

The role of sociability in developing online health communities for people with diabetes

Rosemary Stockdale, Kathryn Thompson

Institute of Information and Mathematical Sciences

Massey University, Albany, New Zealand

r.j.stockdale@massey.ac.nz

Abstract

The escalation in the incidence of chronic diseases has led to a significant number of people coping with conditions such as diabetes. The use of online communities to support patients in managing their condition is increasing as people seek information and emotional support from peer groups. This study examines the role of sociability in online diabetes communities and identifies key factors that contribute to the development of vibrant communities. It identifies key sociability factors that affect the commitment of owners and members to the community and enable people with diabetes to gain social networking benefits that enhance their ability to manage aspects of their condition. Early indications are that a vibrant sociable community can contribute to educating and encouraging people to maintain a higher degree of self management of their chronic disease.

1. Introduction

The incidence of chronic diseases across the world is increasing steadily with the escalation in the number of people diagnosed with diabetes reaching epidemic proportions. With nearly 4 million deaths per year worldwide, diabetes is one of the major health threats of our age [1]. The use of online communities to support individuals in improving their self management of chronic disease may be one way of alleviating some of the burden on healthcare services.

Two key elements of chronic disease management have been found to be access to information and provision of emotional support [2]. On diagnosis, people with a chronic disease such as diabetes first seek to learn more about their condition and then seek support to cope with the diagnosis. The Internet can be a key support tool in enabling people to search for information and to easily access peer support groups such as online communities. Online communities offer a range of facilities that meet members' needs including the most complex element of members' social needs [2]. While social needs include communication and involvement with other members, network quality, trust and norms of reciprocity [2,3] there is currently little understanding of how sociability can be created and supported in an online community. Examination of such communities to determine what makes them sociable will aid in the design and maintenance of an online health community that is able to educate and encourage people in the control and self management of their chronic condition.

This paper addresses the issue of sociability in online diabetes communities to facilitate their development and enhance and complement health care delivery. It first addresses what constitutes an online community before examining the key activities of information exchange and social networking by members within the context of chronic disease communities. The study then builds on a previous study of informational activity in online diabetes communities to undertake an analysis of the sociability aspects of such sites.

2. Characteristics of Online Communities

The terms online and virtual community are used interchangeably and are commonly used to refer to groups of people interacting through the Internet. Despite the frequent use of the terms and a broad understanding of what is meant by them a clear definition of either remains imprecise [4]. Kollock [5] includes the basic characteristics of ongoing interaction, identity persistence and memory of previous interaction in his clarification of meaning. He argues that interaction must continue regularly over time, a record of previous interaction be maintained and that members must maintain their chosen identities in order that recognition and trust can develop. This builds on Jones' [6] argument that the existence of group computer-mediated communication (CMC) is not, in itself, sufficient to establish existence of a community which requires recognition of the virtual space or settlement. The virtual settlement must exhibit four conditions to validate the existence of the virtual community:

1. Minimum level of interactivity
2. Variety of communicators
3. Minimum level of sustained membership
4. Virtual common-public-space where significant portion of interactive groups CMCs occur.

Further work contributes the need for common obligations and responsibilities [7].

Online communities are seen to have a number of advantages over face-to-face support groups including the potential to reach population groups that are traditionally difficult to access and cost effectiveness in disseminating information to large number of people. They are also accessible in terms of flexibility in time and location and enable a level of anonymity. Of particular importance to health community members is the lack of social cues that might be used to stigmatise or marginalise and this acceptance of the online persona often leads to a diverse, inclusive community.

Disadvantages of online communities are held to include the need to access technology and to have the requisite skills to use that technology. Also, where communication is text-based misunderstandings may easily occur with no visual cues that people rely on when interpreting dialogue [8]. Hostile postings are not uncommon [9] and may cause sociability to deteriorate. Moderation of interaction and adherence to common obligations and protocols overcomes much of this behaviour and can be used to promote positive dialogue, and foster an understanding of how to avoid misinterpretation to maintain sociability and longevity.

The virtual environment also bestows the ability to 'lurk' in online communities, taking and not giving back. Lurking behaviour is reported as having the potential to upset the balance of sharing or reciprocating necessary in gift economies such as the Internet¹⁰ where the norms of reciprocity are seen as an essential element of the social needs of an online health community [2]. However, health communities often acknowledge the lack of requirement to actively participate as an advantage to many who are able to take information and even emotional support from an online community without input [9].

2.1. Online Health Communities

There have been several studies into the benefits of online health communities. Fulfilling information needs and social networking are key activities of members of chronic disease communities [2]. The former activity is reported by Klemm et al [11], who found that both information seeking and information giving were prevalent in their review of research into cancer online support groups. There are concerns, particularly from the medical profession, about the quality of health information on websites [12] and the risk that patients may follow incorrect advice. One study on diabetes found that highly regarded sites provided trust mechanisms by which to assess the quality of information. These included providing details about controlling complications and modifying risk factors of the disease, identifying authorship and separating advertising from informational text [13]. Another study found that the main social support activity of a bulletin board from an Irritable Bowel Syndrome community was to communicate information. This information was particularly focused on how to interpret symptoms and manage the disease [9]. Again, the quality of information, its reliability or trustworthiness was perceived as very important, particularly where there is potential for a person to follow incorrect or dangerous information and to suffer physical harm [9].

Social needs and the provision of emotional support are the constructs that differentiates the online community from a purely informational website [2]. The interaction between members is a key feature of any such community [6] and social support is reported as having the ability to affect quality of life and mortality by encouraging people to take better care of themselves [14]. To encompass the meanings of social needs and social support, the term sociability is frequently used in examining these concepts in online communities. However, sociability features are not reliably identified and there are no standards and few techniques to evaluate sociability support and the perception of a successful online health community.

In one extensive study surveys were used to analyse member satisfaction with the social interaction component of a health community site to verify the 'success' of the community [15]. The measures of success for this online health community were identified as:

- an increase in registered member numbers
- a stable and active core community evolving
- an extended community as evidenced by lurkers
- reciprocity among members with offers of informational, empathetic or active support
- empathy and trust apparent in dialogue
- few violations of the accepted rules of behaviour
- continuity of core membership

Leimeister & Krcmar [15] also identified the need for perceived competence and goodwill in order to build the essential element of trust. This element of trust as a measure of success has been further addressed by Sillence et al [16], who conducted a longitudinal study to examine how patients determine which health websites to trust and which to reject. They identified a phased approach as people determine what sites they trust and further engage as deeper trust develops over time. The authors concluded that design and in particular home page design is essential to grab the attention of site visitors and make clear the motivations of the site providers. However, content is the key to engage visitors to a community site where people are motivated by illness to search out information not only from experts but from people who have experienced similar health issues to themselves. Participants preferred sites enabling them to connect to other people like themselves [16], supporting the identification of sociability as a key factor in the success of an online health community. Both these studies highlight difficulties in measuring sociability, with few techniques available and no benchmark of what is meant by excellence in sociability in online health communities.

Preece, Abras, & Maloney-Krichmar [17] found that in online communities, sociability overshadows usability, which is seen as a key success measure in information systems [18]. Ease of use is not a reliable measure when members' judgement of their community relates strongly to their social networking needs and ability to interact. To overcome this Preece et al [17] proposed a set of sociability heuristics for online health communities to aid in the development and evaluation of such communities while avoiding lengthy and costly evaluations. These heuristics include commitment by the provider and members of the community, discussion support mechanisms, policies and rules of behaviour, a clear purpose, capturing the history of previous interactions, and social representation tools to aid positive interaction. Adding other identified elements from the literature to these heuristics then informs the examination of what contributes to sociability in an online community. This will increase the facility of online health communities to meet the social needs of members and ultimately improve their ability to self-manage their chronic conditions.

3. Methodology

Qualitative heuristics is a methodology for discovery through exploration and introspection applied within psychology and the human and social sciences [19] and therefore appropriate in a study on sociability. Any examination of the sociability of an online community requires an examination of dialogue. This study uses sociability factors drawn from the literature to explore the discussion boards of online diabetes communities.

3.1. Data sample, collection and analysis

The data sample for this study is drawn from a previous research project that examined 90 websites aimed at people with diabetes [20]. That project took an objective quantitative approach to examining the information quality of each website with regard to the accuracy and completeness of information given on the sites. In contrast, this paper reports on the more complex of the two key activities that are held to be essential elements of a successful online health community; that of sociability. This requires a different approach to address the more uncertain nature of sociability and the lack of standards, identifiers or benchmarks that define what is meant by success in terms of this construct.

Preece et al's [17] heuristics are drawn together with the sociability factors from Leimeister & Krcmar [15] and Sillence et al [16] to contribute to a framework. These were styled into questions to provide an instrument, shown in Appendix 1, which could be used to empirically examine online health communities to assess their sociability. The key constructs used to categorise the sociability constructs are: discussion forums, commitment, policies, purpose, social representation, empathy and support, trust and privacy, and feedback.

An examination of the information-quality ranked diabetes websites from the previous study [20] identified 11 websites that met the criteria of an online community as defined from the literature. This was further refined to 6 communities following the piloting of the evaluation tool on 3 sites (a further two sites were abandoned as they displayed little activity). Details of the case communities are given in Table 1.

Table 1: The population studied

Community site	URL
BBC	www.bbc.co.uk/health
About.com	http://diabetes.about.com
WebMd	www.webmd.com
International Diabetes Institutes	www.diabetes.com.au
ADA	www.diabetes.org
Diabetes Mall	www.diabetesnet.com

The sites were examined over a period of four months to investigate their sociability and to identify commonalities that lead to a high perception of sociability. Consideration as to whether particular sociability factors contribute more to the health and life of such online communities occurred alongside this process. The reasonableness of the measure was then considered with the view that the instrument could be thoroughly tested in a larger project in the future if the reasonableness was found to have sufficient merit. Therefore, at this stage no procedures were put in place to ensure reliability and validity of the results through triangulation techniques particularly as only two researchers and a small population were available. For instance, the instrument would require greater consideration as to what constituted a high score at a micro level for each factor and testing with multiple evaluators to ensure validity through correlation techniques were it to be applied in a larger study.

4. Findings

The sociability quality instrument was used to examine each of the six named sites and the findings from the analysis support severally previously identified points from the literature. They also contribute to a clearer understanding of how sociability is supported with the constructs of an online community.

The sociability constructs from the instrument were found to interlink to a large degree and the findings have been grouped to reflect where there is considerable overlap.

4.1. Discussion Forums, Commitment from Owners and Members

With regard to the discussion forums, three of the case sites commit well to their online health community. In the case of WebMD, ADA and About.com, the forums are all easily accessible from the home page. About.com posts extracts drawn from the forum to the website's diabetes homepage alongside news article links thereby actively promoting the forum and indicating that information obtained from it is a valuable source of information. WebMd actively promotes its forum by stating that personal advice and encouragement from others is 'the best kind of support there is' and that such support can be found on the diabetes board. The language of all three sites is welcoming, inclusive and empathetic, indicating a high level of commitment from the owners. In contrast, the BBC, Diabetes Mall and IDI do not promote their discussion boards in any way either on the home page or within the forum links. Language on the site is less welcoming, empathetic and inclusive than that observed on the other sites. The community providers appear to do little to encourage community or improve the chances of people finding peers in order to interact to gain emotional support and exchange information. These are major reasons for people searching for and engaging with an online health community [16] and lack of such facilities would suggest a lack of sociability.

In the more encouraging sites the discussion boards are well structured by topic and visitors can quickly find their way to an area for the newly diagnosed, to information on how to use the forum, and to sources of informational, empathetic and welcoming support. This structure, particularly on a large board enables a member to find tailored content specific to their stage of the disease and thus a reason for committing to the community. Tailored content and personalised advice were reported as necessary for long term engagement to occur [16]. Well structured discussion forums support long term membership as they enable members to connect easily with others who know 'what they are feeling' and 'going through'. This may fulfil the particular needs of a newly diagnosed patients or it may support interaction for a long term member struggling to control side effects of the disease.

There appeared to be no relationship between the provision of information regarding statistical data, such as membership levels, number of postings and frequency of visits, and the vibrancy of the community sites. In IDI and Diabetes Mall it is possible to see how many people read and respond to messages and to establish how long a member has belonged to the community. The effect of this on the IDI site is to highlight an imbalance between the few messages being responded to and the high lurker population. Against this, the three most vibrant communities display little statistical information and it is difficult to gauge how long each community has existed or how many active members there are. In WebMd, one cannot see how many people view a post but only how many people respond to one, although the number of threads, responses, and unique user names suggest a sizeable community. While this makes it difficult to assess size, age, evolution and activity of the community, the lack of this information does not appear to influence sociability.

4.2. Purpose

WebMd has as their stated purpose that they provide a forum as an opportunity to share experiences with others and get relevant information back. They further state, "you are not alone". Such inclusive language directed to 'you', may well lead a person to believe that the forum provider has their best interests at heart. Indeed, the importance of clear purpose statements was emphasised by participants in a longitudinal study into why hypertension sufferers preferred certain online health websites over others [16]. Such inclusive and empathetic statements along with clear intentions to support sociability evidence goodwill and may go a long way to creating a climate of trust and a sense of belonging. About.com also uses more inclusive language stating that their diabetes discussion forum is a place "where you can get the inside story....about coping...from people who do". This is very different from the IDI community where a clear purpose statement was lacking, while the BBC and Diabetes Mall used a less empathetic tone than WebMD and About.com that suggested provision of information was more important than sociability on these sites.

Where forum providers support their community there were several example of unobtrusive, but effective commitment to the membership. For example on one community tools to personalise posts and establish profiles are available, although only taken up by a small proportion of members. On other sites, the providers ensure information for a new member is always readily available, and where the community asks for sticky threads these are provided. In these cases there appears to be a consequent effect on the sociability of the site as community members reciprocate in kind. They use friendly, welcoming and supportive language in posts to

each other. The tone and feel of these examples of online diabetes communities was very friendly and members often used their own names in their posts to sign off as well as their identifier or user name. Most dialogue can be seen as sociable with community members offering messages of support and empathy and sharing their tactics to control their chronic disease.

4.3. Empathy and Support and Social Representation

Core members who participate in the forums, and in particular that are active in welcoming new members, are easily observable and appear to be crucial to the tone and success of these forums. They are empathetic and giving and this in turn seems to encourage reciprocal behaviour. On one discussion forum for example, a member replies to a call for help from another member posting their first message to the community, "Hi Cindy, welcome to the boards... you and hubby. First take a deep breath ...you've found the right place for good information and I hope you'll continue to ask lots of questions..." This supports previous findings where new members getting assistance from experienced members ranked 4th of 26 factors as important to members [15]. This is in direct contrast to the lack of responses on the Diabetes Mall as shown by the following posting: "D Buzz is silent...hey people you can type questions, answers and gripe here. You'll be amazed how much experience and shared situations are out here, yet you have to speak...." Another comment on the same forum reads "76 views of this post and no replies?"

On the more responsive discussion forums there is greater evidence of support when core members admit to feeling angry or depressed. After posting messages expressing a need for some form of emotional support members often receive multiple messages including 'hugs' and bolstering comments. When regular members fail to post for a while worry messages can appear about their health and once they return to the forum they are welcomed back and told how they were missed. There has been much discussion in the literature over whether or not online health communities can improve health outcomes [21,22]. One example in support of good outcomes relates to the need for personal health management of diet and exercise for people with diabetes [13]. On the ADA forum in the 'meeting at Morris' home' thread direct evidence was observed that an online community may make a difference to patient well being. Each contributor included a ticker showing how far they had travelled from their home state en route to Morris' home or how much weight they'd lost since joining this motivational support thread to keep exercising towards a slimmer, fitter body. 'Mollythed' for instance had travelled 689 miles by bike with 1,313 miles still to go to get to Morris' home. Though not empirically founded, this example shows that where people form friendships online they can find the support base to commit to lifestyle changes to improve their health and well being.

Policies, Procedures, Trust and the Role of the Moderator The role of moderators on health community sites has not been extensively researched although policies and procedures that imply the use of some form of moderations are recognised in other online communities [17]. Moderators are not always visible on discussion forums although the lack of any adverse postings on some sites would suggest that some form of monitoring is taking place. The WebMD moderators were identified as staff and clearly identified along with explicit information about the type of information they could supply. Thus diagnosis or medical advice was not offered by moderators who were responsible for making information they consider topical available for discussion. They are responsive within these guidelines and contribute to sociability by ensuring new members are welcomed. In contrast the moderator on About.com, is medically qualified and biographic information provided on her own page. She is describes as guide and is active in promotion of topical issues and moving discussion forward. In contrast, the IDI site states that no moderation of the discussion forum takes place and the danger inherent in this approach was made obvious by the pornography links embedded in the site. This site had few posting and displayed very little evidence of sociability. The BBC discussion forum on health is stated to be pre-moderated. Although there are frequent postings, threads can get very argumentative. One exchange noted in the research period became very abusive but continued for over 15 days before being banned. This impacts on development of trust which is seen to be an important factor in the development of sociability. Where there are very detailed terms and conditions of use and also information on improving one's experience online, postings to discussion forums are seen to be more open and responses more common. It is not the appearance of moderation that contributes but the experience of the members and their subsequent actions that signal the presence of trust.

5. Discussion

Certain factors were highlighted by the iterative qualitative heuristic examination of the online health communities selected for study. In particular the findings show that where community commitment and efforts to develop trust were observed a stable, active, core community formed, with evidence of dialogue that was ongoing and sociable.

A level of commitment by both the provider and members is essential for an online community to form and become vibrant. Provision of the virtual space or settlement is not sufficient for a sociable vibrant community to evolve. Where the community provider gives a stated purpose for the site and promotes interactivity, benefits accrue and sociability is seen to flourish. Owner commitment can be demonstrated in a number of ways, which are found from this research to be visible management of discussion boards, publicising and ensuring that the rules of behaviour are followed and the creation of trust. Members who are exposed to pornography, inappropriate posts or subjected to tirades from other posters do not commit to the site and cease to interact with fellow members with consequent degradation in sociability of the community. These findings confirm the identification of commitment as an important sociability construct [17].

Structure in a new community is important. By providing structure community owners can promote a sense of a common personalised space to support quality discussions. New members need to be able to readily find the rules and purpose of the community and require clear intentional statements as to the purpose of the discussion forums. These statements need to demonstrate goodwill and support for the community and thereby encourage trust to develop and engagement to occur. Members need to be welcomed, understand what they can expect from the community and how they can participate in it. Structure is not specifically referred to in the sociability heuristics proposed by Preece et al [17] but is seen in this study to align with the quality constructs of policies, purpose and social representation and to include a specific role for moderators of the site (i.e. discussion support). This last point carries great weight in the development of sociability.

The quality of the discussion within an online community is crucial to its vibrancy and ability to generate new memberships. A sharing of specific experiences and knowledge by people with similar conditions and concerns may occur and trusting relationships form that provide the emotional support that is seen a key need of community members [2]. This requires support for members at different stages of their chronic condition. New members, often newly diagnosed, require reassurance and encouragement. One moderator was noted to be very active in greeting new members and ensuring they were welcomed and in another community, established members were quick to respond to new posters. In the same way longer term members will seek different information and support to a newly diagnosed diabetic and the community needs to provide space for these members with their different needs to find each other and interact. Empathetic and supportive friendly language invites responses of the same kind. Successful and vibrant communities have a core of active members available who often take on the moderator role themselves welcoming new members and sharing their experiences and knowledge voluntarily, setting the tone for positive supportive dialogue. Where degrading conversations occur early intervention is necessary to limit the damage they can cause to sociability either by the provider, moderator or members who have taken on a lead role.

The question of identity, raised by Kollock [5] appears to vary and is perhaps linked to the level of trust generated for members. In one forum the question of whether or not it was unsocial to use 'anon' in a user name was widely discussed with the consensus was that it was unsocial. This was particularly so when applied to the role of a moderator. Whether the moderator was identified by name or pseudonym, detailing their experience of the subject area and encouraging the use of unique identifiers appears to engender trust and in turn promote sociability. This also applied to members, where the identification of individuals that were active in the community was considered important.

However, there were indications that all communities have a high number of lurkers that are not identified by name or pseudonym. These are people who follow discussion boards, seek for information and appear to frequently visit an online community, but who do not contribute to interactivity. There are opposing views on the status of lurkers in health communities. There are communities where lurkers are acknowledged and to a certain extent welcomed in the hope that they will eventually become active members or are drawing support from their visits [9]. In other communities they are seen to have a negative impact. For example, if members are aware of lurkers, but find that few people are engaging in dialogue or responding to an enquiry they make, it

may well discourage them from further participation [10]. A new community may fail to form an active core while in an older community a core member could withdraw, feeling that they are getting little or nothing in return for their gifts to the community of information and support. The balance of reciprocity necessary for such online communities to continue is lost and the sociability declines. For example on one site, a member was seen to post a question that received no replies despite 732 people viewing the enquiry. This challenges the need of visible recordings of statistical information that is used as a success indicator for a sociable online health community [15]. Such data could have a negative impact on perceived sociability where a lurker may wish to be involved more actively in a community or a member fails to get a response to a query despite being aware of multiple views of their posting. Indeed Veale [10] had suggested a risk to sociability where if more people lurk, taking rather than giving to a community, reciprocity may not occur or may cease and the cycle of sharing necessary to successful online health communities may break. The commitment of members may wane.

6. Conclusions

Online communities are increasingly seen to make a significant contribution to the management of chronic disease and there is growing evidence that sociability plays an important role in supporting membership of such communities. Sociability is not easily measured and conventional metrics are of little use in determining its concepts. However, the use of the instrument detailing concepts of sociability including Preece et al's [17] heuristics confirmed that sociability is crucial for a successful, vibrant online health community to evolve.

Commitment by the provider and by the members is crucial to the quality and friendliness of the ongoing interaction within a community. There must be frequent interaction of an informative, supportive and caring nature for members to revisit. Rules of behaviour are necessary to ensure misunderstandings are avoided particularly in a medium where there are no visual and few situational cues as to intention and the community provider must check for breaches in these rules, and be prepared to take remedial action. There are a number of critical design elements that contribute to a successful online health community. These include discussion support, commitment by the community provider and members to the community, empathetic and supportive messages, and expressions of goodwill. Such elements foster trust and a sense of belonging. Where they were deficient sociability was found to suffer. In these cases, the community providers did not promote their sites or make clear what their purpose was in providing their discussion forums nor did they make any attempts to foster an active core of members interacting with appropriate language. Active participation was not encouraged and sociability was not evident in the interactivity of the members. In summary, key sociability factors that contribute to the evolution of a vibrant online health community include promotion of the discussion boards, management of the site, and moderation of interactivity between members. The use of empathetic, inclusive language, clear purpose and goodwill intentional statements encourages reciprocal behaviour by members. Good structure on the site, especially within the discussion forum enables like-minded people to find a common area to meet, interact further and encourages trusting relationships to form. While all of these things can be provided in an online health community, commitment by the members is also important. This enables an active core community to form and frequent participation enables established member to undertake mentoring roles and all members to form attachments that keep them coming back to continue participating and sharing their knowledge and experiences. Without sociability, it is unlikely that a vibrant online health community will become established and long lasting.

7. References

- [1] International Diabetes Federation. UN resolution caps momentous year for diabetes world. 2006. Available from: http://www.unitefordiabetes.org/press/releases/un_resolution_caps_momentous_year_for_diabetes_world.html. Accessed on 19 March 2007.
- [2] Stockdale R. Peer-to-peer online communities for people with chronic diseases; a conceptual framework. *J Syst Inf Technol*. 2008. (in publication)
- [3] Wang Y, Fesenmaier D. Modeling participation in an online travel community. *J Travel Res*, 2004;42:261-270.

- [4] Lazar J, Preece J. Social considerations in online communities: Usability, sociability, and success factors. In: H van Oostendorp, ed. *Cognition in a digital world*. Mahersh, NJ: Lawrence Erlbaum Assoc; 2003. p127-151.
- [5] Kollock P. The economies of online cooperation: gifts and public goods in cyberspace. In *Communities in Cyberspace*. London: Routledge; 1999.
- [6] Jones Q. Virtual communities, virtual settlements and cyber-archaeology: A theoretical outline. *Journal of Computer Mediated Communication*. 1997;3(3). Available from: <http://www.ascusc.org/jcmc/issue3/jones.htm>. Accessed 14 January 2007.
- [7] Preece J, Maloney-Krichmar D. Online communities: focusing on sociability and usability. In: Jacko & Sears, eds. *Handbook of human-computer interaction*. Mahersh, NJ: Lawrence Erlbaum Assoc; 2003.
- [8] White M, Dorman SM. Receiving social support online: implications for health education. *Health Educ Res*. 2001 Dec;16(6):693-707.
- [9] Coulson, N. Receiving social support online: an analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychol Behav*. 2005 Dec;8(6):580-4.
- [10] Veale K. Internet gift economies: voluntary payment schemes as tangible reciprocity. *First Monday*. 2003;8. Available from: www.firstmonday.org/issues/issue8_12/veale/index.html. Accessed 22 October 2007.
- [11] Klemm P, Bunnell D, Cullen M, Soneji R, Gibbons P, Holecek A. Online cancer support groups: A review of the research literature. *Comput Inform Nurs* 2003 May-Jun;21(3):136-42.
- [12] Malhotra R, Stockdale R. Online communities for people with diabetes; A New Zealand Perspective. *Proceedings of the 7th International Conference on Applications and Principles of Information Science*, Auckland, New Zealand, January 2008.
- [13] Bedell SE, Agrawal A, Petersen LE. A systematic critique of diabetes on the world wide web for patients and their physicians. *Int J Med Inform* 2004 Sep;73(9-10):687-94.
- [14] Barrera Jr M, Glasgow RE, McKay HG. Do internet-based support interventions change perceptions of social support?: An experimental trial of approaches for supporting diabetes self-management. *Am J Community Psychol*. 2002 Oct;30(5):637-54.
- [15] Leimeister JM, Krcmar H. Evaluation of a systematic design for a virtual patient community. *J Comp Mediated Commun*. 2005;10:29. Available from: <http://jcmc.indiana.edu/vol10/issue4/leimeister.html>. Accessed 25 March 2007.
- [16] Sillence, E., Briggs P, Harris P, Fishwick L. Health websites that people can trust - the case of hypertension. *Interact Comput*. 2007; 19:32-42.
- [17] Preece J, Abras C, Maloney-Krichmar D. Designing and evaluating online communities: research speaks to emerging practice. University of Guelph, 2004. *International Journal of Web Based Communities* 2004; 1(1): 2-18.
- [18] DeLone W, McLean E. The DeLone and McLean Model of Information Systems Success: A Ten-Year Update. *J Manage Inf Syst*. 2003;19(4):9-30.
- [19] Kleining G, Witt H. The qualitative heuristic approach: a methodology for discovery in psychology and the social sciences. *Rediscovering the method of introspection as an example*. *Forum: Qual Soc Res*. 2000;1(1). Available from: <http://www.qualitative-research.net/fqs-texte/1-00/1-00kleiningwitt-e.pdf>. Accessed 28 April 2008.
- [20] Seidman JJ, Steinwachs D, Rubin HR. Design and testing of a tool for evaluating the quality of diabetes consumer-information web sites. *Journal of Medical Internet Research* 2003; 5(4), e30.
- [21] Zrebiec JF. Internet communities: Do they improve coping with diabetes? *Diabetes Educ*. 2005 Nov-Dec;31(6):825-36

8. Appendices

8.1. Instrument to Assess the Sociability of Online Health Communities

Developed from: Preece et al 2004 [17], Leimeister & Kremer 2005 [15], Sillence et al 2006 [16]

SOCIABILITY QUALITY

Discussion Forums

- How often are new topics introduced?
- What types of questions are posted,?
- How natural and active are discussions?
- Do they resemble face to face dialogues?
- Dependant on topic is there variation in how deep discussion is vs. trivial and light?
- Is there evidence that topics are of interest or helpful?

Commitment: community

- Can posters be identified?
- Is there evidence that the community is growing membership?
- How does the community attract new members - are they welcomed?
- How does the community reach out to lurkers? (How do they show it is OK just to observe but encourage participation?)
- What evidence is there that members are in control of discussions not moderators?
- How regularly is information /topics/ updated?

Commitment: members

- What evidence is there that members visit frequently?
- Are they active?
- Is there an identifiable core of members?
- What evidence is there that individuals identify and revisit?
- In what circumstances do members participate in discussions - if a question is asked is a response always given, by whom, how quickly
- Are weak ties important, and strong ties not?

Policies

- Are there statements that feedback from other members is important and valued?
- Are policies clear, and easily accessible?
- What evidence of enforcement when necessary is there?
- What are the rules of behaviour?

Purpose

- What is the forums stated purpose?

- Is the purpose relevant to members?
- Does the purpose change and evolve?
- What evidence is there of evolution - first posts vs. later additions?

Social representation

- Are avatars and/ or photographs required?
- What evidence of a sense of belonging is there?
- Does the community adapt and change to fit changing needs?

Empathy and support

- What evidence of support is there - informational, empathetic or active offers of support?
- Caring atmosphere, responsiveness?
- What evidence of reciprocity is there?
- What is its nature?
- What tools do members have to individualise themselves - profiles, emoticons?
- What evidence is there that members have consistent identity?

Trust and privacy

- Would you call the discussions positive? Why?
- What security is in place -is there password access?
- What evidence that trust is felt that personal medical information is not shared with others inappropriately is there?
- What evidence of trust that the medical information is reliable is apparent?

Feedback

- What evidence is there of sharing of experiences among members?
- What evidence is there that moderators are not active in discussions except where discussions are inappropriate e.g. flaming?

Further observations

- Are moderators identifiable?
- Evidence that moderators are qualified?
- Is their experience and knowledge explained?
- How present are they?
- Reminders and cautions about need to seek personalised medical advice and dangers of acting on advice on pages apparent?