Online Cancer Support: A Pilot Study to Implement and Evaluate a Support Blog at ARC Cancer Support House (Cork)

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CARL Research Project

UCC

Community
- Academic
Research
Links

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Name and year of course:	Master of Social Work (MSW) 2013
Date completed:	26th April 2013

What is Community-Academic Research Links?

Community Academic Research Links (CARL) is a service provided by research institutes for the Civil Society Organisations (CSOs) in their region which can be grass roots groups, single issue temporary groups, but also well structured organisations. Research for the CSOs is carried out free of financial cost as much as possible.

CARL seek to:

- provide civil society with knowledge and skills through research and education;
- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

What is a CSO?

We define CSOs as groups who are non-governmental, non-profit, not representing commercial interests, and/or pursuing a common purpose in the public interest. These groups include: trade unions, NGOs, professional associations, charities, grass-roots organisations, organisations that involve citizens in local and municipal life, churches and religious committees, and so on.

Why is this report on the web?

The research agreement between the CSO, student and CARL/University states that the results of the study must be made public. We are committed to the public and free dissemination of research results.

How do I reference this report?

Author (year) Project Title, [online], School of Applied Social Studies, Community-Academic Research Links/University College Cork, Available from: http://www.ucc.ie/en/scishop/completed/ [Accessed on: date].

How can I find out more about the Community-Academic Research Links and the Living Knowledge Network?

The UCC CARL website has further information on the background and operation of the Community-Academic Research Links at University College Cork, Ireland. http://carl.ucc.ie

CARL is part of an international network of Science Shops. You can read more about this vibrant community and its activities on this website: http://www.scienceshops.org

Disclaimer

Declaration of Authorship:

I hereby declare that the thesis presented here is, to the best of my knowledge and belief, entirely my own original work except where otherwise indicated. I certify that this thesis has not been submitted, either in part or whole, for a Degree at this or any other University. I am aware of the University's regulations concerning plagiarism. I further declare that any use of the works of any other author, is referenced and attributed to that author accordingly.

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Signed:_Rob O’Connor____________

Dated:_26th April 2013_____________

This study is a Community Action Research Links (CARL) project between UCC Social Work Department and Cork ARC Cancer Support House. The study explores the feasibility of Cork ARC Cancer Support House offering an online Support Blog. A participatory research approach was adopted. An Initial Survey was carried out to discover if a Support Blog would be a support service people would use and what helpful features it should contain. A Support Blog was then piloted for 2 months. Following this, a Final Survey was completed to gauge if users found the Support Blog helpful and in what way.

This project presents the findings of both Surveys and the experiences of the Cork ARC team from piloting the Blog. The project concluded that it would be feasible for Cork ARC to offer a support Blog depending on a number of conditions that would need to be considered for the support to be offered in a long-term capacity. These are highlighted in the recommendations of the study.

Keywords: Cancer Support, Support Blog, Online Support, Participatory Research

Abstract:

What is ‘Cancer Support’…

In our Final Survey we asked respondents to choose an image that represented 'Cancer Support' to them and this image stood out. We thought that this would be a nice way to begin our project...........

"The participatory research process is engaging, invigorating and likewise, exhausting. But then, that is the beauty of it. You will not be detached. You too, not merely the participants, will be rehumanized

(Maguire, 1993, p. 175).

"if we're aware of how to use them [Blogs] and how they are being used, we can help to shape the future"

(Walker-Rettberg, 2008, p. 160).

Acknowledgements:

I would just like to say thank you to my UCC tutor Kenneth Burns for his support and input. A big thanks also to all my other fellow MSWers who helped me out along the way. Thank you also to all the Staff at Cork ARC Cancer Support House who always offered great support and who continue to offer a fantastic service to those affected by cancer. Finally, the biggest thanks of all goes to all of those who used our pilot Blog for the 2 months and who completed our research surveys. Thank you so much for taking the time to be part of our little project. I only hope that you got something from being part of our Blog pilot in return for what you gave us.

[Please note that the TOC page numbers may not match in the PDF version]

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Chapter 1:

Introduction:

This chapter introduces the title, research questions, aim and objectives of this project. Following this, the rationale and background behind the research are articulated. As this research is part of a Community Action Research Links (CARL) project, this context is then explained. Next, I outline my own reflexive positioning concerning the research and the social work context relating to the project. Finally, a Chapter Outline is presented.

1.1 Title

The Diary of ARC House: A Feasibility Study to Explore the Development of a Support Blog at Cork ARC Cancer Support House.

1.2 Research Questions

1. Would Cancer patients/relatives make use of a Cancer Support Blog offered by ARC House?

2. If yes, what are the key areas of support that cancer patients/relatives find effective and why?

1.3 Aim

- To create/pilot a support Blog for ARC House for two months, in order to ascertain the main features that users find helpful/unhelpful? To use this data to evaluate the feasibility of Cork ARC Cancer Support House offering a support Blog long-term.

1.4 Objectives

- Carry out a literature review to identify the general features of Support Blogs that users find helpful/unhelpful.

- Create/administer an Initial Online Survey to determine if an ARC Blog would be a support tool that people would use.
- Design/maintain a Support Blog on behalf of Cork ARC Cancer Support House for a two month pilot period.
- Create/administer a Final Online Survey to determine what features of the Blog users found helpful/unhelpful.
- Offer an account of our experience of piloting a Support Blog, to inform other Civil Society Organisations (CSOs)[1] who may be considering same.
- Prepare conclusions/recommendations to inform ARC House of the feasibility of continuing an online support Blog.

1.5 Background

As the world becomes increasingly more technologically savvy, the use of the internet has changed the nature of social support (Guadagno *et al,* 2007). Eysenbach (2003) estimates that, in the developed world, approximately 39% of persons with cancer use the internet (2.2 million) and a further 20% will use the internet indirectly through family and friends. Guadagno *et al* (2007) claim that recent Web 2.0[2] trends suggest that online support is becoming more personalised, following a dynamic of informality and ownership. Blogs are at the cutting edge of these recent trends (Guadagno *et al*, 2007; Boyd, 2005; Nardi *et al*, 2004).

A Blog is a combination of the words Web and Log and could be understood as a frequently updated public online diary or log-book (Walker-Rettberg, 2008; Herring *et al*, 2004). Blogs are maintained by an individual (Blogger) with regular posts of commentary, descriptions of events, links to other material such as articles/graphics/video (Blogging). Posts are displayed in reverse-chronological order and older posts are archived. Blog followers can comment on these posts and create a dialogue. It is this interactivity of a Blog, with the invitation to readers to leave

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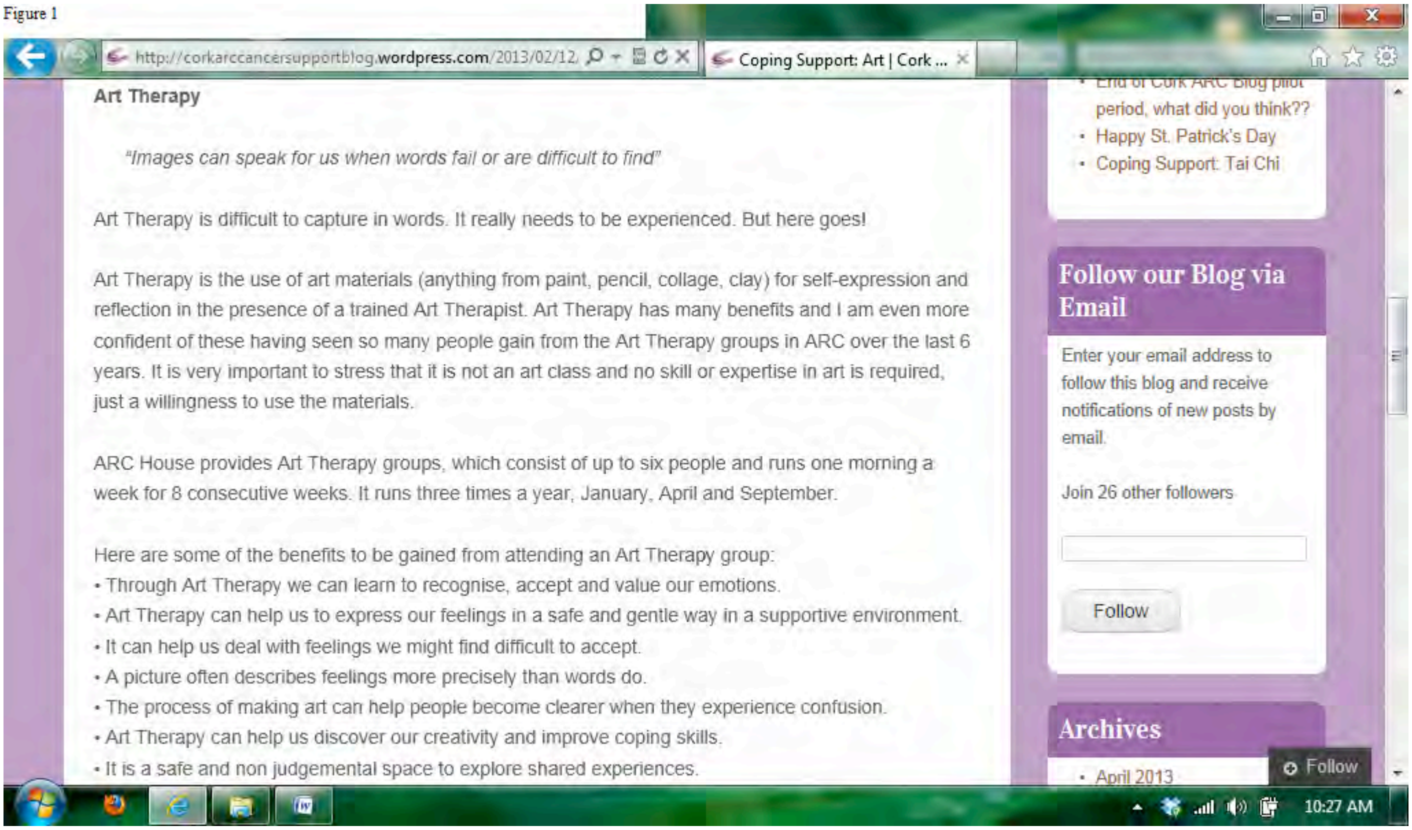
[1] As will be explained later, in a CARL project the community organisation involved is known as the Civil Society Organisation (CSO).

[2] Web 2.0 refers to a shift in focus on the World Wide Web from publishing information to a more participatory sharing platform (Walker-Rettberg, 2008).

comments/give feedback, which distinguishes Blogs from static websites (Baker & Moore, 2011 b). Comments are posted in an asynchronous fashion[3]. Figure 1 is an example of a Blog Post.

Figure 1



Art Therapy

"Images can speak for us when words fail or are difficult to find"

Art Therapy is difficult to capture in words. It really needs to be experienced. But here goes!

Art Therapy is the use of art materials (anything from paint, pencil, collage, clay) for self-expression and reflection in the presence of a trained Art Therapist. Art Therapy has many benefits and I am even more confident of these having seen so many people gain from the Art Therapy groups in ARC over the last 6 years. It is very important to stress that it is not an art class and no skill or expertise in art is required, just a willingness to use the materials.

ARC House provides Art Therapy groups, which consist of up to six people and runs one morning a week for 8 consecutive weeks. It runs three times a year, January, April and September.

Here are some of the benefits to be gained from attending an Art Therapy group:
- Through Art Therapy we can learn to recognise, accept and value our emotions.
- Art Therapy can help us to express our feelings in a safe and gentle way in a supportive environment.
- It can help us deal with feelings we might find difficult to accept.
- A picture often describes feelings more precisely than words do.
- The process of making art can help people become clearer when they experience confusion.
- Art Therapy can help us discover our creativity and improve coping skills.
- It is a safe and non judgemental space to explore shared experiences.

- End of Cork ARC Blog pilot period, what did you think??
- Happy St. Patrick's Day
- Coping Support: Tai Chi

Follow our Blog via Email

Enter your email address to follow this blog and receive notifications of new posts by email.

Join 26 other followers

Follow

Archives

- April 2013

Blogs began in 1996 and the blogging trend grew exponentially after 1999 with the release of the first blogging software (Herring *et al*, 2004; Blood, 2002). Nowadays, the Blogging community defies exact enumeration (Kumar *et al*, 2004; Blood, 2002) but Technorati[4] is currently tracking nearly 133 million Blogs, with nearly 21,000 of these Blogs being about health.

The Cork ARC Cancer Support House Developmental Plan for 2012 explored the possibility of ARC House extending its support services into the realm of internet support. A small-scale research study identified that a support Blog best matched the holistic support ethos of ARC

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[3] This means that a message is posted and then individuals leave comments on this whenever they want to, responses are not instant.

[4] Technorati is one of the largest trackers of Blogs in the world and acts as a search engine for Blogs similar to the way Google acts as a search engine for information (www.technorati.com).

House[5]. It also established that a support Blog would be a cost-effective pilot project to determine if an online support intervention would be a useful addition to the support services offered and hence, this project was born. Figure 2 below shows a sample of the eventual format the Blog adopted, in order to introduce the reader to the layout.

Figure 2

ForPeople Living with cancer and those who care for them

The Cork ARC cancer support blog is a pilot project offering online support to people with cancer, their relatives & friends

Part of a Master of Social Work Shop & a Community Academic Research Links (CARL) project by University College Cork (UCC)

Cork ARC Cancer Support Blog

About

Cork ARC Cancer Support House is a voluntary organization that provides support for people with Cancer, their family and friends. We provide practical help, information and emotional support. Our aim is to provide therapies that complement the medical model, so as to make a difference to the lives of those affected by Cancer.

The Cork ARC Blog offers online support to people with Cancer and their relatives and friends. The Blog acts like an interactive online support network for you to connect with peers.

Our Blog will provide regular posts of information that we hope will be helpful to you and that you can access at any time. It will also have descriptions of our programmes and events, as well as links to articles and other materials, such as graphics and videos or personal stories. Older posts are then archived and can be accessed at any time.

Cork ARC's Blog is a support and information service. We do not provide medical advice.

Interesting Imaginings...

This week's theme is around exercise and cancer. I thought that this image of these happy looking stretching people represented this well! What do you think...?

Recent Posts

- Cork Dragons
- Exercise and cancer
- What would you like the blog to become?..
- Talking to Children about Cancer
- Interesting Article: Writing About Emotional Experiences as a Therapeutic Process

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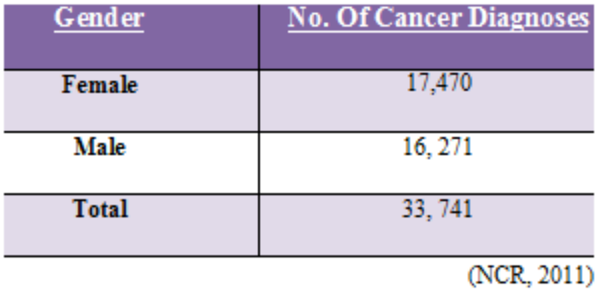
[5] The Cork ARC Cancer Support House ethos and mission statement articulate that "Cork ARC Cancer Support House is a voluntary organization established to provide a holistic centre in which people with cancer and their families can find emotional support and practical help. Our aim is to provide therapies that complement the medical model, so as to make a difference to the lives of those affected by cancer" (www.corkcancersupport.ie).

1.6 Rationale

Figure 3



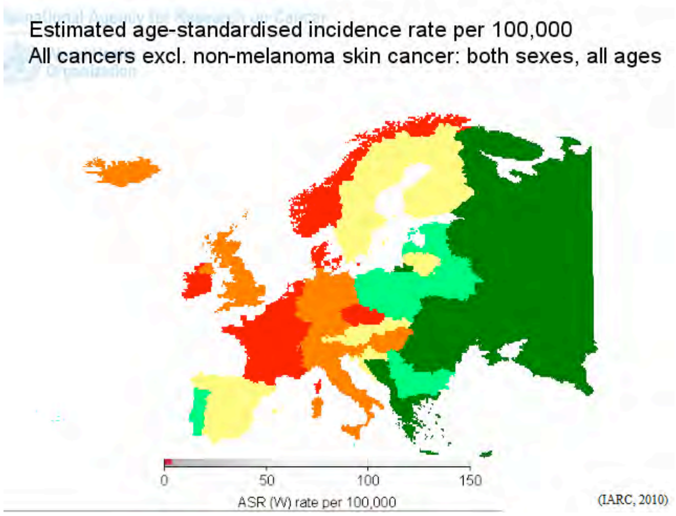
Gender	No. Of Cancer Diagnoses
Female	17,470
Male	16, 271
Total	33, 741

(NCR, 2011)

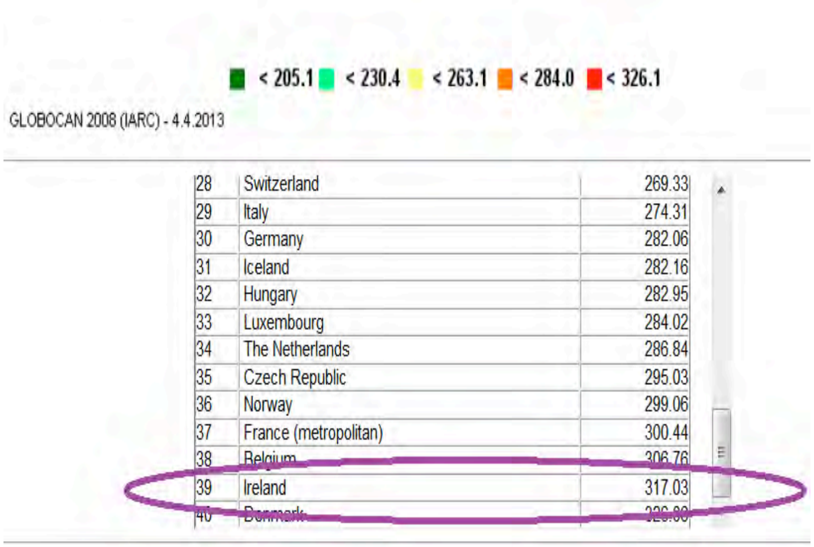
According to the National Cancer Registry (NCR, 2011), Figure 3 represent the number of cancer diagnoses registered in Ireland for 2010[6]. Between the years 2007-2009 an average of 29,745 cancer diagnoses were registered. This represents a 12% increase from the 3 years beforehand (2004-2006) and approximately 50% more cancers registered per year than in the mid 1990s. The cumulative lifetime risk of invasive cancer is around 1 in 3 for men and 1 in 4 for women (NCR, 2011).

According to the International Agency for Research on Cancer (IARC, 2010) and the European Cancer Observatory (Ferlay *et al*, 2010), Ireland has the second highest cancer incidence rate in Europe per 100,000 population, as illustrated in Figure 4.

Figure 4



(IARC, 2010)



🟩 < 205.1 🟩 < 230.4 🟨 < 263.1 🟧 < 284.0 🟥 < 326.1

GLOBOCAN 2008 (IARC) - 4.4.2013

28	Switzerland	269.33
29	Italy	274.31
30	Germany	282.06
31	Iceland	282.16
32	Hungary	282.95
33	Luxembourg	284.02
34	The Netherlands	286.84
35	Czech Republic	295.03
36	Norway	299.06
37	France (metropolitan)	300.44
38	Belgium	306.76
39	Ireland	317.03
40	Denmark	[illegible]

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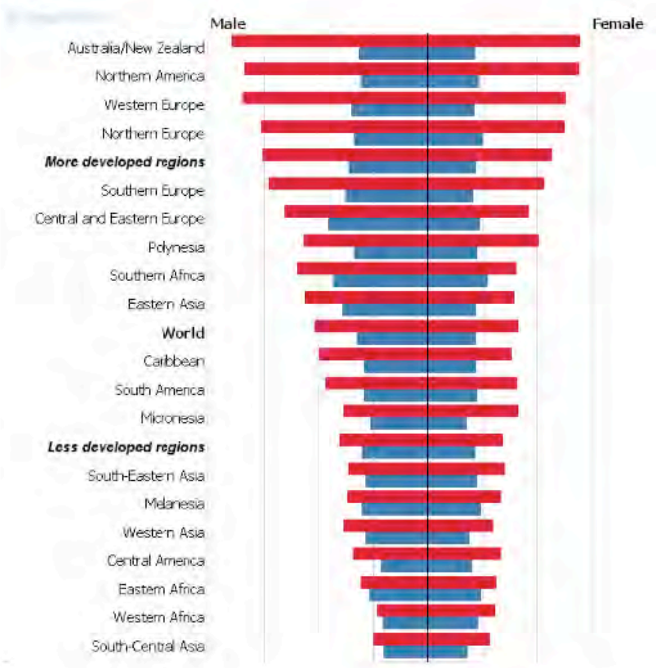
[6] These are the most recent statistics available.

Figure 5



(IARC, 2010)

In global terms, Western Europe is the third highest world region in relation to cancer incidence per 100,000 population (IARC, 2010). This is highlighted in Figure 5, where incidence rates are red.

These combined statistics illustrate that there is a large body of the Irish population affected by cancer and that prevalence rates are increasing. They also highlight that Ireland is a Global and European region where cancer rates are particularly high[7]. Cancer is a stressful life event to cope with (Wiggers *et al*, 1990) but research demonstrates that people benefit from social and informational coping support (Farnham *et al*, 2002). Therefore, there are ever increasing numbers of people in Ireland who could benefit from being offered support around cancer. Based on the above, the main rationale behind this project is a desire by Cork ARC Cancer Support House to expand their support services into the online realm to reach the increasing number of people affected by cancer in Ireland.

Furthermore, Clauser *et al* (2011) articulate that Information Technology (IT) is a foundational element in aiding cancer care organisations in offering person-centred support and enabling service-users to become more empowered through increased involvement in their own care. However, to date there has been a shortage of studies in this area (Clauser *et al*, 2011). Furthermore, blogs specifically related to health support are seen as a relatively new medium with little previous research studies (Kim & Chung, 2007). As such, this project is topical and timely and will address the paucity of studies in relation to improving cancer care through online supports such as Blogs.

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[7] The WHO (2013) has also identified that cancer is the leading cause of deaths worldwide. The NCR (2011) articulate that most recent statistics show that for the year 2007 there were 8, 189 cancer deaths in Ireland. However, as this support mechanism focused mainly on coping with cancer rather than bereavement support, I have not included this element in this discussion.

1.7 Community Action Research Links (CARL) Context

In this research project the Social Work Department (UCC) was linked with Cork ARC Cancer Support House (CSO) through a CARL project and I acted as the student researcher from the Master of Social Work (MSW) programme. A CARL project "involves students and/or academic staff collaborating with community partners to address local and/or societal research questions identified by CSOs" (Bates & Burns, 2012, p. 67). I approached UCC on behalf of ARC and applied to be considered for a CARL project. The application was approved and a Research Contract was drawn up (See Appendix 1).

The ethos behind CARL projects is linked to Universities being criticized for being disconnected from communities (Stoecker *et al*, 2011). CARL projects aim to counter this by being a vehicle for more diverse ways to strengthen interactions between researchers and CSOs through community-engaged student research (Boland, 2011). In a CARL initiative the University uses its research skill-base to respond to the needs of communities (Bates & Burns, 2012; Stoecker *et al*, 2011). As a result, not just universities but all citizens are "able to share their mutual knowledge and expertise, and to collaborate on the creation of new knowledge" (Bates & Burns, 2012, p. 67).

In this project the bottom-up CARL process accrued benefit for all involved. Firstly, it aided in forging a link between UCC and a local CSO, which facilitated enhanced responsiveness by UCC to societal concerns. Secondly, it assisted ARC House in becoming more attuned to the needs of the cancer 'community' and to augment their research and development capacity. Finally, the process helped me in building my research knowledge, skills and competencies (Bates & Burns, 2012).

1.8 My Reflexive Positioning

Participatory research also involves my own reflexivity (discussed further in Chapter 2). Researcher reflexivity is defined by Finlay (1998, p. 453) as "a self-consciously critical, systematic and analytical approach towards capturing more subjective and inter-subjective dimensions". In application to this project, reflexivity concerns making explicit the possible subjective influences that may have shaped how I have designed and interpreted the research. If personal biases or pre-understandings are made plain and 'owned', then this increases credibility of the research, as the reader knows why it was shaped in a certain way (Ballinger, 2004; Mays & Pope, 2000). As Finlay (1998, p. 455) states, “as researchers, we are part of the equation, so we need to look inwards as well as out”.

My own lens is formed by my social work training and value base. Some core values that are important to me include equality, participation, autonomy, and social justice. I feel particularly strongly about social work becoming increasingly professionalised and moving away from its mission to affect social change and be an advocate for those most in need (Walz & Grozes, 1991). Consequently, I have concentrated heavily on service-users having a voice in this project. It is likely that these values have influenced my approach to this research and the reader will likely notice permeations of them throughout.

Furthermore, I did not have ‘distance’ from the subject, as cancer is something that has personally affected my family. I have also seen firsthand the benefit of practical and emotional support around cancer. As I am from a rural community I have directly experienced the difficulties in trying to access support when it is centralised in one location. As such, a possible favourable bias is that I wanted this project to work, to be able to reach people such as those in my rural community. This personal attachment added a further emotional element to the project as I have ‘lived’ the experience of being affected by cancer. This is not always a bad thing as your emotions and values are always engaged as a researcher and it is just about drawing the links to these and making them explicit as I have done here (Finlay, 1998).

1.9 Social Work Context

This section will outline the social work context in relation to the research approach and the relevance of the findings to social work will be discussed later in Chapter 6. Core social work values also happen to be participatory research values (Stoecker *et al*, 2011; Blum *et al*, 2010; Healey, 2001). The participatory approach used in this project is founded on producing knowledge in a way that values respecting unique worth and voice (Trevethik, 2010; Cummins *et al*, 2006; IASW, 2007). The approach achieves this by bringing users’ perspectives to the fore, as a dimension of central importance and working with service-users to co-construct an intervention (CORU, 2011; Ramon *et al*, 2001). I feel that a participatory approach is important in the field of cancer support research specifically, as the focus of support is dominated by the medical voice.

Another core social work value contained in the research approach to this project was that of empowerment (Thompson; 2009; Cummins *et al*, 2006). Co-constructing and developing the Blog in conjunction with participants acted to build user knowledge of themselves as self-conscious experts of their own experience, which acts to empower and respect the autonomy of those involved (Killett, 2006; Chambers, 1994). This demystified the research approach and placed the Blog in the hands of the users (Park, 1993; Rahman, 1993).

1.10 Chapter Outline

- ***Chapter Two*** *– outlines the research design behind this project. It covers the theoretical positioning that informs the research and also the data collection and data analysis methods used.*

- ***Chapter Three*** *– explores the literature placing this research project in a wider context. The key areas of anonymity, peer support, blogging as a writing support and geographical/physical isolation are discussed.*

- ***Chapter Four*** *– outlines the key findings involved in the project in relation to an Initial Survey carried out to discover if a Support Blog would be a support service people would use and what helpful features it should contain and a Final Survey to gauge if users found the Support Blog helpful and in what way.*

- ***Chapter Five*** *– offers a discussion of some key experiential findings from the Cork ARC inquiry team, generated by running the pilot Support Blog for a 2 month period. Tips are also offered for future CSOs who may be considering online support.*

- ***Chapter Six –*** *provides an overall conclusion in response to the 2 initial research question. This draws out the importance of the findings of chapters four and five. Recommendations will also be offered in relation to the future direction of the online support intervention.*

1.11 Chapter Conclusion

This chapter provided a general introduction to the title, research questions, aim and objectives of the project. After that, the rationale and background behind the project were outlined. The CARL context was then described, followed by a personal reflexive piece. The social work context relating to the project was then articulated and finally, a Chapter Outline was given.

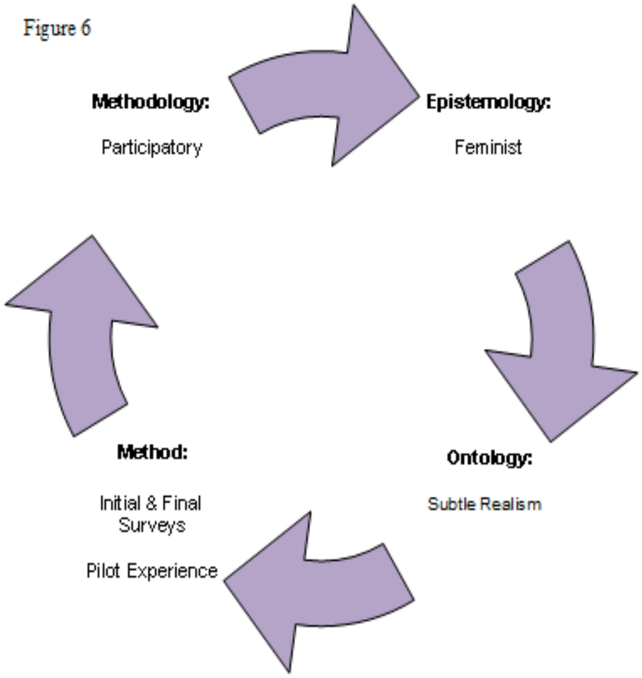
Chapter 2:

Knotty Problems? - My Research Design[8]

In my understanding, methodology is 'supposed to' clearly explain to the reader how we[9] went about conducting the research rather than being an academic exercise.

The chapter conveys the main methodological approach; participatory research. This approach is traced back up into the epistemological and ontological theoretical positioning of the study. These positions as interconnected, with each part informing the next. This is conceptualised in Figure 6. Following this, I outline the practical elements of the project. These include the sample selection, data collection and analysis

Figure 6



06, p. 245) where she speaks about tackling the knotty
phrase as for me research design is often something you

[9] It will be discussed later how a participatory research approach involves collaboration and co-ownership. As such, I have chosen to use terms such as 'us' and 'we' to make this clear. As a participatory researcher I prefer these terms to ones such as 'the researcher' as these suggest objectivity and distance from the research. As discussed later, these are not the positions that I take.

methods. I finish by discussing the ethical considerations and limitations relating to the project.

2.1 Methodology: Participatory Research Approach

REFLECTIVE EXTRACT:

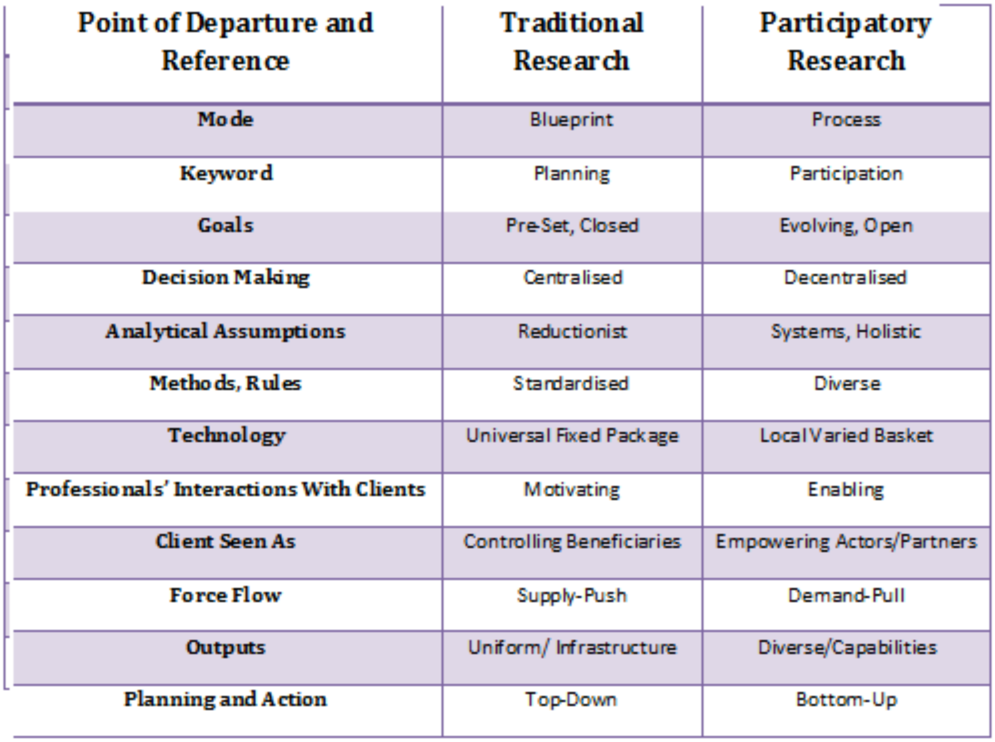
What drew me to a CARL project and participatory research is my belief that research should not be so abstract that it means nothing to the group that is being researched. As I had previously worked in research I was already familiar with research approaches and as such, before beginning my research this time round I was determined that it would be based on two key principles:

1. The research has a purpose and is *for* the group that is being researched.
2. The research is *led by* input from the group that is being researched

2.1.1 Key Principles of Participatory Research:

Park (2001, p. 83) describes participatory research as an approach "in which ordinary people address common needs arising in their daily lives and, in the process, generate knowledge". It may first be useful to highlight how participatory research differs from more traditional approaches. This is reviewed in Figure 7 and unpacked further in the bullet-points that follow.

Figure 7



Point of Departure and Reference	Traditional Research	Participatory Research
Mode	Blueprint	Process
Keyword	Planning	Participation
Goals	Pre-Set, Closed	Evolving, Open
Decision Making	Centralised	Decentralised
Analytical Assumptions	Reductionist	Systems, Holistic
Methods, Rules	Standardised	Diverse
Technology	Universal Fixed Package	Local Varied Basket
Professionals' Interactions With Clients	Motivating	Enabling
Client Seen As	Controlling Beneficiaries	Empowering Actors/Partners
Force Flow	Supply-Push	Demand-Pull
Outputs	Uniform/ Infrastructure	Diverse/Capabilities
Planning and Action	Top-Down	Bottom-Up

(Adapted from Chambers, 1994, p. 3).

- Participatory research values the experiential knowledge of participants (Killett, 2006; Rahnema, 1990).
- Participatory research is useful and applicable to the community involved (Killett, 2006).
- A participatory approach creates better maps for change, as it generates holistic understandings of peoples' lived realities (Healey, 2001; Foote-Whyte *et al*, 1991; Rahnema, 1990).
- Participatory research is undertaken *with* people rather than *on* people (Heron & Reason, 2001, Martin, 1996; Park, 1993).

- Participants feel a sense of ownership over the research and lead its direction[10] (Heron & Reason, 2001).
- Participatory research is evolving, interactive and dialectical (Burke *et al*, 2003; Biggs, 1989).
- Participatory research involves a consideration of researcher reflexivity (Foote-Whyte *et al*, 1991).

2.1.2 Participatory Approaches as Applied to this Project:

Participatory approaches occurred at one level between myself and the ARC staff and at another level between the inquiry team[11] and the Blog-Users. I will use two different models of participation to explain this.

REFLECTIVE EXTRACT:

When thinking about my methodological positioning I also considered a phenomenological or hermeneutic approach. However, my logic for not choosing either was that the depth that these approaches would focus on in relation to engaging deeply with subjective constructions around the phenomenon of cancer was not necessary for this project as a feasibility study

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[10] Blum *et al* (2010, p. 460) refer to this bottom-up approach as "user-controlled research" and Ramon *et al* (2001, p. 12) talks about participants as "user-researchers".

[11] I count myself and ARC staff as the 'inquiry team' (Ruano, 1991). I use the term inquiry team rather than 'research team' or any derivative thereof, because a participatory process focuses on collaboration and co-construction rather than a team of research 'experts'.

- Contractual – individuals are entered into projects by researchers to provide information on the area of research.
- Consultative – researchers consult individuals or seek their opinion on the area of research.
- Collaborative – individuals and researchers work in partnership on a research project designed and managed by the researcher.
- Collegiate – individuals and the researcher bring together their skills and expertise to conduct a research project designed and owned by members of the community.

(Biggs, 1989, p. 3).

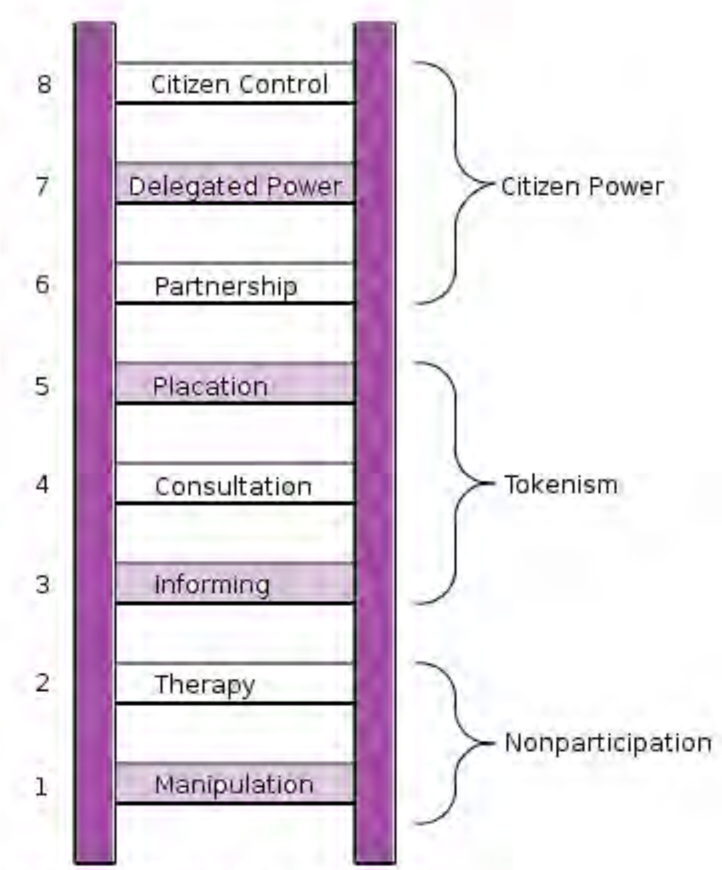
2.1.3 Participation with ARC Staff

Biggs (1989) identifies four forms of participation that are useful to apply in this case.

The participatory relationships between ARC and I started as consultative and moved into collaborative/consultative. The project began with me as a researcher and ARC as field-experts. We respected each other's knowledge and consulted in relation to our various expertise, which links to social work proficiencies concerning working in partnership with other professionals (CORU, 2011). However, as the project grew, we became involved in processes of collaborative inquiry (Heron & Reason, 2001). We engaged in multiple peer-meetings where interpretations were co-constructed and adjustments were made, so that Blog posts were co-produced (Ballinger, 2006).

2.1.4 Participation with Blog-Users:

Figure 8

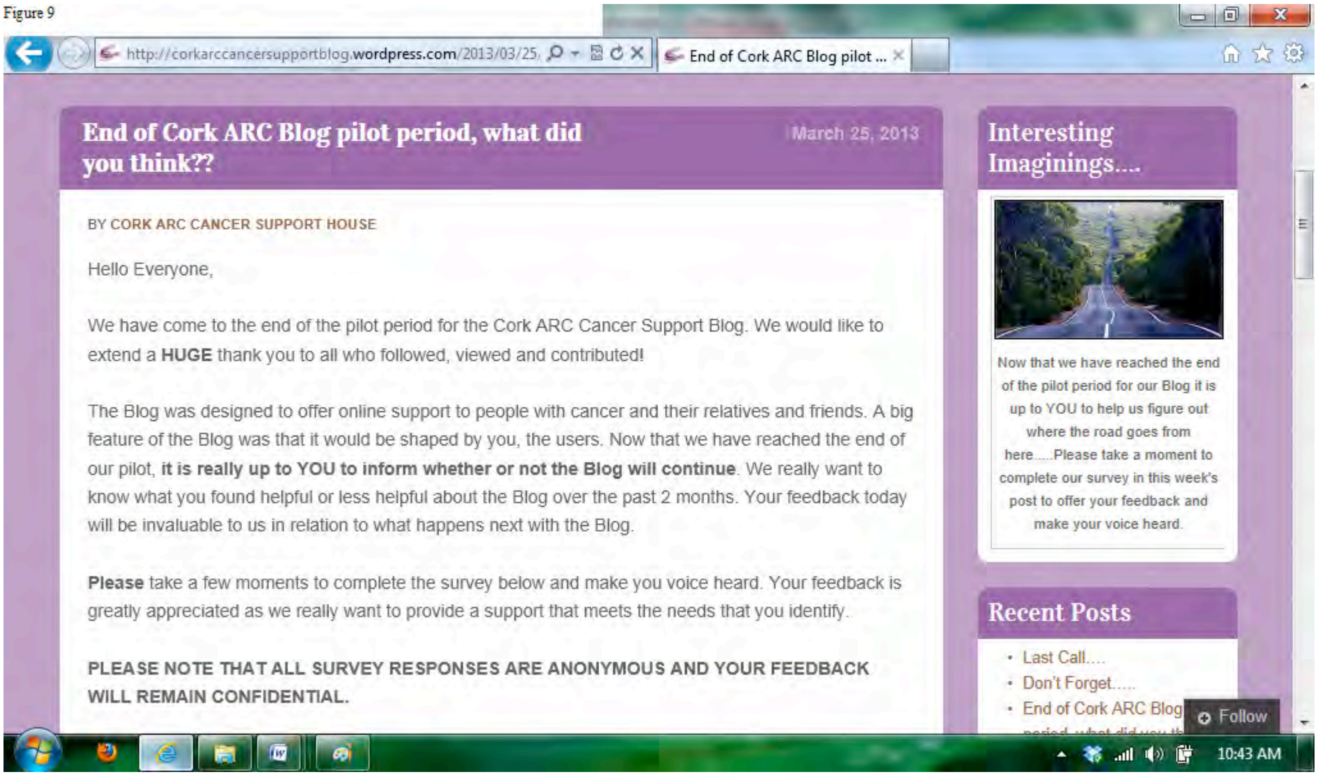


(Arnstein, 1969, p. 217).

I apply Arnstein's (1969) Ladder of Participation (See Figure 8) to the participatory process with the Blog-users. I locate this project between partnership and delegated power (Arnstein, 1969). We developed the Blog in participation with users (Boland, 2011). A cancer diagnosis can leave one feeling that nothing about the disease is in their control and the medical system can be disempowering (Killett, 2006). We recognised Blog-users' experiential knowledge as valid and important. In this way, we worked in conjunction *with* the Blog-users rather than conducting research *on* them, so that they could be empowered to shape the social support that they received through the Blog (Lundy & McGovern, 2008; Park, 1993).

There was also a sense of delegated power in that we promoted user ownership and control over the Blog. Our dialogue with the users emphasised that the Blog was *their* support, so that it would be practically *useful to them*. The process continuously evolved and we constantly 'put the Blog back' to the users to emphasise their ownership and power over it. Figure 9 is an example of a Blog-post emphasising the participant's ownership over the Blog and encouraging them to shape its direction.

Figure 9



End of Cork ARC Blog pilot period, what did you think??

March 25, 2013

BY CORK ARC CANCER SUPPORT HOUSE

Hello Everyone,

We have come to the end of the pilot period for the Cork ARC Cancer Support Blog. We would like to extend a **HUGE** thank you to all who followed, viewed and contributed!

The Blog was designed to offer online support to people with cancer and their relatives and friends. A big feature of the Blog was that it would be shaped by you, the users. Now that we have reached the end of our pilot, **it is really up to YOU to inform whether or not the Blog will continue**. We really want to know what you found helpful or less helpful about the Blog over the past 2 months. Your feedback today will be invaluable to us in relation to what happens next with the Blog.

Please take a few moments to complete the survey below and make you voice heard. Your feedback is greatly appreciated as we really want to provide a support that meets the needs that you identify.

PLEASE NOTE THAT ALL SURVEY RESPONSES ARE ANONYMOUS AND YOUR FEEDBACK WILL REMAIN CONFIDENTIAL.

Interesting Imaginings....

Now that we have reached the end of the pilot period for our Blog it is up to YOU to help us figure out where the road goes from here.....Please take a moment to complete our survey in this week's post to offer your feedback and make your voice heard.

Recent Posts

- Last Call....
- Don't Forget.....
- End of Cork ARC Blog

2.2 Epistemology: (How Knowledge is Understood in the Project)

The epistemological position behind this research is influenced by feminist epistemic theory. Feminist epistemology challenges traditionally produced knowledge that is associated with what can only be measured objectively (Park, 1993; Stanley & Wise, 1993; Oakley, 1981). Firstly, feminist epistemological understanding sees knowledge as something that is dynamic and indexical; constantly created through experience (Hodgson & Brooks, 2007; Stanley & Wise, 1993). Secondly, feminist epistemology places knowledge in the context of people's lived experiences and multiple sources of knowledge are validated rather than meta-theories (Stoecker *et al*, 2011; de Koning & Martin, 1996; Stanley & Wise, 1993).

A key feature of participatory research is the practice-based nature of knowledge, produced by 'non-experts', in this case blog-users who are affected by cancer (Park, 2001; de Koning & Martin, 1996). This links to the above interpretation, which presents knowledge not as something stuffy in an academic tome but instead values the 'everyday' knowledge of someone who has been affected by cancer, as something that is alive, meaningful, practical and valid

(Brooks, 2007; Sprague & Kobrynowicz, 2004). This is the understanding of knowledge that this project considers.

2.3 Ontology: (Worldview Informing the Project)

To adopt the methodological and epistemological positions outlined above, one must also hold a particular world-view. I understand ontological positioning to involve where one fits on the spectrum of realism-relativism[12]. This research focuses on people who have been affected by cancer. This presupposes two things in my mind.

Firstly, it accepts the reality that cancer is a fact. I do not expand this to mean that I believe in only 'one world' based on grand-narratives and universal truths that can be 'discovered' and empirically measured, nor do I wish to become lost in antirealist, deconstructed, postmodernist concepts concerning the repeated questioning of multiple subjective interpretations of disease. All this means for me is that as a starting point I accept the reality that cancer is a disease caused by the uncontrolled growth of abnormal cells in various parts of the body.

Secondly however, as well as accepting the 'reality' of cancer, I also accept a constructionist position in relation to how each person's experience of cancer is specific to them and based on subjective factors. In simple terms, the worldview that this project holds accepts some social reality (cancer is real) but also accepts some social constructionism (how one interprets and responds to cancer and the support offered around this). This could be seen as a halfway point between realism and relativism and could be classed as 'subtle-realism' (Mays & Pope, 2000)[13]. It is this position of subtle-realism that informs my ontological view throughout this project.

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[12] It is beyond to scope of this project to discuss this in detail but it is important to note that this is not a 'fixed' position and where one locates oneself on this spectrum is contextual, depending on the research question one seeks to answer.

[13] This halfway position is referred to by different terms in methodological literature including 'critical realism' (Ballinger, 2006) or naturalism (Lincoln & Guba, 1985).

2.4 Data Collection Methods

Data was collected using online social surveys and recording our experiences. Online surveys were deemed practical and appropriate as they allowed for physical distance, appropriate anonymity and ensured respondents had internet access[14].

REFLECTIVE INSERT:

As an alternative to surveys we discussed asking a group of service-users to follow the Blog for the two months and then form a focus-group afterwards. However, it was decided that the initial project should involve getting a Blog up and running and some preliminary analysis to gauge general interest, rather than in-depth analysis. It was agreed that surveys were better suited at this stage and that focus groups could be a later research phase.

2.4.1 Initial/ Final Survey:

Survey Monkey was used to create/administer and analyse survey data[15]. In both surveys, questions were generated in collaboration between myself and ARC staff and my UCC tutor. Both surveys consisted of fifteen-twenty questions. The first questions were closed-questions designed to identify demographic information. The remaining questions were open-ended and scaled questions. The Initial Survey was piloted for a two week period in ARC House with the

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[14] As the Blog is an online support intervention participants would have to have online access to be able to use the it.

[15] Survey Monkey was accessed through the UCC Department of Applied Social Studies who hold a subscription (www.surveymonkey.com).

ARC volunteers[16]. Both surveys ran for a two week period. 94 people responded to the Initial Survey and 10 responded to the Final Survey. This will be the focus of Chapter 4.

2.4.2 Experience of Running the Blog:

Interpretations were generated from Blog activity rates, my understanding of Blogging literature, reflections from my research journal but mostly from regular peer discussion meetings with the ARC staff (Ryan & Bernard, 2003). Our experiences and interpretations will be presented in Chapters 5 and 6 and also through 'Reflection Extract' bubbles throughout the report.

2.5 Sample

There are two separate commonsense sample-sets involved in this project (Mason, 1996). The first sample-group completed the Initial Survey and the second sample-group completed the Final Survey.

1. This sample-group was purposive and targeted people who had been affected by cancer and who were computer literate (Patton, 2002). We designed posters containing the survey URL[17], which were displayed in ARC House and in the Oncology Clinics in the three main local Cork Hospitals. We created links to the survey through other digital media outlets used by ARC[18].

2. This sample-group was also purposive and targeted people who had viewed or followed the Blog (Mason, 1996). As such, the final survey was disseminated through the Blog for people who were already using it. We also used ARC digital media outlets again.

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[16] Due to time constraints the final survey was not piloted before launch but it was felt that experience had been gained from already completing the initial survey.

[17] Survey Monkey allows for the dissemination of the link to the survey through e-mail or sharing of the URL.

[18] These digital media outlets included the ARC Facebook and Twitter pages and also on the main ARC website.

2.6 Data Analysis

2.6.1 Initial/ Final Survey:

Survey Monkey automatically compiled the online survey results. For both surveys, the demographic questions were converted into figures and graphs. For the open-ended questions, only a small amount of people chose to give responses. As such, the open responses generated were small enough to allow each response to be a 'theme' (Bryman, 2008)[19]. Therefore, if ten responses were generated then these were all seen as 'themes'. As each point became a 'theme' in itself, very little coding was needed. A simplistic version of coding was used when people made the same point. Essentially, both points were combined into one[20]. This will be discussed further in Chapter 4.

2.6.2 Experience of Running the Blog:

This analysis is presented in the form of interpretations and reflections on the process. The data is generated mainly from the minutes of peer-group meetings with ARC staff, correspondence between ARC staff and myself and from my own reflective research journal. The co-constructed interpretations from our experience of facilitating the Blog were 'put back into' the Final Survey to allow for social verification (discussed below) and gauge if the participant group agreed with them. This will be discussed further in Chapters 5 and 6.

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[19] It is important to bear in mind that this was a feasibility study and as such the term 'themes' is used quite loosely. These were not themes in the traditional sense of identifying areas to be explored in depth. At this initial phase, it was just about identifying what would be helpful for the Blog to include.

[20] This may require a further example to clarify. In the initial survey the question that generated the most open responses was "what would be helpful for the Blog to include?" Of the 95 respondents to the initial survey, forty gave responses to this open-ended question. Ten of the open responses were raising exactly the same point so these were grouped together. As such, we ended up with thirty general 'themes' of what respondents would like the Blog to contain.

2.7 Trustworthiness & Credibility[21]

A challenge of any qualitative research approach is to answer claims that such research is merely "subjective assertion" (Ballinger, 2006, p. 236). My position is one of "strong objectivity" (Harding, 1987, p. 62). This is the idea that no research can be disembodied from the researcher but if influences and bias are explicitly put on the table, then the data produced is deemed more credible (Lennon & Whitford, 1994; Harding, 1987). I have attempted to make influences visible through reflexivity (Hammersley, 1990) and test interpretations through social verification (Mays & Pope, 2000).

Reflexivity is demonstrated through the use of an audit trail (Lincoln & Guba, 1985). Social work researchers are particularly well equipped to demonstrate 'strong objectivity' through an audit trail as they are experienced in the use of reflective practice (CORU, 2011; Trevethik, 2010; Thompson, 2009). An audit trail concerns my reflexive positioning in the research project including possible biases (See Chapter 1) and also a demonstration of how my thinking and interpretations progressed throughout the project (See Reflective Extracts throughout and reflections included in Chapters 5 and 6) (Ballinger, 2004; Finlay, 1998).

Social verification is the idea that there are no pre-established universal objective rules that can be applied to guarantee validity but that the people being researched can accept by consensus that the data produced makes sense to their situation at that particular time (Mays & Pope, 2000; Rahman, 1993)[22]. In order to achieve this we presented our interpretations back to the Blog-users in the Final Survey to ascertain if they agreed with them (de Koning & Martin, 1996).

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[21] I have chosen to use the terms trustworthiness and credibility instead of a more positivistic conceptualisation such as 'rigor and quality' as these are based on objectivism, whereas my research purpose involves qualitative relativist interpretation.

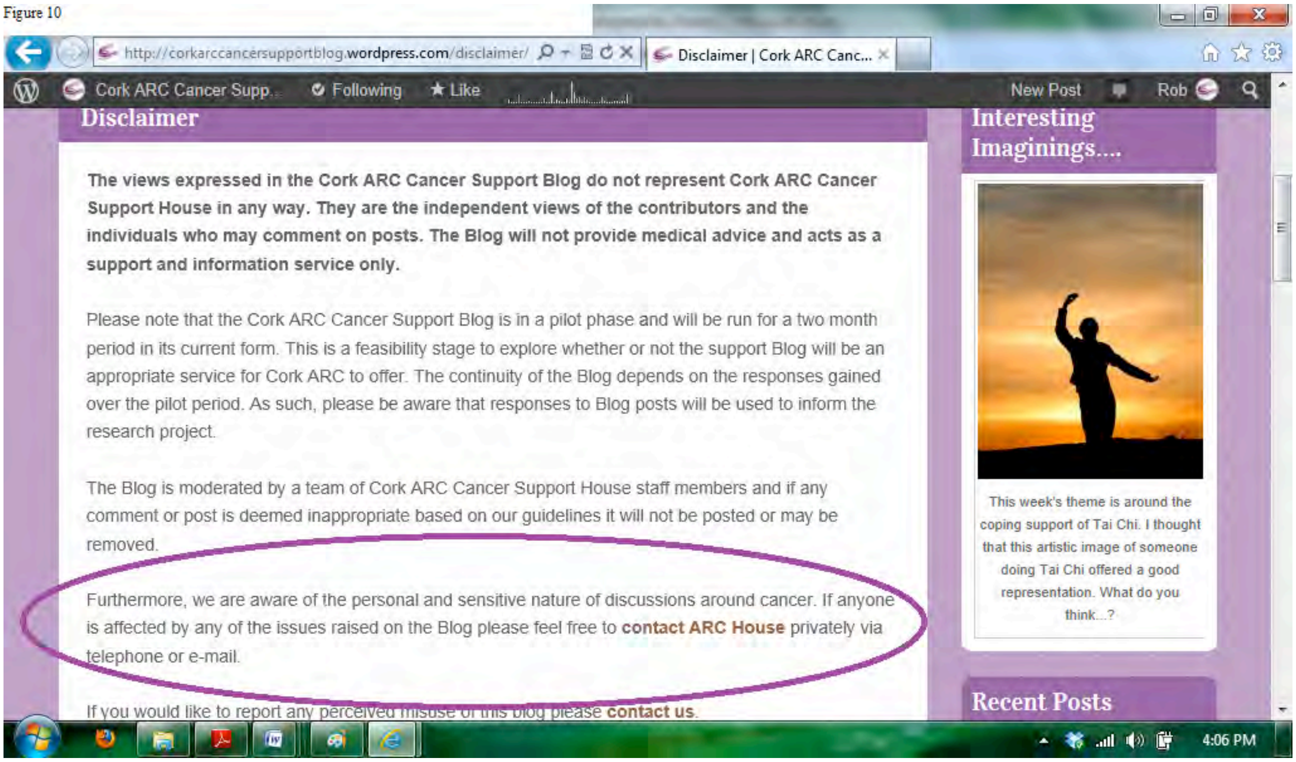
[22] This process is known by many terms including 'participant cross-checking', 'member checking', 'respondent validation' or 'collective verification' (Mays & Pope, 2000; Rahman, 1993).

2.8 Ethical Considerations

2.8.1 Potential Distress:

We acknowledged that the Blog may produce distressing reactions because of the sensitive nature of cancer (SAI, 2009; Elliot, 2006). The "Disclaimer" on the Blog specified that if anyone was affected by the issues raised, they could contact ARC privately by other means for support (Bryman, 2008) (See Figure 10).

Figure 10



Disclaimer

The views expressed in the Cork ARC Cancer Support Blog do not represent Cork ARC Cancer Support House in any way. They are the independent views of the contributors and the individuals who may comment on posts. The Blog will not provide medical advice and acts as a support and information service only.

Please note that the Cork ARC Cancer Support Blog is in a pilot phase and will be run for a two month period in its current form. This is a feasibility stage to explore whether or not the support Blog will be an appropriate service for Cork ARC to offer. The continuity of the Blog depends on the responses gained over the pilot period. As such, please be aware that responses to Blog posts will be used to inform the research project.

The Blog is moderated by a team of Cork ARC Cancer Support House staff members and if any comment or post is deemed inappropriate based on our guidelines it will not be posted or may be removed.

Furthermore, we are aware of the personal and sensitive nature of discussions around cancer. If anyone is affected by any of the issues raised on the Blog please feel free to **contact ARC House** privately via telephone or e-mail.

If you would like to report any perceived misuse of this blog please **contact us**.

Interesting Imaginings....

This week's theme is around the coping support of Tai Chi. I thought that this artistic image of someone doing Tai Chi offered a good representation. What do you think...?

Recent Posts

2.8.2 Privacy:

We maintained the privacy of participants through the guarantee of confidentiality and anonymity (CORU, 2011; PAI, 2008; UCC, 2007). At the beginning of both surveys we explained to respondents that they would be guaranteed anonymity and no identifying information would be required. On the Blog itself people are given the option to remain anonymous or use a pseudonym.

2.8.3 Informed Consent:

We ensured that participants had as much information as possible before completing each survey and on entering the Blog (AAI, 2005). Each survey was prefaced with a description of the project. The final question in each survey asked respondents if they consented to their responses being used as part of the research (CORU, 2011). Likewise, as much information as possible was contained in the 'Disclaimer', 'Introductory post' and 'About Us' posts on the Blog. The 'Disclaimer' also contained a section outlining to participants that their comments on the Blog would be used to inform the research.

2.9 Limitations

The project did not use a purist participatory approach but more of an adapted one (Blum *et al*, 2010). A criticism of participatory research, when not used in a purist manner, is that it ends up being tokenistic (White, 1996; Chambers, 1994). Any participatory project has to achieve a balance between participation and practicality but I acknowledge that if the project had been more purist in nature it is possible that different results may have been produced.

The sample method was relatively biased in terms of targeting a sample-group that already had a certain amount of computer literacy (Cleaver, 1999). I recognise that socioeconomic infrastructure and knowledge-base can be roadblocks to participation (Biggs, 1989; Arnstein, 1969). There was also an over-representation of females in the survey sample[23]. Finally, the response rate of the Final Survey was quite small. One could question whether this resulted in a support intervention that was tailored predominantly to the voices of women or to a particular computer literate socioeconomic class. I recognise that, the views expressed in the project are only those of a particular group and it would be interesting if future research addressed the issue of access to online supports and specifically focused on gathering more male and minority voices and accessed a bigger sample.

This research focuses on the 'cancer community' but this cannot be seen as a homogenous entity (Cleaver, 1999; White, 1996; Rahnema, 1990). This is the notion of whose voices are actually heard (Lundy & McGovern, 2008; Chambers, 1994). As such, the findings drawn are tentative

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[23] This would reflect users of ARC generally were there is a 2:1 female to male service-user ratio

and I claim no universality over the data produced. I further acknowledge that had a different group of people followed the Blog or answered the online surveys, with different situationality or historicity, then different data could have been produced.

2.10 Conclusion

This chapter conveyed the participatory methodological approach used in the project. It then outlined the epistemological and ontological theoretical positioning of the study. Following this, the sample selection, data collection and data analysis methods were explained. Finally, the ethical considerations and limitations relating to the project were discussed.

Chapter 3:

Literature Review:

Studies have found that online support interventions have improved quality of life for people affected by cancer (Høybye *et al*, 2005), offer useful practical/emotional support (Fernsler & Manchester, 1997; Gustafson *et al,* 1993), and offer a safe, supportive space (Ziebland *et al*, 2004)[24]. This chapter focuses on five literature themes in relation to why online support interventions are effective, with particular application to support Blogs and cancer support. The themes include; anonymity, informational support, social support, therapeutic Blog-writing and Blogs addressing geographic/physical barriers. Finally, some general limitations in relation to online supports are outlined.

3.1 Relative Anonymity

A key feature of online communication is anonymity (Eysenbach, 2003; Postmes, Spears & Lea, 2002). Blogs offer a "protective cloak of anonymity" (McKenna & Bargh, 2000, p. 62) and as such, people take greater disclosure risks, which allows for discussion of sensitive issues or illnesses, such as cancer (Kim, 2007; Bargh & McKenna, 2003; Joinson, 2001). Studies have found that people who converse anonymously online often feel less anxious and uncertain and leave the encounter feeling more positive (Joinson, 2001). Anonymity can also contribute to the formation of close relationships and increased bonding between Blog-users (Bargh & McKenna, 2003; Colon, 1996). Due to the anonymity afforded, online relationships can be formed on the basis of deeper, more durable groundings such as shared values, beliefs, or experiences, as opposed to physical characteristics or proximity (Bargh & McKenna, 2003; McKenna & Bargh, 2000).

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[24] It is beyond the scope of this study to go into great detail but just to give a brief insight into the types of support interventions studied. These included an online support mailing list (Høybye *et al*, 2005); Cancer entitled Comprehensive Health Enhancement Support System (CHESS) (Gustafson *et al,* 1993); a computer support network (Fernsler & Manchester, 1997); and online informational support generally (Ziebland *et al*, 2004).

The main caution is that online anonymity can reduce self-awareness (deindividuation[25]), which may make is easier for people to express negative comments; uninhibited behaviour; and react immediately to cues based on emotional state (Bargh & McKenna, 2003; Postmes, Spears & Lea, 2002; McKenna & Bargh, 2000). In simple terms, people behave more bluntly as they do not have to face a reaction (Nardi *et al*, 2004)[26]. A further caution is that individuals may reveal more than they realise because of a reduced self-awareness; "because of the absence of others' nonverbal cues when interacting online, individuals focus more on themselves and less on their audience" (Guadagno *et al,* 2007, p. 1995).

However, the cautions that are raised do need to be considered within context and a recognition of individual agency. Anonymity by itself does not produce negative behaviour, it merely acts to decrease the influence of self-standards and behavioural guides and increase the influence of external situational context and cues (Bargh & McKenna, 2003; Postmes, Spears & Lea, 2002; McKenna & Bargh, 2000). In relation to agency, Gumbrecht (2004) found that Bloggers exercised self-control, as they were aware that a remark deemed inappropriate may have a negative impact on future interaction. Bloggers are savvy and are aware that they are speaking in a public forum and can negotiate levels of public-ness and only reveal what they are comfortable revealing (Boyd, 2005).

3.2 Informational Support

The internet is increasingly used for informational support in relation to cancer (Eysenbach, 2003; Fogel *et al*, 2002; Klemm *et al*, 1998). Patients are less comfortable with the paternalistic approach of the medical system and want to source their own information (Fogel *et al*, 2002; Jenkins *et al*, 2001; Wiggers *et al*, 1990). Studies also show that people often do not take in the initial information that Doctors tell them, as they 'screen out' what is particularly frightening to hear. As such, they often search for information online after consultation (Gattellari *et al*, 1999a; Gattellari *et al*, 1999b; Ley *et al*, 1973). People affected by cancer tend to search for information

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[25] Deindividuation is defined as an individual's self-awareness being reduced by environmental conditions (McKenna & Bargh, 2000).

[26] In Blogging literature this is often referred to "flaming" (Sharf, 1997, p. 56).

particularly after their diagnosis and before starting treatment, with the hope of making more informed choices (Clauser *et al,* 2011; Fogel *et al*, 2002)[27].

Firstly, people affected by cancer can access up-to-date information on a Blog in a relatively informal way and at their own pace (Chung & Kim, 2008, p. 298). Informational support on a Blog is archived and can be accessed when the user feels ready. This is useful, as the desire for information shifts depending on where the person is on the illness/wellness spectrum (Ziebland *et al*, 2004; Degner *et al*, 1997). This can combat the above concerns in relation to paternalism or screening-out information as it allows for a "shift of mainstream control of information into the hands of the audience" (Kim & Chung, 2007, p. 445). This also links to the participatory approach discussed in Chapter 2.

Secondly, cancer can often cause feelings of vulnerability and inadequacy (Helgeson & Cohen, 1996). Informational support has been found to have a positive impact on people affected by cancer in terms of: allowing them to acquire some 'expertise' on their situation; increasing feelings of control and coping ability; reducing anxiety; creating realistic expectations; promoting self-care; and creating feelings of safety and security (Ziebland *et al*, 2004; Mills & Sullivan, 1999). Studies show that people who participate in their treatment, progress and cope better than those who do not (Degner *et al*, 1997). In order to feel like they can participate, people first need information (Chen & Siu; 2001; Gattellari *et al*, 2001).

Thirdly, Blogs allow for the provision of helpful information given by others in similar circumstances (Høybye *et al*, 2005; Ziebland *et al*, 2004; Sharf, 1997). One of the main reasons that people, post on Blogs or access online support is to share opinions and information (Technorati, 2011; Chung & Kim, 2008; Nardi *et al*, 2004). This could be seen as countering the 'medicalisation' of cancer knowledge (Høybye *et al*, 2005). Patients also share personal stories of shared experiences and triumph, which is also a form of useful information (Hillan, 2003). As Ziebland *et al* (2004, p.568) conclude "the internet extends the scope of the best stocked medical library, through access to experiential knowledge as well as medical information".

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[27] Studies show that online informational support covered areas such as, chances of cure; treatment options; adverse effects of treatments, home self-care, impact on family, social activities and sexuality; information around dealing with Doctors and practical issues such as diet; information from others regarding what to expect and how to cope with the illness (Cheng *et al*, 2000; Degner *et al*, 1997).

The main caution for people affected by cancer is the reliability of the online information obtained (Chung & Kim, 2008; Ziebland *et al*, 2004). It is essential to ensure information is reliable, presented clearly to avoid misunderstanding; and that lay information is not harmful or inaccurate (Chen & Siu, 2001; Carlsson, 2000). The main way to guarantee reliability and to clarify and regulate information is to ensure that a facilitator monitors and authenticates the information flow (Farnham *et al*, 2002; Chen & Siu, 2001).

3.3 Social Support

Social support[28] is recognised as a means of buffering the impact of stressful life events and aiding with coping (Weinberg *et al*, 1996; Thoits, 1986). Medical research indicates that social support contributes positively towards healing and coping with illness (Cheng *et al*, 2000; Helgeson & Cohen, 1996). With particular reference to cancer, studies show that online social support can reduce loneliness, increase feelings of empowerment, break down social isolation, aid people in adjusting to their diagnosis and prepare for illness-related experiences (Helgeson & Cohen, 1996; Cheng *et al*, 2000; Fernsler & Manchester, 1997). As well as actual social support, perceived social support has also been found to affirm self-worth and increase subjective wellbeing. If a person perceives themselves to be part of a supportive social-network their sense of connectedness and self-esteem may improve (Kim & Lee, 2011; Baker & Moore, 2011b).

Social support can be offered online through “cyber-support” (Sharf, 1997, p. 72), which occurs through the formation of virtual communities[29]. Blogging has been found to lead to expanded social-networks and increased social support due to shared interests and values (Baker & Moore, 2011b; Bargh & McKenna, 2003). A Blog lends itself well to facilitating an online social support-network, as Blogs are “a community, of sorts, a small town sharing gossip and news, recreation and sport, laughter and tears, all for the commonweal” (Graham, 199, p. 39). Blogs facilitate social interaction through conversational exchanges in the form of comments on posts (Walker-Rettberg, 2008; Hillan, 2003; Blood, 2002). This can also increase perceived support,

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[28] Social support includes areas like: being there, listening, reassuring and empathising with the person (Helgeson & Cohen, 1996).

[29] Virtual Communities are defined as “social aggregations that emerge from the Net when enough people carry on public discussions long enough, with sufficient human feeling, to form webs of personal relationships in cyberspace” (Rheingold, 1993, p. 16).

as mentioned above, as people can see who else is online or see comments responding to their posts (Farnham *et al*, 2002). Technorati (2011) found that over half of the Bloggers they surveyed had made friends through their Blogs.

The principal feature of social support that a Blog facilitates is mutual peer support based on a commonality of experience (Klemm *et al*, 1998; Thoits, 1986). Support is offered in a similar way to a face-to-face cancer support group, through "the supportive, cohesive effect of empathic interaction among peers" (Cella *et al*, 1993, p. 129). Cancer support groups in general have been found to improve quality of life, aid in the normalisation of feelings around cancer, and increase survival of those with cancer (Han *et al*, 2012; Cella *et al*, 1993; Spiegel *et al*, 1989)[30]. As Cella & Yellen (1993) affirm, current cancer treatment networks often leave a gap of unmet psychosocial needs, which professionals cannot meet but that can be fulfilled through mutual support.

The main criticism of online social support is the 'internet paradox'. This suggests that using online support could weaken 'real' community relationships and increase loneliness and depression, as 'superficial' online relationships replace meaningful ones (Nie & Erbring, 2000; Kraut *et al*, 1998). Another criticism expresses that a Blog cannot develop a 'community' as it is not synchronous. In simple terms this is because you are not part of a conversation in the same time and place as the other person (Cory Ondrejka: Chief Technology Officer of Second Life speaking at MIT Conference 2007, cited in Walker-Rettberg, 2008). A further critique is that a virtual community may include a considerable amount of expression of negative emotion (Eysenbach, 2003). As such, a cancer support Blog could become a place for ruminating on negative emotions, resulting in 'bringing down' other members instead of supporting them (Helgeson & Cohen, 1996; Bandura, 1997). A final caution is that each person on the Blog may be so eager to tell his/her own story that they do not listen or respond to the facilitators' posts and one voice dominates or similarly, that there are so many individual single voices that a community dialogue is never really engaged in (McLellan, 1997).

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[30] Other more practical beneficial elements of online peer support include; expressions of good luck or best wishes; affirmation of actions taken; expressions of sorrow; sending positive energy; welcoming new members to the group; responses to fears; sharing coping strategies experiences and humorous storytelling (Clauser *et al*, 2011; Høybye *et al*, 2005; Klemm *et al*, 1998 ; Sharf, 1997).

However, the ‘internet paradox’ has been strongly refuted in nearly all other studies, with most participants stating that online support has improved their lives (Bargh & McKenna, 2003; Kraut *et al*, 2002[31]; McKenna & Bargh, 2000). In relation to online support being asynchronous and therefore not community-like, studies have shown that asynchronous communication may facilitate better community building (Mckenna & Bargh, 2000; Nardi *et al*, 2004). This is because an asynchronous Blog allows a person to ‘hold the floor’ longer than in a ‘real-life’ conversation, or maintain an uninterrupted flow of writing, to be able to fully say what they want to get off their chest (Gumbrecht, 2004). The issues raised in relation to negative rumination in the group and dominance by individual members can be avoided by appropriate facilitation.

3.4 Writing as a Therapeutic Support

A Cancer diagnosis can cause much anxiety, worry and confusion, which is difficult to process (Chen & Siu, 2001). Writing on a Blog could help to cope with these feelings in different ways. The first way could be seen as venting. Blogging may have a cathartic affect as it allows users a place to ‘get their thoughts out’ and release emotional tension (Boyd, 2005; Nardi *et al*, 2004). Powazek (2000) describes a Blog aptly as a forum for the voices in his head that did not seem to fit anywhere else. This in turn can create physical, emotional and mental health benefits (Shaw *et al*, 2006; Pennebaker, 1997; Lepore, 1997). This mainly links to the idea that ‘bottling up’ negative emotions is physiological work that can have a negative impact on health and that there are positives to be garnered from writing about difficult experiences (Shaw *et al*, 2006; Pennebaker, 1997). A number of studies describe online cancer support forums as places where people can express emotions around the losses engendered by the illness, have an outlet to work out issues, a place to vent through writing and a place for emotional management (Chung & Kim, 2008; Nardi *et al*, 2004; Gumbrecht, 2004; Sharf, 1997).

The second way could be seen as introspective meaning-making. Blogs facilitate meaning-making, created through the reflection that occurs during writing, especially writing about illness (Shaw *et al*, 2006; Høybye *et al*, 2005; McLellan, 1997). Studies have found that Blogging can facilitate ‘thinking, through writing’ in order to better make sense of the feelings involved (Nardi

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[31] This Kraut *et al* (2002) study is actually a follow up study to the original Kraut *et al* (1998) piece, which began the discussion on the internet paradox. However, in the 2002 study the authors used the same sample but the finding was that internet use was actually associated with positive psychological and social outcomes.

et al, 2004). By cognitively processing and linguistically expressing a stressful life event, a person can better understand and cope with it (Lepore, 1997). According to Blood (2002b, p. 14) this could begin a journey of “self-discovery and intellectual self-reliance”.

A third helpful aspect is that blogging may be an easier way of expressing distressing feelings or emotions as it is usually done in a narrative format. For instance, some of the women in the Høybye *et al* (2005) study found that online forums made it easier to initiate discussions on difficult topics. Similarly, one of the Bloggers in the Nardi *et al* (2004) study spoke about communicating distress more easily online, as she could put up that type of post knowing that no one was obliged to reply. In this way the Bloggers are free of conversational partners or reaction but still know that an audience is there and this may allow them to share difficult feelings (Gumbrecht, 2004).

3.5 Blogging and Geographical/Physical Isolation

A key advantage of an online support Blog is the absence of geographical barriers and the potential to connect people to support (Bargh & McKenna, 2003; Postmes, Spears & Lea, 2002; Cheng *et al*, 2000). Geographical barriers are identified as reasons why people with cancer do not avail of face-to-face support services, even if they feel a need for support (Weinberg *et al*, 1996). Mckenna & Bargh (2000, p. 66) describe virtual spaces as “transcending the problems of physical distance and wide dispersion”, and state that this is especially important for those living in rural areas. Studies have found that engaging in online support by reading a Blog can reduce feelings of isolation even if the person does not actively post (Chung & Kim, 2008; Klemm *et al*, 1998; Weinberg *et al*, 1996).

Blogs can also circumvent the barrier of time (Cheng *et al*, 2000). A Blog-user can access the support any time, day or night (Ziebland *et al*, 2004; Sharf, 1997; Weinberg *et al* 1996). Again, inconvenient times are a reason cited for people with cancer not availing of support services (Weinberg *et al*, 1996). The asynchronicity of Blogs allows conversations to be started but then continued over days/weeks and users can take as much time as they need/want to respond (Mckenna & Bargh, 2000).

Blogs can also address physical barriers in relation to restrictive or medical isolation[32]. There may be occasions when it is difficult for an immune-compromised patient to meet with others in a similar circumstance or a patient may have obtained a physical disability or may simply feel too weak or sick to participate in face-to-face support (Høybye *et al*, 2005; Cheng *et al*, 2000; Klemm *et al*, 1998). A Blog allows users access to support without having to leave their current location, even if that location is a recovery bed (Høybye *et al*, 2005; Colon, 1996).

3.6 Drawbacks of Online Support

The main limitation of online support is the idea that face-to-face interaction is richer and higher is socio-emotional content (Eysenbach, 2003; Halavais, 2002; Joinson, 2001). Some see Blog support as impersonal disembodied voices or messages (Katz, 2001); or as Sharf (1997) puts it, there is an inability to offer a hug or an understanding eye. From this it could be concluded that a Blog will be a source of support suited to some but not to others (Eysenbach, 2003). Hillan (2003, p. 334) expresses this point well stating that while some people:

> "may feel free to post their inner feelings, concerns and experiences through writing and publishing on the Internet, others will not find their personality or skills suited for this sort of public, or semipublic expression".

The other key limitation is that an online support Blog may exclude people with low literacy skills or visual impairments (Klemm *et al*, 1998). Sharf (1997, p. 78) stresses this point, stating that exclusion from internet support can take place along demographic lines and that this creates "classes of people shut out on the basis of ethnicity, income, gender, and age in terms of access to equipment, software, and Internet connections; basic computer skills; and, even more fundamental, literacy".

3.7 Conclusion

This chapter has presented some general literature around blogging under the themes of anonymity; informational support; social support; therapeutic writing; and geographic/physical barriers. Following this some of the general limitations were identified in relation to online support services.

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[32] There are certain cancer treatment plans, such as those involving radioactivity, where the patient is required to remain in isolation for a certain period of time.

Chapter 4:

Research Findings:

This Chapter focuses on the key findings of the Initial/Final Surveys.

4.1 Initial Survey

4.1.1 Demographic Context:

The highest response rate was the middle-aged 40-49 (27 people: 28.7%) and 50-59 (24 people: 25.5 %) age cohort. 86 (91.5%) of the respondents were female and 8 (8.5%) were male (Figure 11). The largest amount of respondents (82 people: 87.3%) identified Ireland as their Country of Origin. The majority of respondents were relatives/friends of people with cancer (34 people: 36.2%) and this was closely followed by 31 (33.0%) respondents who identified as cancer patients (Figure 12). Most respondents (56 people; 62.9%) had not used the services of ARC House previously. **In summary, our survey was mainly answered by Irish, middle-aged women who were either cancer patients or relatives/friends of someone with cancer and had not previously used ARC's services.**

A total of 94 people answered our Initial Survey (n=94)[33]. (See Appendix 2 for Initial Survey Questions).

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[33]

Figure 11.

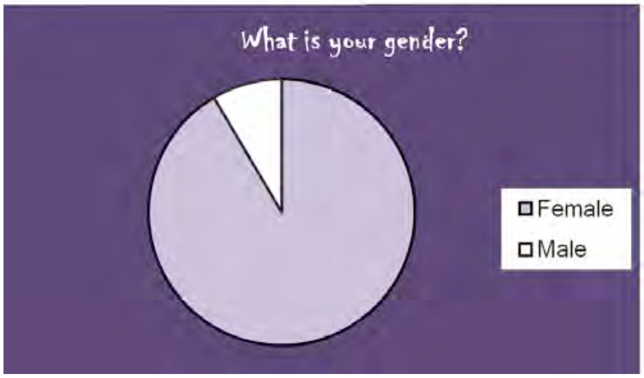
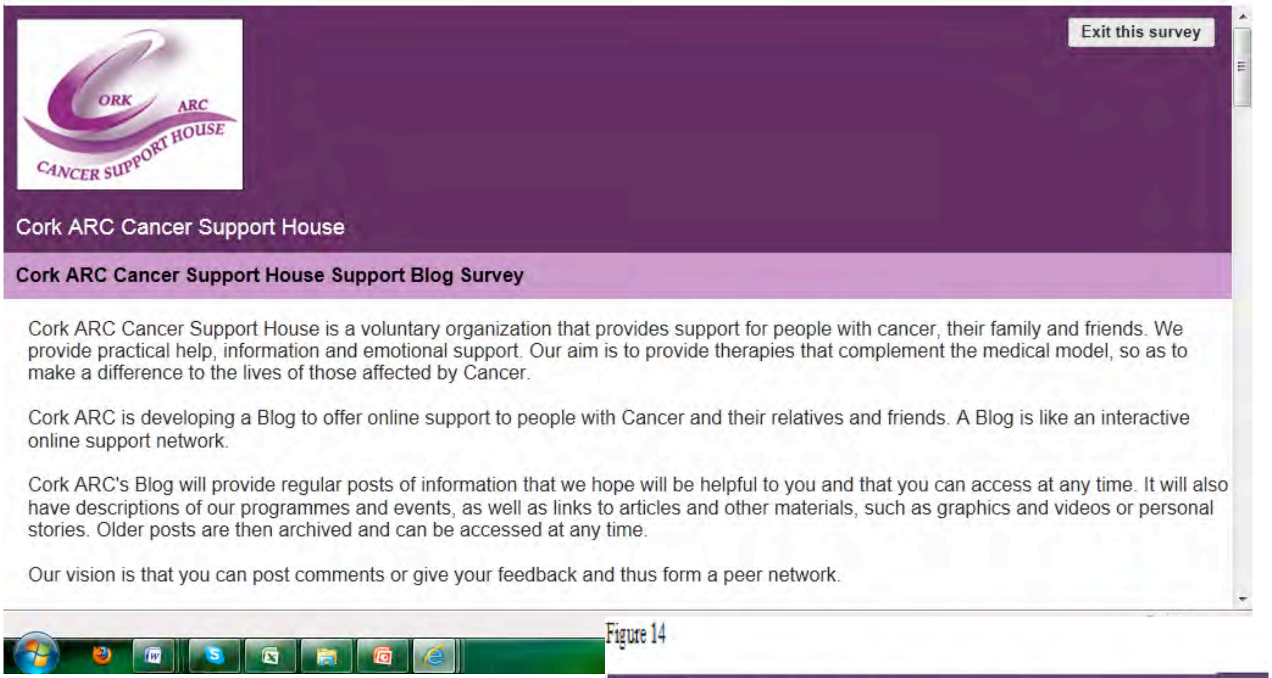


Figure 12.

4.1.2 Using a Cork ARC Support Blog:

Our first Research Question asked: would people affected by cancer make use of a Blog? (See Chapter 1). This survey question sought to provide an initial answer. We outlined in the survey introduction an explanation of what a Blog is and what areas the Cork ARC Blog covers (See Figure 13).

Figure 13



Cork ARC Cancer Support House

Cork ARC Cancer Support House Support Blog Survey

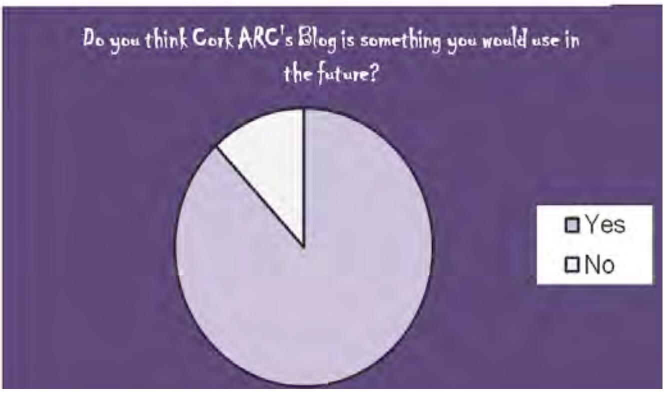
Cork ARC Cancer Support House is a voluntary organization that provides support for people with cancer, their family and friends. We provide practical help, information and emotional support. Our aim is to provide therapies that complement the medical model, so as to make a difference to the lives of those affected by Cancer.

Cork ARC is developing a Blog to offer online support to people with Cancer and their relatives and friends. A Blog is like an interactive online support network.

Cork ARC's Blog will provide regular posts of information that we hope will be helpful to you and that you can access at any time. It will also have descriptions of our programmes and events, as well as links to articles and other materials, such as graphics and videos or personal stories. Older posts are then archived and can be accessed at any time.

Our vision is that you can post comments or give your feedback and thus form a peer network.

Figure 14



81 people (88%) stated that they would use ARC's Blog (Figure 14). This positive

survey response was a key determining factor in deciding to pilot the Blog. The response suggests that most people surveyed could see the benefit of a support Blog and would be willing to engage with it.

4.1.3 Influencing Factors:

We asked respondents what factors that would influence their decision to use the ARC Blog[34]. These questions provided initial answers to our second Research Question around effective support features the Blog should contain (See Chapter 1).

The majority of respondents identified that being able to speak to others in a similar position (72 people) was most influential. This would confirm literature points around social support aiding with coping with an illness (Cheng *et al*, 2000; Weinberg *et al*, 1996) and the benefits of Blogs to create mutual socially supportive peer-networks (Walker-Rettberg, 2008; Blood, 2002). The second factor rated as influential was the ability to access support from one's own home (69 people). This links back to literature around online supports acting to overcome geographical/isolation/time barriers (Ziebland *et al*, 2004; Postmes, Spears & Lea, 2002; Cheng *et al*, 2000; Klemm *et al*, 1998).

In relation to having an alternative to face-to-face support, the majority stated that this was only fairly important. This would correlate with research findings that illustrate that some people gain benefit from online support (Mckenna & Bargh, 2000; Gustafson *et al*, 1993) but others feel that online supports are a poor alternative to face-to-face support (Eysenbach, 2003; Joinson, 2001). This links to the conclusion that online support can be a helpful support to some but is not a support medium suited to all people (Hillan, 2003). Regarding anonymity there was a split between rating this as extremely important or not important at all (33 people and 32 people respectively). This would again reflect the literature quite well, as some appreciate that anonymity allows users to feel more comfortable discussing sensitive issues (McKenna & Bargh,

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[34] We presented respondents with influential factors drawn from the Literature Review in Chapter 3 and asked them to rank them in accordance of importance.

2000; Joinson, 2001) but others fear that anonymity may reduce self-awareness and create uninhibited behaviour (Nardi *et al*, 2004; Bargh & McKenna, 2003; Postmes, Spears & Lea, 2002).

In the open text a key additional point[35] was expressed by one respondent in the statement:

- *"I know that the information provided by ARC will be up to date and relevant. The internet can be a very frightening and overwhelming place for information if you search alone".*

This ties in with literature suggesting that people increasingly use the internet for informational support around cancer (Fogel *et al*, 2002; Klemm *et al*, 1998) but that one of the key issues around online information is its reliability (Chung & Kim, 2008; Chen & Siu, 2001).

4.1.4 Helpful Features for the ARC Blog to Contain:

Based on majority ratings the three features rated most helpful for a Blog were:

1. To have a credible organisation that I can have contact with (77 people).
2. Peer support (74 people).
3. To have contact with an organisation when I feel unable to visit in person (69 people).

We also provided an open comment box asking respondents about features that they would like to see on a Blog and respondents provided 30[36] key features. These are presented in Figure 15. We used these 30 areas to inform the features that our Blog should contain (See Content Plan in Chapter 5).

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[35] Some other additional features mentioned were: to have a support service that was available outside of work hours through the Blog; to have a means to keep in contact with others through the Blog; and if the Blog was user-friendly. This would link to points made above around time barriers, peer support and easy accessibility.

[36] We initially had 42 features but as some features were stated twice we combined suggestions where there was overlap (basic coding) and ended up with 30 suggested features (see Data Analysis in Chapter 2).

Figure 15

Features the Blog Should Contain

1. Diet
2. Coping Skills
3. Exercise
4. Information on Conditions
5. Information about Cancer Stages
6. Benefits & Entitlements
7. Communication Skills
8. Managing Side-Effects
9. Information About Upcoming Events
10. Links to Other Cancer Support Sources
11. Dealing With Symptoms
12. Managing Fatigue
13. Information on Products
14. Massage Therapies
15. How to Find the Old Me
16. Dealing with Re-occurrence
17. Managing Grief
18. Understanding Cancer
19. Returning to Work Tips
20. Research on New Treatments
21. Information on Contacting ARC
22. Practical Information re Wigs etc.
23. Managing Feelings Around Cancer
24. How to Allow Others to Help
25. How to Support a Relative
26. Practical Caring Tips
27. Dealing With Family Members
28. Coping with Surviving Cancer
29. Information on Support Groups
30. Information on Reducing Isolation

4.1.5 Off-Putting Blog Features:

We also asked respondents what Blog features would be off-putting and respondents suggested 18 features[37]. We used this open commentary to inform what would be best to avoid on our Blog. These are presented in Figure 16.

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[37] Again there was initially 20 responses but as there was some overlap in responses, similar responses were combined and we ended up with 18 identified factors.

Figure 16

Off-Putting Blog Features

1. A Bit Impersonal
2. Lack of Computer Knowledge
3. Health Issues/ Feeling Up to Logging On
4. Confidentiality/ Fear of Being Identified
5. Misinformation
6. A 'Negative Loop' in relation to expressing the negatives
7. Not Motivated to Use Computer Much
8. Poor English
9. If Not Easy to Use
10. Advertising
11. Unfamiliarity with Process
12. Too Much Effort to Type
13. Long Personal Stories, I would Prefer themes
14. Spam
15. If it Does not Stay Current
16. To Know That it is Only People who are Affected/ Interested that are Reading
17. Too Much Information
18. Not Enough Variation in the Blog

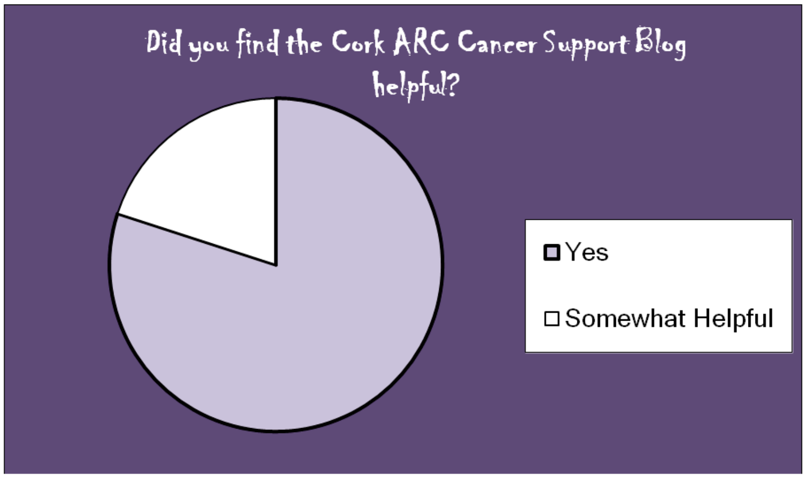
4.2 Final Survey

Our Final Survey evaluated how users found the Blog over the pilot period and also ‘tested’ some of our interpretations though social verification (see Chapter 2 and 6)[38]. 10 people responded to this survey (n=10). (See Appendix 3 for Initial Survey Questions).

4.2.2 Was the Blog Helpful:

8 of ten respondents (80%) identified that the Blog was helpful and 2 people classed it as somewhat helpful (20%). No one stated that the Blog was unhelpful. This is represented in Figure 17.

Figure 17



4.2.1 Demographic Context:

The largest response to the survey was from the 40-50 age bracket (3 people: 30%) and over two-thirds were female (8 people: 80%). The majority of respondents identified Ireland as their Country of origin (9 people: 90%). The biggest response was from people who identified as a cancer patient (4 people: 40%) followed by relative/friend (3 people: 30%) and Healthcare Professional (3 people: 30%). The respondents were mostly past users of ARC House (6 people: 60%). **In summary, the respondents to this survey were mostly middle-aged Irish women who were either cancer patients/relatives/friends or healthcare professionals and had used ARC services in the past.**

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[38] I will present how people found the Blog in this Chapter. However, I will present the ‘social-verification’ responses in Chapter 6 as I feel it is more appropriate to include the interpretation ‘tests’ with the conclusory interpretations themselves.

This links to the literature that discusses how the internet is increasingly being used for support for people affected by cancer (Ziebland *et al*, 2004; Bargh & McKenna, 2003; Farnham *et al*, 2002) and how Blogs are recognised as the newest form of this support (Chung & Kim, 2008; Nardi *et al*, 2004).

4.2.3 How Helpful were Features of the Blog:

Respondents outlined that the three most helpful features of the Blog were:

1. Being able to go back to archived information
2. Coping supports
3. Information

Points two and three have been discussed above, however, being able to access archived information was ranked highest and this has not yet been discussed. This could link to the idea that users require different information at different stages of a cancer diagnosis and it is helpful to be able to return to the Blog archive and pick-out what they need at that particular time (Clauser *et al*, 2011). As Ruland *et al* (2007, p. 2) articulate, “to be truly useful, Internet resources should be able to address patients’ individual symptoms, problems and health concerns that can change during different stages of their illness and rehabilitation”.

Some respondents also scaled some features of the Blog as unhelpful. The top three unhelpful features included:

1. Peer-Support
2. Sharing experience
3. Having contact with support as do not live close to supports

As mentioned in Chapter 3, the cautions around peer-support/sharing experiences may render this unhelpful for some people. For example, areas like the ‘internet paradox’ (Kraut *et al*, 1998) or the possibility of negative rumination (Helgeson & Cohen, 1996; Bandura, 1997). It is also likely that not living near supports did not impact on some who do live near supports. This reflects the subjective nature of support and the fact that some areas that one person find helpful, another does not (see below where other respondents cite peer-support as helpful).

We also included an open-ended question, asking if there were any other features that people found helpful. The responses included:

- *"I liked that readers were asked for their input about what would be on the blog"*
- *"Getting e-mail notification of a new entry to the blog was wonderful".*
- *"Got an insight of how my feelings are the same as others".*
- *"The wonderful thing about the Blog is that you can turn to it rather than burden your family with your worries on the bad days".*

The idea of asking for input would link to the overall participatory approach adopted in this project and our adoption of a collaborative power-sharing relationship to shape the Blog (Brooks, 2007; Rahnema, 1990: Arnstein, 1969). It was heartening that this was identified as a helpful feature and may work towards achieving a more meaningful intervention (Cleaver, 1999; Park, 1993). The second comment above links to the idea of ease of accessibility of a Blog due to automatic updates (Kim, 2007)[39].

The final two points link back to the idea of peer-support, the normalisation of feelings and peer-networks as an alternative to familial-networks (Cella & Yellen, 1993; Thoits (1986). Cancer can put a strain on existing relationships and there is often a need for support from others outside of existing familial relationships (Helgeson & Cohen, 1996; Weinberg *et al*, 1996). In simple terms, by talking to others in a similar situation, one realises that he/she is not the only person feeling that way (Klemm *et al*, 1998; Cella & Yellen, 1993).

We also offered an open-dialogue box for respondents to identify unhelpful features. The majority of people did not identify anything as unhelpful. However, one person did state that:

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[39] Automatic updates mainly occur through the use of technology know as a Really Simple Syndication (RSS) feed. This automatically delivers a list of updated information to people who are subscribed to the blog via e-mail. In simple terms, people who use the blog are automatically given updates as to what is going on with the blog rather than having to go and search for updates.

- *"I wasn't sure what day new posts/articles were put up".*

As discussed in Chapter 5, we adjusted our posting-pattern a few weeks into the project. When we changed we did not specify any particular weekday to post on. On reflection, this may have been confusing for followers as regular posting-patterns are a standard feature of most Blogs (Walker-Rettberg, 2008; Herring *et al*, 2004).

4.2.4 Feeling a sense of ownership over the Blog:

LeFever (2004) establishes that Blogs create personal connections in ways that other online mediums do not. As such, we thought that a sense of ownership could be fostered to promote participation (Lundy & McGovern, 2008; Park, 1993). We asked an open-question in relation to whether or not users felt a sense of ownership over the Blog. The main responses fell into the categories of 'not yet' and 'no'. In the 'not yet' category the respondents stated that:

- *"I think because it's early days it would be difficult [to feel a sense of ownership]".*
- *"Not yet but that is my fault as I did not make any comments and was content to read only. I am only shortly joined to it".*

These comments suggest that users feel that the Blog is still in its 'early days'. Literature suggests that it takes time to build up relationships between users and Blogs (Blum *et al*, 2010; Walker-Rettberg, 2008). However, there are signs that users could build towards a sense of ownership.

In the categorization that identified 'no', respondents articulated:

- *"Personally no - it just didn't hit the note for me".*
- *"Not really, read the blog and some areas were appealing to me while others weren't but that was my perspective".*

The first response is quite subjective and could link to literature that suggests that online support mediums are not for everyone (Hillan, 2003; Eysenbach, 2003). However, it could also suggest that not enough effort was made on our part to emphasise the sense of ownership we hoped to promote. It would have been interesting if there would have been a bit more expansion on detail.

The second comment could emphasise subjectivity of experience and how people may only be interested in areas that apply to them. However, although our Content Plan (See Chapter 5) was drawn from the Initial Survey, it could also suggest that our content may not have been broad enough and there may be scope for further development here.

4.2.5 A Sense of Social Support:

We asked if users felt a sense of social support from the Blog. The majority who responded to this question stated that they did feel this. Respondents told us:

- *"Yes. I feel that if I did need some information re my condition, I can just reach to the Blog Community".*
- *"Yes, I felt there was great social support attached to this Blog and it would especially benefit more isolated people".*

Again these comments suggest that social support and a sense of 'community' can be achieved through a Blog. Literature shows how this can aid with coping (Han *et al*, 2012; Weinberg *et al*, 1996; Helgeson & Cohen, 1996) especially in relation to commonality of experience (Fernsler & Manchester, 1997; Thoits, 1986); a sense of community (Gumbrecht, 2004); and a reduction in feelings of isolation (Høybye *et al* 2005; Cheng *et al*, 2000).

However, one person who responded to this question offered a converse opinion stating:

- *"Not as much as I would've liked".*

Again, it would have been interesting if the respondent had expanded on this comment to also mention why they felt this way. However, as articulated above, this could be linked to literature which suggests that some people do not feel a sense of social support on a Blog because of reasons like the asynchronous nature of a Blog (Walker-Rettberg, 2008) or that the relationships seeming more superficial (Kraut *et al*, 1998). However, Rushkoff (2000) posits that a successful social Blog is dependent on the ability to make excuses for people to talk to one another and although we attempted to do this, perhaps we did not do so enough.

4.2.6 Feeling Comfortable Commenting or Asking Questions:

We asked users if they felt comfortable commenting or asking questions on the Blog. Respondents stated that they would be comfortable but attached conditions to this. Responses included:

- *"I have not done it yet but yes, I feel that I would be able to ask questions as we are all at various stage of coping with the same thing. Other comments and questions could prompt people to make comment".*
- *"I would definitely feel comfortable asking questions or commenting on the Blog if I were a more regular user".*

As aforementioned, we sought to create the sense of a virtual community (Rheingold, 1993) where peer discussion and support could aid users with the challenges associated with their experience of cancer (Fernsler & Manchester, 1997; Helgeson & Cohen, 1996). The comments above outline that people would feel comfortable commenting but that it would have been easier if others had commented first (Baker & Moore, 2011 b). This is something that we attempted to do by having a member of ARC staff acting as a 'ghost writer' on certain posts. However, our 'ghost posts' were more conversational than questioning and perhaps if users would have seen more questions they would have been more comfortable. The second point is again related to the newness of the Blog and the fact that if users engage with the Blog more regularly they may build up a relationship and feel more comfortable interacting (Blum *et al*, 2010; Walker-Rettberg, 2008).

4.2.7 Recommendations for the Blog:

We asked users to make recommendations to improve the Blog. The majority of respondents stated that they had no recommendations and outlined:

- *"No, it's a great idea that will grow and develop".*
- *"No, You have the right approach in that you ask us what we want. As long as that continues the content will be good. Please keep the Blog going".*

Again, the idea of growing/developing suggests that people view the Blog as something in its early stages and relationships are still being built. The final comment also relates back to valuing the knowledge of users by giving them the power to shape the Blog through asking them what they want (de Koning & Martin, 1996; Arnstein, 1969) (See Chapter 2). It seems that the respondent appreciated this approach and encouraged it to continue.

Some respondents did make practical suggestions for improvement including:

- *"More images, maybe pictures on ARC House inside and out as it is so welcoming"*.
- *"More regular posts and maybe letting readers know if there are regular posting days"*.
- *"Maybe encourage people to Blog about their feelings in confidence and then others will reply and people will realise their feelings are normal"*.

These practical recommendations link to literature in relation to visual features such as pictures being a useful element of Blogs (Fullwood *et al*, 2009); having a regular posting-pattern (Walker-Rettberg, 2008; Herring *et al*, 2004) and emphasising the nature of a confidential arena to express feelings (Shaw *et al*, 2006; Pennebaker, 1997). Any of these recommendations would be relatively easy to include in the development of the Blog.

The last respondents' comments related to encouragement in relation to keeping the Blog going. Respondents stated:

- *"Just keep building"*.
- *"Keep up the good work"*.

These were encouraging as they suggested that users found the Blog helpful and wished it to continue.

4.2.8 Additional Comments:

Finally we asked if users had any additional comments or suggestions. Responses articulated include:

- *"Well done to all involved in the blog! great job!"*.

- *"Well done, a truly excellent Blog"*.
- *"Keep pushing it, it is early days yet!"*.

The final comments were mainly around messages of congratulations/encouragement and again a sense that the Blog was in the early days and was something that could keep developing.

4.3 Conclusion

This chapter has presented the key findings from both the Initial and Final Surveys. As aforementioned, the Final Survey also contained a number of questions in relation to 'testing' our interpretations and these are presented in Chapter 6 with the accompanying interpretations.

Chapter 5:

Discussion:

This Chapter presents key experiences[40] generated by the Cork ARC team from piloting the Support Blog. In line with the CARL ethos, we feel that other CSO's may benefit from our experience. I have structured this Chapter using 'inquiry cycles'[41] (Good-Heron & Reason, 2001). Each Cycle contains bullet-point 'tips' drawn from our experience of being involved in a constant endogenous process of systematic reflection and co-action (Rahman, 1993; Healey, 2001; Hicks, 1997). I will focus on 2 key Inquiry Cycles:

1. Beginning the pilot Blog
2. Running the pilot Blog

5.1 Inquiry Cycle 1: Beginning the Pilot Blog

- **Have a face-to-face meeting with all involved & draw-up an Action Plan:**

I feel that it is beneficial for any CSO piloting a support intervention to have an Action Plan, including a research question and aims. This acts to formalise what the project will achieve, keep the process on track and also re-focuses the trajectory of the intervention when necessary. In this project, an initial face-to-face meeting led to the co-creation of an Action Pan between myself, ARC and UCC as an 'inquiry team' (Ruano, 1991).

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[40] As this is a Chapter of restricted wordcount I will only focus on key learning experiences and helpful practical advice attached to these.

[41] Inquiry cycles are similar to 'stages' in relation to the development of the Blog but I feel that the term 'cycles' applies better to the project, as we were constantly moving between reflection and action in a cyclical manner.

REFLECTIVE EXTRACT:

It was helpful that I already had a relationship with the CSO. I was already familiar with the ethos of the organisation and the disciplines involved. Blum *et al* (2010, p. 458) refer to as a “social location fit”. If there is an external researcher or designer involved in the online intervention, it would be useful to afford some time to familiarise with the organisation and what it is about beforehand. This can aid in the process of co-negotiating and consensus building

- **Work out practicalities in advance:**

This includes frequency of meetings, venues, roles, resources needed etc. (Burke *et al*, 2003). We created a regular schedule of meetings where all involved would meet face-to-face fortnightly for feedback and a progress report. When there are a number of actors involved, this is essential to ensure that all involved are on the same page. However, it is likely that there will be some initial teething problems, as communication can be distorted when everyone is coming from a different place and it takes a little time to reach equilibrium (Ruano, 1991). A second useful practical element was the drawing-up of a realistic draft Calendar of Deadlines around when certain elements needed to be completed. If the length of the pilot period is know, it is useful to set markers as to what should be happening at certain points.

- **Assign roles/tasks to those involved from the outset:**

Something that we did not do at the initial meeting was assign roles. As Maguire (1993, p. 176) simply states, “collective work is messy”. It was hoped to contract-in an outside co-ordinator that would act as the link between researcher and CSO. However, a suitable candidate was not found within ARC’s limited resource budget. I would caution against sourcing an outside co-ordinator unless one has a large budget to spend, as the search process was quite lengthy and ultimately fruitless, which delayed the project a little. As a result of not sourcing an outside co-ordinator, there was a sense of diffused responsibility and no one person with the dedicated role of link person between CSO and researcher.

The project worked well with different people taking responsibility at different times and one person took on the practical role as facilitator/moderator of the Blog. However, on occasion it did feel like ‘too many chiefs and not enough Indians’. It would have been easier if one person was assigned a dedicated role as link person from the outset. All information could then be filtered through this person, which could aid in avoiding a blurring of responsibility or to negate two people doing the same job.

- **Ensure that frontline staff are briefed and included:**

Having a group of ‘leaders’ in our project meant that the nurses/volunteers on the floor felt a sense of disconnection from the project. They expressed that they were busy and at times they got the impression that the project was extra work for them. No one wanted to take on this perceived extra work and consequently they did not seek inclusion. This only came to light a few weeks into the pilot and we decided to have a briefing session for the nurses/volunteers. Both parties seemed to understand the purpose of the project and feel a bit more connected to it after the briefings but it would be useful to have had them earlier.

- **Ensure that a marketing professional is part of the team from the outset:**

We did not have a marketing professional on board at the initial meeting and she became involved at a later stage[42]. It is beneficial to have a marketing professional as a team member from the beginning, as a large element in the process of piloting an online intervention is the promotion and dissemination of the intervention. A marketing professional will have the necessary expertise to appropriately promote the project and also be able to give input into the aesthetics of design and development.

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[42] At the time of the initial meeting ARC House was in the process of hiring a Marketing Manager so it was not that a marketing professional was excluded we just did not have one on staff at the time. As soon as ARC House filled the position of Marketing Manager, that person became part of the inquiry team.

5.2 Inquiry Cycle 2: Running the Pilot Blog

- **Design a Content Plan:**

Inital Survey respondents identified thirty features that they would like to see on the Blog and a Content Plan was drawn-up around these (See Chapters 2 and 4). One of the thirty topics was allocated to each particular day for the 2 month period, so that we could determine in advance the information that we would need for each date. An example of our Content Plan for February is given in Figure 18.

Figure 18

February	Sun	Mon Main Post	Tue Coping Skill	Wed	Thu Main Post	Fri
Week 1	Picture	Meet the ARC Staff	Art Therapy	Interesting Article	Diet and Cancer	Quote
Week 2	Picture	Exercise & Cancer	Mindfulness	Interesting Article	Therapeutic Writing	Quote
Week 3	Picture	General Coping Skills	Journaling	Interesting Article	Personal Story	Quote
Week 4	Picture	Taking to Children	Tai Chi	Interesting Article	Managing Side Effects	Quote

The Content Plan was incredibly useful at this stage, as we knew in advance the information we needed to source for each post. Even if the CSO does not adopt a participatory approach, as in this project, it is beneficial to elicit the opinions of the group affected so that the intervention will include useful content.

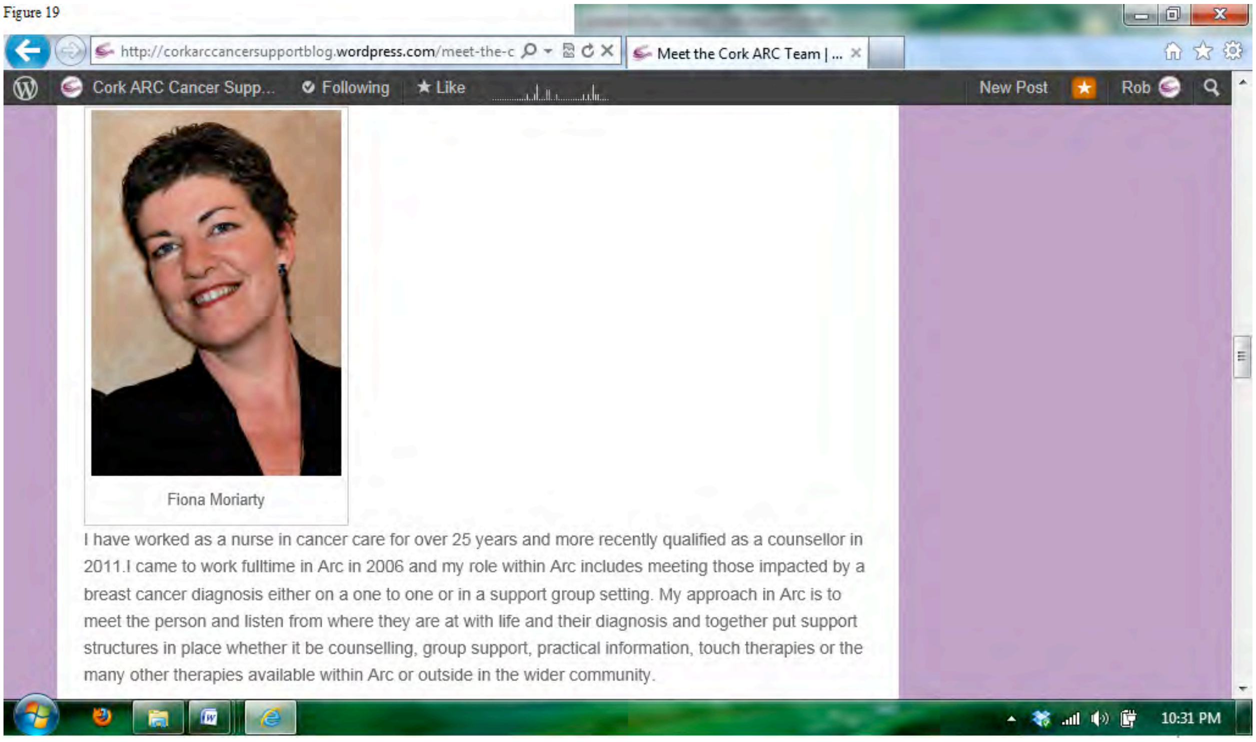
- **Use a shared-server:**

It was useful for anyone who was contributing to the Blog, who did not work ‘in-house”, to have access to an online shared-server. For this project we used a shared Dropbox folder that all team-members could contribute to. This meant that if anyone saw something potentially useful for the Blog, then they could upload it into Dropbox for other team-members to review. The goal was to build up a database of content that we could all draw on either on or off-site.

- **Include an introduction of project and people:**

It is important to use initial posts as a means of building rapport with the online community. We introduced ourselves in order to be ‘accepted’ as a participatory pilot intervention, introduce the project and its purpose, and ask for help from participants. We achieved this through our initial ‘Welcome to the Cork ARC Blog’ post and separate ‘Meet the Cork ARC Team’ post. For example, Figure 19 is an extract from the ‘Meet the Cork ARC Team’ post introducing the ARC Breast Care Nurse.

Figure 19



I have worked as a nurse in cancer care for over 25 years and more recently qualified as a counsellor in 2011.I came to work fulltime in Arc in 2006 and my role within Arc includes meeting those impacted by a breast cancer diagnosis either on a one to one or in a support group setting. My approach in Arc is to meet the person and listen from where they are at with life and their diagnosis and together put support structures in place whether it be counselling, group support, practical information, touch therapies or the many other therapies available within Arc or outside in the wider community.

- **Interact regularly with the intervention at the start:**

We planned to post daily in accordance with our Content Plan. We were aware that non-static, frequently updated content was central to the premise of a Blog (Walker-Rerttberg, 2008; Blood, 2002). We also wanted to ensure that we achieved maximum exposure in the initial stages, to make people aware that we existed and what we were about. I believe that we did achieve this, as many followers joined in the first week. The frequency of our posting also meant that after the first week we had a good supply of archival posts.

- **Match the posting-pattern[43] to the rhythm of the organisation:**

Although I do feel that an initial intensive posting-pattern is important to create interest and exposure, one of our principle experiential findings was the importance of adjusting the posting-pattern to what is sustainable for the CSO. We initially attempted to continue with a daily posting-pattern. However, the 'experts' that we asked to provide contributions rarely had their input sent to us on time. This meant that the Content Plan often had to be re-arranged and we ended up filling in a lot of the posts ourselves. A knock-on affect of this was that we all became stressed, attempting to follow up on 'experts' and trying to write pieces ourselves on top of our pre-existing workloads. The concern was also raised that if we were posting daily, then the Blog was steering more towards becoming an information source, as there was little room for Blog-users to comment and tell us what they wanted to see. This latter participatory principle was what the Blog was designed to achieve.

We came to the conclusion that a daily posting-pattern was unsustainable long-term. Therefore, following a team discussion, we changed to a weekly posting-pattern based around one particular theme. The only way that a daily posting-pattern would work would be to have a full-time staff member with Blog management as their sole task. The content would also have to be gathered in advance of posting so that you have enough to cover yourself, content wise, at least a month in advance. As such, I would advise planning a two week period of intensive posting and then

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[43] A 'posting pattern' refers to how often the CSO contributes to the intervention.

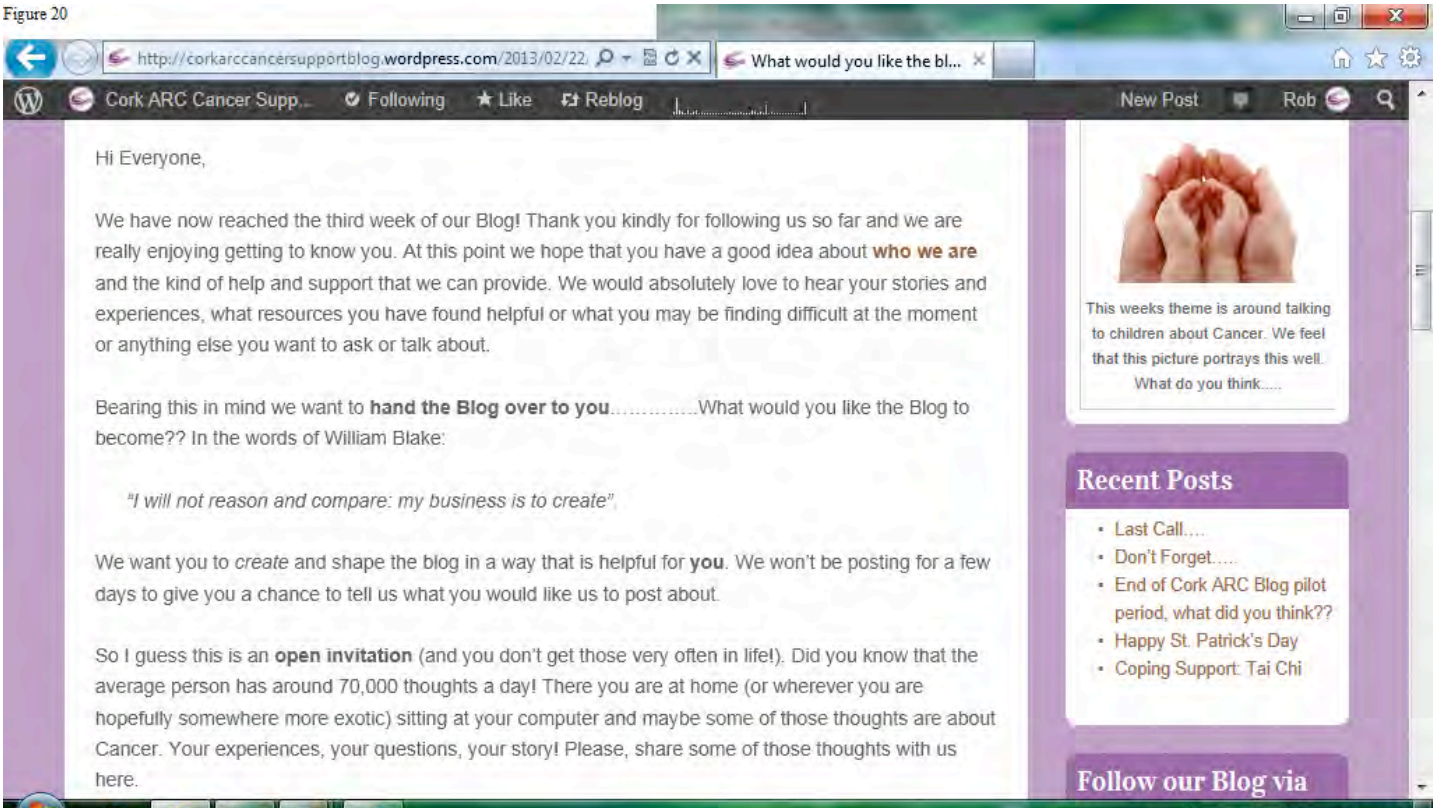
tapering off into a sustainable posting-pattern. What is sustainable will be different for each CSO.

REFLECTIVE EXTRACT:

I pushed for the initial format to work but my tutor reminded me that it was not my responsibility to be sole organiser in a participatory project. It was difficult not to intervene, as I wanted the intervention to be successful (See Reflexive Positioning Chapter 1). However, there is a point where you have to step back and see if the project will float without you as initiator. People are reluctant to take the organiser role if you step back but it may be the only way to see if the

We designed a 'handover post' re-emphasising that we wanted people to identify their own themes and share their experiences rather than us providing information. An extract from this post is presented in Figure 20. We kept the weekly posting-pattern for the rest of the pilot

Figure 20



Hi Everyone,

We have now reached the third week of our Blog! Thank you kindly for following us so far and we are really enjoying getting to know you. At this point we hope that you have a good idea about **who we are** and the kind of help and support that we can provide. We would absolutely love to hear your stories and experiences, what resources you have found helpful or what you may be finding difficult at the moment or anything else you want to ask or talk about.

Bearing this in mind we want to **hand the Blog over to you**………….What would you like the Blog to become?? In the words of William Blake:

"I will not reason and compare: my business is to create".

We want you to *create* and shape the blog in a way that is helpful for **you**. We won't be posting for a few days to give you a chance to tell us what you would like us to post about.

So I guess this is an **open invitation** (and you don't get those very often in life!). Did you know that the average person has around 70,000 thoughts a day! There you are at home (or wherever you are hopefully somewhere more exotic) sitting at your computer and maybe some of those thoughts are about Cancer. Your experiences, your questions, your story! Please, share some of those thoughts with us here.

This weeks theme is around talking to children about Cancer. We feel that this picture portrays this well. What do you think.....

Recent Posts

- Last Call….
- Don't Forget…..
- End of Cork ARC Blog pilot period, what did you think??
- Happy St. Patrick's Day
- Coping Support: Tai Chi

Follow our Blog via

period.

- **Hold lightly to the initial conceptual framework:**

If the CSO adopts an iterative approach, then they must be willing to adjust their initial conceptual framework based on how practice conforms or not to the original ideas (Heron & Reason, 2001). In the initial creation of the Blog, it was planned that all approaches and ideas could be adjusted, reframed or rejected based on the feedback of the users, which is the definition of power-sharing in partnership (Arnstein, 1969). Our change in posting-pattern signified a shift in the direction of the Blog from one that was becoming information led to one owned and directed by its users. What is slightly difficult about an iterative approach was that we could not consistently prepare for how the participants would shape the Blog or the questions that they would ask. As such the intervention is designed in a reactive rather than proactive way and it is important to be aware of what this means form the start.

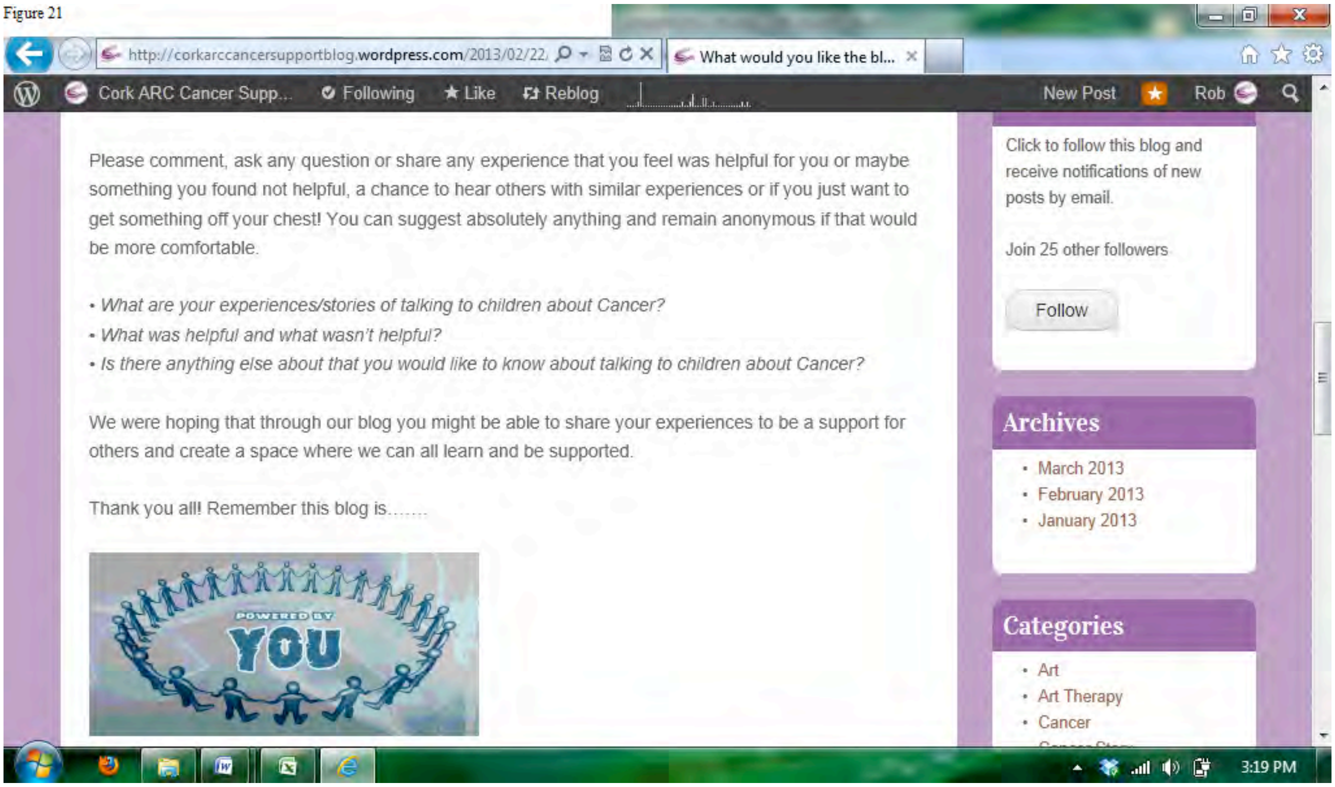
- **Be prepared for a lack of interaction by Blog-users:**

Our Initial Survey informed that the biggest influential factor in relation to Blog use was being able to speak to others in a similar situation (See Chapter 4). However, our experiential finding was that people were very slow to interact with our Blog and speak to one another. We received very few comments throughout our pilot period. We tried a number of different approaches in our attempts to generate discussion.

A member of the research team acted as a ‘ghost writer’ and commented on some of the posts. We thought that users may be reluctant to be the first comment but that they might join a conversation thread already started. However, this did not encourage input. We asked direct questions in our posts as we thought that this might stimulate direct answers. For example, in Figure 21 below we were using the theme of talking to children about cancer (generated from our Initial survey, Chapter 4) for the week and before running this theme we asked direct questions in relation to people’s experiences.

This approach did generate one comment in relation to someone sharing their own experience but it did not create a discussion.

Figure 21



Please comment, ask any question or share any experience that you feel was helpful for you or maybe something you found not helpful, a chance to hear others with similar experiences or if you just want to get something off your chest! You can suggest absolutely anything and remain anonymous if that would be more comfortable.

- *What are your experiences/stories of talking to children about Cancer?*
- *What was helpful and what wasn't helpful?*
- *Is there anything else about that you would like to know about talking to children about Cancer?*

We were hoping that through our blog you might be able to share your experiences to be a support for others and create a space where we can all learn and be supported.

Thank you all! Remember this blog is.......

Click to follow this blog and receive notifications of new posts by email.

Join 25 other followers

Follow

Archives

- March 2013
- February 2013
- January 2013

Categories

- Art
- Art Therapy
- Cancer

REFLECTIVE EXTRACT:

As our attempts to stimulate input to the Blog were not successful, I did question at times if the Blog was being led in a participatory way as much as we wanted it to be. However, I feel that the participatory ethos behind the project and our repeated attempts made the project as participatory as possible. As Chapter 6 will illustrate, users did feel a sense of the participatory ethos behind the project.

5.3 Conclusion

This Chapter has presented key experiences from running the ARC Blog. Throughout the whole process it felt like we were all working together to create something useful and dynamic. I never really felt like a researcher but like a facilitator and a piloter of new things. If these things did not work, we all went back to the drawing board and tried different things. The Blog was developed and adjusted through these constant Inquiry Cycles and there was huge learning in this approach.

Chapter 6:

Conclusions & Recommendations:

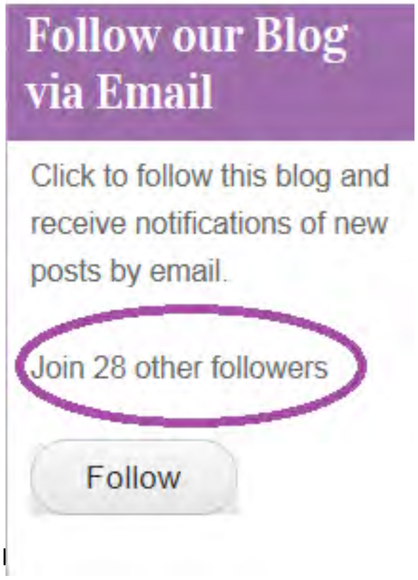
This Chapter concludes the project, using the Research Questions as structural headings, followed by a Final Conclusion to summarise. Some recommendations for future direction are then presented. Next I provide a reflection on my own development as a researcher. Finally, I reiterate the relevance of the research findings for social work.

6.1 Would Cancer patients/relatives make use of a Cancer Support Blog offered by ARC House?

The Initial Survey indicated that cancer patients/relatives would make use of ARC's Blog. A substantial 81 people (88%) (n=94) affirmed that they would use a Support Blog. Furthermore, the open comments in the Final Survey were all positive, encouraging the Blog to keep developing and building.

Blog-usage statistics did not reflect such a large uptake. During the pilot period 28 people officially followed the Blog[44] (See Figure 22). The Blog acquired an average of around two new followers a week. Figure 23 below illustrates the total number of Blog views for each pilot month and also the average number of daily viewings for each month.

Figure 22



Follow our Blog via Email

Click to follow this blog and receive notifications of new posts by email.

Join 28 other followers

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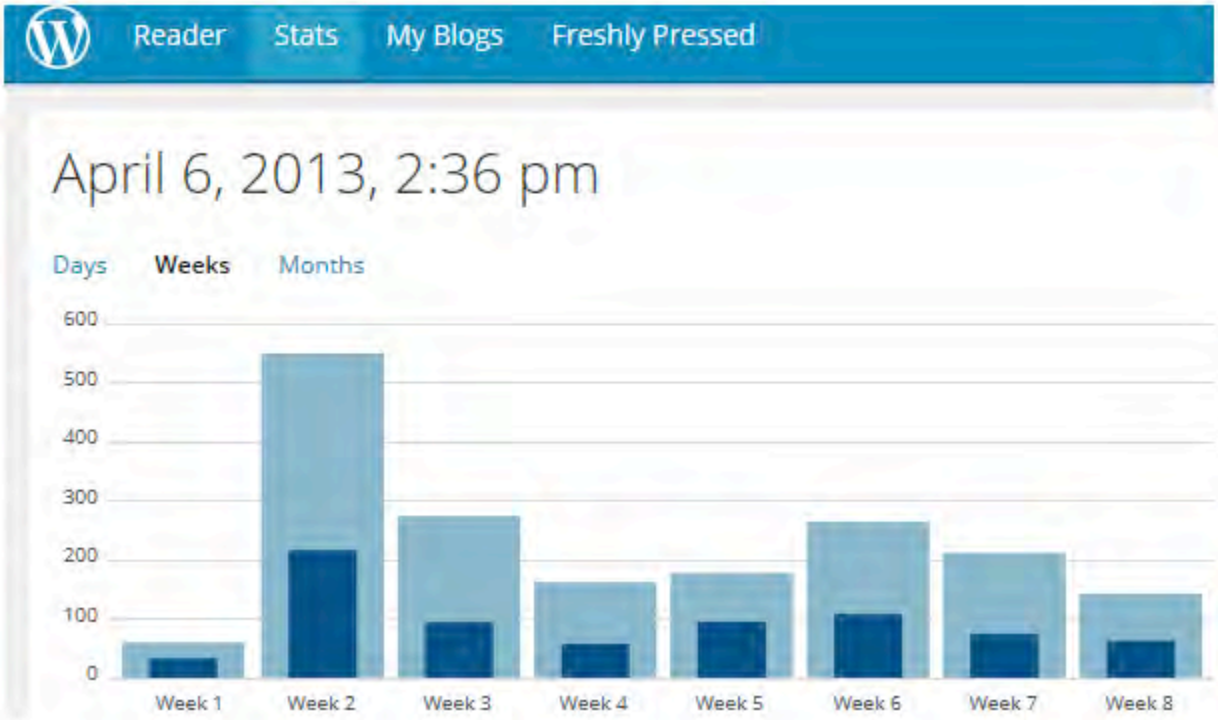
[44] This is where you sign up to receive an e-mail whenever a new post is put u developments on the Blog. You can just 'view' the Blog without being a follower.

Figure 23

Month	Total Views	Average Daily Views
February	950	34
March	862	28
Total	1,812	31

This illustrates almost 1,000 monthly views, with an overall average of approximately 31 views each day[45]. This is a considerable amount of views, indicating that there is a group of people that have, and would, continue to use ARC's Blog[46]. Figure 24 shows a graphic representation of these views on a weekly basis.

Figure 24



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[45]

[46] It is important to note that the dark blue is visitors to the Blog and the light blue is views. We can see from this that on average there was half as many visitors as views. This generally means that the same computer viewed the Blog more than once. However, statistics are usually generated on the basis of views as even if the same computer visits more than once, there is no way of knowing if this is the same person or not.

6.1.1 Who Used the Blog:

The group that used the Blog most, or expressed interest in using the Blog, were middle-aged women aged 40-60. This finding was surprising, as research indicates that younger people are more likely to use the internet for cancer support and to Blog (Fullwood *et al*, 2009; Herring *et al*, 2004; Carlsson, 2000). However, studies have found that Blog reading is transcending into the older generation and older-adults are using Blogs as an emotional outlet (Gumbrecht, 2004; Herring *et al*, 2004). As the ARC Blog did identify as a Support Blog, it could have appealed to the interests of the older Blogging community.

The fact that more women than men expressed interest in the Blog was also surprising as Technorati (2011) identifies that over three-fifths of Bloggers are male. However, the literature does outline that females are more likely to use Blogs for therapeutic purposes, whereas men use Blogs for informational (Baker & Moore, 2011). Although the ARC Blog did attempt to provide a mix of information and support, perhaps it was constructed more as a 'therapeutic Blog' and as such attracted more female users.

6.1.2 How the Blog was Used:

The Initial Survey identified that the primary reason people would use a Support Blog, would be to communicate with peers (See Chapter 4). However, during our pilot period there were a total of only 7 comments on the Blog[47]. This led us to think that firstly, perhaps people may read the Blog and gain support in this way without using it for social support (Chung & Kim, 2008; Kim, 2007; Weinberg *et al*, 1996). Studies such as Han *et al* (2012) show that although availability of online support for cancer patients is increasing, many still 'lurk' rather than post. We put this interpretation to the users in our Final Survey and the majority agreed, stating:

- *"I would agree and I read only. My reason is that I am currently recovering well and have no questions. I also try to forget about having had cancer and try to move on with my life, especially for my family. If the Blog had been there when I was going through treatment, I certainly would have asked questions through it. What a pity it wasn't!"*

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[47] However, 2 of these were comments by our 'ghost writer' in order to stimulate conversation

- *"Agree, as the Blog was in the pilot stage I think people would be viewing the Blog more around support for information and maybe peer support at a later stage".*

Secondly, we felt that perhaps users are in a relationship-building phase with the Blog and are not comfortable interacting with peers yet (Nardi *et al*, 2004). Participatory interventions take time to build up meaningful relationships and the process is likened to getting to know someone (Blum *et al*, 2010; Walker-Rettberg, 2008; Maguire, 1993). Again we put this interpretation to our users in the Final Survey and everyone agreed with it stating:

- *"Yes, especially because the blog is so new. It's about getting to know the blog as well as the people who use it".*
- *"Agree, absolutely people are curious at first at when they are out of their comfort zone, it takes time to build up a trusting rapport with a new Blog before they feel comfortable contributing to it".*

Research Question 1: Conclusion Summary:

- *81 people (88%) stated in the Initial Survey that they would make use of a Cancer Support Blog.*
- *The Blog attracted approx 1, 000 views a month*
- *There was an average of 2 new followers every week*
- *Blog mainly used by middle-aged women 40-60 age bracket*
- *The Blog was mainly used as an informational support through reading*
- *It takes time for a Blog to develop into a peer-networking support*

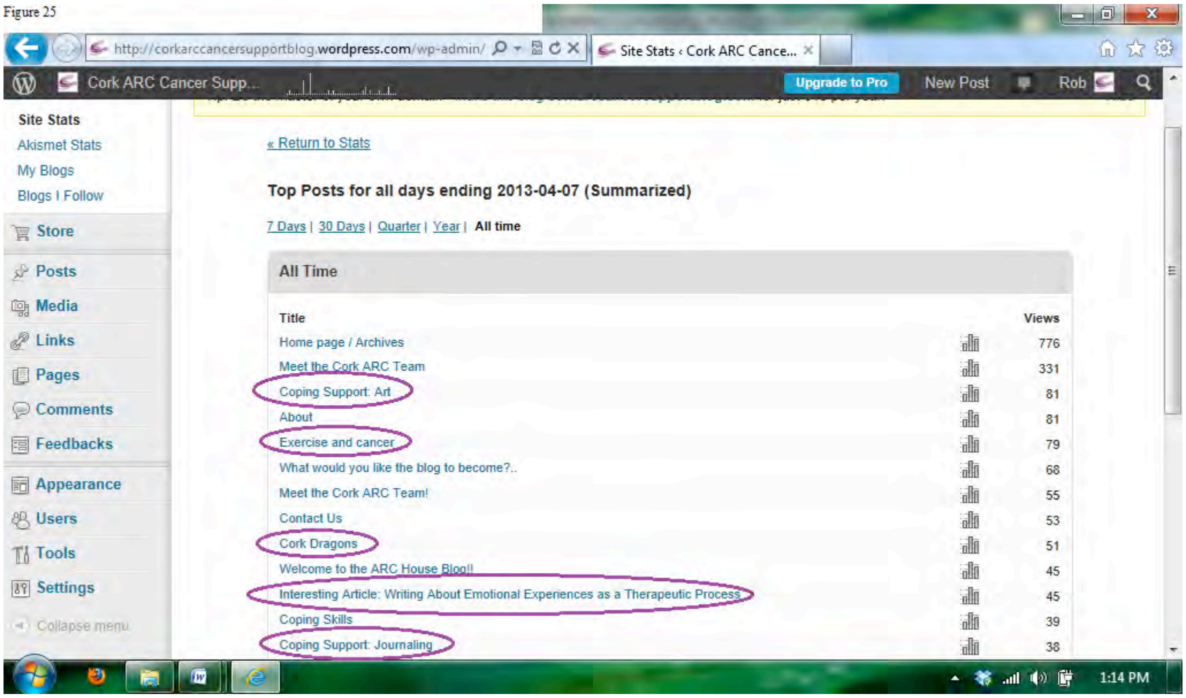
6.2 What are the key areas of support that cancer patients/relatives find effective and why?

Our Initial Survey informed that respondents would find being able to talk to others in a similar situation and being able to access support from home as key features that would be helpful for a Blog. The survey also identified 30 content areas that a Support Blog should include and 18 areas that a Blog should avoid (See Chapter 4). Our Final Survey identified that the areas users found most helpful included; having access to archived information; having credible information: being asked what they wanted; the RSS notifications; normalising of feelings; and a support group outside that of the family (See Chapter 4).

6.2.1 Coping Supports Most Viewed:

Blog posts in relation to 'Coping Supports' were understood to be the most effective, as they were most viewed and 'liked'[48]. As demonstrated in Figure 25, the highlighted 'Coping Supports' posts are highest on the list of posts viewed, in between the more 'admin' related introductory and general informational posts. Furthermore, 'Coping Supports' were identified as the second most helpful element of our Blog by respondents in our Final Survey.

Figure 25



Top Posts for all days ending 2013-04-07 (Summarized)

7 Days | 30 Days | Quarter | Year | All time

All Time

Title	Views
Home page / Archives	776
Meet the Cork ARC Team	331
Coping Support: Art	81
About	81
Exercise and cancer	79
What would you like the blog to become?..	68
Meet the Cork ARC Team!	55
Contact Us	53
Cork Dragons	51
Welcome to the ARC House Blog!!	45
Interesting Article: Writing About Emotional Experiences as a Therapeutic Process	45
Coping Skills	39
Coping Support: Journaling	38

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[48] This was determined by people clicking the 'like' button after the post.

Again we put this to the users and the majority agreed, describing Coping Supports as “vitally important” and an “essential” element in dealing with cancer. Some of the other reasons that respondents gave for agreeing included:

- *“Yes. I am interested in learning about how others get through difficult times and what gets them through”.*
- *“Absolutely. I think that we all need to find the activity that keeps us calm and strong. I exercise a lot but also need to find something that helps me chill on the bad days”.*

6.2.2 Helpfulness of Participatory Approach:

We wanted the Blog to be a good deal more participatory and that Blog-users would self-identify areas of support that they required. Although the Initial Survey allowed us to consult with the cancer community and identify a number of content areas, not many commented on the Blog to ask a question or state something that they would like information on (as mentioned above).

REFLECTIVE EXTRACT:

As we did not receive the interaction and ‘participation’ with the Blog that we had hoped for, when I was writing my conclusion I did contemplate going back over my report and revising it. I focused a lot on participation and the initiative being user-led. However, I decided not to make any revisions as, although the Blog was not purely user-led in relation to people commenting about what they wanted to see it was designed around the contribution of users in the Initial Survey and guided by somewhat by users clicking ‘like’ on certain topics. Furthermore, there was an ethos of user ownership behind the intervention and we attempted to express this throughout, so this was always the intention behind the project. Although it did not necessarily happen in the way that we wanted, user Blog participation was still an important influence throughout the project.

However, as indicated in Chapter 4, users did recognise the participatory element we were attempting to achieve. As some respondents commented:

- *"You have the right approach in that you ask us what we want".*
- *"I felt our views were valued though and made a small impact on the blog".*

As such, I feel that a participatory approach would make it possible for the Blog to ultimately be completely user-led, but it would require a lot of groundwork and a good deal of promotion. I feel that this links back to the comments around the Blog still being in a relatively nascent stage and requiring more time to develop and create relationship.

Research Question 2: Conclusion Summary:

- *The Initial Survey identified talking to others in a similar situation, getting information from a credible organisation and being able to access support from their own home as the most helpful features of a Support Blog.*
- *The Final Survey identified having access to archived information; people being asked what they wanted; the RSS notifications; normalising of feelings; and a support group outside that of the family as the most important features*
- *Posts about 'Coping Supports' were the most viewed and 'liked' feature of the Blog*
- *The participatory element of the Blog was seen as helpful*

6.3 Final Conclusion

My ultimate conclusion is that it would be feasible for ARC House to provide online support through developing a Support Blog.

However, a number of conditions would need to be considered for the support to be offered in a long-term capacity and these are highlighted in the recommendations below. It is up to ARC House to evaluate whether the balance between the input required to run the Blog long-term would reflect the uptake of support offered.

6.4 Recommendations

If a Blog is to be part of ARC services long-term:

- there is a need for someone to be the 'driving force' of the project. During this project the researcher acted as the key driving figure and constantly pushed to get the intervention off the ground. I feel that without allocating this person, the Blog intervention would not 'stay off the ground'.
- there is a need for a dedicated person with a position as Blog Manager. This time commitment could be an add-on to the duties of a current staff member or the addition of a new post. This could be a full-time or part-time position depending on the posting frequency. If the ARC Blog ran a weekly themed post, a part-time position would suffice.
- The Blog Manager would ideally need a certain amount of IT skills and also some social support training. Although there are other disciplines that may meet this need, I would

see a social worker as an ideal candidate as they are required to have appropriate proficiencies in both of the aforementioned areas according to CORU (2011).

- Although it would be possible to continue posting with the initial framework free of charge, I feel that ultimately some resources would have to be allocated towards the Blog; whether these resources be targeted at the development of the Blog itself or into the creation of a Blog Manager post. However, there is funding potential for participatory research approaches and I recommend that ARC engage in research around funding possibilities through Grants available for IT based research projects.
- The Blog needs to be promoted further and I recommend that the ARC Marketing Manager develop a Promotional Plan to further increase exposure to the Blog. This project did not have time to monitor and link to other Blogs on a regular basis and this is an essential networking and promotional tool for Blogging, which could be utilised in this regard.
- More effort should be made to include groups that this survey did not engage with including more male users and younger users.
- Ultimately, a 2 month pilot period is too short to adequately evaluate an online support intervention and I feel that another project phase would produce a substantial amount of useful findings. A second phase could incorporate a group following the Blog for a period and the researcher running focus-groups as a data collection method to gather more in-depth opinions.

6.5 My Development as a Researcher: A Reflection

Throughout this project my role was not a 'researcher' in the traditional sense but more that of a facilitator, discussion organiser and technical resource person (Park, 2001; Williams, 1999; Park, 1993; Chambers, 1994; Foote-Whyte *et al*, 1991). Through acting in this role I have learned a substantial amount in relation to social work skills concerning communication, presentation, self-management, co-ordination, creativity and reflection (Thompson, 2009). I learnt how to act as the bridge between the participants and ARC; to listen, understand and help interpret the contributions of both groups (Ruano, 1991). As Blog facilitator, I learnt how to give effective feedback to ARC and present them with any issues that arose. I also had the opportunity to learn from adopting a training role in terms of explaining to ARC staff various project areas including research terms involved in the project and also in this case how the actual Blog works. Linking with this, I also learnt from my role as interpreter in relation to translating concepts from research terminology, or from Blogging literature, into 'normal' language that we could all understand and apply (Williams, 1999).

I think a key learning element for me involved 'balance', which is essential to a collaborative project involving teamwork and power-sharing. Firstly, balance was required between someone with a strong academic background as a researcher and those with a strong experiential background in the ARC staff. Secondly, balance was struck between the medical and social models. Working with professionals in an inter-disciplinary manner at ARC illustrated to me the contrast between the social model of my training and the predominant medical training of the ARC staff. Although this was never a major issue, I feel that our backgrounds did inform the lenses through which we viewed elements of the project. The final area was a balance of personalities. I feel that I am quite task-orientated but a substantial amount of the participatory project is process orientated. As such, I had to adjust my pace to this and to the pace of other members on the team.

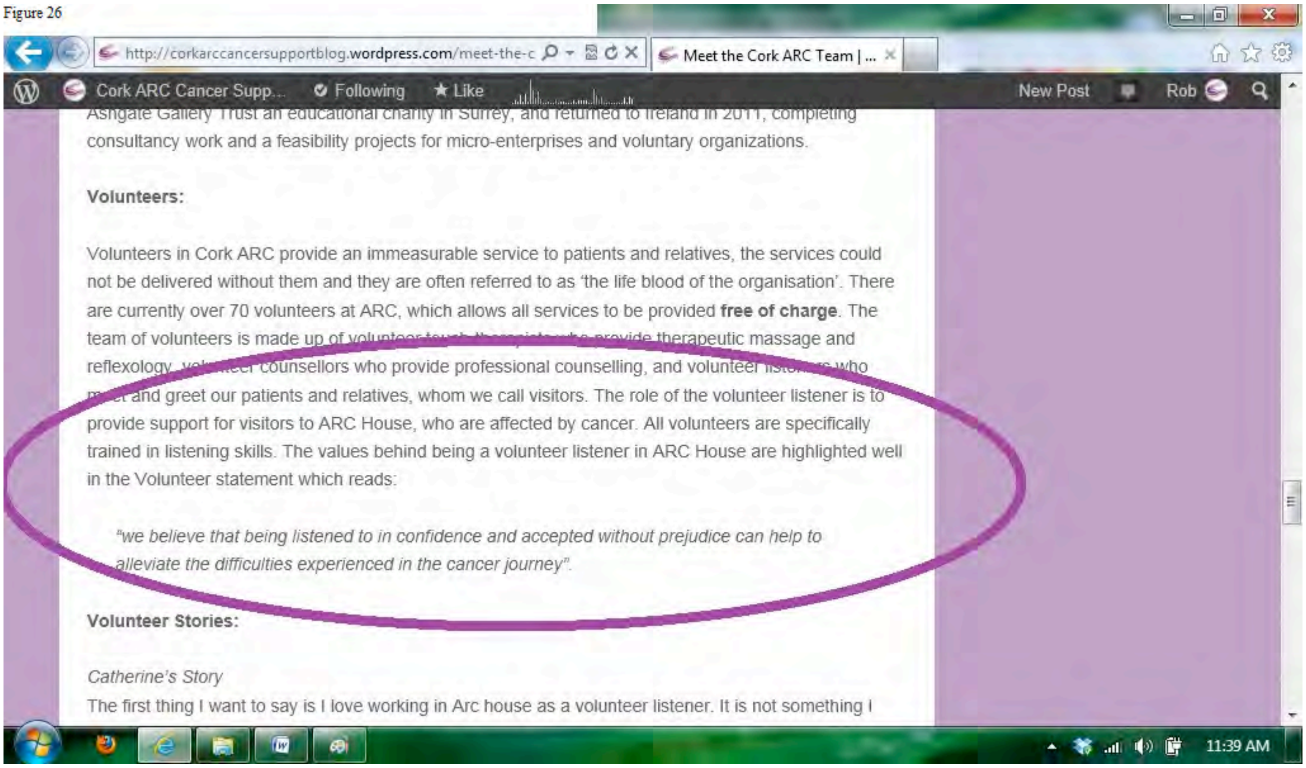
In all of the above areas I feel that balance was achieved through maintaining open and honest communication and a willingness to hear and understand the perspective of others. I will carry this learning with me into any future collaborative projects.

6.6 Social Work Context

Chapter 1 has discussed the social work context in relation to the research approach and here I will outline the relevance to social work concerning the findings produced.

The ARC Blog provided people with a safe space to be heard, which can be therapeutic and cathartic for those dealing with a stressful illness (Farnham *et al*, 2002; Wiggers *et al*, 1990). This approach could be seen as matching the person-centred, strengths based social work ethic and the holistic ARC ethos (CORU, 2011; Rogers, 2004). This ethic is exemplified in the highlighted section of the ARC Volunteer Statement in Figure 26.

Figure 26



Ashgate Gallery Trust an educational charity in Surrey, and returned to Ireland in 2011, completing consultancy work and a feasibility projects for micro-enterprises and voluntary organizations.

Volunteers:

Volunteers in Cork ARC provide an immeasurable service to patients and relatives, the services could not be delivered without them and they are often referred to as 'the life blood of the organisation'. There are currently over 70 volunteers at ARC, which allows all services to be provided **free of charge**. The team of volunteers is made up of volunteer touch therapists who provide therapeutic massage and reflexology, volunteer counsellors who provide professional counselling, and volunteer listeners who meet and greet our patients and relatives, whom we call visitors. The role of the volunteer listener is to provide support for visitors to ARC House, who are affected by cancer. All volunteers are specifically trained in listening skills. The values behind being a volunteer listener in ARC House are highlighted well in the Volunteer statement which reads:

> *"we believe that being listened to in confidence and accepted without prejudice can help to alleviate the difficulties experienced in the cancer journey".*

Volunteer Stories:

Catherine's Story

The first thing I want to say is I love working in Arc house as a volunteer listener. It is not something I

The links between social work and groupwork have long been established (Trevethik, 2005; Northen & Kurland, 2001; Johnson & Johnson, 1978). Cancer support groups have been found to improve the quality of life of people with Cancer, offer health benefits and increase survival time (Clauser *et al*, 2011; Cella *et al*, 1993; Spiegel *et al*, 1989). Essentially, the ARC Blog ran similarly to a virtual cancer support group led by a social worker (Gumbrecht, 2004; Graham, 1999). The formation of an online community group on a Blog draws on ecological (Brofenbrenner, 1979) or biopsychosocial (Beder, 2006) social work approaches in relation to fostering small dense networks of small audiences with multiple inter-connected supports (Walker-Rettberg, 2008; Schiano *et al*, 2004).

Blood (2002) and Katz (2001) articulate that the appeal of each unique Blog is grounded in the personality, voice and value base of its author. A social worker is particularly well equipped to be the author, as their value base is grounded in concepts such as valuing unique worth, participation, respect and social justice (IASW, 2007; Cummins *et al*, 2006) and their skill-set includes maintaining confidentiality, demonstrating empathy; interdisciplinary practice and communication skills (CORU, 2011; Trevethik, 2010; Thompson, 2009).

Furthermore, a key area of interest for me is the link between social work and social activism (Walz & Groze, 1991). In my understanding, being a research-minded social work practitioner is a form of activism that engenders change. Social workers draw on their research skills to co-construct reports with service-users and advocate for change (CORU, 2011; IASW, 2007). ARC's Blog gave users a voice to challenge the discursive medical voice on the issue of cancer support and valued their knowledge, intrinsic worth and dignity (Cummins *et al*, 2006; Healey, 2001; Hicks, 1997). This can act to take away the paternalism of an organisation merely providing support to the needy and instead focuses on the resilience, self-determination and ability of the Blog-users (Ramon *et al*, 2001).

6.7 Final Remark

This Chapter has concluded this project using the Research Questions as headings, complete with a summarised Final Conclusion. Recommendations for future direction were also presented. I offered a reflection on my own development as a researcher and lastly I articulated the relevance of the research findings for social work.

In my understanding, the goal of any CARL project is to provide the CSO with a co-constructed framework for something that can be sustainably developed further when the researcher, and his/her skill-set has left. I feel that this was achieved in this project, as the bones of an online support intervention has been established and an initial evaluation has been carried out. Wherever the project goes from here is up to ARC but it is a beginning for them. Furthermore, this thesis has acted to illustrate the culmination of my academic and practice learning as a social worker on the MSW Course and also marks a beginning for me as I enter into professional practice.

As such, for both myself and the ARC Blog, I think it is appropriate to finish this report with the same quote by Meister Eckart, which I used to open our very first Blog post:

> *"And suddenly you know: It's time to start something new and trust the magic of beginnings..."*

Chapter 7:

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Appendix 1:

CARL

Research Agreement

Name of student(s):	Rob O'Connor
Name of civil society organization/community group:	Cork ARC Cancer Support House
Date:	29/05/12

An agreement between *Cork ARC Cancer Support House* and *Rob O'Connor* of MSW University College Cork, Cork.

This agreement relates to arrangements agreed between the student and the group for the execution of a research project entitled: *The Diary of ARC House: A Feasibility Study to explore the development of internet support (a support blog) at Cork ARC Cancer Support House (Phase 1).*

1. It has been agreed that *Rob O'Connor* will carry out research on behalf of and in participation with *Cork ARC Cancer Support House* as follows:

The Project seeks to answer 2 Research Questions:

- Would Cancer patients/relatives make use of a Cancer Support Blog offered by ARC House?
- If yes, what are the key areas of support that cancer patients/relatives find effective and why?

The aim of the project is to create/pilot a support Blog for ARC House for two months, in order to ascertain the main features that users find helpful/unhelpful? To use this data to evaluate the feasibility of Cork ARC Cancer Support House offering a support Blog long-term.

The objectives that Rob will undertake to answer the above questions and meet the above aim include:

- Carry out a literature review to identify the general features of Support Blogs that users find helpful/unhelpful.
- Create/administer an Initial Online Survey to determine if an ARC Blog would be a support tool that people would use.
- Design/maintain a Support Blog on behalf of Cork ARC Cancer Support House for a two month pilot period.
- Create/administer a Final Online Survey to determine what features of the Blog users found helpful/unhelpful.

- Offer an account of our experience of piloting a Support Blog, to inform other Civil Society Organisations (CSOs) who may be considering same.
- Prepare conclusions/recommendations to inform ARC House of the feasibility of continuing an online support Blog.

2. The time of the academic supervisor of the student undertaking the research will normally be provided without charge as part of the student's degree course at the University.

3. The University will provide accommodation, the use of equipment, the services of technical and other supplies to the extent that is normally provided for internally based student projects. Where the provision required for the timely and efficient execution of the project exceeds the normal allowance for student projects or exceeds the host department's budget, the client may be asked to pay for such provision or to join with the University in securing provision from a third party source. No costs will be incurred without prior agreement. (These additional provisions will be listed in an appendix at the end of the Agreement if deemed necessary).

4. The name of the student(s) will be listed below. The names of the students, the academic supervisor, or the University may only be used after obtaining prior approval. Permission to refer to the University will not be unreasonably withheld.

5. The copyright, or any other intellectual property rights, created by the project will rest with the University. Free and full use by the Client Group for the purpose declared when the project was initiated is agreed in advance. Use for any further purpose(s) will be for negotiation and approval on a case-to-case basis. Permission will not be unreasonably withheld.

6. Use of the project report in other than its complete form will be checked with the University in reasonable and sufficient time before the intended date of such use to allow discussion as to the accuracy or suitability of the modified form.

7. Students will normally carry out the project. Notwithstanding the contributions by the University and its staff, the University gives no warranty as to the accuracy of the project report or the suitability of any material contained in it for either general or specific purposes. It will be for the Client Group, or users, to ensure that any outcome from the project meets safety and other requirements. The Client Group agrees not to hold the University responsible in respect of any use of the project results. Notwithstanding this disclaimer, it is a matter of record that many student projects have been completed to a very high standard and to the satisfaction of the Client Group.

8. Upon completion of the project the student (as well as completing the requirements of his or her University course) will be responsible for providing the group with a completed copy of their project report. The student shall provide them with the completed project report within a

reasonable amount of time, not more than two months after submission of the dissertation to the University.

9. All parties agree that upon completion of the project, the research report will be placed, with the approval of the course tutor providing it reaches the requisite academic and presentation standards, on the UCC CARL website: http://carl.ucc.ie.

Student dissertation submission date:	26th April 2013

Completion date of research report to Group: *(normally after examinations board has formalised grade, which is usually 2 months after submission of dissertation)*	26th April 2013

Date report to go on CARL website: *(normally after examinations board has formalised grade, which is usually 2-3 months after submission of dissertation)*	Date TBC

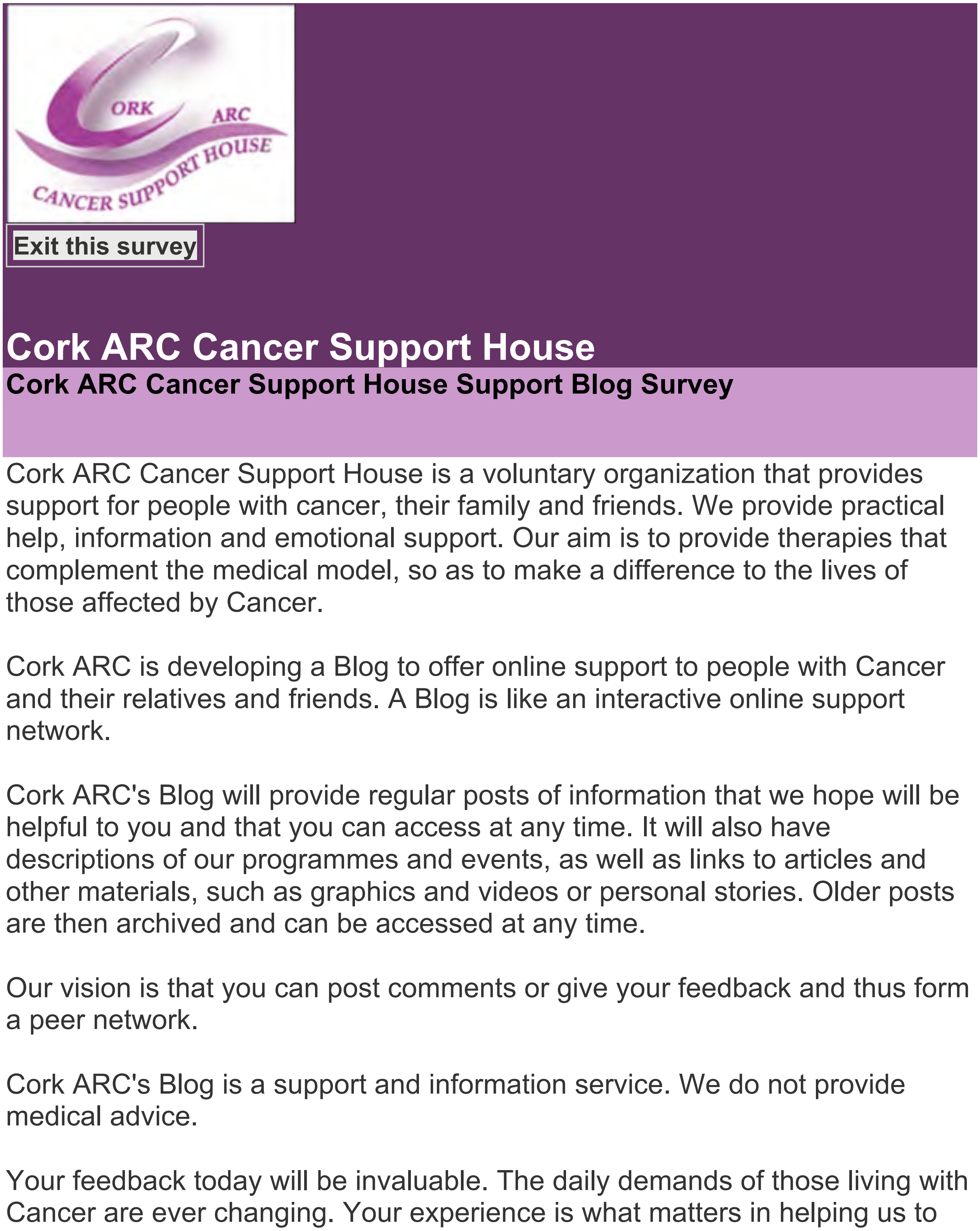
Signed on behalf of (the name of Client Group)

Signature:	Ellen Joyce
Print Name:	Ellen Joyce
Title/Role in Group:	Director of Services
Date:	29/05/12

Signed by student(s)

Signature:	Rob O’Connor
Print Name:	Rob O’Connor
University Course and Year:	MSW 1
Date:	29/05/12

Appendix 2:



Cork ARC Cancer Support House

Cork ARC Cancer Support House Support Blog Survey

Cork ARC Cancer Support House is a voluntary organization that provides support for people with cancer, their family and friends. We provide practical help, information and emotional support. Our aim is to provide therapies that complement the medical model, so as to make a difference to the lives of those affected by Cancer.

Cork ARC is developing a Blog to offer online support to people with Cancer and their relatives and friends. A Blog is like an interactive online support network.

Cork ARC's Blog will provide regular posts of information that we hope will be helpful to you and that you can access at any time. It will also have descriptions of our programmes and events, as well as links to articles and other materials, such as graphics and videos or personal stories. Older posts are then archived and can be accessed at any time.

Our vision is that you can post comments or give your feedback and thus form a peer network.

Cork ARC's Blog is a support and information service. We do not provide medical advice.

Your feedback today will be invaluable. The daily demands of those living with Cancer are ever changing. Your experience is what matters in helping us to help others. The questionnaire below is designed to gather your feedback to help us tailor the Blog to best support you.

Please take a moment to complete the survey below. Your feedback will influence the design of the Blog so that it acts as a support for those who need it, in the way that they need it.

PLEASE NOTE THAT ALL SURVEY RESPONSES ARE ANONYMOUS AND YOUR FEEDBACK WILL REMAIN CONFIDENTIAL.

Thank you

*

1. Which category below includes your age?

○ 17 or younger
○ 18-20
○ 21-29
○ 30-39
○ 40-49
○ 50-59
○ 60 or older

*

2. What is your gender?

○ Female
○ Male

3. What is your Country of origin?

*

4. Which category below best describes your situation?

☐ Cancer Patient
☐ Relative/Friend
☐ Healthcare Professional

☐ Cancer Support Worker/Volunteer

Other (please specify) ☐

5. Have you used Cork ARC Cancer Support House Services?

○ Yes, in the past

○ Yes, I am a current visitor

○ No

6. Have you ever used the Internet for support in coping?

☐ Never

☐ Sometimes

☐ Regularly

☐ All the time

7. Do you think Cork ARC's Blog is something you would use in the future?

☐ Yes

☐ No

8. Have you ever used a Blog?

○ Yes

○ No

9. If yes, please state the way in which you used the Blog?

☐ I host my own Blog

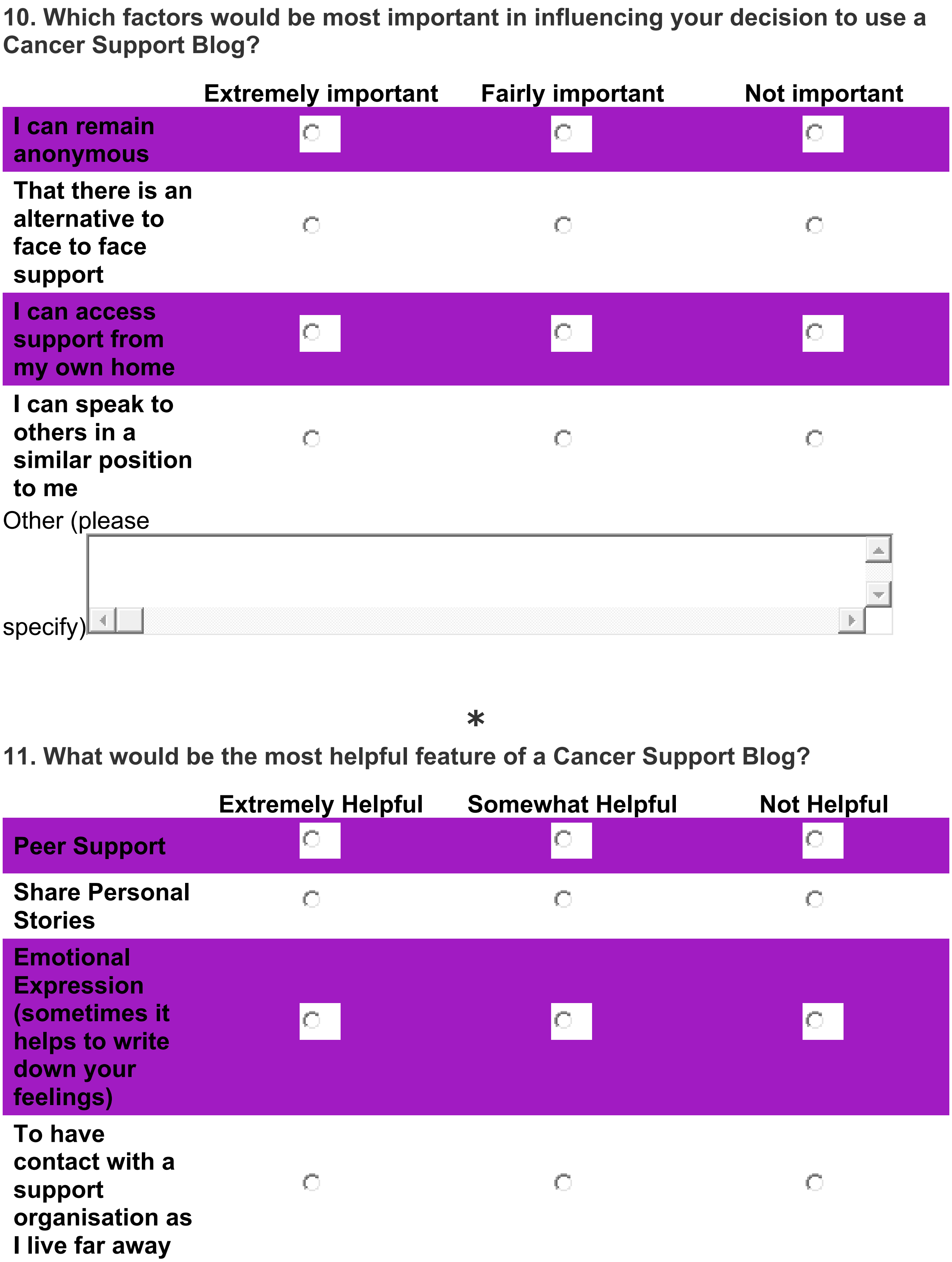
☐ I read other people's Blogs

☐ I post comments on other people's Blogs

☐ All of the above

Other (Please state in what way) ☐

*



10. Which factors would be most important in influencing your decision to use a Cancer Support Blog?

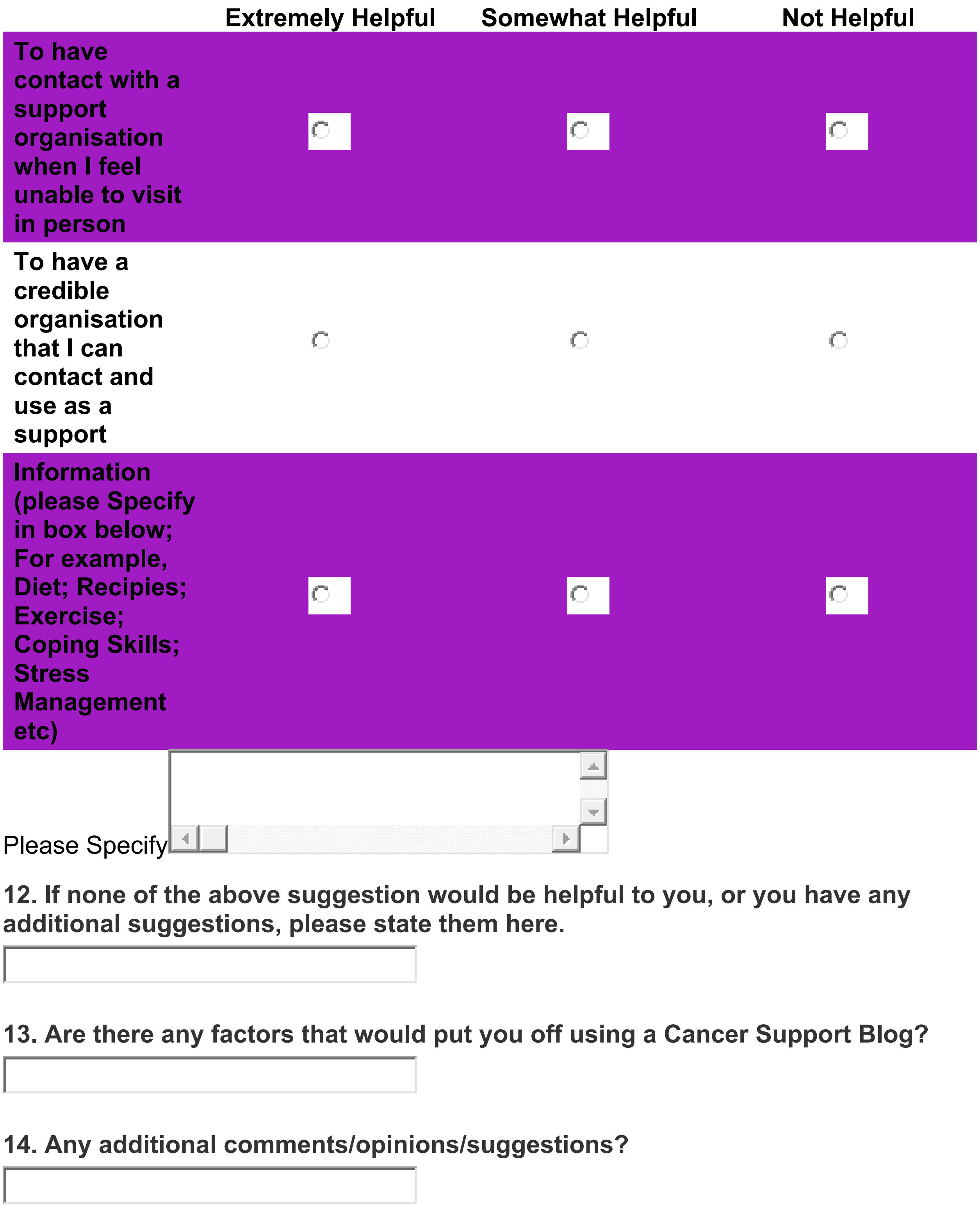
	Extremely important	Fairly important	Not important
I can remain anonymous	○	○	○
That there is an alternative to face to face support	○	○	○
I can access support from my own home	○	○	○
I can speak to others in a similar position to me	○	○	○

Other (please specify)

*

11. What would be the most helpful feature of a Cancer Support Blog?

	Extremely Helpful	Somewhat Helpful	Not Helpful
Peer Support	○	○	○
Share Personal Stories	○	○	○
Emotional Expression (sometimes it helps to write down your feelings)	○	○	○
To have contact with a support organisation as I live far away	○	○	○



	Extremely Helpful	Somewhat Helpful	Not Helpful
To have contact with a support organisation when I feel unable to visit in person	○	○	○
To have a credible organisation that I can contact and use as a support	○	○	○
Information (please Specify in box below; For example, Diet; Recipies; Exercise; Coping Skills; Stress Management etc)	○	○	○

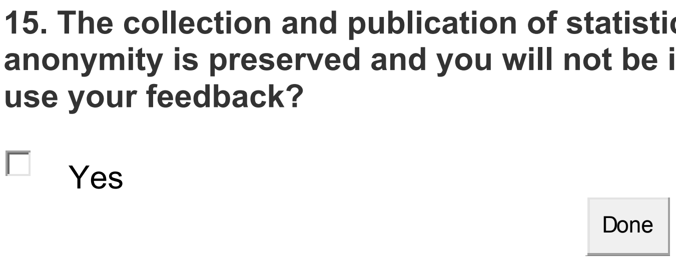
Please Specify

12. If none of the above suggestion would be helpful to you, or you have any additional suggestions, please state them here.

13. Are there any factors that would put you off using a Cancer Support Blog?

14. Any additional comments/opinions/suggestions?

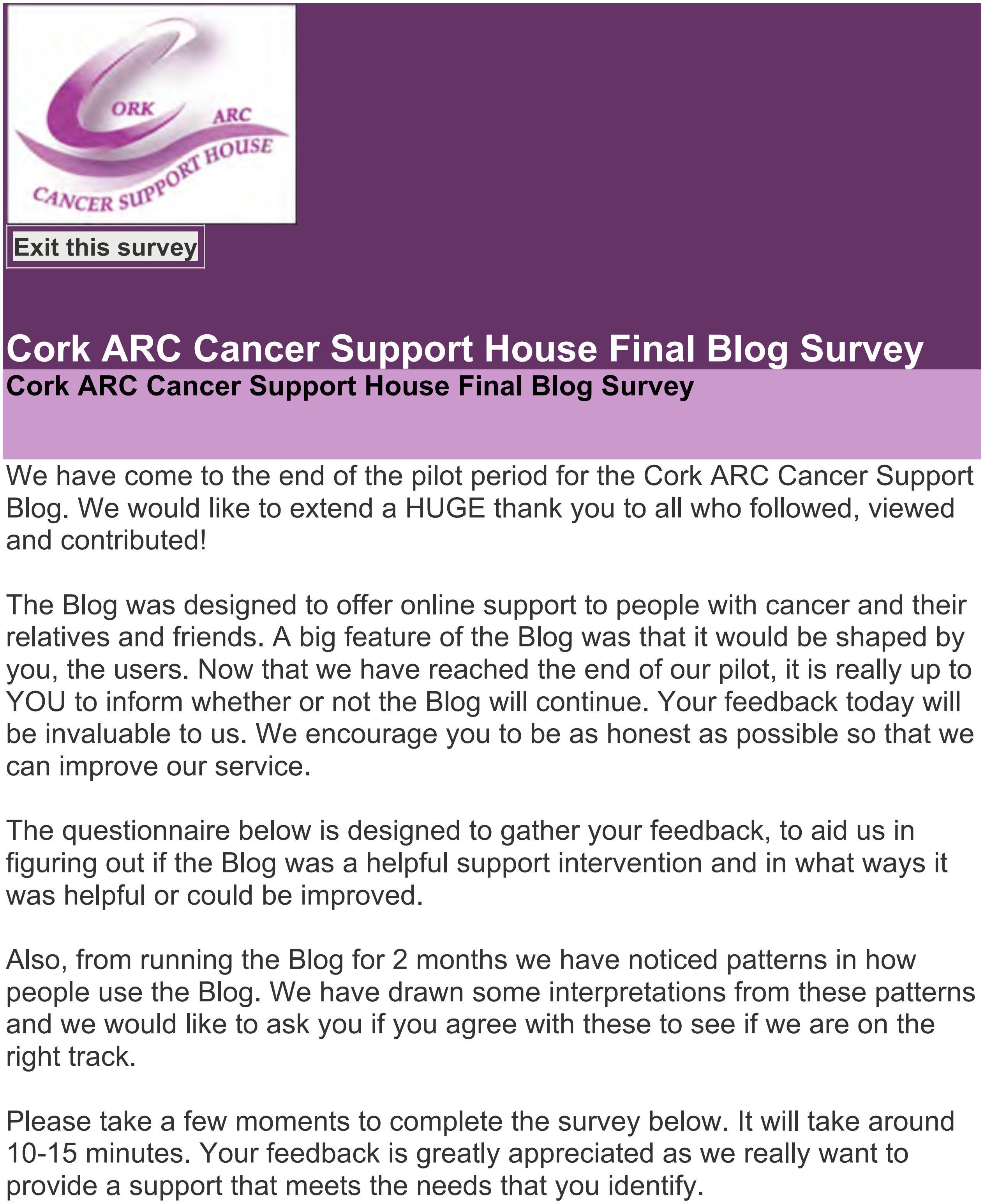
*



15. The collection and publication of statistics is part of this survey. Your anonymity is preserved and you will not be identifiable. Do we have consent to use your feedback?

☐ Yes

Appendix 3:



Cork ARC Cancer Support House Final Blog Survey

Cork ARC Cancer Support House Final Blog Survey

We have come to the end of the pilot period for the Cork ARC Cancer Support Blog. We would like to extend a HUGE thank you to all who followed, viewed and contributed!

The Blog was designed to offer online support to people with cancer and their relatives and friends. A big feature of the Blog was that it would be shaped by you, the users. Now that we have reached the end of our pilot, it is really up to YOU to inform whether or not the Blog will continue. Your feedback today will be invaluable to us. We encourage you to be as honest as possible so that we can improve our service.

The questionnaire below is designed to gather your feedback, to aid us in figuring out if the Blog was a helpful support intervention and in what ways it was helpful or could be improved.

Also, from running the Blog for 2 months we have noticed patterns in how people use the Blog. We have drawn some interpretations from these patterns and we would like to ask you if you agree with these to see if we are on the right track.

Please take a few moments to complete the survey below. It will take around 10-15 minutes. Your feedback is greatly appreciated as we really want to provide a support that meets the needs that you identify.

PLEASE NOTE THAT ALL SURVEY RESPONSES ARE ANONYMOUS AND YOUR FEEDBACK WILL REMAIN CONFIDENTIAL.

Thank you very much

*

1. Which category below includes your age?

○ 17 or younger
○ 18-20
○ 21-29
○ 30-39
○ 40-49
○ 50-59
○ 60 or older

*

2. What is your gender?

○ Female
○ Male

3. What is your Country of origin?

*

4. Which category below best describes your situation?

☐ Cancer Patient
☐ Relative/Friend
☐ Healthcare Professional
☐ Cancer Support Worker/Volunteer

Other (please specify)

*

5. Have you used the support services of Cork ARC Cancer Support House Before? (e.g. telephone, Drop-in, Groups, therapies, Counselling).

○ Yes, in the past
○ Yes, I am a current visitor
○ No

6. How often did you use the Cork ARC Cancer Support Blog?

☐ Never
☐ Sometimes
☐ Regularly
☐ All the time

*

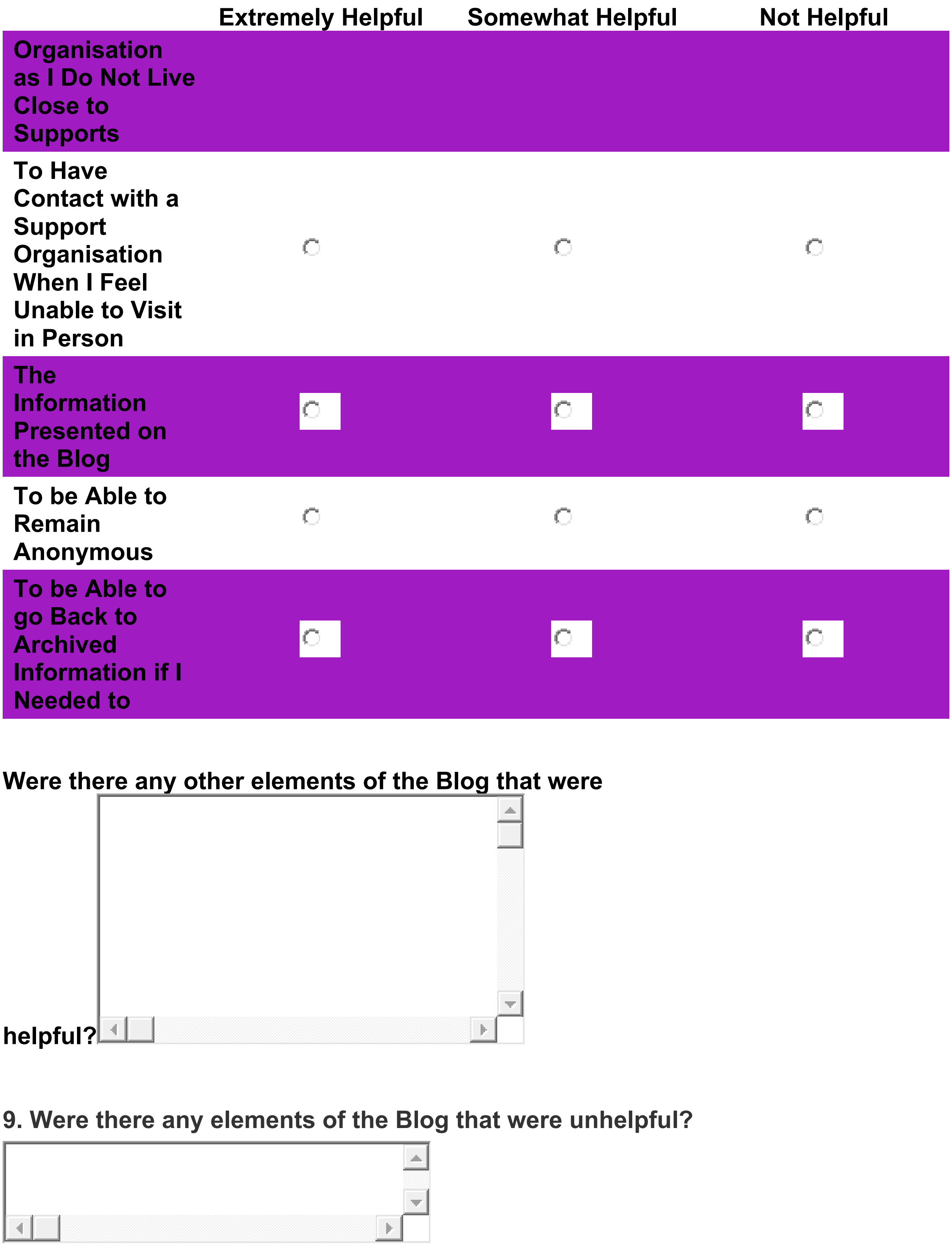
7. Did you find the Cork ARC Cancer Support Blog helpful?

○ Yes
○ Somewhat Helpful
○ No (If no skip to question 9)

*

8. How helpful were the below elements of the Blog?

	Extremely Helpful	Somewhat Helpful	Not Helpful
A Sense of Peer Support	○	○	○
Reading Personal Stories	○	○	○
Reading Coping Supports	○	○	○
Being able to Comment and Share my Experience or Feelings	○	○	○
To Have Contact With a Support	○	○	○



	Extremely Helpful	Somewhat Helpful	Not Helpful
Organisation as I Do Not Live Close to Supports			
To Have Contact with a Support Organisation When I Feel Unable to Visit in Person	○	○	○
The Information Presented on the Blog	○	○	○
To be Able to Remain Anonymous	○	○	○
To be Able to go Back to Archived Information if I Needed to	○	○	○

Were there any other elements of the Blog that were helpful?

9. Were there any elements of the Blog that were unhelpful?

10. ARC House aimed to make the Blog YOUR Blog for support. Did you feel a sense of ownership over the Blog Why/Why Not?

11. Did you feel a sense of social support (like you were linked to a community of peers going through similar experiences) by being part of the Cork ARC Blog community? Why/Why Not?

12. Did you feel comfortable asking questions or commenting on the Blog if you wanted to? Why/Why not?

13. We noticed that.........

individuals viewed the Blog more than they commented. So we thought that people preferred using the Blog for support around information rather than peer support (talking to others). Would you agree with this interpretation? If so why/why not?

14. We noticed that....

'Coping Support' posts were the most popular posts on the Blog (e.g. Art Therapy as a Coping Support, Tai Chi as a Coping Support etc). So we thought that coping supports were seen as one of the most helpful features of the Blog. Would you agree with this interpretation? If so why/why not?

15. We noticed that.....

some of our Blog posts varied in length. We thought that readers might prefer shorter rather than longer Blog posts ? Would you agree with this interpretation/ Why/Why Not?

16. We noticed that......

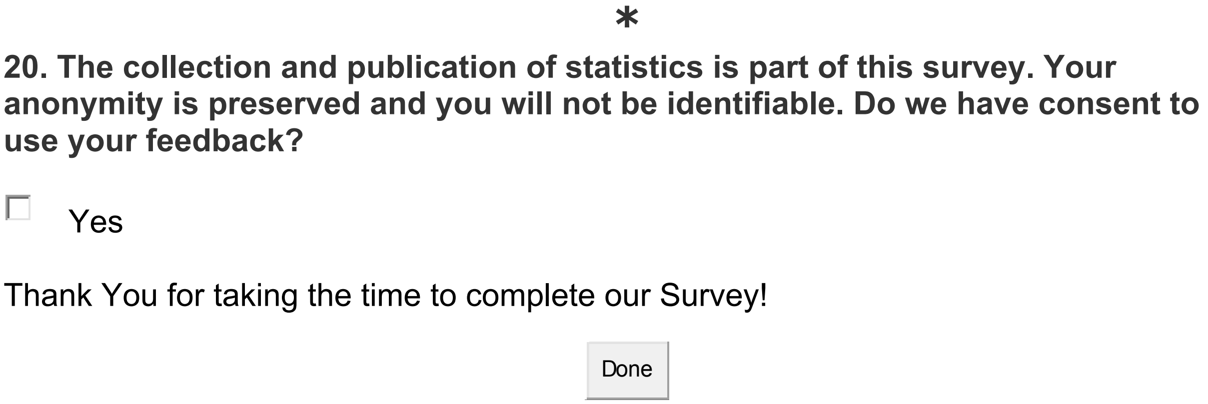
people are beginning to comment and interact with the Blog more now after 2 months. We thought that perhaps it takes time to build up a relationship with a Blog before interacting with it . Would you agree with this interpretation? If so why/why not?

*****

17. Do you have any recommendations to improve the Cork ARC Cancer Support Blog?

18. From running the Blog for 2 months we noticed that people often express themselves through images as much as words. So we thought a nice way to finish the pilot period would be to ask you to share an image with us that represents 'cancer support' for you? Please copy the link to this image into the box below. (Please note that this question is optional).

19. Any additional comments/opinions/suggestions?



*

20. The collection and publication of statistics is part of this survey. Your anonymity is preserved and you will not be identifiable. Do we have consent to use your feedback?

☐ Yes

Thank You for taking the time to complete our Survey!