

# Online Communities Are Valued by People With Type 1 Diabetes for Peer Support: How Well Do Health Professionals Understand This?

Kate Gilbert, BA, MPH, Sarity Dodson, DPsych, Marie Gill, RN, PGDip Comm Health, MEdu, and Rosemary McKenzie, BA, PGDip Health Promotion, MPH

Type 1 diabetes is a chronic, incurable, and life-threatening metabolic illness. Management demands of the condition are complex and intensive, and clinical management requires a specialist multidisciplinary team.<sup>1,2</sup>

Despite the support of health providers, the daily management tasks of type 1 diabetes are all actions that people with diabetes must carry out themselves to prevent acute and chronic physical complications. This responsibility may bring with it significant psychological strain.<sup>3</sup> Furthermore, although health outcomes are controllable to a significant extent, fluctuations in health status are inevitable, and complications can befall even the most diligent illness managers. The resulting uncertainty and knowledge of the potential for death or disability can compound the psychological strain.<sup>4</sup> There can also be a tangible burden associated with the considerable time, energy, and focus required to establish and maintain metabolic control, which places considerable strain on patients' ability to attend to occupational, social, familial, and personal needs and desires.<sup>3,5-8</sup> Social stigma may also be associated with carrying out the demands of diabetes management.

Together, these experiences often leave individuals with diabetes feeling isolated from members of their immediate social network who may fail to understand their daily experiences. Seeking connection with others with the same medical condition is one strategy that people in this situation pursue, and the resulting process has been termed "peer support."<sup>9</sup>

Peer support has been defined as assistance by a person who has experiential knowledge of the specific health issue and similar characteristics as the target population.<sup>10,11</sup> Fisher<sup>12</sup> describes peer support's role in health behavior change as assisting people with chronic disease to translate a plan developed with or by a health professional into action.

Peer support can be delivered in many different forms. As theories for implementing any complex interventions state, it will have a "hard core" of functions that it delivers and a "soft periphery" of elements that are adapted through the implementation according to local and individual needs.<sup>13</sup> Boothroyd and Fisher,<sup>14</sup> in describing the work of Peers for Progress (a global initiative of the American Family Physicians Foundation), similarly propose that the way in which peer support programs are delivered will always need to be "shaped by cultural, organizational, and national factors," but that there are four core functions that underpin all peer support programs:

1. Assistance in applying disease management in daily life. Peer supporters use their own experiences with nutrition, physical activity, and medication adherence in helping people figure out how to manage diabetes in their daily lives. They can also help in identifying key resources such as where to buy healthy foods or pleasant and convenient locations for exercise.
2. Emotional and social support. Through empathetic listening and encouragement, peer supporters are an integral part of helping patients cope with social or emo-

tional barriers and stay motivated to reach their goals.

3. Linkage to clinical care. Peer supporters can help bridge the gap between patients and primary care providers and encourage individuals to seek out clinical care when appropriate.
4. Ongoing support. Peer supporters successfully keep patients engaged by providing proactive, flexible, and continual long-term follow-up.<sup>14,15</sup>

The evidence for peer support's effectiveness in improving clinical and psychological outcomes is growing.<sup>11,16-18</sup> A recent systematic review<sup>19</sup> found 40 studies in eight countries, of which 15 showed modest benefits and 18 showed strong evidence of benefit. The review concluded that "peer support is effective in promoting complex health behaviors across a variety of diseases and national settings."<sup>19</sup>

Some studies comparing the effects of volunteer-led peer support with that of support and education led by health professionals have shown similar or better outcomes for the peer-support interventions on both clinical and psychosocial outcomes. However, peer support has been predominantly studied and defined as a process that is complementary, not an alternative to, interventions led by health professionals.<sup>17,20</sup>

Health professionals' perspectives of volunteer-led or online peer support are not well understood. There is some evidence that some health professional groups value the complementary role that peer supporters may play in supporting chronic condition self-management.<sup>21,22</sup> There is also some evidence that peer supporters value interaction with the medical team.<sup>23</sup> However, peer support is not currently recognized as a core part of health service delivery by health professional groups in most countries.<sup>2,17,24,25</sup>

Support programs that are both online and peer-led are a growing phenomenon given the rapid changes in access to technology and social media.<sup>26,27</sup>

Research and evaluation of peer-support programs that are

volunteer-led or online are both extremely rare.<sup>16,17</sup> An online community group for women with breast cancer found that the group increased coping skills and improved psychological well-being.<sup>28</sup> Lorig et al.<sup>29</sup> conducted a randomized, controlled trial of a 6-week self-management program involving peer facilitators and peer discussions. They found significant improvements in health status at 1 year and showed that improvements were similar to those achieved in a face-to-face version of the program.

Our study aimed to identify what key stakeholder groups (health professionals, people with diabetes, and both users of the program and observers) most value about the Reality Check online community. Øvretveit<sup>30</sup> argues that "value explication" is an important part of evaluation. Where the values relate to benefits, impacts, or outcomes of a program, they can be described as "success values." Success values can be determined through what has been measured in other research studies on the topic if the primary user of the evaluation is the scientific/research community; otherwise, they should be specifically investigated with relevant stakeholders.<sup>31</sup>

The second aim of our study was to contribute the experiences from this long-running and self-sustaining online program to the growing field of peer-support research. Identifying what users value most could inform the selection of outcomes that are most important to measure in summative evaluations of this and other peer-support programs.

### Study Methods

The study involved conducting online focus groups with both users and observers of an online community of people with type 1 diabetes and conducting an online survey of health professionals.

The University of Melbourne's Population Health Human Ethics Advisory Group granted approval for this project on 3 June 2010 (Ethics ID 1033676).

### Reality Check online community

Reality Check is an Australian open-

access online community (located online at [www.realitycheck.org.au](http://www.realitycheck.org.au)), where people with type 1 diabetes discuss topics of interest to them in real time. After a brief registration process requiring only a user name and an e-mail address, participants type a message on their computer that is then immediately published on the Web site, where others can similarly log in and post responses to the message, creating discussions threads. Discussions can be read and observed on the Web site freely without registering or requiring a password. At the time of this study, the program was 13 years old and had 1,558 registered members.

The online community's purpose has been defined by its founders as facilitating sharing of personal experiences of living with diabetes. Notably, provision of medical advice is actively discouraged and removed if it occurs.

The program is an active forum. A 2010 content analysis showed that, in a 1-week snapshot, 75 unique participants posted 197 messages covering 23 different topics. The median time for a participant to receive a response was 1 hour and 14 minutes, and there was a median of 15 responses in each discussion.

Volunteer moderators, all people with type 1 diabetes themselves and longstanding members of the community, actively monitor the Web site. There is no formal training system for the volunteers, but they enforce a published set of rules. A weekly roster system is used to ensure that a moderator is monitoring the Web site at least daily. Moderation can involve removing inappropriate messages such as advertising or the provision of medical advice, contacting members by e-mail to explain the Web site's rules, and banning inappropriate participants. However, the most frequent activity of the moderators is to make proactive contributions to the community and model and reinforce appropriate behavior and discussion, such as welcoming new members, contributing their own experiences, and providing links to high-quality information resources.

Its founders describe Reality Check as an online peer-support program.<sup>27</sup>

**Online focus groups**

Online focus groups were conducted with users of the Reality Check online community. Conducting focus groups online had practical benefits in that the target population was geographically dispersed and known to be active online. Methodological benefits were also identified. Walston and Lissitz<sup>32</sup> studied online focus groups' effectiveness as a methodology in direct comparison with in-person focus groups, concluding that they could be equally effective and that there may be added benefits of the online format, including that "the online environment may . . . discourage participants from withholding embarrassing information." Stewart and Williams<sup>33</sup> examined the use of online focus groups in qualitative research, identifying among the benefits that participants can have time to reflect and form a more considered response.

The focus groups were conducted within a private, password-protected section of the same online community Web site as that being evaluated. Participants used their own computers to access the focus groups and were asked to participate for a minimum of two 15-minute occasions during a 2-week period. Discussions were asynchronous, as is common in online communities.

Participants were recruited through a third-party e-mail invitation. The recruitment directly sought both contributors to the Reality Check forum and users who visit the site and read messages without directly contributing (observers). Participants were allocated to focus groups based on their patterns of use (observers, active observers, or occasional, regular, or frequent contributors) to achieve optimal group dynamics, which is crucial in focus groups, including those conducted online.<sup>34-36</sup> Focus groups were led by an experienced, independent facilitator.

Participants responded to seven questions raised by the facilitator (Table 1). The facilitator viewed the focus groups daily, adding prompts

and additional questions to encourage responses and discussion among participants.

At the conclusion of the focus groups, transcripts were copied and saved to secure, electronic computer files by the evaluator, and the transcripts were deleted from the Web site. All user accounts created for the purpose of the research were closed and deleted at the focus groups' conclusion.

**Health professional survey**

A survey of health professionals was designed to investigate their success values for the program. The survey explored health professionals' own use of the online community and their experiences of referring people with diabetes to use it (Table 2).

The survey was administered in an online format and was anonymous. It was piloted with six health professionals and subsequently dis-

**Table 1. Focus Group Questions**

1. What is it about the Reality Check online discussion forum that attracts you to it?
2. When you visit the Reality Check online community, what are you hoping to get out of it?
3. Please describe a memorable experience that has been very positive, where you found the Reality Check online community to be very successful and valuable?
4. Please describe a bad experience that you have had on the Reality Check online community.
5. Have you ever had any of the following happen on the Reality Check online community: Received incorrect information about diabetes or its treatments? Received unsupportive or unhelpful responses to your queries? Or, found the people on Reality Check to be unwelcoming or unsupportive?
6. In the previous several questions, we have been discussing what you value about the Reality Check online community, why you visit, and what you hope to get out of visiting. Can you please comment on the extent to which you feel Reality Check achieves those things that you have identified as important to you when you visit?
7. What would make the Reality Check online community more successful for you? And can you suggest any specific changes to Reality Check that would make it more successful for you?

**Table 2. Summary of Areas Included in Health Professional Survey Questions**

- Health professionals were asked a set of questions about their experiences of the Reality Check online community or discussion forum, such as:
- What is it about the Reality Check online discussion forum that attracts you to it? What are you hoping to get out of it?
  - If you refer people with type 1 diabetes to it, why, and what are they hoping they get out of it? What is it about the Reality Check online community that attracts you to referring or encouraging people with diabetes to visit the Web site?
  - Provide examples of where you found Reality Check to be very successful and valuable, such as observing where a person with diabetes benefited from Reality Check.
  - Comment on the extent to which you feel Reality Check successfully achieves those things that you have identified as important to you or to people with type 1 diabetes that you refer to Reality Check.
  - What is it about the Reality Check online community that discourages you from referring people with type 1 diabetes to it?
  - Provide examples of negative experiences with the online community that you or people you have referred may have had.
  - What would make the Reality Check online community more successful for you and for people with type 1 diabetes that you may refer?

seminated via an e-mail sent to all health professionals subscribed to the managing organization (the Type 1 Diabetes Network) e-mail newsletter, which invited them to participate in a survey exploring health professionals' experiences of the Reality Check online community. Recruitment and data collection took place over 35 days.

**Data analysis**

Thematic analysis was used for both the online focus group transcripts and the health professional survey data. The analysis was conducted by the internal evaluator together with an independent person; for the focus groups, this was the independent focus group facilitator, and for the health professional survey, it was a diabetes nurse educator with experience in social research.

Data were analyzed using a three-stage approach endorsed for qualitative research in public health: data immersion, coding, and then creating categories and subcategories<sup>37</sup> (Figure 1). In stage three, a deductive process was applied to determine whether coded data could be categorized into the four core functions that underpin all peer-support programs as described by Peers for Progress,<sup>14</sup> namely, 1) assistance in applying disease management in daily life, 2) emotional and social support, 3) linkage to clinical care, and 4) ongoing support. A fifth category, acceptability

of specific program delivery features, was also used, consistent with the Peers for Progress<sup>14</sup> assertion in their definition that issues of delivery and implementation of peer-support programs should be considered separately from those describing the functions of the peer-support process.

Initially, the definition of each function of peer support was used to create subcategories, and coded responses were matched to these subcategories. New subcategories were created for remaining data that fit within a function area but did not fit the precise definition of that function. For example, "assistance in applying diabetes management in daily life" has been given a precise definition as described above, and from that, two subcategories were created: "real-life experiences of diabetes" and "identifying key resources." Three new subcategories were created by the researchers to describe data grouped in this category that did not fit into the definition above. These were "problem solving," "learning," and "improve management of diabetes."

**Study Results**

**Online focus groups**

**Participation and recruitment.** A recruitment e-mail was sent to 4,119 subscribers to the managing organization's monthly e-mail newsletter. The recruitment information was

also placed as an advertisement within the online community for 2 weeks. Ninety-nine people registered their interest in participating over a 2-week period. Ten did not meet the study's inclusion criteria; eight had not visited the Web site in the preceding 3 months; one exceeded the age limit, and one was a moderator of the Web site. Eight-nine people were invited to participate in the focus groups.

Forty-two people participated in six focus groups. The average age of participants was 37.2 years (range 22–60 years). Twenty-six percent were male. The average duration of type 1 diabetes was 17.5 years (range 1–46 years). All participants spoke English at home. Thirty-nine participants (93%) resided in Australia, two (5%) in the United Kingdom, and one (3%) in New Zealand. Participants' duration of participation in the program was most commonly reported as > 5 years (by 14 people, 33%), with 12 (29%) at 2–5 years, 8 (19%) at 1–2 years, 4 (10%) at 3–12 months, and 2 (5%) at 1–3 months. The frequency of participation in the program (by visiting the Web site) was most commonly reported as daily (36%), with 26% monthly, 24% weekly, 10% several times per day, and 5% visiting once in the past 3 months. Thirty-one percent were observers, having visited the Web site but not posted any messages in the preceding 3 months.

**People with diabetes' success values.** Through the first phase of analysis, 66 codes were developed to describe what participants most valued about the program. The 66 codes were examined to determine whether they could be categorized into the four core functions of peer support or the fifth category, which we called "program delivery features." A large volume and wide diversity of data were found within the first three of the five categories, and, to accurately represent the data, a total of eight subcategories were drawn from the Peers for Progress definitions of the categories. The data in those categories were allocated to subcategories as appropriate, as shown in Table 3.

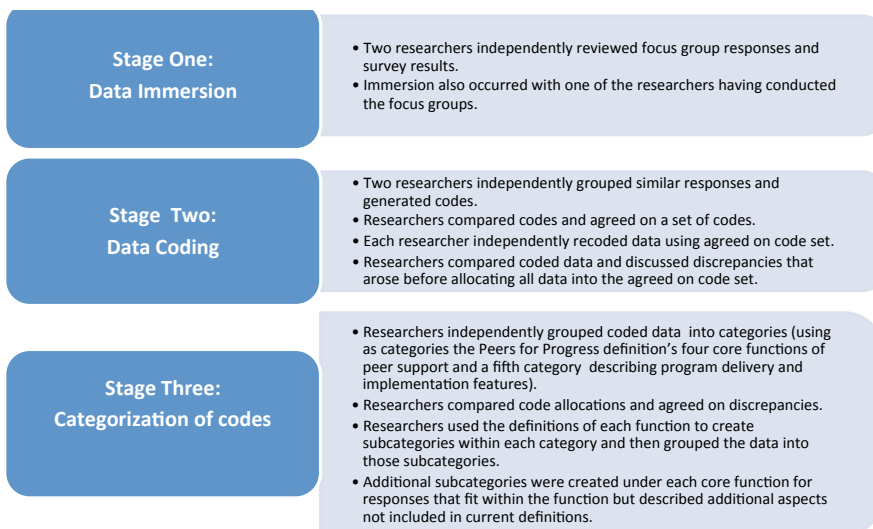


Figure 1. Data analysis methodology.



Finally, there were some data describing success values for the program held by people with diabetes that fit into the broader categories of the Peers for Progress model of peer support but did not fit the more specific definitions of each function of peer support and therefore did not fit the subcategories created directly from the definition. A total of eight new subcategories were created to describe these remaining data, as shown in Table 4.

*Program delivery features valued by people with diabetes.* In addition to the success values that aligned with the core functions of peer support, participants identified a range of program delivery features they valued. Consistent with the Peers for Progress<sup>14</sup> definition of peer support, data relating to delivery and implementation issues were considered separately from those describing the function of the peer support process and were therefore considered as a

fifth data category. Within this category, five subcategories were created to describe the program delivery features participants valued, as shown in Table 5.

*Participants' negative experiences.* Specific focus group questions purposefully sought to elicit negative experiences, and together with those recounted throughout general discussions, 14 codes were developed to describe these data.

**Table 3. Success Values Held by People With Diabetes That Aligned Directly With the Peers for Progress Definition of Peer Support**

Categories Drawn From Core Functions of Peer Support <sup>14</sup>	Subcategories Drawn From Definitions of Each Core Function of Peer Support <sup>14,15</sup>	Examples of How People With Diabetes Described Their Values
Assistance in applying diabetes management in daily life	Sharing real-life experiences of living with diabetes	“The people on here have direct experience of T[ype] 1 . . . It’s not theoretical info or what might be the correct medical answer from someone who has no idea what they might be asking of us to do or to add to a busy life.”
	Help in identifying key resources	“I just log in to see what is happening, who has posted, any exciting news ie A CURE lol & just lurk around and read whatever interests me. I generally feel satisfied that I have learned something or contributed my 2 cents’ worth whenever I visit.”
Ongoing social and emotional support	Empathetic listening; reflected as making participants feel understood and validated as well as the program being an opportunity to offload or vent	“I don’t know anyone else who has type 1 so the forums are really useful for information, to vent our frustrations, to make you feel like your [sic] not alone.”
	Providing encouragement	“I typed out my story . . . The responses were astronomical! People who had done the same—skipping insulin to lose weight—and all the positive encouragement in my process to recovery was something I never expected but really appreciate.”
	Support to stay motivated	“It is not there to tell me off for not doing the expected diabetic management but it sometimes motivates me to improve how I care for myself.”
	Help coping with social and emotional barriers	“Sometimes it is like having [type 1 diabetes] fills your cup right up to the brim and one more drop and it will over flow. Reality Check is the saucer to catch the over flow.” “The most important thing I get out of RC is the humor. It is critical in me keeping my feet grounded. I guess it’s just what the name says it is—a reality check!”
Ongoing availability of support, proactive contact	Ongoing availability of support	“I see my endo [doctor] . . . every 4 months or so. This site is there all the times in between and especially when I don’t need a medical opinion . . .”
	Proactive contact	“I pop in every few weeks or so, often as a result of receiving the Yada Yada e-mail newsletter.”

**Table 4. Success Values Held by People With Diabetes That Expand on the Peers for Progress Model of Peer Support**

Categories Drawn From Core Functions of Peer Support <sup>14</sup>	Subcategories Created Originally, Expanding on the Definition	Examples of How People With Diabetes Describe Their Values
Assistance in applying diabetes management in daily life	Problem solving; participants' responses specifically noted that they used the online community to solve problems related to diabetes	"[I am hoping to get out of visiting Reality Check] answers to problems and issues with day-to-day living and hearing people's responses about their own experiences."
	Learning; using the program to learn about diabetes, including new technologies such as insulin pumps and discussions about applying new treatments in daily life	"Because of [the program] I am now very well educated and have an outstanding understanding of diabetes."
	Improve management of diabetes; specifically noted as something participants had achieved or wanted to achieve through using the program	"A friend found your Web site and . . . I spent the next 16 hours reading posts, replies to posts with tips and suggestions. I have never had a reading of more than 12 [mmol/L, or 216 mg/dl], and the lowest I have ever gone is 2.1 [mmol/L, or 38 mg/dl] thanks mostly to your site. My aim is to live a life with D[iabetes] with little to no boundaries; your site helps me to achieve [sic] this goal."
Ongoing social and emotional support	Feel supported; separate from coping with emotional barriers; described a more general sense of feeling supported	"General support during tough times such as pregnancy when the guilt and fear levels are high, or when you need to have a grumble about D[iabetes] in general."
	Self-reflection	"It gets me thinking about this condition . . . its [sic] gentle, enjoyable even . . . I spend a lot of time either consciously or unconsciously thinking about d[iabetes] . . . which I find a chore and a bore. So to actually set aside some time meditating on it in a more enjoyable way has been good for me."
	Connection and interaction with peers; the value of simply connecting with other people with shared experiences	"I also like to read other people's experiences. Sometimes the responders offer advise [sic] but mostly it just helps to confirm that there are others in the same boat as I am."
	Sense of community	"The sense of belonging is really important; it helps in all aspects of your life. [Reality Check] is like a family. Sure these are people you don't know, and will probably never meet, but you all have the same thing in common. One common link that brings you together."
	Assisting others; participants valued assisting others by sharing their own experiences and knowledge	"Being able to offer support that is appreciated is really valuable. It makes you feel that your journey and the choices you've made are worthwhile and purposeful."

Twenty-two participants (53%) stated that they had no bad experiences to report. One representative comment stated, "I have not had a bad experience on Reality Check. Obviously not all posts are equally important or interesting to me, but I

just don't read those ones. That's the beauty of a forum."

Discussion about how the program is managed or moderated elicited some concerns that the manner in which participants who break the rules are "reprimanded" could

be taken badly. Generally, however, discussion of program management was positive, with an understanding of the complexity and challenges that moderators face.

Other negative experiences reported by participants can be

Table 5. Program Delivery Features Valued by People With Diabetes

Subcategory	Examples of How People With Diabetes Describe Their Values
Sizeable and active community encompassing diverse perspectives	“It’s great here because the community runs the gamut of diabetics. I feel as though I can identify with many here.”
Open-access online delivery model, allowing anonymity, access from home, free of obligation, and low-cost, without the social complexities of in-person gatherings	“Online is good from the perspective that it’s anywhere anytime access. . . . I’m stuck in the middle of not wanting to be in a diabetes social club as I don’t want my diabetes to define me and a place where I can go to share when I want [or] need to.” “I tried to engage in [diabetes] social events but found, unsurprisingly, that having T[ype] 1 doesn’t necessarily amount to enough of a commonality to make for a workable social experience. Online, people can take or leave what I write, and vice versa, with much less anxst [sic] about real-world social dynamics.”
Active and effective management	“If R[eality] C[heck] did not provide the culture it does, that is open, well moderated, and supportive, I would not visit it.”
Local relevance with it being Australian	“It is critically important that it is Australian, because we have a different medical care model here, and a way of life that doesn’t seem to translate on other fora.”
Peer-led or peer-driven nature of the program	“The moderators are regular contributors. They don’t just pop up if there is a problem. They are there, sharing the journey, offering advice but also asking questions. They are real, interested, committed [sic], and having them pop up so often subconsciously reminds people of the expectations of the forum.”

summarized through the codes developed: not allowing provision of medical advice within the forum is a form of censorship; feeling judged by other participants; negativity/victim mentality of some participants; criticism of health professionals is wearying; repetition and predictability of some topics discussed; being misunderstood led to someone being offended; strong negative views of type 2 diabetes and the public’s confusion with type 1 diabetes and the differing management demands between the conditions; not enough people using it at one point; scary experiences discussed (e.g., complications); conflicting opinions causing hostility; and incorrect information is sometimes posted but it is quickly corrected.

**Survey of health professionals**  
*Participants and recruitment.* An e-mail invitation was sent to 588 people who had identified themselves as health professionals when subscribing to the managing organization’s monthly e-mail newsletter. Eighty-one (14%) complete survey responses were received and analyzed.

The average age of respondents was 44 years, ranging from 21 to 64

years. The majority of respondents were female, with only 15 (19%) male. The majority (83%) were based in Australia, with some from New Zealand (5%). Thirty-four (42%) were in rural or regional areas, with the remaining 47 (58%) in metropolitan areas.

The majority (54, or 67%) identified their profession as diabetes nurse educator; the remainder were 7 (10%) other types of nurses, 2 (3%) pharmacists, 1 (2%) paramedic, 1 (2%) medical, and 1 (2%) community program coordinator. There were no specialist physicians or general practitioners. Respondents’ work settings were diverse: 40 (49%) hospital, 12 (15%) community-based health service, 6 (7%) primary care/medical clinic, and 7 (9%) private practice. Thirty-two (40%) reported that they or someone in their immediate family had type 1 diabetes, 41 (51%) did not, and 8 (10%) did not state.

*Health professionals’ success values regarding use of the program by people with diabetes.* The health professional survey investigated participants’ success values for the Reality Check online community, that is, what they personally valued as defining success for the program.

Success values were explored with regard to what health professionals valued about both people with diabetes participating in the program and their own personal use of the program. This article reports what health professionals valued with regard to people with diabetes who they refer to the program. Ninety-one percent of respondents indicated that they refer people to the program.

Through the first phase of analysis, 64 codes were developed, and, as with the analysis process for the focus groups, these codes were subsequently grouped into categories and subcategories drawn from the Peers for Progress definition of peer support,<sup>14,15</sup> as shown in Table 6, which offers examples of success values identified.

As with the focus group data analysis, some data fit into the broader categories of the Peers for Progress<sup>14,15</sup> model but did not fit the more specific definitions of each function of peer support. Therefore, six new subcategories were created to describe these remaining data, as shown in Table 7.

*Acceptability of program delivery features.* The program delivery features that health

**Table 6. Success Values of Health Professionals That Aligned Directly with the Peers for Progress Definition of Peer Support**

Categories Drawn From Core Functions of Peer Support <sup>14</sup>	Subcategories Drawn From Definitions of Each Core Function of Peer Support <sup>14,15</sup>	Examples of How Health Professionals Described Their Values
Assistance in applying diabetes management plans in daily life	Access to other people’s experiences of living with diabetes	“[I refer people to the program because ] I like to think I can teach them ALL about t[type]1 d[iabetes] . . . But it is real life that gets in the way of their ability to ‘manage!’” “[I refer people for] real life problems and stories and solutions for people with [type 1 diabetes] by [people with type 1 diabetes].”
	Source of key resources, information, and learning about diabetes	“When [patients] turn 18 they loose [sic] the security of [children’s hospital diabetes services]. This gives them another way to keep uptodate [sic].” “Sometimes I cannot answer a question from a patient, and I suggest they ask the forum [program].” “[I am hoping they get out of it] any info I have missed.”
Emotional and social support	Empathetic listening and encouragement	“It is a great support network for type 1’s, a place to talk, or just listen, and know they are not alone with their health issues.” “Pregnant patient, finding reassurance that she was doing ok and getting support.”
	Coping with social or emotional barriers	“I recognized a patient that I saw who joined the [program]. I didn’t realize how socially isolated he had become after his diagnosis, as I had seen him in hospital immediately after his diagnosis. It was wonderful to see him get all the encouragement he needed to get back out there into the community.”
Linkage to clinical care	Facilitates access to services	“People who come to this Web site can expect information, support, and access to various services that assist them with their diagnosis.”
Ongoing, proactive support	Available as needed, on demand	“Stretches beyond physical geographical boundaries that face-to-face peer support is often challenged by.”

professionals most valued included three aspects. First, they described a group of success values relating to program delivery features that are intentional parts of the program delivery, including it being Australian, focused on type 1 diabetes, anonymous, not moderated by health professionals, online, technically accessible, and well monitored. Second were a group of realized program characteristics, including the positive and constructive attitudes to living with diabetes, the welcoming and supportive nature of the community, the fact that it is easy to understand, and the honesty of participants. Finally, professionals described specific client groups for whom the program is acceptable, including newly diagnosed patients, young people, clients with the necessary intellect to use it, clients who

have the “capacity to filter” information, and people living in rural and remote areas or anyone experiencing geographical barriers to other forms of peer support.

**Negative experiences.** The survey actively sought information about respondents’ negative experiences with the program. Thirty-six (44%) stated that they had not had any bad experiences. Thirty-one (38%) did not answer the question. Of the 18 (12%) respondents who described a negative experience, the following codes describe their experiences, and the number of respondents who identified each type is shown in parentheses.

Professionals’ responses related both to feedback from patients referred to the program and to personal experiences of using the program. Feedback from patients

referred included: the participant could not find someone who had had a similar experience to own(1); participant was attacked for having a different perspective (2); discussing anxiety heightened anxiety (1); negative feedback about my diabetes service was discussed on the Web site (1); moderation of posts was overzealous, and a participant therefore withdrew participation (1); negativity of some discussions had an adverse effect(2); and participants perceived to be “needy” (1). Health professionals personal experiences included: cynical attitudes toward health services (1); negative discussion of type 2 diabetes (1); diabetes management techniques discussed are not consistent with standard recommendations (3); gossip about health professionals (2); and “inappropriate advice”(1). One further negative experience



**Table 7. Success Values of Health Professionals That Expand on the Peers for Progress Definition of Peer Support**

Categories Drawn From Core Functions of Peer Support <sup>14</sup>	Subcategories Created Originally, Expanding on the Definition	Examples of How Health Professionals Describe Their Values
Assistance in applying diabetes management plans in daily life	Problem-solving	“What they are experiencing others may have done before and may have some really practical ideas on how to deal with issues.”
	Improved clinical management of diabetes	“[I am hoping they will] learn how to manage there [sic] diabetes from day to day.” “I suggested one of my lady’s [sic] contacted Reality Check as she was considering pregnancy and couldn’t understand why the team were keen for her to get diabetes under better control before conception. She read a few of the forums . . . and came to her own conclusion that she would wait for a while before trying for a baby and would get her vaccinations, bloods, etc., sorted out.”
Emotional and social support	Psychological well-being	“[I am hoping they will get out of it] a decrease in the risk of burnout/depression.”
	Feel supported	“It is a support tool for people with diabetes talking about issues that affect them with support from their peers.”
	Connection with peers, including people realizing they are not alone and receiving positive role modeling	“Real people with real stories, all connecting and communicating over common link of diabetes.” “Warm positive nature of many discussions promotes a ‘get on with life’ approach rather than dwelling on having diabetes.” <sup>3</sup>
	Parents/caregivers feel supported	“We are from a rural area; for some people they don’t know anyone else with type 1 and this site allows that connection. Also a good site for loved ones to go.”

related to other services provided by the managing organization: difficulties in supply of some printed resources.

**Differences between stakeholder groups’ success values.** Table 8 shows what was valued, which of the values aligned with the established definitions of peer support, and how the values vary between the stakeholder groups studied: health professionals and people with diabetes.

Values that were associated with the first core function of peer support, “assistance in applying diabetes management in daily life,” were similar between health professionals and people with diabetes. In the second core function of peer support, “emotional and social support,” people with diabetes identified more values for the program than health professionals, with the additional concepts that they valued being encouraged, staying motivated,

facilitating self-reflection, feeling a sense of community, and assisting others. Health professionals’ main differential was that parents and caregivers could gain support from the program. Finally, although health professionals valued the program for providing linkages to clinical care, which is a part of the Peers for Progress definition of peer support,<sup>14</sup> people with diabetes did not identify this as something that they valued.

## Discussion

### Online community valued for peer-support function

A consumer-led online community is valued for a function that is similar to more structured peer-support programs that are more commonly delivered in person. People with diabetes said the online community provides them with a wide range of supports that are distinct from what they may receive from clinical care provided by health professionals and

provides complementary processes that participants value highly as contributing to their ability to manage their diabetes.

The success values that people with diabetes identified were consistent with the Peers for Progress definition of peer support,<sup>14</sup> with the exception of it providing a “linkage to clinical care.” The success values that health professionals identified were also consistent with the peer-support definition, covering all four core functions of peer support encompassed in the definition.

Despite the definition having been developed predominantly around more structured programs delivered in person, the study confirms that an online community can be conceptualized as providing peer support.

### Health professionals’ views of online communities

What health professionals reported as being valuable about the online

**Table 8. Success Values Identified by Stakeholder Group Compared to an Established Definition of Peer Support**

Peers for Progress Core Functions of Peer Support <sup>14</sup>	Subcategories Drawn From the Definition <sup>14,15</sup>	Original Subcategories Developed in This Study That Expand the Definition	Valued by People With Diabetes	Valued by Health Professionals
Assistance in applying diabetes management in daily life	Access to personal experiences of living with diabetes		✓	✓
	Identifying key resources		✓	✓
		Problem-solving	✓	✓
		Learning	✓	✓
		Improve management of diabetes	✓	✓
Ongoing social and emotional support	Empathetic listening		✓	✓
	Encouragement		✓	
	Cope with social or emotional barriers		✓	✓
	Stay motivated to reach their goals		✓	
		Feel supported	✓	✓
		Self-reflection	✓	
		Connection and interaction with peers	✓	✓
		Sense of community	✓	
		Assist others	✓	
	Parents/caregivers gain support			✓
Ongoing availability of support, proactive contact	Peer supporters successfully keep patients engaged by providing proactive, flexible, and continual long-term follow-up		✓	✓
Linkages with clinical care	Peer supporters can help bridge the gap between the patients and primary care providers and encourage individuals to seek out clinical care when it is appropriate.			✓

community for their patients was similar to what people with diabetes valued for themselves. However, health professionals identified fewer forms of emotional and social support than people with diabetes themselves valued receiving from the program. Although

health professionals and people with diabetes both identified “empathetic listening,” “coping with social or emotional barriers,” “feeling supported,” and “connection and interaction with peers,” people with diabetes also valued some additional types of support, including “encour-

agement,” “staying motivated to reach their goals,” “self-reflection,” “a sense of community,” and “assisting others.”

There was some similarity among those concepts that people with diabetes identified and health professionals did not, in that they may

be conceptualized as broader and deeper forms of social and emotional support. Given that there has been limited exploration of health professionals' perceptions of peer-support programs and barriers to them referring to and supporting such programs, these differences may make a valuable contribution to understanding the opportunities for increasing health professionals' understanding of what peer support can provide for people with chronic conditions.

### Expanding the definition of peer support

Although the range of concepts that both people with diabetes and health professionals consistently identified as valuable about the online community fit broadly within the established definition of peer support, some new concepts were also identified that increase our understanding of the many benefits that participants may receive from peer support. For example, within "ongoing social and emotional support," the concepts of "feeling supported," "self-reflection," "connection and interaction with peers," "a sense of community," and "assisting others" were identified in this study but not addressed in current definitions.

The study also identified a bias in the current definition of peer support towards place-based programs. The peer-support function of helping people to "identify key resources" is explained as "where to buy healthy foods or . . . locations for exercise," which assumes a common location, whereas people with diabetes valued Reality Check for assisting them to identify key resources, yet they described this differently, as involving "new products and equipment," "hot topics," "current issues," and "upcoming events." Given that there have been few previous exploratory studies of long-running peer-support programs to identify what stakeholders value about them, these concepts provide insight into what people with long-term conditions value about peer support and may make valuable additions to the current definition of peer support.

### Study limitations

This study had some limitations. In the health professional survey, nurses were overrepresented (77% of respondents), and no specialist physicians participated. A high proportion of health professional respondents had type 1 diabetes themselves or had an immediate family member with diabetes (40%, when population prevalence in Australia is 0.7%). The focus groups were conducted within the same Web site as the program itself; although the high response rate of 42 participants suggests that that choice was acceptable, the bias toward those for whom the program is already acceptable must be noted.

An additional potential limitation is that the evaluation was designed and led by one of the founders of the program, thereby making it an internal evaluation, which has both benefits and risks. Cummings<sup>38</sup> describes the advantages of an internal evaluator as knowing the nuances of the agency and knowing how evaluation can make a difference, as well as having credibility that fosters stakeholder commitment and the ability to promote the use of evaluation findings. Owen<sup>39</sup> also argues that an internal evaluator can play a crucial role in promoting learning within an organization, analyzing organizational culture and surfacing and challenging assumptions.

Owen's guidelines for evaluation by "insiders"<sup>39</sup> were used to assess the risks of an internal evaluation. Three potential issues were identified: compromise of objectivity, coercive recruitment, and resistance to negative findings. Strategies were embedded in the evaluation design to address these risks, including third-party recruitment, ongoing engagement with the program managers, an independent focus group facilitator, and independent coanalysts of the qualitative data.

Risks associated with the use of an internal evaluator appear to have been minimized, as shown by the high response and participation rates and the successful collection of negative experiences, which suggests that participants felt that their anonym-

ity was protected. The immediate uptake of some early findings from the evaluation by the program managers has demonstrated that the risk of resistance to negative findings was also minimized.

The generalizability of this qualitative study's findings to other peer-support programs is not clear, and further study of other online communities formed around health conditions is required to understand the current and potential role of online communities in health care. However, this study has provided a rare opportunity to investigate two fast-growing phenomena—online communities and peer-support programs—and to explore in some depth the perspectives of both participants and health professional referrers.

The fact that the program has been long-running, allowing stakeholders' viewpoints and experiences the opportunity to have developed over time and through repeated interactions with the program, enhances the findings. Enhancements to the program itself, our understanding of peer support, and our ability to evaluate peer-support programs have all resulted from the study.

### Acknowledgments

This study was submitted as part of a Masters of Public Health degree undertaken at the University of Melbourne, and the project was supervised by Rosemary McKenzie. Dr. Sarity Dodson facilitated the online focus groups and assisted with data analysis. Marie Gill assisted with interpretation and analysis of data from the health professional survey. The authors would like to thank the volunteer management committee of the Type 1 Diabetes Network and moderators of the Reality Check online community, without whom the subject of this evaluation would not exist, for their generous and wholehearted support of this effort. Special thanks go to Colleen Clarke, administration coordinator with the Type 1 Diabetes Network, who managed the third-party recruitment for the focus groups.

## References

- <sup>1</sup>Daneman D: Type 1 diabetes. *Lancet* 367:847–858, 2006
- <sup>2</sup>Royal Australian College of General Practitioners and Diabetes Australia: *Diabetes Management in General Practice, 2009/10*. Canberra, Australia, Royal Australian College of General Practitioners and Diabetes Australia, 2010
- <sup>3</sup>Revenson TA, Felton BJ: Disability and coping as predictors of psychological adjustment to rheumatoid arthritis. *J Consult Clin Psychol* 57:344–348, 1989
- <sup>4</sup>Egede LE, Zheng D: Independent factors associated with major depressive disorder in a national sample of individuals with diabetes. *Diabetes Care* 26:104–111, 2003
- <sup>5</sup>Bailey BJ: Mediators of depression in adults with diabetes. *Clin Nurs Res* 5:28–42, 1996
- <sup>6</sup>Stanton A, Revenson TA, Tennen H: Health psychology: psychological adjustment to chronic disease. *Ann Rev Psychol* 58:565–592, 2007
- <sup>7</sup>Bradley C, Brewin CR, Gamsu DS, Moses JL: Development of scales to measure perceived control of diabetes mellitus and diabetes-related health beliefs. *Diabet Med* 1:213–218, 1984
- <sup>8</sup>Littlefield CH, Rodin GM, Murray MA, Craven JL: Influence of functional impairment and social support on depressive symptoms in persons with diabetes. *Health Psychol* 9:737–749, 1990
- <sup>9</sup>Brownson C, Heisler M: The role of peer support in diabetes care and self-management. *Patient* 2:5–17, 2009
- <sup>10</sup>Dennis C-L: Peer support within a health care context: a concept analysis. *Int J Nurs Stud* 40:321–332, 2003
- <sup>11</sup>World Health Organization: Peer Support Programmes in Diabetes: Report of a WHO Consultation. Geneva, Switzerland, 5–7 November 2007
- <sup>12</sup>Fisher E: Peer support as a key approach to self-management and community support in chronic care: evidence and models for implementation. Presentation at the Australian Disease Management Association meeting, Melbourne, Australia, 2010
- <sup>13</sup>Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakou O: Diffusion of innovations in service organizations: systematic review and recommendations. *Milbank Q* 82:581–629, 2004
- <sup>14</sup>Boothroyd R, Fisher E: Peers for Progress: promoting peer support for health around the world. *Fam Pract* 27 (Suppl. 1):i62–i68, 2010
- <sup>15</sup>Peers for Progress: What is peer support? [article online] Available from [http://www.peersforprogress.org/learn\\_whatls.php](http://www.peersforprogress.org/learn_whatls.php). Accessed 4 September 2010
- <sup>16</sup>Heisler M: *Building Peer Support Programs to Manage Chronic Disease: Seven Models for Success*. Oakland, Calif., California Healthcare Foundation, 2006
- <sup>17</sup>Tang TS, Ayala G, Cherrington A, Rana G: A review of volunteer-based peer support interventions in diabetes. *Diabetes Spectrum* 24:85–98, 2011
- <sup>18</sup>Eldstad EA, Boothroyd R, Henes A, Maslow G, Nelson K, Fisher E: Global systematic review of peer support for complex health behaviour. Presentation at the International Congress of Behavioral Medicine, Washington, D.C., 2010
- <sup>19</sup>Fisher E, Boothroyd RI, Coufal MM, Baumann LC, Mbanya JC, Rotheram-Borus MJ, Sanguanprast B, Tanasugarn C: Peer support for self-management of diabetes improved outcomes in international settings. *Health Aff* 31:130–139, 2012
- <sup>20</sup>Carolan M: In individuals with poorly controlled diabetes, a reciprocal peer support programme gives greater 6-month improvement in HbA<sub>1c</sub> than does nurse care management. *Evid Based Nurs* 14:49–50, 2011
- <sup>21</sup>Docherty A, Dale J: The role of the lay health advisor in enhancing psychosocial well-being and self-management in diabetes: a feasibility study. Presentation at the annual scientific meeting of the Society for Academic Primary Care, Belfast, Ireland, 2004
- <sup>22</sup>Nordqvist C, Hanberger L: Health professionals' attitudes towards using a Web 2.0 portal for child and adolescent diabetes care: qualitative study. *J Med Internet Res* 11:e12, 2009
- <sup>23</sup>Brown C, Hennings J, Caress AL, Partridge MR: Lay educators in asthma self-management: reflections on their training and experiences. *Patient Educ Couns* 68:131–138, 2007
- <sup>24</sup>National Collaborating Centre for Chronic Conditions: *Type 1 Diabetes in Adults: National Clinical Guideline for Diagnosis and Management in Primary and Secondary Care*. London, Royal College of Physicians, 2004
- <sup>25</sup>Australasian Paediatric Endocrine Group and Australian Diabetes Society: *Draft National Evidence-Based Clinical Care Guidelines for Type 1 Diabetes in Children, Adolescents, and Adults*. Canberra, Australia, Australian Diabetes Society, 2011
- <sup>26</sup>Heisler M: Overview of peer support models to improve diabetes self-management and clinical outcomes. *Diabetes Spectrum* 20:214–221, 2007
- <sup>27</sup>Gilbert K: Diabetes Online: Benefits, Risks, and Many Opportunities. Presentation at the International Diabetes Federation World Diabetes Congress 2009, Montreal, Canada
- <sup>28</sup>Rodgers S, Chen Q: Internet community group participation: psychosocial benefits for women with breast cancer [article online]. *J Comput Mediat Commun* 10:5, 2005. Available from <http://jcmc.indiana.edu/vol10/issue4/rogers.html>
- <sup>29</sup>Lorig KR, Ritter PL, Laurent DD, Plant K: Internet-based chronic disease self-management: a randomized trial. *Med Care* 44:964–971, 2006
- <sup>30</sup>Øvretveit J: *Evaluating Health Interventions*. Maidenhead, England, Open University Press, 1998
- <sup>31</sup>Øvretveit J: Concept 2: value criteria. In *Action Evaluation of Health Programmes and Changes: A Handbook for a User-Focused Approach*. Oxford, England, Radcliffe Medical Press, 2002, p. 90–92
- <sup>32</sup>Walston JT, Lissitz RW: Computer-mediated focus groups. *Eval Rev* 5:457–483, 2000
- <sup>33</sup>Stewart K, Williams M: Researching online populations: the use of online focus groups for social research. *Qual Res* 5:395–416, 2005
- <sup>34</sup>Preece J: *Online Communities: Designing Usability, Supporting Sociability*. Chichester, U.K., Wiley, 2000
- <sup>35</sup>Murray P: Using virtual focus groups in qualitative health research. *Qual Health Res* 7:542–549, 1997
- <sup>36</sup>Patton MQ: *Qualitative Research and Evaluation Methods*. Thousand Oaks, Calif., Sage, 2002
- <sup>37</sup>Green J, Willis K, Hughes E, Small R, Welch N, Gibbs L: Generating best evidence from qualitative research: the role of data analysis. *Aust N Z J Public Health* 31:545–550, 2007
- <sup>38</sup>Cummings OW: Business perspectives on internal/external evaluation. *New Directions for Program Evaluation* 39:59–74, 1988
- <sup>39</sup>Owen J: Guidelines for evaluation by insiders. In *Program Evaluation: Forms and Approaches*. Melbourne, Australia, Allen & Unwin, 2006, p. 142–145

The authors are all based in Melbourne, Australia. Kate Gilbert, BA, MPH, is the founder and immediate past president of the Type 1 Diabetes Network. Sarity Dodson, DPsych, is a research fellow in public health innovation at Deakin University. Marie Gill, RN, PGDip Comm Health, MEd, is managing director at Gill & Willcox Consulting. Rosemary McKenzie, BA, PGDip Health Promotion, MPH, is the coordinator of the health program evaluation MPH stream at the University of Melbourne School of Population Health.

**Note of disclosure:** Ms. Gilbert was one of the founders of the online community that is the subject of this study and, at the time the study was undertaken, was president of the Type 1 Diabetes Network, which manages the online community.