Sustaining online communities in the charitable health sector: how to keep a good thing going

Leesa Costello, Julie Dare, Lelia Green and Vanessa Bradshaw
Edith Cowan University
L.costello@ecu.edu.au

Abstract

What happens when an online community part-funded by a competitive grant process in partnership with a relevant charitable organisation reaches its use-by date? What reasons might an organisation have for continuing (or not) to support the community and its future development? How is 'ownership' transferred from the research institution to the not-for-profit organisation, along with any possible risks? These are all good questions: not least because it seems that most communities in this position are not 'adopted' by their not-for-profit sponsors, but languish on the sidelines waiting for a benefactor to pick up the potential costs and risks.

This paper explores the Australian experience of forming online communities to support not-for-profit organisations' user populations, and then finding the sponsoring organisation hesitating to adopt the project after the research has successfully demonstrated need and demand. It identifies drivers and inhibitors affecting the decision to support, neglect or abandon online communities.

Background

The Australian government and its competitive grants bodies have funded the development and investigation of a number of specialist online research communities and social networks to facilitate communication within specific health populations. However, it now seems that many of these not-for-profit organisation-sponsored online communities, which have been successful in delivering health-related benefits, are under-supported and even at risk of being abandoned. Australian-based not-for-profit organisations perceive structural and fiscal barriers as compromising the possibility of them maintaining these online communities, even though need, demand, and effectiveness are convincingly established (Love et al., 2012).

While best practice management and moderation helps to ensure that communication and support can be generated responsibly through Web-based communities, issues of risk management and litigation avoidance are key considerations should service fall short or be compromised. Even where best practice is maintained, risks around loss and liability are all too evident to sponsors and decision-makers, as past research makes clear (Green and Costello, 2009).

There is some indication that a similar dynamic was experienced in the Netherlands during the mid-2000s (Oudshoorn and Somers, 2006). Unfortunately, there appears to be no published evidence which documents how they responded to such challenges. In the absence of such research, Australian universities and their research partners desperately seek interim strategies for sustaining and resuscitating online communities and networks which are no longer specifically funded as part of active research projects.

Is it inevitable that such communities are entirely self-supporting, or run by medical or pharmaceutical interests? Is there an appropriate communication model which might offer a cost-effective response to this range of critical challenges while protecting the host not-for-

profit organisation from a potentially crippling liability? Information is already being collected from an established online community, which offers some pointers to future developments that might successfully address these challenges. If a number of communities are co-hosted to provide economies of scale, for example in relation to moderation, is the cost of that strategy an unacceptable loss of specificity, and consequently challenging to the charities' and members' sense of identity? No readily available research addresses the minimum quantum of specific communication services which need to be provided to allow core constituencies to feel their needs are being properly met.

Introduction

This paper interrogates the changing environment within which a not-for-profit organisation might choose to support an online therapeutic community targeted at a core, health-compromised, supporter base. Informed by a (successful) 2003 grant application, it seeks to compare differences between 2003 and 2013 in terms of constructions around the risks and benefits to a not-for-profit or charitable organisation of supporting a therapeutic online community. Although the authors have been associated with several not-for-profit organisations, and several therapeutic online communities, this paper specifically addresses generalities and seeks to move the discussion into one of principles, rather than individual cases. It accepts that academics have only a partial understanding of the challenges faced by not-for-profit organisations, and seeks to examine ways in which further research might make the support of therapeutic online communities more feasible for the charitable health sector.

It is worth acknowledging the usefulness of the research conducted to date. The complexities faced by not-for-profit organisations in deciding whether or not to offer ongoing organisational and financial support to an online community have only become apparent as a result of a decade or so of successful research projects which investigate such communities.

In this paper, we reflect on factors observed through research that have persuaded not-for-profit organisations against supporting successful online therapeutic communities, and in response, we argue that research is urgently needed to investigate strategies and mechanisms to inform a best practice model for sustainable charity-supported online communities.

"Let me know when we can pull the plug". This is a chilling comment to hear about an online therapeutic community of some eight or so years' standing. It is a particularly tough prospect when that community includes, among its regular contributors, people who believe that their membership has helped to save their lives. It was difficult to know whether the IT professional meant what he was saying, or whether he was joking. But there was no question that the community was, and is, under threat. It languishes, in search of a home.

This community is one of several experiencing similar issues, affected by a whole raft of circumstances that were not considered when the original risk assessment was undertaken. At that point, the choices had seemed fairly straightforward. The community would be a success, and would be adopted by the research partner with a continuing role into the future; or it would be a failure, and would close down. Not much harm would be done, it had seemed, if it closed, since few people mourn the ending of a failure. What had not been addressed as a possibility in those early stages was the success of the community, coupled with its failure to be 'adopted' by the not-for-profit organisation which sponsored it.

This is the role of research: to uncover both the expected and the unanticipated. Interestingly, once the new knowledge exists it can be difficult to reimagine what it was like to believe differently, or to think that the outcome was anything other than obvious. However, having had direct experiences with two such communities, and discussed the circumstances of at least two others in equivalent situations, it becomes clear that there are several important factors which inhibit organisations, especially not-for-profits, from taking on responsibility

for an online community - even when that community has been set up specifically to serve the charitable organisation's target audience. These inhibitions may be evident to more not-for-profits now than was the case in the first decade of this century, but this is only as a result of the research undertaken. For many reasons, online therapeutic communities supported by not-for-profit organisations seemed a very good idea at the time. For their many passionate and committed members, they remain a good idea.

Not-for-profit organisations, the internet and online community in the early 2000s

Back in 2003, when we were first applying for competitive research funding around the construction of a charity-supported online community, the issues facing not-for-profits were predominantly constructed as technical and skill-based. As a 1999 report had made clear, "'Many nonprofits don't yet know how powerful an impact technology can have in their work, […] They don't know how to weave technology into their overall organizational plan and budget. They lack the resources to acquire the needed hardware and software, and for the training and support to put it to good use." (National Strategy for Nonprofit Technology, cited in Pedraza, nd: 1). It seemed as though the inhibitors were issues around getting a community up and running and building social and emotional capital in digital realms. To some extent, the value of the community itself was taken to be self-evident.

The internet offered at least five specific areas of potential for not-for-profits. At that time these were identified as offering benefits for fundraising, volunteers, information credibility, advocacy and community building (Spencer, 2002). In terms of fundraising, Jamieson (cited in Spencer, 2002: Fundraising section, para. 3) commented that "although the Web and e-mail have the potential for fundraising they are still fundamentally relationship building tools, instead not-for-profit organizations should be understanding and fulfilling the information and communication needs of their existing and target audiences." Such a perspective strongly

favours the development of therapeutic online communities, supporting key populations of specific interest to the not-for-profit concerned.

Trumpeting the benefits of the internet for volunteer recruitment, Spencer (2002) also highlighted its value for presenting information about the not-for-profit: "Internet searchers are often advised to consider information provided on .gov and .org sites in preference to commercial ones". These same credibility dynamics underline the value of a not-for-profit sponsored online community for people with, for example, a specific medical condition. A commercial community sponsored by a pharmaceutical company, or a private health insurer, carries a totally different set of connotations. While internet advocacy was comparatively new in 2002, with Spencer citing Civille's (1997) comment that "government organizations now commonly accept public comment via e-mail and forms submitted through Web sites", community building was seen as a well-accepted reason for not-for-profits to invest resources in an internet presence (Spencer, 2002).

It was in the cultural studies sphere, however, that the compelling potential for online therapeutic communities was articulated. Bakardjieva and Smith (2001: 71) identified the benefits of online connection in relation to reducing isolation, removing locational barriers, maintaining dispersed networks, promoting intellectual involvement, reducing uncertainty and adding a sense of belonging to a dispersed community, who may be "quite often a community of suffering". This tied in with the two motivations of our first industry partner. First was to support their patient-base in the complex attitudinal and lifestyle changes that help people recover from a disease episode. This was particularly important for patients in rural and remote areas, where face-to-face services are (still) less accessible. Secondly, the industry partner sought to build a community of supporters which might also lead to an increased donation base.

Back in those early days of experimenting with 'manufacturing' online communities (rather than providing an online location for an established community of interest, or community of practice), a range of evidence was identified as indicative of the success of the project. The primary research question to be investigated was: 'Can community be fostered through web-based interactivity?' The tests for steps leading to effective community building were constructed as:

- Increased perceptions of credibility and trustworthiness of the Industry partner (WA) (which may be linked to the future adoption of more appropriate health behaviours);
- Increased perceptions of gratitude towards the Industry partner (which may be linked to an increase in donated resources of time or money);
- A decrease in the sense of social isolation, according to an established instrument that measures a participant's sense of social isolation/support.

At that preliminary stage of imagining the value of the research, the success of the online support program was to be judged by:

- Increased adoption of life-preserving attitudes, intentions and behaviours by patients included in the Industry partner online community, particularly those in rural and remote areas;
- An increase in the rate of donation by those supporters involved in the community-building activities.

However, given that large-scale behavioural changes take some time to become established, it was argued that changes in attitudes would indicate progress towards the ultimate goals.

It is fair to say that the therapeutic online research community created as part of the funded research fulfilled the various criteria established for its evaluation. In many ways it exceeded

everybody's expectations for it. The next part of this paper explores why such communities, for there are a number of these known to the authors, have not subsequently been adopted by their not-for-profit sponsor.

Not-for-profit organisations, the internet and online community in 2013

In 2004, Herman and colleagues published their ground-breaking work on *Managing risk in non-profit organisations: a comprehensive guide*. As a lawyer and the Chief Executive Officer of the *Nonprofit Risk Management Center*, which at that time offered services to over 20,000 not-for-profits annually, Melanie Herman was particularly well qualified to lead the writing team and scope out the range of threats faced by charitable and other not-for-profit organisations. The contents pages constitute an education in themselves. From what we now know as researchers in the area of the creation and support of online and web-based communities, these communities expose organisations to a range of possible threats, in terms of both tangible and intangible property. A community crisis, such as publicity around the health implications for a distressed or disaffected member, might lead to both a decrease in revenue and an increase in costs. Relevant to online communities, legally protected interests include: performance of contractual promises, personal safety, protection of property, security of reputation, right of privacy and community protection from crime (Herman et al., 2004: ix).

Future revenues for not-for-profit organisations are particularly dependent upon a robust reputation, so reputational risk has a range of potentially catastrophic implications including economic, intellectual capital and public confidence risk (Herman et al., 2004: x). According to the National Statement on Ethical Conduct in Human Research (NHMRC, 2007), to which all Australian universities subscribe, the typical user of a therapeutic online community can

be identified as being in "a dependent or unequal relationship" (as a result of their compromised health) and/or the member of a vulnerable community to which a service (community-provision) is provided (NHMRC, 2007: 59). Herman and colleagues (2004: 191-210) assign a specific chapter to the risks to non-profits of working with such clients: "Chapter 10 – Managing risks related to serving vulnerable clients."

Naturally, there is a wide range of risk mitigation strategies available to not-for-profits, and to the universities which carry out research in this area. A robust ethics environment helps, as do explicit terms and conditions which are accepted on every occasion that a community member logs in. However, as in all communities, online communities run the risk of experiencing extensive and intensive interpersonal conflict. In an online therapeutic community, there is also the possibility that a member will post information which will persuade another member - someone who is potentially vulnerable - to change their diet, exercise or medication regimes, with what might later be construed as disastrous results. The kinds of actions which might mitigate against such outcomes include the vetting of all comments before posting, and 24-hour moderation. However, not only would such measures be hugely expensive, they would also prevent the development of an organic and effective online community. Communities depend upon members sharing time together online and building a sense of trust (Blanchard et al., 2011).

It is hard to spend any time in online communities without developing an awareness of the pervasive challenges posed by some vulnerable people whose chaotic and unpredictable online behaviour probably reflects equally troubled lives offline. The behaviour of such troubled community members has the capacity to undermine trust in the community, and sometimes to undermine the community as a whole. One manifestation of such behaviour is 'Munchausen by internet' syndrome (Feldman, 2000; Cunningham and Feldman, 2011; Uridge et al., 2012). Sometimes a community member will attribute a seriously worsening

state of health to events that are part of their community membership (Green, 2010). Another situation is when distress with everyday life, sometimes as a result of tensions in the online environment, is used by a community member as a reason to threaten self-harm (Green and Costello, 2009).

The complexity and challenges associated with such events have serious implications for the not-for-profit organisations impacted by them. For example, following a serious incident at an in-person Christmas gathering for online community members, one charity adopted "a formal policy that at least two team members attend offline meet-ups to support each other should something unexpected occur, and to calm the other group members if one member of their community should unexpectedly have a 'meltdown' or need medical assistance" (Costello et al., 2012: 9).

It is not difficult to see why a lawyer evaluating the possible risk/benefit ratio of a charity taking on responsibility for an online community would advise against this, particularly since such legal work itself is often pro bono. Lawyers are very aware of the range of issues that can arise when relationships of all kinds sour, and they are cognisant of the costs of defending even successful actions in the event of a dispute. If a community member were to die or come to other harm in circumstances which permitted them or their families to argue that their community membership had been a factor in the events as they transpired, this could have significant ramifications for the organisation's core business.

Discussion

Many charities and not-for-profit organisations see their core business as providing support and succour for their members at all times of the day and night, and wherever they might be living. For people with access to the internet, online communities can offer a sense of belonging and a health-promoting sense of camaraderie and, sometimes, wellbeing. Such

benefits are unlikely to be offered by commercial sites, such as those promoted by pharmaceutical companies (Corritore et al., 2012), or overly moderated sites. As social benefit is likely to be enhanced when site sponsors are motivated by a wider commitment to the promotion of wellbeing, charities are the best organisations to establish these communities (Dimitrov, 2008). Online communities sponsored by not-for-profit organisations provide a valuable social space (Nambisan, 2011) for the exchange of peer-to-peer emotional and instrumental support (Ancker et al., 2009). Future research into the development of online therapeutic communities needs to focus on ways in which charity-supported sites might be made more viable, given that no current model offers sustainable solutions to challenges around resource allocation and risk management.

In response to our research findings in this domain over the past 10 years, the charities we have worked with believe that the inclusion of professional advice-giving as part of a therapeutic online community is a key component of an effective, communication-based risk management approach - regardless of their capacity to implement this or not. Where professional advice-giving is provided, the trained professional – maybe a nurse, or counsellor – might only be required online for a few hours a week. By setting up a reliable and qualified professional source of advice for the community, any conflicting and potentially harmful advice can be countered.

Coupled with the risk-mitigation strategy of part-time health professional advice-giving is the proposal that charities collaborate to share the infrastructure supporting the development and operation of separate, targeted, online communities. Intriguingly, there are some indications that a similar approach has been trialled in the Netherlands in a project entitled "Patienten Organisaties, Actuele Informatie en Internet (Patient Organizations, Timely Information and the Internet)". The aim of this research was "to support patient organizations to develop digital health services" (Oodshoorn and Somers, 2006: 660). While it seems the charities did

not collaborate with each other, they were able to collaborate with the government-supported health centre as a means to develop and potentially sustain their online presence. Tantalisingly, little has been written in English about the outcomes of this initiative, whether it succeeded and, if not, why it might have failed.

There is a strong possibility that inter-charity cooperation and collaboration will reduce both costs and risks, leading to online communities which are more sustainable. Cost-effective cyber communication can enable charities to reach out to and beyond their key constituencies and their supporter base (Laakso et al., 2011). Organisations with wide supporter-bases can tap into and harness the goodwill, the sense of association, and the shared knowledge generated through membership of these communities and networks (Hesse et al., 2011). The social support offered by online communities and networks, and the opportunities provided for creativity and constructive engagement with others, impact positively upon members' sense of well-being and their quality of life (Lieberman and Goldstein, 2005; Witney et al., 2013), promoting improved psychosocial wellbeing (Bonniface and Green, 2007), and enhancing the users' sense of self-efficacy in managing acute health conditions on a day-to-day basis (van Uden-Kraan et al., 2009), which links to improved health outcomes (Bandura, 1997). Such communities can support positive behavioural change such as weight reduction, increased exercise and smoking cessation and can serve an educative function (Bonniface et al., 2006).

Conclusion

The first ten years of our research into everyday interactivity in online communities has established that these web-based entities offer many benefits for a range of people facing daily challenges in terms of coping with a variety of adverse circumstances. This research, along with others, has also demonstrated that there are a number of social, emotional and

other risks associated with communicating with others online, as is the case in alternative aspects of life. A range of organisations are motivated to support the development of vibrant and productive online communities to support key constituencies who might otherwise find it difficult to gain help. These not-for-profit organisations are risk-averse, however, and may perceive the risks associated with supporting an online community as potentially impacting upon their long-term viability. Given this, and the fact that organisations remain keen to have memberships avail themselves of mutual support in online contexts, further research is required. The next suite of investigations into the operations of online community will need to address issues of specificity and sustainability. Specifically, can organisations collaborate effectively to manage the costs and risks of community-creation and management? How much infrastructure and community space can be shared without compromising a member's sense of being part of a group of people who understand exactly who they are and where they are at when it comes to battling a life-limiting condition? This research is urgent if the past decade's knowledge base around the operation and dynamics of online communities is not to falter.

References

Ancker, J. S., Carpenter, K. M., Greene, P., Hoffman, R., Kukafka, R., Marlow, L. A. V. and Quillin, J.M., 2009, 'Peer-to-peer communication, cancer prevention, and the Internet', *Journal of Health Communication*, vol. 14, s.1, pp. 38-46.

Bakardjieva, M. and Smith, R., 2001, 'The Internet in everyday life', *New Media and Society*, vol. 3, no. 1, pp. 67-83.

Bandura, A., 1997. *Self-efficacy: The exercise of control*, W.H. Freeman, New York.

Blanchard, A. L., Welbourne, J. L., and Boughton, M. D., 2011,. 'A model of online trust: The mediating role of norms and sense of virtual community', *Information, Communication & Society*, vol. 14, no. 1, pp. 76-106.

Bonniface L., and Green, L., 2007, 'Finding a new kind of knowledge on the HeartNET website', *Health Information and Libraries Journal*, vol. 24, s.1, pp. 67-76.

Bonniface, L., Omari, A., and Swanson, M., 2006, 'Shuffling Buddies - How an online community supports healthier lifestyle choices: An early indication of physical activity and exercise outcomes from the HeartNET intervention', in F. Sudweeks, H. Hrachovec and C. Ess (eds), *Proceedings of the Fifth International Conference on Cultural Attitudes Towards Technology and Communication, Tartu, Estonia,* pp. 90-101), Tartu, Estonia.

Corritore, C. L., Wiedenbeck , S., Kracher, B., and Marble, R. P., 2012, 'Online trust and health information websites', *International Journal of Technology and Human Interaction,* vol. 8, no. 4, pp. 92-115.

Costello, L., Witney, C., Green, L., and Bradshaw, V., 2012, 'Self-revelation in an online health community: Exploring issues around co-presence for vulnerable members', in C. Anyanwu, K. Green and J. Sykes (eds.), *Proceeding of the 2012 Australian and New Zealand Communication Association Conference*, Adelaide, Australia, accessed at: http://www.anzca.net/past-conferences/anzca12-proceedings.html

Cunningham, J. M., and Feldman, M. D., 2011. 'Munchausen by Internet: current perspectives and three new cases', *Psychosomatics*, vol. 52, no. 2, pp. 185-189.

Dimitrov, R., 2008, 'The strategic response: An introduction to non-profit communication', *Third Sector Review,* vol. 14, no. 2, pp. 9-50.

Feldman, M. D., 2000, 'Munchausen by Internet: Detecting factitious illness and crisis on the Internet', *Southern Medical Journal*, vol. 93, no. 7, pp. 669-672.

Green, L., 2010, *The Internet: An introduction to new media*, Berg, Oxford.

Green, L., and Costello, L., 2009, 'Fractures between an online and offline community (and the ethical responses)', *International Journal of Web Based Communities*, vol. 5, no. 3, pp. 462-475.

Herman, M. L., Head, G. L., Jackson, P. M., and Fogarty, T. E., 2004, *Managing risk in nonprofit organizations: A comprehensive guide.* John Wiley & Sons, New Jersey.

Hesse, B.W., O'Connell, M., Augustson, E.M., Chou, W.Y., Shaikh, A.R. and Finney Rutten, L.J., 2011, 'Realizing the promise of Web 2.0: Engaging community intelligence', *Journal of Health Communication: International Perspectives,* vol. 16, s. 1, pp. 10 – 31.

Laakso, E. L., Armstrong, K., and Usher, W., 2011, 'Cyber-management of people with chronic disease: A potential solution to eHealth challenges', *Health Education Journal,* vol. 71, no. 4, pp. 483-490.

Lieberman, M. A., and Goldstein, B. A., 2005, 'Self-help on-line: An outcome evaluation of breast cancer bulletin boards', *Journal of Health Psychology,* vol. 10, no. 6, pp. 855-862.

Love, B., Crook, B., Thompson, C. M., Zaitchik, S., Knapp, J., LeFebvre, L., et al., 2012, 'Exploring psychosocial support online: A content analysis of messages in an adolescent and young adult cancer community', *Cyberpsychology, Behavior, and Social Networking,* vol. 15, no. 10, accessed at: http://ejournals.ebsco.com.ezproxy.ecu.edu.au/Article.asp?ContributionID=28421730

Nambisan, P., 2011, 'Evaluating patient experience in online health communities: Implications for health care organizations', *Health Care Management Review,* vol. 36, no. 2, pp. 124-133.

NHMRC, 2007, *National Statement on Ethical Conduct in Human Research 2007 – Updated 2009*, National Health and Medical Research Council, Canberra, Australia, accessed at: http://www.nhmrc.gov.au/guidelines/publications/e72

Oudshoorn, N., and Somers, A., 2006, 'Constructing the digital patient: Patient organizations and the development of health websites', *Information, Communication & Society,* vol. 9, no. 5, pp. 657-675.

Pedraza, C., n.d., 'Navigating change in non-profit technology', *The Resource Connection*, vol. 4, *no.* 3, p. 1, accessed at: http://www.nationalserviceresources.org/filemanager/download/304/tech.pdf

Spencer, T., 2002, 'The potential of the Internet for non-profit organizations', *First Monday*, vol. 7, 8-5, accessed at: http://firstmonday.org/htbin/cgiwrap/bin/ojs/index.php/fm/article/view/976/897

Uridge, L., Rodan, D. and Green, L., 2012, 'A moderator's dilemma: Munchausen syndrome by internet', in C. Anyanwu, K. Green and J. Sykes (eds.), *Proceeding of the 2012 Australian and New Zealand Communication Association Conference,* Adelaide, Australia, Retrieved from http://www.anzca.net/past-conferences/anzca12-proceedings.html

van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Seydel, E. R., and van de Laar, M. A., 2009, 'Participation in online patient support groups endorses patients' empowerment', *Patient Education and Counseling,* vol. 74, no. 1, pp. 61–69.

Witney, C., Green, L., Costello, L., and Bradshaw, V., 2013, 'Creativity in an online

    community as a response to the chaos of a breast cancer diagnosis', *M/C Journal,* vol.

    16, no. 1.,Accessed at:

    http://journal.mediaculture.org.au/index.php/mcjournal/article/view/598