

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

A Research Protocol for a Backward and Forward Evaluation

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Abstract—A Personal Health Record (PHR) 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 PHR for patients with type 2 diabetes mellitus in primary care (e-Vita), differences have been reported between the number of registered users in the participating primary practices. To gain insight into the factors that influence the implementation of the PHR into daily health care processes and into the possibilities to improve the content, interviews have been conducted with participating primary practice nurses and other stakeholders in the research project. A first impression of the interviews indicated that in many cases, the low impact of the PHR is due to a lack of information about the purpose, content and use of the system.

Keywords-component: *personal health record; type 2 diabetes mellitus; implementation; interviews, contextual inquiry; value specification; summative evaluation*

I. INTRODUCTION

A. Personal Health Records

The aging population and increased prevalence of 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 [1-3]. 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 [4-6]. 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 [7, 8].

The electronic personal health record (PHR) is a promising technology for improving the quality of chronic disease management [9, 10]. 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” [11], a definition that is adopted by many researchers over the years (e.g., [12-14]).

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 [13].

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 [12, 13].

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 [9], and up to now, evaluations have only provided little insight into why a particular outcome did occur [15, 16]. Consequently, the added value of the existing evidence is often limited for decision making in relation to the strategic direction of implementation efforts [17]. To gain insight into factors that contribute to a successful implementation of eHealth technologies in daily health care processes, it is necessary to look for methodological approaches that go beyond a before and after measurement of health outcomes.

B. The CeHRes Roadmap

The CeHRes Roadmap [18] is a framework that can be used 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. Also, it requires continuous evaluation cycles. Through a contextual inquiry and a value specification, a support basis can be created for the development and implementation of the eHealth technology.

C. e-Vita

The PHR e-Vita is an initiative of the Dutch foundation Care Within Reach, a partnership between Philips and

Achmea, a Dutch health insurance company. Currently, 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. e-Vita is deployed in primary care in the Netherlands via a trial to study the effects of using a PHR in primary care for patients with type 2 diabetes mellitus (T2DM) (ClinicalTrials.gov number NCT01570140).

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, we signaled differences in the uptake and impact of e-Vita between the participating primary practices in the research project. To gain insight into the factors that influence the use of e-Vita in primary care, an evaluation via interviews has been conducted. These interviews serve as both a forward (contextual inquiry and value specification) and a backward 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. The outcome of the interviews will provide critical factors for the improvement of the content and the implementation process of e-Vita in primary care. The main research question is:

What factors influence the uptake and impact of a PHR for patients with type 2 diabetes (T2DM) in primary health care, according to primary health care workers and other stakeholders?

In the next paragraphs, we will describe the methods and the preliminary results of the interview study. In the discussion, we elaborate on future research.

II. METHODS

A. Participants

The interview study consists of two parts. In the first part, primary care nurses (PNs) of general practices in Drenthe, in the north of the Netherlands, were invited to participate in an interview. In the Netherlands, PNs are responsible for educating patients about their disease, guiding patients with the use of medication and lifestyle changes and performing health checks. In the e-Vita project, all selected PNs are responsible for explaining the purpose of e-Vita to the participants in the study and administering questionnaires regarding the effects of the PHR. No guidelines for intended use in daily care processes were defined.

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

$$\text{Inclusion percentage} = \frac{\text{(number of included patients for e-Vita in the study / total number of patients with T2DM in the practice)} * 100.$$

The aim is to conduct five interviews in every group, 15 interviews in total. When primary practices have indicated before 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.

In the second part of the study, five other stakeholders in the e-Vita diabetes project (e.g. project leaders) will be invited to answer questions about their view on the topics as revealed in the first part of this study and the choices that have been made regarding these topics during the project.

B. Design and Procedure

First, semi-structured in-depth interviews were conducted among PNs that already take part in the e-Vita project. During the interviews, questions were asked regarding the purposes, reasons and incentives to use and implement a PHR in their primary practice, the use and the users of the PHR so far, the bottlenecks and barriers that are encountered or expected, the results so far and the way that a PHR will change the primary health care for patients with T2DM and their caregivers in the future. All PNs received a gift voucher of 50 euros for participating.

Based on the identified themes, a second interview scheme will be prepared for other stakeholders in the e-Vita project (e.g., project leaders). These interviews will be used to test the topics as discussed during the interviews among the PNs. These questions are asked via e-mail and validated by telephone. Ethical approval for this study was obtained by the ethics committee of the University of Twente.

C. Analyses

All interviews (among PNs as well as the other stakeholders) will be transcribed and themes and categories will subsequently be coded via open coding, axial coding and selective coding [19]. In this way, recurring themes and items of interest regarding the implementation and use of eHealth technologies in primary health care practice can be identified.

III. PRELIMINARY RESULTS

A first impression of the eleven interviews among PNs so far indicated that, despite respondents' enthusiasm, the PHR has a rather low reach. In many cases, this is due to a lack of information about the purpose, content and use of the PHR. The participating PNs were mostly trained to administer the questionnaires in the research project and little attention has been gone to the content of e-Vita and the integration of the PHR in daily health care routines. Also,

PNs reported that they find it difficult to promote a platform they hardly know.

Second, little thought has gone towards the integration of PHRs with other health care systems and the integration of the PHRs with national guidelines for the treatment of chronic diseases in primary care.

IV. DISCUSSION

In the current research project, we signaled differences between the inclusion percentages of the participating primary care practices. The goal of this study is therefore to identify the factors that influence the uptake and impact of a PHR for patients with T2DM in primary health care. Because the PNs are responsible for promoting the PHR e-Vita among their patients, we identified the bottlenecks for the implementation of a PHR in primary care from the view of PNs.

We believe that the development of eHealth technologies is an ongoing process that requires continuous evaluations. We therefore conducted both a forward and a backward evaluation in order to not only gain insight into the factors that influence the uptake and impact of a PHR, but also to identify possibilities for improving the content of the PHR in the future.

To understand the choices that have been made regarding the process of development and implementation of the PHR so far, recurring themes in the interviews with PNs will be tested among the other stakeholders in the e-Vita project. To gain insight into the developmental course of the e-Vita, this evaluation cycle is planned to be repeated in the next two years.

Because we feel that the development and implementation of eHealth technologies is a matter of co-creation, we plan to involve both health care providers and patients as potential end-users. Therefore, we will also plan interviews with patients to gain insight into the factors that influence the use of the platform.

At this moment (November 2013), the interviews among the PNs, eleven in total, are conducted. The results of the first part of the study are expected in January 2014. The results of the second part of the study are expected in March 2014.

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