Empowering Patients through a Patient Portal for an Improved Diabetes Management

Ioannis Karatzanis[1], Vasilis Kontogiannis[1], Emmanouil G. Spanakis[1], Franco Chiarugi[1], Joanna Fursse[2], and Russell W. Jones[2]

[1] Computational Medicine Laboratory, Institute of Computer Science, Foundation for Research and Technology - Hellas, Heraklion, Crete, Greece
{karatzan,vasilisk,spanakis,chiarugi}@ics.forth.gr
[2] Chorleywood Health Centre, Chorleywood, Hertfordshire, United Kingdom
j.fursse@gmail.com, russellwjones@live.com

Abstract. Type 2 diabetes is increasing worldwide. When compared with other chronic diseases, deaths due directly to type 2 diabetes are less. The problem though, is the mortality rates caused by the consequences of type 2 diabetes; complications that represent a major health burden which may destabilise health economies. Recognised complications are: cardiovascular disease, peripheral vascular disease, renal failure, retinal eye disease, and neuropathy leading to high levels of morbidity and mortality from heart attack, foot ulceration and leg amputation, stroke, renal failure, and blindness. Better care of type 2 diabetes and early recognition and treatment of its complications reduce levels of morbidity and mortality. There is a need to support the diabetic patient in achieving effective glucose control and life-style changes leading to improved nutrition and healthy levels of physical activity, and to early recognize and treat complications. To make this possible and efficient, a patient portal has been developed, as part of the REACTION platform, which supports interactions between the diabetic patient and both their professional and non-professional carers. Introducing the patient portal and the REACTION platform to real-life healthcare systems will empower patients more by increasing their ability to self-manage, improve the quality of their life and the overall management of their diabetes, reduce the risk of developing complications and lessen their use of health services.

Keywords: Patient empowerment, Patient portal, Diabetes management, Blood glucose measurement, Insulin delivery, Closed-loop control.

1 Introduction

Diabetes mellitus is a state of high blood glucose concentration (hyperglycaemia). It is caused by impaired secretion and/or effectiveness of insulin. There are a number of causes of diabetes mellitus and many diseases that develop because of it; it is difficult to determine a single and simple definition of diabetes mellitus. In essence, without insulin, cells cannot use glucose effectively. This metabolic fault varies in its impact

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from an acute life-threatening illness to impaired glucose tolerance that is without apparent clinical effect.

There are two forms of diabetes. The auto-immune destruction of β-cells of the Islets of Langerhans in the pancreas causes type 1 diabetes. This occurs in children and young adults. People with type 2 diabetes, usually over 50 years old with additional health problems, exhibit reduced insulin production and resistance or reduced sensitivity to insulin [1]. There are young people now presenting with type 2 diabetes in whom there is an abnormality of the glucokinase gene and others who secrete less potent insulin because of a genetic error. There is a further group of people who become type 2 diabetics because of the impact of impaired placental function and maternal malnutrition on the development of their β-cells. Type 2 diabetes is increasing markedly and has a number of causes.

Life-style change in the last century has led to an increase of almost epidemic proportions in the incidence of diabetes worldwide. This is mainly related to type 2 diabetes. Together with genetic susceptibility in certain ethnic groups, type 2 diabetes is brought on by environmental, social and behavioural factors such as bad life-style, physical inactivity, overly rich nutrition and obesity [2]. The increased incidence and the population growth and ageing have raised the number of people with diabetes worldwide [3]. In 2010 the world prevalence of diabetes among adults (aged 20–79 years) was 6.4%, affecting 285 million adults. An increase to 7.7% and 439 million adults by 2030 can be expected. Between 2010 and 2030, there will be a 69% increase in numbers of adults with diabetes in developing countries and a 20% increase in developed countries [4]. The global health expenditure on diabetes was about $376 billion in 2010 and it is estimated to be $490 billion in 2030. Globally, 12% of the health expenditures and $1330 per person have been spent on diabetes in 2010 [5]. The human and economic burden is considerable now and is destined to grow. Diabetes complications make managing diabetes more difficult and have a profound impact on levels of morbidity and mortality.

The effective care of type 1 diabetes is achieved by reducing the likelihood of both hyperglycaemic and hypoglycaemic levels of glucose by administrating basal and bolus insulin and adjusting the dosage by continuous blood glucose monitoring. Management of type 2 diabetes consists in the control of a healthy blood glucose level through oral anti-diabetic drugs (OADs) and, when necessary, insulin. Best care also involves monitoring and advising on levels of physical activity, nutrition and maintaining optimal body weight. This helps reduce the risk of complications - particularly cardiovascular diseases. In both types, people with diabetes should receive education by a specialized team skilled in the self-management of diabetes.

Patient empowerment is a new approach in health care with the point of view of having patients as active participants in the health care process for the attainment of optimal outcomes [6]. The active participation implies a higher involvement in the decision making process. An appropriate decision making can be performed only if a proper communication between patient and clinicians is assured and the patient is provided with appropriate education material and supported with the necessary information resources. An appropriate use of healthcare best practice supported by electronic processes and communication (eHealth) may enable the patient

empowerment, especially in case of patients with chronic diseases [7], where a life-long daily disease management is required.

Patient empowerment is a necessary pre-requisite of effective disease self-management. At the first European conference on patient empowerment, it was agreed that Europe cannot afford not to self-empower in case of chronic disease management, since cardiovascular diseases, cancer, diabetes, obesity, and chronic respiratory diseases cause an estimated 77% of the disease burden in Europe [8]. Although self-management cannot substitute the acute care provided by professionals, it can help people with chronic diseases stay in the workforce and remain integral and active members of their community. Programmes on chronic disease self-management teach and support patients to identify warning symptoms, measure and evaluate vital signs, decide the most suitable treatment for them, and take medications.

In the specific case of diabetes more attention has to be paid to the emotional charge related to diabetes. The stress of supervising constantly their activity, diet and medication implies an emotional involvement of patients with their disease. Depression is common in diabetes and worsens levels of morbidity and mortality. Emotional distress results in poor motivation for self-management and inadequate adherence to the treatment. Thus, monitoring of depression and patient motivation are other major tasks for general practitioners in the primary care environment [9].

eHealth technological platforms can support both clinicians and patients in the short and long term management of diabetes. A key component, specifically focused on supporting patient empowerment and self-management, of such solutions is the patient (web) portal because it can provide at any time and in any place the relevant information to patients, improve their interaction with the clinicians, support education and motivation, and provide information about life-style, behaviour and emotional status. Patient portals integrate the electronic health record and the patient health record since patients themselves contribute to the maintenance of their health care information. Patient portals are more and more used in chronic disease management, but in diabetes management they have an even more fertile ground.

A recent review about patient portals for people with diabetes showed that such systems enhance interactions between patients and clinicians, increase patient overall satisfaction with care, provide better, more prompt and ubiquitous access to health information, and improve diabetes management and patient outcomes. Key points in the delivery of patient portals to patients are good usability, reliability and availability of user choices for patients, while providers should apply more extensive training and assistance when the portal addresses elderly and not highly computer-literate populations [10]. In fact, although diabetes is today quite common even to young adults, it is mainly prevalent among adults aged 65 and older. Thus, the interface design should be made trying to avoid potential design problems for this specific target group.

Another recent study [11] proved that patient portals have the ability to provide patients with the opportunity to be increasingly involved in their own care (thus increasing self-management capability) and to reduce inequity in the access to care.

Patient portals can help in increasing the health literacy and the capability for self-management of diabetes if designed with high usability criteria for not highly computer-literate populations, otherwise the health literacy barrier will not be removed [12].

2 Methods

The REACTION project [13] aims to support management of diabetes in different clinical settings through a platform that will offer professional management and therapy services to diabetes patients [14]. This platform provides healthcare services to diabetes patients and caregivers such as blood glucose monitoring, monitoring of other relevant parameters (e.g. complication indicators, activity, and food and medication intake), decision support systems, therapy management, support of life-style changes, and crisis detection and management.

When at home, the diabetic patient is managed through the platform and the services provided by the primary health care centre. Main components of the system from the stakeholders' point of view are: a) the home or mobile platform composed of medical and environmental devices and a home or mobile gateway for the secure connection with the back-end servers; b) the health professional (clinician) portal; c) the patient portal. All components have also the capability to interoperate with each other and at least weakly with the electronic health record of the primary care centre.

The home or mobile platform is dedicated to the automatic collection of vital sign, environmental and context measurements with a focus on user friendliness, low costs, use of standards and use of wireless medical and other devices. The health professional portal supports the clinicians with the following main functionalities: a) system administration; b) user management; c) patient management; d) education and care plan (life-style and medication) management; e) remote monitoring scheme plan; f) daily measurement management; g) view of additional data and questionnaire responses; h) risk management; i) notification management. The patient portal supports the patients and informal carers with the following main functionalities: a) capture of life-style data (activity, diet, emotional status); b) capture of medication data (insulin, OADs); c) support of life-style and compliance questionnaires; d) view of care plan (life-style and medication); e) view of own measurements; f) view of feedbacks; g) view of notifications, alerts and reminders; h) view of material in support of education and motivation; i) manual input of measurements (as back-up solution).

All components of the overall solution have been developed in order to be simple, easily usable by elderly people (hiding technology as much as possible), with low cost and with easy procedures for installation and removal.

This paper will focus on the design, development and first usability tests of the prototype patient portal.

2.1 The REACTION Patient Portal

The REACTION patient portal is a secure multiplatform web application built on previous experiences of the Foundation for Research and Technology - Hellas (FORTH). The creation of the REACTION patient portal was based on a multi-step procedure, where every step was carefully designed and validated. The procedure started from the general requirements of the platform, created by the stakeholders, selecting the specific requirements for the patient portal including the ones specifying its interactions with the other components. All these requirements were translated into functionalities that were analysed and described in detail. The functionalities were logically grouped, optimizing the typical workflows performed by patients and, thus, organizing the patient portal into logically distinct sections. The functionalities were decoded as software modules and graphically represented in the user interface by big buttons that contain easily identifiable icons and easily readable captions. Special attention was given to the design of the user interface, having in mind accessibility, user-friendliness and usability criteria. The colour of the text, the icons, the button control sizes, the graphical unit display of the glucose and the other vital signs were carefully selected in such a way to fulfil the usability criteria specified in the requirement list (e.g. using high contrast with the background of the buttons). This, in addition to the careful design of the layout and the organization of the functionalities, contributed to the creation of a modern and friendly user environment.

The REACTION patient portal was implemented in C# using the ASP.NET v4.0 framework. The selected database engine was the Microsoft SQL Server 2008 R2. The implementation of the user interface was performed using html5 and css3 technologies. Complementary technologies to design a modern and user friendly interactive interface include the latest versions of the JavaScript libraries of jQuery and jQuery UI and an interactive JavaScript library for the chart drawing elements. The development environment used was mainly composed of an integrated development environment (Microsoft Visual Studio 2010) and an integrated environment for the database management (SQL Server Management Studio). The target environment, where the application was deployed, was a Microsoft Server 2008 R2 standard server with IIS as web server on board.

Since the patient portal has been designed as a web application, any type of device, personal computer, smart phone or tablet PC, can access it, as long as it has a web browser (that supports the present common web standards and technologies defined by the World Wide Web Consortium (W3C)) and it is connected to the Internet. The REACTION patient portal has been accurately tested to operate properly with the last versions of all the major web browsers (Internet Explorer 8+, Mozilla Firefox12+, Google Chrome15+, Opera 10+, Safari 5+ & Dolphin HD+) in the three major desktop operating systems (Windows XP+, Mac OS X 10.7+, Ubuntu Linux 10.04+) as well as in the three major mobile operating systems (iOS5, Android 3+, WP7+).

Some interactive screenshots of the patient portal on tablet PC are shown in Fig. 1.

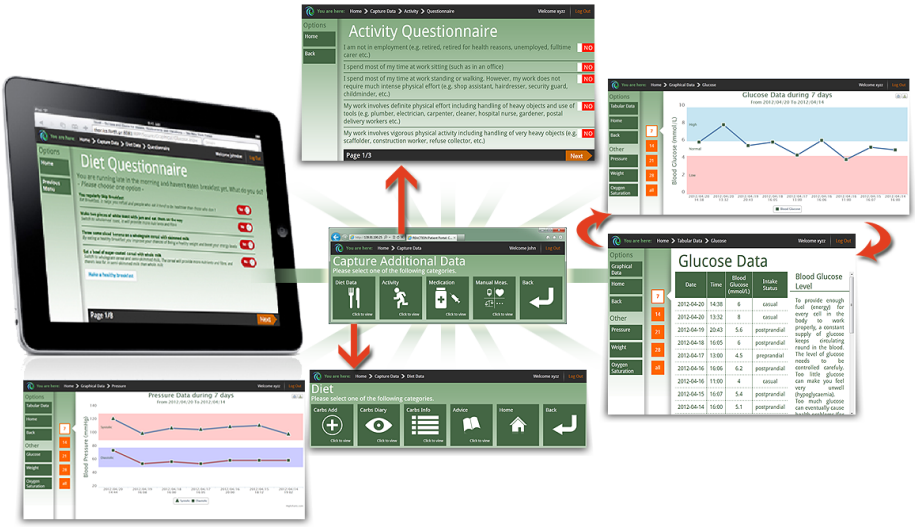

Fig. 1. Some interactive screenshots of the REACTION patient portal

Several reviews of functionalities and user interface on paper and then with mock-ups were performed with simulated end-users. The adopted design choices were verified by usability tests, performed in the sites of the clinical partners, scoring high on the "ease of interaction" and "user satisfaction". Usability tests were also performed with actual elderly users and users with little computer-literacy focused on the optimization of the user friendliness of the patient portal. Retrofits were continuously provided and modifications implemented and deployed in an iterative process, towards the attainment of a version suitable for clinical use.

3 Results

Prior to commencing the primary care field trials, a series of tests on the overall platform have been undertaken in the clinical site. The testing process has been undertaken in 2 stages, friends and family testing and field testing.

Friends and family testing involved users that were not from the target population. They included researchers, friends and neighbours of those working within the study.

The main objectives of the friends and family phase were to:

- Test reliability and robustness in a non-lab environment
- Test functionality of the equipment in a non-lab environment
- Test usability and functionality of patient and clinician portals
- Receive usability feedback

A small number of users undertook this testing for 7 days following a test script protocol. Following the friends and family testing, a number of patients with very

basic computer-literacy from the target sample were approached and asked to take part in a series of field tests.

The main objectives of the pre-pilot field testing phase were to:

- Test functionality of the equipment in a patient home environment
- Test installation procedures in a home environment
- Receive usability feedback from end-users to the technical teams

Patients were trained and asked to use the patient portal and the home platform following specific protocols for a period between 7 and 28 days.

In both test phases actions were reviewed regularly via meetings with the technical partners and the technical solution was updated and improved in an iterative process.

The main outcome of these initial field tests related to the patient portal was that all patients were able to gain access to the patient portal on both the tablet and their own PC. There was one functional error reported by a patient using the PC. This was to do with the date range when entering manual readings and was fixed by the technical team updating the patient portal version.

Patients using a personal computer generally stated that the patient portal was easy to use. It was simple to log onto and was quick to navigate and complete the tasks. A minor usability raised by the patients was solved by changing the yes/no check box control in the questionnaires and in all parts of the portal with a different one, which, in subsequent tests, was considered very satisfactory by patients. Another minor usability issue came from a patient accessing the patient portal with an old version of web browser not matching the patient portal pre-requirements. In that case, the solution was to update the browser version.

In case of use of a tablet PC, it was verified that when there is a level of reduced mobility in hands, the use of a standard PC is preferred, thus the multi-platform design adopted for the patient portal is a clear advantage being able to address a heterogeneous set of end-users.

Finally, all patients considered the patient portal helpful in their daily self-management of diabetes.

4 Conclusion

Diabetes management is complex. The impact of physical activity, diet variation and stress on glucose levels must be assessed and taken into account. This, along with blood glucose measurements will determine the insulin dose or the appropriate use of hypoglycaemic drugs. The complexity of professional care and self-management increases with the necessary effort to achieve the best care and treatment of co-morbidities along with effective life-style changes. Daily management has to be performed appropriately by the patients themselves, and proper education, information and support have to be provided. It is also necessary to take into account the difficulties that older adults may experience due to the decline in cognition, vision, and motor skills, and for this reason, before the deployment, an evaluation and comparison of results against the Web Content Accessibility Guidelines 2.0, in order to determine the e-accessibility level of services offered, will be performed and eventual retrofits applied.

The proposed patient portal within the framework of the REACTION platform, deployed in real-life healthcare systems, is expected to greatly empower the patient, increase the self-management capacity, improve the quality of life and the overall management of diabetes, reducing the risk of developing complications in general, and the rate of hospital admissions. Results of initial tests and first experiences with real end-users are encouraging and seem to confirm these expectations.

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