

Connecting rural and remote women through online social media

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Di Treble is Online Engagement Manager for Breast Cancer Network Australia, and provides leadership on web and social networking strategy, particularly BCNAs own online social network. Her focus is on providing a welcoming and supportive online environment for those who have experienced breast cancer, where the emphasis is less on technology and more on user experience. In particular, the goal of BCNAs online network is to create opportunities for people affected by breast cancer to connect with others and support each other by sharing stories and experiences.

Key achievements at BCNA include a redesign of www.bcna.org.au with a new architecture that is topic based and easy to navigate, launch of BCNA's online network, which grew to 2000+ users in the first six months, and establishment of a group of online network champions who provide a welcoming and supportive experience for new users.

Di has qualifications as a registered nurse, having trained at the Royal Children's Hospital in Melbourne. She worked in the Paediatric Cardiac Unit there, and also as a home-visit nurse.

Di's love of art and design led her back to university to complete a BA in Fine Art (majoring in painting and printmaking). Following graduation she focused on using digital art and design-related software, which led to a role with Design Graphics magazine on the publications Design Graphics, Art and Design Education Guide and OzGraphix.

Di has also worked with Australian Red Cross, coordinating the National First Aid program and website; a key achievement being the implementation of a web performance management framework to monitor and improve user experience and performance outcomes.

Di has postgraduate qualifications in electronic design and interactive media (web/digital media) and was a foundation member of the International Federation of Red Cross and Red Crescent Societies Social Media Advisory Group in 2009.

Background

In 2011 it is estimated that more than 14,000 women in Australia will be diagnosed with breast cancer, making it the most common cancer for women. Of those diagnosed, 30% will live outside a major city and it is estimated that about 43,000 women living in rural areas have been diagnosed with breast cancer in the last 25 years¹.

A diagnosis of breast cancer is a challenging and emotionally distressing time for women and their families. The diagnosis is only the first step – the journey is on-going. Women continue to seek up-to-date information and support long after their initial diagnosis.

The role of BCNA

Breast Cancer Network Australia (BCNA) works to ensure that women diagnosed with breast cancer, and their families, receive the very best information, treatment, care and support possible, no matter who they are or where they live. As the peak national breast cancer consumer organisation we support these women and families on a national and local level by:

- **informing** women and families by providing quality, up-to-date information about breast cancer, its treatment and services
- **empowering** women to have a voice in their own health care and to play an active role in improving breast cancer treatment, care and services
- **representing** women's voices and ensuring they are heard by policy makers, health providers and planners through our programs, policy and advocacy work
- **linking together** those affected by breast cancer, through our events, Member Groups, and online network.

A need to engage and support rural communities

Geographic isolation and limited contact with specialist health care workers may add to the difficulties facing rural women with a breast cancer diagnosis. In addition, the need to travel for treatment and to visit specialist health care providers often results in extended periods of time away from family and existing support networks.

Living out here it's a given that people have to go away for medical treatment. ... For most of my chemo doses, we decided it was best for our children to stay with friends out here and keep to their usual routine. Each time we left them behind it was a wrench. —Sue

The *Supporting Women in Rural Areas Diagnosed with Breast Cancer (SWRDBC)* Program, jointly funded by the Federal Department of Health and Ageing, BCNA and the National Breast and Ovarian Cancer Centre, aims to address the challenges facing rural women, with one of the program elements being the development of social support networks using technology.

BCNA's commitment to rural women is further guided by the fact that, relative to the number of women diagnosed, BCNA membership is strongest in remote and very remote areas.

Social networks and better outcomes

The benefits of social networks and social support to the outcomes for women diagnosed with breast cancer have been established over the last decade, with Kroenke et al finding "an elevated risk of mortality among breast cancer survivors who were socially isolated, specifically related to a lack of close relatives, friends, or living children."²

Online social networks play a valuable role, with as many as 2 out of 3 people with cancer using the internet as a supportive care resource even after medical treatment has ended³. Sharing experiences with others has been reported to reduce feelings of isolation and uncertainty regarding prognosis and ambiguous painful symptoms, to validate concerns ignored by health professionals, and to enable cancer patients to become better informed about their condition and to formulate questions for their health professionals³.

The benefits for health professionals and health-care providers of participating in online social media is also evident. The Mayo Clinic, when announcing the creation of its Centre for Social Media, noted that social media provided "immense opportunities for collaboration among our employees to improve patient care, education, research and administration".

Project goals

BCNA's online network provides a way for members to connect in real time, share experiences and stories, and provide peer-based psycho-social support. It is a natural extension of BCNA's existing face-to-face network and provides increased opportunities for those for whom access to face-to-face support groups is not feasible, in particular, those in rural and remote areas. Some women have also expressed their preference for the online environment, noting that they feel more comfortable sharing their thoughts and experiences in that way.

I have never been much of a 'sharer' but on this forum, I find it easy, maybe because I don't have to sit face to face and look into someone else's eyes. I find I can hold it together fine until someone looks at me with sadness and sympathy and then I tend to crumble. —Sara, online network member located in a major city.

Early research

Project research into what members wanted and would find useful consisted of interviews and a survey of a small group of website users. Participants included those diagnosed with breast cancer, family and friends, BCNA Community Liaisons and breast care nurses. Questions were asked about information sources and networking with others in the context of breast cancer, and also about the use of computers, the internet and the existing BCNA website.

Some of the key findings of the research were:

- Newly diagnosed people consistently reported being overwhelmed with information relating to breast cancer
- Those diagnosed with secondary breast cancer had different needs to those dealing with early breast cancer
- Stories were very important
- The ability to create online profiles, stories and blogs for network members and family and friends was considered important.

The desire for a more private environment than Facebook was articulated, where people could connect in real time, share their stories and find support from others of similar experience.

It would be good to have someone to talk to who wouldn't freak out – ideally someone going through the same experience. I don't want people who try to brush over topics or simply say 'it will be alright'.
—research participant

Process

BCNA's rural and remote women's working party was involved throughout the research and development stages to ensure ongoing input from this important demographic.

We also examined general social technographics for the Asia Pacific region⁴ to ensure the chosen technology met the needs of our target demographic, and their likely participatory behaviour.

Key considerations in the construction of the online network were:

- Privacy and the provision of tools to give users control over how much personal information is displayed, and to whom.
- Provision of 'search' and 'find' functionality to help members connect with others of similar experience regardless of location by searching in specific categories, such as 'breast cancer experience', 'year of diagnosis', 'relationship to person diagnosed', and 'age range'. This is of particular benefit to rural and remote members who often have difficulty connecting with others of similar experience because of the nature of rural isolation.
- The ability for each member to set up a personal profile that includes a brief 'about me', a profile picture, and an opportunity to share their personal breast cancer story.
- The ability to keep a personal blog, or online journal to document their journey and share information with others.
- The ability to setup and join online interest groups.

An active network

Those joining the online network cover the entire spectrum of people affected by breast cancer including those newly diagnosed (some who have joined on the day of diagnosis), through to those whose diagnosis was many years ago, and others who make up a diagnosed woman's support network (family, friends).

The online network is not topic-based, however the majority of conversations among members centre around diagnosis, treatment and psycho-social support. In effect, the network helps to 'normalise' the abnormal experience of a breast cancer diagnosis by providing a vehicle for women to find and converse with others who have had similar experiences.

After reading a few of the blogs, I am surprised to see just how many people there are like me out there. We all assume there is no-one else like us and our situations are all unique to ourselves, which they are in a way, but the similarities far outweigh the differences. —Tracey, online network member

A group of 18 active 'Online Network Champions' have been trained. Their role is to help set the tone of the online network as safe and welcoming, actively engage with new members and ensure all new members receive a warm welcome when posting for the first time. As a result members who have been welcomed in turn extend a welcome to other new users ensuring a healthy and self-sustaining environment.

Online network members are encouraged to share their stories and experiences while acknowledging that each woman's journey is unique. Network Champions take the role of encouraging members to add their experience and show appreciation for different points of view.

The network is not pre-moderated, however members are encouraged to use the 'report as inappropriate' functionality to report spam and inappropriate posts. As with all social networks, the BCNA online network has experienced some link-spam-related activity which is moderated, but to date there have been no instances of inappropriate posting by online network members. Commercial, promotional or research activity is not permitted in the online network.

Participants' experience of the online network

At the end of December 2010, the new website and social network had been live for just over seven months with more than 2500 registered members, 39% of whom are from regional Australia and 5% from remote or very remote Australia.

The majority of participants have been diagnosed with breast cancer (84%). Of those diagnosed with breast cancer, 25% indicated they were under 44 and 75% were over 44.

Network activity as measured by posts and comments continues to increase and is ahead of expectations.

The following is a breakdown of registered online network users according to breast cancer experience (as at end December 2010):

Breast Cancer Experience (n=2,338)

| | # | % |
|---|------|-----|
| Diagnosed | 1969 | 84% |
| Family/Friend of someone diagnosed | 165 | 7% |
| Health professional | 117 | 5% |
| Not applicable | 53 | 2% |
| Not diagnosed but strong family history | 34 | 1% |

The tables below compare the breakdown of members of the online network to the incidence of breast cancer in Australia⁵:

| Location | Online network (n=2,439) | Breast cancer incidence* |
|---------------------------|--------------------------|--------------------------|
| | % | % |
| Inner Regional Australia | 25% | 21% |
| Major Cities of Australia | 57% | 68% |
| Outer Regional Australia | 14% | 9% |
| Remote Australia | 3% | 1% |
| Very Remote Australia | 2% | 0.4% |

*% expressed is of average annual number of cases

| Age range | Online network (n=2,498) | Breast cancer incidence |
|-----------|--------------------------|-------------------------|
| | % | % |
| Under 25 | 2% | 0.07% |
| 25 - 34 | 10% | 1% |
| 35 - 44 | 20% | 11% |
| 45 - 54 | 37% | 23% |
| 55 - 64 | 23% | 27% |
| 65 - 74 | 8% | 18% |
| 75+ | 1% | 17% |

Participants frequently express an appreciation of the value of the online network and the experience of sharing their journey with others:

Thanks for your welcome it is great to have this site to find out that we are all going through the same things and you all just want to help. I remember reading about one of the ladies going through depression after chemo because I was suffering it pretty badly that time and thinking that I was just being stupid and not realising that it was a common problem it made a big difference to know that other women were going through the same thing.

Blog comment, online member -- Shazbo.

I didn't join this network until I was quite a way through my chemo and it has been great and have met up with some of the ladies for coffee, wish I had joined earlier. There is always someone here.

Blog comment, online member – Sarah51

Been reading some of your blogs and this is just going to be so good to keep in contact with people. I've just had a right mastectomy, lymph node (3 positive), start chemo and radio in the new year. Bit nervous but very positive and this site will be a blessing as living in the Pilbara it feels a little isolated for information.

Blog post, online member – Nicky

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