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3 **“Oh dear, should I really be saying that on here?” Issues of identity and**  
4 **authority in an online diabetes community.**  
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10 **Abstract**

11 We explore peer-to-peer discussions which took place in a UK-based diabetes ‘Virtual  
12 Clinic’ online community. In particular, we seek to understand the rhetorical nature and  
13 content of exchanges over a period of six months from the community’s inception. Data  
14 were captured weekly and analysis based on thematic discourse analysis. Two key  
15 issues emerged regarding how the community shaped the nature of the discussion  
16 forum. First, the identity of the forum was established, and boundaries drawn about  
17 what was, and was not, acceptable. Second, participants sought to present themselves  
18 as reliable and authoritative sources of information. Internet discussion communities  
19 are shaped in important ways early on by the community of users, including how the  
20 character and focus of discussion is formed, and how both information and users can  
21 be constructed as authoritative and reliable.  
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Keywords: ehealth; diabetes; internet; discourse;

## Introduction

The promise, or at least the rhetoric, of self-management by increasingly 'expert' patients has obvious attractions for health services needing to make cost-savings in the face of ageing populations living longer with chronic disease (Holman & Lorig, 2004; Department of Health, 2007). Self-management programmes generally aim to support healthy living by improving self-efficacy and health knowledge (Pearson et al., 2007). Diabetes is an area which has seen a plethora of initiatives in recent years and there is evidence that self-management can reduce long-term complications (Brownson et al., 2009). Diabetes is a chronic and debilitating disease characterised by an inability to regulate blood glucose levels adequately and its prevalence is rising rapidly. There are 2.8 million people currently diagnosed with diabetes in the UK (Diabetes UK, 2011). Day-to-day management is carried out almost exclusively by the patient and can often be complex and emotionally challenging, meaning that many do not achieve good control over their blood glucose levels. For patients to be effective self-managers of their diabetes they need to be provided with the information and support necessary to make informed decisions.

Interventions based on new technologies have the potential to support individuals to effectively manage their diabetes over a lifetime (Chen & Li, 2009). Technological innovations include interactive websites, automated telephone calls, touchscreen kiosks, mobile devices and DVDs (Piette, 2007), but have mixed results (Welch & Shayne, 2006; Costa et al., 2009). Initiatives that mobilize and build on online peer support have been described as a particularly promising way to improve self-management support (Heisler, 2010). For example, anonymous internet-based information exchange and interaction with other patients has been shown to be a key strategy providing autonomy and a feeling of control for young women with diabetes managing life transitions (Rasmussen et al., 2007), and posting messages in online

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3 forums has been shown to bring benefits relating to social support, information  
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5 exchange and sharing of experience for adolescents (Ravert et al., 2004).  
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10 In recent years the internet has become an increasingly important resource for health  
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12 consumers. A 2009 survey found that 70 per cent of United Kingdom households now  
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14 have internet access (over 18 million households), and 42 per cent of internet users  
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16 have used the internet for health information within the last three months, a significant  
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18 increase from 34% in 2008 (Office of National Statistics). Similarly, a survey conducted  
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20 in 2009 found that 74 per cent of United States adults use the internet, and 83 per cent  
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22 of internet users have used the internet for health information (Pew Internet and  
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24 American Life Project, 2010). Perceptions of the internet as a source of health  
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26 information appear to be changing. A survey of ehealth trends in seven European  
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28 countries found that in 2005 6.5% of the population perceived the internet as an  
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30 important source of health information, whereas by 2007 this figure had risen to 46.8%  
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32 (Kummervold, 2008).  
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38 As health-related internet use has grown, the sociological literature has considered  
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40 whether the informed e-consumer presents a challenge to professional dominance  
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42 (Hardey, 1999) or whether online health information continues to support a model of  
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44 biomedical authority (Fox et al., 2005; Nettleton et al., 2005). Research on peer-to peer  
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46 interaction in virtual communities suggests that these too can reinforce mainstream  
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48 discourses of medical knowledge (Fox et al., 2005; Sandaunet, 2008). At the same  
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50 time, they can address issues not dealt with (or at least not to individuals' satisfaction)  
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52 in traditional settings (Sandaunet, 2008; Schaffer et al., 2008).  
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3 The emergent body of literature on online health communities in general supports a  
4 model of 'empowerment within limits' where the individual user has the opportunity to  
5 feel more competent or in control through the peer-led exchange of information and  
6 emotionally supportive messages, within the cultural constraints of the particular  
7 community being accessed. Empowerment comes from information exchange (Fox et  
8 al., 2005; Coulson, 2005), emotional and social support (Bar-Lev, 2008), access to  
9 others in similar situations (Schaffer et al., 2008; Powell & Clarke, 2006), and other  
10 factors which facilitate user empowerment such as feelings of control and autonomy  
11 (van Uden-Kraan et al., 2009; Lemire et al., 2008). Through the sharing of experiential  
12 information, users can re-shape ideas of authoritative knowledge (Schaffer et al., 2008)  
13 and construct online identities as expert patients (Fox & Ward, 2006).  
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29 Online communities are not without their problems, though. For example, in addition to  
30 these positive outcomes, studies of computer-mediated communication have also often  
31 commented on the phenomenon of online hostilities of variable intensity such as  
32 disagreements, criticism or aggressive emotional outbursts (Burnett and Buerkle,  
33 2004) that can potentially cause stress and anxiety both for the interactants involved  
34 and other community members. If the potential benefits of online communities are to  
35 be most effectively harnessed then it is important to understand how they develop from  
36 the very early stages as the community's character is likely to be established relatively  
37 quickly and may then prove difficult to change. Understanding the processes through  
38 which a community's character develops highlights useful lessons that those setting  
39 up, or moderating, such communities could learn from as they seek to ensure they are  
40 as effective as possible at promoting information-sharing and supporting users to feel  
41 confident in their ability to manage their condition.  
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3 The vast majority of studies analysing peer-to-peer discussion fora have focused on  
4 publicly accessible websites, and have taken an opportunistic sample of online  
5 communication over a set period. This approach can be found in many contexts for  
6 both common conditions including diabetes (Ravert et al., 2004:), pregnancy  
7 (Fredriksen et al., 2008), and cancer (Gooden & Winefield, 2007) and rarer diseases,  
8 such as Huntington's disease and primary biliary cirrhosis (Coulson et al., 2007;  
9 Lasker et al., 2005). While this approach is helpful in exploring how an established  
10 discussion forum operates, the topics that are discussed, and the different ways  
11 individual users navigate the forum, it does not allow exploration of how the character  
12 of the forum is shaped by its users during the very early days of its existence, and how  
13 issues of identity and authority are established.  
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29 In this paper we explore precisely these issues by presenting data drawn from a  
30 purpose-built discussion board only available to known participants within a research  
31 project as part of a broader pilot study of an internet-based diabetes self-management  
32 tool. We demonstrate how the identity of the community was established early on by its  
33 users, and how this acted to shape the kinds of interactions and discussions that took  
34 place thereafter. We also discuss the important ways in which individuals sought to  
35 establish themselves as reliable and authoritative sources of information.  
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## 46 **Methods**

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48 The data presented in this article were collected as part of a wider programme to  
49 develop and pilot the Virtual Clinic internet-based self-management system for  
50 diabetes (author citation). This work consisted of three main stages: (i) a detailed  
51 consultation with a variety of stakeholder groups, including patients and relevant health  
52 professionals; (ii) a hands-on pre-test session with patients, followed by a focus group  
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3 to elicit their views; and (iii) a 6-month pilot study. This paper is based on data  
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5 collected during the pilot study phase.  
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### 9 ***Participants***

10 The study was reviewed and given a favourable opinion by the West Midlands Multi-  
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12 centre Research Ethics Committee. The particular group of patients we worked with  
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14 were adults who all used insulin pumps providing continuous subcutaneous insulin  
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16 infusion to manage their Type 1 diabetes. Participants were recruited by convenience  
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18 sampling, as is appropriate for pilot or exploratory work (Green and Thorogood, 2004),  
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20 from three UK hospitals in the West and East Midlands. Health professionals within the  
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22 three study sites issued recruitment packs to all eligible patients in their clinics. The  
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24 recruitment pack contained a letter inviting patients to participate and an information  
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26 sheet outlining the research and what participation would involve. All the participants  
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28 were over 18 years of age, had used an insulin pump for at least 6 months, could  
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30 communicate effectively in written and spoken English (we had no resources for  
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32 translation), had internet access, and reported they possessed basic computer literacy  
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34 skills. Patients were informed that participation was voluntary and that refusing  
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36 participation or withdrawing from the study at any time would not affect the standard of  
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38 care they received.  
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47 The study involved 17 patients who used the Virtual Clinic over a period of six months.  
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49 The study sample consisted of six males and 11 females and the age range of  
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51 participants was 22 to 70 years. All participants reported themselves as being of white  
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53 British ethnicity, with eight being educated to undergraduate level or above. All  
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55 participants described themselves as regular users of the internet, with 11 reporting  
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57 daily use, and most reporting using it more than once a week. On average,  
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59 respondents reported using the internet for 8.9 hours a week.  
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### ***The forum***

The Virtual Clinic tool had three main features: (i) secure messaging between patients and their health professionals; (ii) relevant links to further internet-based information and support; and (iii) asynchronous peer-to-peer discussion board, from which the data presented in this paper are drawn. The Virtual Clinic was password-protected and only available to the participants involved and those working directly on the study.

Participants in the pilot study were asked to log-in to the Virtual Clinic at least once a week, but were free to use the features within it as much or as little as they wished.

Data from the discussion board were captured on a weekly basis throughout the six-month pilot study.

The discussion board was not anticipatorily moderated; each message posted appeared without prior scrutiny. A system of reactive moderation was used in which the discussion board was regularly reviewed by the research team, and participants were encouraged to report postings they regarded as problematic. No such reports were made and review by the research team did not identify any problems. As a result no postings were amended or deleted during the study.

The suggestion that participants use the Virtual Clinic's features as much or as little as they wished and the reactive approach to moderation adopted, together mean that the 'social design' of the discussion board (Bar-Lev, 2008) was very light touch. This approach, in particular the lack of formal guidelines for usage, may have influenced the way in which the community developed and played a role in establishing the overall social atmosphere.

### ***Analytic approach***

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3 We use thematic discourse analysis (Potter and Wetherell, 1987; Braun and Clarke,  
4 2006) to apply insights from discursive psychology (Edwards, 1997) to the thematic  
5 categories identified in the online accounts. A distinct feature of thematic discourse  
6 analysis is the focus on both the rhetorical composition of themes and the  
7 accompanying assumptions (Peel et al, 2005). According to Potter and Wetherell  
8 (1987) the approach consists of two phases: a search for patterns in the data  
9 followed by analysis of the function or purpose of the identified themes. This  
10 process represents the 'latent' as opposed to the 'semantic' approach to analysis in  
11 that it 'goes beyond the semantic content of the data, and starts to identify or examine  
12 the *underlying* ideas, assumptions, and conceptualizations -- and ideologies -- that are  
13 theorized as shaping or informing the semantic content of the data' (Braun and Clarke,  
14 2006: 84, original emphasis). The approach has been adopted in various studies of  
15 health and illness discourses (Singer and Hunter, 1999; Peel et al, 2005), and has  
16 also proved useful in online social research (Walstrom, 2004).  
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36 In this study, thematic analysis of the discussion board postings was based upon the  
37 constant comparative method (Glaser and Strauss, 1967). Each message was read 3-  
38 4 times and open codes initially applied line-by-line in order to represent the meaning  
39 or significance of each sentence or group of sentences. The open codes were then  
40 incrementally grouped into organising categories or themes. These categories were  
41 then modified and checked constantly as further open codes were incorporated. The  
42 categories and their specifications (the coding scheme) were then programmed into  
43 the NVivo qualitative software. The coding scheme was used to process the dataset  
44 systematically by assigning each section of text to a category, according to the  
45 category specifications. The identified categories served as primary lenses for our  
46 analysis of identity construction through such socio-interactional business as  
47 establishing legitimacy and displaying competence (Edwards, 1997). We then turned to  
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3 discursive psychology to identify and describe the latter processes, as this approach  
4 enables a detailed examination of identity construction through the lens of  
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7 'accountability work' (Potter and Wetherell, 1987). In this way, discursive psychology  
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10 allowed us to deepen our analytical understanding of the legitimating and supportive  
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12 functions of participants' exchanges, indexed in the structural features identified via the  
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14 constant comparison method.  
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19 In following the discursive psychology approach, we examined how participants  
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21 created legitimacy and authority within the broader rhetorical and interactional  
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23 processes of eliciting, giving, and receiving practical advice and emotional support  
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25 (Harrison and Barlow, 2009). Such a non-cognitivist approach treats identities as social  
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27 phenomena; when people describe events, 'they attend to accountability. That is to  
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29 say, they attend to events in terms of what is normal, expectable and proper (Edwards,  
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31 1997: 7). Participants' replies (or next turns) were used for validating our interpretation  
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33 of an initial post/question (Seale, 1999). However, unlike previous analyses of  
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35 interaction in long-standing, well-established online fora, we did not focus on *individual*  
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37 narratives per se but instead attempted to explore how the discursive management of  
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39 participants' identities might have contributed to, and have been influenced by the  
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41 emergence and maintenance of the group's *collective* identity. Here the classification  
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43 of features characterising an online group as a community, namely *identity*, *sociability*  
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45 and *support*, is particularly apposite (see Herring, 2004). Active participation and  
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47 continuous interaction of its members (*sociability*) allows an online group to develop  
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49 shared norms and values as well as create an awareness of its distinguishing features  
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51 (*identity*). By demonstrating solidarity and reciprocity and following any existing as well  
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53 as emerging social participation guidelines, members can then maintain the group  
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55 (*support*) (Herring, 2004). From this perspective, online discursive community is seen  
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3 as first and foremost a 'mutable construct, determined by social actors who create  
4 meaning about it' (Fernback, 2007: 66).  
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## 9 **Findings**

### 10 ***Topics discussed***

11  
12 The discussion board was active throughout the six months of the pilot study, although  
13 usage as a whole gradually declined over this period. In total, 34 distinct discussion  
14 threads (by which we mean a series of related communications on a particular topic)  
15 were created with a total of 219 individual messages posted across these. The  
16 discussion board emerged as the most valued feature based on both qualitative and  
17 quantitative user feedback (author citations).  
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29 The issues discussed centred around three core areas. Firstly, and as to be expected,  
30 there was a substantial focus on issues related to diabetes self-management. These  
31 discussions tended to revolve around the challenges faced by participants in achieving  
32 and maintaining good control of their blood glucose. Blood glucose levels featured  
33 prominently as an indicator of control in many of the messages posted as participants  
34 reported unexpectedly high or low levels and described (sometimes at length) their  
35 attempts to understand the symptoms they were experiencing and regain some feeling  
36 of control (Charmaz, 2000). Secondly, participants were also keen to receive  
37 information about and discuss new possibilities or future treatments. These could be  
38 new developments per se (such as possible new treatment options or medical  
39 advances that might be on the horizon), or simply things they had not yet experienced  
40 themselves to date. In the latter case, participants were particularly keen to hear from  
41 other users who may have had diabetes for a longer period or have experienced  
42 complications that they themselves could see approaching. Thirdly, a distinct group of  
43 threads involved coping psychologically with diabetes, for example sharing and  
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3 exchanging ideas about how to 'look on the bright side' and see the possible 'silver  
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5 linings' of the condition.  
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### 8 9 ***Developing the community's identity and boundaries***

#### 10 *Diabetes-focused, with no space for purely social interaction*

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12 There was a relatively clear distinction between a small minority of, typically younger,  
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14 participants who initially appeared to want the discussion board to act as a general  
15  
16 social interaction space and the majority who were simply concerned with discussing  
17  
18 diabetes-related issues. Those that fell into the former group created and participated  
19  
20 in a small number of discussion threads in the very early days that were designed  
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22 specifically to find out more about others as individuals rather than just as people who  
23  
24 had diabetes. However, these were often not replied to and stopped appearing as the  
25  
26 days and weeks passed. In contrast, frequent postings on practical issues of diabetes  
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28 management received positive appraisal:  
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35 *RE: Welcome to the Virtual Clinic!*

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37 *What a lot of activity since I last logged on. All very useful info and views.*

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39 (Participant 1, male)  
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44 Although emotional support was also acknowledged, the most common way of  
45  
46 expressing gratitude was to thank other participants for their 'informative' replies.  
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48 As a result, the discussions that took place within the community came to focus solely  
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50 on diabetes-related issues.  
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#### 53 54 *Creating and maintaining solidarity and support*

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56 Although active social interaction was implicitly discouraged, participants developed  
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58 different ways of eliciting social information during their diabetes-specific interaction,  
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3 which allowed them to conform to the unspoken rule of prioritising informational  
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5 exchange. One member, for example, posted a series of diabetes specific questions  
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7 followed by a question about the name of one's pump:  
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12 *QUESTIONS FOR YOU? PLEASE ANSWER*

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14 *What insulin do you use? What is your TDD? What is your Carb/Insulin Ratio?*

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16 *What is your pump called?*

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18 *Me:*

19  
20 *Humalog*

21  
22 *about 26 units*

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24 *1:20g cho*

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26 *satan*

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29 (Participant 13, female)  
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34 The question attracted a number of replies, most of which were phrased using the  
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36 same strategy of mixing diabetes-specific information with more personal disclosures.  
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40 As posts increased in number, participants started to use different interactional  
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42 resources to construct their experience as 'shareable', such as making oblique  
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44 references to comparable experiences and prior speakers.  
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49 *RE: Welcome to the Virtual Clinic!*

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51 *Great here [to hear] from you all. Seems that the going is a bit rough for some of*  
52  
53 *us. Let's hope that sharing problems will help.*

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55 (Participant 1, male)  
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3 This, in turn, may have gradually contributed to creating and strengthening the group's  
4 solidarity. For example, the following comment begins with an appreciation of a  
5 previous participant's story, and proceeds to stress the benefits of participation for 'the  
6 newcomers':  
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14 *RE: The Weather*

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16 *What can I say except that your diabetic history, problems, hopes and aspirations*  
17 *(the read and adjust gadget, when it comes) sound just like mine. [...] Hopefully*  
18 *the newcomers will benefit by getting advice that no-one else can give them,*  
19 *except people who've been there, done it, and got the hospital gowns. (20 years*  
20 *ago) and the pump (now).*

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27 (Participant 9, male)  
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32 Participants also repeatedly emphasized the reciprocity of mutual help, which allowed  
33 them both to express their gratitude and demonstrate their own contribution in assisting  
34 others. This rhetorical work, referred to as 'the rhetoric of gratitude' (Arminen, 2001),  
35 seemed to have functioned as an important social glue that might have facilitated  
36 participation in this community from its inception onwards. One of the indicators  
37 pointing to this effect was an increase of newcomers who might have 'lurked' for some  
38 time on the forum trying to learn the local interactional ropes before deciding to  
39 contribute. Approximately a month after the start of the group, both existing and new  
40 members began to post more personal questions that can be seen as potentially  
41 compromising their identity as 'sensible' or rational individuals. The following question  
42 about having children with diabetes is an example:  
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57 *Diabetes and Pregnancy*  
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3 *Hello. . . . Ok! This has taken some guts to start this, but i've got sooooo many*  
4 *questions that I would love answers to but always clam up when I start asking*  
5 *them when I go to clinic. So . . . I'm hoping people on here can give me some*  
6 *answers etc. [...]* Ok . . . here goes (congratulate me on my bravery)  
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11 (Participant 16, female)  
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16 The above post contains a number of hedging devices used to demonstrate the  
17 author's feelings of insecurity about participation and expectations of this group.  
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19 Although we have no direct evidence, it may be plausible that earlier discussions on  
20 this site made the person feel safe (Mitra, 2006) as they had been observing the spirit  
21 of 'togetherness' and good natured expressions of mutual support and respect.  
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29 Overall, through references to shared experiences and the rhetoric of gratitude this  
30 discussion forum started to function as an interactional mechanism for enabling and  
31 fostering the exchange of practical information and support. As one of the participants  
32 stated in his 'goodbye' post: 'I think the beauty of this forum has been to remind us that  
33 we're not on our own. Don't ever give up!'  
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#### 42 *Testing the limits*

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44 One of biggest rhetorical challenges faced by people who consider participating in an  
45 online group is demonstrating their legitimacy – that their discursive contributions are  
46 genuine and valid. Other studies have shown that when joining a long established  
47 online forum participants draw on their history of disease, past experiences, and/or  
48 tailor their posts to the most discussed topics to legitimate their claim for the group's  
49 attention (Gallagher et al, 1998). In this study we had an opportunity to examine how,  
50 in the absence of prior discussions, the very first posts served simultaneously to create  
51 legitimacy and test the limits of what can or cannot be discussed. In his first post, one  
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3 participant starts by outlining his medical history to legitimate his contribution to this  
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5 diabetes-focused forum.  
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10 *RE: Welcome to the Virtual Clinic!*

11 *I am 59 years old and have been brittle insulin dependent type 1 diabetic for 29*  
12 *years. I have always, with great effort, managed to get good HBA results but,*  
13 *being averages, the HBA results do not show the often wild blood sugar*  
14 *fluctuations I suffered before using an insulin pump. To clarify, BG readings of*  
15 *2mm and 11mm are obviously bad news, and yet they give an "average" of*  
16 *6.5mm, often described to me as "excellent". One could only wish that the*  
17 *Doctors concerned could try out this "excellence" for themselves.*

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27 (Participant 9, male)  
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31 With the help of this story the participant presents himself as a person who, despite the  
32 difficulties, is able to manage his condition (*'with great effort, managed to get good*  
33 *HBA results'*). After undermining potential assumptions regarding a lack of competence  
34 in interpreting *BG readings ('2mm and 11mm are obviously bad news')*, the participant  
35 proceeds to introduce a thinly veiled criticism of 'the Doctors'.  
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44 This reference to prior interaction with medical authorities was quickly picked up and  
45 expanded upon by other members on this 'introductory' thread:  
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51 *RE: Welcome to the Virtual Clinic!*

52 *I sometimes wonder whether the experts have got their lines crossed as some*  
53 *will tell you that the peaks and troughs are all important, others that it is only the*  
54 *3 monthly HbA1c that is significant. How can anyone avoid the ups and downs, I*  
55 *ask?*  
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3 (Participant 1, male)  
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8 In some cases, participants involved in posting what they were aware were likely to be  
9 seen as 'unorthodox' views or behaviours took steps to actively draw attention to this  
10 and questioned whether it was suitable for discussion within the community. In the  
11 following example, after the original posting, another member of the community  
12 responded to sanction or legitimise the view expressed in the original message, and to  
13 encourage the further free expression of views:  
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16  
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18  
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22

23 *RE: Welcome to the Virtual Clinic!*

24 *I managed to keep blood sugars between 4 - 8 by testing my sugar about 14*  
25 *times per day, even twice at night and ate next to nothing. Very low carb meals.*  
26 *yeah, EXCELLENT control but NO LIFE.... that's just not cool. So it can be done,*  
27 *but it's booooooring. It's ideal though, go low carb about a month b4 your HBA1C*  
28 *and hurrah, good result and no telling off from your doc!! \*oh dear, should I really*  
29 *be saying that on here????\**  
30  
31  
32  
33  
34  
35  
36  
37

38 (Participant 13, female)

39 *RE: Welcome to the Virtual Clinic!*

40 *You should say EVERYTHING on here, perhaps if enough of us shout then*  
41 *maybe people will listen...SO KEEP SHOUTING - let's all make a noise.*  
42  
43  
44  
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46  
47

48 (Participant 9, male)  
49  
50

51 As the community developed over time, the limits on what points of view could be  
52 expressed began to be tested, established and policed. One of the most obvious  
53 examples concerned whether participants were 'allowed' to identify themselves as not  
54 always strictly following prescribed courses of action in relation to their diabetes self-  
55 management. Common examples of this concerned individuals' personal admissions  
56  
57  
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3 of knowingly not always doing the 'right thing', which is a way of attending to  
4  
5 accountability by carefully balancing the presentation of 'deviant' cases and their  
6  
7 justifications. The following is a typical example of this:  
8  
9

10  
11  
12 *RE: End of cartridge highs*

13  
14 *Thank God I'm not alone and other people are pretty 'naughty' on not changing*  
15  
16 *cannulas as often as we should. When it's in a comfortable spot it's such a bitch*  
17  
18 *to think of changing it. I usually go 3/4 days to be honest but I know for a fact that*  
19  
20 *on some sites (usually where it's been uncomfortable from the start) it definitely*  
21  
22 *affects the rate at which the insulin's absorbed. I think your problem could be*  
23  
24 *changing the cannula more often.*  
25

26  
27 (Participant 12, female)  
28  
29  
30

31 Here the participant demonstrates her awareness that the first sentence of her post is  
32  
33 potentially controversial as it refers to the transgression of established norms. She  
34  
35 therefore proceeds to account for the lapse (2nd sentence). The final two sentences  
36  
37 function to present the participant as someone knowledgeable and in control as well as  
38  
39 enable the provision of indirect advice. Below we will explore this strategic use of  
40  
41 personal stories in more detail,  
42  
43  
44  
45

### 46 ***Doing identity work within established boundaries***

47  
48 It was particularly interesting to study how the interconnected processes of identity  
49  
50 building and advice giving proceeded in this newly established community, where  
51  
52 'everything should be said' despite the awareness that their talk will be studied by  
53  
54 researchers.  
55  
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2  
3 Perhaps in adhering to the earlier assertion that the forum is a legitimate place for  
4 expressing 'unorthodox' views, some of which involved blaming 'professionals' or  
5 questioning and contradicting medical advice, some participants contrasted their  
6 experiential knowledge and/or professional experience with biomedical expertise. The  
7 following example relates to a post concerning the effect of diabetes on pregnancy:  
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15  
16 *Diabetes and Pregnancy*

17  
18 *Firstly, I'm in no rush to have children (but) my ultimate worry is diabetes*  
19 *affecting my ability to have 'healthy' babies, and the complications that I will incur*  
20 *etc etc. It's all the things you read, like if you plan to have a baby you must tell*  
21 *your specialist a few months before to get stable sugars, and then during the first*  
22 *few weeks your blood will go mad and you have to keep it stable. Then there's*  
23 *the bit about the baby getting really big, and recently there was something about*  
24 *babies being born having a dependency on insulin. Also years ago a nurse told*  
25 *me I would never be able to give birth I would have to have a c section . . . I've*  
26 *just got sooo many questions and I just need anyone who has either gone*  
27 *through it, or knows any words of wisdom to put my little mind at rest.*

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38  
39  
40  
41 *Thank you (pew)*

42  
43 *(Participant 16, female)*

44  
45 *RE: Diabetes and Pregnancy*

46  
47 *Hi, just some input on this cos I have my own child and I work in a special care*  
48 *baby unit so see a lot of babies from IDDM (Insulin-Dependent Diabetes Mellitus)*  
49 *mothers. I found that the first 2 months of pregnancy were the worst and I*  
50 *couldn't believe how unstable and fragile I was, after that things just kinda fell*  
51 *into place and all went well until 35wks when I delivered [child], normally. Healthy*  
52 *and well. From a prof point the things to keep in mind are that the more stable*  
53 *your BGs are the less likely you will have problems. Diabetics always have*  
54  
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3 *bigger babies and it's no good keeping your BGs too low cos this can lead to*  
4 *problems with the baby. The other thing is when you do go into labour make sure*  
5 *you get to hospital ASAP as this can be the most dangerous time in any*  
6 *pregnancy esp when you are IDDM.*  
7  
8  
9  
10

11 (Participant 15, female)  
12  
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16 Here Participant 16 is explicitly interested in hearing from others who have 'gone  
17 through it' and in this way is seeking descriptive accounts rather than direct advice and  
18 evaluation ('what was your experience?' rather than 'Is this the right thing to do?'). In  
19 response to such an interactional environment, participant 15 carefully manages her  
20 response by using a softener ('just some input on this') followed by a short story  
21 drawing on her own experience as a mother but additionally highlighting her  
22 experience of working on a special care baby unit (although she does not specify in  
23 what capacity). In addition to functioning as a politeness strategy of demonstrating  
24 empathy and enabling indirect advice giving, the short one-sentence story ('I found  
25 that...') also helps to construct the participant as experientially knowledgeable. The  
26 participant then switches from personal to professional source of expertise using the  
27 phrase 'from a prof point of view' to bring in the biomedical discourse and  
28 accompanying factual references ('diabetics always have bigger babies').  
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A small number of users presented themselves as authoritative and knowledgeable through references to their activity and research in the area of diabetes, and by emphasizing that they went to great lengths to keep themselves well-informed and up-to-date with medical knowledge and new developments. They were frequently keen to share this knowledge with others and typically had their input, judgement and evaluations accepted and valued by others. The extract that follows, in which one

1  
2  
3 participant asks for (and receives) feedback on the demonstration of a new piece of  
4  
5 equipment, is an excellent example:  
6  
7  
8

9  
10 *Continual Monitoring Pump*

11 *Does anyone have any feedback on the continuous monitoring pump that was*  
12 *demonstrated at [Hospital Name] a couple of weeks ago. I couldn't make the*  
13 *meeting and am intrigued to have an update and opinions.*  
14  
15  
16  
17

18 (Participant 12, female)

19  
20 *RE: Continual Monitoring Pump*

21 *The Continuous monitoring pump was the [product name], see [weblink].*  
22  
23 *However, also see [weblink] and notice the difference between UK and US*  
24 *[product] prices, about 4x as much. Note that the unit has to be calibrated (with*  
25 *ordinary BG tests) twice a day and 'no CHO or insulin action should be taken*  
26 *without BG test verification' which seems to make the whole thing a waste of*  
27 *time. It is, however, the cost of sensors which kicks the whole thing into*  
28 *touch...Also independent tests at Diabetes Mail confirm that it ain't very accurate,*  
29 *see [weblink] Oh well, maybe in the future...*  
30  
31  
32  
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34  
35  
36  
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38  
39

40 (Participant 9, male)

41  
42 *RE: Continual Monitoring Pump*

43 *Cheers [name]. Don't think I'll even bother taking a look on the website. I thought*  
44 *we were getting a little closer to a pump that measured BGs and reacted*  
45 *accordingly. Do I dream or what!!!!*  
46  
47  
48  
49

50 (Participant 12, female)

51  
52  
53  
54  
55 In this case, Participant 9 demonstrates his expertise by drawing on a range of sources  
56 to support his assessment of the situation. Participant 12 is apparently so persuaded  
57 by the assessment of the new technology that Participant 9 has provided she does not  
58  
59  
60

1  
2  
3 feel the need to undertake any further research on the topic herself even though he  
4  
5 has provided her with links to the websites to which he has referred.  
6  
7  
8

9  
10 A final, but less common, strategy was for a participant to claim some form of  
11 professional recognition for a perspective that they had developed and advanced. The  
12 following extract is a particularly powerful example in which one individual describes  
13 how he had noticed a correlation between episodes of severe hypoglycaemia (low  
14 blood glucose) or 'hypos' and sudden and severe drops in the temperature.  
15  
16  
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22  
23 *RE: The Weather*

24  
25 *29 years ago when I first became unstable diabetic, trying to stay upright was far*  
26 *more difficult, as there were no home blood-testing kits and severe hypos were*  
27 *thus far more frequent. After the first 3 A&E visits (in as many weeks) I couldn't*  
28 *understand what I had done wrong, having stuck religiously to what 'rules' there*  
29 *were. Then I suddenly realised that the common denominator was sudden and*  
30 *severe drops in temperature, which had happened immediately before each*  
31 *incident. I told the 'professionals' about this but they all humoured me and clearly*  
32 *thought I was talking rubbish and making lame excuses for carelessness.*  
33

34  
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40  
41  
42 *Recently, the 'temperature factor' has been officially recognised, and is written in*  
43 *text-books. The same 'professionals' give you the same advice (now scientifically*  
44 *smothered) that you originally gave them, in plain English, a long time before....*  
45  
46  
47

48  
49 (Participant 9, male)  
50

51  
52  
53 Participant 9 states that, whilst he felt that health professionals had humoured him at  
54 the time rather than taking his idea seriously, medical text books were now beginning  
55 to include this information, thereby endorsing the idea that he had advanced sometime  
56 earlier. The telling of this story works to construct this participant as someone who is  
57  
58  
59  
60

1  
2  
3 actually 'ahead of the game' and with whom the professional community will eventually  
4  
5 'catch-up'. This strategy might be particularly effective with other participants who feel  
6  
7 that their health professionals are not taking their ideas or experiences seriously.  
8  
9

### 10 11 *Going too far*

12  
13 As explained earlier, we adopted a reactive approach to moderation, meaning that all  
14  
15 messages posted were immediately visible without prior scrutiny. Instead, we regularly  
16  
17 reviewed content, and participants were encouraged to notify us of any messages they  
18  
19 regarded as problematic. No messages were brought to our attention during the study.  
20  
21 In fact, on the rare occasions that a particular comment was perceived by participants  
22  
23 as inappropriate or as having 'gone too far', it was quickly dealt with by either  
24  
25 themselves or other participants. This is demonstrated in the following example, in  
26  
27 which one user's advice to adopt a particular weight loss strategy (cutting down on the  
28  
29 amount of insulin taken) is quickly problematised and highlighted as dangerous by  
30  
31 another user:  
32  
33  
34  
35  
36  
37

### 38 *Losing weight*

39  
40 *Next of my questions...has anyone got any hints on how to lose weight? I don't*  
41  
42 *eat loads, I eat healthy food and I go to the gym, however it won't shift. When I*  
43  
44 *asked the doctor about this, he said I was unlikely to lose weight, but need to be*  
45  
46 *careful not to put any on as I won't lose it. I'm not big, I'm a size 12, but I'd like to*  
47  
48 *get rid of some wobbly bits.....any ideas anyone?*  
49

50  
51 (Participant 16, female)

52  
53 *RE: Losing weight*

54  
55 *Of course, cut back your insulin.*

56  
57 (Participant 13, female)

58  
59 *RE: Losing weight*  
60

1  
2  
3 *But my sugar levels are fine...and cutting back will make me high*

4  
5 (Participant 16, female)

6  
7 *RE: Losing weight*

8  
9 *I was worried to see someone suggest running high bloods to lose weight*

10  
11 *though, don't do it! It's really dangerous!*

12  
13 (Participant 18, female)

14  
15  
16  
17  
18 Other research exploring discussions taking place within health-related internet-based  
19  
20 fora has shown that, whilst most information posted by participants is accurate, that  
21  
22 which is not is very quickly corrected or challenged by other users (Esquivel et al.,  
23  
24 2006). We can see that the community, through its individual members, came to  
25  
26 actively negotiate and enforce the boundaries surrounding what could and could not be  
27  
28 expressed. As a result the community came to develop a particular identity.  
29  
30  
31  
32

### 33 **Discussion**

34  
35 Our study showed that a small number of motivated users who shared specific health  
36  
37 characteristics (having type 1 diabetes and using insulin pumps) who were recruited to  
38  
39 a closed internet forum participated in focussed discussions over a sustained period of  
40  
41 time. The main topics discussed related to self-management of blood glucose levels,  
42  
43 information on new treatments, and illness coping strategies, therefore indicating the  
44  
45 formation of a task-oriented group. This is not surprising given the clear parameters  
46  
47 under which the community was constructed and the individual participants recruited.  
48  
49  
50

51  
52  
53 As has been found in other online support groups, user empowerment can be fostered  
54  
55 through the sharing of information (Fox et al., 2005; Coulson, 2005), and the promotion  
56  
57 of self-confidence and feelings of independence and control (van Uden-Kraan et al.,  
58  
59 2009; Lemire et al., 2008). This is especially important in long-term conditions such as  
60

1  
2  
3 diabetes where self-efficacy (the belief that one has the capabilities to execute the  
4  
5 courses of action required to manage prospective situations) has been shown to have  
6  
7 a positive relationship with successful self-management and better health outcomes  
8  
9 (Brownson et al., 2009). Indeed, studies of other internet-based diabetes communities  
10  
11 have shown positive effects on self-management (for example, Rasmussen et al.,  
12  
13 2007).

14  
15  
16  
17  
18 Health-related internet communities are clearly subject to the social psychological  
19  
20 processes present in all groups, as well as those more specifically found in online  
21  
22 settings (Bargh & McKenna, 2004). For example, normative social influence and  
23  
24 intragroup conformity occurs online, even in anonymous settings (Sassenberg &  
25  
26 Jonas, 2007). We were particularly interested in how, in a new community, issues of  
27  
28 identity and authority were interactively managed. Participants used brief stories to  
29  
30 make indirect suggestions, which also served to demonstrate shared concerns and  
31  
32 experiences as well as authority. This supports the findings of Harrison and Barlow  
33  
34 (2009:94) who showed how the use of short narratives in online support fora can  
35  
36 “simultaneously (1) function as a positive politeness strategy demonstrating empathy,  
37  
38 (2) enable participants to give advice indirectly, and (3) help to construct participants’  
39  
40 identities as expert patients”. Furthermore, by demonstrating how the participants were  
41  
42 constructing legitimacy and authority through online talk, this study resonates with  
43  
44 recent ethnographic research that aims to develop a nuanced understanding on online  
45  
46 socialities (Kozinets, 2010). This stream of research disputes earlier assertions by  
47  
48 social psychologists that online communications would be characterised by a reduction  
49  
50 of social cues and flattening of hierarchies (Dubrovsky et al, 1991).  
51  
52  
53  
54  
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56

57 In line with the tenet that online group norms are not static but develop over time and  
58  
59 change in relation to local discursive contexts (Walstrom, 2004) we have also paid  
60



1  
2  
3 attention to the temporal aspects of the online interaction. The identity of the  
4  
5 community as a space for focussed discussion of diabetes, rather than for any broader  
6  
7 social interaction, was established quickly during the first two months and the  
8  
9 boundaries of this, when tested, were soon reinforced and continued to be maintained  
10  
11 until the end of the six month period. No hostile behaviour was noted and  
12  
13 misinformation was quickly corrected. We can only speculate about the reasons for this  
14  
15 lack of interest in the Virtual Clinic acting as a forum for more general social  
16  
17 interaction. It would seem likely though that, given participants valued the discussion  
18  
19 board precisely for the way it allowed them to be in touch with other people with  
20  
21 diabetes, they would not want this focus to be diverted or diluted by more general  
22  
23 social interaction which they could (perhaps) easily gain elsewhere.  
24  
25  
26  
27  
28

29 Although the online community under study did not demonstrate a high level of  
30  
31 commitment and interpersonal interaction observed in other, mostly non-support-  
32  
33 oriented online fora (e.g. Ley, 2007), this did not prevent it from establishing itself as an  
34  
35 efficient instrumental grouping where participants were able to share highly targeted  
36  
37 practical advice as well as emotional support. It is possible that such social  
38  
39 architectural features as reactive moderation and open-ended, non-prescriptive  
40  
41 participation guidelines have encouraged participation and affected the nature of  
42  
43 discursive contributions by providing a relatively secure space for the exchange of  
44  
45 views and advice. As a result, participants successfully co-constructed their group  
46  
47 identity through shared understandings of 'behaviours and meanings within a collective  
48  
49 realm of action' (Fernback, 2007: 66).  
50  
51  
52  
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55 These findings are resonant with the research conducted on face-to-face groups  
56  
57 (Arminen, 2004) and found that "the organization of AA members' experiences cannot  
58  
59 be located in individual turns or within individual's talk and cognitive processes. Rather,  
60

1  
2  
3 AA meetings are a seamless web of interconnected turns in which speakers build their  
4  
5 turns as new contributions to the context provided by previous turns" (2004: 323). From  
6  
7 this perspective, the rhetorical and interactional dynamics of online support groups,  
8  
9 such as the one investigated here, call for a further in-depth study of group-level  
10  
11 phenomena that cannot be directly attributed to individual discursive acts.  
12  
13

### 14 15 16 **Limitations**

17  
18 Due to its nature as a local, pilot study the project only has a small sample and the  
19  
20 inclusion criteria were relatively tight. The sample was relatively diverse in terms of age  
21  
22 and educational level, but as it was drawn on the basis of convenience we cannot  
23  
24 claim to have a representative sample and other groups of participants may have  
25  
26 interacted differently. In addition, a small number of participants appear more than  
27  
28 once throughout our presentation of the findings. While we have tried to avoid this  
29  
30 where possible, it has sometimes been necessary for example due to their key role in  
31  
32 shaping the discussion forum. The fact that the discussion forum operated only as part  
33  
34 of a wider study of an internet-based self-management tool means that we would  
35  
36 perhaps expect the focus of discussions to be self-management and for this to be  
37  
38 prioritised over more general social interaction. It is also possible that knowing they  
39  
40 were part of a research study influenced the way participants used the discussion  
41  
42 forum, although in subsequent interviews participants reported using the discussion  
43  
44 forum as they would other non-study related fora (author citation). Participants were  
45  
46 aware that the pilot study would only be for six months' duration and it is possible that  
47  
48 this knowledge influenced the way in which the identity and authority of both the group  
49  
50 and its individual members were established.  
51  
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### 56 57 **Conclusion**

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3 Internet communities can have a valuable role in engaging people with long-term  
4  
5 conditions such as diabetes in issues that affect their health and health care. Internet  
6  
7 discussion fora are shaped in important ways early on by the community of users. If  
8  
9 promoting self-efficacy is the key to effective self-management, then peer-to-peer  
10  
11 communication is a promising area and has the advantages of being low (or indeed  
12  
13 no) cost and highly acceptable to patients. However, there is a clear need to be aware  
14  
15 of the social processes that shape online communities. In order to harness the  
16  
17 potential benefits, health services need to acquire a multi-faceted understanding of the  
18  
19 social processes that occur in online communities, including how the character and  
20  
21 focus of the discussion is formed over time, and how both information and individual  
22  
23 users can be constructed as authoritative and reliable. Health practitioners should note  
24  
25 that such communities can have clear empowering benefits and at the same time that  
26  
27 concerns about the propagation of inaccurate or misleading information are not  
28  
29 supported by our findings. Future research should consider the influences of  
30  
31 participant authority and identity on the health behaviour of participants in internet  
32  
33 communities.  
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