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# The Role of Online Health Communities in Patient Empowerment

An Empirical Study of Knowledge Creation and Sharing on Diabetes.co.uk

Findings Report

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### *Disclaimer*

This report presents the findings of an independent study led by Royal Holloway, University of London in collaboration with Diabetes.co.uk. The study comprises a survey, one focus group and eleven interviews with members of Diabetes.co.uk's forum online. The views expressed in this report are those of the study's participants and the authors and do not necessarily represent the views of Royal Holloway University and other partners involved in the study.

### *Acknowledgement*

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## Executive Summary

The report presents the main findings of a study about knowledge sharing on the online forum of Diabetes.co.uk. The study builds on previous research about the role of online communities in patients' empowerment and health self-management. The study has two objectives: i. analyse the impact of participating in the diabetes online community on members' wellbeing and ii. understand how knowledge shared in the community influences patient-doctor interaction and the quality of healthcare patients receive.

Data were collected through a survey, one focus group, and eleven interviews with members of the online forum. Findings demonstrate that the forum can have a positive impact on its members' wellbeing and can help members manage their relationship with healthcare professionals.

The survey results show the key drivers of members' participation to the forum and the impact of the knowledge shared on the forum on members' sense of empowerment, their ability to manage diabetes, and the relationship with their doctor or nurse. Findings from the focus group and interviews provide more evidence about how the forum empowers members to take better care of their diabetes and discuss their needs with their doctor or nurse. They show how forum members use knowledge from the forum to become empowered and provide further insights into the impact of the forum on members' relationship with their healthcare professionals. In particular, they highlight the tension between the traditional medical advice from the health service and the alternative approaches to diabetes management in the forum.

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## Introduction

This research focuses on how members of the online forum of Diabetes.co.uk co-create knowledge and how they use this knowledge in managing their own health. Various studies suggest that online health communities are a source of peer-support for their members (e.g., Nambisan 2011). In particular, community members can tap into the collective knowledge of people with a similar medical condition, which increases their confidence in making informed health decisions (Hall et al. 2015; Willis 2016). Knowledge shared in online communities also empowers their members in navigating healthcare systems and interacting with medical professionals and institutions (Foster 2016).

Central to patients' empowerment is a less hierarchical, more collaborative relationship between healthcare professionals and patients. To foster such relationship, more evidence is needed about 1) the significant role of online health communities in patients' self-management in terms of knowledge sharing and co-creation; and 2) the potential value of online health communities to healthcare professionals in designing and providing patient-centred care.

Using Diabetes.co.uk's online community as a focal case, this research has two main objectives:

1. Analyse the impact of participating in the diabetes online community on members' wellbeing;
2. Understand how knowledge shared in the community influences patient-doctor interaction and the quality of healthcare patients receive.

## Methods

The study adopts a mixed-method approach with both quantitative and qualitative elements and was conducted between April and August 2017. We designed an online questionnaire to collect anonymous data from a random sample of 2,000 participants from Diabetes.co.uk's online forum. From the quantitative survey, we intended to explore the important factors that drove participation in the online community and how the online community could empower its participants.

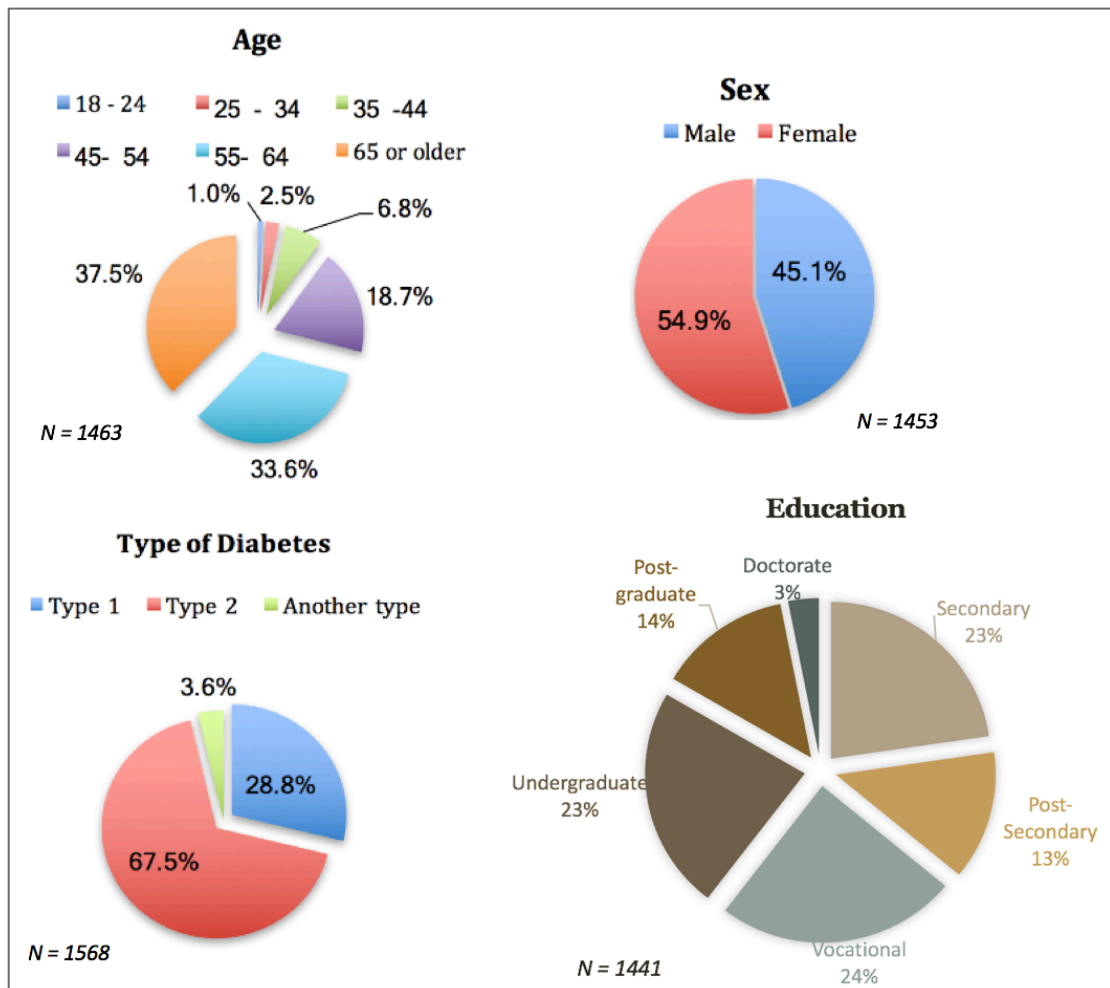
We adopted a qualitative approach to examine how members of Diabetes.co.uk's online forum exchange knowledge and the impact that the forum has on their wellbeing and on their interactions with their doctor or nurse. For this part of the study, we conducted one focus group with seven forum members, two of which were members of staff of Diabetes.co.uk. We also conducted 11 in-depth Skype/phone interviews, 10 interviews with forum members and one interview with a GP, also a member of the forum. All participants were from the UK except for one participant from Australia. The focus group lasted 1 hour and a half whereas each interview was about 1 hour long. Focus group and interviews were recorded and transcribed. Data were analysed with a qualitative data management software application (Atlas.ti).

## Results

### A. Survey Results

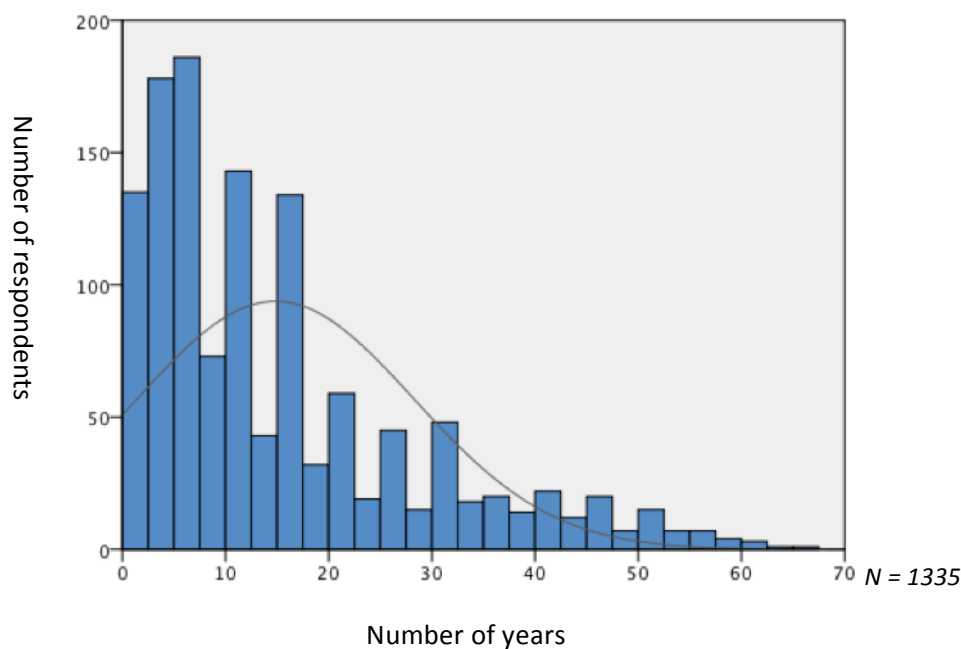
#### Descriptive Statistics

The online survey invitation was sent to 2150 users of Diabetes.co.uk's forum in late April 2017 and we received over 1500 usable responses by the 7th of May (response rate = 75%). More women (798, 54.9%) than men (655, 45.1%) participated in the survey. The majority of respondents were mid-aged or older adults, with "65 or older" being the largest category (548, 37.5%), followed by "55-64" years old (491, 33.6%). A significant proportion of the respondents (40%) had an undergraduate or higher degree. In terms of type of diabetes, 1059 respondents (67.5%) had Type 2 diabetes, 452 respondents had (28.8%) Type 1 diabetes, and 57 respondents had (3.6%) another type of diabetes. Figure 1 summarizes the demographics of survey participants.



**Figure 1. Demographics of survey participants**

Approximately half of the respondents (50%) have had diabetes for 10 or more years, with an average of 14.8 years and a standard deviation of 13.4. Many respondents have been members of Diabetes.co.uk's forum for a long time, with an average tenure of 3.9 years (standard deviation 4.5) (Figure 2).



**Figure 2. Number of years with diabetes**

### Hypotheses and Modelling

The survey was a pilot study for exploring possible research models and examining the questionnaire’s reliability and validity. Nevertheless, since most measurement items in the survey showed a good degree of reliability and validity, we performed a series of regression analyses to test potential linkages between online community participation, sense of empowerment, and patient wellbeing.

### Drivers of Community Participation

We first ask what may motivate people to participate in Diabetes.co.uk’s forum, both in terms of visiting the site and (more importantly) contributing knowledge to the forum. Based on prior academic research, we hypothesize that the **perceived knowledge quality** (Chiu et al. 2006) shared in the forum, forum users’ **knowledge self-efficacy**, i.e., their confidence in their knowledge of diabetes (Ray et al. 2014), **reciprocity** (Chang et al. 2015), and a **sense of community** (Chiu et al. 2006; Ray et al. 2014) all have positive influence on people’s use of the forum.

**Knowledge quality** indicates the quality of content shared in the online community. Knowledge quality is subjective and depends on community members’ perception of its utility in addressing their needs. The greater the perception that the community’s knowledge can satisfy their needs, the higher the likelihood that members will continue to engage with the community and share knowledge. At the same time, a person needs to have confidence about his or her knowledge when sharing it with others. Past studies have found the positive effect of **knowledge self-efficacy** on knowledge contribution behaviour in online spaces. Being able to help other members in a community confirms knowledge self-efficacy, which in turn encourages continued community participation. In the context of online knowledge sharing, **reciprocity** refers to the belief that sharing knowledge will lead to future requests for knowledge being met. That is, a person who has helped others expects a return



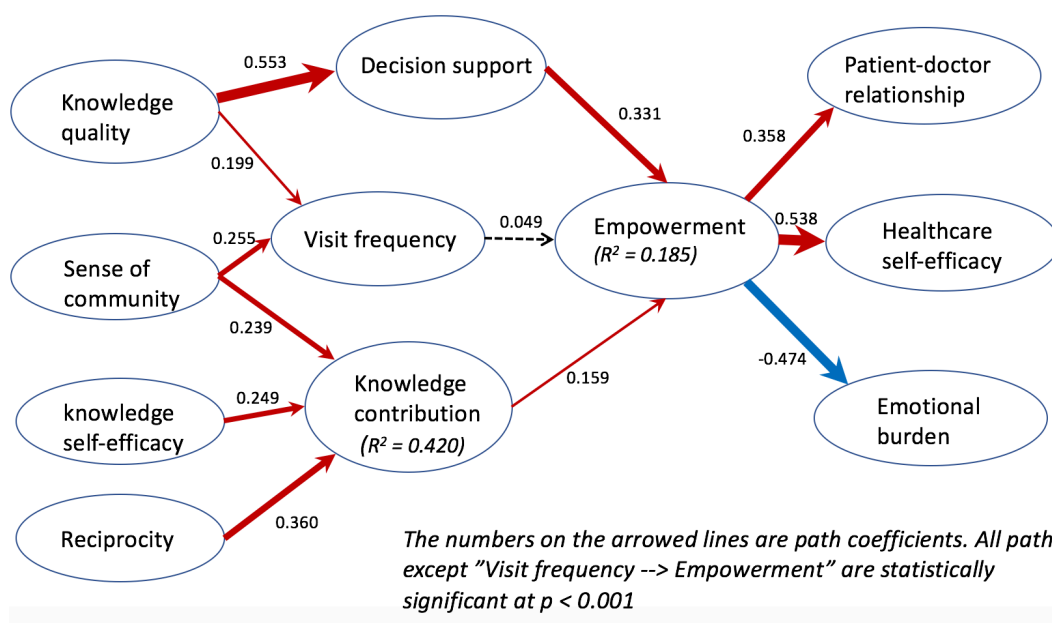
of favour when he or she needs it. **Sense of community** has been defined by community psychologists as “a feeling that members have of belonging” (McMillan and Chavis 1986, p. 294). This sense of belonging entails, among other things, identification with and affective commitment to the social group.

We adapt measurement items already validated in the literature to assess these factors. We quantify community participation with two measurements: forum **visit frequency** and **perceived knowledge contribution**. That is, we ask how frequently one visits Diabetes.co.uk’s forum and how much he or she “has contributed/will likely contribute” knowledge to the community. In addition, we hypothesize that the quality of knowledge shared in the forum influences **decision support** (Graham and O’Connor 1995), i.e., members’ perception of the support they receive from the forum in making a healthcare decision.

### *The Influence of Community Participation on Patients’ Wellbeing*

We believe that participating in online health communities such as Diabetes.co.uk helps to improve patient wellbeing. We further hypothesize that visiting the forum, contributing knowledge, and decision support in the forum give people a sense of **empowerment**. With empowerment we measured forum members’ motivation for and ability of making choices about the care, developing workplans, overcoming barriers to their goals, coping with emotions, and asking for support (Anderson et al. 2000). In turn, we hypothesize that empowerment increases patients’ confidence in managing their health (**health management self-efficacy**) and reduces the **emotional burden** of coping with diabetes.

Furthermore, a confident and emotionally strong patient is more likely to maintain a **good relationship with his/her doctor or nurse**. Putting these premises together, we have developed a statistical model to test the hypothesized relationships among the factors. To summarize, we want to find out what influences people’s participation in Diabetes.co.uk’s forum and the extent to which participation to the forum helps manage their care of diabetes. We found that the model depicted in Figure 3 provides reasonably good results.



**Figure 3. Results of statistical analysis**

Without going into technical details, we highlight the more interesting observations as follows.

- 1) All causal relationships depicted in the model, except for that between Visit frequency and Empowerment, are statistically significant ( $p < 0.001$ ). The strength of these relationships varies. The numbers on the lines are path coefficients ( $\beta$ ), which indicate the relative strength of the causation within the structural model. For example, Knowledge contribution seems to have a relatively weak effect on Empowerment ( $\beta = 0.159$ ), while Empowerment has a strong positive effect on patients' Self-efficacy ( $\beta = 0.538$ ).
- 2) A forum user's perceived knowledge quality and a sense of community have positive influences on his/her forum visit frequency. That is, the more one perceives the shared knowledge in the forum to be high-quality and the more he/she feels a sense of belonging to the community, the more likely he/she is to visit the forum. At the same time, there is strong positive relationship between Perceived knowledge quality and Decision support ( $\beta = 0.553$ ,  $p < 0.001$ ). This suggests that high quality knowledge in the forum could significantly improve members' ability of making decisions about their health.
- 3) Sense of community, perceived knowledge efficacy, and reciprocity explain 42% of variation in Knowledge contribution ( $R^2 = 0.42$ ). This means that sense of belonging to the community, members' confidence in the knowledge they share in the forum, and a sense of reciprocal support in the forum are indeed important drivers of knowledge sharing in the forum.
- 4) Regarding the influence of participation in the forum on patients' wellbeing, we found that the two variables we used for measuring community participation – visit frequency and knowledge contribution – did not seem to account for a significant portion of variation in Empowerment ( $R^2 = 0.185$ ). This could mean a few things, such as: a) community participation was not sufficiently captured by our measurement variables; b) the sense of empowerment was not accurately measured by our survey instrument; c) empowerment is determined by other more significant factors.
- 5) Visiting the forum does not necessarily lead to empowerment ( $\beta = 0.049$ ,  $p = 0.051$ ). This seems to suggest that empowerment derives from a deeper engagement with the community than mere visiting/browsing. Sharing knowledge and utilising acquired knowledge for decision making ( $\beta = 0.331$ ,  $p < 0.001$ ) are more meaningful ways of empowerment through the forum.
- 6) A sense of empowerment has strong, positive effects on patients' wellbeing. The results show that an empowered diabetes patient tends to develop a good patient-doctor (P-D) relationship ( $\beta = 0.358$ ,  $p < 0.001$ ), has a high confidence or self-efficacy in managing his/her health condition ( $\beta = 0.538$ ,  $p < 0.001$ ), and feels less emotionally burdened ( $\beta = -0.474$ ,  $p < 0.001$ ).

In summary, the pilot survey confirms most of our hypotheses, particularly with regard to factors influencing community engagement, decision support, and the benefits of empowerment for a diabetes patient. In the qualitative phase of this study, we endeavour to further explore the meaning of empowerment to the users of Diabetes.co.uk's forum and

how the forum affects their relationship with healthcare providers. The qualitative findings will then inform our next stage of survey development.

## B. Qualitative Study Results

This section summarizes findings from the focus group and 11 interviews with members of the forum. Table 1 summarizes the details of participants to the focus group and interviews.

| Focus group participants |                        |        |                  |                                   |
|--------------------------|------------------------|--------|------------------|-----------------------------------|
| Participants             | Role                   | Sex    | Type of diabetes | Length of membership to the forum |
| P1                       | Forum and staff member | Male   | Type 1           | 5-10 years                        |
| P2                       | Forum and staff member | Male   | None             | 5-10 years                        |
| P3                       | Forum member           | Female | Type 2           | 3-5 years                         |
| P4                       | Forum member           | Female | Type 2           | 3-5 years                         |
| P5                       | Forum member           | Male   | Type 1           | 3-5 years                         |
| P6                       | Forum member           | Female | Type 2           | 3-5 years                         |
| P7                       | Forum member           | Male   | Type 2           | N/A                               |
| Interview participants   |                        |        |                  |                                   |
| Participants             | Role                   | Sex    | Type of diabetes | Length of membership to the forum |
| P8                       | Forum member           | Female | Type 1           | 3-5 years                         |
| P9                       | Forum member           | Male   | Type 2           | 1-3 years                         |
| P10                      | Forum member           | Male   | Type 1           | 1-3 years                         |
| P11                      | Forum member           | Male   | Type 2           | 1-3 years                         |
| P12                      | Forum member           | Female | Type 1           | 1-3 years                         |
| P13                      | Forum member           | Male   | Type 2           | Less than a year                  |
| P14                      | Forum member           | Female | Type 2           | Less than a year                  |
| P15                      | Forum member and GP    | Male   | None             | 3-5 years                         |
| P16                      | Forum member           | Female | Type 1           | 1-3 years                         |
| P17                      | Forum member and carer | Male   | None             | 3-5 years                         |
| P18                      | Forum member           | Male   | Type 2           | 3-5 years                         |

**Table 1. Summary of focus group and interview participants**

### The Impact of the Forum on Members' Wellbeing

#### *The Forum Empowers Members in the Control of their Diabetes*

Participants with either Type 1 or Type 2 diabetes found that the forum helped them control their diabetes. Some participants with Type 2 Diabetes (T2D), for example, learned how to practice a low carb diet from the forum, which has resulted in improved health outcomes such as lower blood glucose levels and weight loss. As a result to their participation to the forum, the majority of participants with T2D can control their diabetes successfully without medication. Some have also managed to reverse their diabetes as mentioned in this quote by a participant with T2D:

*"I think actually the forum probably saved me [...] through [the forum] and through modifying things, personally, I've lost a lot of weight and I've actually found that my doctor says I'm in remission as far as diabetes is concerned".*

On the forum participants can find information and advice about diet, testing kits, blood glucose monitoring technology such as FreeStyle Libre, how to store insulin, side effects of medications, and so on. Various participants agreed that the forum has increased their

knowledge and understanding of diabetes, which has given them more confidence in managing their condition as explained in this quote by a participant with T1D:

*"I was on a basal bolus regime [...], but I had no idea that's what it was called. [...] I'd been told by my doctors, 'Just take 14 units, 12 units, 12 units [of insulin] for breakfast, lunch and tea and 44 units in the evening' [...]. I had no idea that I could change the amount of insulin for the number of carbohydrates that I had. [...] It was the understanding of the information that I could gather from the forum [...] that engaged me with diabetes".*

In particular, according to some participants, the forum is an open and supportive community that, also thanks to the activity of moderators, lets them talk freely about the undesired effects of diabetes without making them feel ashamed or negatively judged. In particular, a few participants described the management of their own diabetes before finding the forum as if in a state of disarray. Others even felt overwhelmed by the condition and its possible complications. They described the forum as a source of psychological support that can reduce anxiety and help members develop the right mindset to manage diabetes effectively.

Participants associated their confidence in managing diabetes with a sense of empowerment. The forum was empowering in two ways. First, the forum provided members with the information and knowledge to make an informed decision and choice about the management of their condition. In particular, some participants felt that the knowledge from the forum was empowering because it enabled members to discuss their needs with their doctor as stated in this quote by a participant with T2D:

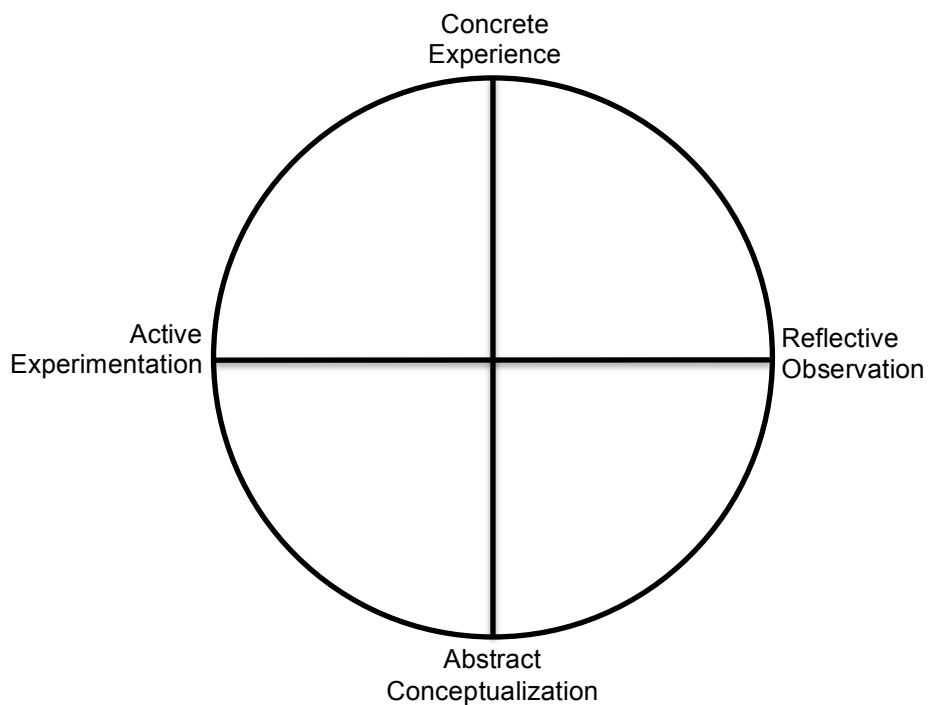
*"It's very empowering to know that your ankles are swelling because of a side effect of a certain drug and you can go back to your doctor and say, 'Can I have an alternative?'"*

Second, peer-support and encouragement from the forum can empower members to take better care of their diabetes. In particular, success stories from other members are a source of confidence and empowerment as shown in this quote by a participant with T1D:

*"I joined the forum [...] and I was just overwhelmed by the fact that one guy [...] who had his type 1 diabetes [whose] HbA1c [was] under five so I thought 'is that right? [...] The more I read up on, 'yes, he's got type 1, yes he is really controlling this so much better than I am', which annoyed me so I was like 'Well if somebody else can do that, I can do that'"*

### *Experiential Learning*

Forum members need to establish whether the knowledge they acquire from the forum is reliable and what solution might work for them. The analysis of findings suggests that participants make sense of and apply the knowledge acquired through "experiential learning". According to Kolb (1984), "experiential learning" is a "process whereby knowledge is created through the transformation of experience" (p. 41) and it is accomplished through an "idealized cycle" of four modes of learning: experiencing or "Concrete Experience" (CE); reflecting or "Reflective Observation"; thinking and generalizing or "Abstract Conceptualization" (AC); and testing or "Active Experimentation" (AE) (Kolb and Kolb 2005) (Figure 4).



**Figure 4. The Experiential Learning Cycle (Kolb 1984)**

Forum members share personal stories about their *experience* with managing diabetes. The tone in which these stories are shared is important. Participants that contribute knowledge to the forum, for example, tend not to be prescriptive and not to give instructions of what others should do. It is up to members of the forum to draw lessons on how to manage their own diabetes from other people’s experience. A participant with T2D said:

*“There are ways of saying things that I think are good, which I always use, as in, “In my experience, I’ve found – I do this – I do that” [...]. There are other people who say, ‘Oh you must do this’; [...] ‘Well no, that’s not necessarily going to work for this particular person’. So sometimes there is [...] advice given in a quite prescriptive way [...] and it’s [...] not always that helpful”.*

Reflective observation (RO) involves members’ evaluation and validation of the knowledge that they acquire from other members’ stories and experience. Knowledge evaluation is an important step through which knowledge is constructed and accepted within the community of users on the forum (Kazmer et al. 2014). Participants mentioned various ways in which they validate knowledge from the forum. First, they check for consistency between what someone states to have done or achieved against his or her previous posts. In this way, they build a profile and establish the credibility of that person. Second, they rely on “peer-validation”, that is, they check whether there is consensus about a post from other members. The activity of moderators and other members’ comments help someone decide whether the advice given is sensible.

Finally, the majority of participants cross-reference what they read in the forum with scientific research available on the Internet. Others discuss the advice given in the forum with a medical professional. Those that have lived with diabetes for a long time also use their experience to judge whether a post is sensible.

Even though many participants agreed that what works for one person might not work for someone else, they regarded multiple success stories from forum members as scientific evidence rather than anecdotes. A participant with T2D said:

*“It’s very, very easy to read through somebody’s [...] forum posts and understand that their journey has been very directly influenced by what they’ve eaten and you can see the outcomes of that. [...] Just in terms of empirical evidence there’s loads and [...] it’s just really, really hard to deny that low-carbing is the way to beat diabetes”.*

Knowledge evaluation leads to “abstract conceptualization”, through which members reflect upon the knowledge acquired and draw general conclusions as shown in this post by a participant with T2D:

*“When you realise that sugar will give you high blood sugars and carbohydrates, which our bodies interpret as sugar, will give you higher blood sugars, that’s the science. So we’re all in agreement on that”.*

The next step is “active experimentation”, i.e., members re-adapt and test what they have learned from the forum on themselves. A participant with T2D said:

*“By reading other people’s experiences, it gives you a huge insight in to what other people are doing and I tend to pick and choose and experiment on myself quite a lot to see what works for me”.*

Active experimentation can start the whole experiential learning cycle again with members posting questions to validate findings from their experience and research. Knowledge validation and the search for information, particularly by new members, can add to the frustration of veteran members who can see the same question asked all over again. One participant pointed out that search results were not always relevant, which explains why people repeat the same question:

*“There is plenty of information on the forum about blood glucose monitors [...] but because people can’t find that easily [...] they put a post up saying, ‘Has anyone experienced problems with their blood glucose meter?’”.*

The majority of participants shared some common personality traits that could explain their willingness and ability of engaging in experiential learning through the forum. First, they were self-motivated individuals with clear diabetes management goals. A common goal for participants with T2D, for example, was to manage diabetes through diet and without medication:

*“My ambition is that over time I can regress diabetes to a stage where I can consume some carbohydrates. I don’t want to go back anywhere near the carbohydrates I consumed before, [...] but I want to be in a stage where I can eat more than I can eat now, and I am prepared to do whatever it takes to make that happen”.*

Second, the majority of participants were self-learners, well educated about their own condition and with an inquisitive mind. They were very cautious about what they read in the forum and aware of the need to back up facts with scientific evidence. A participant with T2D said:

*“In the last two years I’ve studied probably on average about an hour a day [...]. On some days I studied more. I would say I’ve done enough to actually take any degree and answer almost any question on diabetes”.*

Experience and the level of confidence about their knowledge is also a key factor that drives participants’ contribution to the forum, which includes answers to specific posts.

### **The Impact of the Forum on Members’ Relationship with Healthcare Professionals**

#### *Patients and Healthcare Professionals Have a Different Understanding of Diabetes*

The majority of participants felt that the support they were receiving from their medical professionals and the health service in general was either insufficient or inadequate. Therefore, they found in the forum the kind of support that they could not find anywhere else in the health service. According to various participants with T2D, the message from their medical professionals was that diabetes is a progressive disease that can be treated only by taking more and more medication. They found this message to be frustrating and void of hope whereas their desire was to feel empowered to take control of diabetes through diet and, possibly, reverse the condition without the need for medication. Other participants with T1D also shared a similar experience and would have liked more medical advice on how to manage diabetes on their own, for example, by being empowered to change insulin doses. The message from various participants is that the health service is disempowering and almost patronizing as explained in this quote by a participant with T2D:

*“Going back to the simple thing of testing your blood, ‘Oh don’t worry about that, we’ll look after your diabetes,’ [...] in defense of the healthcare professionals, [...] I think they’re trying to say, ‘We’ll help you look after this.’ But they say, ‘We’ll look after it, we’ll tell you what you to do.’ Rather than saying ‘We’ll help you to learn what to do to manage it better for yourself’”.*

Various findings in this study suggest that there is a “cognitive dissonance” or lack of mutual understanding between patients and health care professionals. What feels right for patients does not feel right for healthcare professionals. A participant with T2D said:

*“My HbA1c had gone down from 76 [...] to 43-46 [...], the [Diabetes Nurse] went on to say, ‘You’re the first person I’ve ever seen who’s actually brought their Hb1Ac down so much’. So, I thought, ‘Okay, I’m the first person that’s taken control and you’re telling everyone else there’s no point in taking control because they’re going to get worse and worse and ending up injecting insulin’ (laughs), cognitive dissonance there.”*

Particularly for T2D, many healthcare professionals would recommend a drug therapy accompanied with a diet high in carbohydrates. Some participants lost faith in the medical advice they were given after reading on the forum and experiencing themselves that a low-carb diet can lower their blood glucose in the normal range without taking medication. Thus, if, on the one hand, the forum empowers patients to discuss their needs with their healthcare professionals, on the other hand, it gives them the confidence to challenge the medical advice they are given. At least, some participants did so because their meter readings and blood counts told them it was the right thing to do. So these are patients that are well controlled. They are also aware of the importance of experimenting since what

might work for one person might not work for others as shown by the experience of this participant with T1D:

*“For the high blood sugars, [...] somebody told me to eat just before I go to bed, so something small, just a piece of fruit or a piece of toast, [...] but I found that that raised my blood sugars even more”.*

#### *Alternative vs. Traditional Knowledge Paradigm*

Many participants found that the medical advice they receive from health care professionals and the health service guidelines are too out-dated as shown in this quote by a participant with T2D:

*“That’s what I mean about treating 21st Century chronic diseases like a 20th Century acute disease; [...] you go to the doctor with an infection and he gave you an antibiotic and it cured it, that’s great, that’s an acute problem. You go to the doctor with a chronic disease, you need to look at the underlying reason why you’ve got high blood sugar which is probably due to insulin resistance [...] and maybe being overweight. [...] Giving someone a tablet to lower their blood glucose doesn’t do anything to address the underlying cause of the chronic condition”.*

By contrast, they feel that the forum is ahead of most healthcare professionals in terms of knowledge. This is because many forum members are well connected with latest research about diabetes management and share this knowledge on the forum. For example, some participants with T2D said they followed posts about the Newcastle Diet on intermittent fasting by Professor Roy Taylor. Others mentioned the low-carb and intermittent fasting programme by Dr Jason Fung from Canada. Therefore, members’ activity on the forum has contributed to the diffusion of these approaches to diabetes management that are innovative and alternative to the “traditional” medicine for the treatment of diabetes. In spite of recent scientific studies that have proven their effectiveness (e.g., Unwin et al. 2015), these “alternative” approaches are not yet accepted in the day-to-day practice of healthcare professionals. In reporting a conversation with his consultant, a participant with T2D said:

*“[The consultant] was very dismissive of the Newcastle diet [...]. He said, ‘You would need 30 years worth of evidence before you could say that that diet had a long term impact on diabetes’. So, I said to him, ‘I haven’t got 30 years mate, [...] I can’t wait for 30 years of research”.*

The examples of the low carb and high fat diet and intermittent fasting show that the forum contributes to the diffusion of an alternative knowledge paradigm that clashes with the more traditional knowledge paradigm adopted by healthcare professionals in the management of diabetes. The tension between these two knowledge paradigms was evident in the forum as well, as shown in this quote by a participant with T2D:

*“When I first discovered the forum [back in 2010], [...] there seemed to be these two camps, the pro-carbs and the anti-carbs and there were endless discussions and wars. [...] and then back in 2012, that phase was beginning to fade and low carb, which is my main interest, [...] was beginning to be tolerated, [...] you weren’t shot down in flames if you mentioned it”.*



Based on the stories of some participants, it appears that alternative approaches to the management of diabetes are usually met with scepticism from healthcare professionals. Some participants showed sympathy towards healthcare professionals. They understand that they are under the pressure of time and resource constraints and that it could be risky for them not to follow the “official” diabetes management guidelines. Nevertheless, some participants felt that the guidelines that most healthcare professionals follow do not fully address their needs. By contrast, they feel that on the forum they can find advice that is more tailored to their personal situation as explained in this quote by a participant with T2D:

*“When the doctor says, ‘According to the text book, [...] I want to put you on statins because the covenants recommendation is that all diabetics should have a statin level of less than five’. Okay, that is nothing to do with me, that is to do with a book that exists in some library somewhere. [...] It just doesn’t feel right, because, when you go on the forum you are talking to people who might even have the same blood glucose as you, the same cholesterol as you [...] and so, it feels like a more tailored conversation than just a text book conversation”.*

Contrary to the scepticism of some healthcare professionals, the forum can be a catalyst of innovation in medical practice. For example, a few participants have shared the knowledge they have acquired from the forum with their doctors. One participant said that her GP practice was interested in the cost-savings of diet-based approaches to the treatment of T2D. One GP became an advocate of the low-carb diet after reading about the experience of patients on the forum. After seeing good results with people with pre-diabetes, he started prescribing a low carb diet to his patients with T2D. Positive results convinced his partners about the effectiveness of the low-carb diet too. Thus, as he said, this example shows a revolution in the innovation of medical practice, which is spread from the bottom rather than the top:

*“The researchers come up with an idea, they research it [...] and then they publish and specialists do things and then it filters down to primary care. This is the opposite [...] this is something that thousands and thousands of people are doing [...] Increasing numbers of GPs now are coming across patients who are getting good results and asking how they’re doing it and so this is feeding up. And then the GPs are feeding up to the specialists”.*

## **Conclusive Remarks**

The study demonstrates that the forum can have a positive impact on its members’ wellbeing and can help members manage their relationship with healthcare professionals. The survey results show that sense of belonging to the forum, perceived knowledge quality, reciprocity, and members’ confidence in their knowledge about diabetes are amongst the key drivers of members’ participation to the forum. In particular, we found that knowledge quality can significantly improve members’ ability of making decisions about their diabetes.

Regarding the impact of the forum on patients’ wellbeing, the survey results show that sharing knowledge and utilizing acquired knowledge for decision making empower forum members to take more care of their diabetes. In turn, sense of empowerment gives members more confidence in managing their condition, mitigates the emotional stress from

living with the condition, and helps members to develop a good relationship with their doctor or nurse.

The qualitative study provides further support to these findings. First, it shows that the forum helped study participants to control their diabetes successfully and, in some cases, without medication. In particular, it provided more evidence about how the forum influences members' empowerment to take better care of their diabetes, first, by providing members with the knowledge to make an informed choice about their health and discuss their needs with their doctor or nurse and, second, through success stories and encouragement from other members.

Second, the study shows how forum members use knowledge from the forum to become empowered. In particular, study participants showed the ability to experiment with the advice and information given on the forum. They were self-motivated individuals with clear diabetes management goals in mind, well educated about their condition, and up-to-date with research.

Finally, findings from the qualitative study provide further insights into the impact of the forum on members' relationship with their healthcare professionals. In particular, they highlight the tension between the traditional medical advice from the health service and the alternative approaches to diabetes management in the forum. Some participants felt discouraged with the medical advice they received. By contrast, they found the success stories from the forum more empowering and full of hope, which can lead to a loss of faith in the health service. In addition, they felt that the advice from the forum was more tailored to their personal needs.

The study has some limitations. First, the relationship between the factors we used to measure community participation and empowerment was not statistically significant. This could mean that a) there are other variables that capture community participation; b) the measurement of empowerment in our survey was not accurate; c) there are more significant factors that determine empowerment. Second, the size of the qualitative study is limited to one focus group and eleven participants. More participants, particularly from healthcare professionals, are needed to confirm the preliminary findings of this study.

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