

# **Cancer Connections: Development of an Online Cancer Carers Community**

**Carers NSW Conference, 11-12 June 2009**

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Over the past five years, increasing emphasis has been placed at Cancer Council NSW (CCNSW) on the provision of online support services. The centrepiece of this initiative is CCNSW's supportive care website, Cancer Connections (initially Cancer Support Online). With funding from the NSW Health Department provided under a recurrent three-year grant, CCNSW has developed specific online resources for carers and is continuing the development of an online community for cancer carers.<sup>1</sup>

This paper sets out the rationale for, and the history of the development of, online services for carers. These services began with an online facilitator-led psycho-educational program, and this paper discusses the results of a formal evaluation of this program and explains how this evaluation led to a refocusing of services for carers across the organisation. The revised service offering included a set of online forums or bulletin boards, and the paper presents a thematic analysis of messages posted by carers (and patients) to these forums. It concludes with a description of CCNSW's new online cancer community, Cancer Connections, and a discussion of the opportunities presented by this new site.

## **I. Why does the Cancer Council NSW provide online support?**

*“Although the research base is limited, studies suggest that the Internet has changed the format, but not the benefits, of cancer support.”* (Klemm and Wheeler, 2005)

Research has demonstrated that consumers are increasingly turning to the Internet for health information and support. A study of US-based cancer patients and their caregivers indicated that 80% were interested in treatment-related information on the Internet, while 65% expressed an interest in online support groups<sup>2</sup> (Monnier *et al*, 2002). Information seeking, particularly through the Internet, is a coping strategy employed by patients and families throughout the cancer experience (Fernsler and Manchester, 1997).

Online information and support has been correlated with positive therapeutic outcomes. Eysenbach (2003) notes that “[p]rovision of information to persons with cancer has been shown to help patients gain control, reduce anxiety, improve compliance, create realistic expectations, promote self-care and participation, and generate feelings of safety and security. Satisfaction with information has been shown to correlate with quality of life, and patients who feel satisfied with the adequacy of information given are more likely to feel happy with their level of participation in the overall process of decision making”. Similarly, Burrows *et al* (2000) found that the sharing and obtaining information through online groups can be empowering for cancer patients and caregivers.

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<sup>1</sup> Cancer Council NSW gratefully acknowledges NSW Health for its ongoing funding of the Carers Project.

<sup>2</sup> “Online support groups” in this context is an umbrella term, which includes facilitated “live chat” (a web-based alternative to a telephone or face-to-face support group), bulletin boards, forum and groups, email listserv or mailing lists, and computer-mediated education-discussion.

Recent research carried out on online support groups has returned similar results. Golant *et al* (2002) found that 80% of participants in an online support group for women with breast cancer “found the experience highly rewarding and saw the people in the group as a relevant new support system that they plan on keeping up after the end of the group experience. In other words, real relationships were formed.”

Therefore, there are two primary aims of the online medium at CCNSW:

1. Providing support through the creation of an online community which connects cancer patients and their caregivers with peers who have had similar experiences (“online community”); and
2. Providing cancer information and resources that may assist cancer patients and their caregivers (“resource centre”).

These two aims are fundamentally interlinked, since the online community will provide a means of sharing resources, and the provision of information resources (particularly psychosocial resources) will encourage users to share feelings and experiences with others in the community.

While these aims can be partially met outside the online medium, there are five key reasons why an online community and resource centre supplements a face-to-face, telephone-based and print media presence at CCNSW.

#### **A. Format flexibility**

The online medium is inherently more flexible than a face-to-face or telephone support service in terms of format, and this flexibility can benefit users (particularly full-time workers, caregivers and others with limited time or limited scheduling flexibility).

This flexibility arises from the fact that online support and information can combine:

- Synchronous support (i.e. “live chat” in a closed or open support group format, at a regular weekly or fortnightly time, with or without a trained facilitator or with “special guests”);
- Asynchronous support (i.e. forums or bulletin boards, public or private groups with “walls” as additional forums, private messaging amongst users, mailing lists);
- Personal “journaling” of the cancer experience (i.e. profile pages, blogs, photos, videos etc.); and
- Information resources available for download, with optional real-time or asynchronous contact with experts (Helpline and “special guests”).

The flexibility of asynchronous support in particular is reputed to have significant benefits. The fact that they are available 24 hours per day, 7 days per week makes them convenient and accessible. In addition, as responses are not required in real-time, members can think carefully and deliberately before sending messages or responding to postings (White and Dorman, 2001). Finally, in forums or bulletin boards in particular, there is an ability to ‘lurk’ (read messages without posting) until one is comfortable with the group milieu (Finfgeld, 2000).

#### **B. Overcoming barriers to community (physical capacity, time, space and disease rarity)**

Secondly, unlike face-to-face groups in particular, and telephone groups to some extent, the online medium overcomes the barriers to community of physical capacity, time, space and disease rarity.

The convenience and accessibility of online support groups make them appealing to those for whom the physical demands of treatment cause debilitating side effects, making attendance at a traditional group unlikely (Fernsler and Manchester, 1997).

Moreover, while the asynchronous format is particularly appealing for those with limited time, a synchronous live-chat support group that can be conducted from one's home computer will at least alleviate the time-cost of travelling.

Like telephone support groups, online support groups are particularly useful for rural, regional and remote cancer patients and their carers, who are unable to attend face-to-face groups on a regular basis because of the prohibitively long travelling time that this would involve. The effectively unlimited geographical reach of the online medium would provide good matching possibilities for age, life stage, cancer stage, family status, sexual preference and so on.

Finally, it has been shown that online groups tend to favour conditions that are poorly understood, difficult or impossible to cure, or overlooked by traditional health care (Davison *et al*, 2000). Lasker *et al* (2005) note that “[t]he Internet offers a highly valued opportunity for those with rare diseases to connect with, learn from, and provide support to others having similar experiences.” For people with rare cancers, an online community provides a unique opportunity to locate and connect with peers who have had the same cancer.

The post, reproduced below, written by a user of the MacMillan cancer support website ‘What Now?’ in the United Kingdom in 2008 illustrates these benefits:

*“After spending my time surrounded by people at work, I found myself completely on my own when I became ill. I was widowed 5 years ago, and as I commute to London to work, I don't have friends where I live. Added to that, my closest family is my cousin, who lives over 80 miles from me. When I knew that I would be off work for some months, I really expected to be alone most of the time and wondered how I was going to cope ...*

*However, with What Now, we're all in it together. One thing in particular - with What Now, it doesn't matter what time of the day or night, someone will always respond. For example, I had a nasty fall late one evening a couple of weeks ago; I was alone in the house, weepy and shaky - it was too late to ring anyone, so I posted a blog and had so many responses and virtual hugs I felt better straight away. As Penny said, I no longer feel lonely or isolated, and I know that I have made lifelong friends through What Now.”*

### **C. Anonymity**

The anonymity provided by the online medium has two primary benefits. Firstly, as several authors have noted, with online communication, sociodemographic factors such as age, gender, racial or ethnic identity, income and social status are not readily obvious, so the medium can act as an “equalizer” (Klemm *et al*, 2003; Madara and White, 1997). Davison *et al* (2000) note that online communication “eliminates stigma associated with certain diseases, weight, disability and other physical appearance issues, social skills and voice issues”.

Secondly, online interaction tends to be disinhibited, allowing discussion of potentially embarrassing or taboo topics ('How do I deal with lost libido?' 'How do I feel sexual?'). In other words, the anonymity provided by online support increases the possibility for self-disclosure, and encourages honesty and intimacy (Ferguson, 1997; Galinsky et al, 1997; Madara, 1997; Klemm and Nolan, 1998).

**D. Preference for online medium amongst certain (often under-served) groups**

There is a recognised preference for the online medium amongst certain groups, particularly men and young adults, who are often under-served by traditional psycho-social support services.

Eysenbach (2003) noted that the anonymity of virtual communities may facilitate the participation of men, who may be culturally and socially conditioned not to ask for help and support. Research by Salem *et al* (1997) and Klemm *et al* (1998) also found that men are more inclined to access online support than face-to-face support, due to their comfort with using computer technology coupled with the anonymity provided by the medium.

Young people, particularly young adults, are also comfortable seeking health information online and may prefer to access psycho-social support services through the online medium. This assertion is supported by Shipard (2008), who recommends an increased focus on “innovative cancer support [for young adults] using technologically rich interventions such as the internet.”

**E. Cost-effectiveness**

Finally, it is noted that online psychosocial support has the potential to be more cost-effective than either face-to-face or telephone support. Galinsky *et al* (1997) found that online support groups may be more cost-effective than face-to-face support groups because they minimise transportation expenses and the need for a physical meeting space.

More broadly, online support combining synchronous and asynchronous support and personal journaling has the potential to provide round-the-clock psychosocial support for cancer patients and their caregivers, with minimal additional resources input by the Cancer Council.

**II. Developing online support services for cancer carers**

**A. Stage 1 – a psycho-educational, facilitator-led online program**

Recognising that cancer carers were a key user group for its services (and particularly the Helpline, with 19% of calls in 2003 from family members, friends or carers of people with cancer), CCNSW sought new ways to provide psychosocial support to carers.

Data collected about the nature and purpose of carers’ calls to the Helpline indicated that carers sought information about cancer and how to support a person with cancer.

**Table 1: Reasons for carer calls to the Helpline**

Issue	Number of calls
Diagnosis	1032
Practical issues	922

Counselling	405
Treatments	793
Palliative care issues	363
General information	127
Screening/self-exam	113
Prevention/risk factors	101
Other	3
Total	3859

**Source: OnCall Management Database, CCNSW<sup>3</sup>**

In addition, it was found that Helpline consultants regularly discussed with carers the need for carer support services including telephone counselling, education, practical support and peer support, which were then unavailable.

In response to these findings, funding was sought in 2004 for an increase in the capability of existing support services at CCNSW to cater specifically for the needs of cancer carers. It was proposed that these be delivered through a ‘Cancer Careline’, which would provide carers with access to a range of services via a single call to the Helpline (13 11 20), including:

- Telephone counselling;
- One-to-one peer support through Cancer Council Connect;
- Telegroup counselling; and
- A community-based education and support program, to be funded by a separate grant application.

The ‘community-based education and support program’ was the subject of a separate grant application to NSW Health in the same year. This application proposed the development of a facilitator-led online program with group participation using screen-based graphics and VOIP teleconferencing. This approach was chosen because:

- Internet connectedness at home was increasing in prevalence in Australia (ABS data indicated that in 2002 approximately 46% of Australian households had a computer which was connected to the internet and approximately 58% of Australian adults had access to a computer connected to the internet);<sup>4</sup>
- The technology was relatively ‘low-tech’: participants could take part from any computer with an internet connection, a sound card and a microphone;
- The approach was relatively low cost: costs were approximately half that of telephone conferencing and one-tenth that of travel and accommodation costs associated with face-to-face delivery; and

<sup>3</sup> From Dr Kendra Sundquist, Paula Vallentine, Professor Jane Ussher and Graham Newling, Application for funding for the development and delivery of a statewide support program for carers of people with cancer in NSW: The Cancer Careline Carers Support Program, 2 April 2004

<sup>4</sup> Australian Bureau of Statistics, Information and Communications Technology Indicators, 2002

- It allowed the facilitator to guide the group through the program, but offered sufficient flexibility for participants to share their experiences by ‘requesting the microphone’.

The grant application was successful, and a program of psycho-educational online interventions for cancer carers was developed with the objective of providing information, support and practical tools on how to manage self-care, as well as the opportunity to connect with other carers.

The program was delivered by a psychologist with extensive cancer experience to small closed groups of 6-8 carers in their home, or wherever they could access the internet. Participants were provided with headsets, and if required a sound card for their computer. Sessions lasting 90 minutes were delivered weekly for six weeks.

Carers were recruited to participate in the program through a variety of means, including 10,000 brochures, promotional presentations, Division of General Practitioners newsletters, regular articles in newsletters, radio announcements, regional office promotions, newspaper advertisements and websites.

Once registered, carers were sent a program package which included information about the program, each session and the evaluation process, as well as advice on getting started, troubleshooting and technical glitches. The package of information also included activity sheets and guidelines for keeping a reflective journal.

Topics covered in the six sessions included coping and communication strategies, enhancing physical and emotional well-being, information and links to cancer and community support networks. After each session, an electronic newsletter was sent to the participants summarising key points. On completion of the program, carers are given the option of participating in CCNSW's telephone support program and encouraged to join a carers' support group.

## **B. Evaluation of the psycho-educational program**

Researchers in the Health Psychology Research Group within the School of Psychology at the University of Western Sydney (led by Professor Jane Ussher) developed a pre and post evaluation matrix using a mixed methodology, to assess the extent to which the program objectives were met. Key evaluation measures included:

- Increased ability to identify and meet own needs as assessed by pre and post surveys on burden of care
- Enhanced carers physical and emotional well being as assessed by pre and post use of Care Giver Quality of Life Index
- Increased skills and coping strategies in caring for a person with cancer as assessed by pre and post questionnaires
- Increased access to community support networks as assessed by number of referrals

The program received positive feedback from those carers who had participated, and UWS researchers found that the program had impacted on anxiety and depression levels, quality of life, perception of unmet needs and burden of care, coping strategies and barriers to receiving support (including ability to ask for help).

64% of participants found the program useful and 66% found it easy to interact with others on the program. Individuals who had difficulty accessing the internet or

logging onto the program and bereaved carers were among those who did not find the program useful.

Despite this positive feedback, recruitment for the program was difficult, and although approximately 40 carers had indicated interest in participating, only two groups of 6 were ultimately recruited. Carers who did not participate cited reasons including that the person who they were caring for had died, or their condition had worsened considerably, they were unavailable during the session times, or did not have time to commit to a six week program.

### **C. Stage 2 – a new approach to online support**

These difficulties eventually resulted in a refocusing of the service offering to cancer carers. CCNSW and NSW Health agreed that the psycho-educational program would cease and CCNSW would instead expand the services offered to cancer carers across the organisation.

At the same time, CCNSW initiated the development of an online cancer community, then called Cancer Support Online. A tender process was undertaken, and a website developer was contracted to develop the website.

The revised service offering to carers included:

- A new forum-based online community for carers at Cancer Support Online;
- A publication for carers funded by an Australian Research Council grant, and produced by CCNSW in partnership with University of Western Sydney.
- A booklet titled “Caring for someone with cancer”, developed by CCNSW as part of its Understanding Cancer series of publications;
- Telephone support groups for carers and bereaved carers;
- Carer-specific modules in face-to-face community education programs, including Understanding Cancer and Living Well After Cancer; and
- Conference presentations on carers’ issues, including the International Psycho-Oncology Society (IPOS) Conference in Venice in 2007 and the Clinical Oncology Society of Australia (COSA) Annual Scientific Meeting in 2008.

The forum-based online community incorporated elements of the psycho-educational program, but reorganised these into static content pages which could be accessed through the site. Comments on the resources could be posted in the forum sections, and this was intended to facilitate discussion around similar issues to those discussed in the psycho-educational program.

### **D. Thematic analysis of messages posted to Cancer Support Online**

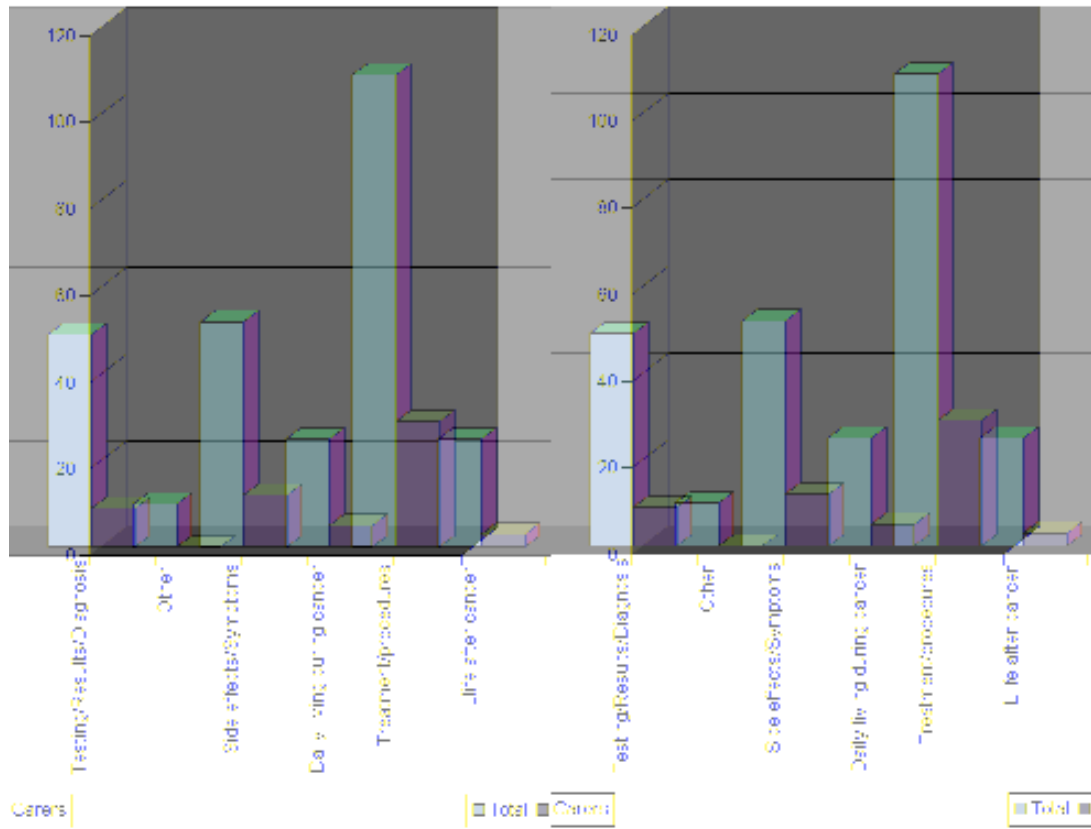
In late 2008, a thematic analysis of the messages posted to Cancer Support Online was conducted and presented at the COSA Annual Scientific Meeting.

Two independent coders coded all messages to determine the categories, and keywords were added to later identify themes or topics and message function. Messages (posted by both carers and patients) were divided into ‘medical’, ‘psycho-social’ and ‘general’ categories. Messages were subsequently recoded based on message function and primary topic. Users’ demographics were also recorded.

The analysis highlighted the following:



**Figure 2: Message topic**



***Psychosocial category messages distribution***

**Figure 3: Message function**

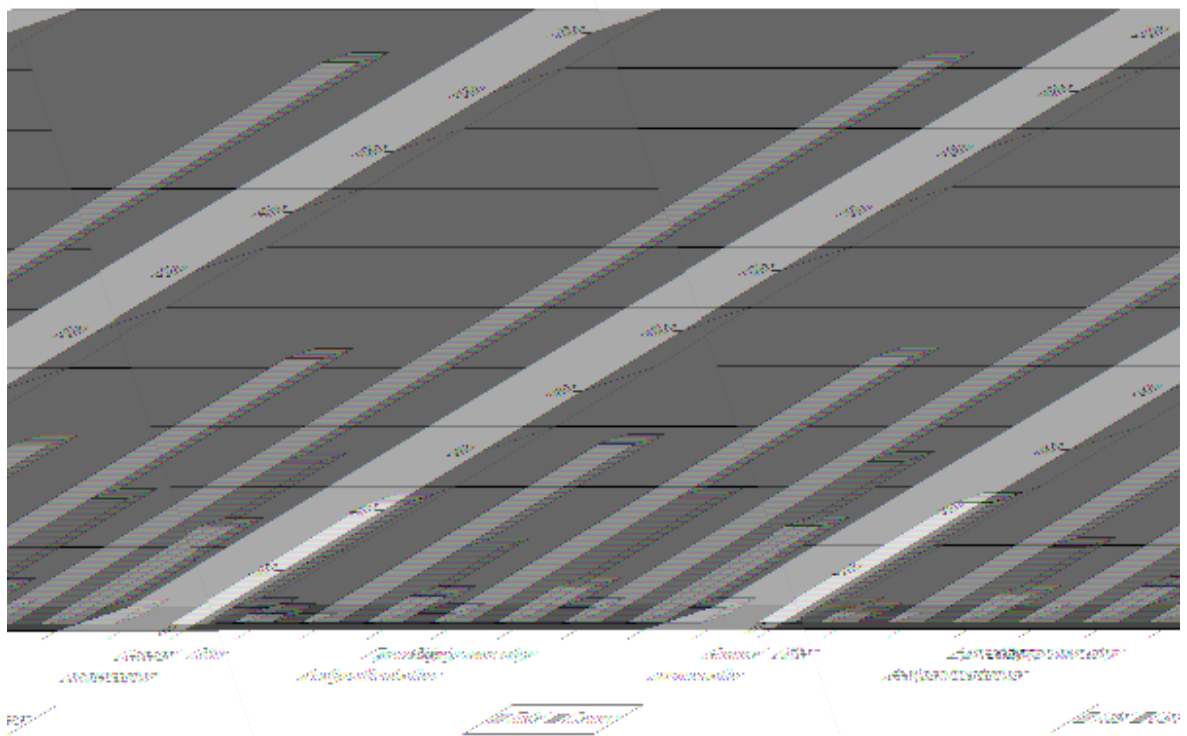
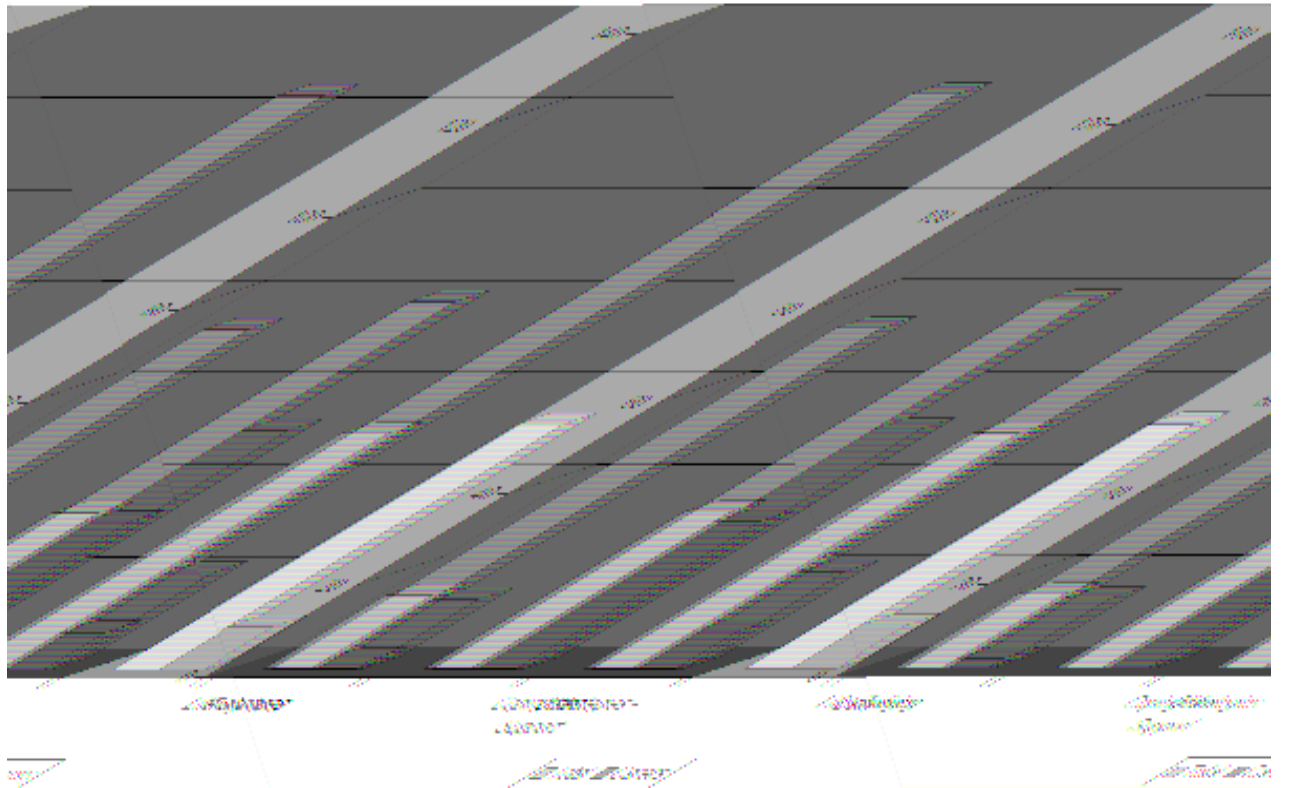
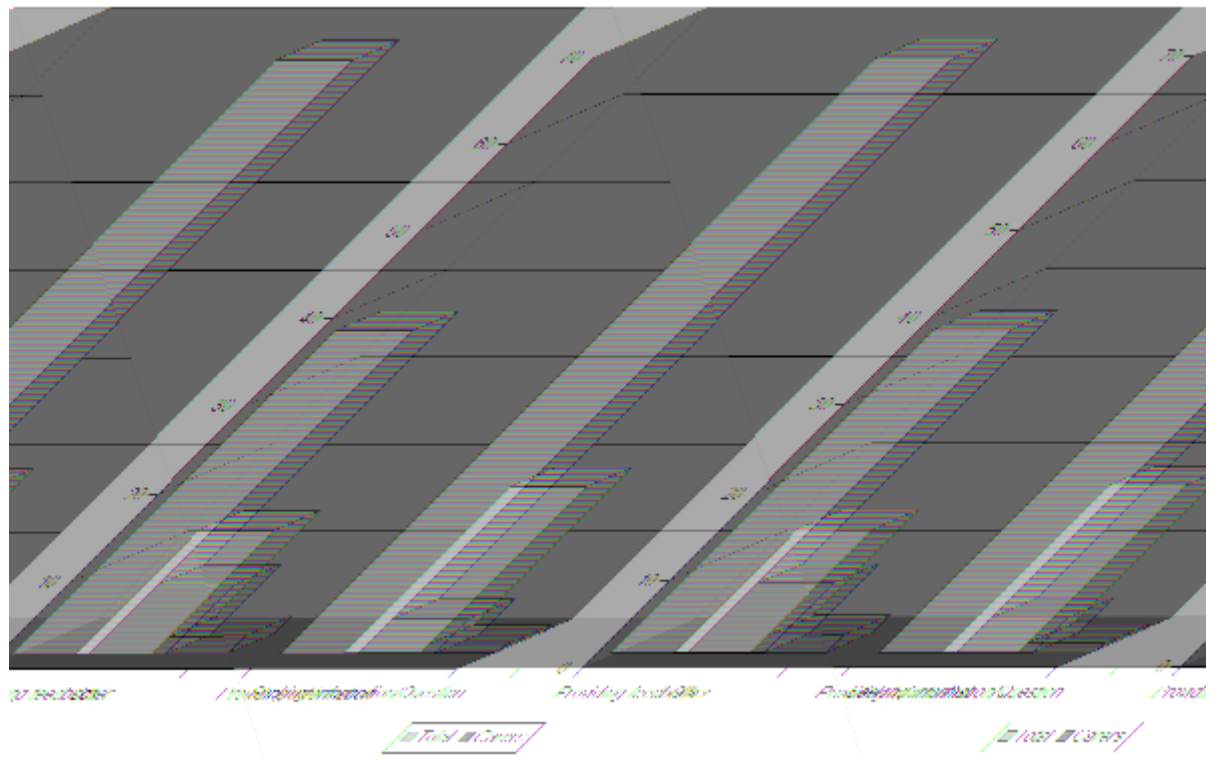


Figure 4: Message topic

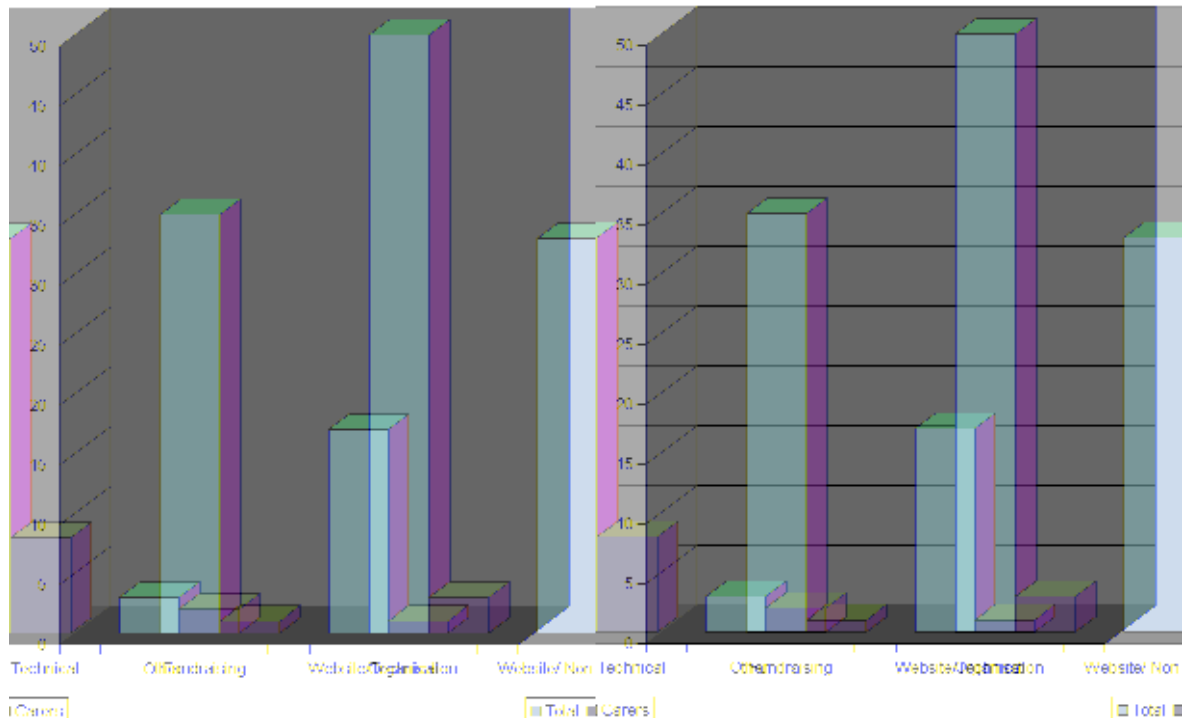


*General/website category messages distribution*

Figure 5: Message function



**Figure 6: Message topic**



### **E. The development of ‘Cancer Connections’**

In late 2008, CCNSW conducted a separate, internal evaluation of the Cancer Support Online focusing on the design and usability of the site. This evaluation found that although the deployment of a social marketing strategy has resulted in a marked increase in the number of visits and users registered on the current site, the perceived level of interaction had not changed since the site was first developed.

When compared with other online cancer communities, in particular the What Now? site developed by MacMillan and CancerBackUp in the United Kingdom, uptake and engagement in the current site had been limited. Feedback from users indicated that the visual design and functionality in that site had been a significant barrier to community engagement.

One important issue was that the word ‘Support’ in the website name discouraged engagement in the community, particularly for males.

#### ***Visual design***

67% of respondents indicated that the visual design could be improved, and qualitative data indicated that the visual design was an obstacle to engagement and the formation of community. Moreover, several users specifically commented that they used other websites of overseas organisations in preference to Cancer Support Online, due to its limited design and functionality.

Objective usage data from the site (obtained through Google Analytics) indicated that even targeted areas designed specifically to encourage users to take a particular action have been ineffective. The data highlight that targeted areas like “register now” had a click rate of 0%, the carers section a 2.6% click rate and cancer survivors section a 3.1% click rate.

### ***Functionality***

Given that a significant time period had passed since the initial development of the site, by 2008 the functionality available lagged behind the standard for online communities. This created some issues and limitations for users, which included:

- Inability to create groups. Several users made specific requests that would require group functionality in order to fulfil them.
- Static front page. At least 3 clicks were required from the front page to access information within the site, which meant that users that were not technologically savvy or already familiar with the site structure were unable to find the information they seek and instead simply leave the site.
- Inability to create calendars. The site did not include a calendar, which is an important feature for online community building as it can remind users of support group meetings, special events or activities.
- Inability to create blogs. In the site, users could fill in only three static fields and were not able to create dynamic personal journals on their home page.
- Limitations on the inclusion of media. The site did not support the inclusion of user generated media like images and video. This is a content based limitation that is now generally expected from an online community.

### ***Redevelopment of the support website***

As a result of these findings, a new website, Cancer Connections was developed at [www.cancerconnections.com.au](http://www.cancerconnections.com.au). The website was developed internally by the Online Community Manager using an open-source software platform, Drupal. Drupal is freely available for online community building but requires software development capability to implement. CCNSW was fortunate that the Online Community Manager had the expertise to develop the site with limited outside assistance, minimising the total cost of the redevelopment.

The new site features forums, blogs (personal online journals), profile pages and live chat. Group functionality will be incorporated over the coming months. Separate areas of the site have been created for carers and survivors, and the psycho-social resources developed as part of Cancer Support Online have been integrated into the new site. In the short- to medium-term, CCNSW intends to develop a multimedia section for young adults, including podcasts and videos on topics such as sexuality, complementary therapies, isolation and survivorship, and specific young adult carer resources will be integrated into these.

### **III. Conclusion**

The development of an online cancer community (and within that, an online community for cancer carers) has been a long and costly process. Two staff members (one full-time and one 0.6 FTE) have been employed to manage the online community, and significant additional resources have been spent in the development, promotion and evaluation of the site. The importance of flexibility in website development has been highlighted given the fast pace of technology innovations. Although it is currently premature to conduct a full evaluation of Cancer Connections for carers, early indications are that it has improved, and will continue to improve, psychosocial outcomes for participating carers.

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