Developing an Online Community for People with Diabetes: A New Zealand Case Study

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Abstract. This study examines the case for the development of an online community for people with diabetes using an analysis of the perceptions of a range of stakeholders in New Zealand. The case study examines three organizations and discusses the issues that affect the building and use of a dedicated virtual diabetes community. Results show a mixed response where members of diabetes support groups express enthusiasm for the concepts of the community while non-profit organizations and medical representatives articulate reservations. Suggestions are made for a framework that incorporates the ideas of all stakeholders.

Keywords : online community, diabetes, stakeholders, revenue model, facilities

1 Introduction

Healthcare is in the midst of a technological revolution. There have been significant advances in the use of information technology to support the effective delivery of healthcare including electronic health records, home care monitoring and improved information management. The use of virtual communities to support people with chronic diseases is an interesting development.

Rheingold [1] defines a virtual community as a result of "social aggregation" (p. 25) that takes place in the virtual world where prolonged discussions are carried forward by people to form a personal relationship with each other. Hagel and Armstrong [2], advocate the use of such communities within a business context, identifying the requirement for a member-generated context within online communities. They argue that content must be generated by members who share a common interest if a community is to develop and both businesses and customers are to gain advantage. The growing number of virtual or online communities has led to some confusion as to what is meant by the term. The common themes of sharing experiences, active participation, support and access to the resources are identified by Rheingold and Hagel & Armstrong. Therefore, this paper takes the definition of an online community to include a virtual space that is built on the surface of

trust, grown by the interaction of users and underpinned by a platform of sophisticated technology provided by computer systems [1, 2].

This paper examines the case for the development of an online community for diabetes within New Zealand. Although the Internet provides opportunities for communities to flourish across international boundaries, there is some thought that national environments may have an impact on members'perceptions of trust and understanding. New Zealand provides an excellent case study for national health studies as the country is geographically isolated, intensely patriotic, and has an ethnically diverse population, while the health service has a national database and services a relatively small population. Lessons drawn from a New Zealand case may be transferable to larger populations.

1.1 Use of the Internet in Healthcare

Use of the Internet in the healthcare industry is growing at a rapid pace with more and more users using social networking as a way of communicating their ideas [3]. Online health communities provide a virtual space where people can communicate with others, gain access to up-to-date information on a range of illnesses, have the opportunity to question expert practitioners and exchange experiences with their peers [4]. In other words, such communities can potentially provide expertise from the medical community, access to new research information and support from peer groups. A study by Harvard University identifies reasons why health seekers access the Internet and further illustrates the potential uses of an online health community (Table 1).

Table 1. Why health seekers go on the Internet:

93%	of health seekers say it is important they can get health information when it is convenient for them
83%	of health seekers say it is important to them that they can get more health information online than they can get from other sources
80%	of health seekers say that they can get this health information anonymously, without having to talk to anyone
16%	of health seekers said they had used the Web to get information about a sensitive health topic that is difficult to talk about

Source: Fox, Rainie, Horrigan, et al., 2001, p. 5 [5]

Fox et al.'s study [5] identifies people's preference for using the Internet to access information about particular health related issues rather than spending the time and money to visit doctors. In America, 80% of people prefer the anonymity of accessing information via the Internet. This adds weight to the argument that access to a resource such as an online community could enhance the ability of people to take a greater role in their health management and improve self efficacy [3].

There are many challenges to realizing the benefits from an online community. Firstly, there are no set rules that identify a community's quality, and perceptions of good or bad may be intensely personal. Secondly, online communities are a relatively new field; there is still a need for more research to be carried out to understand what benefits could be gained from membership. Thirdly, the success of an online community tends to be measured by two main factors: user friendliness and sociability [2]. The website designers therefore play an important role in providing an accessible site that members find easy to navigate and use. Lastly, the development of policies and protocols has been slow in some sites with unmoderated communities occasionally stifling interaction as one or two members try to force their opinions on others, leading to withdrawal.While online communities in no way replace medical care, there is growing evidence that social networking and peer group sharing of information has a positive effect on people's ability to learn about and manage the implications of chronic disease. To date there is little empirical evidence on how to best develop online communities that complement patients' medical care, alleviate demands on healthcare services and enhance the work of support organizations.

1.2 Diabetes in New Zealand

The five countries with the highest rate of diabetes sufferers in the world are India, China, USA, Russia and Japan [6]. New Zealand has an ethnically diverse population with large numbers in Asian and Pacific communities where diabetes is above the national average. Within some ethnicities in New Zealand, psychological and associated taboos may lead to feelings of isolation and reluctance to discuss a health condition. Furthermore, newly diagnosed patients perceive that they will get unwanted attention, which may be a source of irritation [7]. Statistics in New Zealand show that in 2006 the Ministry of Health reported that there were 125,000 people with Type 1 or Type 2 diabetes out of a total population of four million. They also estimate that there are a further 115,000 people with Type 2 diabetes who remain undiagnosed and who do not attend support groups [8, 9].

Online communities can support the needs of people seeking solutions to their problems [10]. This study examines the possibilities for people with diabetes to access an online community within a New Zealand context. In such a virtual environment, people can not only communicate (providing psychological comfort) but also access resources that promote self-management for their chronic illness.

The pilot study described here examines the potential of online virtual communities to enhance information access and social networking for people with diabetes in New Zealand. It addresses the need for more peer-to-peer channels of communication between people with diabetes and analyses the benefits and barriers of developing an online community from a New Zealand perspective. It examines issues of ownership, revenue models, facilities and governance.

2 Online Communities

Online communities appear to be categorized into two main types: business sponsored online communities and socially constructed communities. A business sponsored online community is constructed by a commercial organization with the purpose of enhancing customer experiences and ultimately to increase business profits. Customer 'buy in' is dependent on the firm's ability to offer a value proposition that encourages membership of the community. An example is the Lonely Planet community [11]. In contrast, a social online community is created with the purpose of interacting with like-minded people on various issues such as art, movies, culture and so on [2]. Health communities appear to be a mixture of the business and social online community, with the emphasis arising from the ownership model. Health communities facilitate interaction with other members but become business orientated when a pharmaceutical company or other for-profit organizations is an important stakeholder. This can result in the business sponsored model with the owner company including sales of their products to members [12].

A key reason for membership of an online health community as observed by many scholars is that it gives a platform to people to access up-to-date information [13-15]. The explanation provided for its popularity is the contribution of the members [1]. The quality of the content has to be appealing and from credible sources in order for the members to join the community [16]. A unique aspect of an online health community is the willingness of people to trust strangers to acquire information on various topics [1, 17-20].

2.1 Stakeholders of an Online Community

An online community typically comprises a community founder, community leader, moderators, members and business managers [21]. The community founder typically perceives success in the form of the community running smoothly. The community would not continue to exist if there are no people posting messages on the discussion board or resources being utilized [21]. The role of community leaders is to provide welcome to new members, to advise members in case of problems or give expert opinions. For community leaders, success appears to be the gaining of status within the community and the gratitude of members who post expressions of thanks to them for services that they render [21].

Moderators are evident in the majority of community sites. For example, in chat groups and discussion boards their main task is to maintain decorum in the online community [22]. They monitor postings to prevent members taking undue advantage of posting random views on the discussion board that do not pertain to the topic [23]. Success might be perceived in two ways for them [24]: Community members engaging in activities that do not disturb the flow of the community discussions and community members being happy about the amount of moderation being done in the community [21-24]. The role of a community

member is to interact with fellow members and to gain benefit from the resources made available on the online community for their benefit. They can measure success in a number of ways [21]. Firstly, access to appropriate information; secondly, a chance to interact with other members and gain social and emotional support and finally, the feeling of being wanted and a "sense of belonging" (p.15) [25].

2.2 Revenue Model

Revenue models for communities vary according to the ownership and target membership. Research into funding remains very limited although it is clear that business sponsored communities have significantly more funding than socially constructed sites [11]. Non-profit organizations' sites may often attract millions of members, but there are few organizations that have yet devised successful revenue models for these online ventures [26]. Revenue models for non-profit organizations may include businesses interested in sponsoring the site. Such stakeholders have an interest in these communities because of the opportunities to promote products to a targeted audience. This may have quality implications for the community in terms of perceived objectivity of information provided and advice given. To date there is a gap in the literature on research into revenue models and sponsorship for online communities.

2.3 Facilities

An ideal online community is one that facilitates positive interaction amongst its members and meets members' needs within the policies and protocols are laid out within the community [11]. Identified facilities provided in online health communities include bulletin boards, live chat systems, online doctor/dietician sections and often wikis or frequently asked questions. With the advent of new technology, a popular choice among many users appears to be the online doctor facility that enables members to interact with medical professionals online [44-47].

2.4 Online Communities for Diabetes

Diabetes is one of the leading causes of deaths in New Zealand [27]. Diabetes New Zealand, a non-profit organization for people with diabetes, estimates there are a significant number of undiagnosed cases of diabetes that would add twenty per cent to the figures estimated by the Ministry of Health in 2001. The NZ Government is planning to spend $540 million on Type 2 diabetes prevention and care in 2007/8 [27]. The high occurrence of diabetes in NZ is reflected worldwide. The number of deaths due to diabetes in the world has from "thirty million to two hundred and thirty million" in the last two decades [28].

The high incidence of chronic disease is reflected in the number of people

seeking health information online. A 2001 research project found that 93% of people reported that having access to health information online is very important to them [29]. Searches online reveal a very high number of online health sites, both informational and community orientated. For example, the Yahoo health-related portal has hundreds of healthsites listed with topics ranging from books on diabetes to personal experiences shared by people [30]. This indicates that the use of the Internet to disseminate information and social support to people with diabetes attracts significant interest and that a community site targeting people with diabetes in NZ may have potential to improve services for those diagnosed.

2.5 Theoretical Framework for an Online Community in New Zealand

A theoretical framework has been drawn up using a review of the literature to identify the themes. The themes are summarized in Table 2 with the key points and sources listed. The four main themes of ownership, revenue models, facilities and the webmaster are then drawn together to provide the framework.

The inclusion of the construct of moderators under the theme of webmaster arises from identification of the need for a focal point for the administration of policies and protocols with an online community. It is not clear either from the literature or indeed the pilot study whether moderators are administered by members, owners or the webmaster. What has been identified is the need for a webmaster to keep the online community site functioning and accessible and this theme has therefore been deemed to include the moderator role. The themes are summarized in Fig. 1. The framework in Fig. 1 is used to form the basis of the research analysis which is described in the following section.
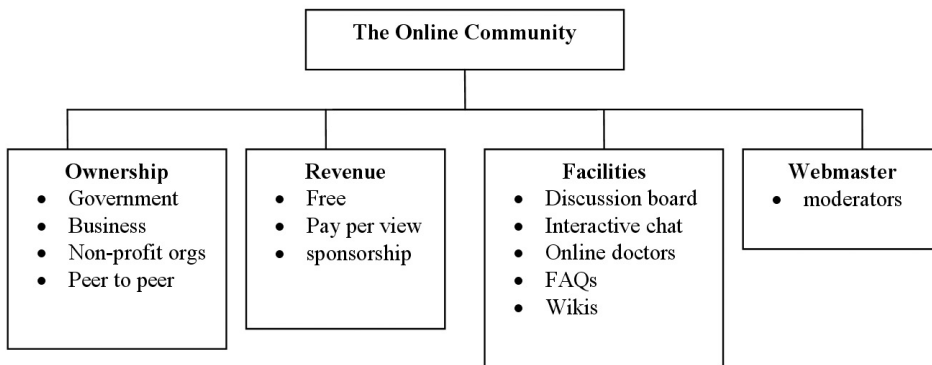

Fig. 1. Framework for an online community for diabetes

Table 2. Constructing the elements of an online health community

Themes	Constructs	References
Ownership/Stakeholders	Community founders: maybe commercial or peer groups. Range of motivations for establishing community	Lazar &. Preece (2002)
	Community leaders: take a lead in welcoming new members, may take role of expert opinion and encouraging ongoing interaction of members through judicious postings etc	Lazar &. Preece (2002); Preece, Nonnecke, & Andrews (2004); Preece, & Ghozati (1998); Collins & Berge (2000); Roberts (1998)
	Community members: Seeking information and emotional / social support from the community.	Lazar &. Preece (2002); Preece, Nonnecke, & Andrews (2004); Preece, & Ghozati (1998);
Revenue source	Free view: no membership fees but may require registration of members. No revenue gained from members although advertising may be present.	Mahadevan (2000)
	Pay per view: Certain areas of community may require some fees to be paid. For example download of information from published sources	Briggs & Hollis(1997); Hoffman & Novak (2000); ClickQuick. (1997)
	Sponsorship: the community costs are met through some form of funding agency or from commercial sources.	Haji & Neichen (2005); Mahadevan (2000) Briggs & Hollis(1997); Hoffman & Novak (2000); Chatterjee, Hoffman & Novak (2003)
Facilities on an online community for diabetes	Bulletin board: posting of notices within the community site. This may involve discussion threads or may have forums for different topics.	Preece (2000); Ridings & Gefen (2004); Butler (2004) ; Jones (1997); Suzuki & Calzo (2004)
	Interactive chat system: chatrooms established with posted times for specific discussion topics or groups within community.	Liu (1999); Ridings, Gefen, & Arinze, (2002)
	Online doctor/dietician: provision of healthcare information by a trained medical professional. Often takes the form of FAQs	Ferguson(2000); Freudenheim (2005); Yellowlees &. Brooks (1999)
	Wikis: accumulation of information from members of the community that forms a knowledge repository for the members. Models may involve only medical staff posting or all members having access to both post and read	Boulos, Maramba & Wheeler (2006); Castel, Figueras & Vigo (2006); Crespo, (2007); Rodzvilla (2002)
Web master/Support staff	Webmaster; responsible for maintaining the online space. Support staff may include moderators who may be paid staff or volunteers from the membership. Responsible for the smooth running of membership interaction and monitoring of abusive or other inappropriate postings	Preece, Nonnecke, & Andrews (2004); Preece, & Ghozati (1998)

3   Research Design

The research methodology adopted is qualitative with a focus on the case study method. The case study findings are researched based on informal interviews. Qualitative research has been chosen for three main reasons. Firstly, the "ontological" stance [48] (p. 50) depicts the technique chosen for the collection of the data. This means that the data collected is an ensemble of the observation that is recorded by the researcher in the field along with the interviews conducted with a variety of stakeholders. This actually helps us in understanding the "epistemology" (p.53) approach, which tells us whether the facts are real, and how we know about that [48]. Secondly, it is useful for exploring the opportunities of having an exclusive online community for people with diabetes in New Zealand that would promote cross-cultural interaction in a virtual space. Lastly, the research questions outlined earlier can be answered more effectively with this methodology. This is because qualitative research is ideal for scenarios where not much is known. It integrates the occurrence through the social context and utilizes 'deduction' as a strategy in research.

3.1 Data Collection and Analysis

Three organizations are chosen as case studies with multiple interview sessions conducted with each. The first of these organizations is a non-profit health related concern where interviews were conducted at managerial level and with a youth related subsidiary section. Further interviews were conducted within two of the diabetes support groups affiliated to the non-profit organization. The second organization was a hospital and the case study involved interviews with a panel consisting of medical professionals with an interest in diabetes. The final organization is a well known New Zealand health related website. Further data about these organizations was collected from their websites, magazines and national newspapers. The interviews were conducted in an informal style with the exception of the final organization where questions were requested prior to the interview.

   Thematic analysis was used to identify themes from the literature. The thematic analysis of the data was ongoing to provide an iterative cycle of analysis. Case study principles of validity and reliability are followed.

4   Discussion

In this section the findings from the case study interviews are examined vis-à-vis the theoretical framework as shown in Fig. 1. There are mixed results with the support group members supporting the venture and other key stakeholders responding with more measured enthusiasm and expressing concerns regarding the quality and authenticity of material that may be posted on community sites.

4.1 Ownership/Stakeholders of the Online Community

Two constructs that have been identified as important for members of an online community are common needs and common interests [2]. This study identifies a common need amongst some stakeholders interviewed, which is the exchange of up-to date information and research into diabetes that will be accessible to members at a central location. This need was evident amongst those interviewed who have diabetes. However, amongst the interviewees in administrative or medical roles the findings reveal a hesitation on the part of organizations to take ownership of such a venture for a variety of reasons.

The managerial members of the non-profit organization had reservations about the community as they were surprised that the model may be based on free-view revenue model. They argued that if there was an online community which allowed people to access information free of cost then there would be reduced need for members to consult their organization thus leading to a loss of revenue from existing membership fees. The representative from the youth related subsidiary did mention a possibility of having an online community for children who are generally regarded as more technologically savvy than adults. As children are not the fee paying members of the organization, there was little concern over the free view model within this group.

The group of medical professionals found the online community idea to be ambitious. They advocated a specific focus such as children or adults with either Type I or Type 2 diabetes. Another reason for them to be skeptical was maintaining the authenticity of the information to be posted on a community site. The panelists felt that the online community should be registered with the New Zealand Health Organization and only then would they support this venture.

Members and the manager of the New Zealand health related website were more enthusiastic with the concept of a dedicated diabetes community within a New Zealand context. They expressed support for any such venture, although the issue of information quality was raised as a potential concern.

All those interviewed in the case studies expressed resistance to the idea of having a pharmaceutical company being a stakeholder for the online community. There was consensus that this ownership model would carry quality implications and impinge on the building of trust.

4.2 Revenue Model

There was unanimous agreement from all sources that generation of funds for developing and running an online diabetes community should come from funding organizations who are able to sponsor such projects. The medical panelists were concerned that hospitals are devoid of funds for such projects and they advocated that other funding organizations would need to be approached. End users want the online community to be free of cost as that would attract more members. The free view model principle is based on the premise that the contents of the

online community can be accessed for free, although people must join as members in order to participate [31]. Many of those considered to be end users of the community (i.e. people with diabetes) were living on a disability or retirement pension and a free of cost model was relevant to their needs.

The manager of the health related website supported the idea of the free membership and free access to information. He substantiated his comments by further remarking that the number of users on his website has increased over the years and that was mainly because all the content on the website had no charge. The Internet is a rich medium wherein information can be accessed by a click of a button. There is a plethora of health information that can be accessed for free [41, 49-52]. Hence, having an online health community that requires people to pay to access information was not seen as an acceptable model.

However, the non-profit organizations had concerns with the no fee model for two reasons. The first was the impact on the revenue for the non-profit's offline facilities which offered educational classes, information, specialized food and books and other services. They further went on to state that the older population liked to have a hard copy of printed facts so the online community would be of no use to that segment of people. Although this latter point was not supported by the retired people in the study, there was no data available on how many of these had access to the Internet or how many were computer literate.

4.3 Facilities of the Online Community

The types of facilities identified from the literature were explained to the participants in the interviews to draw comments on how beneficial they might be to members considering the benefits of joining an online community.

The bulletin board is perceived to be the most important by all the cases. Bulletin board helps to get centralized information at one place and gives members an opportunity to ask questions of other members. These bulletin boards would be supported by interactive chat to provide emotional and social support of fellow members.

The facility of an online doctor as suggested in the literature was proposed in the interviews. This idea was not well received by the medical panelists. They feel that with an ailment like diabetes it is important to monitor the patient, for example take their blood sugar readings, and this is not possible through the Internet. Although there are examples of the concept of an online doctor being successfully implemented overseas [41]there was little enthusiasm for it except for the potential members of the community (i.e. those interviewed who have diabetes) and the NZ website manager. The former group agreed that a full time moderator from the health care industry could check the medical terminologies being posted by members, although this did have cost implications for the running of the community site. In the latter case, the website manager responded positively as his experience with the health community site indicated that people with chronic illnesses like diabetes do not need to meet doctors regularly. Individuals can

monitor the blood sugar content and send the report to the doctor via the Internet and can gain feedback through private conversations.The use of FAQs and Wikis are seen to be an important support for the provision of the virtual doctor. There are arguments that people with a chronic illness have the onus on themselves to take some control of their condition and merging self management with an online doctor facility could be beneficial [41-43]although further research on this issue is seen to be an important requirement.

4.4 Webmaster

There was little discussion of the role of the webmaster in any of the groups interviewed. There was a perception that someone would administer the online community site, but no clear distinction was made between the responsibilities of a webmaster and those of a moderator. The role of the latter was held to be important in the context of overseeing policies and protocols. There was some suggestion that the moderator should be have a medical background in order to support the monitoring of medically related material posted within the community.

4.5 The Perceived Need for an Online Community in New Zealand

There was consensus from the interview set that an online community for diabetes would be more acceptable within the context of a New Zealand focus. Although there was no discussion of the ability of one community to appeal to many demographic groups within the country, there was a clear perception that a national community was preferable to joining one overseas.

This was the only point of consensus between all the groups in the study. Overall, the administrators of the non-profit organization and the medical panelists oppose the idea of developing an online community for diabetes in NZ. The non-profit have yet to identify how to incorporate such a community within their own organization to meet the needs of their members. Despite this, the representative of the youth related subsidiary of the non-profit organization is keen and willing to join a venture targeting adolescents with diabetes. This seemed a legitimate stance as this age group likes to surf online as evidenced by the popularity of social networking sites such as FaceBook and Orkut.

The other opposing group, the medical panelists, appear to see the online community as a threat to the existing doctor-patient relationship. They feel that it may be easier for patients to go to the online community rather than visiting the doctor and that this would be detrimental to the patients' health. This is a particular risk with a disease such as diabetes that requires individual monitoring of a patient's condition. The medical professionals further perceive that the online community would substitute for their services rather than provide complementary support and that this would damage the patient-doctor relationship.

Support for an online diabetes community was found to be strongest amongst

the diabetes support groups and from the manager of the health-related website.

4.6 Suggestions for a future theoretical framework

The initial challenges identified by this research may be overcome by adopting a three-tiered approach to community development. The first tier could be the doctors where a platform is provided to exchange and brainstorm professional ideas regarding the treatment of diabetes. This tier is perceived as a Community of Practice for diabetes health professionals. The second tier of the community would be tailored to NGOs and the Ministry of Health and could serve as a bridging component between the doctors and the community members. For example, it could support an administration role that would include the collection of detailed statistics related to treatment of diabetes within NZ. The third tier would be the end users or those with diabetes who would have access to discussion boards as well as a wealth of data from diabetes specialists.

5   Conclusion

The study found diverse opinions on the need for an online community dedicated to people with diabetes, with little consensus on how it should be developed. Support group members are enthusiastic about the potential for social networking and exchanging of information. Age or gender was not found to be a factor in enthusiasm for the Internet. The study supports the need to devise solutions to overcome social exclusion issues. Medical staff are more concerned with the quality of information and had reservations regarding exercising control of content. Non-profit organizations expressed similar views together with concerns regarding selection of a suitable revenue model. There is a strong consensus that commercial sponsorship of a site would be undesirable, while government funding was not seen as a viable option. Interviewees had little knowledge of the different facilities currently used in online communities and existing overseas communities dedicated to diabetes.

   The main benefits of social networking and information sharing from membership of an online community are recognized by study members with diabetes. Enthusiasm was high but involvement with communities was low. Barriers to community development figured most strongly in responses from organizational interviewees in the study. Strong reservations as to the ability of community governance procedures to effectively monitor the quality of medical content and to control sharing inappropriate information was raised. They failed to identify any benefits arising from facilitating peer-to-peer interaction in this way. The pilot study shows that people with diabetes have great enthusiasm for the potential of social networking and sharing information and experiences using an online community that is relevant to New Zealand.

   The research is now examining a suitable online community model for people

with diabetes in New Zealand, including an analysis of the effects of different design and governance models, of ownership and the demographics of target membership. There are questions of what information should be shared and of how to integrate the 'gift economy' of Internet online communities with a need to make such sites self-financing.

6   Further Research

More concrete evidence is required to extend this pilot study to answer a range of questions that would arise from the development and use of an online community. Such questions could include:

- Would online health communities for diabetes actually help people in management of their disease?
- Would online communities influence or bring a change in the patient-healthcare provider relationship?
- Would online health communities be compatible/complementary with present healthcare system?

This study provides a road map for future research in this area by elucidating evidence in the needs for having an online health community for people with diabetes in New Zealand. The concluding section provides a suggestion for a theoretical framework of an online health community for people with diabetes in New Zealand, which would try to eliminate the barriers to setting up an online community.

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