BUILDING AN ONLINE COMMUNITY IN THE CONTEXT OF AN EXISTING SOCIAL NETWORK SITE

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Abstract. This paper compares the characteristics of the Purple Boot Brigade, a social network for supporters of Breast Cancer Care WA, with the characteristics of Breast Cancer Click, an online community. Whereas online communities might be conceptualised as relatively flat structures, in which membership is developed as a result of time spent online and in communication with fellow members, a social network can be seen as hierarchical, where members invite their face-to-face colleagues and friends to join with them in online activities. In the case of this research it was hoped that the two environments would offer different benefits and exhibit complementary and mutually-supportive characteristics. The Purple Boot Brigade is a well-established social network site which espouses consciousness-raising, education and sponsorship to develop knowledge and awareness of breast cancer in its many forms. However, this social network had a number of drawbacks when it came to supporting people with breast cancer. Hence it was decided to establish Breast Cancer Click as an online community where people with breast cancer could seek support. This paper interrogates the contemporary challenges of building an online community, even with the benefit of a pre-existing social network site.

1. Introduction

Although online communities have a significant history, the context in which they are built and used is continuously changing. This paper examines the challenges faced in 2011 while creating an online community for people affected by breast cancer, even though there was a starting point for community recruitment in the shape of an existing breast cancer-related social network site, the Purple Boots Brigade (PBB).

The heart of the actual research project, which will only be touched upon here, centres upon the role of the professional advice-giver in an egalitarian, flat-structured, online community. The project has two stages: firstly Breast Cancer Care WA, a charitable organisation, sought to establish an online community to support people

affected by breast cancer. This has been done, and the development of an online community with a strong research component, Breast Cancer Click ('Click'), is the subject of this paper. Subsequently, and this is the stage of the current research, Breast Cancer Care WA seeks to create opportunities within the operation of Click to provide health-related professional advice to community members on request. While investigating and recording the provision of such advice, the research project will analyse the change of dynamics in community interactions (if any), and subsequently develop a set of guidelines to help other organisations and professionals in equivalent circumstances to introduce the services of advice-givers with minimal disruption to the effective functioning of an online community.

Breast Cancer Care WA have already had award-winning success (AMI 2008) in setting up a social network site, the Purple Boot Brigade, to support "national awareness and education" about breast cancer (PBB 2012). The PBB project, created by safety boots manufacturer Steel Blue, manufactured a product line of purple safety boots as a talking point to raise the subject of breast cancer between wearers and those with whom they interact. People joining the PBB network can test their knowledge of breast cancer in terms of signs, symptoms, risks etc as part of their engagement with the site. This equips PBB members to talk about the illness when asked questions as a result of their wearing purple safety boots. The site is not set up to provide support to people with breast cancer or those that care about them. Whereas Breast Cancer Care WA does offer such support, these services had previously been provided in person or via the phone. Aware that some people were attempting to use PBB to access support for their breast cancer journey, Breast Cancer Care WA decided to set up an online community to meet the needs of people affected by breast cancer who chose to access services online. As part of their service provision they were keen to offer professional advice from a breast care nurse experienced in counselling people with breast cancer and their families. When looking for guidelines as to how best to introduce and integrate such advice-giving, it became clear that such guidelines were yet to be written. This is a future priority of the research discussed here.

2. Research Methodology

The methodology adopted in this research combines perspectives from media and communications studies, online ethnography ('netnography', Kozinets 2010) and cultural studies. The media and communications studies work is mainly drawn from audience studies, including debates around the domestication of technology and technology uses, and the integration of technology into everyday domestic life (Silverstone & Hirsch 1992). It also engages with the concept of "the user as an agent in the field of technological development" (Bakardjieva 2005, p. 7). One example of how this methodology was used was when a number of people affected by breast cancer were interviewed in order to determine the kinds of features they would like included in the site to be built. This phase of the research involved identifying target users and working with them as they navigated prototypes of the Click site, interviewing these potential users about their current online behaviours, and the features they would like to

have as part of the Click service. The research has also used surveys as a means of determining, for example, good time-slots for line chat sessions.

Online ethnography, or netnography, is the term used for the application of ethnographic principles to web-based online community research. It aims to achieve the scientific description of the customs, symbols, beliefs and practices of individual peoples and cultures. In this instance, the individuals concerned are breast cancer patients and their supporters, i.e. family, friends and carers, and the culture to be investigated is that which is developed by, and expresses, the Breast Cancer Care WA online community, Click. According to Kozinets (2010, p. 1), netnography is "a specialized form of ethnography adapted to the unique computer-mediated contingencies of today's social worlds". One example of the use of netnography to research an earlier online support community is HeartNET, a community for heart patients and their supporters, developed and researched by Costello (previously Bonniface), Green and others (e.g. Bonniface et al. 2005; Bonniface et al. 2006; Green & Costello 2009).

One aspect of conducting ethnographic research online is that the process of community construction leaves digital trails which are themselves accessible to analysis. As Kozinets notes, "the term persistent world has been coined to refer to the persistence of virtual worlds online, and changes made to them by users." (2010, p. 72). Where due ethics processes have been undertaken, and a site is clearly labelled as being for research, the development of an online community can be investigated from inception to autonomic operation. Thus, as well as using netnography to examine the details of community development, it is possible to examine the texts through which the community develops. In this way the netnographic element of the methodology shares practices with textual analysis from media and communications studies. Additionally, as indicated previously, the project also includes face to face interviews and small-number focus groups in the form of prospective user-gatherings.

Like cultural anthropology, netnography emphasises full participation of key researchers in the community under investigation. This element of participant observation is a cornerstone of much cultural studies research (Gray 2003, pp. 79-106). It is through interacting with the community that the netnographer becomes a community member. Membership allows community members to feel confident that the researcher truly understands their circumstances and can accurately interpret what they say. This knowledge builds trust, and that in turn allows people to share personal and, in some cases private, feelings. The netnographer in this project, Witney, combines being a community member and a moderator. It is because of this dimension of participant observation in a community, and the trust engendered, that Click is clearly signposted as a research community. All community members are guaranteed that any identifying details about them will be obscured in materials cited from the site and through the use of pseudonyms when their posts are directly quoted.

3. Literature Review and Definitions

3.1. SOCIAL NETWORK SITES

boyd and Ellison (2007, p. 210) describe social network sites as being "web-based services that allow individuals to: (a) construct a public or semi-public profile within a set system, (b) show a list of other users with whom they share a connection, and (c) see and move through their list of connections and those made with others within the site". This complements Lin and Lu's (2011, p. 1152) rather more prosaic description of the 'social networking site' as offering "an important social platform for computer-mediated communication […] employing computers as a collaborative tool to accelerate group formation and escalate group scope and influence".

The terms social networking site and social network site are often used interchangeably, or without discrimination. Whereas boyd and Ellison give Facebook as an example of a social network site (2007, p. 210), Lin and Lu (2011, p. 1152) use it as an example of a social networking site. Ahmad says: "Social network sites are also called 'social networking sites' to emphasize relationship initiation, often among strangers" (Ahmad 2011, p. 522). Chen argues that, in addition to using online communication to maintain existing offline networks, "An equally important function of social network sites is *networking*, i.e. expanding one's online social network beyond existing offline relationships" (Chen 2011, p. 14, original emphasis). boyd and Ellison argue that there is a valuable distinction to be made between social network sites and social networking sites, however. They say that:

> What makes social network sites unique is not that they allow individuals to meet strangers, but rather that they enable users to articulate and make visible their social networks. This can result in connections between individuals that would not otherwise be made, but that is often not the goal […] On many of the large SNSs, participants are not necessarily 'networking' or looking to meet new people; instead, they are primarily communicating with people who are already a part of their extended social network. (boyd & Ellison 2007, n.p.)

Naturally, what might be designed as a social network site, in which people who are already bound by strong ties offline also connect with each other online, can also be used for the purposes of *networking* (Harrison & Thomas 2009, p. 120), and weak ties can be transformed into strong ties through extended communication and emotional investment (Granovetter 1977; Verbrugge 1977).

Under boyd and Ellison's definition, PBB is a social network site. As one of its originators commented, when asked about its inception and history, its initial purpose "was to encourage people to support PBB and invite their existing social networks to view educational content, purchase boots and sign up as members." The idea had been that members would post stories about their fundraising, and about how useful it had been to have the additional knowledge and information about breast cancer. However, that was not quite how it worked out: "Being a PBB member was like a 'badge' to show support for people touched by breast cancer and to be an active member [in] sharing breast cancer education and information within [a person's] own social circles" (Personal communication, email, 23/04/12). One aim of the research was to use PBB as

a way of seeding Click, so that the online community could start life with a critical mass of members.

There is reason to believe that a social network recommendation can be an effective spur to action. Pintado (2009, pp. 123-4) conducted a test whereby he sent personal invitations to his 200 Facebook friends, inviting them to become fans of a particular website, to see if over a seven day period he could increase the number of fans on this site. The number of fans increased from 34 to 116 during this time, showing that there is considerable power in an individual's personal recommendation and there is also the ability for a group to be formed quickly and efficiently through a social network site suggestion. However, a recommendation is not sufficient to guarantee engagement, and Pintado's experiment was not designed to develop a community on the site he recommended.

3.2. ONLINE COMMUNITIES

While a community used to be thought of as a group of people who live in a specific geographical location, and have similar local concerns, this is no longer the case. Instead, the definition more commonly used focuses upon shared social exchange where "people come together to get and give information or support, to learn, or to find company" (Preece 2001, p. 347). Online communities formed soon after the inception of the internet and burgeoned with the development of the World Wide Web. Whereas the first social network site is judged by boyd and Ellison (2007) to have started in 1997, with the launch of SixDegrees.com, the formally-recognisable online community was already well into its second decade at that point. Rheingold's book about *The Virtual Community*, first published in 1993, contains his definition of how a digital environment is transformed into an online community, where people feel they belong. He said online communities are "social aggregations that emerge from the Net when enough people carry on those public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyber space" (Rheingold 2000, p. xx). This definition makes it clear that it is time, intensity and commitment that underpin the transformation of a group of interacting people into an online community.

As social network sites and communities mature, however, so the differences between them seem less. Further, Rheingold's definition of community operates independently of any overarching digital environment: a community can form anywhere that 'personal relationships' are built. Pintado's view (2009, p.116) is that social networks offer "a platform for building online communities of people who share interests and activities and who may also want to explore other's interests and activities". Sethi (2010) combines the terms to talk about how "Online social communities have made it easier for us to connect to, and stay in touch with people who are either important to us or share similar experiences to ours, or both".

The two terms, 'social network site' and 'online community', are not interchangeable however, and this implies a continuing differentiation. One perceived difference is with the separate structures of these online environments. Social network sites assume the primary role of importing existing relationships into the online environment, whereas online communities assume the building of new relationships online. Such relationships would usually form around a shared community of interest

which might be geographical, demographical or topical (Hagel & Armstrong 1997). In the case of Click, the shared interest is in the topic of breast cancer, although there is also a demographical dimension since most people diagnosed with breast cancer (although not all) are women, and most of the women engaging with Click are also in their middle years.

Essentially, the purposely-built online community begins as a flat social structure which seeks to attract members and encourage them to interact. Status online reflects a community member's engagement with the community, rather than a person's status offline. It is not dependent upon who invites whom to join, or related to the people with whom someone interacts, but is instead driven by time and investment in community-membership (Lampel & Bhalla 2007). Apart from moderators, the online community starts off with all members joining as newbies and collaboratively developing a shared sense of belonging. Community lies in communication and in company: in the construction of shared social capital.

3.3. SOCIAL CAPITAL

There has been intensive interest in what makes a network or community thrive (Howard, 2010). Arguello et al (2006) contend that the survival of an online community depends on whether or not it provides the benefits and experiences that members seek. Posts and emails are still the main means through which members communicate online, although the use of voice over internet protocol networks is growing. Either way, to gain any benefit from this medium, the member must attract others to respond to, and share, a conversation. Members' responsiveness to posts and blogs is an essential element of any successful online community. This assumes a critical mass of engaged members which can prove a challenge in the early stages of building a community: people will only interact if there are others to engage with, and others only engage when they see people interacting.

According to Putnam (2000) the core idea of social capital theory is that social aggregates have value; that social capital is the connection among individuals, along with the norms of reciprocity and trustworthiness that arise from them. This is sometimes called civic virtue or a 'public good' (Pruijt 2002, p. 109), but it is only powerful when embedded in a network of reciprocal relations (Putnam 2000, p. 19; Wellman et al 2001; Best & Kruger 2006). While online community members create social capital through their interactions; the more frequent the interactions, the more likely it is that a norm of generalised reciprocity and trust will be produced. Putnam describes this as "I'll do this for you without expecting anything specific back from you, in the confident expectation that someone else will do something for me down the road", and argues that this trust in others "lubricates social life" (2000, p. 21).

There are two different dimensions to social capital, notes Putnam (2000, p. 23), bridging or inclusive and bonding or exclusive. Within communities and networks alike, the social dynamics are such that some people are invited into a conversation through a bridge that links them with others who are well-established members, while other people are excluded by the close bonds that already connect those who are involved, and the cost of acquiring sufficient social capital to gain entry to the communicating circle. Networks can help in these circumstances since being linked

with someone who already has membership in a social setting can serve as an introduction, and allow the sharing of established bona fides on the part of the newcomer.

The internet is increasingly a site for the building and use of social capital, through networks and communities. This became particularly evident in the week of March 13, 2010, when Facebook overtook Google as the most visited website on the internet (Dougherty, 2010). At this point, arguably, the desire of people to use the internet for social and networking purposes overtook the desire of people to use the internet as a place to search for information or do business.

4. Case Study: Using a Social Network Site to Seed an Online Community

The Purple Boot Brigade (PBB) was set up in 2007 as a social network site by Breast Cancer Care WA (previously Breast Cancer Foundation of Western Australia) in conjunction with Steel Blue, a leading safety footwear manufacturer also based in Western Australia. As part of their sponsorship of the site, Steel Blue began making purple boots for workers who were willing to pay a few extra dollars to support people with breast cancer. Community take-up was so enthusiastic that an initial ambition to raise $30,000 (AMI 2008) was dwarfed by the eventual income generated for Breast Cancer Care WA, currently around $500,000 (Personal communication, email 30/04/12), leading Steel Blue to introduce men's and women's boots in an everyday boot style as well as the originally-planned men's and women's safety boots. With the slogan "these boots were made for talking", purchasers were encouraged to use the PBB website to educate themselves and others about the facts of breast cancer, and to work with people in their networks to overcome ignorance and misinformation. The exceptional outcomes of this association between Breast Cancer Care WA and Steel Blue resulted in the two organisations receiving a 2008 Australian Marketing Institute Award for Excellence in the Sponsorship category (AMI 2008).

As is the case with most social network sites, PBB recruits new members through the active engagement and recommendation of existing members. It also benefits from the support of Steel Blue, and hotlinks are provided from Steel Blue's website and from the Breast Cancer Care WA website. People who wish to become members of PBB apply via completion of an online form and providing a personal profile. Administrative sign-off is required before a person is accepted as a member. Membership of the site is available to everyone apart from people who might wish to promote or sell merchandise or services on the site. Once membership is established there are facilities to email other members and to post a message on the individual's 'my page'. Members can post videos and photos, and some start blogs on the site. They can also 'friend' other PBB members. The site is regularly monitored by an administrator in order to avoid offensive content or language, sales advertisements, copyright infringements and to determine if the content posted is relevant to the PBB's general theme:

> The objective of the Purple Boot Brigade is to support education and awareness programs across the nation, with our first project supporting the great work of Breast Cancer Care WA (formerly the Breast Cancer Foundation of WA) as they target youth to make the younger generation breast aware. With the number of

> women being diagnosed with breast cancer increasing from one-in-eleven to one-in-nine over recent years, the need for breast awareness education from a young age is vital. (PBB 2012, 'Our story')

The PBB site is very much focused on awareness-raising to support the work of Breast Cancer Care WA and the majority of blog posts, or 'boot stories' as they are known, refer to the members' reasons for purchasing their purple boots, or their experiences at fund-raising events. The following from the Our Story section of the site is one example.

> My mum recently passed away following tragic accident. The first thing that springs to all our minds when thinking of our mum's particularly wonderful style is her Purple Boots - which she'd only had for a few short months - but already the whole town knew about them. Now I have found where she got them I will recruit all my friends and family to the Purple Boot Brigade! What a fabulous way to support a fabulous cause! (PBB post, 2009).

The PBB site has a Breast IQ section featuring a breast awareness quiz which asks questions about breast cancer signs and symptoms. The score achieved by a member is an indication of whether or not they know as much as they think they do about breast cancer. The site also advertises fundraising events with a purple theme, which raise money for Breast Cancer Care WA. Purple Bra Day is the major community-based fundraiser for the organisation with men as well as women joining in the fun (*Perth Now* 2010). While Breast Cancer Care WA provides a range of counselling and other support service for people with breast cancer, PBB was not designed to reach out to patients and their friends and family in that way. Even so, there were occasions when people experiencing breast cancer would post to the PBB site and be supported through referral to the phone and in-person services provided by Breast Cancer Care WA.

Ultimately, it became a Breast Cancer Care WA priority to build a community in which people affected by breast cancer could support each other, leading to the blueprint for Click. The hope was that the existing network on the PBB site would seed the online community, kick-starting the kind of engagement and exchange required to fulfil Rheingold's recipe for a community: enough people carrying on public discussions long enough, and with sufficient human feeling, to form webs of personal relationships (2000, p. xx, paraphrase). Click was developed in 2011 to be "A new Australian support site for those with breast cancer and their supporters, friends, family and carers. This is a place for you to connect with others, share your experiences in a safe environment and know you are not alone" (Click 2012). The site was engineered from the ground up by the same IT professional who had designed PBB, to be compatible with the existing social network. People who knew their way around the PBB site would also feel at home on Click.

Since Click was established to provide a support site for people who have been touched by breast cancer, to help them gain advice and share support with others in the same situation, the site is a closed or 'members only' website, and provides resources and information about breast health. Membership is restricted to people who have had a diagnosis of breast cancer and their supporters or health professionals. As well as creating a community to offer online support, Click was set up to be a research website, funded through an Australian Research Council Linkage partnership between Breast

Cancer Care WA, supported by sponsors Steel Blue, and Edith Cowan University. One aim of the research was to build an open-entry, non-hierarchical community around the experience of breast cancer and then establish guidelines for integrating professional information-giving from a health specialist such as a breast care nurse or counsellor. This meant that the researchers hoped to build a vibrant and viable community prior to introducing the services of an online health professional. In this way the research could establish whether the communications dynamics had been altered as a result of introducing an expert into a flat-structured online community.

To become a Click member, an applicant must provide key demographic details i.e. name, postcode, birth date, and select the type of membership category they belong to: a person with breast cancer, or a supporter; and indicate where they heard about Click. The prospective member must also read and agree to the terms and conditions of the site and the code of conduct; read the research project details, and consent to participate in the research project. People are also asked to provide a current indication of their distress level, where 0 equals nil distress and 10 equals extreme distress. This latter indicator gathers data which will eventually help assess whether communicating in an online community helps with some of fear and uncertainty sometimes associated with experiencing breast cancer. In the early stages of the community every membership application was independently checked prior to the member being accepted, but this procedure meant that there was a gap between application and enrolment and a number of would-be members never returned to the site. Eventually it was decided that people needed to be able to access the site at the point of need and desire, and anyone completing the online requirements was accepted immediately, the view being that 'undesirables' could be handled after the event. A 'captcha' system for authenticating human engagement with the website was deferred pending more funding.

The Click website was launched as a trial in April 2011 to ensure all the features worked correctly and to allow the Click team, which consisted of the netnographer, research supervisors and the web designer, to become familiar with the site and their respective roles. PBB members were emailed an invitation to join Click at the beginning of May 2011. The indications of activity (below) demonstrate that people joining the site was necessary, but not sufficient, to ensure the development of community. The jump in membership in May was associated with a flurry of posts, page views, comments and blog entries, but these then tailed off to a low point in September until the introduction of live chat sessions in October 2011.

Table 1.   Month by month Click membership activity

	Apr 11	May 11	Jun 11	Jul 11	Aug 11	Sep 11	Oct 11	Nov 11	Dec 11	Jan 12	Feb 12	Mar 12
New members	11	80	22	17	9	10	15	17	9	4	12	21
Sign-ins		913	216	103	177	90	158	337	266	255	315	313
Page views	3715	9788	5088	2571	3931	3119	5448	6265	6698	6748	13139	10799
Posts		464	127	59	119	66	104	159	92	75	148	170
Comments		78	36	24	22	20	66	128	82	86	73	101
Blog entries		176	3	4	2	1	3	2	4	3	3	11
Forum posts		34	10	2	6	2	12	6	1	4	15	9

Click membership started with an influx of members over the first month, as a result of the publicity on the PBB network, but the majority of members did not post anything on the site. Those that did post were generally responded to by the Click team members, rather than by community members who had personal knowledge of the concerns and problems faced by people with breast cancer and their families. This situation continued for the first four months of operation, and whilst new members joined the site they were not active posters.

In October, the research team decided to instigate live chat sessions or 'Click Chat' on a fortnightly basis, at a specific, advertised time, to be hosted by members of the Click research team. While the numbers of members joining the Click Chat sessions increased from two members (plus the Click team) at the first Click Chat, to anywhere between six and ten members (plus the Click team) at more recent Click Chat sessions, the effect of bringing members together in a specific time and place was galvanising. The live chats were originally scheduled to run for a three hour period, but they occasionally over-ran, and during that time members were able to engage in Rheingold's (2000, p. xx) "public discussions long enough, with sufficient human feeling" to create personal relationships with each other and with the Click team. As a result of these live chats, members who have joined in the sessions have carried over their chat engagement to post on the forums, and to message those they met during chat. The Click Chat session is now weekly, in response to member requests, and there are burgeoning signs of community growth.

Table 2. PBB and Click membership at the end of the first 11 months of each website's
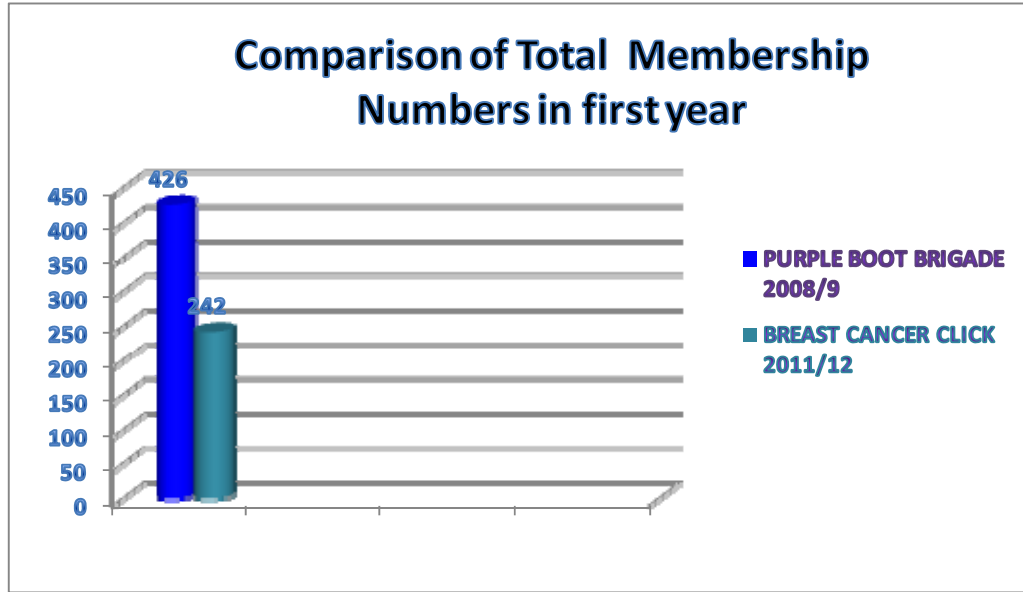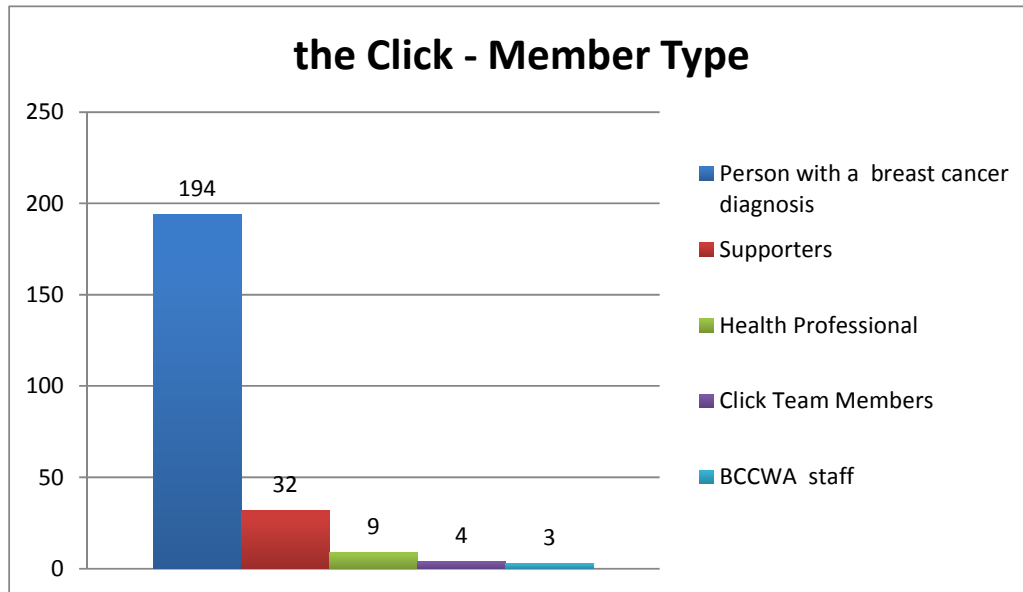operation

Table 3. Click membership categories

5. Discussions and Conclusions

While the authors had some success around the construction and operation of online communities in the mid-2000s (e.g. Bonniface et al. 2005, Green 2010, pp. 152-8), the take-up of Click proved problematic, even though it started with the benefit of a thriving social network as a lead-in source through which to recruit Click members. An online community needs to offer more than the potential of 'community' to thrive. It needs to offer a real opportunity for connection, and to demonstrate the potential benefits of community membership. Notwithstanding the influx of members as a result of PBB-based recruitment, it was hard for the site to present a vibrant and viable community to first time users without there being regular online activity. In the absence of a critical mass of online engagement, what community there was withered away.

The circuit breaker in this dynamic was the introduction of Click Chat. These live chat sessions might seem to be undermining the benefits of a self-sustaining online community in that they are staged 'events' unlike those that might seem ordinarily associated with the everyday operation of a digital community. In particular, they tie up personnel resources in terms of team members, who make themselves available for Click Chat, which occurs outside normal working hours. Such events do have precedents in terms of the everyday, however. They operate as a get-together, or a coffee with friends. Such events are very much a part of everyday communities and are a major means through which people meet new acquaintances and possibly develop new friendships.

For those involved, and as the data indicate, there is no question that Click is now a success. As envisioned, membership combines access to both a supportive network of people with experience of breast cancer and also to caring moderators and health care professionals. Click needed more than awareness and an unmet need to get started, however. It needed to prove itself to potential members before people would trust it enough to share their thoughts and feelings in a way that builds community.

Acknowledgements

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