

The Diffusion of a Personal Health Record for Patients with Type 2 Diabetes Mellitus in Primary Care

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Abstract—A Personal Health Record is a promising technology for improving the quality of chronic disease management. Despite the efforts that have been made in a research project to develop a Personal Health Record for patients with type 2 diabetes mellitus in primary care (e-Vita), considerable differences have been reported between the number of registered users in the participating primary practices. Interviews among practice nurses indicated that a lack of infrastructure (integration in daily care processes), the ability to try the Personal Health Record with minimal investments and without commitment (trialability) and the relative advantage of using a Personal Health Record in comparison with other methods were important factors for the diffusion of the Personal Health Record in primary care.

Keywords - Personal Health Record; type 2 diabetes mellitus; implementation; diffusion of innovation; interviews; contextual inquiry; value specification; summative evaluation.

I. INTRODUCTION

In this paper, we provide an extended version of our paper as presented at eTelemed 2014, the sixth International Conference on eHealth, Telemedicine and Social Medicine [1]. We present the results of an interview study to identify factors perceived as important in the diffusion of a personal health record (PHR) for patients with type 2 diabetes mellitus (T2DM) in primary care, from the perspective of health care workers.

A. Personal Health Records

The aging population and the increasing need for chronic care requires an integral approach to disease management that is well coordinated and consistent with (inter)national care standards in order to support a shift from institutionalized care to home care [2]-[4]. Disease management may be viewed as a set of interrelated services that spans from prevention and self-management to intramural care for patients with chronic diseases [5]-[7].

Information- and communication technology (eHealth) will play an important role in disease management, e.g., in providing online support for self-management, in improving information exchange among professionals and with patients, as well as in monitoring the performance of the disease management program [8][9].

The electronic PHR is a promising technology for improving the quality of chronic disease management [10][11]. A PHR can be defined as “an electronic application through which individuals can access, manage, and share their health information and that of others for whom they are authorized, in a private, secure and confidential environment” [12], a definition that is adopted by many researchers over the years (e.g., [13]-[15]).

However, PHRs are becoming more complex and potential functions of current PHRs may not only include sharing clinical and personal data (e.g., history, test results, treatment, appointments), but may also include self-management support (patient-provider communication, information about the illness, peer support or monitoring health behavior data) [14].

Potential benefits of a PHR include empowering patients in managing their diseases and the reduction of geographical and communication barriers. This may, in turn, lead to a transition from episodic to continuous care, which has the potential to shorten the time to address disease-related complaints that may arise [13][14].

Despite these benefits, the use of such systems in diabetes care has only led to small improvements in diabetes quality measures that were of marginal clinical relevance [10], and up to now, evaluations have only provided little insight into why a particular outcome did occur [16][17]. Consequently, the added value of the existing evidence is often limited for decision making in relation to the strategic direction of implementation efforts [18]. To gain insight into factors that contribute to a successful implementation of eHealth technologies in daily health care processes, it is therefore

necessary to look for methodological approaches that go beyond a baseline and follow-up measurement of health outcomes.

B. e-Vita

The PHR e-Vita is an initiative of the Dutch foundation Care Within Reach (in Dutch: Zorg Binnen Bereik), a partnership between Philips and Achmea, a Dutch health insurance company. Currently, e-Vita is deployed in the Netherlands via three trials to study the effects of the PHR for patients with T2DM, chronic heart failure or COPD. In this paper, we will focus on results from the T2DM study. For patients with T2DM, the main content of e-Vita consists of insight into personal health data (e.g., lab values, blood pressure), self-monitoring health values (e.g., weight), education and a coach for reaching personal health-related goals.

The T2DM research project consists of two parts. First, a prospective observational cohort study (a benchmarking study) is being conducted to assess clinical parameters and, on the long term, quality of life and disease-related complications. Within this study, questionnaires among participants are administered periodically and health data and blood samples are collected.

When patients agreed to participate in this benchmarking study, they are invited to participate in the PHR trial. Main goal of this trial is to study the effects of using a PHR in primary care for patients with T2DM (ClinicalTrials.gov number NCT01570140) [19]. In total, 44 primary care practices participate in this trial.

C. Diffusion of Innovations

Despite the efforts that have been made to develop a technology that has added value in the treatment of patients with T2DM in primary care, differences in the diffusion of the PHR are signaled between the primary practices that participate in the research project.

The pace at which new innovations in health care diffuse through the system, depends on several factors. In Table I, an overview of critical factors for the diffusion of innovations according to Cain & Mittman [20] is given. To gain insight into the factors that influence the diffusion of a PHR in a primary care practices, an evaluation via interviews has been conducted. The main research question was:

What factors influenced the diffusion of a PHR for patients with type 2 diabetes (T2DM) in primary health care, according to primary health care workers?

The sub-questions were:

1. What were the reasons and incentives of primary health care workers to participate in research project regarding the use of a PHR?
2. What training did the primary health care workers receive at the start of the research project?

TABLE I. CRITICAL DYNAMICS FOR THE DIFFUSION OF INNOVATIONS [19]

Critical Dynamic	Explanation
1. Relative advantage	The higher the potential of the technology in comparison to current practice, the more rapidly it will diffuse.
2. Trialability	The ability to try out an innovation without total commitment and with minimal investment.
3. Observability	The extent to which potential users follow the adoption of an innovation by others.
4. Communication channels	The communication channels through which others communicate about the innovation.
5. Homophilous groups	Innovations diffuse faster among groups with similar characteristics.
6. Pace of innovation	The extent to which innovations evolve and are being altered by its users.
7. Norms, roles and social networks	Innovations are shaped by the rules, formal hierarchies, and informal mechanisms of communication operative in the social systems in which they diffuse.
8. Opinion leaders	Individuals whose opinions are respected by others in a population affect the pace of diffusion.
9. Compatibility	The ability of an innovation to coexist with technology and social patterns already in place.
10. Infrastructure	The presence of some form of infrastructure that cluster with the innovation.

3. How did the primary health care workers embed the PHR in their daily care routines?
4. What were the perceived and expected barriers and facilitators for embedding a PHR in daily care routines, according to primary health care workers?
5. What are the expectations of primary health care workers regarding the use of PHRs in the future?

The outcome of the interviews provides critical factors for the improvement of the diffusion and implementation process of a PHR in primary care.

This paper is organized as follows: in Section II, we will describe how the interviews were conducted. In Section III, the results of the interviews are described. In Section IV, the results and directions for future research are discussed. Finally, in Section V, the conclusions of this paper are given.

II. METHODS

In this section, we will present the framework for the interview study, the participants, the design and procedure of the interviews and how the data was analyzed.

A. The Center for eHealth Research (CeHRes) Roadmap

The CeHRes roadmap [21] is a framework that is used to develop new and to evaluate and improve existing eHealth technologies. The roadmap states that eHealth development is a participatory process and that development is intertwined with implementation into daily health care processes. The roadmap consists of five different phases (Fig. 1):

1. *Contextual inquiry*: First, the needs and problems of the stakeholders (e.g., patients, caregivers, health insurers) are described, in order to gain insight into the context and whether or how technology can contribute to minimizing problems.
2. *Value specification*: Second, information about the added values that key-stakeholders attribute to the eHealth intervention is gathered. Together with the contextual inquiry, the value specification provides the functional requirements for the design of the technology.
3. *Design*: On the basis of these requirements, prototypes of the technology are developed and tested.
4. *Operationalization*: The final version of the eHealth technology is launched.
5. *Summative evaluation*: Finally, the uptake, effects and impact of the eHealth intervention is evaluated.

According to the roadmap, the development of eHealth technology also requires continuous evaluation cycles after every step, in order to create eHealth technologies that have the potential to diffuse among its end-users.

For this study, the interviews serve as both a forward evaluation (contextual inquiry and value specification) and a backward (summative) evaluation to gain insight into the uptake and impact of e-Vita as well as into the possibilities to improve the content of e-Vita according to health care providers.

B. Participants

For the interview study, primary care nurses (PNs) of general practices in Drenthe, a province in the north of the Netherlands, were invited to participate in the interview study. In the Netherlands, PNs are the main responsible caregivers for educating patients about their (chronic) disease, advising patients regarding medication use and lifestyle changes and performing health checks. In the

current trial, all selected PNs are responsible for explaining the purpose of the PHR to the participants in the study and administering questionnaires regarding the effects of the PHR. No guidelines for intended use of the PHR are defined.

To reveal the differences between the diffusion

processes of practices with high and low numbers of participants, potential practices for the interview study were selected by the means of an inclusion percentage (high, middle, low). The inclusion percentage was calculated as follows:

$$\text{Inclusion percentage} = \left(\frac{\text{number of included patients for the benchmarking study}}{\text{total number of patients with T2DM in the practice}} \right) * 100.$$

Our aim was to conduct five interviews in every group, 15 interviews in total. We therefore invited the five primary practices with the highest and lowest percentages. Also, five primary practices with an average inclusion percentage were invited to participate. When primary practices had indicated on beforehand that the inclusion of participants was postponed due to explainable circumstances (e.g., long-term diseases among the staff), practices were not contacted to participate in the interview study.

All PNs who met the criteria for the interview study received an e-mail with information about the purpose and the topics of the interview. When PNs agreed to participate, they were contacted to make an appointment for the interview.

C. Design and Procedure

Semi-structured in-depth interviews were conducted. During the interviews, questions were asked regarding the following themes: reasons and incentives to use and implement a PHR in their primary practice, the use and users of the PHR so far, bottlenecks and barriers that are encountered or expected, the (positive) results so far and the expected changes a PHR will make in the primary health care for patients with T2DM. The duration of the interviews was 45-60 minutes (non-stop). All participating PNs received a gift voucher of 50 euros.

Ethical approval for this interview study was obtained by the ethics committee of the University of Twente.

D. Data Analysis

All interviews were transcribed verbatim and themes and categories were subsequently coded via open coding, axial coding and selective coding [22]. In this way, recurring

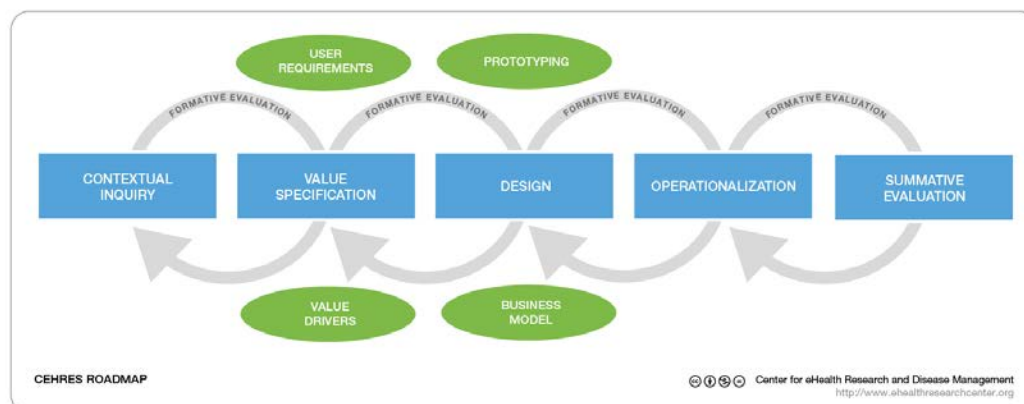


Figure 1. The Center for eHealth Research and Disease Management Roadmap [21]

themes and items of interest regarding the implementation and use of eHealth technologies in primary health care practice were identified. Occurring themes were categorized using the critical dynamics for the diffusion of innovations, according to Cain & Mittman [20]

III. RESULTS

In this section, we will present the results of the interview study.

A. General Results

After receiving the invitation, 11 PNs agreed to participate in the interview study. An overview of the number of potential and included participants for the primary care practice of every PN at the start of the interviews (August 2013) is given in Table II.

TABLE II. OVERVIEW OF PARTICIPATING PRIMARY PRACTICES IN THE INTERVIEW STUDY

PN number	Inclusion group	Patients	
		# T2DM patients	# participants included (%)
1	High	204	126 (62)
2	High	56	33 (59)
3	High	61	37 (61)
4	High	88	45 (51)
5	High	146	63 (66)
6	Middle	98	22 (22)
7	Middle	122	25 (20)
8	Middle	182	45 (25)
9	Middle	94	18 (19)
10	Low	163	4 (2)
11	Low	235	7 (3)

In total, 5 PNs of practices with high inclusion percentages, 4 PNs of practices with average inclusion percentages and 2 PNs of practices with low inclusion percentages participated in the interview study.

B. Reasons and Incentives to Participate

In total, 5 PNs (interview numbers 2, 4, 7, 8 and 11) indicated that they participate in the trial because they find it important to stimulate the development of self-management skills of their patients:

“If we can offer patients tools to learn about their own disease and to take their own responsibilities, we must not miss this opportunity.”

Two PNs indicated that they want to keep abreast of the times (interview numbers 1 and 2), that they are curious about the added value of a PHR in primary practice (interview numbers 1 and 6), and that they want to offer their patients something extra during their treatment, for example information about T2DM (interview numbers 7 and 8).

Also, one PN indicated that the primary care practice wanted to participate because of their (relatively young) patient population (interview number 3) or to participate in a research project besides the daily working routines (interview number 9).

Two PNs (interview numbers 6 and 11) indicated that they were curious about the results of the benchmarking study: how do their practices perform in comparison with other practices and how satisfied are their patients about the care they receive?

C. Training

Regarding the training the PNs received before the start of the project, 6 PNs indicated that they attended a plenary information meeting (interview numbers 1, 2, 3, 4, 8 and 9). During this meeting, information was given about the purpose and the course of the research project and instructions were given regarding the inclusion of participants and administering the questionnaires for the benchmarking study. One PN (interview number 4) indicated that there was a short explanation about the purpose and the functions of the PHR during that meeting.

Eight PNs indicated that they were not trained in using the PHR and how to integrate the PHR in daily care routines (interview numbers 1, 3, 5, 7, 8, 9, 10, 11). One PN received some instructions for using the PHR (interview number 6) and another PN logged in once with one of the researchers (interview number 2).

D. Integrating the PHR in Daily Care Routines

In total, 8 PNs indicated that they did not integrate the PHR with consultations with their patients. The remaining 3 PNs occasionally ask their patients if they visited the PHR and if they have questions regarding the information on the PHR.

E. Perceived Barriers for Using a PHR

All PNs indicated that there is a lack of time to use the PHR in the treatment of their patients. According to 7 PNs (interview numbers 1, 2, 3, 5, 6, 7 and 8), this is due to a lack of integration of the PHR in daily work routines:

“For me, it [the PHR, red.] is quite difficult to fit in the 20 minutes that I have for every patient. I need that time for the health checks. How do you start a dialogue about the PHR, then?”

Also, 9 PNs (interview numbers 1, 2, 3, 5, 6, 7, 9, 10 and 11) indicated that they did not have access to the PHR. They were not able to see what patients see, and find it therefore difficult to promote and explain the PHR among their patients:

“It is quite difficult. You don’t know e-Vita, and you have to explain it to the patients. That doesn’t work.”

“I was not able to see what patients see for a long time. I have to recommend something I don’t know.”

When they were able to log in to the PHR via their patients, 4 PNs (interview numbers 1, 5, 6 and 9) experienced usability problems:

“When you want to visit e-Vita, you have to take the hurdle of logging in first.”

Also, 4 PNs (interview numbers 2, 8, 9 and 11) indicated that they have easy accessible alternatives:

“One patient was quite motivated, so I printed the health data and gave it to him. That is a much shorter way.”

Regarding their patients, 5 PNs indicated that many of their patients do not have Internet access (interview numbers 1, 6, 7, 8 and 10) or experience usability problems (interview numbers 1, 2, 3, 4 and 6).

Furthermore, according to 5 PNs, the PHR does not meet the needs of their patients (interview numbers 1, 4, 5, 6 and 7), and patients are afraid that the usual care will become less personal (n=4, interview numbers 1, 6, 8 and 10).

F. Perceived Facilitators for Using a PHR

Although the PHR is not yet used in daily care routines, some potential factors for the successful implementation of a PHR were mentioned during the interviews.

All PNs indicated that they could easily contact a help desk when they experienced technical problems with the PHR or when they have questions regarding the benchmarking study:

“Nothing is too much. It is really important that it is never inconvenient to have contact.”

“A strong point is that they are easy to reach. When I have a problem, I send an email and the next day, I have an answer.”

Second, 5 PNs (interview numbers 1, 3, 4, 7 and 10) indicated that they were able to fit the activities necessary for the benchmarking study into their own workflow:

“I made a Word file with a list of participants, this gives me an overview of the procedure.”

“Every time I realize that I have to establish a system to create a routine.”

Third, 4 PNs (interview numbers 4, 5, 7 and 9) indicated that triggers for using the PHR are probably important, for example, via news letters or via (financial) incentives:

“I think you should give a financial incentive, for example, a bonus from the health insurance company.”

“Maybe a newsletter, a stimulus to let patients think, ‘let’s visit e-Vita again’.”

G. The Future of PHRs in Primary Care

Finally, PNs were asked about their opinion regarding the future of PHRs in primary health care. In total, 5 PNs (interview numbers 1, 2, 4, 5 and 11) indicated that they find it hard to predict whether there is a future for PHRs in health care, and how PHRs will be used in the future.

On the other hand, 5 PNs (interview numbers 2, 4, 6, 9 and 11) expect better-informed patients during consultations, but they also believe that their own role is not likely to change.

Three PNs (interview numbers 3, 5 and 6) believe that a PHR in primary care will mainly be used for communication purposes between patients and health care providers.

IV. DISCUSSION

The interviews indicated that, despite the participants’ enthusiasm and understanding of the importance of stimulating self-management skills of patients with chronic conditions, the diffusion of the PHR for patients with T2DM in primary care is still rather low. The goal of this study was to identify the factors that influenced the diffusion. We signaled differences in the inclusion percentages between the participating primary practices in the research project, and therefore we wanted to gain insight into the factors that influenced the diffusion from the view of primary health care workers.

Because we believe that the development of eHealth technologies is an ongoing process that requires continuous evaluation cycles [21], we conducted both a forward and a backward evaluation. With this evaluation, we tried not only to gain insight into the factors that influenced the uptake and impact of a PHR, but also to identify possibilities for improving the PHR in the future.

Although we aimed to identify differences between the factors that influenced the diffusion of the PHR experienced by PNs from primary practices with high, medium and low inclusion percentages, the experiences of all PNs were fairly similar, which indicates that a high inclusion of participants in the study does not necessarily lead to using the system in daily practice. This finding made it difficult to identify factors that contributed to the use of the PHR. However, we did find some important factors that influenced the diffusion of the PHR.

First, a lack of *infrastructure* that is necessary for the implementation of an innovation in health care [20][23] played an important role. Most PNs indicated that at the start of the research project, little attention has gone towards education and guidance regarding the integration of the PHR with daily practice, and thus, with national guidelines for the treatment of chronic diseases in primary care. Most PNs indicated that they were mainly trained to administer the questionnaires for the benchmarking study, and during that training, only little attention has gone to the content and the functions of the PHR and the integration of the system with daily practice.

As a result, the awareness of PNs regarding the added value of the PHR is low, which can reduce its diffusion and subsequent use [24]. PNs indicated that they do not use the PHR in the treatment of their patients. They have a certain amount of time for every patient during the consultations, and in this time, PNs have to finish the health checkups (blood pressure, control of the feet, et cetera), talk with the patient about how they are doing and administer the questionnaires for the benchmarking study. Because no guidelines were given regarding the use of the PHR, asking patients about their experiences is not on top of the minds of the PNs. Also, PNs indicated that there is often no time to ask their patients about the experiences and the use of the PHR.

A first study of log data of the PHR showed that the use by patients is suboptimal. After an invitation to visit the renewed PHR, 28% of all registered users visited the PHR at least once, with a mean of 1.5 visits in the first six weeks [25]. It is well possible that creating a routine in using a PHR during consultations will lead to an increased use of the PHR by patients at home. After all, it is likely that patients will use a system that is being promoted by their health care providers, who are often in a relationship of trust with their patients and are therefore seen as *opinion leaders* [20].

Another finding of the interview study is that the *trialability* [20] of the PHR played an important role in the diffusion of the technology. Due to technical problems, PNs were not able to log on to the PHR with test accounts and could therefore not see what their patients see. Subsequently, PNs reported that they find it difficult to use and promote a technology they hardly know.

At the time of the interviews, test accounts were available for PNs, which enhanced the *trialability* of the system [20]. However, because of the reported work pressure and established working routines for administering the questionnaires regarding the benchmarking study, it often had no priority anymore to visit the PHR.

Also, 4 PNs indicated that they have easy accessible alternative tools and resources available for the PHR, for example by providing patients with lab values on paper, instead of viewing them on the PHR. In other words, the *relative advantage* [20][23] of the PHR is rather low, which is probably another important factor for the slow diffusion of the PHR [23].

To increase the diffusion of the PHR in the future, it is therefore useful to guide health care providers in integrating the system in daily routines. By creating an infrastructure for the use of the PHR, new working routines are being established. Also, it might be of added value to appoint ambassadors: health care providers who already successfully use the PHR in daily practice. By increasing the *observability* of the PHR, other health care providers are able to see how others use the PHR and can acknowledge that the use of the PHR is safe and beneficial [20].

However, the results also showed that the PHR is mostly illness-driven instead of user-centered (with little attention for the needs of the end-users), indicating that involving the end-users (via a contextual inquiry and value specification [21]) is valuable in the development of new technologies [24]. By involving the end-users and having an eye for their needs, the added value of the new technology is already evident in the first stages of the developmental cycle [26], which may in turn lead to a better diffusion of the technology.

The interviews not only served as a backward evaluation, but also as an forward evaluation to gain insight into the possibilities to improve the PHR in the future. However, because of the lack of insight into the system, PNs found it rather hard to give directions for the improvement of the PHR. Also, they find it hard to indicate how PHRs will be used in the future. In general, PNs expect better informed patients during consultations, but they also believe that their own role in the treatment of patients is not likely to change.

In the future, we are planning to conduct a further process analysis of the implementation of the PHR using a mixed-methods approach via interviews and usability tests among both patients and health care providers. Also, we are planning to conduct advanced log file analyses, containing real-time data about the actual use of the PHR, collected by the web server. With this data, we will analyze who the actual users of the PHR are, how they use the system and how the PHR supports the users in reaching their health related goals in order to gain insight in how a PHR can be of added value in primary care.

V. CONCLUSION AND FUTURE WORK

The results of the interviews indicate that PNs understand the importance of stimulating self-management skills of patients with chronic diseases via a PHR. However, the diffusion of the PHR is still rather low, mostly due to a lack of training in using the PHR and a lack of guidance in integrating the system in daily care routines. Also, the *trialability* and the *relative advantage* of the PHR played an important role in the uptake and impact of the new system.

In the future, we will involve end-users (both patients and health care providers) in our research, in order to create a PHR that is of added value for patients with chronic diseases in primary care.

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