultation.

Recruitment of participants

Fourteen caregivers participated in this study, including GPs, physicians specializing in communicable diseases, and a psychologist. All caregivers were current users of one of the web-based care applications. Participating caregivers were recruited by email by the systems' providers and used their practice website and email to recruit patients. A total of 14 patients agreed to participate. Eligible patients were at least 18 years old, Dutch speaking, and had experience with using one of the web-based applications.

Scenario-based tests combined with in-depth interviews

We used scenario-based tests combined with in-depth interviews to describe the use of the web-based applications and the accompanying user problems. Trained observers watched users communicating with the interface of the application while doing simulated tasks and thinking aloud [16]. The test consisted of six 'what if' scenarios (see Multimedia Appendix) representing health complaints related to self-limiting diseases. All scenarios were tested by physicians. Patients were instructed to read a scenario out loud and to imagine that they were in the situation described. Caregivers, on the other hand, were instructed to answer patients' questions. The participants' activities were recorded with audio-visual equipment. The tests were carried out at the participants' home or workplace. Each test lasted about 90 minutes.

Data analyses

Two researchers independently identified user problems from the verbal reports of the scenario-based tests. Repeated or reworded descriptions of the same problem were only counted once. Agreement on categorization of the problems was high [17], both for the patient problems (Cohen's kappa = 0.95) and the caregiver problems (Cohen's kappa = 0.87). In the event of disagreement, researchers discussed the categorization of the problems in order to reach consensus. All of the 358 identified user problems were categorized as quality demands for supporting self-care by technology [10]:

1. *Problems with user-friendliness*: referring to technical and design features (presentation of information) that are relevant to the use of the applications
2. *Problems with the quality of care*: referring to patient-caregiver communication and self-care advice generated by the application, especially the responsiveness of the applications [18,19]
3. *Implementation problems*: referring to the incorporation of the applications into daily practice and to policy issues concerning e-consultation

Results

The results present the problems observed while using the applications for self-care aims. The results section is split into two parts: the first addresses patients' use of the applications and the problems experienced, and the second addresses caregivers' use of the applications and the problems experienced with handling patient requests. To indicate the main problems, a full overview is given for each.

Patient problems

Searching for self-care information

By means of digital medical encyclopedia with alphabetically ordered lists of medical terms, patients could seek self-help information about their health complaint. Patients experienced difficulties in finding information. The navigation structure of the website (home page) appeared troublesome for patients trying to find the information they were looking for. For instance, the search options were not equipped for finding the right information quickly and also provided irrelevant or useless results. As patients wanted to retrieve health information with as little effort as possible, and the applications did not meet this need, they opted for a search engine, such as Google, to find the right information.

"Because I can't find a 'search function' and the structure of the menu is unclear, it means that I have to carry on scrolling. For me, that's a big enough reason for quitting this site. It's just too much bother, and I'm someone who uses the Internet on a daily basis." [P13]

"With Google, you get the right answer straight away. It's much faster than this. I can't ask my question here. I have to search." [P8]

Semantic shortcomings hindered the search process because the search options used medical terms that were not defined or explained, which meant that patients could not match their health complaint with the terminology offered.

"I read 'muscular weakness'. Now what is muscular weakness?" [P10]

"Lots of difficult words. Better information about what it is would be handy." [P3]

Comprehension problems arose because the virtual body of the application did not provide sufficient information for labelling a health complaint. Patients had to click on the body to label their complaint in order to get more information. However, patients were not accustomed to describing their complaint via the labels of a virtual body, and they were not able to label ailments like tiredness, insomnia, and mental problems. The possibilities offered by the medical encyclopedia were often irrelevant and/or too general to be helpful for self-care.

"I expect the ABC [medical encyclopedia] to comprise both physical and mental problems. I am now looking for sleep disorders, but that isn't my main problem. Apparently I first have to make a diagnosis about what's wrong with me before I can search further." [P7]

"I was expecting more of a medication advice. This information just deals with common solutions. I find that general knowledge."[P5]

Interpreting computer-generated self-care advice

Via self-tests and web-based triage features, patients could receive fully automated self-care advice to identify the possible causes of a health complaint or to decide whether a doctor's visit was necessary. M provides a so-called Symptom Scan, a self-test to gather information on the possible causes of a health complaint. The self-test can be consulted for four health complaints: dizziness, chest pain, headache, and tiredness. It consists of a list of questions about specific symptoms. The self-test generates a list of probabilities of medical causes for a certain disease or injury; for example, a test for headache resulted in a 96% chance of migraine, a 1.1% chance of a brain tumor, and a 0.1% chance of meningitis.

Patients had difficulty interpreting the results of the Symptom Scan. It was unclear to them how they should interpret a percentage of 0.1. Is this chance negligible or is it a realistic 0.1% chance of meningitis? As the system failed to provide further information on this, a doctor still needed to be consulted. The system thus did not provide the security the patient was seeking or support the patient in his or her self-

care demand. In certain cases, the test results even evoked fear. This was due to the fact that most of the presented terms were related to injuries and diseases instead of common conditions. Furthermore, patients noted that in many cases the questions of the self-test were irrelevant or incomplete. The consequence of this was that patients lost confidence in the Symptom Scan and no longer took the results of the test seriously. Besides this, the patients appeared to have insufficient expertise to answer the Symptom Scan's questions; consequently, the results did not coincide with the patient's complaint.
"It doesn't help me much. A percentage of 0.3-1 have no idea what that means. In my opinion, those questions were totally irrelevant." [P6]

Patients could check the necessity of a visit to the doctor by means of a symptom-driven question-and-answer system (web-based triage). Patients felt that they were referred to a doctor too quickly. Consequently, the advice to visit a doctor was not always taken seriously, particularly in the case of an apparently less serious health complaint, like a cough. Moreover, the generated advice frightened patients when they were told to visit a doctor after answering only a few questions.
"Sounds ominous: 'Contact your GP'. I would prefer some explanation why that is necessary." [P8]

What do patients expect from computer-generated self-care advice? The question-and answering system (web-based triage) seemed appealing to patients because of its ability to adjust to personal characteristics (i.e., patients fill in their personal symptoms and the system responds to their personal data). The fact that patients have to fill in personal information results in an expectation of tailored health care advice. However, patients found the self-care advice to be insufficiently tailored to their specific needs; it was no different from the general information available in public health leaflets or encyclopedia. Consequently, patients attached greater importance to personal advice from a caregiver, whether through the Internet or from a doctor's visit.
"I am quite interested in what it comes up with, whether it's identical to what has been said before [in the medical encyclopedia] or if I will be given more specific information on my current symptoms." [P11]

Furthermore, patients found that the web-based triage function did not yield as much as expected. The number of questions they had to answer on an ailment was not in accordance with the perceived severity of their health problem. For example, for a problem like a cough, patients had to answer about 50 questions before they received advice on what to do (application D). Patients found the number of questions disproportionate to their complaint. With more a complex health problem, such as tiredness, patients had fewer objections to a greater number of questions because they understood that more questions are needed if a complex problem is to be considered.
"That cough question, it takes you 15 minutes to run through all the questions, whereas you might just as well have picked up the telephone." [P2]

Formulating health complaints via email

Patients faced problems describing their health problem; mental health problems were especially difficult to verbalize. In these cases, patients were already heading for a doctor's visit during their email consultation.

One of the applications (P) requires patients to classify their complaint under a category such as shoulder complaint or headache before they can pose a question to their GP by email. These rubrics appeared insufficiently tailored to the language patients used for verbalizing their complaint.
"It's quite tricky, having to categorize your question. Look, if you have cystitis, it's not so difficult. But if you think you've got a pain in your stomach, or are constipated, those kinds of things are difficult to classify." [P13]

Patients also found it difficult to decide what kind of information a caregiver needs in order to be able to answer their questions. The completeness of information given to a caregiver depended on the type of interaction with him or her. In the event of a pre-existing relationship, patients anticipated the GP's knowledge about their medical history (information about their personal situation and activities that had already been undertaken to solve the health problem). When consulting an unknown caregiver, patients gave as much information as possible about their personal situation and health problem, often accompanied with information about the actions they already had undertaken. By doing so, patients took into account the fact that the caregiver could not pose a counter question because of the lack of feedback features. With application M, patients can consult several clinical experts for advice on a specific health problem; however, it appeared to be difficult for patients to choose the right expert for their complaints (e.g., they found it difficult to select an expert for a complaint of headache).

Implementation of applications in practice

Patients were not trained to use the self-care applications. Moreover, they had no idea whether use of the applications would continue to be free in the future. Due to lack of training or education, not all features of the applications were used, such as the possibility for patients to store the information generated by the applications (P and D) in a patient file. The structure of the websites seemed so unclear that all kinds of features to document and upload information were overlooked.

Overview of patient problems

Table 1 presents an overview of the problems patients experienced while they were observed using the applications' features for controlling their health. Problems were categorized into quality demands for supporting health care through technology. Patients experienced 260 problems in total. They faced problems mainly with the quality of care provided via the web-based applications. The information was insufficiently tailored to patients' needs, and language (semantics) appeared one of the main obstacles to providing appropriate and useful self-care advice. Problems with the user-friendliness of the applications were mainly related to navigation features, such as inadequate search options and unclear presentation of information; the menu on home pages failed to enable patients to find the information they were looking for. Implementation problems occurred because of vagueness concerning regulations about free access and lack of training on how to use the applications for solving health-related problems.

Table 1. Overview of patient problems ($n = 260$)

Quality demand	Identified patient problems
User-friendliness ($n = 106$, 40.8%)	*Navigation problems:* Lack of a search engine Lack of an adequate search option Unclear navigation structure; hyperlinks were nonexistent or useless Unclear or unattractive layout of web pages No features for printing information *Technical problems:* Software bugs Drop-down menus or back buttons failed
Quality of care ($n = 146$, 56.1%)	*Problems with relevance of information:* Information provided by the digital medical encyclopedia was too general to be useful Information provided by the virtual body was too limited to be useful Self-care advice insufficiently tailored to personal needs *Problems with comprehensibility of information:* Semantic mismatch between system and users because of unclear medical terms and lack of features to verbalize a problem in their own vocabulary Self-care advice hard to interpret Self-care advice frightening *Problems with responsiveness:* Caregiver used more than prescribed response time to answer patients' questions
Implementation ($n = 8$, 3.1%)	*Lack of education:* Underuse or misuse of applications because of lack of education Uncertainty about regulations for using Internet for self-care

Caregiver problems

Identification of patients

In the event of a pre-existing relationship between a patient and caregiver, the caregiver first looks up the name and date of birth of the patient in order to identify him or her. Next, the caregiver looks for additional information in his or her own patient record. Although caregivers authenticate the patients by checking the personal data, they still have concerns about the service being misused (i.e., they might receive requests from unknown patients who were using the account of a patient already on file). In case of anonymous email encounters, caregivers were also aware of the risk of not knowing the patient. With application M, they are trying to curtail this by asking all patients approaching them for an e-consultation to fill in a health statement first. To this end, patients must answer questions specifically selected with regard to what the caregiver needs to know as well as the health risks the patient might run. In this way, the caregiver can soon see in an overview how or where he or she must adjust the advice to the situation of the unknown patient. All the questions have to be answered with 'No' if a patient desires an e-consultation. The health statement does not eradicate all risk, however.

"Because that's the last thing you want, right? That they leave with wrong advice but then it turns out that we did ask the question only that they didn't answer it, that they thought, "Oh, it's not a problem," which later turns out to be one after all. That's the drawback of not knowing somebody and still advising them on the basis of a health statement that they have had to fill in themselves." [C7]

Interpreting patient requests

For the P and D applications, email communication is only possible with registered patients. In this way, it is clear to the caregiver who is asking the question. For M, the people asking the questions are anonymous, which means the caregiver has no background information on the person concerned. However, to be able to give a more personal or tailored answer, it is necessary to have background information or a medical history.
"It can be difficult sometimes. You only have a smidgen of background information about somebody, whereas with real-life contact you can see how someone reacts. When you say something and the message does not come across at all, someone starts to look vague or something, then you can try to explain it again in a different manner, but this way you just don't see anything, so it's difficult. If someone hardly gives background information, you have to keep your advice rather general, but when somebody imparts a good deal of background information, your answer can be more exhaustive."[C7]

With application D, caregivers received a history of the patient's health problem via the questions and answers from the web-based triage system. Although the caregivers valued the medical history questionnaire differently, they remarked that it offered many advantages when interpreting the patient request. In their opinion, it offered a lot of information that helped to understand the complaint or the problem better and thus allowed them to distinguish important alarm signals. On the other hand, the medical history questionnaire appeared insufficiently capable of analyzing the health complaint to result in clear advice. It took too long to filter the relevant information.
"Look, if all I can see is 'No' everywhere [answer indicating non-urgent symptoms], I am inclined to stop reading all the answers and overlook the 'Yes'." [C6]

Answering patient requests

Aware that their written answers can have legal consequences, caregivers take great care with the formulation of their answers to patients. Moreover, with the absence of a clear protocol for communicating online with patients, caregivers also worry about the quality of care. With application M, caregivers are alert to mentioning that their advice could be a possible indication of the cause of the complaint, but that it is not a diagnosis.
"Well, I'm always on my qui vive, so as not to write things down in the file that could later be used against me in court, shall we say. So I tread cautiously with the formulation of a number of things."[C5]

"You can give general advice. You can always do that, but you have to incorporate a kind of safety device by saying: 'Oh, in a number of cases, there will be exceptions'. And that's why we are constantly pleading for a quality protocol for these kinds of things, and that protocol must comprise three elements: expertise of the person manning

the desk - it must be someone with considerable experience; there must be a certain guarantee that the questions will be answered within a certain time limit; and the third, and that is the trickiest of them all, is that you must try to give answers that are safe, and…if you think 'There's a risk here', you must also clearly communicate that with… 'if you want to be sure, you must make an appointment'." [C9]

With application D, the web-based triage generated a standard advice (ready-made answer) based on an ICPC code. In the Netherlands, the International Classification of Primary Care (ICPC) is accepted as a standard for coding and classifying health complaints, symptoms, and health disorders in primary care [20]. In most cases, the generated ICPC code did not correspond with the caregiver's expectations. Sometimes an ICPC code could not even be generated and the caregivers themselves had to allocate a code, which was not always easy due to lack of relevant medical information. Moreover, the ready-made answers did not correspond with the professional beliefs of practicing medicine and, as a consequence, they were changed or reformulated (i.e., geared more to the personal and/or medical characteristics of the patient).

"It's just too general. I have to rewrite things quite often. And not all questions from patients refer to an illness. I remember someone asking me once about genetic research. That's not a medical problem. Things are not always run-of-the-mill." [C8]

Documentation of patient requests

The system's features, like sending attachments and archiving patients' questions and answers, were hardly used due to a lack of education about the usage of the applications. Furthermore, despite most caregivers wanting to know how patients acted on their advice, two of the applications (M and D) did not offer a feedback feature. Caregivers thus emphatically advised patients to visit a caregiver in case of doubt about their health problem.

"I find it quite difficult at times, when I get so little feedback on how my answer has been interpreted. Was it successful or not?" [C7]

"It's true it's difficult, because you're not given any feedback. If the patient doesn't react, fine, but if that leads to mistakes being made, that's a pitfall." [C9]

The medical records of caregivers' patients could not be integrated with the documentation system of the web-based applications. Although patients' demographics and medical histories could be saved, caregivers did not use this functionality because they found it inconvenient. All notes on an e-consultation, including date and content were made in their own medical records.

"At this moment I still don't have the option to look at information coupled to my medical record. And no link to your own record is inconvenient." [C11]

"If something really special has to be recorded, then I would do so in my medical record. I regard this [application P] merely as a means of communication, whereby I do not feel the need to document patient information." [C13]

Implementation in practice

Caregivers faced difficulties with the incorporation of e-consultation into daily practice. The web-based care applications were not compatible with the patient administration systems already in use, and e-consultation usually takes place outside of office hours. Moreover, caregivers were ignorant about the conditions (rights and obligations) of e-consultation. Directives for the use of electronic patient-caregiver communication were unavailable or unclear about the care delivery process and the definition of a pre-existing relationship. Caregivers wondered whether a personal encounter was required before an online encounter and about the definition of the first personal contact. Moreover, they expected greater inspection from government on the influence of health care insurers regarding privacy. They also felt the need for an unambiguous view on the admission of email communication for anonymous contact between patient and caregiver. Caregivers are of the opinion that the rate of a web consultation (€4.50) is too low. They think that although e-consultation can be an added value to regular care because access to care could be enhanced, they would restrict its use to simple non-urgent health complaints and to known patients.

Overview of caregiver problems

Table 2 presents an overview of problems faced by caregivers while using the applications for handling patient requests. Caregivers experienced 198 problems in total. About half of the problems concerned the user-friendliness of the applications, such as unclear navigation structures and lack of feedback or documentation possibilities. Quality of care problems concerned laborious answer procedures, the non-profitability of e-consultation, and legal or ethical problems with respect to possible misuse of e-consultation. Implementation problems occurred due to unclear policy on e-consultation and the lack of training for e-consultations. Caregivers found the applications too time consuming because these systems could not be integrated with their existing patient information system or medical records.

Table 2. Overview of caregiver problems (*n* = 198)

Quality demand	Identified caregiver problems
User-friendliness (*n* = 101, 34.8%)	*Navigation problems:* Unclear navigation structure, hyperlinks lacking or useless Lack of feedback features Lack of documentation features Unclear answer procedures/formats *Technical problems:* Software bugs
Quality of care (*n* = 43, 37.9%)	*Non-profitability* of e-consultation:* Requests from patients still required personal contact with a caregiver Concerns about a higher chance of interpretation difficulties: Carefulness with formulating answers to patient requests, such as being extremely careful when formulating the answer because of possible legal consequences *Concerns about a higher chance of misuse:* Requests from unknown patients through using the account of known patients
Implementation (*n* = 54, 27.3%)	*Unclear regulations about e-consultation:* Lack of a transparent protocol for e-consultation Unclear regulations about prerequisites for using e-consultation Lack of quality inspection of e-consultation applications Insufficient reimbursement for e-consultation Lack of education and training: Underuse or misuse of applications because of lack of education Interoperability of systems: Applications could not be integrated with the existing patient information system or medical records Concerns about patient equity of access: Concerns about the risk of widening of the gap between those who have access to new technology and those who have been excluded

*Profitability: the degree to which the health service can be delivered in a quick, effective, and economical manner

Discussion

Patient and caregiver expectations did not correspond with their experiences with the use of the web-based applications for self-care. Patients thought that the applications would support them in solving their health problems, that they would guide them on a 'problem-solving journey on the Internet' by consulting various interactive components that would enable them to make informed decisions about their health condition. Caregivers were more reserved about the applications because of medico-legal concerns about misuse. However, the applications failed to support self-care because eHealth is more than just a technological intervention. The design of the applications should include a way of thinking about how to deliver health care with the aid of technology [21]. The applications provide various interactive components disconnectedly, so users themselves have to find out which feature will be convenient and profitable for what purpose. In terms of diffusion of innovations [11], we know that only very motivated people will persist.

We aspired to determine user-centered criteria for web-based applications for self-care. We focused, therefore, on quality demands for interactive health communication applications as formulated in prior studies [2,11]: user-friendliness, quality of care, and implementation. Based on our results and prior studies, it can be concluded that technology should be simple and easy to use, in line with end users' ways of thinking and behavior with respect to solving health problems via technology. Moreover, to develop or improve web-based applications for self-care, language and comprehensibility of information are important content criteria. Self-care support applications should match the vocabulary of the users and the language of the medical systems. This requires rethinking the presentation of information for self-control via the Internet. From the perspective of caregivers, the applications failed because of their inability to store medical data in the patient records already in use. The adoption of a new technology depends on the presence of an adequate infrastructure or other technologies that cluster with the innovation [11].

What health care functions can be delegated to web-based health care systems? We evaluated three applications with various components for self-care, such as symptom-driven question-and-answer systems, self-tests for preliminary evaluation of the urgency of a health complaint, and e-consultation services for electronic patient-caregiver communication. Patients appreciated email communication more than the other components because they preferred convenient access to a high level of personalized health care. Web-based triage was insufficiently geared to their expectations and was more medico-technology driven than user centered. The applications have multiple components for self-care to appeal a wide range of users, but without a thorough analysis of how people think and frame their problems, how they expect to be responsible for their own care and decisions, and what they need to support this self-care, the components might well result in an overload of information. People get lost on the Internet, so personal assistance is needed. In our opinion, we feel that the organization of patient-centered care expectation management is a prerequisite to delivering health care through technology.

Despite these shortcomings, we believe the applications have the potential to mature. The findings of our study are consistent with the results of previous studies [2,3,22-28]. For instance, the study by Car and Sheikh [24] presented key features for optimal e-consultation, such as ease of adoption; combining new technology with existing ones; user-friendliness; easy to set up, manage, and use by doctors and patients; integration with existing medical records; and archiving and logging. These key features should therefore be addressed in the development of new web-based self-care applications. According to the Institute of Medicine [10], care needs to be customized according to patient needs and values, which we also found in our study. Problems related to quality of care resulted from patients' inability to formulate their complaints as a health problem. The applications should be designed to solve this semantic problem by providing an adequate search engine and by avoiding the use of medical jargon. Moreover, the systems were incapable of delivering personalized and tailored health care, which seems one of the most important requirements for high-quality patient care. In order to improve the quality of care, applications should be designed to meet the most common types of need, but should also have the capability to respond to individual patient choices and preferences [10]. The Kerr et al study [2] identified quality criteria for Internet interventions for long-term conditions. The user-generated criteria relating to information content, presentation of information, language, and interactivity (tailored and personalized advice, question-and-answer functionality) correspond with the findings of our study in the sense that the absence of these criteria impeded self-care.

This correspondence in study findings illustrates that web-based technology in health care is evolving throughout the world and that it encompasses comparable quality demands. Although the impact of web-based technology may not be fully clear until diffusion becomes widespread, explorative studies such as this one can give insight into the requirements necessary for widespread use in the future.

The use of scenario-based tests combined with in-depth interviews proved to be a powerful method for describing and identifying user problems and for supporting the re-design processes of the web-based applications for self-care. From prior studies [4,29], we know that such a qualitative approach provides reliable and meaningful data for developing and implementing web-based technology for supporting self-care. Moreover, the use of the scenario-based tests provided patients and caregivers with the opportunity to learn about the functionality of the applications and how to use them more efficiently, and it gave them more confidence in the utility of the web-based technology.

Notwithstanding the relatively small size of our sample, which limits the generalizability of our results, we now have more insight into the requirements for successful web-based technology for supporting self-care. The aforementioned criteria on user-friendliness, quality of care, and implementation of the technology are key elements in creating an efficient and effective Internet consultation process. To foster widespread use of web-based technology, like electronic patient-caregiver communication and self-assessment via the Internet, the needs of end users should be the starting point for the development of such applications [29-31]. In order to prevent the risk of providing inaccurate or inadequate advice, self-assessment tools that are neither efficient nor effective should not be part of eHealth services. The most powerful application for self-care is e-consultation, combined with a suitable triage mechanism to empower patients' self-awareness.

There will be ongoing demand for evaluation of eHealth services. Future studies should focus on the possibilities of self-care via web-based triage systems combined with email communication to create awareness of illness and to make timely care possible and feasible. These systems should be interoperable with electronic health records and tailored to particular usage (i.e., users with comparable disease profiles).

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Chapter 3.2

Abstract

We studied a web-based triage system which was accessible to the general public in the Netherlands. In a retrospective analysis we investigated the type of complaints that were submitted and the kind of advice provided. Over a period of 15 months, 13,133 different people began using the web-based triage system and 6538 patients went right through the triage process to the end. The most frequent complaints were common cold symptoms, such as cough and a sore throat (22%), itch problems (13%), urinary complaints (12%), diarrhea (10%), headache (8%) and lower back pain (8%).

Two main problems with the use of the system were observed: (a) high dropout rates and (b) invariability of the generated advice. The high drop-out rates were caused because the system was more medically-driven than user-centered. To support self-care and decision-making, it is important to match the expectations of users and the technology. The invariability was caused because the system most commonly generated the advice to contact a doctor (85%); only in 15% of the cases a self-care advice was given, which may not reduce GP visits very much. A clear policy and new legislation about practicing online consultation will be needed to maximize the accessibility and effectiveness of web-based triage and to clarify responsibility for online consulting.

A total of 192 patients participated in a prospective study and completed an online survey immediately after the delivery of advice. A follow-up questionnaire on actual compliance was completed by 35 patients. Among these, 20 (57%) had actually complied with the advice provided by the system. A regression analysis revealed that intention to comply was strongly related to actual compliance. In turn, intention to comply was strongly related to attitude towards the advice ($p < 0.001$).

In conclusion, web-based triage can contribute to a more efficient primary care system, because it facilitates the gatekeeper function. This implies that empowering patients by means of web-based triage requires interventions to instruct and motivate users; which is not common in the implementation of health care technologies. As self management is the focus of electronic care, an in-depth evaluation of patients' needs for autonomy and their readiness to make decisions about their health care is important. Especially in the case of chronically ill patients, who are overrepresented among emergency department visitors, web-based triage systems could reduce uncertainty by delivering alternative access to care, could reduce costs and could facilitate more adequate communication for self-management.

Introduction

Conventionally, triage is applied to urgent conditions [1], but it is also used in primary care to reduce after-hours referrals, usually by telephone [2]. However, telephone triage depends on the ability to make consistent and accurate decisions based on the responses from patients. The advice given by caregivers during telephone triage is often inconsistent and inadequate [2].

Web-based triage may provide advice about the necessity of visiting a general practitioner (GP) in case of minor ailments like a sore throat, which in practice usually leads to self-care advice [3]. To our knowledge, there is little published information about the effect of web-based triage on the care delivery process. Studies of the use of web-based triage in a college health setting indicate good accuracy [4]. There are also indications that web-based triage can reduce utilization costs (e.g., hospital emergency room visits) by directing people to the most appropriate place for care [5]. However, there is a lack of knowledge about the potential of web-based triage to reduce unnecessary doctors' visits by the general public.

The aim of the present study was to investigate the use of a web-based triage system in primary care, and compliance with the medical advice delivered by it. In a retrospective analysis we investigated the type of complaints that were submitted and the kind of advice provided by a Dutch web-based triage system in primary care. In a prospective study, we investigated the users' compliance with the advice provided and the factors that promoted compliance.

Web-based triage system

We evaluated a web-based triage system (http://www.dokterdokter.nl), which is accessible to the general public in the Netherlands and provides diagnoses and advice in primary care. The symptom-driven triage system was developed for 25 health complaints based on the following criteria: high frequency [6], no physical contact required to assess the medical condition and the possibility of ruling out emergencies. No GPs or caregivers are involved in the triage system.

The system gathers the information required to assess a specific health situation by identifying a complaint on a virtual body and using an evidence-based online questionnaire. The questionnaire is adaptive, depending on gender, age and answers provided to previous questions. In the case of non-urgent symptoms, the triage system provides a probable diagnosis, information about the severity of the disease and detailed self-care instructions. Box 1 gives an example of tailored self-care advice for a cough problem. In the case of urgent symptoms the triage system provides the advice to visit a doctor, based on the national health-care standards for triage by telephone [1].

Text box 1. Examples of self-care advice

- Although your complaints can be (very) irritating, there are no reasons to worry
- You have a common disease, you do not need to visit your GP
- Your complaints indicate an upper airway disease, caused by a virus or a bacterium
- This is a non-severe disease, which recovers spontaneously in 1 to 2 weeks
- What a doctor can do, what you can do

Methods

We analyzed the use of the triage system over a period of 15 months. During this period, 13,133 different people began using the web-based triage system and 3812 patients went right through the triage process to the end. We examined the frequencies of the submitted complaints and the types of advice generated by the system. In the retrospective study, we used an existing database where 'clicks' per user were stored, while negotiating the web-based consultation process. To determine which factors were related to compliance with the advice delivered by web-based triage, we carried out a prospective online survey with two waves (wave 1: $n = 192$; wave 2: $n = 35$). Immediately after the delivery of web-based triage advice, patients completed the first wave questionnaire. Using Likert scales (range -2 to +2), we assessed the usability of the web-based triage system, satisfaction with the generated advice, attitude towards the advice (Chronbach's $\alpha = 0.91$), perceived social norm to comply with the advice ($\alpha = 0.79$), perceived self-efficacy to comply with the advice ($\alpha = 0.89$), perceived severity of the complaint ($\alpha = 0.84$), response cost and response effectiveness. Users also indicated their intention (yes/no) to follow up the advice. After three months, the patients received a follow-up questionnaire which assessed their actual compliance with the advice. Using data from two completed questionnaires we carried out a regression analysis to assess the factors that were most strongly related to compliance with the provided advice.

Results

On average, the web-based triage system was used for 29 consultations per day. The numbers of people who started a consultation, submitted a complaint and received advice are summarized in Figure 1. Out of 13,133 patients, who started a consultation, 6538 entered a complaint and 3812 completed the triage process and received medical advice (29% of all those started). There were two critical points regarding drop-out during the triage process. Half the users left the system at the point where they had to identify their complaints. The second critical point was just before receiving the advice.

The most frequently submitted complaints (Table 1) were common cold symptoms, such as cough and a sore throat (22%), itch problems (13%), urinary complaints (12%), diarrhea (10%), headache (8%) and lower back pain (8%). Together, these complaints covered more than 70% of all submitted complaints. The frequency of complaints was similar to the complaints for which GPs are most frequently contacted in the

Netherlands [6]. In general, self-care advice could be given more often for these complaints [7]. The advice generated is summarized in Table 2.

Most commonly, the system generated the advice to contact a doctor (85%) and in 15% of the cases the system provided fully automated, problem-tailored, self-care advice. The relation between the submitted health complaints and the delivered advice is shown in Table 3. In general the system most frequently delivered the advice to visit a doctor in the short-term (within 24 hours or a couple of days with persistent complaints). The frequency of tailored self-care advice was limited, even for complaints that could be treated via self-care [7]. In the case of high frequency complaints, such as common cold, the system generated the advice to visit a doctor, while in the case of lower frequency complaints like itch the system generated tailored self-care advice. For headache and urinary complaints, self-care seemed not to be appropriate.

Compliance with the medical advice

A total of 192 patients participated in a prospective study and completed an online survey immediately after the delivered advice. Most were females (n = 127, 66%) with a middle (n = 101, 53%) to high level of education (n = 55, 29%) and most were 16-35 years old (n = 107, 56%). Patients knew about the web-based triage system by surfing on the Internet (n = 73, 38%) and by advertisements of a health insurer (n = 62, 32%). At the time of completing the questionnaire, most patients (n = 104, 54%) had visited the web-based triage system for the first time.

The triage system was used to gather information about a health complaint (n = 72, 38%) and to decide whether it was necessary to contact a GP (n = 38, 20%). Prior to triage, 73 patients (38%) intended to visit a GP for their complaint. The evaluation of the web-based triage system is summarized in Table 4. All scores were neutral to slightly positive, which indicates that patients did not have a clear mental representation of what to expect from a triage consultation. This can be explained as a lack of experience, as only a minority had used the web-based triage system more than once. A follow-up questionnaire on actual compliance was completed by 35 patients. Among these, 20 (57%) had actually complied with the advice provided by the system.

A regression analysis (Table 5) revealed that intention to comply was strongly related to actual compliance. In turn, intention to comply was strongly related to attitude towards the advice ($p < 0.001$). Attitude towards the advice was primarily shaped by the perceived effectiveness of the delivered advice ($r = 0.71$, $p < 0.01$) and trust in the web-based triage ($r = 0.52$, $p < 0.01$).

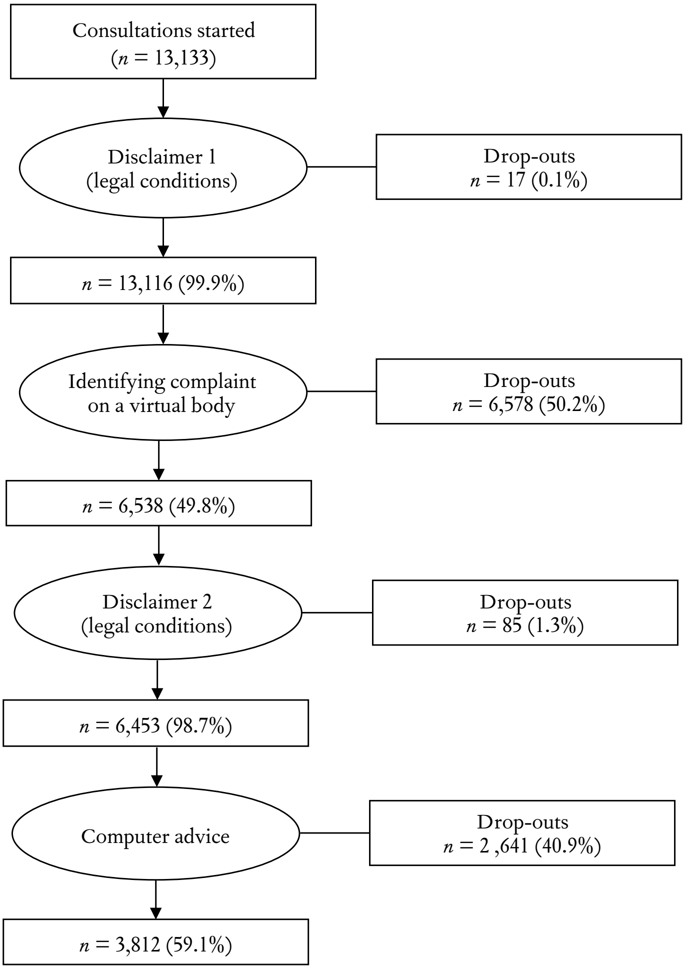

Figure 1. Consultation process

Table 1. Overview of complaints

	n	%
Cough, running nose, throat pain	1432	22
Itch, red spots and/or bumps	863	13
Urinary complaints	765	12
Diarrhea	667	10
Headache	523	8
Lower back pain	490	8
Shoulder complaints	294	5
Itch in armpit/pubic hair	281	4
Bitten by human or animal	203	3
Eye complaints	183	3
Ear complaints	177	3
Foot complaints	170	3
Forgotten contraceptive	137	2
Ankle complaints	98	2
Itch on the head	85	1
Swollen legs	85	1
Knee complaints	85	1
Total	6538	100

Table 2. Overview of generated advice

	n	%
GP - urgent	126	3
GP - soon	560	15
GP - short term	640	17
GP 24 hours	1914	50
Self-care	572	15
Total	3812	100

Table 3. Overview of submitted health complaints ($n = 2930$) and advice given

	Advice to contact a doctor		*Tailored self-care advice*
	Urgent[a]	*Short-term*[b]	
	%	%	%
Common cold complaints ($n = 877$)	14	71	14
Itch, red spots and/or bumps ($n = 462$)	0	73	27
Urinary complaints ($n = 417$)	0	98	2
Diarrhoea ($n = 435$)	0	75	25
Headache ($n = 305$)	0	95	5
Eye complaints ($n = 138$)	0	75	25
Ear complaints ($n = 114$)	0	79	21
Foot complaints ($n = 102$)	0	78	23
Forgotten contraceptive ($n = 80$)	0	51	49

[a] Urgent: call the emergency number 112/911

[b] Short-term: contact a doctor within 24 hours / within a couple of days with persistent complaints

Table 4. Evaluation of web-base triage of complaints

	Mean score	*Scale*
Attitude towards advice	0.42 (neutral to positive)	(scale -2 to +2)
Self-efficacy	1.0 (positive)	(scale -2 to +2)
Social influence	1.3 (neutral)	(scale -10 to +10)[a]
Perceived complaints	-0.24 (slightly severe)	(scale -2 to +2 (-2= non severe)
Intention to comply with advice	0.49 (neutral to positive)	(scale -2 to + 2)

[a] Social influence was computed from the product of two variables: "do you think your family finds it important" (-2 to +2) and "to what extent the opinion of your family is important for you" (1 to 5)

Table 5. Predictors of intention to comply with medical advice delivered by the system

Determinants of intention to comply with advice ($R^2 = 0.53$)	*Beta*	*Determinants of actual compliance with advice ($R^2 = 0.47$)*	*Beta*
Attitude	0.69***	Attitude	0.21
Subjective norm	0.05	Subjective norm	0.26
Self-efficacy	0.08	Self-efficacy	0.15
Severity of complaint	0.07	Severity of complaint	0.08
		Intention to comply	0.72**

Note. ** $P < 0.01$, *** $P < 0.001$

Discussion

The present study suggests that a web-based triage system has the potential to reduce costs and to promote self-care. However, there are two main problems: the high dropout rates and invariability of the generated advice. The dropout rates were high, especially before entering a complaint (50%) and just before the system delivered advice (40%). Based on the retrospective study we were only able to investigate the moments when users left the system, not their motives in dropping out or the perceived barriers in continuing with the system. In the future, in-depth interviews will be necessary to understand these matters.

A second problem was the invariability of the generated advice. In most cases the system generated the advice to visit a doctor (85%). In the case of high frequency complaints such as the common cold, the system generated the advice to visit a doctor, while in the case of lower frequency complaints like itch the system generated tailored self-care advice. This indicates that the system was more medically-driven than user-centered. In only 15% of the cases was self-care advice given, which may not reduce GP visits very much. A clear policy and new legislation about practicing online consultation will be needed to maximize the accessibility and effectiveness of web-based triage and to clarify responsibility for online consulting. Our findings are consistent with the findings of other studies about similar web-based triage systems. A web-based triage system, operated in the USA, was mainly used by women for high frequency, non-urgent complaints [4].

A second aim of our study was to investigate the factors that were related to compliance with the generated advice. A prospective survey revealed that attitude to the advice was strongly related to intention to comply with the advice, while intention to comply was strongly related to actual compliance with the advice. This means that web-based triage can promote self-management of minor ailments, especially among patients with a positive attitude towards the computer-generated advice. This positive attitude leads to intentions to follow up the advice and to actual follow-up. A limitation of the study was the limited response to the online surveys and the incompleteness of the responses. Patients did not respond to all questions. The explanations could be the period of examination, summer time and the lack of experience with online triage. On the other hand, the results were similar to findings in other studies about web-based triage [4,5].

Although there were start-up problems, we foresee opportunities for web-based triage. Online patient interviewing via web-based triage can be used for diagnosis and early detection of risks, for instance for preoperative screening and handling taboo complaints, see for example http://www.incocure.com. It appears that web-based triage can promote effective treatment of urinary incontinence [8]. Also, web-based triage could be used in preparation for a GP visit [9]. From prior research we know that reduction of uncertainty was the main factor in using web-based triage [10].

To support self-care and decision-making, it is important to match the expectations of users and the technology. Patients experienced a high percentage of referrals to a doctor, which was higher than they expected. So there was an imbalance between the central idea of web-based triage and the intended use of it. As self management is the focus of electronic care, an in-depth evaluation of patients' needs for autonomy and their readiness to make decisions about their health care is important. Especially in the case of chronically ill patients, who are overrepresented among emergency department visitors, web-based triage systems could reduce uncertainty by delivering alternative access to care, could reduce costs [11] and could facilitate more adequate communication for self-management [12].

In conclusion, web-based triage can contribute to a more efficient primary care system, because it facilitates the gatekeeper function. This implies that empowering patients by means of web-based triage requires interventions to instruct and motivate users; which is not common in the implementation of health care technologies.

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Chapter 4

Conditions for sustained use of eHealth technologies for supporting self-care of patients with long-term care needs

Based on: Nijland N, van Gemert-Pijnen JEWC, Kelders SM, Brandenburg BJ, Seydel ER.
Factors influencing the long-term use of a web-based disease management program for supporting self-care of patients with diabetes type II. Submitted to Journal of Medical Internet Research.

Abstract

Background: The take-up of eHealth applications in general is still rather low and only limited information is available about the level of technology usage among specific patient groups.

Objective: The aim of this study was to explore the factors that influence the use - initial and long-term - of a web-based disease management program for supporting the self-care of patients with diabetes type II.

Methods: Using a mixed-methods research design with log files, usability tests, interviews and a survey, we assessed the actual use of the web application over a 2-year period along with the motivation to use the web application and the barriers that hindered this, and the patients' demographics and health-related characteristics.

Results: The DiabetesCoach was predominantly used for interactive features like online monitoring, personal data and patient-nurse email contact. It was the continuous, personal feedback that particularly appealed to the patients; they felt more closely monitored by their nurse and encouraged to play a more active role in self-managing their disease.

Despite the positive outcomes, usage of the web application was hindered by low enrollment and non-usage attrition. The main barrier to enrollment had to do with a lack of access to the Internet (65%, 146/226). Although 68% (34/50) of the enrollees were continuous users, of which 30% (15/34) could be defined as hardcore users (highly active), the remaining 32% (16/50) did not continue using the web application for the full duration of the study period. Barriers to long-term use were primarily due to poor user-friendliness of the system, the absence of 'push' factors (reminders), and selection of the 'wrong' users; the well-regulated patients were not the ones that could benefit the most from system use because of a ceiling effect. Patients with a greater need for care seemed to be more engaged in long-term use; highly active users were significantly more often medication users than low/inactive users ($p = .005$), and had a longer diabetes duration ($p = .03$).

Conclusions: Innovations in healthcare will diffuse more rapidly when technology is employed that is both simple to use, and has applicable components for interactivity in order to foresee the patients' need for continuous and personalized feedback, in particular for patients with a greater need for care. This study has set out three key strategies for increasing the use of eHealth technologies: (a) avoid selective enrollment, (b) make use of participatory design methods, and (c) develop persuasive technology. Further research should focus on the causal relationship between using the system's features and actual usage, as such a view would provide important evidence on how specific technology features can engage and captivate users.

Introduction

The prevalence of diabetes is rising quickly. Diabetes among adults - aged 20-79 years - affected 285 million adults in 2010 (6.4%) and is estimated to increase worldwide to 439 million adults by 2030 (7.7%) [1]. Between 2010 and 2030, there will be a 69% increase in the number of adults with diabetes in developing countries and a 20% increase in the developed countries. Most people with diabetes fall within the 60-79 year-old age-group and approximately 90% have diabetes mellitus type 2. Improving diabetes care management has therefore become a priority for healthcare facilities and patients' organizations worldwide. The ultimate goal of diabetes care management is to optimize self-care in order to reduce the mortality, morbidity and healthcare costs [2,3].

The introduction of the Internet into clinical practice has brought about many opportunities for self-care [2-7] as it can be used as a powerful medium for promoting a healthy lifestyle and for increasing the understanding about the condition. However, to be effective in empowering patients' self-awareness and engagement, web applications should be designed to allow individuals to tailor the program to their own specific needs, because patients are increasingly demanding convenient access to a high level of personalized healthcare [8,9]. To promote self-care, interactive eHealth applications have been developed for continuous self-monitoring, feedback, and information exchange. One example of such an application is a web-based disease management program for self-care support among patients with diabetes type 2, which is the subject of this study.

From previous studies we know that interactive eHealth technologies contribute positively to healthcare for patients with a chronic illness, realizing increased patient-provider communication, positive impact on metabolic control and behavior change, improved therapy adherence and cost reductions [6,7,10-14]. However, to date the uptake of eHealth in general is still rather low [15,16]. Therefore, more research should be directed towards the factors that provide insights into the actual usage and the accompanying reasons for use and non-use of eHealth technologies.

Expanding the uptake of eHealth requires, first and foremost, a better understanding of the obstacles that prevent access (initial use) [15,17-19], and secondly a better understanding of the factors that influence the long-term use of eHealth technologies [20-23] since many projects still fail to survive beyond the pilot phase. To this end, a longitudinal study was performed. The aim of the study was to explore the factors that influenced the use - initial and long-term - of a web-based disease management program for supporting the self-care of patients with diabetes type 2. Using a mixed-methods research design with log files, usability tests, interviews and a survey, we assessed the actual use of the web application over a 2-year period along with the motivation to use the web application and the barriers that hindered this, and the patients' demographics and health-related characteristics.

Methods

Description of the web application

The DiabetesCoach, a web-based disease management program for supporting self-care among patients with diabetes type 2, was developed to persuade patients to play a more active role in their own care. The web application is a low-tech solution for a large group of patients and is provided free of charge as an additional supplement to regular diabetes care. The application was developed by Medicinfo in 2007 in close collaboration with GPs, nurses, patients, behavioral scientists and vendors i.e. health insurance companies. Initial development costs were relatively limited and the running costs of the application were low. Therefore, a rise in use would not lead to an exponential rise in costs.

These are the core features of the DiabetesCoach:

- *My personal data*; patients can document their personal details such as their treatment plan, medication use, and information about their treatment and caregivers.
- *Online monitoring*; patients can register their metabolic values such as weight, blood glucose level, blood pressure and cholesterol. These levels have to be between certain margin values. The nurse can adjust these levels according to the individual patient.
- *Email contact*; secured possibility for patients and nurses to send and receive email messages. A nurse responds to messages from the patients within 5 working days.
- *Online education*; information about diabetes and instructions on how to live with it.
- *Calendar*; the nurse and the patient can write down their comments. The nurse can write down his or her advice, the patient can write down any special circumstances. There is also space to fill in the appointments with the nurse, GP or dietician. The patient also sees his or her own personal goals in the calendar, e.g. how many kilos must be lost within a certain period. The notes in the calendar can be used in the discussion that takes place during the regular consultation;
- *Personal lifestyle coach*; patients are provided with different tools such as self-tests (healthy-living test, sports selector) which support them in an attractive way in their lifestyle changes or help them to become more aware of their own personal situation and what they should do to improve it.

The patients' self-monitored data are made available to the nurses with alerts signalling alarming metabolic values. Each nurse has access to each of her own patients' DiabetesCoach details, via her own account (protected via username and password). Access for other healthcare professionals is denied. The DiabetesCoach was not integrated with the medical record of the nurse. The web application enabled nurses to set individual goals for their patients, add selected lifestyle programs and highlight the appropriate chapter of the e-learning program. The patients received no particular instructions with regard to how often they should log-on to the DiabetesCoach (no fixed use). Patients measured metabolic values both at home and at the primary care practice during office visits. Nurses were allowed to have two extra consultation sessions per patient to compensate for the extra time needed to participate in the study. The information and guidelines provided in the DiabetesCoach were in accordance with diabetes care standards and protocols in the Netherlands.

Participant recruitment

A primary healthcare foundation in the Netherlands consisting of ten primary healthcare practices and a home care organization employing the diabetes nurses ($n = 6$) agreed to become partners in the pilot. Three primary healthcare practices volunteered to take part in the DiabetesCoach project. The selection criteria for patient enrollment included: patients having diabetes mellitus type 2 (the primary focus was on fostering lifestyle changes), patients being motivated to perform self-care activities, patients having access to the Internet and being sufficiently skilled to use the Internet. Via a recruitment letter, 350 patients were invited to use the DiabetesCoach. Patients were informed about the purpose and possibilities of the web application both through the letter and during the office visit. Fourteen per cent (14%) (50/350) responded positively to the invitation. In total, 50 patients enrolled in the project. Training sessions (offline) were set up for the enrollees. During the training sessions the participants received instructions on how to use the application, plus a user manual. Also, an email functionality was created for technical support. All 50 enrollees agreed to participate in the pilot study and filled out the informed consent forms.

Research design

A 2-year pilot study (2007-2009) with a mixed methods research design [24,25] was set up in order to explore the conditions for long-term use of a web application among patients with diabetes type 2. Table 1 presents an overview of the research instruments and the accompanying characteristics of the study.

Table 1. Research instruments and study characteristics

Research instruments	*n*	Purpose	Participants
Survey	50	Enrollee characteristics	Enrollees[b]
Interviews by nurses	226	Barriers to enrollment	Non-enrollees[a]
Usability-tests/interviews	20	Motivations for use Usability problems	Enrollees[b]
Log files/content analysis	50	Use of system features Email message content Long-term use	Enrollees[b]
Follow-up emails	6	Barriers to long-term use	Enrollees[b]

[a] primary care patients who chose not to participate in the DiabetesCoach project (n = 300)

[b] primary care patients who chose to participate in the DiabetesCoach project (n = 50)

A *paper-based survey* was administered at baseline among all the enrollees ($n = 50$) to assess patients' demographics and health-related characteristics: age, gender, education, health status, diabetes duration, diabetes treatment (medication use), and treatment satisfaction. In total, 42 patients returned the survey completely filled out.

The *nurses interviewed* 226 of the 300 non-enrollees during office visits to assess the reasons for non-enrollment. *Log files* were used to register the actual use of the web application by participating patients during the 2-year study period. We measured the frequency of use of the features of the web application by patients, the long-term use (mean number of hits over the course of 2 years) of the web application by patients per practice, the long-term use (mean number of hits over the course of 2 years) of the main features of the web application by patients, and the content of the patient-nurse email messages.

Usability tests combined with interviews were performed after three months of usage with 20 out of 50 patients to investigate patients' experiences with using the web application. The interview with open-ended questions aimed to assess the patients' eHealth literacy, motivations for enrollment in the DiabetesCoach project, and their positive or negative experiences with using the system based on the Critical Incidents Technique [26,27]. The usability test contained several tasks for each feature of the web application to track the problems that occurred during use. Trained observers watched users communicating with the interface of the application while doing simulated tasks and thinking aloud [28]. The participants' activities were recorded with audio-visual equipment (MORAE version 2.1, TechSmith). The sessions were carried out at the participants' home or at the healthcare practice. Each test lasted for about 90 minutes. One year after the initial use of the web application (July 2008), 20 patients who were not actively using the application by that time were asked via *email (follow-up)* to report their reason for discontinued use. Out of the twenty e-mail messages that were sent, six responses were received.

Data analysis

Statistical analyses were performed using SPSS version 16.0. Standard descriptive statistics were performed and chi-square tests (Fishers' Exact Test for categorical variables) and F-tests (for continuous variables) were used to identify significant differences between the different interest groups - highly active versus low/inactive users - in demographics and use of the system's features.

A content analysis was performed to assess the content of the patient-nurse email contact. Before the actual analysis, duplicate messages were removed. The coding process was based on the grounding theory [29], and the codes that emerged were discussed and classified (10 categories, see Appendix 1) by two coders (NN, JvG). The unit of analysis in our coding is the unit of meaning (or thematic unit), which can be defined as a single statement reflecting a complete thought or idea [30,31]; this may be expressed as a simple sentence, a sentence clause, a sentence fragment, or a single word. Statements with the same meaning within the same message were only coded once. All email messages were coded independently by two authors. There was 85.7 per cent agreement across categories, with the few instances of disagreement discussed and reconciled.

Usability tests combined with interviews were administered with 20 patients. The data was analyzed using deductive analysis. The researcher (NN) used standard approaches for qualitative data and took detailed notes during the sessions. Notes included the navigational choices that each respondent made as he or she worked through the tasks, his or her comments while thinking aloud, responses to the questions the researcher asked, times when actions occurred, and remarks made during the debriefing sessions [32,33]. In total, the researcher noted 166 problems among 20 patients. The coding for problem categories was derived from a conceptual framework developed earlier for the identification of usability problems with eHealth technologies [34].

In order to distinguish the hardcore users from the ones that discontinued using the web application, we measured the actual use of the DiabetesCoach by enrollees (n = 50) during the entire study period (2 years). Our measure of user activity was defined by three measures:

(1) *Activity pattern*; measures how regularly patients have actually used the web application until the end of the total study period of 24 months (Appendix 2-3).
(2) *Activity degree*; measures how many months patients have actually used the web application during the total study period of 24 months (Appendix 3).
(3) *Frequency of log-ins* (Appendix 4).
To set the norm for discontinuity, we looked at the activity pattern of patients (measure 1). We found that after a period of 7 months of no activity at all, patients began using the DiabetesCoach again (see for example patient 38 in Appendix 2-3), but none of the patients did this after 8 months of no activity. In this study we therefore chose to set the norm for discontinuity at 8 months or more of no consecutive activity (Appendix 3: search within the activity pattern (non-active) for the number (8) or higher). It turned out that several continuous users had an activity degree that was comparable to that of the discontinued users, though spread over a longer period. This group of continuous users can be characterized as low active users.

Results

Use of the web application

Who uses the web application and why?

Enrollees (*n* = 50) were aged between 43-80 (mean 61) years. The study sample consisted of 37 male and 13 female patients. The majority of the patients were of Dutch origin (80%, 40/43). Most had a high or medium level of education (Table 2), were treated with a special diet and used tablets such as Metformin. Treatment satisfaction was already high before implementation of the web application (95%, 40/42).

Table 2. Enrollee characteristics

Characteristics		n	%
Education (*n* = 43)	Low	5	12
	Medium	22	51
	High	16	37
Health status (*n* = 43)	Excellent	0	0
	Very good	6	14
	Good	25	58
	Fair	12	28
	Poor	0	0
Diabetes duration (*n* = 42)	0-2 year	12	29
	3-6 years	16	38
	>7 years	14	33
Diabetes treatment (*n* = 43)	No treatment	2	5
	Diet	4	9
	Diet & tablets	37	86
	Diet, tablets & insulin	0	0

Using the web application yielded three major advantages concerning the quality of care:

- *Increased possibilities for self-care*; the systems' features stimulated patients to play a more active role in self-managing their diabetes.
- *More continuously received feedback from the nurse*; patients experienced the feeling of being better looked after by their nurse. The technology made intensified contact between patient and nurse available, also in-between the regular three-monthly visits.
- *Improved access to care*; e-mail was convenient for the patients because the nurse is hard to reach by phone.

What system features are used?

The DiabetesCoach was predominantly used for online monitoring (35.2%; total hits of the core features of the web application by patients during the study period: $n = 6289$), personal data (26.2%) and patient-nurse email contact (23.2%), and to a lesser extent for online education (7.5%), calendar (5.3%), personal lifestyle coach (2.5%), and the printing feature (1.7%). Patients were particularly interested in *online monitoring* for creating measurement overviews (graphs) of their blood sugar levels, weight and blood pressure (see Appendix 5). The *email feature* was used to supplement the online monitoring feature to inform the nurse about clinical values that had been entered and to provide explanations for their monitored values. The nurse provides weekly feedback to patients, provided that the patient uses the DiabetesCoach i.e. by entering values. As such, the email feature serves as an additional means of surveillance; it allows the nurse to respond more quickly to changes in metabolic values and adjust the treatment regime (medication) when necessary. In total, 142 messages were sent by patients from July 2007 until July 2009. *Personal data* was primarily used to document medication use. The use of this feature was surprisingly high, because the need to use it was expected to be less high compared to the more interactive features such as online monitoring. Once the personal data, such as medical details, have been documented, these details will not change that much over time, whereas metabolic values can vary from day to day and therefore require a higher level of interactivity, namely a higher need for active participation between patient and nurse. It turned out that the Personal Data feature is used together with the online monitoring feature. Patients like to track medication use to see if a drug has been effective for improving health. The *Calendar* - which is used to schedule appointments and actively set goals - is also interactive, but was used to a lesser extent. The most likely reason for this was that the appointments could only be made by the nurse and there was no possibility for the patient to react e.g., to accept or reschedule the appointment. As such, the level of interactivity was lower than expected and instead of using the Calendar, email was used to communicate about appointments. *Online education* was used to a lesser extent. Appendix 5 presents the chapters that were being looked at. There was no specific content that patients were looking for; interest among the different themes was rather diffuse. Patients wandered around and glanced at all the chapters.

What sort of information is communicated in the emails?

In order to get more detailed insights into the functioning of the email feature we registered all of the messages sent between the patients and their nurse during the study period from July 2007 until July 2009. In total, 323 email messages were sent during this period with 193 messages from the nurse and 130 messages sent by patients (12 duplicate patient messages were removed from the analysis). During the total study period, the nurses initiated email contact more than the patients (respectively 59.8% and 40.2%). It was during the first months of use in particular that nurses sent their patients emails to encourage them to use the web application. In the qualitative content analysis of the email messages, a total of 10 content categories were distinguished (Table 3). As displayed in Table 3, the top three ratings of content that were most prevalent within the patient-nurse email exchange concerned communication about clinical values (online measurement of metabolic values), administrative issues like appointment scheduling, and affective statements (expression of emotions).

Table 3. Email message content

	Total messages (n = 323) Statements		Patients' messages (n = 130) Statements		Nurses' messages (n = 193) Statements	
Content categories	n	%	n	%	n	%
Measurements[a]	104	32.2	42	32.3	64	33.2
Administrative communication[b]	101	31.3	25	19.2	77	39.9
Affective communication[c]	99	30.7	38	29.2	63	32.6
DiabetesCoach remarks[d]	49	15.2	28	21.5	21	10.9
Medication use[e]	42	13.0	12	9.2	31	16.1
Physical symptoms[f]	29	9.0	19	14.6	10	5.2
Use of DiabetesCoach functionalities[g]	24	7.4	3	2.3	21	10.9
Lifestyle support[h]	20	6.2	14	10.8	8	4.1
Current events[i]	18	5.6	6	4.6	12	6.2
Other[j]	20	6.2	10	7.7	10	5.2

Note: Statement = a thematic unit (a unit of meaning within a message); one single message can contain one or more statements

[a] Communication about clinical values such as blood sugar, blood pressure, weight and cholesterol

[b] Communication about referrals, appointment scheduling, etc.

[c] Expression of emotions such as compliments, relief, worries and also social talk (warm wishes and thanks)

[d] Communication about (technical) problems with the use of the web application

[e] Communication about medication use

[f] Communication about physical symptoms/health problems

[g] Communication about nutrition, exercise, etc.

[h] Communication about DiabetesCoach functionalities, other than online monitoring e.g., use of the lifestyle coach

[i] Communication about new diabetes-related websites and courses

[j] Communication not related to the use of the web application

Certain contrasts were noticed in the content of the patient-nurse email exchange. It turned out that the nurse, more so than the patients, communicates about administrative issues and treatment plans. Communication about treatment plans referred to medication use, with a particular emphasis on medication adjustments. Administrative statements concerned (re)scheduling appointments, also for contact by telephone, and to pass on out-of-office (holiday) data. In this way, for the nurse the DiabetesCoach functioned primarily as a means of coordinating care for more efficient communication (time savings). Patients, on the other hand, communicate more than nurses about their state of health and how they are feeling. For example, they let their nurse know that they were doing well, as a confirmation or ratification of the treatment regime. As such, email is primarily used to pass on information, so that the nurse is aware of what is going on. Nurses, for their part, respond by giving affective feedback. Affective communication by both patients and nurses conveyed in essence social conversations, like best wishes, friendly gestures like thanks, and expressions of worry or concern (among patients). The nurses reacted to such concerns with expressions of empathy (statements that convey the nurses' alliance with the patient in terms of help and support, and decision-making). Yet, affective communication by the nurses contained primarily expressions of approval such as compliments.

Non-use of the web application

Low enrollment

Patient enrollment was lower than expected; only 50 (14%) out of the 350 patients who were approached responded positively to the invitation to use the DiabetesCoach. The nurses interviewed 226 non-enrollees during office visits to gain insights into the barriers that inhibited their enrollment.

The reasons given for non-participation were: lack of Internet (65%), use will not have any added value (11%), not in the mood to spend much time on the PC (10%), not in the mood to be occupied with the disease (4%), lack of skills to use the Internet (4%), too busy, no time (2%), other, such as 'patient is about to move to another town' (4%). Obviously, patients experienced more external barriers to access (not having the equipment and lacking the right skills: 69%) than internal motivational barriers (not willing to use it, no added value: 28%).

Non-usage attrition

Over the total 2-year study period, from July 2007 until July 2009, a decline in usage can be observed in all three practices (Figure 1). Practice 3 had a relatively higher overall usage. Probably, because most technical problems had been solved by the time practice 3 started to use the application; three months after practice 1 and 2.

Figure 2 presents the long-term use of the main features of the web application. The three features concerning 'personal data', 'online monitoring' and 'e-mail contact' were all used regularly until the end of the 2-year study period. Online education was used primarily during the first months of use (the curiosity plateau) and diminished over time.

Reasons for non-usage attrition could be attributed to the absence of triggers to use the web application (lack of push factors) which hindered system usage. Patients forgot to use the DiabetesCoach because of the absence of a reminder-feature.

"I regret having to inform you that I have not been using the DiabetesCoach a great deal so far. The reason was that, initially, logging-on to the programme went wrong a few times, after which I more or less forgot about it." (Patient 14)

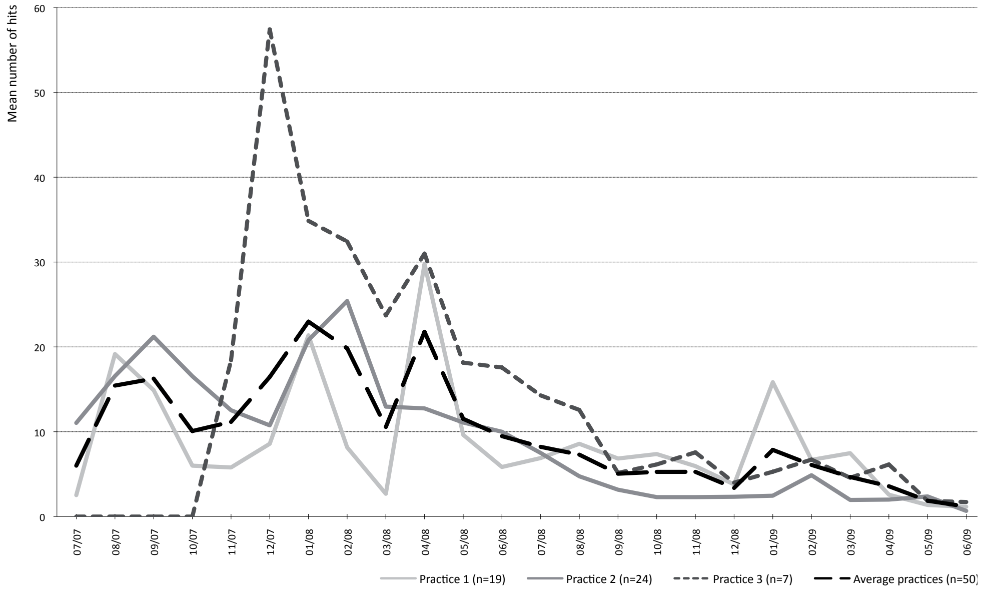

Figure 1. Long-term use of the web application by patients per practice

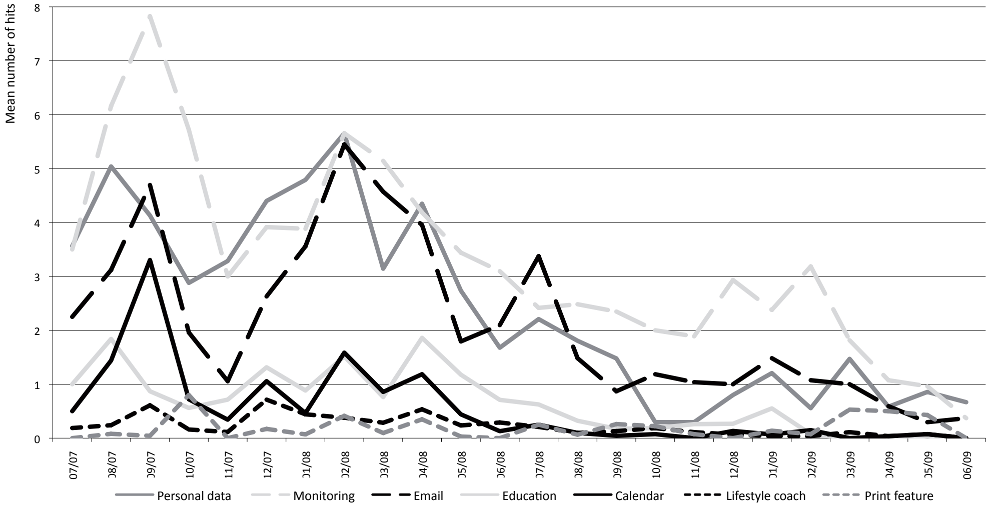

Figure 2. Long-term use of the main features of the web application by patients

Poor user-friendliness

Usability tests revealed some more in-depth insights into the problems that were encountered with the technology. In total, 166 problems were identified. These problems could be categorized as:

(a) *Poor navigation structures (n = 99)*; the most remarkable observation during the usability test was that the patients were oblivious to the possibilities of the system, caused by uncommon navigation structures. In particular, the e-mail feature was undiscovered, which could explain why the message overview was used more extensively than the actual sending of messages (see Appendix 5). Patients were reported to favor a mailbox structure, which they were used to.

(b) *Lack of push factors (n = 43)*; patients wished to get reminders to use the web application, preferably via their regular (daily) e-mail program. Patients wished to get notifications on newly posted messages on the DiabetesCoach by their nurse and for new and updated information on the site.

Integrating eHealth technology with existing traditional 'offline' care could also serve as a push factor. For example, patients with Diabetes type 2 can be asked to use the technology for discussing online monitoring during their visit to the GP or nurse.

Moreover, the Calendar could be more interactive; patients wished to schedule their own appointments via the log book. However, the current log book settings only allowed the nurse to do this.

(c) *Technical errors (n = 16)*

(d) *Problems with logging onto the system (n = 6)*

"She (the nurse) had emailed me and I just didn't see it." (Patient 43)

"Quite simply, I just forget and I'm really not that preoccupied with it. Perhaps if my diabetes nurse would provide some more help or pay some more attention to it, it might result in more interest. I have also failed to see the added value for my health so far." (Patient 17)

"I wouldn't mind it being a bit more interactive; that you would get a signal, so to say, to at least enter something every week and then to get some reply. Then you would get a slightly more stable rhythm, instead of 'I'll have a look to see if something came in'. A sign would have to be linked to my regular mailbox saying: you have received a message. It should force me, encourage me and trigger me as in: hey what's this then?" (Patient 1)

Ceiling effect

For some, using the application no longer had any added value. The results suggest that patients with their diabetes (e.g., blood sugar level) under control have a less pronounced need to use a web application for self-care support.

"My blood sugar level has been 'normal' for two years now without using medication, and my weight, cholesterol, and the like have also been continuously good without medication. Medical check-ups have been reduced to twice a year by mutual consultation with my general practitioner. A good result for me personally, but as a result there is very little for me to report." (Patient 46)

User profiles

Continuous versus discontinued users

Log files were used to investigate the user profiles of continuous and discontinued users. Appendix 2 and 3 (activity pattern) present an overview of the monthly use of the web application during the entire study period of 24 months. It can be seen that use of the web application fluctuates over time. There is no fixed regime; each patient used the DiabetesCoach whenever it suited them (free use).

From the three measures defined: activity pattern, degree of activity and number of log-ins (methods; analysis of user profiles), three groups of users could be distinguished:

(a) *Continuous users who are highly active (n = 15)*:
- period of no activity < 8 months (based on the activity pattern, see Appendix 3)
- activity degree varying from 68% to 100% (17-24 months use, see Appendix 3)
- frequency of log-ins: 45-191 (see Appendix 4)

(b) *Continuous users, but with lower levels of activity (n = 19)*:
- period of no activity < 8 months
- activity degree varying from 29% to 67% (7-24 months use)
- frequency of log-ins: 10-96

(c) *Discontinued users (n = 16)*:
- period of no activity ≥ 8 months
- activity degree varying from 0% to 67% (0-16 months use)
- frequency of log-ins: 0-56

Figure 3 presents user activity over a sustained period of time. About 68% of the enrollees continued using the web application. Of those regular visitors, 30% can be defined as hardcore users; patients who are highly active in using the web application.

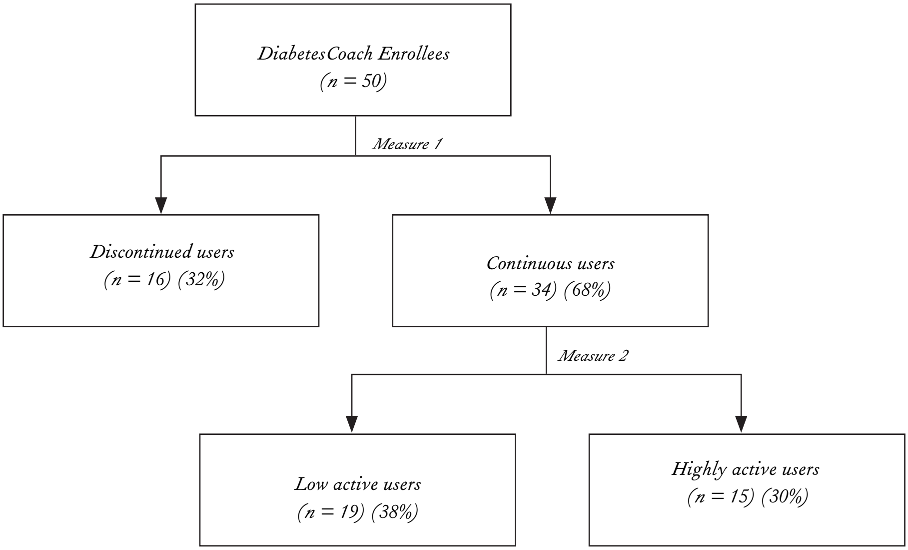

Figure 3. User activity of DiabetesCoach enrollees

Appendix 2 and 3 show that all patients from practice 1 were continuous users, whereas patients from practice 2 were more likely to be discontinued users. One possible reason for this is the closer contact between the patients and their nurse; the nurse of practice 1 was more actively involved in e-mail contact (interactive feedback) with her patients than the nurses of practice 2 and 3 (respectively 4.5, 3.8, and 2.4 messages sent per patient).

When taking into account patient characteristics, the discontinued users did not differ substantially from the continuous users, although a trend could be observed whereby the discontinued users were more often patients without medication (92%, 11/12).

We believe that more engagement in system use (being highly active) might result in better adherence to self-care activities. This is why we compared the following two groups: (a) highly active users vs. (b & c) low/inactive users with respect to their characteristics and preferences.

We also expected that patients with a greater need for care such as the elderly, people on medication, and patients who suffered from diabetes for a longer time, would benefit most from the technology and would therefore be more inclined to use the web application. Table 4 presents the results on demographic and health-related characteristics. These results show that the hardcore users of the web application were significantly more often medication users than low/inactive users (two-sided Fisher Exact Test, $p = .005$). Hardcore users also had significantly longer diabetes duration (one-sided Anova Test, F (1;41) = 5.0, $p = .03$). Other p-values were not significant (values ranged from .279 to .938).

Table 4. Patient characteristics related to user activity

		Highly active (*n* = 15)		Low/inactive (*n* = 35)	
		n	%	n	%
Gender (*n* = 50)	Male	12	75.0	25	73.5
	Female	4	25.0	9	26.5
Age (*n* = 50)	43-56	6	37.5	11	32.4
	57-64	7	43.8	9	26.5
	65-80	3	18.8	14	41.2
Education (*n* = 43)	Low	2	13.3	3	10.7
	Medium	7	46.7	15	53.6
	High	6	40.0	10	35.7
Health status (*n* = 43)	Very good	3	20.0	3	10.7
	Good	8	53.3	17	60.7
	Fair	4	26.7	8	28.6
Medication use (*n* = 43)[a]	Yes (tablets)	6	40.0	1	3.6
	No	9	60.0	27	96.4
Diabetes duration (*n* = 42)[a]	0-2 years	2	13.3	10	37.0
	3-6 years	5	33.3	11	40.7
	> 7 years	8	53.3	6	22.2

[a] $P < .05$

To gain an insight into the preferences of the two distinct groups: highly active users and low/inactive users, we presented the frequency of use of the system's core features. Table 5a presents an overview of the core features and ranks them according to use (the features that are preferred most). As already seen earlier, the top three most preferred features (that is, the most frequently used) included: personal data, online monitoring and email. Yet table 5b reveals slight differences between both groups:

- Ranking among the highly active group: (1) online monitoring, (2) email, (3) personal data.
- Ranking among the low/inactive group: (1) personal data, (2) online monitoring, (3) email.

Of all the core features, online monitoring was most extensively used among the hardcore group of users. This can be explained by the fact that the hardcore users are more likely to be frequent medication users who regularly have to pass on their clinical values to their nurse, which requires a higher level of contact (interactivity) between the patient and the nurse. Using the web application will be more beneficial in this case because it increases the efficiency of the care process. The most frequently used feature among the low/inactive users was "Personal data". This result can be explained as follows: although low/inactive users require a lower level of contact because there is less to report (clinical values), the ability to document personal details such as treatment plans and medication use, which is comparable to a personal health record (PHR), seems to appeal to patients.

Although each of the features - personal data, monitoring and email - appealed to both groups, the highly active users have been using all of the features more often, that is spread over a longer period of time (see Table 5b). The interactive features of online monitoring and email, in particular, were used more extensively.

Table 5a. User activity related to the use of system features – Ranking of the features

	Personal data	Monitoring	Email	Education	Calendar	Lifestyle
Highly active (*n* = 15)						
Total hits	781	1601	908	240	244	96
Ranking	20.2%	41.4%	23.5%	6.2%	6.3%	2.5%
Low/inactive (*n* = 35)						
Total hits	867	615	550	233	120	64
Ranking	35.4%	25.1%	22.5%	9.5%	4.9%	2.6%

Table 5b. User activity related to the use of system features – Mean number of hits

	Personal data	Monitoring	Email	Education	Calendar	Lifestyle
Highly active (*n* = 15)						
Total hits	781	1601	908	240	244	96
Mean hits	52	107	61	16	16	6
Low/inactive (*n* = 35)						
Total hits	867	615	550	233	120	64
Mean hits	25	18	16	7	3	2

Discussion

Main findings

The aim of this study was to explore the factors that influenced the use - initial and long-term - of a web-based disease management program for supporting the self-care of patients with diabetes type 2. The results demonstrated that most enrollees were already well-regulated, and satisfied with their current diabetes treatment.

The major advantages of using the DiabetesCoach yielded improved access to care and enhanced patient-nurse communication. The features that appealed to the patients most, and with which they were often engaged, were online monitoring in combination with personal feedback via email and documentation of medication usage. These personalized and interactive features stimulated active participation by both the patient and the nurse. Patients felt better monitored by means of the continuously received feedback and were also more motivated to take a more active role in self-managing their diabetes.

Unexpectedly, there was a high preference for the documentation of personal data referring to medication and treatment plans. The documentation feature is not interactive; no communication takes place. However, it is comparable, in a certain way, to a PHR [35-37] as it includes relevant data over the course of the individual's lifetime. Patients liked to track how medication use affects their health. The personalized aspect means a lot to the patients.

Despite the observed advantages, usage of the web application was hindered by: low enrollment, enrollment of the 'wrong' users, and usability problems, including a lack of 'push' factors.

Enrollment of the 'wrong' users

A great concern among eHealth technologies in general, and behavioral intervention programs in particular, is that they may reach those who need them the least (ceiling effect), or they fail to reach the ones with the greatest need for care, such as patients with chronic conditions (inverse care law) [38,39]. Although in the Netherlands the e-patient is taking shape [40], this study's results still demonstrate a digital divide; the most prominent barrier to enrollment concerned the lack of Internet access in the patient's home. Moreover, we found a selective enrollment of relative healthy people, for it turned out that most diabetes patients were well-regulated and thus were not the ones who could benefit most from the system. Goldberg et al. [5] found similar results in their study; patients felt unengaged because they had already achieved adequate glycemic control. The use of convenience samples should be avoided, for it encourages selective enrollment. It attracts patients who are already motivated and who are often the ones who are in least need of the technology.

Ceiling effect

In the present study a ceiling effect ('I am doing well, so I do not need the technology') caused non-usage attrition. According to Wangberg et al. [23] attrition as such is not necessarily a bad thing, because in this case it can also be seen as an indicator of success, since the intervention is no longer needed. However, the ceiling effect can have another side to it; because patients do not always have a good insight into their health conditions they might wrongly think that the technology is no longer needed (over-estimators). Such a ceiling effect should be avoided. Technology should therefore have persuasive elements like feedback mechanisms and triggers (e.g., email messages) to stimulate users to persist in such cases.

Poor user-friendliness and an absence of 'push' factors

The results also illustrated the importance of providing automated reminders, a simple user interface, and personalized content by anticipating the needs of the individual patient. If the patient is not in need of education, then the other features should encourage the patient to use the system. The provision of features with various purposes will be more encouraging to use for a wider audience. Some users asked for the integration of monitoring, recording personal data and logistics e.g., scheduling appointments. However, most of the features were presented as stand-alone applications.

Implications

To foster the widespread use of eHealth technologies like the DiabetesCoach, Internet use should be encouraged among the 65+ age range of the population; it is among the elderly that we have the largest growth potential [41,42]. To do so, the primary healthcare practices could consider providing training in computer and Internet skills and an opportunity to use a computer with Internet access in the practice itself if one cannot afford the technology.

Furthermore, we believe that the use of eHealth technologies will have the most significant effect on the more 'unmotivated', or relatively 'unhealthy', patients because of their greater need for care and their greater challenge for health improvement. Verheijden et al. [39] found that patients with deteriorating health conditions, who are thus more healthcare-dependent, will benefit more from system use and are therefore more inclined to persistently use the web application. In this study we found evidence, albeit very tentative, for our assumption that use of medication and the duration of the diabetes contributed to technology engagement; highly active users of the DiabetesCoach were significantly more often medication users and were significantly longer sufferers of diabetes. Our results correspond to the findings of Wu et al. [43], who found in their study among patients with chronic heart failure that the patients who used the system had more symptoms. The findings suggest that patients with worse disease conditions are most likely to benefit from eHealth applications. It is therefore expected that the web application could be most useful for insulin users and recently diagnosed diabetics. Future studies should focus on the encouragement of eHealth among patient populations who can get the most out of it, like those populations with high rates of behavioral risk factors and multiple chronic conditions [19,44].

In order to understand and overcome technical flaws, users should be able to give feedback during usage so that the system can be fine-tuned to their needs and user profiles. Preferably, users should actively participate in the development of the content (health 2.0) [45]. Patient-centered and participatory design methods should be used when developing eHealth applications in order to ensure high-quality, user-informed products of demonstrated effectiveness [6,8,46,47]. Via such design approaches we are better able to customize the technology to individual preferences and user profiles. This means that the design of eHealth should start with a careful analysis of individual needs and accompanying system requirements to explore which technology is best suited for whom. Next to a participatory design, training plays a central role in the implementation process to guide every user -in particular the "laggards"- in how to use the application. We know from the experiences of this study that the more interactive the training is, i.e. learning-by-doing; the more users will get out of it.

To increase adherence, technology should have persuasive elements like feedback mechanisms and triggers [48]. As such, it is relevant to know what kind of technology features, or cues, trigger users e.g., either via words, images, or sounds. Reminders or triggers for use could be applied via text-messages [49] and sent to the patients' regular mailbox via email [50]. Mobile phone technology is gaining ground as a simple interface for the health consumer, given the increasing ubiquity of this technology world-wide, and will therefore be especially useful for patients who seldom use their computer.

Personalized feedback appeared to be one of the most promising features for long-term usage. In fact, two types of personalized feedback via e-mail messages can be distinguished: eHealth lifestyle technologies with patient-professional interaction via secure e-mail and eHealth technologies without patient-professional interaction (automated messages and prompts). From the results of this study and a recent publication of Fry et al. [51] on lifestyle interventions we can assume that the use of personalized feedback from a real person will be more persuasive than automated tailored feedback. Future research should focus on establishing which type of personalized feedback works best for whom (patients with short-term care needs (prevention/cure) versus patients with long-term care needs (chronic disease management) and in which situation (purpose of the communication: task-focused versus affective).

Moreover, integrating the technology with existing clinical care could serve as a push factor. Stevens et al. [52] found that higher levels of engagement can be reached when technology requires users to log-in, for example once a month. Therefore, it is expected that the effects of technology use will be stronger on patients who log-in every month (fixed regime) than on patients who log on only once in a while. By integrating eHealth technology into existing traditional 'offline' care (visits), patients will be triggered to log-in within the framework of a fixed regime.

Besides, education should be provided in a more interactive way, for example via Web 2.0 tools that are built around user-generated or user-manipulated content, such as wikis, blogs, podcasts, and social networking sites [45,53-56].

Limitations

The limitations of this study include the very small and select sample of participants. Users were self-selected as they were motivated to use the web application. It is possible that the patients and nurses who chose to participate in the project may differ from other patient groups. Further research should be conducted, preferably with larger sample groups and also among non-enrollees, to gain more thorough insights into the technology preferences of the different patient groups. Nevertheless, we believe that our results provide insights beyond the current literature into patients' engagement in web-based disease management programs. The use of a mixed-methods design [24,25] has contributed positively to this. Via interviews and usability tests we were able to explain the actual usage, and the survey provided insights into who uses the technology. All of the results combined provided an insight into the preferences of individual users for specific technology features. Log files enabled us to assess the actual and long-term usage of the technology features.

In this study, attrition was not measured with the usual measures, such as Kaplan Meier[57,58]. Most attrition measures perform survival analysis. However, these measures could not be used in our study because they only provide insights into the drop in usage and not in the pattern of usage. Such survival curves are useful for eHealth interventions with a fixed use, for example with e-therapy interventions. In our study, the pattern of usage was not fixed. Therefore, we searched for activity patterns in measuring continuity of use and we measured the degree of activity to distinguish between the infrequent users versus the highly active users.

Conclusions

In conclusion, our findings stress the need for further research into usage patterns and user profiles. Strategies that engage users with technology are important for addressing the low take-up of eHealth technologies. This study has set out three key strategies for increasing the initial and long-term use of eHealth technologies: (1) avoid selective enrollment, (2) make use of participatory design methods, and (3) develop persuasive technology. Innovations in healthcare will diffuse more rapidly when technology is employed that is both simple to use, and has applicable components for interactivity in order to foresee the patients' need for continuous and personalized feedback, in particular for patients with a greater need for care. Longitudinal research on the use of eHealth technologies is needed to provide insights into the way usage fluctuates over time. Through the present study we gained an insight into the differences between highly active users and non-usage dropouts, which can be seen as a first step towards decreasing attrition. The next step could be found when examining the opportunities technology has to offer. Future research should therefore focus on the causal relationship between using the system's features and actual usage, as such a view would provide important evidence on how specific technology features can engage and captivate users.

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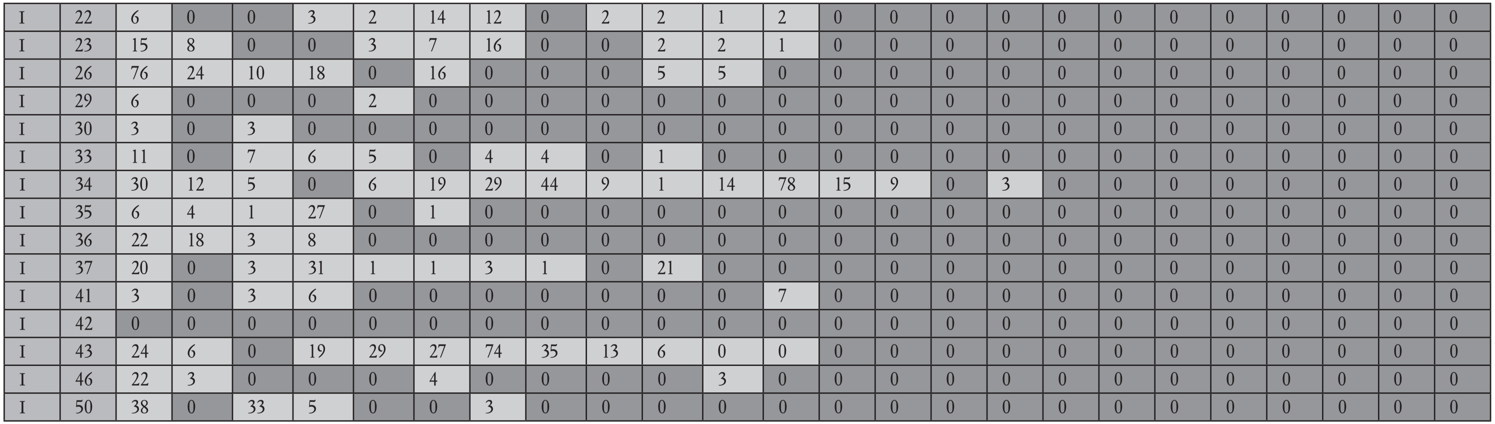
Appendix 1. Categorization of patient-nurse message content

Code	Category	Example:
1	Affective communication: expression of emotions such as compliments, relief, worries and social talk (wishes, thanks)	Post of patient: At least I am relieved that it has got nothing to do with my diabetes! Post of nurse: I see you've been actively engaged in self-control. It looks really good! Keep it up!
2	Administrative communication: communication about referrals, appointment scheduling, etc.	Post of patient: During the last visit, I received prescriptions for three out of four medicines. That all went well; the medicines were ready and waiting for me at the pharmacy. Now, I only need a prescription for Nedios. I hope to hear from you soon. Post of nurse: We have an appointment on Thursday December 6. Unfortunately, I will not be present at the practice that week. Therefore, I would like to reschedule our appointment to Wednesday, December 12, at 08.15 hrs. Please let me know if this new appointment suits you.
3	Online monitoring: communication about clinical values like blood glucose, blood pressure, weight and cholesterol	Post of patient: Values of the last times: 16 Febr.: 6.7; 17 Febr.: 6.3; 19 Febr.: 7.0; 20 Febr.: 7.4 After the 8+ of Tuesday, February 18, it has constantly been a bit higher these past few days. Do you think we should do something? Or should I just wait and check my blood sugar level more often? Reply of nurse: Your measured blood sugar values are almost all below 7.0, as we like to see. (…) All in all I don't think we need to do anything.
4	Lifestyle support: communication about nutrition, exercise, etc.	Post of patient: White rice is not recommended, or only occasionally. And yellow rice? And what about fried rice and (Chinese) noodles? Do these products contain a lot of sugar/carbohydrates? Reply of nurse: White rice, but also (Chinese) noodles contain proportionally more carbohydrates, compared with the same weight of potatoes. When I see the dietician, I will ask about yellow rice.
5.	Communication about physical symptoms	Post of patient: Just a question about my feet. I have got a blue toenail now three times in a row after a long-distance run. My running shoes fit perfectly and are not too tight.. Is this a bruise and can it do any harm or is it normal? Reply of nurse: As promised, I forwarded your question to the podotherapist. According to the therapist, it is most probably a bruise caused by pressure on the forefoot. Possibly, the shoes are too short or don't fit the instep, which means the foot can slide in the shoe.
6.	Communication about medication use	Post of nurse: First I have a question for you: are you still on Avandia? Next, given that your blood sugar levels are going down a bit, I would like to propose we increase the insulin. According to my data, you are now injecting 38 EH, the plan is to go to 42 EH. After the increase, please send me a new blood sugar count. Reply of patient: Since I have been injecting, I am not on Avandia anymore. From 26 March onwards, I will inject 42 EH.
7.	Use of DiabetesCoach features such as the lifestyle coach	Post of nurse: Often people eat more - and less healthily - during the (Christmas) holidays. The "healthy nutrition guide" will (again) help you make the right choices.
8.	Current events: communication about new diabetes-related websites and courses	Post of nurse: I want to take this opportunity to ask you the following: The Dutch Institute for Sports and Exercise (NISB) is going to develop an exercise program especially for people with (a high risk of) diabetes. Would you like to participate in this exercise program?
9.	DiabetesCoach remarks: communication about the (technical) working of the application	Post of patient: During my last check of the web application it turned out that my blood sugar values no longer appeared on the screen. Is it possible the previously entered data are therefore lost? Post of nurse: This is a test. It concerns a new function for simultaneously e-mailing all DiabetesCoach participants. Please confirm receipt of this message by sending me an e-mail.
10.	Other	Post of nurse: Last week the DiabetesCoach pilot study officially ended. Thanks to your participation much has become clear about the usefulness of this site.

Appendix 2. Overview of activity patterns in months

a	b	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
H	1	19	34	11	27	13	10	34	16	9	47	32	29	51	9	10	3	8	4	35	16	12	14	0	0
H	2	8	39	7	1	8	2	8	2	0	45	5	2	2	1	0	20	2	0	2	2	0	0	0	0
H	3	11	50	5	1	20	2	5	15	0	2	2	2	2	16	0	1	2	7	2	5	3	0	0	0
H	4	10	50	9	1	20	5	6	49	3	2	11	44	0	11	0	1	2	12	2	8	0	0	0	0
H	5	81	69	33	1	11	14	0	0	4	7	20	43	1	0	1	2	34	88	5	14	9	0	0	2
H	6	44	43	17	30	10	24	0	5	2	4	2	0	1	1	1	3	0	6	2	0	2	0	0	2
H	11	27	41	3	0	55	8	0	0	4	75	86	52	10	36	29	58	15	26	3	2	13	21	29	0
H	12	13	147	58	34	110	6	0	6	13	4	10	2	0	15	5	12	9	0	19	2	0	21	0	0
H	21	8	36	24	12	35	19	14	20	14	10	24	17	8	20	15	17	13	6	24	15	19	16	21	4
H	24	4	159	257	198	55	47	43	96	37	28	35	23	9	8	32	16	20	24	13	68	0	14	16	6
H	27	61	60	49	9	34	73	70	59	55	34	37	28	42	52	6	17	15	22	13	21	4	0	6	0
H	31	48	27	20	16	31	3	62	61	16	5	3	13	22	3	3	2	0	0	5	0	2	0	0	0
H	44	51	142	104	109	32	43	18	6	56	9	3	15	0	0	6	0	3	3	0	0	8	6	0	0
H	47	34	161	45	9	18	39	27	59	4	15	9	8	7	16	11	7	9	14	0	12	20	0	3	0
H	48	24	22	18	30	32	37	30	10	24	3	0	8	3	7	28	17	6	0	0	3	0	0	0	3
H	49	44	40	12	27	26	16	5	6	13	12	11	9	3	10	3	3	0	13	0	0	11	0	9	3
L	7	33	57	16	6	8	7	0	0	38	0	0	0	1	0	1	2	0	2	2	0	0	0	0	4
L	8	10	27	10	7	7	1	0	0	87	27	0	0	1	6	6	20	2	2	2	0	0	0	0	2
L	9	11	44	6	3	18	5	0	0	3	2	2	0	1	0	1	2	0	2	2	0	0	0	0	2
L	10	12	11	2	2	0	7	0	0	22	2	3	6	0	0	1	2	0	2	2	1	0	0	0	2
L	13	10	14	0	0	3	0	0	0	3	0	1	2	0	2	2	0	0	0	0	2	0	0	0	0
L	14	2	12	0	0	20	0	0	0	3	25	1	2	0	2	13	0	0	0	0	2	0	0	0	0
L	15	27	0	0	2	0	0	0	2	0	1	2	0	2	0	0	0	0	0	2	0	0	0	0	0
L	16	6	4	0	55	20	0	0	3	1	2	2	0	2	2	0	0	0	0	2	0	0	0	0	0
L	17	38	41	8	0	68	2	0	0	1	0	0	2	0	2	13	0	0	0	0	2	0	0	0	0
L	18	7	0	0	1	2	4	0	2	3	2	2	0	71	5	0	0	0	0	17	0	0	0	0	0
L	19	53	3	21	90	5	1	2	3	26	12	42	0	0	0	9	0	0	0	4	1	20	0		
L	20	6	7	0	20	5	0	56	12	0	4	22	9	43	9	2	0	0	0	0	8	9	14	0	0
L	25	1	84	4	1	0	45	15	11	7	0	1	4	0	0	0	0	0	0	5	8	0	12	0	0
L	28	1	0	0	1	0	11	0	0	43	0	3	0	0	4	0	0	0	0	0	0	4	0	0	0
L	32	28	3	3	11	30	3	1	10	2	1	14	3	8	0	0	0	7	0	0	0	0	0	0	0
L	38	9	0	8	4	17	90	43	4	0	7	3	0	0	0	0	0	0	0	5	0	0	6	6	0
L	39	5	0	0	31	19	0	15	105	89	155	104	30	17	0	14	0	0	0	4	0	0	0	0	0
L	40	12	0	0	30	18	11	8	19	19	1	4	0	0	13	0	0	0	4	0	0	0	0	2	0
L	45	22	28	33	41	59	40	24	23	24	24	6	9	29	6	3	9	0	0	0	0	0	0	0	0



I	22	6	0	0	3	2	14	12	0	2	2	1	2	0	0	0	0	0	0	0	0	0	0	0	0
I	23	15	8	0	0	3	7	16	0	0	2	2	1	0	0	0	0	0	0	0	0	0	0	0	0
I	26	76	24	10	18	0	16	0	0	0	5	5	0	0	0	0	0	0	0	0	0	0	0	0	0
I	29	6	0	0	0	2	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	30	3	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	33	11	0	7	6	5	0	4	4	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	34	30	12	5	0	6	19	29	44	9	1	14	78	15	9	0	3	0	0	0	0	0	0	0	0
I	35	6	4	1	27	0	1	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	36	22	18	3	8	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	37	20	0	3	31	1	1	3	1	0	21	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	41	3	0	3	6	0	0	0	0	0	0	0	7	0	0	0	0	0	0	0	0	0	0	0	0
I	42	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	43	24	6	0	19	29	27	74	35	13	6	0	0	0	0	0	0	0	0	0	0	0	0	0	0
I	46	22	3	0	0	0	4	0	0	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0
I	50	38	0	33	5	0	0	3	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0	0

a. Column 1: H=highly active, L=low active, I=inactive; b. Column 2: patient number; ☐ active ■ non-active

Appendix 3. Overview of user activity

Patient	Practice	Activity pattern in months Active-(non-active)	Activity in months	Activity degree	Discontinued/ continuous use	User activity
1[a]	1	22-(2)	22/24	92%	continuous	high
2[a]	1	8-(1)-5-(1)-5-(3)	17/24	71%	continuous	high
3	1	8-(1)-5-(1)-6-(3)	19/24	79%	continuous	high
4	1	12-(1)-1-(1)-5-(4)	18/24	75%	continuous	high
5	1	6-(2)-5-(1)-7-(2)-1	19/24	79%	continuous	high
6	1	6-(1)-4-(1)-4-(1)-2-(1)-1-(2)-1	19/24	75%	continuous	high
7[a]	1	6-(2)-1-(3)-1-(1)-2-(1)-2-(4)-1	13/24	54%	continuous	low
8[a]	1	6-(2)-2-(2)-7-(4)-1	16/24	67%	continuous	low
9	1	6-(2)-3-(1)-4-(1)-2-(4)-2	16/24	67%	continuous	low
10[a]	1	4-(1)-1-(2)-4-(2)-2-(1)-3-(3)-1	15/24	63%	continuous	low
11[a]	1	3-(1)-2-(2)-15-(1)	20/24	83%	continuous	high
12[a]	1	6-(1)-5-(1)-4-(1)-2-(1)-1-(2)	18/24	75%	continuous	high
13	1	2-(2)-1-(3)-1-(1)-2-(1)-2-(4)-1-(4)	9/24	38%	continuous	low
14	1	2-(2)-1-(3)-4-(1)-2-(4)-1-(4)	10/24	42%	continuous	low
15	1	1-(2)-1-(3)-1-(1)-2-(1)-1-(5)-1-(5)	7/24	29%	continuous	low
16[a]	1	2-(1)-2-(2)-4-(1)-2-(4)-1-(5)	11/24	46%	continuous	low
17[a]	1	3-(1)-2-(2)-1-(2)-1-(1)-2-(4)-1-(4)	10/24	42%	continuous	low
18	1	1-(2)-3-(1)-4-(1)-2-(4)-1-(5)	11/24	46%	continuous	low
19[a]	1	11-(3)-1-(3)-3-(3)	15/24	63%	continuous	low
20[a]	2	2-(1)-2-(1)-2-(1)-6-(4)-3-(2)	15/24	63%	continuous	low
21	2	24	24/24	100%	continuous	high
22	2	1-(2)-4-(1)-4-(12)	9/24	38%	discontinued	inactive
23	2	2-(2)-3-(2)-3-(12)	8/24	33%	discontinued	inactive
24[a]	2	20-(1)-3	23/24	96%	continuous	high
25	2	4-(1)-4-(1)-2-(6)-2-(1)-1-(2)	13/24	54%	continuous	low
26	2	4-(1)-1-(3)-2-(13)	7/24	29%	discontinued	inactive
27[a]	2	21-(1)-1-(1)	22/24	92%	continuous	high
28[a]	2	1-(2)-3-(2)-1-(1)-1-(2)-1-(6)-1-(3)	8/24	33%	continuous	low
29	2	1-(3)-1-(19)	2/24	8%	discontinued	inactive
30	2	1-(1)-1-(21)	2/24	8%	discontinued	inactive
31[a]	2	16-(2)-1-(1)-1-(3)	18/24	75%	continuous	high
32	2	13-(3)-1-(7)	14/24	58%	continuous	low
33	2	1-(1)-3-(1)-2-(1)-1-(14)	7/24	29%	discontinued	inactive
34[a]	2	3-(1)-10-(1)-1-(8)	14/24	58%	discontinued	inactive
35[a]	2	4-(1)-1-(18)	5/24	21%	discontinued	inactive
36	2	4-(20)	4/24	17%	discontinued	inactive
37	2	1-(1)-6-(1)-1-(14)	8/24	33%	discontinued	inactive
38[a]	2	1-(1)-6-(1)-2-(7)-1-(2)-2-(1)	12/24	50%	continuous	low
39[a]	2	1-(2)-2-(1)-7-(1)-1-(3)-1-(5)	12/24	50%	continuous	low
40	2	1-(2)-8-(2)-1-(3)-1-(4)-1-(1)	12/24	50%	continuous	low
41	2	1-(1)-2-(7)-1-(12)	4/24	17%	discontinued	inactive
42	2	(24)	0/24	0%	discontinued	inactive
43[a]	2	2-(1)-9-(12)	11/24	46%	discontinued	inactive
44	3	12-(2)-1-(1)-2-(2)-2-(2)	17/24	71%	continuous	high
45	3	16-(8)	16/24	67%	discontinued	inactive
46	3	2-(3)-1-(4)-1-(13)	4/24	17%	discontinued	inactive
47	3	18-(1)-2-(1)-1-(1)	21/24	88%	continuous	high
48	3	17-(2)-1-(3)	19/24	79%	continuous	high
49	3	16-(1)-1-(2)-1-(1)-2	20/24	83%	continuous	high
50	3	1-(1)-2-(2)-1-(17)	4/24	17%	discontinued	inactive

[a] Patients who participated in the usability test/interview ($n = 20$, highly active: $n = 7$, low active: $n = 10$, inactive: $n = 3$)

Appendix 4. Frequency of log-ins and use of main features per patient

Patient	Practice	User activity	Log-ins	Personal data	Monitor-ing	Email	Educa-tion	Calendar	Lifestyle coach
1	1	high	108	63	34	89	17	30	8
2	1	high	45	26	8	14	12	8	3
3	1	high	47	18	29	10	8	3	0
4	1	high	58	63	35	18	19	1	0
5	1	high	106	52	109	49	4	9	1
6	1	high	55	53	26	5	2	0	10
7	1	low	43	39	18	31	8	4	4
8	1	low	50	41	5	42	23	6	9
9	1	low	34	20	5	3	5	1	3
10	1	low	28	6	2	4	4	1	2
11	1	high	147	31	119	94	3	4	0
12	1	high	81	87	16	163	6	25	4
13	1	low	13	1	3	0	6	0	0
14	1	low	19	30	5	6	1	2	4
15	1	low	11	11	2	1	4	0	0
16	1	low	26	22	7	1	13	2	4
17	1	low	25	54	28	11	13	10	4
18	1	low	20	26	10	12	11	2	1
19	1	low	54	78	18	43	11	4	1
20	2	low	50	21	53	42	0	2	7
21	2	high	118	9	186	24	9	6	1
22	2	inactive	17	0	0	0	0	0	0
23	2	inactive	17	4	2	6	0	1	0
24	2	high	191	81	387	200	57	80	9
25	2	low	29	34	33	44	15	12	6
26	2	inactive	28	22	41	0	0	26	1
27	2	high	153	28	104	260	30	12	19
28	2	low	10	11	4	17	4	3	1
29	2	inactive	3	0	0	0	2	0	0
30	2	inactive	2	0	2	0	0	0	0
31	2	high	80	30	87	62	11	6	1
32	2	low	31	24	14	15	3	0	2
33	2	inactive	8	10	5	1	1	1	0
34	2	inactive	56	41	25	69	22	3	0
35	2	inactive	14	7	1	0	0	0	1
36	2	inactive	9	9	16	7	6	1	0
37	2	inactive	11	30	24	2	2	4	1
38	2	low	39	38	24	32	7	8	5
39	2	low	55	171	81	148	52	14	3
40	2	low	25	30	43	2	0	2	1
41	2	inactive	5	1	3	0	5	0	0
42	2	inactive	0	0	0	0	0	0	0
43	2	inactive	51	19	5	97	7	0	1
44	3	high	112	126	161	31	7	42	4
45	3	low	96	32	112	28	5	5	3
46	3	inactive	6	9	10	1	0	0	0
47	3	high	127	43	143	25	42	5	22
48	3	high	85	22	95	7	4	2	4
49	3	high	52	49	62	16	9	11	10
50	3	inactive	14	26	14	8	3	6	0
Tot.			2464	1648	2216	1740	473	364	160

☐ Continuous users, highly active; ░ Continuous users, low active; ▒ Discontinued users

Appendix 5. Frequency of use of specific features of the web application by patients

Features of the web application	n
Online monitoring (*n* = 2216): place where patients can record their metabolic values	
Blood sugar	1109
Blood pressure	481
Weight	571
Cholesterol	109
My personal data (*n* = 1648): place where patients can document their personal data	
Personal details	335
Practitioners' details	221
Medical details	273
My medication	344
Annual check-up	241
Treatment plan – Standards	79
Treatment plan – Insulin	56
Treatment plan - Oral medications	99
Email contact (*n* = 1458): possibility to email with the patient/nurse	
Message overview	1316
Send message	142
Online education (*n* = 473): diabetes information and instructions	
What is diabetes?	64
High blood pressure	51
Lifestyle	52
Treatment	32
Low blood pressure	40
Self-care	59
Daily life	50
Kidneys	42
Eyes	16
Feet	7
Insulin injection	3
Blood sugar	22
Dietician	10
Hba1c	15
Smoking cessation	10

Chapter 5

Towards a holistic framework for sustainable eHealth technologies

Chapter 5.1 is based on: Van Gemert-Pijnen JEWC, Nijland N, Van Limburg MAH, Kelders SM, Brandenburg BJ, Ossebaard HC, Eysenbach G, Seydel ER. Introducing a holistic framework for eHealth technologies. Submitted to Journal of Medical Internet Research.

Chapter 5.2 is based on: Nijland N, Gemert-Pijnen JEWC, Van Limburg MAH, Kelders SM, Brandenburg BJ, Ossebaard HC, Eysenbach G, Seydel ER. A guideline for the development of sustainable eHealth technologies. Submitted to Journal of Medical Internet Research.

Chapter 5.1

Abstract

Many eHealth technologies (eHts) are not successful enough in realizing sustainable innovations in healthcare practices. One of the reasons for this is that the development of healthcare technology is expert-driven, resulting in technology that does not meet the users' needs and that disregards the social-cultural habits and the complexity of healthcare. In addition to this, eHealth interventions are often based on classic behavioral theories and medical models. They focus on rational decision-making and discrete individual behavior change and neglect the very interdependencies between technology, care, context and communication that influence the uptake of eHealth technologies.

In chapter 5.1 we introduce a holistic framework that will advance the development of eHts which are human-centered and provide added value for all the stakeholders involved. The framework is based on a narrative review of current frameworks for the development of eHts and on empirical research on the use of eHts in practice. It provides a comprehensive set of methods and instruments for the development of eHts. The framework is intended for researchers, developers and healthcare professionals and will be made available via an eHealthwiki-platform. In the subsequent chapter 5.2 we will describe the content of the eHealthwiki and the instruments for creating human-centered and value-driven technology.

Towards a holistic eHealth framework

Since eHealth and more social networking-targeted Health 2.0 initiatives emerged, a growing number of studies have stressed the importance of a participatory development process involving users or other stakeholders [1,2]. However, most of the eHealth frameworks presented so far do not provide the strategies or methods that are required to realize the participation of users or stakeholder-engagement.

This chapter (5.1) aims to introduce a new and holistic framework for the development of e-technologies in healthcare. The framework provides a structure for the development process and is based on key principles for human-centered and value-driven eHealth. The framework will be made available via an eHealthwiki platform for developers, researchers, healthcare professionals, patients, health IT specialists, and financers. This eHealthwiki platform is composed of theoretical and empirical research outcomes, methods and instruments as it was designed to serve as a guideline for co-creating eHts.

The chapter begins by outlining the urgent need for a holistic approach towards the development of eHts and explains the principles for human-centered technologies that have an added value for all stakeholders. It ends with the conceptual presentation of the eHealth framework and the introduction of the eHealthwiki platform (the methods and instruments will be described in detail in chapter 5.2).

Why we need a holistic framework for the development of eHealth technologies

Today's healthcare system faces problems such as aging, a growth in multimorbidity, a serious decrease in the number of available personnel, and a limited budget. Technology could contribute to the solution of these problems by supporting a better balance between self-care and professional care. Current demands by 'e-patients' to manage their own health and well-being may be met by technological interventions.
From systematic reviews and empirical-based studies, we know that the uptake of technology in daily practice is rather low [3-8]. The low uptake of eHts is caused by an expert–driven developmental process that produces technology which fails to meet users' needs and disregards social-cultural habits and the complexity of healthcare [3,9]. It is also caused by the classic behavioral theories and medical models that underpin these eHts [9-11]. These worn-out and tired constructs mainly focus on rational decision-making and a discrete individual behavior change while completely neglecting the complex interdependencies between technology, care, context and communication that influence the uptake of eHealth technologies. We believe that a *holistic* view on supporting healthcare via technology is needed to ensure that eHts are used and that they are effective. A holistic view on eHTs considers human characteristics (e.g., biological, psychological), socio-economical and cultural environments, and technology (design, usability) as indistinguishable connected to each other. The development of eHts involves much more than simply designing or engineering a good 'thing' or tool. Rather, it is about creating an infrastructure for knowledge dissemination, communication and the organization of healthcare. In fact, creating a new technology works as a catalyst for innovating healthcare, since the development of technology induces clarification of how the process of healthcare delivery and reimbursement runs, who the key actors are, and how payment

is organized. Developers should be aware of the interaction between technology, people (patients, citizens, healthcare professionals) and their social-cultural environment e.g. the healthcare organization. Without addressing the need for a total fit between people, technology and the healthcare organization in the development process, eHts run the risk of being ineffective in promoting healthier living.

eHts that are meaningful, empathic, and tailored to personal needs presumably have a much greater (cost-) effectiveness than eHts that lack (one or more of) these features. In order to develop these it is important to consider how people live their daily lives and what their drivers are for managing their health and well-being. Besides this, one must also take socio-cultural environments into account such as family support, (e)Health literacy, social economical status (SES) and the possibilities for supporting healthcare via technology.

To develop technology that is meaningful for all the stakeholders involved (like patients, healthcare professionals, financers, government) and that fits into the healthcare system, the participation of stakeholders is essential for specifying the values, critical design issues and resources (skills, capacities, etc.) that are at stake. To sum up, we need a holistic view on eHts to develop technology that is *human-centered* and that has *value* for all the stakeholders involved

Review of current eHealth frameworks

We conducted a narrative review [12,13] of the scientific literature (1994-2009) on existing models or frameworks for designing and evaluating eHts. We searched for developmental principles of eHealth frameworks and relevant criteria as reported in the literature as empirically established and determining factors for the quality of eHts.

We reviewed the strengths and limitations of current frameworks from our holistic perspective to eHealth research and development, backed by our research experiences in eHealth research and development, and by insights from dialogues with other researchers in the field of eHealth.

Qualified models were selected using the following criteria for inclusion:

- *Selection of frameworks:* the peer-reviewed journal paper must either describe an eHealth theory, perspective, framework (or model), or contain a literature review. We included those studies that propose factors for enhancing the success of eHts. The title of the journal paper must include at least one of the following search terms: *eHealth* or similar terms e.g., telemedicine, telecare, telehealth, health information systems/technology, interactive health communication applications; AND *development* AND/OR *design*, AND/OR *implementation*, AND/OR *evaluation*, AND *framework*, AND/OR *quality*, AND/OR *success*. We performed the literature search via the electronic databases of PubMed, Science Direct, Web of Knowledge, PiCarta and Google Scholar. Journal indexes were searched (examples of journals searched include: *Journal of Medical Internet Research*, *International Journal of Medical Informatics*, *Telemedicine and E-health*, *Journal of Telemedicine and Telecare*, *Journal* *of the American Medical Informatics Association*). Using a snowball method we included relevant cited and related articles.

- In total, 55 journal papers were identified based on the search criteria (see Appendix A). Journal papers that exclusively described methodological issues in eHealth research (7 papers) and journal papers with a more general focus which described the potential of eHealth (17 papers) were excluded from the analysis. Out of 55 papers, 31 were identified for a full review.
- *Reviewing selected eHealth frameworks:* out of the 31 papers that were identified we excluded those papers that did not describe a framework in detail (17 papers), following a full reading. In addition, we incorporated only those frameworks in which research had been integrated into the development process and which had, -to some extent, a focus on human, organizational and technological factors in the development process. From the results retrieved, 14 eHealth frameworks were identified that matched the inclusion criterion. The Appendix A shows the excluded papers. Appendix B displays the 14 selected eHealth frameworks under review. For reasons of comparison we have arranged the frameworks around the general elements of a development process; needs analysis, content and system-design, implementation process and measuring effects. Each concept consists of the indicators mentioned by the authors in their frameworks.

Strengths and limitations of current eHealth frameworks

We reviewed the frameworks for the characteristics and indicators presented in Appendix B. Studies are presented during a period ranging from 2009-1999. The frameworks in Appendix B are arranged around the year of publication, the focus, purpose and theoretical foundation of the frameworks, and the concepts they address (needs, content and system, incorporation and effects or outcomes).

Focus, purpose and perspective

All frameworks presented in Appendix B[frameworks:1-14] (see also Appendix A) mention to evaluate eHts by providing criteria for all concepts: needs, content &system, incorporation and effects. The frameworks differ in their focus; Yusof[2], Hamid[2], Kaufman[5], Dansky[6], Shaw[10], Kazanijan[11], Hebert[12], Eysenbach[13], Eng[14] provide frameworks for evaluation. Esser[1] and Pagliary[4] provide frameworks for design and evaluation. Ganesh[7], Van der Meijden[8], and Kukafka[9] provide frameworks for implementation.
Considering the concepts the frameworks address, a minority of the frameworks[2,3,8,10] do not include criteria for human or organizational needs. One framework[12] does not address the technology (content and system) as a concept of its framework. Some frameworks[4,5] consider the design of content and system as a laboratory activity; only then, when it comes to a prototype, the 'real-world' comes in.
Given the problems with adopting eHts, the majority of the authors[1,2,7-14] mention the importance of achieving the right fit between technology and organizational infrastructure. Training, organizational support, resources and other activities are mentioned as indicators for the quality of the incorporation in practice (cf. Appendix B; Incorporation).
Most of the frameworks provide indicators for the measurements of the effects. Six of them[1,2,4,8,9,12] also offer indicators for measuring the process of the usage of the technology (cf. Appendix B; Effects).

Purpose

Some authors[5,9,11] state that their evaluation frameworks can be used as a guideline for developers. However, in most cases it is not always clear for whom the frameworks are meant. Some authors indicate that their frameworks are intended for developers, professionals, researchers, or decision-makers (cf. Appendix B; Framework purpose), though they do not specify whether the development process is an individual activity or a collaborative, professional activity as in the case of Pagliari[4] and Esser & Goossens[1].

In general, authors argue that their frameworks can be used for different kinds of technologies, although most frameworks have their technical foci on stand-alone, web-based technologies or health information systems. Neither technologies that support communication, social relationships or safety (serious gaming, eCoaching, robotics, domotics, social media) nor technologies that are interoperable are represented. In general, the user-friendliness of a technology is seen as the major indicator for success; almost all of the frameworks provide criteria for increasing their usability (cf. Appendix B; Content & System).

Perspective

The majority of frameworks[2,6-9,11-14] have a broader perspective than the end-user (patient and or care professional) perspective (see Appendix B), arguing that stakeholders have to be addressed to determine critical issues for the implementation of eHts in the healthcare organization.

Foundation

The frameworks (cf. Appendix B; Foundations) are based on a review of the literature, individuals' points of views[7], and theories or models like information system models (DeLone[2,8,12]), engineering software design systems[4], Acts[6] (legislation), behavioral theories (Technology Acceptance model[3], Precede, Proceed[9)], media richness theory[2], or innovation models (Donabedian[3,12,13]). None of them are based on empirical research.

The current frameworks could potentially be used to develop sustainable eHts because they include indicators for creating a good fit between the technology, the people (users/stakeholders) and the healthcare environment or organization. Only two of them[9,14] stress the need to address all these factors (technology, people, organization) together during the development process because of the interdependencies between the factors. The implementation frameworks[7-9] have a large scale perspective, including indicators for the whole 'spectrum' of the development process (needs, content, incorporation, effects). In fact the evaluation and implementation frameworks are complementary and together they address the concepts relevant for the development of eHts.

The limitation of the frameworks is the lack of a clear vision about how the frameworks can be used in practice. Although collaboration between the developers and the researchers is recommended, there are no guidelines or prescribed activities available for managing this type of development cooperation. Very often, technical designers make decisions without involving the key stakeholders from the medical, social, or other professions. Designers often work in their own space and their product-driven approach often results in prototypes that do not match with the end-users' expectations [11]. The development process should not start in academic or laboratory settings but with a needs analysis of the stakeholders involved.

The participation of users and stakeholders is considered important, but the methods and instruments needed to guide this participatory process are missing. The frameworks prescribe what should be done, but do not provide the instruments or tools to realize it. Another limitation is the bias towards information systems rather than social or safety technologies. The use of social media for co-creation is beyond the scope of the frameworks. They are still too narrow for developing the 2.0 technologies.
Based on the review of the current framework for eHts and our empirical research [3,4,9,14] we have developed a holistic framework. The need for a *holistic* framework has been notified by other researchers who have developed eHealth frameworks, but they did not work their ideas into their frameworks.

> *"By seeking to actively collaborate in the process of design and evaluation and sharing research approaches, the aim of achieving technologies that are truly user-informed, fit for context, high-quality, and of demonstrated value is more likely to be realized." (Pagliari[4])*

> *"Human, organization and technology are the essential components of Information Systems. These three evaluation factors can be evaluated throughout the whole system development life cycle namely planning, analysis, design, implementation, operation and maintenance." (Yusof et al.[2])*

> *"Without addressing the full range of factors, strategies to change behavior run the risk of being ineffective because they fail to recognize interdependencies between individual and organizational factors." (Kukafka[9])*

The need for a *value-driven* approach towards eHts has been expressed by other authors, who nevertheless did not incorporate it systematically into their frameworks.

> *"Health technology assessment examines a broader context than the technology alone, including costs and comparing alternatives that would exist in the absence of telehealth. It considers performance measures; outcomes; summary measures, operational considerations, and other issues." (Hebert[12])*

> *"The ability of eHealth to empower consumers, support dynamic information exchanges among organizations, and "flatten" organizational hierarchies might result in a need for new organizational strategies, business models, service delivery models, and management mechanisms." (Ganesh[7])*

Some authors[4,9,11] have also addressed the need for a *multidisciplinary* approach towards the development of eHts to ensure that they fit in the healthcare organization and fulfill human and organizational needs. However, their frameworks do not involve how to manage a multidisciplinary development approach.

Principles for a holistic eHealth framework

Given the strengths and limitations of the current frameworks and our research into the usage of eHts in practice, we can formulate key principles for human-centered and value-driven technology. These principles underpin our holistic framework:

- eHealth development requires multidisciplinary project management
- eHealth development is a process of co-creation
- eHealth technology is not a blind spot, but a social medium
- Evaluation is integrated in the development process and has no fixed end
- Implementation is intertwined with the development process, and not a post-design-step
- The development process consists of interdependent strategies for human-centered design and business modelling
- Innovative methods and instruments are needed to evaluate the process and outcomes

eHealth development requires multidisciplinary project management

To facilitate and streamline the development process, and to avoid a 'design-build-run and see what happens' approach, multi-disciplinary project management is needed. This implies cooperation between *developers, researcher and care professionals* from different disciplines such as engineering, medicine and behavioral sciences. Project management should facilitate and stimulate the cooperation to avoid a situation in which developers work at different tempi and spaces than the researchers and medical professionals, which often results in "high tech but with a low impact" [7,9].

eHealth development is a process of co-creation

Health-technology-development is a participatory process of co-creation and collaboration with stakeholders [15,16]. Stakeholders are all those who are affected by the technology, including patients, caregivers, vendors, government, and insurance companies [17]. Co-creation requires the engagement of stakeholders during the development process. The development process starts with identifying problems and assessing the needs. These determine the values and conditions that are necessary to realize and successfully implement an eHt. Health 2.0 ideas to advance sustainable healthcare technologies and the participation of stakeholders from different backgrounds and with different interests (political, medical, policy, commercial) are important for trust, commitment and creating ownership and for organizing the resources and capacities for developing the technology [15,18].

eHealth technology is not a blind spot, but a social medium

eHt is not neutral, it is a social medium functioning in the lives of real-life, flesh-and-blood men and women. Yet in eHealth research, technology is often a blind spot, not considered as a medium to persuade or to affect people [3,19]. Patients want to communicate with and through technology and they expect technology to show understanding, persuade them to do the right things, or provides rewards and appraisal for good behavior [3,14]. Therefore, technology itself should be the focus of design, in order to incorporate persuasiveness into the technology. Health communication is only effective when it is hyper-personalized and empathic; tailored to the needs of users. ePatients demand technologies such as social media to communicate and to share information, they expect health technologies that support them in collaborating with other patients or caregivers. Emerging technologies, like social media, require a different approach to the development of eHts. Via co-creation and participation, the development of technology becomes a process without a fixed end, also referred to as 'perpetual bèta' [18]. As technologies evolve, they function as social media in the process of co-creation. This implies that we need persuasive theories and methods to create technologies that increase the adherence to technology, with the aim to support behavioral change.

Evaluation is integrated in the development process and has no fixed end

Evaluation is an activity of research that is interwoven with the development process and that has no fixed end. The development of eHt is an iterative, flexible and dynamic process resulting in ideas and concepts that have to be continuously evaluated by the intended users and stakeholders. The technology will be used and, by its usage of the content and system, it will be reshaped or redesigned, so evaluation is an ongoing reflexive process of creating technology that fits with its users and contexts. While using technology patients or care professionals create new content (in case of interactive social media) or reflect on the content or system via feedback (interactive eHts), this means that technology evolves, and evaluation research is therefore a continuous process to reshape technology to its usage. Other authors also stated that evaluation is a longitudinal process interwoven at each stage of development but they see evaluation as a process that ends after roll out:

> *"There is a growing acceptance that evaluation should ideally be approached as a longitudinal process occurring through a series of overlapping and iterative stages relevant to the maturity of the technology in its lifecycle, from initial conception to rollout." (Pagliari[4])*

> *"There is a need for evaluation research at each stage of development and implementation, from conception to the routine operational use of a system." (Kaufman et al.[5])*

> *"Promoting evaluation of interactive health communication (IHC) applications should be a central strategy for improving their quality and effectiveness. Evaluation should be ubiquitous in product development. Evaluation methods should be woven throughout the conceptualization, design, implementation and dissemination phases of product development." (Eng[14])*

Implementation is intertwined with the development process and not a post-design-step

Technology for healthcare is often developed in academic settings or laboratories. Implementation is seen as a post-production activity [3,4]. To prevent the incorporation of failures, a technology should be developed in a recurrent process. Right from the start of thinking about a technology to support healthier behavior, conditions for implementation have to be set to avoid the incorporation of problems (such as lack of time, resources, skills, and a lack of commitment).

The development process consists of interdependent strategies for human-centered design and business modelling

The development of eHts is often based on user-centered models, focusing on the needs of individual end-users. Given the problems with the incorporation of eHts, the lack of commitment and trust to finance eHealth projects, there is a need for a more value-driven approach. Business Modelling (BM) is such an approach with an origin in strategic management that assesses innovations. To develop sustainable technologies it is essential. Business modelling in the context of eHealth helps to determine critical factors regarding eHt *a priori* with the involvement of all the relevant stakeholders [20,21]. These factors determine the success of the eHt in practice. Stakeholders have to collaborate and articulate each others' critical factors in order to co-create a 'fit-for-all' solution that determines the value of the eHt. This value forms an implementation in the form of a business model and describes the rationale of how the eHt will create, deliver and capture value for all relevant stakeholders.

This value-driven approach is interwoven with designing the content and system, as it can prioritize functionalities, specifications and requirements through a value-adding perspective from the intended users. This helps to determine which functionalities are important to develop -they add relatively the most value- and which are not.

Innovative methods and instruments are needed to measure the process and outcomes

Technology changes the way research is conducted. Technology influences our social lives and daily routines, so we need innovative methods and instruments for assessing the effects of technology on replacing traditional care in our homes or work. In addition, we need methods to understand *what* differences eHts can make in healthcare, *why* eHts make these differences, or *why* eHts may not have the impacts expected of them.

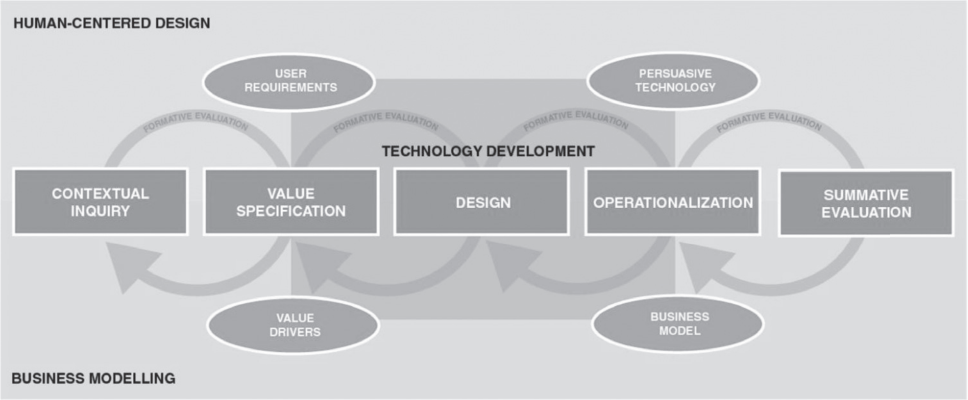
Robust methods are needed to assess the full spectrum of potential benefits that eHealth can offer. Research is carried out in the context of academic or clinical studies,in which the future sustainability or generalizability of the eHts being evaluated cannot be assured [11]. There is a need for multiple methods for the measurement of the process and outcomes that include all stakeholders' points of view, not just an individual end-user: including monitoring the longitudinal usage of technologies in practice (an interaction process evaluation), methods for involving the participation of stakeholders, and methods for assessing the values of eHTs for all stakeholders and the effects on society. Such a combination of methods that includes different points of views can be a guide for developers, researchers and policy-makers to assess the added values of eHts in a holistic view taking into account the fit between human, technology and environmental or social contexts.

> *"A good evaluation should include multiple, carefully selected periods of data collection and should include all stakeholders' points of view."* *(Van der Meijden et al.[8])*

A new holistic eHealth framework

Figure 1 presents the ceHRes (center for eHealth research) Roadmap for the development of eHealth technologies. This framework consists of two interdependent strategies: Human-Centered Design (HCD) and Business Modelling (BM). It comprises five concepts for co-creation that are explained below. Evaluation is a research activity that is intertwined with development and usage in practice, summative evaluation is aimed at measuring whether technology makes sense and has value for all stakeholders at a given time. The design of technology is based on the user requirements and the values specified; using persuasive theories to develop technologies that make sense to their users. The business modelling process results in a business case based on the values stakeholders specified for the cost/benefits of a technology. The model is based on the narrative review, abovementioned principles, and empirical research [3,4,6,22].

Figure 1. ceHRes Roadmap for the development of eHealth technologies



Human-Centered Design

The core of HCD is to create a fit between human (with the end-user as the key stakeholder) and technology [11]. It can be characterized as a problem-solving and needs driven process that requires both analysis and prediction of how end-users (e.g., patients, family carers, professionals) are likely to use a technology in practice. Therefore, engaging the users is a prerequisite for the design of a technology. As such, HCD can optimize the technology around how users can, want, or need to use the technology, rather than forcing the users to change their behaviors to accommodate to the technology. The HCD activities are interwoven with the business modelling activities; the methods and instruments are primarily aimed at the co-creation of content and the system via the involvement of the intended end-users; based on the users' needs and requirements and values that key-stakeholders have identified for using technology to support healthcare. The methods and instruments of the HCD will be worked out in detail in chapter 5.2 and they will be made available via an eHealthwiki to stimulate discussion and to share information among those involved in developing eHts.

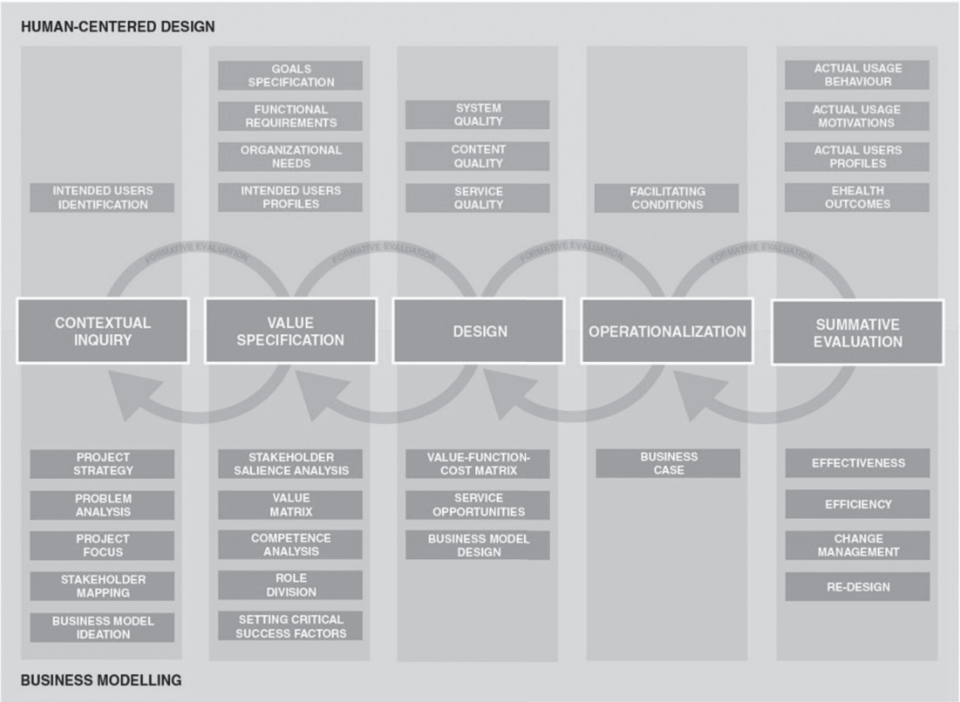
eBusiness Modelling

eHealth Business modelling is a process of identifying the critical factors for design and implementation via stakeholder-engagement and co-creation [20,21,23]. It is different from business modelling in commercial industries as there will be a stronger focus on non-economical values and the stakeholder network shall be complex due to a rigid status quo. A challenge lies in reducing this complexity by making the value creation process central and not the stakeholders themselves and finding the right incentives for collaboration. The chances of a successful implementation will improve by focusing on finding the right fit for the value needs for an eHt with all the stakeholders involved. Co-creation and collaboration are essential for this successful implementation as a fit-for-all also requires mutual interest and continuous support. An eHt evolves over time, so co-creation and collaboration also needs to continue post-development. The operationalization needs to be sustainable and dynamic for the changes that lie ahead. Business modelling makes the value creation process iterative and reflective and creates a platform for future collaboration to safeguard this sustainability and dynamic. In another paper we elaborate on the use of business modelling for eHts (not included in this thesis).

Concepts of the ceHRes Roadmap

Figure 2 shows the concepts of the framework and research activities related to each concept for the participation of stakeholders. In two subsequent papers the research-instruments will be described and discussed in more detail.

Figure 2. Research activities related to the ceHRes Roadmap



Contextual Inquiry

Contextual inquiry entails information gathering of the environment the technology will be implemented. It starts with a scenario that represents the environment of the technology and the tasks or actions that are relevant to support with technology. Stakeholders with different backgrounds (payers, decision-makers, patients, caregivers) identify problems with the current healthcare delivery via the scenario's, and articulate their needs and demands to solve the problems. In addition they define who are the key-problem owners or those who have stakes in the solution of the problems identified. It is important that the needs and demands of all those involved are taken into account and that the intended users are identified. In sum, contextual inquiry is aimed to find out what the problems in healthcare are, what the contribution of technology can be to stakeholders, end-users, and who might benefit from the technology. Figure 2 provides the activities related to contextual inquiry, in the next paper these activities are described in detail.

Value specification

The value specification process elaborates on the outcomes of the contextual inquiry. In this process the key stakeholders determine their values (economical, social, and behavioral) and rank them based on importance for finding solutions to the identified problem(s). Value specification refers to goal-setting and to defining the functional and organizational requirements to realize the values. It is aimed at exploring what healthcare improvements are foreseen and what the possibilities or expected limitations are to realize the values. The specified values have to be translated by the stakeholders into functionalities of the design and critical factors for (skills, resources) the operationalization. For example, during the course of developing a teledermatology application, the key stakeholders identified problems with measuring the possible risks of infection of diabetic feet, and insufficient communication among caregivers (GP, dermatologist). The values they formulated were higher quality of care and efficiency to reduce the number of errors and misinterpretations. The technology should therefore have functions to measure the conditions of the wound in an objective and standard way and the measurements should be communicable in a standardized way.

Design

The project management team has to coordinate the contextual inquiry, the value specification and the design activities. Once the requirements are defined, the actual design process starts. The project management team has to visualize the ideas via mock-ups keeping in mind the values, goals and the tasks that have to be fulfilled. Mock-ups, Storyboards or paper prototypes are created and discussed with intended end-users, and as a result of this, the prototype will be refined. The prototypes will be tested in real-life situations. The user is invited in several rounds via concrete scenarios or tasks to test whether the prototypes match with their expectations and mental models (way of thinking, working). The prototype will be discussed via a canvas for a business model [24] by the key stakeholders to identify the cost-benefits (value-function cost matrix) and to set conditions for the operationalization (business model). In general the quality of the design can be assessed at different levels. System quality; creating technology that is user-friendly and matches end-users' profiles and roles or tasks in the care delivery process, content quality; creating content that is meaningful and persuasive and service quality; providing a service that is adequate (timely, responsive, empathic) and feasible.

Operationalization

The operationalization refers to the activities needed to incorporate eHts into practice. The project management team has to plan activities for dissemination, adoption and diffusion. The key stakeholders have to develop a business case, based on the business model which describes a reality on a strategic level; however it is still a model. Multiple so-called meta-models exist that can be used as a blueprint and as business model to thoroughly describe reality best. Once the right template is chosen, based on the value needs, competences, roles and critical success factors strategic choices are made and described in the business model and further specified in a business case (quantification of costs/revenues) for the operationalization (described in the next papers in detail).

Evaluation cycles

Formative and summative evaluation cycles represent the refection activities as feedback and feed forward during the development and usage process. Reflection is important to criticize tacit understanding and make new sense of the situation of uncertainty or uniqueness [25]. End-users and other relevant stakeholders provide feedback and feed forward comments during the development process via participation in the aforementioned activities and they participate in the research activities for monitoring the usage in practice. Formative is used in a broader sense than evaluating, or feedback about, the design; it is a longitudinal activity during the development process and during the actual usage of a technology in practice. Summative evaluation activities consist of determining what has been achieved at a given time. The summative evaluation measures the outcomes at different levels; the usage of a technology and the effects on performance criteria for high-quality care.

The critical success factors that became apparent determine the successfulness of the eHt and therefore need to be closely monitored. If certain critical success factors start to have negative effects in the summative evaluation phase the choice needs to be made to iterate to change and improve the current implementation or totally re-design the implementation. This way the eHt can be kept sustainable and cost-effective.

eHealthwiki: a web 2.0 presentation of the eHealth framework

The framework will be presented as an eHealthwiki for sharing and improving knowledge and information. By using a wiki based on web 2.0 tools [15], we can open up our toolkit with research activities and instruments for those who are interested in contributing to the development of high-quality eHt. Openness is grounding principle for discussing research findings and practical insights to deliver new perspectives on the uptake of eHts for policy, practice and academics involved in the development of eHts [15]. This way, the toolkit can be enriched with knowledge from multidisciplinary fields and different sources and conferences on this issue (medicine 2.0). The main page of the toolkit consists of the framework, with clickable objects (development process and activities) that lead to its corresponding wiki page presenting relevant information and instruments.

The information consist of a brief description of the subject, links to related academic publications on the subject, a checklist and further relevant information and remarks that can be contributed by anyone interested. We hope that through this initiative the uptake of eHealth will be stimulated. At the moment the eHealthwiki is under construction (eHealthwiki.org).

Conclusion

In this chapter we have demonstrated the need for a holistic approach towards the development of eHealth technologies (eHts). Based on a narrative review, we formulated seven principles for developing human-centered and value-driven eHts. These principles underpin our framework. To support a discussion about developing technology for health and healthcare we created an eHealthwiki with our framework. The eHealthwiki represents an open and collaborative approach to the development of technologies for health. It will provide a growing and ever-improving collection of instruments and tools to facilitate developers, researchers and policy-makers. In the subsequent chapter (5.2) we will elaborate on the eHealthwiki and its content.

Case development of eHealth technologies using our holistic framework

The added value of our framework and instruments will be tested in empirical studies. At the moment, the framework is being used in several research projects.

EurSafety Health-net

The European Union wants to optimize the mobility and safety of European patients in the form of adequate cross-border healthcare. However, differences in quality between cross-border healthcare remain problematic. The EurSafety Health-net project has one goal: to improve cross-border cooperation and reduce healthcare-associated infections (HCAIs) with extra attention for multi-resistant pathogens. To achieve this goal, we co-created with all stakeholders a Health-net; a multidisciplinary, Internet-based platform to facilitate this cooperation by allowing professionals to communicate and share infection-related information. The platform will be formed by researching and identifying the necessary evidence-based (expert) content, and also the indispensible, practice-driven structure. This project uses our eHealth framework to guide the development of the Internet based platform.

DiaDerma

DiaDerma is a project to develop a tele-diagnostic device for the effective screening and monitoring of chronic wounds on the skin. Most chronic wound diagnoses occur in a home situation and often these diagnoses are not optimal. The device shall help home caregivers to make a snapshot of the wound for an eventual automated diagnosis with a chronological collection of snapshots to see how the wound evolved. We used our framework to identify the problems and specify what the technology wants to achieve (problem statement); to perform a stakeholder analysis and needs assessment, to translate the critical values into functionalities of technology (program of requirements), to match user requirements with technical requirements, to set criteria for resources and competences, to test the scenarios for using the technology in different care settings and to make a business model.

Diabetes Interactive Education Program

DIEP is an online application for persons with type 2 Diabetes Mellitus. It has been developed to support patient education and stimulate self-management. Though rated by experts and patients as one of the best interventions available in the Netherlands, some deficiencies impede its nationwide implementation among a diversity of people. To remove these deficiencies we re-designed DIEP using a collaborative approach. Using concepts and techniques from participatory (re)design and business modelling we determined the user needs (patients, health care providers, and other stakeholders) and define what should be done to improve usability, adherence, and acceptance. The outcome is an optimized DIEP; a persuasive tool that people use and keep using since is serves the goals they have set and supports them in coping with diabetes.

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Appendix A. References journal papers narrative review

Total (55):	*Refs:*	*In- and exclusion criteria:*
Framework (31)	[1-14]	papers included; describing a framework in detail (14)
	[15-31]	papers excluded; not describing a framework in detail (17)
General (17)	[32-48]	papers excluded; not describing framework concepts
Research (7)	[49-55]	papers excluded; not describing framework concepts

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Appendix B. Overview of eHealth frameworks included in review

Ref	*Author, year, framework title & focus, purpose, perspective*	*Foundation*	*Needs*	*Content & System*	*Incorporation*	*Effects/outcomes*
	Esser et al. 2009 Framework for the *design* of user-centered teleconsulting systems & checklist for designers Practical tool for design for professionals, basis for a checklist, overview of relevant components; Users' perspective	Based on the interpersonal teleconsultation framework of Miller, 2002 + review of doctor-patient communication & technology acceptance & technology-mediated communication literature& media richness theory	INPUT: BACKGROUND VARIABLES Individual context -Patient characteristics -Provider characteristics -Disease characteristics -Relationship characteristics INPUT: BACKGROUND VARIABLES Organizational context -Organizational context characteristics: voluntariness of use, social influence, compatibility, facilitating conditions	INPUT: BACKGROUND VARIABLES Technical context -Medium characteristics: mode/ interactivity, compatibility, facilitating conditions	THROUGHPUT: TELECONSULTATION PROCESS Communications -Instrumental behaviours -Affective behaviours Perceptions -Task-Performance (usability, reliability, effectiveness) -Effort (efficiency, learn ability. accessibility etc -Experience (pleasant vs unpleasant)	OUTPUT Process evaluation -Satisfaction -Adoption -Health outcomes
	Yusof et al. 2008 *Evaluation* framework for health information systems Structured debating tool for researchers and practitioners. Addressing the fit between human, organizational and technology factors. Flexible taking in to account different settings, contexts and users' and stakeholders' points of views.	Based on the IS Success Model of DeLone & McLean, 1992 + the IT-Organization Fit Model adapted from Scott Morton, 1991 + review of health information systems' literature		TECHNOLOGY -System quality e.g., ease of use -Information quality e.g., usefulness -Service quality e.g., responsiveness	ORGANIZATION -Structure e.g., culture, leadership -Environment e.g., government policy and politics, financing sources.	HUMAN -System use -User satisfaction NET BENEFITS (users+stakeholders) -Clinical practice -Efficiency -Effectiveness -Decision making quality -Error reduction -Communication -Clinical outcomes

Hamid & Sarmad 2008 *Evaluation* of e-health services: user's perspective criteria Criteria for user-centered ehealth services (technology), criteria from a users' perspective	Behavioral theories, TAM & DOI Innovation) + broad examination of existing evaluation initiatives based on eHealth services case studies; multi-disciplinary, instead of one single theory		EVALUATION CRITERIA Easy to learn and use: -Easy to learn: the time needed to work with a service -Easy to use: the simplicity of the service and how easy it is to understand and comprehend its functions Accessibility: -Content accessibility: the degree of compliance with the *web Content Accessibility Guidelines* -User interface: judged by the available options of user interfaces (e.g. graphical, multi-screen, attentive) -Disability access and translation: is the system offering some form of disability access and foreign language translation features? Compatibility: -Compatibility: the degree to which the e-service can fit into the whole healthcare system Functionality: -Accuracy: the degree to which information provided by the service is free of errors -Validity: the clarity and regularity of information updating -Robustness: the technical functionality of the service -Speed: the system's response time; web page load time; download time -Availability: the availability of the service 24h/seven days per week and the existing alternative choices User satisfaction: -Utility: the completeness and usefulness of service content -Reliability: the appropriateness of the service functions in terms of the technology as well as the accuracy of the content -Efficiency: the time spent to complete the information task, quality of the information found, appropriateness of the information found, and satisfaction with outcome -Customization: the degree of service tailored to the needs of individual users -Flexibility: judged by whether a system of service provides choice of ways to state a need and delivers dynamic information		EVALUATION CRITERIA Costs: -Money saving -Time saving Benefits -Effort saving: the degree of convenience in using a particular eHealth service -Quality: the added value to the citizens, information and knowledge about their conditions, diagnoses, treatment options, and healthcare facilities, as well as the appropriate timing of the service -Access: judged by access level comparing to the same quality of services through alternative channel

Pagliari 2007 *Design & evaluation* framework for eHealth Framework for Interdisciplinary collaboration (developers, researchers; different disciplines), research activities related to different stages from design to implementation; Users point of view	Based on engineering; software design/system development life-cycle models (SDLC) and Health service Research evaluation methods	GENERATE IDEAS/CONCEPTS/THEORY -Define/redefine intended function and specific requirements in consultation with relevant stakeholders (engineering, medical)	EVALUATION OF CONCEPTS & PROTOTYPES -Develop/refine prototype to meet stated aims -Test in lab or small field trials to assess functionality, etc. -Refine/repeat if indicated	IMPLEMENT IN ROUTINE CLINICAL PRACTICE	EVALUATION OF IMPACTS -Assess impact e.g., clinical outcomes, cost, perceived value, barriers, quality of life, uptake PRAGMATIC EVALUATION -Ongoing monitoring of uptake, effectiveness and safety in routine practice
Kaufman et al. 2006 *Evaluation* framework for health information system design, development and implementation Heuristic for developers (not specified) for matching the design system stages with evaluation levels, users' perspective	Based on the evaluation framework of Stead et al., 1994	STAGE 1: SPECIFICATION AND NEEDS REQUIREMENTS -Evaluate definition/specifications	STAGE 2: COMPONENT DEVELOPMENT -Evaluate in the lab STAGE 3 INTEGRATION OF COMPONENTS INTO SYSTEM -Evaluate in the field	STAGE 4: INTEGRATION OF SYSTEM INTO A CLINICAL SETTING -Evaluate validity	STAGE 5: ROUTINE USE OF A SYSTEM -Evaluate efficacy
Dansky et al. 2006 A framework for *evaluating* eHealth research Framework depicts the interwoven dimensions of ehealth: design, environment, logistics, technology; Communication is seen as the adhesive that holds the framework together; multi-stakeholder perspective. Framework for researchers (not specified)	Health Insurance portability and accountability Act regulations	LOGISTICAL ISSUES -Roles and responsibilities of a multi-disciplinary team -Procedures for data collection -Communications	TECHNICAL ISSUES -Technical requirements related to the hardware and software -Infrastructure and resources to support the technology -Changing requirements of the system -Vendor relations -User issues such as training and satisfaction with the system -Overall system maintenance and performance	ENVIRONMENTAL ISSUES -HIPAA regulations -IRB requirements -Funding/reimbursement for services provided	

Ganesh 2004 Conceptual framework for eHealth - drivers, applications, challenges ahead and strategies *Implementation* Conceptual framework with key-enablers eHealth (needs assessment, defining infrastructure, health service, technical medical, human factors; mobilizing organizational support; planning technically feasible and medically valid applications; conducting pilots; benchmarking; promoting partnerships); multi-perspectives (users, policy and other stakeholders), not specifying the target group for whom the framework is meant	Based on author's viewpoints towards eHealth derived from non-systematic review of literature	HEALTHCARE PLAYERS AND THEIR KEY INFORMATION NEEDS; FACTORS THAT NEED TO BE ADDRESSED IN PROTOCOLS Patient perspective: -Privacy, confidentiality -Patient education -Informed consent Practitioner perspective: -Education about and training to use the technologies -Consultation, supervision roles and responsibilities -Referral decision-making and plan of care management -Licensure and credentialing Provider perspective: -Needs assessment and marketing analysis -Business plan and requirements for sustainability -Content, structure, data security, privacy, confidentiality, data storage and functionality -Compatibility and connectivity with other healthcare information systems -Consumer's culture, i.e. language, physical and mental status -Adherence to quality standards -Personnel performance -Training and education -Patterns of use -Productivity -Documentation -Directory of services provided and not provided -Referral decision-making and plan of care management -Establish when, where, and how eHealth is used DEFINING EHEALTH NEEDS -Conducting a needs assessment (clinical, economic and technical perspective); Doolittle & Cook's needs assessment model	KEY ENABLERS FOR SUCCESS Developing infrastructure requirements: -Technical: high degree of telecommunications network security, availability, adequate transmission capacity and reliability -Medical: selecting equipment that meets a defined need and that is easy to use, professional expertise, reinforcement of physician-patient relationship -Human: education for healthcare staff and consumers/patients on opportunities and challenges and on how and when to use the service Planning technically feasible and medically valid applications -Provide flexibility (to address healthcare delivery needs, provide a wide range of applications and allow any member organization to connect with another in an open architecture system) -User-centered design is advantageous Conducting pilot projects: -Start with scaled down program initially and then ramp up as recognition and value and patient volume increases	KEY ENABLERS FOR SUCCESS Benchmarking successful delivery models (WHO strategy to design and reconfigure healthcare systems): -Develop health policies and legislation to support comprehensive care -Coordinate care across conditions, healthcare providers and settings -Enhance flow of knowledge and information between patients and providers and across providers -Educate and support patients to manage their own conditions -Link healthcare to other resources in the community -Monitor and evaluate the quality of services and outcomes Mobilizing organizational support: Crucial determinants for successful eHealth programs: -A shared vision of what the organization is trying to accomplish -A clearly articulate mission -Institutional leadership Promoting partnerships: -Identify appropriate partners -Specify appropriate technology -Find financing IMPLEMENTING ECONOMICALLY VIABLE AND SUSTAINABLE PROGRAM

Van der Meijden et al. 2003 Determinants of success of inpatient clinical information systems *Implementation* Criteria for success; large-scale user perspective (end-users and organization); evaluation interwoven with design and aimed at users; aimed at organizational factors; not specifying the target group for whom the framework is meant	Based on DeLone & McLean's dimensions of IS success, 1992		EVALUATION CRITERIA System quality attributes: -Ease of use -Response time -Time savings -Intrinsic features creating extra work -Perceived ease of use -Usability -Availability -Ease of learning -Rigidity of system; built in rules -Reliability -Security -Easy access to help -Data accuracy Information quality attributes: -Completeness -Accuracy of data -Legibility -Timeliness -Perceived usefulness -Availability -Comprehensiveness -Consistency -Reliability -Format System development attributes: -User involvement -Redesign work practices -Reconstruction of content/format -Technical limitations	EVALUATION CRITERIA Implementation attributes: -Communication -Training -Priorities chosen -Technical support -User involvement Organizational aspects attributes: -Organizational culture: control and decision-making, management support, professional values, collaboration/ communication -Support and maintenance -Champions -Rewards	EVALUATION CRITERIA Usage attributes: -Number of entries -Frequency of use -Duration of use -Self-reported usage -Location of data entry -Frequency of use of specific functions User satisfaction attributes: -User satisfaction -Attitude -User friendliness -Expectations -Competence Individual impact attributes: -Changed clinical work patterns -Direct benefits -Changed documentation habits: more administrative tasks, time of day for documenting, documentation frequency -Information use: information recall, accurate interpretation, integration of information/ overview, information awareness -Efficiency and effectiveness of work -Job satisfaction Organizational impact attributes: -Communication and collaboration -Impact on patient care -Costs: time savings, reduction of staff, number of procedures reduced

Kukafka et al. 2003 Information technology implementation framework in behavioral science Framework to facilitate the cross-theoretical integration of behavioral models; to guide IT-implementation plans. Framework for planners, developers (not specified), user and other stakeholders perspective in needs analysis, individual behavior perspective in implementation	*Integrative* framework for implementation Adapted from Green and Kreuter's PRECEDE and PROCEED conceptual framework, 1999 + literature review of models that explain IT usage	ASSESSMENT OF ORGANIZATIONAL NEEDS AND GOALS -Identification of the organizational needs amenable to IT system solutions	SYSTEM USE-INDUCING STRATEGIES -System specification, functionalities related to needs and behaviors -Developing approaches that are proactive and specifically targeted to favorably influencing the predisposing, enabling and reinforcing factors	SYSTEM USE-INDUCING STRATEGIES -Implementing approaches that are proactive and specifically targeted to favorably influencing the predisposing, enabling and reinforcing factors	ASSESSMENT OF THE BEHAVIORAL AND ENVIRONMENTAL FACTORS (associated with system use) -Identification of factors that influence behaviors linked to IT use: predisposing (perceived ease of use), enabling and reinforcing factors
Shaw 2002 'CHEATS': a generic information communication technology (ICT) *evaluation* framework Multi-disciplinary approach (knowledge of different disciplines underpin the framework); Evaluation dimensions (clinical, technical, human, organizational, educational, administrative, social); Perspective of patients and professionals			TECHNICAL -Appropriateness of technologies implemented -Video and sound quality for the application (if appropriate) -Differences associated with different techniques -Ease of use -Technology specific training -Reliability of technology	HUMAN AND ORGANIZATIONAL -Primary–secondary interface -Secondary–tertiary interface -Primary–primary interface -Secondary–secondary interface -Primary–community interface -Secondary–community interface EDUCATIONAL -Impact on recruitment and retention of staff -Training provision, acceptability and continuity (non-technology specific)	CLINICAL -Quality of care -Diagnostic reliability -Impact and continuity of care -Acceptance of technology (both by patients and professionals), -Changes in work practices and redistribution of resources, -Differences in acceptance and efficacy between different areas -Cultural differences -Different patient/client groups -Interviewing techniques -Effects on referral rates -Appropriateness of referral ADMINISTRATIVE -Convenience (improved access to care) -Change in interaction styles -Cost effectiveness SOCIAL -Impact of computerized systems on social interaction

Kazanjian & Green 2002 Beyond effectiveness: *the evaluation* of information systems using a comprehensive health technology assessment framework For decision-makers (policy, administrative. developers of information systems) to provide an empirical, evidence based foundation for health technology decisions; key-dimensions are epidemiological context (populations at risk, population impact), social context, economic concerns, technology assessment information Stakeholders' perspective		POPULATION AT RISK -Reduced health deficits of the population -Increased accessibility to services POPULATION IMPACT Disability, quality of life	TECHNOLOGY ASSESSMENT Target/goal: -Increased understanding of conflicting interests -Improved relevance of evaluative research	SOCIAL CONTEXT Target/goal: -Balanced gender: participation in decision-making, gauging political will -Development of legal perspective	POPULATION IMPACT Target/goal: -Healthier lifestyle -Improved quality of life and well-being -Reduced burden of illness ECONOMIC CONCERNS Target/goal: -Optimization of total social returns by weighing estimated costs and perceived benefits -Recognition of allocative efficiency
Hebert 2001 *Evaluation* framework for telehealth success Conceptual framework, using performance indicators (structure, outcome, process) to assess the quality of eHealth, perspective of patients and organization (resources), not specified for whom the framework is meant	Based on Donabedian's quality of care measures: structure, process and outcome, 1980 + DeLone & McLean's dimensions of IS success, 1992+ HTA approach			STRUCTURE (Structure includes the human, physical and financial resources (i.e. inputs) that are needed to provide health care) Individual structure: -Patient: access to services, acceptability -Provider: training to use the equipment, change in practice Organizational structure: -Scheduling -Equipment location -Culture -Cost -Equipment effectiveness	PROCESS (Process of care is the set of activities that goes on between practitioners and patients) Process of care: -Satisfaction with care -Effectiveness of interaction compared to face-to-face -Management of care process (provider and patient) OUTCOME (Outcome is the change in patients in health status) Individual outcomes: -Patient: satisfaction with outcome of care; quality of life, functional status -Provider: satisfaction with outcome of care, number of re-admissions, frequency of adverse effects Organizational outcomes: -Efficient use of resources -Cost effectiveness -Utilization of services

Eysenbach 2000 *Evaluation* framework for assessing the quality of eHealth Conceptual and methodological framework for evaluating the quality of eHealth; evaluation perspectives (information providers, users, patients); not specified for whom the framework is meant	Based on Donabedian's quality of care measures: structure, process and outcome, 1980		STRUCTURAL QUALITY Communication setting, infrastructure, resources: -System criteria: ease of access, speed, readability, disclosure, attribution, displaying the date, clarifying the target population, accountability, indirect measures (popularity, number of links pointing to the site) -Internal standard operating procedures and quality assurance processes, commitment to quality PROCESS QUALITY Communication process itself (acting in line with clinical and ethical guidelines): -Actual accuracy -Accuracy of advice -Ethical behavior, including privacy and confidentiality -Validity of health risk assessment tools	STRUCTURAL QUALITY Communication setting, infrastructure, resources: -Resources: capital, infrastructure -Staff: number, qualification, leadership - Training	OUTCOME QUALITY Effect of communication on improving patient outcome: -Mortality -Morbidity -Quality of life -Cost effectiveness -Behavior change, change in attitude and knowledge
Eng et al. 1999 *Evaluation* framework for interactive health communication applications Framework with concepts and activities; conceptualization and design; implementation and assessment and refine; provides a checklist and research methods for evaluation. Stakeholder perspective (developers, consumers, policy-makers; purchasers). Framework for evaluators (not specified);	Partially adapted from the National cancer institute. Making health communication programs work, 1989	CONCEPTUALIZATION Key development activities -Describe the health issue/problem -Identify existing programs and gaps -Identify target audience and needs -Identify program goals and objectives -Identify messages and content -Identify and collect relevant raw information and data -Identify resources -Develop business plan and marketing dissemination -Draft product time table -Identify media access among target audience -Select specific media to utilize Key evaluation activities (formative evaluation) -Assess scientific literature -Assess relevance of completed evaluations of similar products -Develop evaluation plan -Develop and pretest communication strategies -Assess and specify system requirements, features and user interface specifications	DESIGN Key development activities -Tailor and develop content and data to fit needs Key evaluation activities (formative evaluation) -Pretests prototypes on target audience -Pretest content on target audience -Assess whether needs of audience(s) are adequately addressed in design	IMPLEMENTATION Key evaluation activities (process evaluation) -Monitor the operational characteristics of the intervention -Assess security, accuracy, reliability, usability, response time -Assess user satisfaction and utilization patterns	ASSESSMENT & REFINEMENT Key development activities -Implement evaluation of short-term and long-term impact -Revise program based on evaluation and feedback Key evaluation activities (outcome evaluation) -Examine intervention's ability to achieve its intended effect, analyze feedback and evaluation results, share evaluation results and lessons learned with others

Chapter 5.2

Introduction

Technology-based interventions in healthcare aimed at changing behavior or the organization of care should be grounded in multidisciplinary theories such as behavioral and social-cognitive theories and those linked to innovation and diffusion in order to develop technologies that make sense for all the stakeholders involved (policy, finance, research, practice). To this end, we proposed a holistic framework; the ceHRes Roadmap, see Figure 1. It functions as a roadmap to help plan and coordinate eHealth technology developments. Chapter 5.1 introduced the key principles for developing sustainable eHealth technologies that underpin the holistic framework.

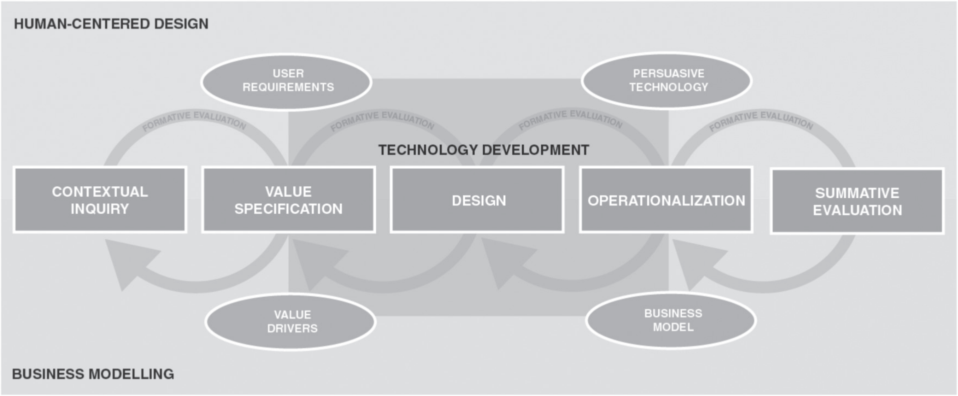

Figure 1. ceHRes Roadmap for the development of sustainable eHealth technologies

The roadmap consists of two interwoven strategies: Human-Centered Design and Business Modelling. In this paper we focus on the research activities and methods for the participation of users in the development process (HCD). In another paper we describe the methods for stakeholder participation as part of Business Modelling (paper not included in this thesis).

Human-Centered Design (Human-Centered Design) is concerned with incorporating the users' perspective (patients, caregivers, or familycarers) into the design of the eHealth technologies [1-7]. In our view we characterize HCD as a participatory process of co-creation with the end-users to create the functionalities and content of the technology, based on values specified by the key stakeholders (including the intended users). The focus of the design approach is on translating values, such as safety and self-care management, into functional requirements. For example monitoring to realize the value of self-care management to guarantee that technology meets the expectations of all stakeholders, such as patients, family members, healthcare professionals, policy-makers, funders, and that it motivates people to support healthier behavior.

This paper provides a guideline for those who are involved in the development of eHealth technologies. The guideline is meant for developers, decision-makers and researchers to help them plan, manage or execute the development and accompanying research activities. The methods and research activities (see Figure 2) are linked to each of the concepts of the roadmap, namely:
(1) Contextual inquiry
(2) Value specification
(3) Design
(4) Operationalization
(5) Summative evaluation

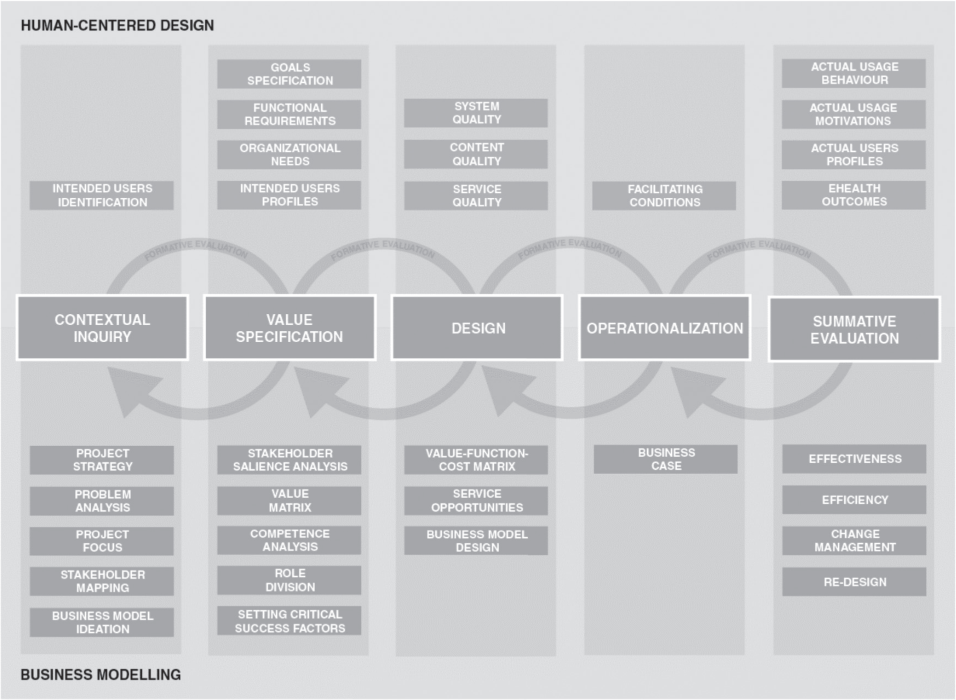

Figure 2. Overview of research activities and criteria within the ceHRes Roadmap

The guideline gives direction on where to start with research, what instruments to use, and defines the criteria for the development. It should not be used as a checklist that simply has to be ticked because the development process is iterative and flexible, which means going back and forth during the development. The research criteria are based on empirical research and a review of the literature on eHealth. The guideline will be extended with an instrument for business modelling (article in press, not included in this thesis).

The guideline is flexible; evaluation and implementation are ongoing activities throughout the entire development process from contextual inquiry to summative evaluation. Depending on the maturity of development, the criteria that are vital can be established. The guideline is also dynamic; the content evolves every time the guideline is used. The idea is for researchers, decision-makers, developers, healthcare professionals and patients to add criteria to the guideline that seem relevant based on their own experience. This is why we will present the guideline through a web 2.0 platform; eHealthwiki.org. It is not just about providing information, but also about enhancing that information with examples such as case studies and research tools.

To facilitate and streamline the development process, and to avoid a 'design-build-run and see what happens' approach, multi-disciplinary project management is needed. This implies cooperation between *developers, researchers and healthcare professionals* from different disciplines such as engineering, medicine and behavioral sciences.

Contextual inquiry

Research activity

Ideally, the development process of an eHealth technology should start with a *contextual inquiry*. Contextual inquiry entails information gathering from the environment in which the technology will be implemented. It starts with a scenario that represents the environment of the technology and the tasks or actions that are relevant to support the technology. Stakeholders with different backgrounds (financers, decision-makers, patients, caregivers), identify problems with the current healthcare delivery via the scenarios and articulate their needs and demands to solve the problems. In addition to this, they define who the owners of the key problems are or those who have stakes in the solution to the problems that have been identified. It is important that the needs and demands of all those involved are taken into account. To sum up, contextual inquiry is aimed at finding out what the problems in healthcare are, what the contribution of technology can be, and who might benefit from the technology.

Research methods

Several research methods can be used to perform a contextual inquiry, including observations, focus groups (stakeholder meeting) [5,8]. A focus group brings together a cross-section of stakeholders in a discussion group format. This method is useful for addressing all the points of views of different stakeholders. The general idea is that each participant can act to stimulate ideas in the other people present, and that, through a process of discussion, a collective view becomes established which is greater than the individual parts. The focus group method, which is also called group interviewing, is an excellent method to obtain a lot of information in a short time about the underlying motivations and needs of different stakeholders about a particular subject.

Research criteria
See Table 1, Contextual inquiry.

Example

Doctors should be easier to reach
General Practitioners (GPs) are unacceptably hard to reach in an emergency. This is the view of the Public Health Inspectorate (IGZ) in the Netherlands and the Dutch Federation for Patients and Consumers (NPCF). In non-emergencies too, GPs are difficult to reach. More than one quarter of the callers cannot get through to the GPs' emergency numbers. By the end of the afternoon, this will have risen to 40% of all callers. Furthermore, many GPs do not even have an emergency number or, if they do, their patients do not know this number. This applies to more than half of the callers. And in seventeen percent of the cases an answering machine is attached to the emergency number. IGZ and NPCF believe that GPs should answer their phone within 30 seconds of receiving an emergency call. In more than one third of all cases this does not happen. It is not much better in the case of non-emergency calls. Forty percent of the callers have to wait for more than ten minutes before they get anyone on the line. IGZ and NPCF believe that non-emergency calls should be answered within two minutes, but half of all callers have to wait longer.

Value specification

Research activity
The *value specification* process elaborates on the outcomes of the contextual inquiry. It is aimed at exploring what healthcare improvements are foreseen and what the possibilities or expected limitations are to realize the values. In this process the key stakeholders determine first their values (economical, social, and behavioral) and then rank them based on their importance for solving the identified problem(s). After specifying and ranking the stakeholders' values, the eHealth goals can be formulated. The next step is to define the functional and organizational requirements to realize the values.

Research methods
Focus group (stakeholder meeting), business modeling, value matrix (described elsewhere).

Research criteria
See Table 1, Value specification.

Example

- ► *Values:* What are the healthcare improvements that have value for the stakeholders?
IGZ and NPCF want GPs to use ICT more effectively. This will reduce the strain on the telephone, which in turn will lead to shorter waiting times for callers.
eHealth goal(s): increasing access to GP via technology (see Table 1, eHealth outcomes)
- ► *Requirements:* what are the functional requirements for realizing the values (increased access to the GP) and the capacities for technology (resources, skills) for realizing the values?
Functional requirements:
For example, easy to reach irrespective of time or place; safety and guaranteed privacy. This could be possible, for example by using a secure Internet line for making appointments and ordering repeat prescriptions. Furthermore, GP's surgeries should, assuming they do not already have them, start using modern telephone equipment and devices (for example, switch-through systems).
Organizational requirements:
The National Association of General Practitioners (LHV) agrees that the accessibility of GPs should be improved, but the GPs want to charge extra fees for this. It also requires sufficient skills in order to work in this way and for the Internet systems to be operable with the GP's information system.

Design

Research activity

Once the requirements have been defined, the actual design process starts. The project management team has to visualize the ideas via mock-ups keeping in mind the values, goals and the tasks that have to be fulfilled. Mock-ups (paper prototypes, storyboards) are created and discussed with the intended end-users and, following on from this, the prototype will be refined. The prototypes will be tested in real-life situations. The user is invited in several rounds via concrete scenarios or tasks to test whether the prototypes match their expectations and mental models (way of thinking, and working). In general, the quality of the design can be assessed at three different levels [9]:

- system quality: technology that is user-friendly and safe [10]
- content quality: content that is understandable and meaningful [10]
- service quality: service that is adequately provided (timely) [11], and persuasive [12,13]

Research methods

Various methods are involved within the design phase, including, storyboarding, card sorting, prototyping, cognitive walkthrough, formulating personas, and scenario-based testing [5,14]. The choice of methods to be used depends on the technology to be developed and on its maturity and status; the design of a new technology versus redesign of an already existing technology.

Paper prototyping [5,15-17]; designers start by creating a paper-based simulation of user interface elements (menus, buttons, icons, windows, dialogue sequences, etc.). When the paper prototype has been prepared, a member of the multidisciplinary team sits before a user and 'plays the computer' by moving interface elements around in response to the user's actions. The difficulties encountered by the user and their comments are recorded by an observer and/or on video or audio tape.

Storyboards [5,18] are sequences of images which show the relationship between user actions or inputs and system (e.g., screen) outputs. A typical storyboard will contain a number of images depicting features such as menus, dialogue boxes and windows. The formation of these screen representations into a sequence conveys further information regarding the possible structures, functionality and navigation options available. Few technical resources are required to create a storyboard. Simple drawing tools (both computer and non computer-based) are sufficient. Storyboards also provide a platform for exploring user requirements options via a static representation of the future system by showing them to potential users and members of a design team. This can result in the selection and refinement of requirements.

Card sorting [5,19-24] is a technique for uncovering the hierarchical structure in a set of concepts by having users group items written on a set of cards; this is often used, for instance, to work out the content and navigation structure of a technology, for example to develop an eHealth technology, users would be given cards with the names of the web pages on the site and asked to group the cards into related categories. After doing so, the users may be asked to break down their groups into subgroups for large sites. After gathering the groupings from several users, designers can typically spot clear organizations across many users. Statistical analysis can uncover the best groupings from the data where it is not clear by inspection, though inconsistent groupings may be a sign of a poorly defined goal for the website or a poor choice of web page names.

Personas; via personas [5,25-28] suitable persuasive styles will be created for the design of the content and system of technology. For example, in home care situations in rural areas, patients want to have information for self-care. Based on their background, eHealth literacy, interest and needs, a persona will be created for choosing the right format of technology to support them (e.g., mobile, Internet).

Scenario-based testing [29-34]; scenarios give detailed realistic examples of how users may carry out their tasks in a specified context with the future system. The primary aim of scenario-building is to provide examples of future use as an aid to understanding and clarifying user requirements and to provide a basis for later usability testing. Scenarios encourage designers to consider the characteristics of the intended users, their tasks and their environment, and enable usability issues to be explored at a very early stage in the design process. They can help identify usability targets and likely task completion times. The method promotes developer buy-in and encourages a Human-Centered Design approach. Scenarios should be based on the most important tasks or roles related to the technologies from the context-of-use information. They are best developed in conjunction with users. User goals are decomposed into the operations needed to achieve them. Task time estimates and completion criteria can be added to provide usability goals.

Cognitive walkthrough [35]; the cognitive walkthrough method is a usability inspection method used to identify usability issues in a piece of software or website, focusing on how easy it is for new users to accomplish tasks with the technology. The purpose of a cognitive walkthrough is to evaluate the cognitive processes of users performing a task. The method involves identifying sequences of actions and goals needed to accomplish a given task. The method is intended to identify potential usability problems that may impede the successful completion of a task. A cognitive walkthrough starts with a task analysis that specifies the sequence of steps or actions required by a user to accomplish a task, and the system responses to those actions. The 'experts' (designers, developers, researchers) explore the system, asking themselves a set of questions at each step. The eHealth technology will be redesigned to address the issues identified.

Research criteria

See Table 1, Design.

Example

Design process

Research activities:	*Tasks of the multidisciplinary team:*
► Visualization of the technology via mock-ups ► User test 1: user assessment of the quality of the mock-ups (methods: paper prototyping, storyboarding) ► Building a working prototype ► User test 2: user assessment of the quality of the working prototype (card sorting, usability testing, cognitive walkthrough, personas) ► Refine the technology	The Multidisciplinary team (consisting of technology providers, designers, healthcare professionals, technical developers, and researchers) plans and organizes the development process. The team acts as a sounding board during the user tests to make sure that the values are not overlooked during the design process.
► eHealth technology is ready-to-use	

Example of usability test outcomes (chapter 3)

Problem type	Identified Caregiver Problems
User-friendliness (*n* = 101, 34.8%)	Navigation problems: - Unclear navigation structure, hyperlinks missing or useless - Lack of feedback features - Lack of documentation features - Unclear answer procedures/formats Technical problems: software bugs
Quality of care (*n* = 43, 37.9%)	Non-profitability* of e-consultation: requests from patients still required personal contact with a caregiver Concerns about a higher chance of interpretation difficulties: caution when formulating answers to patient requests, such as being extremely careful when formulating the answer because of possible legal consequences Concerns about a higher chance of misuse: requests from unknown patients who are using the account of known patients
Operationalization (*n* = 54, 27.3%)	Unclear regulations about email consultation: - Lack of a transparent protocol for email consultation - Unclear regulations about prerequisites for using email consultation - Lack of quality inspection of email consultation applications - Insufficient reimbursement for email consultation Lack of education and training: underuse or misuse of applications because of lack of education Interoperability of systems: applications could not be integrated with the existing patient information system or medical records Concerns about patient equity of access: concerns about the risk of widening the gap between those who have access to new technology and those who have been excluded.

*Profitability: the degree to which the health service can be delivered in a quick, effective, and economical manner

Operationalization

Research activity

During the development process key-stakeholders have to decide the strategies and activities for the operationalization of the eHealth technology [36-41]. Operationalization refers to the planning and actions for dissemination, adoption and incorporation or internalization of the technology. The plan consists of activities and resources for training, education, financing the operationalization to enable the use of the eHealth technology in daily practice by the end-users. Disregarding these conditions may limit the technology's usefulness and delay decision-making. Nevertheless, these factors are usually not considered at all when eHealth technologies are implemented in health care. Yet an early assessment of the facilitating conditions may decrease the risk factors that can come along with the operationalization of eHealth technologies, such as high costs, legal constraints, eHealth literacy, and a missing infrastructure. Based on the resources and capacities, a business model can be developed for implementing the technology in the healthcare system [38,42-46].

Research methods

Business modeling instruments could help us to minimize the risks, because via business modeling we are able to pay attention to the overarching infrastructure at an early stage of the design of the eHealth innovation, which may in turn greatly accelerate the adoption and effectiveness of eHealth. Instruments for business modeling are described elsewhere (not included in this thesis).

For methods for dissemination, diffusion and adoptions such as communication planning, see Cain & Mittman [37].

Research criteria

See Table 1, Operationalization.

Example

See previous example under Design: example of usability test outcomes.

Summative evaluation

Research activity

Summative evaluation activities consist of determining what has been achieved at a given time. The summative evaluation measures refer to the actual uptake of a technology (its usage) and its outcomes at different levels; system, process, and client level.

In measuring eHealth usage, we should look at the actual usage behavior and the accompanying user profiles. It answers questions like: how and why do people (not) use eHealth technologies and how can technology motivate people to good (self-care) behavior?

Together with usage behavior, eHealth outcomes should be measured to assess whether the intended objectives of the eHealth technology as specified within the value specification phase are being realized.

Research methods

Research methodologies for assessing eHealth usage (actual usage and user analysis) include log files, content analysis, critical incidents, and satisfaction surveys.

Log files can be used to register the actual use of the technology features and content. Next to log files qualitative research (interviews, critical incidents technique) can be used to address the users' motivations for using the eHealth system, the meaning the system use has for users, and whether or not they will adopt it into routine practice [1,47-52].

Content analysis [53] gives us additional insight in the reasons for use. Moreover, surveys can be used to identify user profiles. The intended user profiles should be compared to the actual user profiles that were identified during the contextual inquiry.

Critical incidents [5] are events that represent significant failures of a design. Verbal reports of the incident are analyzed and categorized to determine the frequency of different incident categories. This enables design deficiencies to be identified. It can highlight the importance of improving features supporting a very infrequent but important task that might otherwise get ignored by other methods.

User satisfaction questionnaires [5] capture the subjective impressions formed by users, based on their experiences with a deployed system or new prototype. This can be achieved by using questionnaires or through direct communication with the respondents.

Research methodologies for assessing eHealth outcomes include quantitative measures such as randomized controlled trails or quasi-experimental research and systematic reviews (for meta analysis).

Research criteria

See Table 1, Summative evaluation.

Table 1. Guideline for the development of sustainable eHealth technologies

1. CONTEXTUAL INQUIRY

Research activity: problem identification & stakeholder analysis

Research questions:

a. What is the problem; why is the eHealth technology needed?

b. Who is involved; who has a stake in addressing the problem?

Research methods: focus group (stakeholder meeting), observations

Research criteria:

Identify the problem…

Select the healthcare context in which the problem is present:

- Preventive care (lifestyle)
- General practice care
- Mental healthcare
- Paramedical care
- Chronic care
- Hospital care
- Other………………………………………………………………………………………………

Identify the stakeholders (including the intended users)…

- Developer
- Designer
- Researcher
- Healthcare professionals
- Patients
- Other………………………………………………………………………………………………

Identify the stakeholders' roles and tasks:

- Role in proces
- Stake in process
- Power to the product (eHts)
- Internal/external stakeholders
- Negative stakeholders

Table 1. Continued

2. VALUE SPECFICATION

Research activity: specification of values, goals, and requirements

Research questions:

a. What healthcare improvements do the stakeholders want to achieve? And why (values)?

b. What are the requirements for realizing the values?

Research methods: focus group (stakeholder meeting)

Research criteria:

Stakeholders have to specify the values…

- Safety: avoiding injuries to patients from the care that is intended to help them.
- Effectiveness: providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit.
- Customized care: providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.
- Timely care: reducing waits and sometimes harmful delays for both those who receive and those who give care.
- Efficient care: avoiding waste, including waste of equipment, supplies, ideas, and energy.
- Equitable care: providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Identify the eHealth objectives in consultation with the stakeholder (see 5B):

Identify the functional requirements:

- Diagnose
- Monitoring
- Mentoring
- Motivation
- Documentation
- Communication:
  - synchronous communication: a channel for one-to-one asynchronous communication (video-conferencing)
  - asynchronous communication: a channel for one-to-one synchronous communication (secure email)
  - synchronous many-to-many channels: chat rooms
  - asynchronous many-to-many channels: newsgroups, forums
  - technical representation of the health care professional (digital triage)

Identify the organizational requirements (see 4)…

Assess the intended users' profiles:

- Socio-demographic characteristics: age, gender, education, socio-economic status
- Heath-related characteristics: health status, quality of life, acute vs. chronic health condition, disease phase, medication use, frequency of GP visits
- Context-related characteristics: motivation to change, capabilities to change, access to computer and Internet, computer and Internet skills, eHealth literacy, attitude towards the eHt (openness towards technology); socio-cultural habits, distance to care, access to care

Table 1. Continued

3. DESIGN

Research activity: users' requirements analysis (quality demands of system, content, and service)
Research question: what constitutes a high-quality design according to the intended users?
Research methods: paper prototyping, storyboarding, card sorting, personas, scenario-based testing
Research criteria:

<u>System quality (the degree to which the user assesses the technology as functional and free of discomfort or trouble):</u>

User-friendliness:

- Ease of access: availability (service is provided at all times), equitability (service is for everyone), accessibility (easy log-in procedure, findability), speed (the ease and speed of accessing the eHt)
- Ease of use: simplicity of technology (how easy it is to understand and comprehend the system's functions)
- Absence of technical errors: absence of malfunctioning features
- Clear navigation structures: clear presentation of information (conveniently arranged, menu bar and headings)
- Efficient search functionality availability
- Efficient feedback channels: automation functions such as automatic replies
- Push factors: notification of newly available information of interest based on the user's profile
- Provision of technical support
- Readability of text: appropriate font size

Safety & technical security:

- Privacy and confidentiality assurance
- Encryption: data transmission security level
- Authentification: identification of users via username and password
- Interoperability

Design persuasiveness:

- Lens for design (design with intent) perspective for design related to user requirements', values, needs, capabilities and behavior change
- Presentation of content:
  - instructive, declarative
  - colors, symmetry
  - empathic, affective, simplifying (step by step)
  - tunneling (eCoaching)
  - tailoring/customization
  - suggestion/information at right moments
  - self-monitoring (support and awareness)
- Observation (surveillance, Hygiene Guard tracks hand washing; rewarding compliance)
- Conditioning (reinforcement, persistence)

<u>Content quality (the degree to which the user assesses the information as meaningful):</u>

- Accuracy: information is up-to-date
- Evidence-based: information is based on theories or standards (inclusion of references, use of behavior change techniques)
- Relevance: provision of information the user is looking for; information is tailored to individual users' characteristics, needs or preferences
- Comprehensibility: provided information is understandable (appropriate language, avoid medical jargon)
- Completeness: provision of sufficient information
- Language and ethnicity: multi language delivery and culture conscious information; language expectancy
- Disclosure: the information context is clear for the user (the information source is made known)

Table 1. Continued

Service quality (the degree to which the user assesses the service as adequately provided):

- Perceived usefulness: the service is of importance (has benefits to the user)
- Responsiveness: ability to provide prompt service (timely)
- Social dynamics: provision of motivational feedback (praise for good work, answering questions, reciprocity, etc.
- Psychological influence: support feelings, empathy, emotions, etc.
- Reliability: the service is provided dependably; keeping on to agreements (e.g., if the service provider says that the service will be provided within two working days, then hold on to that agreement)
- Credibility: the provider of the service is familiar and trusted (e.g., health risk assessment tools are valid)

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4. OPERATIONALIZATION

Research activity: assessment of facilitating conditions

Research question: what conditions facilitate the use of the eHealth technology?

Research methods: focus group (stakeholder meeting)

Research criteria:

Facilitating conditions for use:

- Compatibility: assess whether the eHt fits with existing technologies or infrastructures (organization of care)
- Voluntariness of use: assess in which setting the user is most likely to use the eHt; voluntary or not
- Effort expectancy: assess the time investment or workload that is required to incorporate the eHt in practice
- Accountability of quality control: assess the role of government or health insurance companies in quality control of the eHt
- Transparency of directions standards: provide clear information about the conditions for use of the eHt(disclosure)
- Financing: assess the costs and reimbursement of the eHt
- Communication channels: identify media access among the target audience and select specific media to utilize
- Trialability: make it possible to try out an eHt
- Observability: the extent to which potential adopters can witness the adoption of an eHt by others (with positive attitudes)
- Opinion leaders: search for individuals with a positive attitude towards the eHt and whose opinions are respected (for example the GP)
- Training: assess who provides the end-user training and assess the appropriate format for the training, tuned to the target audience (group or individual level training? Interactive or static training?)
- Opinion leaders, advocates
- User guidelines: provide clear and usable user guidelines, tuned to end-users
- Social influence: assess the degree to which the user perceives that important others believe he or she should use the eHt

Table 1. Continued

5A. EHEALTH USE

Research activity: assessment of actual eHealth usage behavior and users profiles

Research questions:

a. Who are the hardcore users and who stopped using the eHealth technology?

b. What are the capabilities, motivations for sustained use or non-use attrition?

Research methods: log-files, content analysis, critical incidents technique, satisfaction questionnaire

Research criteria:

<u>Usage behavior:</u>

- Frequency of use of the system's features and functions (monthly number of log-ins)
- Continued use: extensive and repeated use of the eHealth application until the end of the study period (for example 2 years)
- Discontinued use: stopped use of the eHealth technology before the end of the study period (search for usage patterns)
- Compliance with healthcare advice delivered via eHealth

<u>User motivations (what explains the usage behavior?):</u>

- Reasons for (sustained) use: purpose of use and satisfaction (related to features & functions)
- Reasons for non-use attrition e.g., inappropriate information, wrong participants, ease of stopping to use it, lack of push factors, lack of personal contact, lack of positive feedback, lack of observable advantages, intervention has not been paid for, competing interventions, external events, no peer pressure, lack of experience of the user, workload and time required is too much, etc.

<u>Actual user profile (who is motivated and capable to use it?):</u>

- Socio-demographic characteristics (see 1)
- Heath-related characteristics
- Context-related characteristics

Table 1. Continued

5B. EHEALTH OUTCOMES

Research activity: assessment of eHealth outcomes (effects and benefits)
Research question: Are the intended objectives of the eHealth technology achieved?
Research methods: survey, (randomized) controlled trial, systematic review (meta analysis)
Research criteria:

Healthcare organization (system level):

- Increased overall satisfaction with healthcare (convenience)
- Increased access to care:
  - increased availability (healthcare at all times)
  - increased possibilities (healthcare is provided in many forms)
  - improved equity (healthcare is available for everyone)
- Increased efficiency of care:
  - reduced utilization of health care services
  - time savings via substitution of tasks
  - improved communication between healthcare professionals
  - easier handling of healthcare equipment (e.g., guidelines)
- Reduced healthcare costs
- Increased safety (error reduction)
- Improved transparency:
  - care delivery based on standards as guidelines
  - protocols for information exchange

Healthcare delivery (process level):

- Increased overall satisfaction with care delivery process
- Increased continuity of care (more continuous feedback)
- Improved interaction: more efficient and effective communication between caregivers and patients or among caregivers or patients themselves
- Increased adherence to guideline - or protocol-based care
- Improved patient-caregiver relationship
- Decision support

Health and well-being (client level):

- Improved clinical values: dietary values, HbA1c, blood pressure, etc.
- Improved quality of life: social functioning, general or mental health, well-being
- Improved lifestyle behavior: change in attitude and increased knowledge, behavioral intention, and actual behavior
  - improved compliance with advice: patient's adherence to treatment
  - improved disease control: increased ability to control disease via self-monitoring, education, personal feedback
- Decreased mortality
- Decreased morbidity

Conclusion

A guideline for the development process can be supportive for the uptake of eHealth. Such a guideline should help researchers to formulate adequate questions, to find adequate methods and tools, and to apply them in a sensible way. Several frameworks have been set up for the development of eHealth technologies, see chapter 5.1. In this chapter (5.2), we provided a guideline that goes more into details; not just providing the methods, but also the criteria that should be addressed with the help of the methods. To this end, we proposed a set of essential research activities and criteria to support the development process. We often see research focusing exclusively on a summative evaluation of outcomes. Through this guide we wish to show that the field of research is much broader than this and in fact begins before technology is mentioned at all (contextual inquiry). We therefore provided instruments that address the full spectrum of the development process, via both formative and summative evaluation activities. This may help to create sustainable eHealth technologies and also to conduct better research and development.

The list of research criteria provided in this guideline serve as a starting point, which means that it is not exhaustive. It gives an indication of what we should pay attention to when developing eHealth technologies, but it is not an all-encompassing list. The guideline is dynamic, in other words the content will evolve over time the more the guideline is used. The intention is for other stakeholders (researchers, decision-makers, developers, healthcare professionals, patients) to supplement the guide using criteria that have proved to be relevant based on their own experiences. This is why we chose to develop a web 2.0-based guideline; eHealthwiki.org. It is not just to provide information, but also to enhance the information-sharing and cooperation with examples from practice and research.

The aim of the eHealthwiki is to foster collaboration and knowledge sharing among those who have a stake in eHealth development and research. Through the eHealthwiki we do not only wish to recognize researchers and developers, but also the other relevant parties too, such as healthcare professionals and decision-makers in order to foster multidisciplinary cooperation. In further research, the value of the guideline will be validated using empirical case studies that will serve as a reality check. In sum, the guideline consists of research activities, methods and criteria that will be available via the ehealthwiki. One can click on a certain part of the ceHRes roadmap and the research activities, instruments and information referring to publications will be available.

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Chapter 6

Conclusions and discussion

Grounding eHealth. Facts that matter

Today's healthcare system faces problems such as aging, a growth in age-related illness and multi-morbidity, a serious decrease of available personnel and a limited budget [1]. The grand theme within healthcare is the need to do more with less [2,3]. Technology is seen as one of the best ways to improve access to healthcare without losing quality. 'eHealth', the use of advanced information and communication technologies (ICTs) in healthcare, may contribute to the solution of these problems by supporting a better balance between self-care and professional care [1,4]. Furthermore, current demands made by 'e-patients' to manage their own health and well-being may be met by innovative eHealth technologies. The time has therefore come to embed eHealth in the healthcare system: *"finances demand it, citizens expect it, and the technology is ripe"* [2]. However, even though everything and everyone seems to be ready for it, the uptake of eHealth is still rather low.

The research carried out for this thesis took place between 2005-2010; although more people have access to the Internet nowadays [3,5], and the focus is more on Human-Centered Design [6], we still see problems with the uptake of eHealth. The actual uptake of eHealth technologies in daily practice is not what was expected. This is due to the low level of exposure to online health communication interventions [7], regulatory restrictions that limit communications with a healthcare professional via the Internet [5], and a more solution-driven development process that disregards the needs of patients and professionals, social-cultural habits and the complex nature of healthcare systems (chapters 2-5). Although there is a growing interest in the user-centeredness of technologies, resulting in more practical technologies from a technical perspective, in fact this interest did not result in better manageable, enjoyable and affordable technologies. The attrition curve still exists (chapter 4).

In this thesis we identified several important factors for a better uptake of eHealth technologies. These factors are linked to the development process of eHealth technologies, the design, and the methods for measuring the impact of eHealth technologies on safety, effectiveness, efficiency, timeliness, human-centeredness, and access (equity) [1]. Given the need for a change in healthcare we think that ehealth technologies should be grounded in the healthcare systems. To support healthcare via technology we need to rethink how and why technology can provide added value for patients, professionals and other stakeholders. Given the problems we are facing with eHealth technologies, the question arises: *"What are the most critical factors for the uptake of eHealth technologies and where are the opportunities for improvement (space of innovation)?"* To ground eHealth, we formulated a number of key principles for developing human-centered and value-driven eHealth technologies (chapter 5). These principles underpin our new holistic framework; the ceHRes (Center for eHealth Research) Roadmap. The ceHRes Roadmap aims to bring together the interdisciplinary fields of policy, research and practice by providing instruments related to participatory development and business modelling (chapter 5). In this final chapter, we will present a reflection of the major findings and conclusion of the studies reported in this thesis, together with the implications for future research and the development of eHealth technologies.

The development of eHealth technologies should be a process of value-creation to match the technology with needs, motivations, incentives, profiles and contexts.

From our studies it appeared that the development process is considered to be merely a design process, while implementation is seen as a separate and post-design activity. This resulted in technology with a low uptake and impact; too low to be feasible in practice. Given the number of people who have Internet access these days, the level of use of eHealth technologies in primary healthcare is relatively low. This can be seen from the small number of requests that are made by email or via the web for (repeat) prescriptions, appointments, or personal advice from a known health professional [5]. The main barriers to enrolling for eHealth technologies are related to limited access; the service is not provided by a GP, a lack of awareness about the existence of eHealth technologies or services, a lack of resources or skills (eHealth literacy), legal and payment constraints, safety and privacy (see chapters 2 and 4). Moreover, decisions about eHealth technologies are usually not based on mental models of the intended users but on medical-based solutions which can also lead to a sub-optimal use of technologies (see chapter 3). Alongside the 'access' barriers, we found that 'motivational' barriers, such as low interest in engaging with eHealth technologies, hinders the diffusion of eHealth (chapter 2). To date, research is increasingly being conducted to discover who is interested in using eHealth services [5,8,9]. Flynn et al. [9] found for example that certain patient groups, such as the conventional patients (those who stick to their habits), and the satisfied patients, may have a low interest in engaging with eHealth services. These findings provide a reasonable explanation for our result, namely that non-users of e-consultation preferred contact with a doctor (chapter 2). These non-users are probably conventional; that is, not pro-active, not eager to try new opportunities, because they are not properly informed about the opportunities of e-consultation, such as having to spend less time on the telephone. Or they are not used to being proactive and making their own choices in healthcare.

The successful uptake of eHealth also struggles with yet another problem; the so-called 'inverse care law' [10]. This law maintains that 'access' barriers are generally present among people who could benefit the most from eHealth initiatives because of their greater need for healthcare. Our study findings (chapters 2 and 4) suggest that eHealth technologies like e-consultation could be especially beneficial for these patient groups, for it can help them decide whether it is necessary to see a doctor and teach them self-care techniques. We also found that among potential users (current non-users) of e-consultation, the patients with a greater need for care such as the elderly, frequent visitors to the GP, less well-educated people and the chronic medication users were significantly more motivated to use e-consultations (chapter 2). However, several studies show that, to date, eHealth technologies are being mainly used by the 'healthy' and not by patients with a greater need for care. Weingart et al. [11] for example found in their study of a patient Internet portal that, compared to non-enrollees, more enrollees were white, younger, fewer had medical insurance, fewer took prescription medications, fewer had medical problems, fewer visited their GP in the previous year, and fewer had been hospitalized.

In our study (chapter 2) and also in the literature [5,9,11,12] we found that the needs for care differ; for example, young families need convenience, namely the ability to call a doctor irrespective of time and place, while elderly people who live in rural areas or who have chronic complaints need social contact, empathy, safety and reduction of uncertainties (chapter 4) [5]. It is important to take these differences in needs into account during the development process in order to provide technologies that meet the needs of people who have a high demand for care but who perhaps have less access to healthcare. Therefore, more research is needed into the needs, motivational factors, contexts, and profiles of different population groups.

Another point of interest is the match of eHealth technologies with the context or socio-cultural habits of healthcare professionals. Our study revealed (chapter 3) that introducing technology into healthcare goes hand-in-hand with a lot of resistance, anxiety that the technology will start to influence the work, and that it will not fit in with the training and the 'hands-on' method of working of health professionals. There is a fear that technology will compromise their autonomy and will require a different method of working [13]. Returning to the definition by Eysenbach [4]; *"eHealth 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 [...]"*, we can conclude that a debate is needed among healthcare professionals to discuss how technology can match their way of working, not because of technology itself, but because their patients ask for it (chapter 2).

The aforementioned results all indicate that the current development approaches are missing the mark. Most approaches disregard the socio-cultural context of patients or healthcare professionals, the individual and organizational needs and the profile on the intended user group e.g., attitude/interest, and demographics. To develop eHealth technologies that match the needs and profiles of their users it is important to bear in mind how people live their daily lives, and what their drivers are for managing their health and well-being. In addition to this, one should also consider the socio-cultural conditions such as family support, (e)health literacy, social economic status (SES) and their personal capacity (resources, skills) for supporting healthcare via technology [11,14].

When developing new technologies, it is especially important to understand the barriers that hinder the underserved groups from access. We should therefore analyze the reasons for non-enrollment, and use social marketing approaches; targeting specific groups such as people with a low social economic status (SES), the elderly, and the disabled with tailor-made participation strategies or using low-threshold media, such as mobile phones, and social media like Facebook, Twitter, and YouTube [7,9,15].

Most research to date is aimed at human-technology interaction with the individual user. However, in reality, we cannot speak of an 'individual' user and certainly not now that technology evolves into web 2.0 technologies that enable communication on a group level. And with multiple stakeholders come different interests, concerns and preferences. Patients and GPs, for example, differ markedly in their preferences for several future healthcare services, with the greatest divergence of views concerning access to medical records (with or without explicit patient consent)[9]. The low uptake of technology also requires an inventive strategy by those financing the technology (often insurance companies), because there are no rewards in optimizing technology for a low volume of clients. This results in half-finished products that in practice could or could not be perfected based on usage. In actual fact, this approach makes demands on the technology itself; it has to be easily accessible, smart, simple and cost-effective to generate enough exposure. To this end, business modelling approaches should be used to identify the key values (economic, social, and behavioral) that the multiple stakeholders hope to realize with a certain technology and determine the resources for implementing technology in home-care or other care settings.

The development of eHealth technologies should be a participatory process of co-creation in order to develop eHealth technologies that matter.

To date, public access to eHealth is growing[5], but eHealth services will not be used unless users' expectations and experiences (of both the patient and the healthcare professional) are taken into account during their design [9,16-19]. Many of the acceptance problems with eHealth technologies have been identified as care that is not customized to users' needs, users who are unfamiliar with what the technology can offer and its advantages, and technology which is more medically-driven than user-centered (chapter 3). To overcome the mismatch between the user and the technology, it is being increasingly acknowledged that health can be improved by engaging the users in the development of eHealth technologies via co-creation [6,20-22].

Co-creation means development with the end-users instead of designing for the end-users. The aim is to develop technology that is in line with the end-users' way of thinking and behavioral patterns with regard to managing health problems via technology[6,23-25]. When including end-users as part of the design team, out-of-the-box thinking is stimulated, which means that designers and other stakeholders such as healthcare providers who are involved in the development process are inspired to think differently, unconventionally, or from a new perspective. Ultimately, this leads to applications that are better tailored to the end-users' needs.

It is not just about the development of new technologies, the technology that exists today can also be used for healthcare, although here too it is important that users should be involved in the reappraisal of existing technology. This is how, for example, sensor technologies and GPS monitoring systems from the security sector are being used to track or safeguard people who are suffering from dementia, but these technologies are not appreciated from the needs and potential of the patient, care-giver or health worker. While existing technology can support security or surveillance, using it at home or in the health sector requires a new set of skills (interpreting data, for example) and for the target user group to make the necessary adjustments to their lives or way of working[26].

Human-centered and participatory design methods should be used when developing eHealth applications in order to ensure high-quality, user-informed products of demonstrated effectiveness [6,23-25,27-29]. The design of eHealth should start with a careful analysis of individual needs and accompanying system requirements to explore which technology is best suited for whom. Alongside a Human-Centered Design approach in developing eHealth technologies, training also plays a central role in the implementation process to guide every user -in particular the 'laggards'- in how to use the application. We know from the experiences of our study (chapter 4) that the more interactive the training is, i.e. learning-by-doing; the more the users will get out of it.

eHealth technologies should be persuasive to increase adherence.

eHealth technologies are promising means for enhancing self-care management skills, for web-based education and self-care programs can improve patient knowledge and have shown themselves to be effective in managing several chronic conditions and lifestyle changes [30,31]. Yet, the adherence (sustained use) of eHealth technologies to date is rather low. We therefore need to increase our understanding about adherence in order to maximize the impact of eHealth interventions for disease management. Yet, despite the fact that most participants in eHealth projects (or trials), and thus must have some intention to use the technology, a substantial proportion of them never uses the technology, and many use it only once [32-35].

In our study (chapter 4), a lack of 'motivational' factors hindered long-term usage. The technology itself should be more persuasive to motivate users to use it. Also, users expect the technology to understand them and expect to receive rewards for using it to change their behavioral patterns (chapter 4). However, in most research, technology is a blind spot; it is not seen as a medium that has the capacity to communicate, to show affection, to stimulate users to do the right things at the right time. Our study (chapter 4) revealed that triggers and reminders serve as motivators for using technology for long-term care.

Reminders or triggers for use could be applied via graphics, visual communication or text-messages [36] and via emails sent to the patients' regular mailbox [37]. Mobile phone technology is gaining ground as a simple interface for the health consumer, given the increasing ubiquity of this technology worldwide, and will therefore be especially useful for patients who seldom use their computer [30]. Moreover, integrating the technology with existing traditional 'offline' care could serve as a motivator. For example, patients can be asked to use the eHealth technology for discussing online monitoring during their visit to the GP or nurse. Stevens et al. [38] found evidence for this whereby higher levels of engagement can be reached when technology requires users to log-in, for example once a month. It is expected that such an approach also will trigger less motivated individuals -those who are not interested in self-care via technology- to use eHealth technologies.

Furthermore, we found that enrollment of the 'wrong' users hindered long-term usage; for a certain group of patients a ceiling effect occurred (I am doing well, so I don't need to use it). During our pilot study, it turned out that most patients were already well-regulated and were not the ones that could benefit most from the system. Goldberg et al. [39] found similar results in their study; patients felt unengaged because they had already achieved adequate glycemic control. According to Wangberg et al. [32] attrition as such is not necessarily a bad thing, because in this case it can also be seen as an indicator of success, since the intervention is no longer needed. However, the ceiling effect can have another side to it; because patients do not always have a good insight into their conditions they think the technology is no longer needed [30]. Such a ceiling effect should be avoided. Technology should therefore have persuasive elements like feedback mechanisms and triggers to stimulate users to persist in such cases.

To stimulate adherence it is relevant to know what kind of motivations and abilities the intended users have in order to realize the goals set, or to adopt a specific behavior (learn, unlearn, short-term or long-term behavior). Feedback appeared to be one of the promising features for long-term usage, and some users asked for the integration of monitoring, recording personal data and logistics e.g., scheduling appointments (chapter 4). However, most of the features were presented as standalone applications. For persistence, hyperpersonalized communication and feedback should be provided by different cues [33,40,41].

The field of persuasive technology might provide us with insights into how technology can persuade and motivate users to change their behaviour without being coercive [42]. Research into persuasive technologies and the associated usage of a computing system, device, or application intentionally designed to change a person's attitude or behavior in a predetermined way is showing the potential to assist in improving healthy living, reduce costs within the healthcare system, and allow the aged to maintain a more independent lifestyle [43]. Persuasive technology focuses on how technology can be manipulated to enable the users to realize their goals. Several persuasive techniques can be used to modify the content and format of the technology related to the users' motivation, ability to use technology, and persuasion styles [43,44]. From our research (chapter 3.2 and chapter 4) and other studies [7] we know that effective communication can be a strong driver for usage, maybe more than a merely cognitive approach [40]. Based on the motivation, abilities and target behavior, the right triggers at the right time and format should be given [43,44]. To persist in using technology for healthcare, we know that, for example, humor, language that matches the intended users, as well as coaching via stepwise information, feedback and incentives, are all drivers for persistence (chapter 4).

eHealth technologies with multiple components for self-care (e.g., e-consultation and online monitoring), that are interactive, interoperable, and customized are most appealing to users (chapters 3 and 4). We found that patients appreciated email communication more than the other components because they preferred convenient access to a high level of personalized healthcare. Goal-setting and feedback appeared to be the most promising features for long-term usage [45], together with interoperability of features, for example; the integration of monitoring, recording personal data and administrative features for scheduling appointments (chapter 4). Moreover, feedback should be provided by different cues e.g., via words, images, or sounds.

As the use of eHealth technologies becomes more pervasive [6], new technologies are emerging such as web 2.0 technologies (online fora e.g., *www.patientslikeme.com*) [46-50]. Such health 2.0 technologies, which are the result of social interaction, sharing information and generating content by users themselves, are likely to promote more personalized healthcare, increased collaboration, and better health education [5,6,46-48,51]. Yet, these emerging social networks require a new vision regarding the technology itself, on becoming a social actor [43,44,48], and on the methods to evaluate its success.

> *A holistic approach is needed to ensure that eHealth technologies will be accessible, applicable, manageable, enjoyable and feasible.*

We believe that a *holistic* approach is needed to ensure that eHealth technologies are used and effective. The development of an eHealth innovation is much more than just designing or engineering a good 'thing' or tool. It is about creating an infrastructure for knowledge dissemination, communication and the organization of care. In fact, creating a new technology works as a catalyst for innovating healthcare, since the development of technology induces clarification of how the process of care delivery and reimbursement runs, who the key actors are or how the payment is organized. Developers, decision-makers, and researchers should be aware of the impact technology can have on people (patients, citizens, healthcare professionals) and their social-cultural context e.g., the healthcare organization. Without addressing the need for a total fit between humans, technology and the healthcare organization in the development process, eHealth technologies run the risk of being ineffective in their efforts to promote healthier living. To this end, we developed a new and holistic framework, called the ceHRes Roadmap, for the development of sustainable eHealth technologies (chapter 5.1). The framework consists of two interdependent strategies: Human-Centered Design (HCD) and Business Modelling (BM). The framework provides a structure for the development process and is based on key principles for human-centered and value-driven eHealth.

The framework will be presented as an eHealthwiki (eHealthwiki.org) for sharing and improving knowledge and information. By using a wiki we can open up our toolkit with instruments for those who are interested in contributing to the development of high-quality eHealth technologies. This way, the toolkit can be enriched with knowledge from multidisciplinary fields and different sources, to deliver new perspectives on eHealth technologies for policy, practice and academics involved in the development of eHealth technologies.

The main page of the toolkit consists of the framework, with clickable objects (development process and activities) that lead to its corresponding wiki page which presents research instruments and information from evidence-based studies. The information consist of a brief description of the subject, links to related academic publications on the subject, a guideline and further relevant information and remarks that can be contributed by anyone who is interested. We hope that this initiative for sharing information will help to stimulate the uptake of eHealth.

General limitations and directions for future research

The main limitation of this thesis is that the conclusions of the empirical studies in the chapters 3.1 and 4 are based on small sample-sizes. This because of our in-depth focus on observing real-time usage of eHealth technologies to explore the reasons behind it. Although the results of case studies research cannot be generalized to populations wider than the sample on which they are based, they can be generalized to other studies and theories. Based on the factors that influence the uptake of eHealth technologies, plus the review of the literature, we have formulated general principles for the development of eHealth technologies. Further research is needed to verify whether these principles retain their value for other care settings and eHealth technologies.

Another point of interest in the field of eHealth concerns the recruitment of participants. Most pilot projects to date use convenience sampling to recruit end-users. The big advantage of this is that it results in motivated people who are interested in the technology and wish to use it. However, there are also a number of disadvantages that could obstruct the uptake of eHealth. Namely that the motivated people are often those who are already quite preoccupied with their health. Consequently, an important group of potential users could easily be overlooked. This group consists of, on the one hand people who do not wish to take part, but for whom eHealth could mean a lot because there is much to be gained in terms of good health. On the other hand, it also consists of people who are keen to get started but who do not have access to the skills or resources (a computer) [10].

Given the focus on use-in-context research, and the aim to explore how certain aspects of healthcare could be supported using technology, quasi-experimental research in combination with user-observation studies is the most obvious choice. This raises the following questions: firstly, how can the recruitment of respondents for experimental and end-users research be improved? Secondly, which methodologies are appropriate to obtain a representative picture of the (im)possibilities of technology to support healthcare and patients? It is hard to influence patient recruitment given that the healthcare system is all about free choice and dividing patients over interventions with and without technology is not an option given that the aim is to find out how they can manage with technology. Moreover, it is not about research into the individual end-user but about research into the interaction between technology, the various end-users and the context in which it is used. Recruiting patients and healthcare professionals will remain a difficult issue given the right to healthcare, the cost of research via technology and the focus on process-research. The focus on use-in-context requires methods that can generate process data about usage and observe trends and visualize data that is interpretable in practical situations. This therefore implies technological adaptations of the eHealth technologies in such a way that research data can be collected automatically, such as registering use via log-files.

In this thesis, we focused principally on the evaluation of usage, not on the effects. The reason for this is that most research focuses on the effectiveness of the interventions, without divulging any insights into how and why the technologies contribute to this effectiveness [17,18]. This results in satisfaction and adoption rates, but does not provide any ideas about the technology as a medium for communication. We found that usage is a major issue in research into the effects of eHealth technologies. No matter how effective a technology is, when there are few users the effects will only hold for a very limited group of people. More research is therefore needed into transforming potential users into actual users and keeping them engaged with the application which, in turn, will help to stimulate them to keep using the intervention. This requires quasi-experimental studies in combination with real life observations to study the capabilities of technology to motivate users and to construct profiles of the various user groups: this will help to ensure that the technology matches their needs more effectively. Moreover, research into strategies that engage and captivate users through technology are important for addressing the take-up of eHealth in order to be better able to customize the technology to individual preferences and user profiles. This means that the development of eHealth should start with a careful analysis of the needs and system requirements to explore which technology is best suited for whom. To increase our understanding of the relationship between preferences for system features (technology factors) and the usage of eHealth, future experimental research should focus on investigating the effects of matching personas with computer persuasion styles (affective, cognitive, etc.) on the adoption and persistence of eHealth technologies and on investigating the predictors for exposure and adoption based on experiments about searching behavior [22] and technology design experiments to identify drivers for motivation.

Technology changes the way research is conducted. Technology influences our social lives and daily routines, so we need innovative methods and instruments for assessing the impact of technology. For instance, on transferring traditional care to our homes or on what differences eHealth technologies can make in healthcare, or why the technologies make these differences, or why eHealth technologies may not have the impacts expected of them. Research should therefore reach beyond the golden standard of random clinical trials [52,53]. Robust methods are needed to assess the full spectrum of potential benefits eHealth can offer. There is a need for process methods to support the participation of stakeholders and co-creation, to monitor the use of technologies in practice, and outcome methods to reveal the meaning of technology for the stakeholders and to measure the impact on society (chapter 5.1).

Moreover, technology not only changes the way research is conducted, it is itself continuously evolving. Social media can be seen as technology that is suitable for reaching users who are difficult to reach via traditional media or the Internet, because it transpires that the use of social media does not depend on education or socio-economic backgrounds (low SES). More research is needed to explore the potential of social media for health communication and the way content is created [54].

In our study (chapter 4), attrition was not measured with the usual measures, such as Kaplan Meier [55,56]. Most attrition measures perform survival analysis. However, these measures could not be used in our study because they only provide insights into the drop in usage and not in the pattern of usage. Such survival curves are useful for eHealth interventions with a fixed use, for example with e-therapy interventions. In our study, the pattern of usage was not fixed. Therefore, we searched for activity patterns in measuring the continuity of use and we measured the degree of activity to distinguish between the infrequent users versus the highly active users. The effects of system use will be stronger on patients who log-in every month than on patients who log on only once in a while, but it is important to have clear thoughts about which patients in particular could benefit from the technology.

Furthermore, long-term research on the use of eHealth technologies is needed to provide insights into the way usage fluctuates over time. Through the research conducted for this thesis we gained an insight into the differences between users and non-users, which can be seen as a first step towards decreasing attrition. The next step could be found when examining the opportunities technology has to offer. Several recent studies show the beneficial effects of adding mobile technology [57-59] and devices which provide automated tailored feedback [60].

Finally, the availability of eHealth technologies that are compatible with existing health system information technology does not ensure their widespread adoption. eHealth technologies require substantial financial investment. The business case for eHealth technologies depends on evidence of a return on investment for these significant expenditures [53,61]. Moreover, the proposition that decreased use of acute care services might offset the costs of the screening, monitoring, and educational services in disease management programs is appealing, but, unfortunately, much of the literature on those programs does not directly address the methods for assessing the cost-benefits from a multi-stakeholder perspective (e.g., healthcare professionals, financers, and patients). Besides, we should not only focus on value in terms of money as the ultimate goal, because eHealth technologies can have value for life. To make technology valuable, a multi-perspective or holistic approach is needed; human-centered and value-driven in the broadest sense of the word.

Grounding eHealth requires cooperation among all players in the healthcare sector; it is only by interconnecting the multi-disciplinary field of science, business, and policy that we will be able to increase the value (medical, economic, and social), diffusion and use of eHealth technologies.

Health 2.0 initiatives to advance sustainable healthcare technologies, the participation of users and stakeholders from different backgrounds and with different interests (political, medical, policy, commercial) are important for trust, commitment and creating ownership and for organizing the resources and capacities for the development of eHealth technologies.

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Samenvatting

Introductie

‘Van goede zorg verzekerd’ luidt het motto van vele zorgverzekeraars. De vraag rijst echter hoe van zelfsprekend dit in de toekomst zal blijven. Immers, de populatie over de gehele wereld wordt ouder en de prevalentie van chronische ziekten neemt toe. De zorgvraag wordt daarmee groter bij een naar verwachting afnemende capaciteit van het zorgpersoneel. eHealth, de innovatieve toepassing van informatie communicatie technologie (ICT) in de zorg, heeft de potentie om de gezondheidszorg toegankelijk, doelmatig en betaalbaar te houden. Helaas moeten we echter vaak constateren dat eHealth nog niet goed van de grond komt. Het gebruik ervan valt tegen in de praktijk. Drie soorten problemen doen zich voor:

- Langzame verspreiding (diffusie); de potentiële gebruikers blijken niet de mogelijkheid of de intentie te hebben om de eHealth technologie te gaan gebruiken.
- Lage acceptatie; de gebruiker blijkt niet tevreden of kan niet overweg met de technologie.
- Lage persistentie; eHealth technologieën worden niet langdurig gebruikt.

Doel van dit proefschrift was om de factoren in kaart te brengen die van invloed zijn op het gebruik en de impact van eHealth technologieën en deze te vertalen in ontwerpprincipes. In de loop der jaren zijn reeds diverse modellen en theoretische kaders verschenen voor het ontwerpen en implementeren van van informatie communicatie technologie (ICT). Bekende benaderingen zijn o.a. het Information Systems Success Model [DeLone en McLean, 1992], het Technology Acceptance Model [Davis, 1989], de Diffusion of Innovations theory [Rogers, 2003; Cain & Mittman, 2002] en Human-Centered Design [Maguire, 2001]. Elk van deze benaderingen heeft een belangrijke bijdrage geleverd aan de bruikbaarheid van ICT, echter deze benaderingen zijn te beperkt om duurzame eHealth technologieën te ontwerpen en te implementeren. In dit proefschrift wordt daarom gepleit voor een holistische aanpak voor het ontwerpen van eHealth technologie; die aanpak is gericht op individuele (behoeften), sociaal-economische (organisatie van zorg, middelen) en technologische aspecten (gebruiksvriendelijkheid) die gezamenlijk van belang zijn voor de realisatie van duurzame technologie in de zorg.

In dit proefschrift wordt zowel empirisch onderzoek naar het gebruik van eHealth technologieën beschreven (Hoofdstuk 2-4), als een literatuur onderzoek aangaande de voorwaarden voor duurzaam gebruik van eHealth technologieën (Hoofdstuk 5). Het empirische onderzoek richt zich op het gebruik van interactieve gezondheidstoepassingen in de eerstelijnszorg, en in het bijzonder ‘e-consultatie’. e-Consultatie wordt in dit proefschrift omschreven als “het proces van zorgverlening, van zelfhulp tot en met het benaderen van de zorgverlener via e-mail in een beveiligde internet omgeving”.

Hoofdstuk 2: Diffusie

Het gebruik van e-consult in de eerstelijnszorg kent een trage start en verspreiding (diffusie). In dit hoofdstuk is onderzocht wat de belemmerende en bevorderende factoren zijn van het gebruik van e-consult onder potentiële gebruikers; mensen die wel internet gebruiken voor gezondheidsdoeleinden, maar die nog geen gebruik maken van e-consult. Er werd onderscheid gemaakt tussen twee verschillende vormen van het e-consult: direct versus indirect. Bij de directe vorm legt een zorgconsument zijn of haar vraag in eigen woorden direct voor aan de zorgverlener. Bij een indirect e-consult worden de hulpvragen automatisch via een kennissysteem en zonder tussenkomst van de arts beantwoord. Dit kan vergeleken worden met een digitaal keuzemenu.

Uit het onderzoek blijkt dat het directe e-consult voornamelijk wordt gebruikt om te voorzien in behoefte aan informatie, bijvoorbeeld het stellen van vragen na afloop van een spreekuurbezoek of vragen over het gebruik van medicijnen. Zorgconsumenten vinden het daarbij minder belangrijk dat degene die het e-consult beantwoordt de eigen huisarts is. Het indirecte e-consult, waarbij hulpvragen automatisch en zonder tussenkomst van een arts worden beantwoord, lijkt vooral geschikt voor het bevorderen van de zelfredzaamheid van mensen. Indirect e-consult voorziet daarbij onder meer in de behoefte om te bepalen of een bezoek aan de huisarts nodig is of om zelf een inschatting te maken van de ernst van de hulpvraag. Het e-consult biedt daarmee zowel een aanvulling op de reguliere zorg als een serieus alternatief voor het vertrouwde huisartsbezoek.

De belangrijkste belemmeringen bij het gebruik van e-consult kwamen voort uit: onbekendheid met e-consult en gebrek aan aanbod. Belangrijke voorwaarden voor gebruik van het e-consult hadden betrekking op: duidelijkheid omtrent de vergoeding van het e-consult, een tijdige reactie op het e-consult, de garantie dat de privacy bij het gebruik van e-consult is gewaarborgd, het garanderen van keuzevrijheid voor het gebruik van e-consult, en de mogelijkheid om vragen in eigen woorden te stellen. Uit de resultaten komt tevens naar voren dat socio-demografische en gezondheidsgerelateerde factoren van invloed zijn op de motivatie; zo blijken personen met een grotere zorgbehoefte, zoals ouderen, chronisch medicatie gebruikers, frequente (huis)artsbezoekers, maar ook minder hoog opgeleide personen meer gemotiveerd om het e-consult te gebruiken dan overige patiëntengroepen. Tevens stellen zij meer eisen aan het gebruik van e-consult; voor minder hoog opgeleide personen was het verkrijgen van instructies over het gebruik van e-consult bijvoorbeeld een belangrijkere voorwaarde dan voor hoger opgeleide personen.

Om het gebruik van e-consult te kunnen stimuleren onder zowel artsen als patiënten is adequate voorlichting over de mogelijkheden en de consequenties van het gebruik van het e-consult vereist. Deze voorlichting en instructies voor gebruik zijn bij voorkeur afgestemd op de individuele gebruiker. Tevens dient rekening te worden gehouden met een diversiteit aan patiëntgroepen bij het opzetten van het e-consult. Personen die het meest van e-consult kunnen profiteren, zoals personen met een grote zorgbehoefte (ouderen), blijken vaak degenen te zijn met de geringste toegang tot dergelijke eHealth services. Wanneer we patiëntgerichtheid, of 'zorg-op-maat' willen kunnen blijven bieden, zullen we bij het ontwerpen van toekomstige eHealth toepassingen meer rekening moeten houden met de voorkeuren en voorwaarden van de individuele patiënt.

Hoofdstuk 3: Acceptatie

In hoofdstuk 3 is onderzocht welke problemen zich voordoen met het gebruik van eHealth toepassingen onder 'early adopters'. Door middel van twee opeenvolgende studies is getracht om meer inzicht te verkrijgen in de factoren die van invloed zijn op de acceptatie van eHealth. In hoofdstuk 3.1 zijn diverse eHealth toepassingen onderzocht gericht op het bevorderen van zelfzorg, waaronder een digitale medische encyclopedie, een online zelftest, en e-consultatie in zowel directe (e-mail contact met de huisarts in een beveiligde internet omgeving) als indirecte vorm (computergegenereerd advies).

Door middel van gebruikerstesten gecombineerd met interviews is het proces van probleemoplossing door de zorgconsument en vraagbeantwoording door de zorgverlener via de diverse eHealth toepassingen onderzocht. De focus lag daarbij op de ervaren problemen tijdens het gebruik van de toepassingen. Uit de resultaten zijn drie type problemen naar voren gekomen die het gebruik (acceptatie) belemmeren:

- Problemen met de gebruiksvriendelijkheid van de technologie, zoals een onduidelijke navigatiestructuur, het ontbreken van een adequate zoekmachine en het ontbreken van een functie voor feedback en documentatie (probleem onder zorgverleners).
- Problemen met de kwaliteit van de geboden informatie via de technologie, zoals het gebruik van medisch jargon, informatie die onvoldoende toegesneden is op de persoonlijke situatie van de zorgconsument en problemen met de veiligheid en betrouwbaarheid van het verstrekken van online adviezen in verband met juridische consequenties (zorgverleners).
- Problemen met de incorporatie van de technologie in de dagelijkse praktijk, zoals onduidelijke financiering en richtlijnen en gebrek aan educatie en training betreffende het gebruik van het e-consult.

Voor de continuering van e-consultatie wordt effectieve voorlichting noodzakelijk geacht om de ‘koudwatervrees’ bij de zorgverleners weg te nemen. Verduidelijkt moet worden welke voordelen het e-consult biedt voor het te verwachten personeelstekort in de gezondheidszorg, welke vormen van e-consultatie effectief en efficiënt gebruikt kunnen worden voor bepaalde klachten en doelgroepen en welke verantwoordelijkheden zorgverleners en zorgconsumenten hebben bij e-consultatie. Daarnaast is afstemming op de behoeften van de gebruiker noodzakelijk. De kwaliteit van advisering kan bevorderd worden door personalisatie van de informatie en door afstemming van de zelfzorgsystemen op het zoekgedrag en probleemoplossinggedrag van de zorgconsumenten. Dit betekent dat de huidige eHealth toepassingen vanuit het perspectief van de zorgconsument ingericht dienen te worden, in plaats van een pure gerichtheid op medische besliskunde. De meest waardevolle vorm van e-consultatie voor het bevorderen van zelfzorg lijkt een combinatie van e-mailcontact met de huisarts (direct e-consult) en een kennissysteem gericht op filtering van klachten (indirect e-consult).

Hoofdstuk 3.2 gaat in dieper in op de werking van het indirecte e-consult, binnen deze studie ook wel digitaal consult genaamd. Het digitaal consult is een online triage service die consumenten zonder tussenkomst van een arts inzicht geeft in de ernst van hun klacht en advies geeft of zij zelfstandig hun klacht kunnen behandelen of dat contact gezocht moet worden met de huisarts. Doelstelling van dit onderzoek was inzicht te verkrijgen in het gebruik van het digitaal consult en de determinanten die ten grondslag liggen aan het wel of niet opvolgen van het verstrekte advies. Het onderzoek is uitgevoerd aan de hand van twee deelonderzoeken. Het eerste deelonderzoek bracht het gebruik van het digitaal consult in kaart door de frequenties van entreeklachten, de verdeling van leeftijd en geslacht en de frequenties van adviestypen en gestelde diagnosen in kaart te brengen via logfiles. Het tweede deelonderzoek is uitgevoerd aan de hand van online vragenlijsten, ‘baseline’ (n = 192) en ‘follow-up’ (n = 35), met als doel te achterhalen of het gegenereerde advies ook daadwerkelijk werd opgevolgd.

Het eerste deelonderzoek laat zien dat gedurende een periode van 15 maanden door unieke gebruikers in totaal 13.333 consulten werden gestart. Het digitaal consult werd vooral gebruikt voor klachten aan de bovenste luchtwegen (22%), jeuk, rode vlekken en/of bultjes (13%), plasklachten (12%), diaree (10%), hoofdpijnklachten (8%) en (uitstralende) rugklachten (8%). Echter, de werking van het digitaal consult werd gehinderd door twee typen problemen: (a) een hoog percentage uitvallers, en (b) de striktheid van het gegenereerde advies. Het hoge percentage uitvallers werd veroorzaakt doordat het systeem meer medisch gericht dan gebruikersgericht. Door de striktheid van het advies werd slechts in 15% van de gevallen een zelfzorg advies verstrekt. In de meeste gevallen (85%) werd een huisartsadvies verstrekt ('neem contact op met uw huisarts'). Het filterend vermogen (triage) blijkt te beperkt om een onnodig spreekuurbezoek te voorkomen, of een spreekuurbezoek effectiever te maken. Om de effectiviteit van online triage te kunnen vergroten, zal het juridische protocol voor online triage herzien moeten worden. Het tweede deelonderzoek laat zien dat 57% (20/35) van de gebruikers het advies daadwerkelijk heeft opgevolgd. Regressieanalyse maakte duidelijk dat de intentie om het advies op te volgen sterk gecorreleerd was aan het daadwerkelijk opvolgen van het advies en werd bepaald door de attitude ten aanzien van het digitaal consult.

De resultaten van deze studie hebben aangetoond dat online triage de potentie heeft om de gezondheidszorg efficiënter te maken door zijn poortwachterfunctie. Echter, om online triage volledig tot zijn recht te laten komen, zijn technologieën nodig die de gebruiker instrueert en motiveert. Wanneer zelfzorg de focus is van elektronische zorgverlening, dan is het noodzakelijk om diepere inzichten te verkrijgen in de behoeften van zorgconsumenten aan onafhankelijkheid en hun bereidheid om zelf verantwoordelijkheid en beslissingen te nemen over hun eigen gezondheid. Dit geldt in het bijzonder voor zorgconsumenten met een chronische aandoening, waar met name nog veel winst te behalen valt in termen van efficiëntie. Online triage kan voornamelijk voor deze groep veel betekenen in beslissingsondersteuning, verbeterde communicatiemogelijkheden, maar ook in het reduceren van kosten.

Hoofdstuk 4: Persistentie

Hoofdstuk 4 vermeldt de resultaten van een longitudinale studie naar een eHealth applicatie gericht op online begeleiding van diabetespatiënten type 2. De applicatie kent drie hoofddoelstellingen, te weten: (a) het aanbieden van online educatie gericht op bevordering van de eigen verantwoordelijkheid van de patiënt en daarmee bevordering van de leefstijl, (b) bevordering van preventie door het monitoren van meetgegevens, zoals gewicht en bloedsuikerwaarden en (c) bevordering van de communicatie tussen patiënt en behandelaar (diabetesverpleegkundige/praktijkondersteuner). In het onderzoek staat de functionaliteit (doeltreffendheid, bruikbaarheid) en acceptatie van de Diabetescoach door de patiënt centraal. Doelstelling van het onderzoek was om inzicht te krijgen in de factoren die van invloed zijn op het lange termijn gebruik (persistentie) van de applicatie. Door middel van een combinatie van verschillende onderzoeksmethoden, waaronder logfiles, gebruikerstesten, interviews en een vragenlijst, is getracht inzicht te verkrijgen in deze factoren.

De resultaten van het onderzoek laten zien dat acceptatie van de eHealth applicatie hoog was. Van de 50 deelnemers gebruikt 68% de applicatie geregeld, waarvan de helft zelfs zeer geregeld. De overige 32% is na enige tijd (variërend van 2 tot 16 maanden) gestopt met het gebruik van de applicatie. Het gebruik werd gehinderd door technische 'opstartproblemen' en problemen betreffende de gebruiksvriendelijkheid van de applicatie, waardoor veel mogelijkheden van de applicatie onbekend en dus onbenut bleven. Ondanks deze aspecten betreffende de gebruiksvriendelijkheid waren patiënten enthousiast over de mogelijkheden van de applicatie. Vooral de mogelijkheid om via e-mail te communiceren met de eigen diabetesverpleegkundige (persoonlijke feedback) en de mogelijkheid tot het bijhouden en visualiseren van meetgegevens via de Diabetescoach werden gewaardeerd en werkten motiverend om de applicatie herhaaldelijk te gebruiken. Het gebruik van de applicatie was tevens gerelateerd aan individuele persoonskenmerken; zo blijken medicatiegebruikers, die hun waarden zoals bloedglucose en gewicht maandelijks bijhouden meer gebruik te maken van de diabetescoach (via het onderdeel Meetgegevens) dan 'goed ingestelde' diabeten, die minder of niets te rapporteren hebben. Deze laatste groep werd minder geprikkeld om de applicatie te gebruiken omdat geen direct zichtbare aanleiding (toegevoegde waarde) bestond om de Diabetescoach te gebruiken. Onder diabetes verpleegkundigen bestond de verwachting dat de applicatie voornamelijk zinvol zou zijn voor recent gediagnosticeerde diabetespatiënten en voor insulinegebruikers.

Om het gebruik van eHealth applicaties te bevorderen en de eindgebruiker te kunnen binden aan technologie, zijn aan de hand van de resultaten van deze studie drie strategieën geformuleerd: (a) stem de technologie af op de juiste doelgroep, bijvoorbeeld daar waar de grootste gezondheidswinst te behalen valt, (b) maak gebruik van een 'participatory design' benadering bij de ontwikkeling van eHealth technologieën, d.w.z. betrek alle relevante partijen (eHealth stakeholders), en (c) ontwikkel technologie die persuasief is, die mensen motiveert om herhaaldelijk te gebruiken, en daarmee zelfzorg stimuleert.

Tot slot speelt de implementatie een belangrijke rol. Naast een adequate training van eindgebruikers, is het van belang de inpassing van de applicatie in de dagelijkse praktijk doortastend te organiseren en uit te voeren. Het instrument zou een vaste plaats moeten krijgen in de behandeling en het consult van praktijkondersteuners. Een koppeling met andere systemen zoals het HIS zou daartoe kunnen bijdragen.

Hoofdstuk 5: Een holistische onderzoeks- en ontwerpaanpak

Hoofdstuk 5 borduurt voort op de vraagstelling welke factoren het succes van eHealth technologieën kan vergroten, maar gaat tevens een stap verder door de vergaarde kennis en expertise om te zetten in een nieuwe onderzoeks- en ontwerpaanpak.

Hoofdstuk 5.1 beschrijft een verkenning van de literatuur op het gebied eHealth. Onderzocht is welke theoretische kaders top op heden zijn gebruikt en hoe deze zich verhouden tot onze eigen resultaten verkregen uit de praktijkstudies. Er bestond tot op heden geen 'holistisch' raamwerk, dat zowel gericht is op het ontwikkelen van een hoogwaardige technologie, als op een technologie die 'inzetbaar' is. Op basis van zowel de literatuur als de empirische studies zijn binnen dit hoofdstuk een aantal basisprincipes die ten grongslag liggen aan het nieuwe holistische raamwerk, genaamd: de ceHRes Roadmap. Een van de basisprincipes waarop deze Roadmap stoelt, is dat onderzoek gedurende het gehele proces van technologie ontwikkeling uitgevoerd zou moeten worden, in feite al voordat er aan technologie gedacht wordt.

Hoofdstuk 5.2 gaat dieper in op ceHRes Roadmap. De ceHRes Roadmap fungeert als onderzoeks- en ontwerpaanpak en heeft als doel om via 'Business modelling' (BM) en 'Human-centered design' (HCD) meer 'sustainable' (duurzame) eHealth technologieën te kunnen ontwikkelen en inzetten. De kern van zowel BM als HCD is om reeds in een vroeg stadium alle relevante stakeholders te betrekken bij het ontwerpproces en de implementatie van de technologie teneinde de technologie zoveel mogelijk te kunnen laten aansluiten op de verwachtingen en behoeften van alle betrokken partijen.

De nieuwe ontwerp- en onderzoeksaanpak wordt gepresenteerd via een web 2.0 instrument, eHealthwiki.org, om de verzamelde kennis en expertise omtrent eHealth te bundelen en open te stellen aan relevante eHealth stakeholders. Via eHealthwiki.org wordt getracht multidisciplinaire samenwerking bewerkstelligen, d.w.z. beleid, onderzoek, en praktijk nauwer tot elkaar brengen met als uiteindelijke doel meer succesvolle en levensvatbare eHealth initiatieven van de grond te krijgen.

Algemene conclusies en discussie

In dit proefschrift is onderzocht welke factoren het gebruik van eHealth beïnvloeden. Vanuit empirische studies en de literatuur hebben we kunnen constateren dat de huidige ontwerpbenaderingen tekortschieten door een expert (engineering) gerichte aanpak van technologie, in plaats van een op de 'gebruikers (zorgvrager en zorgverlener) gerichte aanpak'. Bovendien abstraheren de huidige modellen van de sociale omgeving en de zorgsituatie. De ontwikkeling van eHealth toepassingen omvat meer dan het ontwerpen van 'hoogwaardige technologie', ook de organisatie van de zorg is ermee gemoeid.

Het ontwerpen van een technologie betekent in feite het ontwerpen van een infrastructuur voor de organisatie van de zorg via technologie. 'Bussiness Modelling' technieken en een 'Human-Centered Design' aanpak stellen ons in staat om beter te kunnen anticiperen op de inbedding van technologie in de zorg (totale infrastructuur). Dit vergt de betrokkenheid van stakeholders met diverse achtergronden en diverse interesses (eindgebruikers, ontwikkelaars, zorgverzekeraars, etc.). Om eHealth beter van de grond te krijgen, is multidisciplinaire samenwerking vereist tussen de disciplines: wetenschap, beleid en praktijk (medisch, technisch & economisch). Web 2.0 initiatieven (eHealthwiki.org) kunnen daaraan bijdragen.

Uit de opkomst van web 2.0 initiatieven blijkt dat de technologie zelf voortdurend aan verandering onderhevig is. Sociale media, zoals Facebook, Twitter, YouTube, online fora, zijn geschikt om veel mensen te bereiken, ook mensen die via traditionele media lastig te bereiken zijn. In toekomstig onderzoek zal meer aandacht besteedt moeten worden naar de mogelijkheden van nieuwe technologieën zoals 'sociale media' voor gezondheidsinformatie- en communicatie (creatie door gebruikers). Ook is in dit proefschrift het belang van 'persuasieve technologie' naar voren gekomen. De technologie zelf moet kunnen overtuigen. Meer onderzoek is nodig naar welke elementen (triggers) de technologie moet bevatten om mensen te kunnen motiveren om de technologie te willen blijven gebruiken om daarmee het gewenste gedrag te kunnen blijven aansporen.

Innovatieve technologie verandert niet alleen de zorg, het verandert ook de manier waarop onderzoek wordt uitgevoerd. In dit proefschrift ligt de focus op evaluatie van gebruik en niet op het effect van de technologie. De reden hiervoor is dat veel onderzoek uitsluitend gericht is op het meten van effecten zonder daarbij te kijken naar hoe en waarom de technologie al dan niet bijdraagt aan het effect. Echter, alleen als de technologie gebruikt wordt zoals bedoeld, dan zijn we in staat om een effect te meten. Meer onderzoek is daarom nodig in hoe potentiële gebruikers kunnen veranderen in daadwerkelijke gebruikers. Niet alleen op de korte termijn (boeien), maar vooral ook de lange-termijn (binden). Daartoe zijn innovatieve methoden vereist; bijvoorbeeld longitudinaal onderzoek via logfiles om inzicht te verkrijgen in het daadwerkelijke en lange-termijn gebruik van de eHealth technologie. Onderzoek reikt daarmee verder dan de gouden standaard; het gerandomiseerde experiment (RCT). Robuuste methoden zijn nodig om het totale scala van voordelen die eHealth technologieën te bieden hebben, aan te kunnen tonen.

Tot slot is succesvolle inzet van eHealth technologie afhankelijk van een gedegen financiële investering. Deze investering wordt alleen gedaan op basis van ‘return for investment’. We moeten ons echter niet blind staren op kostenreductie als het primaire doel van eHealth. eHealth heeft zeker de potentie om kosten in de zorg te reduceren, maar technologie die kwaliteit van leven bevordert, is zeker even waardevol. Om de waarde van technologie volledig tot zijn recht te laten komen, is een holistische aanpak nodig; ‘human-centered’ (op de mens gericht) en ‘value-driven’ (waardevol) in de breedste zin van het woord.

Dankwoord

De belangrijkste leer uit dit proefschrift is dat de techniek niet volledig tot zijn recht komt, wanneer de mens niet betrokken is bij het ontwerp ervan. Je kunt 'high tech solutions' ontwerpen, maar zonder 'human touch' is het ontwerp vrijwel betekenisloos. De 'human touch' is waar het uiteindelijk allemaal om draait. Zo was het de belangrijkste 'driver' achter de totstandkoming van dit proefschrift; het zijn de mensen om mij heen van wie ik heb geleerd, die mij hebben geïnspireerd, gesteund en gemotiveerd, die ervoor hebben gezorgd dat dit boek betekenis heeft gekregen. Op deze plek wil ik alle mensen bedanken die hieraan hebben bijgedragen. Een aantal mensen verdient een speciaal woord van dank, te weten:

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