

Design, construction, and implementation of an online platform for patients with type 1 diabetes: EncoDiab

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Purpose: The purpose of this study was to develop, build, and implement a virtual platform equipped with practical tools, relevant contents, and communication rooms, with the aim of facilitating patients' self-management of type 1 diabetes mellitus (T1DM).

Materials and methods: The design of the platform was based on the suggestions of T1DM patients who were being managed at two reference hospitals. Patients' needs and preferences were identified in group discussion sessions. Before having access to the platform, patients underwent a baseline assessment, which included physical examination and the administration of validated questionnaires for evaluation of clinical background, quality of life, treatment satisfaction, and well-being.

Results: A total of 33 patients were included in the study; 54.5% of them were men, their median age was 34 (18–50) years, the median duration of diabetes was 15 (1–38) years, and the median A1C was 7.4% (6%–12.6%). Based on their suggestions and requests, the online platform EncoDiab was built and organized into four domains: a personal domain, two domains shared by the patients and the staff of each of the two participating hospitals, and one domain that was accessible to all participants. The platform included practical tools (a body mass index calculator, a carbohydrate counting tool, and an insulin-dose calculator), a library with relevant information (documents on prevention and treatment of acute complications, nutrition, exercise, etc), and a chat room.

Conclusion: Although the study is still ongoing, our current results demonstrate the feasibility of building and implementing an online platform for helping T1DM patients in the self-management of their disease in the public health setting.

Keywords: eHealth, behavioral health, telehealth, education

Introduction

Tight glycemic control in type 1 diabetes mellitus (T1DM) reduces the risk of developing chronic complications of the disease.¹ However, barriers preventing glycemic improvement can be found in the patient, in health care professionals, in the disease itself, and in the organization of health care services.^{2,3} Indeed, the daily management of the disease usually falls on the patient. Although providing an environment that facilitates diabetes self-management and allows for informed decision making is a challenge, it may contribute to improve the management of T1DM.⁴

Comanagement of this disease has already proved feasible.^{5,6} The aim of the present project was to shift the task of disease management and responsibility from health care professionals to patients themselves by providing high-quality resources to support them in self-management and informed decision making.

The incorporation of the Internet into our daily life has transformed the relationship between patients and health care professionals.⁷ Nowadays, “the web” is the most

frequently consulted source of information on diseases. Nevertheless, the reliability of certain content is uncertain, and myths and lies are also spread efficiently.⁷ In the context of a reliable virtual environment, accurate information can be a powerful tool to support patients' self-management of this disease, without the time and space limits of other resources.

New technologies can be used by health care professionals to assist patients in the management of diabetes. Actually, randomized controlled trials have shown that web-based support may have a positive impact on the process and quality of diabetes care, quality of life, and treatment satisfaction.^{8–10} Virtual interaction among patients with the same disease has not been rigorously assessed, but reports on discussion groups, chats, or a combination of these with news groups have been published.¹¹ Most of them are run and promoted by health professionals, who stimulate discussion, propose or answer questions, or post useful pieces of news. A study analyzing patients' perspectives highlighted the importance given to peer support, their awareness of the need to evaluate external information in each patient's own context, and the value given to the experiential knowledge of other people with the same disease.¹²

The goal of this study was to design, build, and implement a virtual management system for patients with T1DM, in the public health care setting. It was conceived as a structure integrating information, education, assistance, and socialization. It followed the principles of the Web 2.0 philosophy, which enhances bidirectional communication and promotes adaptation of technological tools to the needs and skills of potential users. In the present article, we describe the design and implementation processes, as well as the baseline characteristics of the patients included in this study. The outcome of the use of the platform will be reported in the future.

Materials and methods

Study population and design

Participants were recruited among T1DM patients who were being treated at any of the two participating hospitals (Complejo Hospitalari Universitario Insular Materno-Infantil of Gran Canaria, Las Palmas, Spain and Hospital Universitari Arnau de Vilanova in Lleida, Spain). Inclusion criteria were: patients older than 18 years, T1DM diagnosed at least 1 year before, Internet connection at home, basic skills in the use of information and communications technology, and having an email account. Pregnant women and people with psychiatric or other conditions that could potentially interfere with follow-up were excluded. The study was approved by the Ethics Committees of both participating hospitals. Patients were contacted in the outpatient clinic, where they were offered a brief description of the study and invited to participate.

Interested patients were appointed for a subsequent specific visit, where they were given detailed oral and written information and those wanting to participate were asked to sign an informed consent form. They were also asked to sign consent for potential promotional use of the pictures taken during the group sessions. Furthermore, the participants committed themselves to honor privacy and to act with mutual respect in the interactions within the platform.

In order to identify the patients' needs and preferences, group sessions were organized, where participants were asked about the tools and contents they would like to find on an online platform. Indeed, one of the main goals of this project was that the patients themselves settled the basis for the design of the platform.

The 17 participants from the Complejo Hospitalario Universitario Insular Materno-Infantil of Gran Canaria were split into two groups, which took part in two parallel 2-hour group discussion sessions. Brainstorming was used to identify and record all the relevant aspects suggested by the participants,¹³ which were then ordered by priority (since it was assumed that covering all the recorded items within this project would not be feasible).

Participants from the Hospital Universitari Arnau de Vilanova in Lleida participated in 2-hour discussion sessions in two groups of eight subjects each. They were asked to discuss those aspects that would improve their quality of life and diabetes management. A sociology PhD student, who was in charge of designing the virtual environment, a diabetes nurse specialist (from the Lleida Patients Association), and the engineer in charge of the final platform design were present in the sessions and provided advice when needed.

Patients' needs and suggestions identified in both hospitals were compiled into a common document, which was used as the basis for the design of the platform. The platform was built by using the content management system Drupal and adapted to the requirements of this type of system, as well as to those established by the patients. It was hosted on an independent dedicated server in compliance with the national regulations (law LO 15/1999 on the protection of personal data [LOPD] and RD 1720/2007, BOE-A-2008-979).

Patients

The initial population of the study included 33 patients (17 from Gran Canaria and 16 from Lleida): 54.5% of them were men; the median age was 34 (18–50) years; they had a median T1DM duration of 15 (1–38) years, a median A1C of 7.4% (6%–12.6%), and a median body mass index (BMI) of 24.6 (16.4–37.7 kg/m²); and 72.7% of them were workers, 24.2% were students, and 3% were homemakers.

Table 1 shows their needs and suggestions as recorded during the group sessions.

Implementation and evaluation

Six months after the initial group sessions, patients were appointed for a baseline evaluation visit, before being given access to the platform. Every participant received an email with their individual username and password to access the platform.

There, they would find the contents and tools they had previously suggested and would be able to communicate with other participants and with health care professionals at their hospital.

During the baseline evaluation visit, information was collected on diabetes, possible associated complications, cardiovascular risk factors, and other possible diseases and treatments. Physical examination included blood pressure, anthropometric measurements, and foot examination. Blood

Table 1 Patient requests for EncoDiab

Features and usability of the environment	Included
It should be possible to identify whether a participant is a health care professional or a patient, even if he/she is anonymous.	x
Frequent updates.	P
There should be a search engine available, to find specific information.	x
It should be usable with any of the standard browsers.	x
It should be usable from mobile phones.	P
It should be linked to social media.	x
It should be possible to label contents to facilitate search.	x
It should be possible to mark contents with "+I" or "I like" and to make comments so that other participants can identify the most popular ones.	x
Contents	
Nutritional information: macronutrient composition, carbohydrate portions, pictures, recipes.	x
Instructions on how to act in special situations: what to do when making a mistake in the dose of insulin.	x
Information for family members, place of work, schools: how to act in acute situations (PDF for convenient printing).	x
Pregnancy: therapeutic targets, pre-pregnancy follow-up, pregnancy, and chronic diabetes complications.	P
Traveling: medical reports needed, what to take in the hand luggage, how to transport and distribute insulin in the luggage, etc.	x
Advances in diabetes: research, new treatments.	x
Blood glucose meters: features and performance of those available.	x
Information about sweeteners.	x
Information about drugs that may alter glycemic control.	x
Insulin injection technique. Sites and rotation.	
Information about chronic complications of diabetes.	P
How to treat hypoglycemia. How to use glucagon (printable PDF).	x
How to treat hyperglycemia: simple hyperglycemia, ketosis (printable PDF).	x
Foot care.	
Legal issues related to diabetes: contracts, health and life insurance, driving license, subsidies, etc.	x
Important telephone numbers: glucose meter and pump manufacturers.	
Geolocalization of pharmacies with insulin available.	
Information about who is the on-call endocrinologist in both hospitals.	
Newsletters. Interviews with celebrities who suffer from diabetes or with other participants in the platform, to share experience.	
Library, resources, etc. Links to important diabetes webpages American Diabetes Association, etc.	x
Applications (with instructions) and related subjects.	x
Application to download information from glucose meters.	
Basic formulas: insulin sensitivity factor, insulin-dose calculation based on carbohydrate intake, correction bolus calculation.	x
A calculator that allows computation of these formulas directly.	x
Modifications of insulin dose in special situations:	x
<ul style="list-style-type: none"> • Exercise (according to the type of exercise) • Illness and other situations (menstruation, fever, vomiting...) • Changes in daily physical activity (weekends, siesta...) • Alcohol intake • Barbecues and celebrations (snacking) 	
Contact management.	x
Contact information of physicians, nurses, manufacturers (insulin, meters, technology...), health institutions, press.	P

(Continued)

Table 1 (Continued)

Features and usability of the environment	Included
Calendars	
A public calendar with activities, congresses, social meetings....	
A private calendar for every participant where all diabetes-related issues could be integrated into daily life.	x
Appointments should be automatically recorded on a private calendar.	
Personal documentation area	
Access to a personal health folder (electronic record).	P
Sampling.	
Personal statistics with graphs.	
Test results.	
Possibility of activating alerts for scheduled visits or prescription expiry. Identification of abnormal results, eg, with a different color.	
Private “virtual” glucose record with links to carbohydrate portion records that can be saved and retrieved for a better interpretation of glucose values. Possibility to submit such data to a health care professional.	
Possibility of consulting a health care professional via videoconference together with availability of editable records, in order to get new prescriptions if needed.	
Online consultation. Urgent questions should be replied to within 24 hours (although it would not be possible to choose the health care professional). For non-urgent questions, it should be possible to choose a health care professional or any one that is available. In both cases, the patient should be able to decide if the consultation is public or private. If public, other participants (patients and health care professionals) would be able to give their opinion and start a discussion.	P
A notice should be sent when the consultation has been replied to. If urgent, it should be sent via SMS. The patient should be able to decide when the event is closed.	x
A printable calendar with scheduled appointments should be available on the platform. It should be possible to change the date of blood testing appointments.	
Diabetes education courses/information	
Food labeling (composition, carbohydrate portions...).	x
Portions: description, how to adjust insulin doses to carbohydrate and fat intake.	x
Diet: healthy diet, losing and gaining weight.	x
How to use software to download glucose meter data.	x
Myths about diabetes (no sweets...).	x
What is type 1 diabetes? Differences with type 2 diabetes regarding treatment and pathogenesis.	
Information about insulin pumps: indications, basic management.	x
Chats	
Interaction with other patients with the participation of health care professionals acting as moderators when necessary.	x
Possibility of asking a health care professional who would reply in a reasonable time.	x
Possibility of synchronous consultation.	P
Mailbox for suggestions for continuous improvement of the platform.	P
Information about patient associations or links to their webs (although patients do not want the associations to access the platform).	x

Note: The column on the right shows which suggestions have been incorporated into the platform, either as expressed by the patients (x) or somewhat modified (P).

samples were collected to measure A1C (high-performance liquid chromatography-National Glycohemoglobin Standardization Program standardized), lipids, kidney and liver assessment (colorimetry), thyroid-stimulating hormone (TSH), and albuminuria.

To evaluate quality of life and treatment satisfaction, the validated, Spanish versions of the following questionnaires were administered: Audit of Diabetes-Dependent Quality of Life,¹⁴ Diabetes Treatment Satisfaction Questionnaire,¹⁵ and 12-item Well-Being Questionnaire.¹⁶ In addition, each patient was asked to define up to three personal goals related to the platform, to be assessed during the follow-up.

All of these parameters were evaluated at baseline and again 12 months later. In addition, participants' activity, use

of resources, and permanence on the platform during the 6 months following their first access were quantified by using tools incorporated into the platform.

The platform EncoDiab was built progressively and did not include all of the patients' suggestions from the start. At present, it is organized into four domains: a personal domain for every participant, one for interactions between the patients and health care professionals in Lleida, one for interactions between the patients and health care professionals in Gran Canaria, and one for general interactions among all participants.

Personal domains include: a customizable entry panel for profile editing, access to interactive tools (BMI calculator, glucose and insulin-dose register, carbohydrate portion calculator, and insulin-dose calculator), and activation of

Calculadora de índice de masa corporal



Introduce tu peso y estatura para empezar

0.0 kilos de peso

Índice de Masa Corporal = $\frac{0.0}{0.0^2 \text{ metros de altura}}$ = 0.0

Figure 1 Body mass index calculator.

subscriptions to notifications. Figure 1 shows the BMI calculator, a simple tool in which patients can enter their weight and height and get their BMI as a result. A color code shows whether the BMI is healthy or not (green for normal, yellow for overweight, and red for obesity). Figure 2 shows the

carbohydrate portion and insulin-dose calculator and Figure 3 shows the glucose and insulin-dose register, which can be submitted to a health care professional for evaluation. In addition, this domain includes an internal mail system for private one-to-one communication, a personal calendar

Inicio Perfil Herramientas Notificaciones Opciones de la cuenta Favoritos

Dashboard Calculadora IMC **Calculadora RHC** Autocontrol Añadir

<p>Total de raciones de carbohidratos:</p> <p>0.00</p> <p>¿Cuál es tu ratio insulina/hidrato de carbono?</p> <p>0.00</p> <p>Tu dosis de insulina es:</p> <p>0.00</p> <p>Reiniciar calculadora</p> <p>Tu comida consiste en:</p> <p>(nada seleccionado aún)</p>	<p>Bebidas</p> <p>Bebidas alcohólicas</p> <p>Cereales de desayuno</p> <p>Cereales y tubérculos</p> <p>Comida preparada</p> <p>Comida rápida</p> <p>Fruta</p> <p>Frutos secos y frutas desecadas</p> <p>Leche y derivados</p> <p>Legumbres</p> <p>Panes</p> <p>Postres, pastelería y dulces</p>
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Figure 2 Carbohydrate portion and insulin-dose calculator.

Registros de autocontrol

Día 1

FECHA:

Formato: 28/05/2014

HORA 1:

HORA 2:

HORA 3:

HORA 4:

HORA 5:

HORA 6:

GLUCEMIA 1:

GLUCEMIA 2:

GLUCEMIA 3:

GLUCEMIA 4:

GLUCEMIA 5:

GLUCEMIA 6:

RHC 1:

RHC 2:

RHC 3:

RHC 4:

RHC 5:

RHC 6:

IR 1:

IR 2:

IR 3:

IR 4:

IR 5:

IR 6:

IB 1:

IB 2:

IB 3:

IB 4:

IB 5:

IB 6:

Día 2

FECHA:

Formato: 28/05/2014

HORA 1:

HORA 2:

HORA 3:

HORA 4:

HORA 5:

HORA 6:

Figure 3 Blood glucose register.

(Figure 4), and access to other areas the participant is allowed to enter.

The other domains are structured as follows: a customizable entry panel, a blog, a group calendar, a list of members allowed interaction in the domain, and a chat room. The library (Figure 5) contains a folder with recent commented articles, a section about physical exercise (how to start an exercise program, recommendations for insulin-dose adjustments, etc), a folder with legal information (subsidies),

a folder with relevant health information (glucose meters, continuous glucose sensors, management of hypoglycemia and ketosis), a folder with documents on nutrition (general recommendations, links, food groups, healthy eating, frequently asked questions, recipes), selected links, and video tutorials about the use of the platform.

There is also a discussion section, which was created with the aim of facilitating interaction among patients (Figure 6).

Octubre 2013

Previo

Próx.

Lunes	Martes	Miércoles	Jueves	Viernes	Sábado	Domingo
30	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31	1	2	3

Eventos

debat

Evento personal

Hospital

Peticion visita

Reunión (cat)

Taller

Tarea

Otros

Buscar

Mis Acciones

Nuevo evento personal

Mis Peticiones de Visita

No tiene actualmente ninguna visita programada. Si quiere puede [crear una aquí](#)

Figure 4 Private calendar.

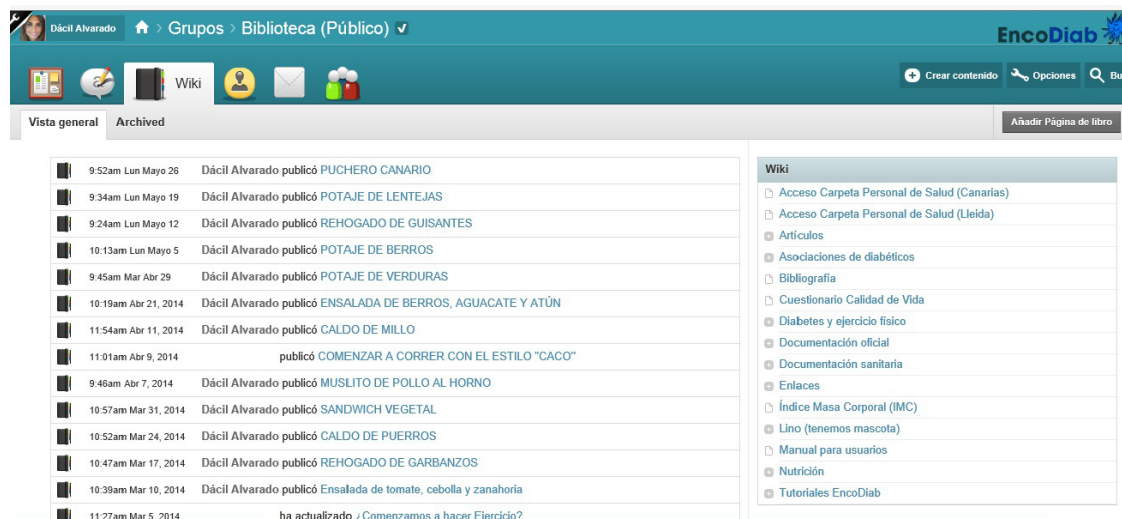


Figure 5 Access to the library.

Notes: The most recent documents are visible. On the right-hand side, accessible folders containing additional documents can be seen.

Validation group

Upon continuation of the project, 6 months after the start of the use of the platform, a new group of 29 patients (who did not participate in the design) has been given access to it after a baseline evaluation equivalent to that of the first group. This second group will be followed for 1 year. The details and results of this validation process will be published in the future.

Amplification of EncoDiab

A few months after the validation group was given access to the platform, it was also opened to other adults with T1DM who were interested. At the time of the present report, a total of 175 users are members of EncoDiab. An online questionnaire will be used to evaluate their satisfaction with the platform.

Discussion

T1DM has a huge impact on the lives of people who have the disease. Strategies aimed at empowering patients to manage it independently have proved to be effective.⁴ EncoDiab offers the tools for establishing a virtual community that facilitates communication among patients and with health care professionals. It provides practical tools for daily diabetes management and reliable information to support informed decision making. Above all, it is conceived as a place where patients play the leading role. This type of platform may offer other benefits, such as reducing isolation, promoting a positive psychological state, and acquiring healthy habits.¹⁷ Studies have shown that discussion forums and conversation rooms for interaction among patients who suffer from the same disease may have a positive effect on the participants, leading them to a more favorable disposition

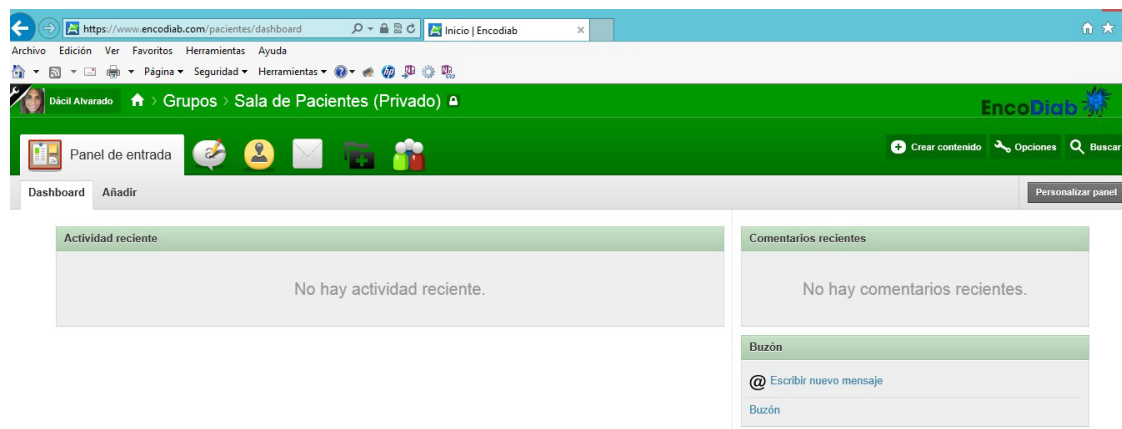


Figure 6 Patient discussion room.

to control their disease.¹⁸ The availability of a reliable setting, with health professionals who offer advice and select and provide appropriate information, may empower patients to take responsibility for the control of their disease, have a positive effect on their level of commitment, and help them establish actions leading to better diabetes care.¹⁹ Other authors have reported the benefits of online platforms like EncoDiab, such as helping reduce communication barriers between patients and health care providers,²⁰ which may eventually lead to improved self-care and self-management of disease.²¹ EncoDiab also facilitates peer support. Indeed, several studies have illustrated the importance of patient–health care provider communication^{22,23} and peer support in diabetes care.²⁴

Previous studies on the effects of mobile tools, including web pages – which promote self-management and communication with health professionals – on T1DM patients, reported either improved glycemic control²⁵ or no additional benefit when compared with conventional treatment.^{26,27}

The development of EncoDiab was based on the participation of patients from the start, which is, in our opinion, the best way to design a system for such a close collaboration between providers and users. The early involvement of the users, even in the design of the platform, does not guarantee its success, but it should improve the odds. Indeed, the requests made by the participants in both centers (located in different and distant regions) were quite similar. Therefore, it is expected that the design of the platform would also meet the needs of other users. Although the analysis of the results is still in progress, the evaluation of the platform by its current users (more than 150) – only a minority being present from the start – is expected to provide further information about its generalizability.

Conclusion

The use of online resources for the self-management of health conditions is a necessity in communication and technology information society. Actually, self-management is being increasingly demanded by patients, and the public health system is expected to provide solutions. In T1DM in particular, self-care is a pivotal element, which could allow patients to live with high levels of independence from the health care team. To our knowledge, there is no previous evidence in our health care system on the feasibility, efficacy, or impact of a patient-centered, patient-designed online system like EncoDiab, which allows for comprehensive self-management of T1DM.

EncoDiab makes use of technology to complement standard diabetes education. Patients are provided with reliable online resources that can be accessed anytime from anywhere.

Since the study is ongoing, the analysis of the outcomes is still incomplete. The goal of this project was not focused on demonstrating the effectiveness of a telemedicine system, but on building, implementing, and evaluating a T1DM self-management system, based on patients' requirements, in a real-world, public health care setting. Conclusions would be premature at this point. However, in case the goal of this project is finally achieved, it could lead not only to further optimization of T1DM self-management, but also to its possible application to other populations (pregnant women, children, and adolescents) or types of diabetes, especially the highly prevalent type 2 diabetes.

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Disclosure

The authors report no conflicts of interest in this work.

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