
Original Paper

Stakeholder Perspectives on the Development of a Virtual Clinic for Diabetes Care

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Abstract

Background: The development of the internet has created new opportunities for health care provision, including its use as a tool to aid the self-management of chronic conditions. Diabetes is one such condition and internet-based interventions may be particularly appropriate for use with young people, 20% of whom fail to attend routine appointments at clinic. There is considerable research evidence that internet-based health interventions have been successful in reaching and working with young people; for example in smoking cessation, eating-disorder prevention and cystic fibrosis. In addition, a report of a small study which pilot-tested the feasibility of allowing patients with type 2 diabetes to co-manage their condition from home showed proof of concept for internet-based co-management of diabetes for adults. This paper reports on the development of an internet-based 'Virtual Clinic' as an innovative way to help people with diabetes manage their condition. The Virtual Clinic allows a person with diabetes to communicate with their healthcare providers, find information about their condition, and share information and support with other users. It is enhanced by being based on the behavioural theory of self-efficacy from psychology.

Objectives: To present the results of a detailed consultation with a variety of stakeholder groups in order to identify what they regard as the desirable, important and feasible characteristics of such a system.

Methods:

- Three focus groups with people with diabetes recruited through a local diabetes clinic
- Five qualitative interviews with health care professionals from the clinic (2 doctors, 2 nurses, 1 dietitian) and 1 with a representative of an insulin pump company
- E-mail consensus gathering with those using internet-based systems for other chronic conditions (asthma, epilepsy, ME, mental health)
- Workshop to gather expert consensus on the use of IT to improve the care of young people with diabetes

Results: Stakeholder groups identified the following important characteristics of an internet-based Virtual Clinic: being grounded on personal needs rather than only providing general information; having the facility to communicate with, and learn from, peers; providing information on the latest developments and news in diabetes; being quick and easy to use. This paper discusses these characteristics in light of a review of the relevant literature. The development of a virtual clinic for diabetes which uses these principles, and which is based on self-efficacy theory, is described.

Conclusions: Involvement of stakeholders is a vital early stage in the development of a complex intervention. Stakeholders have clear and relevant views on what a virtual clinic system should provide, and these views can be captured and synthesized with relative ease. This work has led to the design of a system that is able to meet user needs.

KEYWORDS

Virtual clinic; diabetes; Internet-based; stakeholder consultation

Introduction

The development of the internet has created new opportunities for health care provision, including its use as a tool to aid self-management of chronic conditions. Diabetes is one such condition and there have been several recent studies of internet-based interventions [1-8]. These may be particularly appropriate for use with young people, and a number of on-line health interventions have been tested, including smoking cessation [9], eating-disorder prevention [10] and an electronic support group for young people with cystic fibrosis [11]. A report of a small study which pilot-tested the feasibility of allowing patients with type 2 diabetes to co-manage their condition from home [12] showed proof of concept. The Virtual Clinic concept studied here is such a system, aimed at people receiving care for diabetes from the UK NHS and enhanced by being based on the behavioural theory of self-efficacy [13]. A systematic literature review of behavioural interventions for adolescents with type 1 diabetes found those that were theoretically based significantly more effective than those that were not [14].

The aim of this research was to consult stakeholder groups and explore their perspectives on the desirable, important and feasible characteristics of an internet-based Virtual Clinic system for people with diabetes, and flag up any potential worries or concerns. This builds on a recently conducted survey of potential users [15]. Gathering stakeholder perspectives is a vital first stage in order to ensure that the system developed meets their needs [16]. It was envisaged that the Virtual Clinic would provide people living with diabetes, and their health professionals, access to the records of their condition (including uploaded blood glucose readings); a messaging facility; information and advice for patients; and a peer to peer support area, therefore meeting many of the criteria identified as desirable within internet-based diabetes management [17].

Methods

Several elements were used. First, 3 focus groups were held with people who used insulin pumps. These users were recruited from a local diabetes clinic and each group had between 3 and 5 participants. The total was 12 (2 male and 10 female). Groups were conducted at the Education Centre within the hospital at which the clinic was based, making a convenient and familiar location, although no health professionals were present at the groups. At each group a short demonstration was given to familiarise participants with the concepts we were planning to develop. The topic guide then focused upon: participants' initial reactions to the concept, the most and least important/useful elements, whether they would be likely to use such a system, factors that may facilitate or hinder use, what the benefits may be, and any concerns they may have. Sessions were audio-recorded and lasted an average of 1 hour.

Second, individual interviews were carried out with health professionals from the same clinic (2 doctors, 2 specialist nurses, 1 dietician) and with a representative from an insulin pump manufacturer/supplier who had emerged from the focus groups as an important source of information and support. The same

demonstration was given and the interviews used similar questions to the focus groups. All interviews were audio-recorded and lasted between 30 minutes and 1 hour.

Third, a process of e-mail consensus gathering was carried out with those using internet-based systems for other chronic conditions in order to gain their views on the potential system and their experiences of using other systems. A message was posted on discussion boards for conditions including asthma, epilepsy, mental health and insulin pump-users, and users were invited to contribute by e-mail. Fourth, an expert workshop was held at which invited delegates from the UK discussed the role of information technology in diabetes care. Delegates discussed the system proposed in small groups and completed questionnaires addressing the same issues as in the focus groups and interviews.

Data analysis was undertaken by the first and second author. Focus group and interview transcripts, e-mail responses from users of other systems, and the questionnaires completed during the expert workshop were all preliminarily analysed independently by each author and emergent themes identified. The two authors then held an analysis meeting at which the emergent themes identified by each were compared and discussed. Following agreement on these, the authors then undertook a full analysis of approximately half the transcripts each, with a small overlap to allow comparison of theme interpretation and allocation of data extracts.

Results

Six key themes, some with sub-themes, were identified from the data: (1) communication between patients and health professionals, (2) presentation of patient data and permanency of the record, (3) the importance and value of peer support, (4) an awareness of the personal nature of diabetes, (5) how an internet-based system would fit with current provision, including the impact on health professionals' time, and (6) that an internet-based system may not be suitable for all people with diabetes.

Communication Between Patients and Health Professionals

The facility to send and receive secure messages through an internet-based system was largely welcomed by all the stakeholder groups consulted, although there were some concerns. For health professionals, one of the key benefits was that the means through which they communicated with their patients outside of their face-to-face appointments would be more standardised. Having an asynchronous messaging system was seen to be beneficial as both parties could check their messages when it was convenient to them and fit this into their other activities, thereby saving a lot of time. This concurs with previous research [18,19]. For example, one health professional (HP) illustrated the time taken in trying to respond to a patient enquiry that had been left on the clinic answer phone:

I rang somebody and she said "I'm right in the middle of shopping in (town) can you ring me back?" so there's a lot of time that you spend sort of ringing them or I've got a school teacher and she's rang four

times today and I have rang her back several times and you know, eventually you get to talk but it might be a couple of days so I think quite a lot of our patients feel that its easier to e-mail us. [HP6]

Similarly, one of the focus group participants (FGP) explained how she had largely given up trying to seek advice through the clinic helpline as she found having to leave a message and then being called back simply unworkable:

it's so hard...you have to leave a message, they ring you back, you're in an open office so you can't talk, so you just bash your way through it and hope it's going to come out right at the end [FGP3]

Being able to send a message and receive a reply was therefore welcomed, so long as the system was adequately supported and health professionals did respond to messages received in a timely manner [20]. There were potential concerns raised by some members of the health professionals that the number of patient contacts would increase, and that the workload of the consultants would increase as most patient messages had previously been filtered by the specialist nurses. These were fairly minor concerns though and did not outweigh the perceived benefits.

Presentation of Patient Data and Permanency of the Record

One of the key advantages to the proposed internet-based system identified by health professionals was the benefit of having ready access to a patient's blood glucose readings. The advantages were two-fold: having up-to-date results readily accessible, and having results in a standard format. At present health professionals were often faced with results in various formats:

some of them might be too scribbled and not really very clear which times of the day those blood tests have been done on...But yes, scraps of paper might have sometimes...written in the corner, and you're trying to see the time of the day and sort of trying to make them in your head into date profile to some extent, so they can be a bit difficult yes. [HP2]

The permanency of the record was also seen as beneficial by health professionals as, in contrast to a paper diary, the readings would not leave the consultation with the patient and would still be available for review and reflection at a later date. The potential for use as a teaching and training tool was also raised. In contrast, patients were more divided on the benefits of uploading their results. Those who found recording their readings problematic welcomed anything that would make it easier and more convenient, but for others the system was seen to offer nothing new. However, all patients recognised the benefit of the health professional having access to their readings when dealing with queries.

The Importance and Value of Peer Support

In common with other research [2,21,22], one of the most valuable elements of the system identified by patients, and also recognised by professionals, was peer to peer support. Patients in particular identified two key ways in which such support would be useful. First, being able to pick up tips and suggestions

for managing their diabetes was viewed as beneficial, even for those who had had diabetes for some time:

but there are so many things that you can come across for the first time and the one I had to seek advice on was the flu injection last year, which caused chaos and I thought, 'well is this the flu injection or is there something else that I'm missing?'...but again a (discussion) board like this, just to push the question in and see what response you get back. [FGP6]

Second, being able to communicate with someone that understood what they were going through was very valuable, particularly for those who did not know others with diabetes, therefore demonstrating the potential of internet-based communication to move beyond the individual's usual sphere of contacts.

within my life, around work, around home and around socialising, I know no-one else with diabetes, so to be able to get on to an internet and sort of like to be able to have a chat with somebody...Even like you say, sometimes it might just be for a moan but sometimes you can get so frustrated with it that you just want to be able to take it all out...you want to be able to talk to someone but finding... you talk to your partner and you talk to your friends, but they don't always understand what you're saying. [FGP9]

The health professionals also recognised the potential benefits of peer to peer support for their patients, particularly the ways in which internet-based provision extended the group sessions currently offered at the clinic.

we have group sessions...and they are teaching each other what, from their experience that they've had and they'll be able to do that on a regular basis, on a daily basis, rather than on a three-monthly basis, and they'll all be there in the chat room, potentially, rather than just the people who turned up to the group clinic. [HP1]

However, there were some minor concerns amongst health professionals that the peer to peer support could lead to the 'propagation of myths' and to individuals passing on what had worked for them to those that it may be inappropriate for. It was generally felt that monitoring the topics under discussion would be sufficient counter these concerns. The issue of patients' awareness and appreciation of the individual nature of diabetes is discussed below. A recent systematic review of the effects of online peer to peer interactions [23] found no evidence to support concerns of them causing harm, although also failed to find robust evidence of health benefit.

Awareness of the Personal Nature of Diabetes

As stated above, one of the concerns health professionals had about the peer to peer support area was that patients using it may not realise that what had worked for one person may not work for others:

patients frequently want to propagate what has been good for them and it might not be good for everybody, if you know what I'm saying? They might have found

some particular way of dealing with situations...but it doesn't always apply to everybody. [HP1]

However, it was clear from the focus groups with patients that they were very well aware of how diabetes affected them personally, and that this may differ markedly between individuals. The knowledge and experience they had built up from managing their diabetes on a day-to-day basis was substantial, and they spoke at length about the need to evaluate suggestions posted on discussion boards in the light of their personal situation. The following is a typical example:

whatever I read on there may be useful but I know it's not individually designed for me. So overall it can be a useful guide when you start out but you really do have to know your own system don't you? [FGP8]

This ability on the part of potential users to appraise the information posted on a discussion board and evaluate whether it is likely to be helpful or useful to them, together with existing research demonstrating that most information posted on boards of this kind is accurate (or very quickly corrected by other participants) [24], indicates that the concerns voiced by health professionals are likely to be largely unfounded.

How an Internet-Based System Would Fit With Current Provision

The general consensus among the focus group participants and health professionals was that the proposed internet-based system would fit well with existing clinic provision. The system would provide a useful means of communication and support between routine clinic appointments and would bring benefits in terms of increased standardisation, more efficient means of communication, and extending the scope of current group consultations through the use of internet-based asynchronous discussion boards and real-time chat rooms. Some concerns were raised about a potential increase in health professionals' time taken dealing with messages received from patients, and this was identified as a potential factor which could hinder usage. However, the general consensus was that, in the local clinic at least, any additional time would be minimal and may well be offset through the time savings brought about by other benefits. This is one of the issues to be explored in a planned pilot study.

Internet-Based System May Not Be Suitable for All

The vast majority of participants in the stakeholder consultation raised the point that an internet-based system of the type proposed would not be suitable or appropriate for all people with diabetes. The main issue centred on the need for potential users to be comfortable with the required technology and to have a computer and internet access. It was suggested that this may limit potential users to those who were younger and therefore more familiar with new technologies, as supported by research by Giménez-Pérez et al [25]. However, a recent study by McKay et al [3] has shown that novice computer users will participate in an internet-based system to assist their self-management. A further concern, raised particularly by a health professional, was that the system could be unsuitable for those with a poor understanding of their condition or for whom diabetes is only one of many health problems.

Discussion

The research was successful in consulting stakeholder groups to explore their perspectives on the desirable, important and feasible characteristics of an internet-based system for diabetes. Involvement of stakeholders is a vital early stage in the development of a complex intervention, yet all too often their views are only gathered in the later stages. Stakeholders have clear and relevant views on what such a system should provide, and these views can be captured and synthesized with relative ease. In this case we identified 6 themes. These support findings from previous studies on the perceived convenience of an asynchronous messaging system [18,19], and the importance and value of peer to peer support [2,21,22]. They also contribute to debates about who is likely to use internet-based systems, and suggests that patients are eminently capable of assessing the advice posted by peers on a discussion board and relating it to their personal situation. Through basing the focus groups and interviews in an existing diabetes clinic, the research can suggest that an internet-based system is likely to fit well with existing care provision, and explore the likely impact on health professionals' time. This consultation has demonstrated that an internet-based system is attractive to these stakeholders and has led to the design of a system that is able to meet their needs. This is now being developed for use in a pilot study.

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Conflicts of Interest

None declared.

References

1. Ferrer-Roca O, Burbano KF, Cardenas A, Pulido P, Diaz-Cardama A. Web-based diabetes control. *J Telemed Telecare* 2004;10:277-281.
2. McKay HG, Feil EG, Glasgow RE, Brown JE. Feasibility and use of an Internet support service for diabetes self-management. *Diabetes Educ* 1998;24(2):174-179.

3. McKay HG, Glasgow RE, Feil EG, Boles SM, Barrera Jr M. Internet-based diabetes self-management and support: initial outcomes from the diabetes network project. *Rehabil Psychol* 2002;47(1):31-48.
4. Glasgow RE, Boles SM, McKay HG, Feil EG, Barrera M. The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results. *Prev Med* 2003;36:410-419.
5. McMahon GT, Gomes HE, Hickson Hohne S, Hu TM-J, Levine BA, Conlin PR. Web-based care management in patients with poorly controlled diabetes. *Diabetes Care* 2005;28(7):1624-1629.
6. Bellazzi R, Larizza C, Montani S, et al. A telemedicine support for diabetes management: the T-IDDM project. *Comput Methods Programs Biomed* 2002;69:147-161.
7. Gomez EJ, Hernando ME, Garcia A, et al. Telemedicine as a tool for intensive management of diabetes: the DIABTel experience. *Comput Methods Programs Biomed* 2002;69:163-177.
8. Cavan DA, Plougmann S, Hejlesen OK. Use of the Internet to optimize self-management of type 1 diabetes: preliminary experience with DiasNet. *J Telemed Telecare* 2003;9(S1):50-52.
9. Woodruff SI, Edwards CC, Conway TL, Elliott SP. Pilot test of an Internet virtual world chat room for rural teen smokers. *J Adolesc Health* 2001;29:239-243.
10. Zabinski MF, Celio AA, Jacobs MJ, Manwaring J, Wilfley DE. Internet-based prevention of eating disorders. *European Eating Disorders Review* 2003;11:183-197.
11. Johnson KB, Ravert RD, Everton A. Hopkins Teen Central: assessment of an internet-based support system for children with cystic fibrosis. *Paediatrics* 2001;107(24).
12. Goldberg HI, Ralston JD, Hirsch IB, Hoath JI, Ahmed KI. Using an Internet comanagement module to improve the quality of chronic disease care. *Joint Commission J Qual Saf* 2003;29(9):443-451.
13. Bandura A. Self-efficacy: toward a unifying theory of behaviour change. *Psychol Rev* 1977;84:191-215.
14. Hampson SE, Skinner TC, Hart J, et al. Behavioural interventions for adolescents with type 1 diabetes - how effective are they? *Diabetes Care* 2000;23(9):1416-1422.
15. Lowe P, Hearnshaw H, Griffiths F. Attitudes of young people with diabetes to an Internet-based virtual clinic. *J Telemed Telecare* 2005;11(S1):59-60.
16. Ralston JD, Revere D, Robins LS, Goldberg HI. Patients' experience with a diabetes support programme based on an interactive electronic medical record: qualitative study. *BMJ* 2004 May 15;328:1159-1162.
17. Mazzi CP, Kidd MA. Framework for the evaluation of Internet-based diabetes management. *J Med Internet Res* 2002;4(1):e1.
18. Tjora A, Tran T, Faxzaag A. Privacy vs usability: a qualitative exploration of patients' experiences with secure Internet communication with their general practitioner. *J Med Internet Res* 2005;7(2):e15.
19. Lin CT, Wittevrongel L, Moore L, Beaty BL, Ross SE. An Internet-based patient-provider communication system: randomized controlled trial. *J Med Internet Res* 2005;7(4):e47.
20. Car J, Sheikh A. Email consultations in health care: 2-acceptability and safe application. *BMJ* 2004 Aug 21;329:439-442.
21. Iafusco D, Ingenito N, Prisco F. The chatline as a communication and educational tool in adolescents with insulin-dependent diabetes. *Diabetes Care* 2000;23(12):1853.
22. Zrebiec JF, Jacobson AM. What attracts patients with diabetes to an internet support group? A 21-month longitudinal website study. *Diabet Med* 2001;18(2):154-158.
23. Eysenbach G, Powell J, Englesakis M, Rizo C, Stern A. Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *BMJ* 2004 May 15;328:1166-1170.
24. Esquivel A, Meric-Bernstam F, Bernstam EV. Accuracy and self correction of information received from an internet breast cancer list: content analysis. *BMJ* 2006 April 22;332(7547):939-942.
25. Giménez-Pérez G, Gallach M, Acera E, et al. Evaluation of accessibility and use of new communication technologies in patients with type 1 diabetes mellitus. *J Med Internet Res* 2002;4(3):e16.