

Exploring Visitors Experiences of Online Cancer Communities

By

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STUDENT DECLARATION FORM

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ABSTRACT

TITLE: EXPLORING VISITORS EXPERIENCES OF ONLINE CANCER COMMUNITIES

Background

There will be approximately four million people living with cancer in the United Kingdom (UK) by 2030. The National Health Service faces a major challenge meeting the support needs of this growing population, who commonly report feeling isolated and lacking social support. Approximately 45 million adults in the UK use the internet, and online communities might be a culturally relevant way to connect people affected by cancer, allowing them to support one another. However, internet communication is fraught with challenges such as misleading or untrustworthy information. We have a limited understanding of how people experience these communities and whether they can provide meaningful support for people affected by cancer.

Aims

To explore and understand the experiences and interactions of people affected by cancer who visit online cancer communities.

Methods

This was a qualitative study involving 23 people who had visited online cancer communities. Participants were affected by a range of cancers and were a combination of cancer survivors and families members. Semi-structured interviews elicited participants' experiences, preferences and perceived consequences of using online communities. Data analysis was guided by principles of Constructivist Grounded Theory.

Findings

Participants used communities to '*navigate*' the challenges they faced with cancer. This navigation produced three categories of experience in online communities. Firstly, advice from fellow community members set participants on a '*journey to become informed*'. Secondly, participants were cast into a '*journey to recreate identity*' as they connected and formed friendships online. Thirdly, participants discovered a '*journey through different online worlds*' to the most relevant and often hidden social communities.

Conclusions

This was the first qualitative in-depth study exploring how contemporary online cancer communities are used by people affected by cancer. Online communities offered multifaceted opportunities to support the cancer experience, and they may promote self-management in cancer care. These findings can inform and improve the delivery of existing online communities.

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Abbreviations

CASP Critical Appraisal Skills Programme
CRUK Cancer Research UK
DoH Department of Health
EU European Union
GP General Practitioner
NHS National Health Service
NICE National Institute Clinical Excellence
ONS Office for National Statistics
RCT Randomised Controlled Trial
UK United Kingdom
USA United States of America
WHO World Health Organisation

CHAPTER ONE – STUDY INTRODUCTION

This research study explored the phenomena of online peer communication as a form of support for people affected by cancer. This study emerged from the research student's personal and academic interests in supportive resources for people living with, and families affected by cancer. It was also developed as a response to United Kingdom (UK) healthcare policy calling for improvements in supportive care (Department of Health, 2011), and a call from the UCLan Cancer Studies Centre to understand how an increasingly digital society can impact on cancer care. This study has offered original insight into the challenges and benefits of using a resource which is increasingly relevant to the UK population. In addition, this study demonstrates how people affected by cancer actively seek online support, and what they require from supportive resources. Thus, this study adds to the body of literature about the needs of people affected by cancer.

This introductory chapter provides a contextual backdrop for the study. It begins by outlining the importance of support for people affected by cancer. The second section in this chapter then summarises the supportive potential of the internet, the current climate of internet access and attitudes to digital technologies. This chapter then focuses on what is known about contemporary online cancer communities and the differences between websites.

1.1. Support needs of people affected by cancer

A diagnosis of cancer has been found to cause psychological distress for people living with cancer, including those diagnosed and their families (Carlson and Bultz, 2003; Strong et al, 2007). Studies have found that up to 50% of people living with cancer and their family members have experienced anxiety, depression or both (Burgess et al, 2005; Carlson et al. 2004; Ohlsson-Nevo et al., 2010). These feelings were often caused by fear of dying, uncertainty of the outcome of treatment, perceived lack of control over the future (Bjørnes, Nøhr, Delmar, & Laursen, 2011; Dickerson, Reinhart, Boehmke, & Akhu-Zaheya, 2011), and difficulty understanding complex cancer terminology and information (Shaha & Cox, 2003; Shaha, Cox, Talman & Kelly, 2008). Furthermore, heightened distress has resulted in a number of exacting experiences for people affected by cancer including fatigue, low satisfaction with care,

perceived social isolation, and lower quality of life (Hagedoorn, Buunk, Kuijjer, Wobbes, & Sanderman, 2000, Montazeri, 2008). Several studies also suggested that heightened distress can result in poorer long term survival for people diagnosed with cancer (Brown et al., 2003; Faller et al., 1999).

Caregivers and families of cancer survivors have also been commonly referred to as 'affected by cancer', and will be hereafter in this thesis. Informal caregivers have been found to experience significant distress after a cancer diagnosis (Stenberg, Ruland, & Miaskowski, 2010). Similarly, families living with cancer have reported feeling a high burden of stress and concerns (Grunfeld et al., 2004; Ohlsson-Nevo et al., 2011). The distress of informal caregivers and families may be explained by families being less likely to have contact with health care professionals than patients. As a result, Stenberg and colleagues (2010) found that families were likely to have unanswered questions about the illness and increased uncertainty. In addition, families and caregivers have often experienced a reduced social network after a cancer diagnosis, which has led to isolation and feeling burdened (Goldstein et al., 2003).

Support has been highly recommended to alleviate psychological distress for people affected by cancer (NICE, 2004). National Institute for Clinical Excellence (or NICE) guidance (2004) has stated that cancer patients and carers need supportive care, and this should include: being treated as individuals; receiving detailed high quality information; receiving emotional support which is listened to and respected; and being able to explore spiritual issues. These aspects of supportive care centred on ensuring opportunities existed to communicate about cancer. Cutrona and Russel (1990) theorised that communication can have five supportive benefits for individual wellbeing; these are emotional, informational, self-esteem, tangible and reciprocal (or network) benefits (Cutrona & Russel, 1987; Cutrona & Russel, 1990). Emotional support referred to being able to communicate about fears and anxieties with others (Gallant, 2003). Informational support occurred when individuals were provided with information that allowed them to develop a richer understanding of their diagnosis, and their future (Eriksson & Lauri, 2000; Gottlieb & Bergen, 2010). Self-esteem support referred to conversations which increased individuals' perceived self-worth (Lahey & Cohen, 2000). Tangible support was

that which offered instrumental and physical aid and supported individuals in everyday tasks (Gallant, 2003). Finally, reciprocal or network support occurred when individuals believed they had a reliable social network to turn to for support (Cutrona & Russel, 1990). Studies have found that supportive communication can lead to an increased ability to adjust to a cancer diagnosis (Dunkel-Schetter, 1982, 1984), with improvements in levels of depression and anxiety and enhanced quality of life (Zabalegui et al, 2005). Thus, NICE guidance suggests people affected by cancer should be encouraged to communicate with healthcare professionals, family and peers, and to engage with self-help groups to gain and share support (Department of Health, 2011; NICE, 2004).

It has been notoriously difficult to meet the support needs of people affected by cancer (Sanson-Fisher et al., 2000; Wakefield, Butow, Fleming, Daniel, & Cohn, 2012). The clinical environment has been intimidating for some individuals, preventing them from seeking information and support from professionals (Leydon et al, 2000). Alternatively, support group attendance has been encouraged in cancer care as an opportunity to speak with like-minded people affected by cancer (NICE, 2004). This was recommended to allow people affected by cancer to have voices heard and respected, thus providing emotional support (Yaskowich & Stam, 2007). Support groups also devoted many hours to their discussions, which has provided prolonged support throughout the cancer journey, and a consistent supportive network (Fobair, 1997). Thus, support groups seemed to meet the requisite for unmet support needs for many people living with cancer. However, traditional, face-to-face cancer support groups have not always been popular amongst people affected by cancer and they typically have low attendance and high dropout rates (Gottlieb and Wachala, 2006; Ussher, Kirsten, Butow, & Sandoval, 2008). People have not found face-to-face support groups convenient. For instance, people experiencing active cancer treatment have struggled to commit to attending group sessions due to treatment-related fatigue and difficulties travelling to support group sites (Clark, Bostwick and Rummans, 2003). Thus, despite efforts to provide face-to-face support, reports have still found that people affected by cancer have unmet needs for information and support. A

review by Harrison et al (2009) found that studies have reported unmet needs for information in up to 93% of people affected by cancer and unmet psychosocial needs in up to 89% of people affected by cancer.

Delivering support to people affected by cancer has been a critical concern for the current political healthcare climate. The number of people living with cancer in the UK is rapidly increasing. Projections have indicated that by 2020 almost one in two people will receive a cancer diagnosis, and this will lead to approximately 4 million cancer survivors in the population by 2030 (Maddams, Utley, Møller, 2012). NICE guidelines (2004) suggested that support should be available to people affected by cancer throughout the cancer pathway, from diagnosis onwards, because cancer survivors often require support many years after active treatment is complete. The growing cancer survivor population has placed a significant strain on the resources of the National Health Service (NHS) in the UK. A recent report published by the NHS England has indicated that the cost of providing cancer support is a major economic burden, and thus more affordable and efficient ways of offering support must be developed and delivered in cancer care (NHS England, 2014). Ultimately, improving support is necessary for the wellbeing of people affected by cancer, but has to be provided with limited NHS resources.

1.2. The supportive potential of the internet

A 2015 report estimated that 44.7 million adults in Great Britain have used the internet (Office for National Statistics, 2015a). There was internet access within 86% of British homes, and in the UK 78% of the population used the internet daily (Office for National Statistics 2015b). The internet has been increasingly used to support health and wellbeing, and it could have supportive benefits for people affected by cancer. The number of people in the UK using the internet to search for health information has tripled since 2007 (Office for National Statistics, 2015b). There have been no surveys specific to cancer populations in the UK to demonstrate health related internet use amongst British cancer survivors and families. However, studies of French and American cancer survivors have found that the internet is a suitable and popular resource for cancer information and support (Eysenbach, 2008; Girault et al, 2015;

Maddock et al., 2011). Moreover, Girault (2015) found that 85% of a sample of French people affected by cancer regularly participated in online activities such as online health communication. It seemed likely that this trend would be reflected, or even magnified in the UK, as the UK had slightly higher rates of internet use and access compared to the averages in the European Union (EU) and the United States of America (USA), in which 81% and 78% of households respectively had access to the internet (Eurostat, 2015; File & Ryan., 2013; Office for National Statistics, 2012).

Studies have found that the internet is becoming a valuable information source for people affected by cancer (McMullan, 2006; Rozmovtis and Zeibland, 2004). People have used information accessed by internet technology to supplement the information they were provided with by healthcare professionals; for instance because they could not recall information, forgot to ask questions during consultations, or needed time at home to process what they had been told by healthcare professionals (Friis, Elverdam, & Schmidt, 2003; Leydon et al., 2000). On the internet, information could be accessed online at home, at any hour of the day, and the person affected by cancer was explore the information at their own pace (Yli-Uotila, Rantanen, & Suominen, 2012). Furthermore, Ludgate et al (2011) found that 75% of cancer survivors who regularly used the internet for cancer information felt they had a greater understanding of their diagnosis and disease management. The internet has also been found to support individuals through many stages in the cancer care pathway (Nanton, 2009). Studies have found that people affected by cancer used many information resources soon after diagnosis, including a combination of the internet, books and leaflets (Basch et al., 2004; Satterlund, McCaul, & Sandgren, 2003). As time from diagnosis has increased, use of other information resources significantly dropped, whilst the internet became peoples' primary source of information about cancer, excepting healthcare professionals (Ryhanen et al., 2012; Satterlund et al., 2003).

The internet has enabled people to connect and communicate with one another, which may make it an ideal source of social support for people affected by cancer. Studies have found that people gained unique insights into the cancer experience when they communicated with fellow patients or families

(Hartzler & Pratt, 2011; Rubenstien, 2012). The information shared between peers affected by cancer has concerned tips about day to day living with cancer, and knowledge which has been gained through the lived experience of cancer (Rubenstien, 2012). Therefore, peers seemed to be best placed to support one another with concerns about the cancer experience (Abramson & Rubin, 2012). The internet, which has been increasingly used for health communication in the UK, may facilitate this peer support (Fisher & Clayton, 2012; Koskan et al., 2014; Madden, 2010; Moorhead et al., 2013). Moreover, theories of internet communication have suggested that discussing cancer online may have unique benefits compared to real life communication. For instance, the online disinhibition effect (Suler, 2004; Barak and Suler, 2008) posited that traditional, facial and social cues associated with face-to-face communication have been missing online, leading to people feeling an increased freedom in online expression. Thus online peer support groups for health have been believed to foster an openness in communicating about illness experiences, which in turn may engender an informative, understanding and supportive response from peers (Barak and Suler, 2008; Mo & Coulson, 2010; White & Dorman, 2001).

Online peer support groups for cancer have been recorded as early as 1994 (Fernsler & Manchester, 1997; Gustafson et al., 1994; Weinberg, Schmale, Uken & Wessel, 1996). Weinberg et al (1996) provided computers to a small sample of young cancer survivors. Their network consisted of a private group which allowed the survivors to discuss issues and concerns relating to their illness. Weinberg and colleagues found that this online communication mirrored offline support groups, facilitating informational and emotional support sharing between peers (Coulson, Buchanan, & Aubeeluck, 2007; Coulson & Greenwood, 2012 Cutrona & Russel, 1991). Moreover, with the majority of people in the UK connected to the internet, online cancer communities may offer an easily accessible option for cancer support. Whilst face-to-face support groups have been found to be inconvenient to many cancer survivors and families (Gottlieb and Wachala, 2006), online communication has not required individuals to travel or attend a meeting at a particular time (Mick, 2004). Thus online communication has been convenient for people who were living with

physical impairments after cancer treatment and for people with commitments to caring for a person affected by cancer (Chung, 2013; Cohen, 2011). Moreover, these online groups have often been peer led, or run by charitable organisations in the UK, rather than using the time and resources of the NHS. If use of online cancer communities became widespread, they could be utilised to address and reduce the growing economic burden of caring for cancer survivors in the UK (NHS England, 2014).

The most recently conducted systematic review on online cancer communities was unable to determine whether online cancer communities have been beneficial to people affected by cancer (Hong, Pina-Purcell, & Ory, 2012). This was a significant gap in understanding, as there were several reasons the communities may not support, or may even harm the psychosocial wellbeing of people affected by cancer. People affected by cancer faced a wide range of emotional sequelae. These fears and uncertainties have been expressed with prevalence within online communities (DiFonzo, Robinson, Suls, & Rini, 2012; Lieberman & Goldstein, 2006). Thus, there was a risk that the communities could exacerbate individuals' negative experiences of cancer (Ludgate et al., 2011). Additionally, researchers have expressed concerns that online cancer communities were not monitored for accurate information, and therefore false information and rumours may be shared in online cancer communities (Bernstam et al., 2008; DiFonzo et al., 2012; Quinn et al., 2012). This may have led people to false expectations concerning the illness, and disappointment with their treatment and illness progression. Furthermore, studies have found that internet communication can encourage people to antagonise or ridicule others online, sometimes known as trolling or flaming (Suhler, 2004). Meanwhile, online health communities have proliferated websites on the internet, and today online cancer communities can be found on websites hosted by healthcare centres, charitable organisations for cancer support, and social media (Bender et al., 2011). Thus, whilst we do not know how online cancer communities benefit or harm people affected by cancer, we may not understand the challenges faced by contemporary cancer survivors and their families in this increasingly digital age. The following section describes online cancer communities, and highlights the potential benefits and risks of different groups.

1.3. The format of online cancer communities

Rodgers and Chen (2005) defined an online community as:

"a group of individuals with a common interest or a shared purpose, whose interactions are governed by policies in the form of rules, rituals, or protocols; who have on-going and persistent interactions and who use electronic communication as the primary form of interaction to support and mediate social interaction and facilitate a sense of togetherness" (Para. 20)

When these communities have focused on an illness, they have been described as online support groups (Klemm, Reppert, & Visich, 1998; Klemm et al., 2003; van Uden-Kraan et al., 2008). Online cancer communication has been available online in a variety of online forms. These different forms can considerably alter the way interactions take place, and could alter the way support can be delivered online (De la Torre-Díez, 2012; Lefebvre and Bornkessel, 2014). Therefore, Hong et al (2012) suggested that it may not be possible to generalise between different forms of online cancer communities in terms of the way they impact people affected by cancer. As communities have been available online for over a decade, there has been considerable discussion of the different features of these online groups (e.g. Im et al., 2007; Moorhead et al., 2014). This section presents a discussion of the ways online cancer communication can vary, and how this may impact cancer support.

Online cancer communities have supported either synchronous, or asynchronous communication (Chong & Teoh, 2010; Stewart & Williams, 2005). Synchronous communities supported 'real time' communication. They have been prescheduled, requiring all participating members to sign in at the same time in order to participate in a discussion. Synchronous groups have been commonly associated with healthcare centres or supportive organisations around the world, and researchers using these groups have usually included a trained professional to moderate the community (Chong & Toeh, 2010; Stephen et al., 2014). Hence, these groups were usually equipped with the expertise to ensure that participating individuals affected by cancer were supported. In addition, these synchronous communities needed to be set at a scheduled time. Like traditional offline social support, this may have limited individuals

participating in the groups if they could not commit time to participate. Synchronous communication had the potential to create an overwhelming amount of activity in a short space of time. This has created what has been referred to as the 'interstate effect' (Lambert, 2008) whereupon questions may be ignored due to the overwhelming amount of activity on in the community. Furthermore, one study reported that synchronous chat has proved more challenging for less technologically literate visitors in comparison to asynchronous communities (Wiljer et al., 2013). Asynchronous communities were those which allowed individuals to enter and view or post messages at any time point. The communication could evolve over hours, days or weeks. Thus studies have found that messages can be overlooked, or people's support needs may not be met at the time individuals' accessed groups and requested support (van Uden-Kraan et al., 2008a). This unmet support may increase feelings of social isolation for people affected by cancer. Despite this apparent drawback, asynchronous online communities have proven immensely popular (Bender et al, 2013; Im, Chee, Tsai, Lin & Cheung, 2005).

Online cancer communities have been either publically accessible or private. Studies of internet websites suggested that people have limited trust for public websites, particularly those which required individuals to share personal information (Naftel et al., 2013; Zhao et al., 2013). Individuals have been particularly concerned about their publically shared information being accessed and used for targeted scams (Smith, 1998; Suler, 2004). It has been less clear whether the status of public or private online support groups has impacted peoples' perception of online support. After all, messages posted in public online groups entered the public domain and have been used as data by organisations and academic researchers (Hookaway, 2008; Keeling, Khan, & Newholm, 2013; Walther & Boyd, 2002). Private groups have ensured that messages posted online can only be viewed by other group members. However, private online cancer communities often required individuals to sign up to the website, and recall log in details. Studies have suggested that private communities can exclude and frustrate less computer literate people, as these individuals were less likely to find a private online forum, or to remember and recall private log on details (DiMaggio, Hargittai, Celeste, & Shafer, 2004; Miller

& Bell, 2012; Sanghvi, Cherla, Shukla, & Eloy, 2012). If the privacy status of online cancer communities can cause different experiences, it may be prudent to understand the preferred format of groups from people affected by cancer in order to direct them to the most appropriate site for support.

Hong et al (2012) noted that most previous studies of online cancer communities had focused on anonymous groups, whereas new social media has been drawing cancer communication to peoples' true identity. Theories of online support have suggested that anonymity has a supportive function, as it has enabled people to be more open to share and receive support (Barak & Suler, 2008). However, in recent years, non-anonymous online communities such as Twitter and Facebook are rapidly gaining in popularity, and increasingly used for health communication (Moorhead et al., 2014; De le Torre-Diez et al., 2012). These social media cancer communities have only recently emerged as popular communication channels and, as Hong et al (2012) found, there seems to have been very little empirical evidence regarding their impact on people affected by cancer. Nevertheless, researchers have questioned whether online communities connected to peoples' true identities might cause people to feel more vulnerable when sharing intimate experiences online, which may reduce the support received in online communication (Bender et al., 2011; Farmer, Holt, Cook, & Hearing, 2009; Lampe, Ellison, & Steinfield, 2007). Thus, it has been unclear whether social media online communities could be recommended as a form of cancer support, or whether there might be greater sites for support in anonymous groups online.

1.4. Summary

Evidence has suggested that online peer communication may play an important role in meeting the supportive care needs of people affected by cancer. Kennedy et al, (2013) argued that supportive resources are best delivered in formats that are embedded into people's everyday lives. Evidence suggested that internet use has become a common daily activity in the UK (Office for National Statistics, 2015b). Furthermore, the 2015 NHS Five Year Forward View, which included projections for the future of the UK health service, has argued that we need to harness the power of the digital revolution (National Information Board, 2015). In the case of online cancer communities,

evidence has suggested that peer-to-peer cancer communication online is indeed becoming a widespread, popular, and regular activity (Fisher & Clayton, 2012; Paul, Clinton-McHarg, Lynagh, Sanson-Fisher, & Tzelepis, 2012). The extent to which this is a suitable support resource for people affected by cancer, however, is not currently clear. A systematic review of resources in 2010 was unable to determine whether online communities have benefitted people affected by cancer (Hong et al., 2012). Furthermore, peer communication has proliferated into a variety of forms, which have different potentially supportive or harmful features for people affected by cancer. Given the growing importance of these online peer communities, there was a need to clarify current knowledge about how these contemporary online cancer communities impact the lives of people affected by cancer.

CHAPTER TWO - THE LITERATURE REVIEW

The previous chapter introduced this study in light of people affected by cancers' need for social and emotional support. It also discussed why the internet might be a convenient way to connect people affected by cancer to encourage and facilitate peer support. Finally, the introduction chapter examined several areas of literature regarding different forms of existing online peer communication for cancer. This concluded by suggesting that a literature review was needed to clarify what we understand about online cancer communities, and to explore whether the communities can indeed provide meaningful support to people affected by cancer. This second chapter of the thesis details this literature review.

This chapter is split into three sections. Firstly, the chapter will describe the process that was taken to accumulate, evaluate, and review evidence. The second section of this chapter will explain the findings of the literature review. The final section of this chapter will summarise current knowledge about online cancer communities and highlight the most important apparent gaps in evidence. This will justify and lead to the aims which were developed for this study.

2.1. The process of conducting the review

A review of the literature was an essential component of this research study. Due to the lack of clarity about support in online cancer communities, this study needed to highlight the most important knowledge and gaps in the evidence base. Moreover, the literature review drove this research as it was used to develop an evidence based rationale for the subsequent empirical study (Aveyard, 2010; Cronin, Ryan, & Coughlan, 2008). There were several potential ways to conduct this literature review: a narrative review; a systematic review; or a systematic style scoping review.

Narrative reviews have been commonly used in psychological and sociological disciplines (Green, Johnson and Adams, 2006). Narrative reviewing has been described as a summary of evidence with undefined methods for searching, critiquing and synthesising literature (Baumeister and Leiry, 1997). Therefore, narrative reviews have been criticised for lacking rigour, and being

difficult to repeat and reproduce (Cook, Mulrow & Haynes, 1997). In the present study that this could have resulted in evidence being cherry-picked to fit the researcher's preconceptions about this area (Popay et al., 2006). As a result, the findings of a narrative review may not have demonstrated the true state of knowledge about online cancer communities, and the most important direction for future research. Thus, this approach was considered inappropriate for the present study.

In contrast to narrative reviews, a systematic review has been described as a formulaic procedure to searching, identifying, screening and reviewing academic evidence (Khan, Ter Riet, Glanville, Sowden & Kleijnen, 2001). Systematic reviews have been considered less prone to bias than narrative reviews, because the procedures aim to retrieve all the available high quality evidence (Briner & Denyer, 2012). Moreover, Mulrow, Cook and Davidoff (1997) recommended a systematic approach for reviewing health research because this can ensure that care related conclusions are informed by the most reliable published evidence. However, a systematic review required several different trained reviewers to evaluate the evidence and form a consensus about the findings (Khan et al., 2001). This was not available for this PhD research study. Furthermore, true systematic procedures required a specific research question and aims prior to conducting the review (Cook et al, 1997). These aims were needed to inform the strict parameters for the search strategy (Briner & Denyer, 2012). In the present study, the research student needed to conduct a literature review in order to define the research focus and question. There was a risk that a specific focused review may have screened out important research and directions for enhancing knowledge about online cancer support. Therefore a true systematic review was not appropriate for this field of study.

For the purposes of this study it was appropriate to adopt the procedural strategy of a systematic review. This allowed the review to benefit from rigorous techniques for retrieving and selecting studies. However, the synthesis of the review findings used a narrative approach in order to describe the wide range of literature concerning online cancer communities. This combined approach has been referred to as scoping the literature about a topic (Arksey & O'Malley, 2005; Armstrong, Hall, Doyle & Waters, 2011; Daudt, van Mossel & Scott,

2013). Scoping reviews have commonly been used to inform a future study, as they are sensitive to identifying gaps in a broad range of literature. This scoping review allowed the range of literature published about online cancer communities to be explored, including studies with different designs and researching different forms of online communities. These studies demonstrated the key evidence about this field, whilst highlighting gaps in the focus of the studies, and the knowledge about online support groups.

The following sections in this chapter describe the steps that contributed to the comprehensive review of the literature. This begins by describing the review aim and objectives, search strategy, screening and data extraction techniques. This concludes with a diagram summarising the process and demonstrating how this review attained 20 studies.

2.2. Aims of the review

The aim and objectives provided a focus for the search strategy, and informed the criteria which were used to include and exclude studies from the review (Aveyard, 2010).

Aim: to explore academic knowledge about whether contemporary online cancer community use supports people affected by cancer.

Objectives:

- To identify, explore and appraise existing high quality evidence concerning online cancer communities;
- To review what is known about how online cancer community use supports people affected by cancer;
- Identify the gaps in current knowledge about how online cancer community use supports people affected by cancer.

2.3. Search strategy

The systematic search method involved several stages. A key word search strategy was developed to search electronic databases. The database searching altered as the research student retrieved studies and became familiar with the literature, and these changes have been documented in this section. The electronic search was supplemented by hand searching the reference lists

of the identified relevant publications, to ensure no further publications had been missed. Furthermore, a screening procedure was conducted to identify the relevant publications and exclude the irrelevant papers. These steps are detailed below.

2.3.1 Developing a keyword search for electronic database searching

The search for academic literature used key terms in the three areas highlighted in the review aim: the internet/online services, support, and cancer populations. Search terms comprised of 'subject headings' or free text. Subject headings referred to indexed vocabulary used by databases to categorise academic papers. It quickly emerged that there were no subject headings which specifically referred to online communities. As a result, subject headings were used if they referred to similar internet resources in order to identify any papers which had been categorised under these headings. Free text terms were also used to identify any papers which specifically referred to online cancer communities in the title or abstract. Since the inception of the internet, there have been a number of different terms used to refer to online communication. These terms were identified from a manual search of well cited papers, and the various names for online communities were incorporated in the search strategy, for instance Online Support Group; Forum; and Social Media. Advanced database search operations, sometimes referred to as Boolean operators, were used to retrieve only papers which referred to internet/online services and support and cancer populations. An example of the terms used in the Ovid Medline (in process and other non-indexed citations 1946 to Jan 2014) database can be found in Appendix 1 of this thesis.

2.3.2 Initial and revised searching

After the initial application of the search strategy, a sample of papers were retrieved and read through. This gave the research student an introductory view of the literature, and allowed an appraisal of the search strategy. It became apparent that studies conducted prior to 2008 contained issues and concerns regarding internet technology that were not relevant to contemporary internet use. For instance, in the UK, USA and many EU countries, dial-up connections were the dominant way of connecting to the internet until 2005 (Office for National Statistics, 2006; Seybert, 2012). Using dial-up would have caused

considerably slower connection and roaming speeds, resulting in difficulty performing tasks such as watching videos, opening email attachments, and performing multiple online activities (Horrigan & Rainie, 2002). Studies of online cancer communities in the early 2000's referred to users' struggling with internet connectivity, disliking disconnecting their phone-line to access this form of internet, and also struggling with the financial implications of dial-up internet (Changrani, Lieberman, Golant, Rios, Damman & Gany, 2008). This problem has largely been overcome in the past decade; a report in 2013 found that dial-up internet was used by less than 1% of households (Office for National Statistics, 2013). Furthermore, early studies of internet support posited groups as most suitable for young people affected by cancer (Gustafson et al., 1994; Weinberg et al, 1996). However, evidence suggests that from around 2008 the population aged over 55 years have had a rapidly growing internet presence (Office for National Statistics, 2008a; Office for National Statistics, 2008b). In 2006 only 58% of those aged 55-64 years and only 21% of those aged over 65 years had ever used the internet (Office for National Statistics, 2006). By 2015, those in the population aged 55-64, 75-74, and 75 years and over, had increased to use at 87%, 71% and 33% respectively (Office for National Statistics, 2015a). Thus, the members of online communities prior to 2008 would have been significantly different to those populating and communicating in current online cancer communities. Data collected before 2008 was likely describing experiences that would not be reflective of contemporary online cancer community use. For this reason, after the initial literature search, the decision was made to review only literature conducted from 2008 to the present day. This was noted as an additional inclusion criteria for a revised search.

A further addition to the search strategy was made when the initial review of the literature found a dearth of studies explored the experience of using online cancer communities. This will be explained in further detail in a later section of this chapter. However, to ensure that studies exploring the experience of using communities had not been overlooked due to the search strategy, terms referring to 'experience' were added to the keyword searches in electronic data bases. No additional relevant papers were produced as a result of this addition.

2.3.3 Manual searching

Manual searching was essential for this review as studies are often not indexed as expected within databases, and not identifiable using keyword searching (Richards, 2008). Authors exploring online cancer resources have previously described problems identifying all of the published relevant papers through database searching alone (Fogel, 2002; Neuhauser & Kreps, 2008). A manual search was conducted by reading through the reference lists of the studies that were retrieved from databases. Manual searching also involved searching relevant electronic journals that commonly publish in this area, namely the Journal of Medical Internet Research. Once these papers were identified, they were screened for relevancy. This will be described in the following section.

2.4. Screening

The final electronic search for this review was conducted in January 2014. This involved inputting the keyword strategy in the following databases: MEDLINE, CINAHL, Cochrane, *PsycINFO*, *PsycARTICLES*, and *SocINDEX*. This retrieved 1446 title and abstracts of relevant papers. Manual searching added three additional papers to this number. All title and abstracts of papers were read to identify papers which might be relevant to the aims and objectives of the review. To ensure that the screening of each paper was consistent, exclusion and inclusion criteria were used in this process. The papers which appeared to be relevant to this study were downloaded into reference management software RefWorks. This allowed the papers collected from the different databases to be stored in one place. This software also allowed for removal of duplicate papers. After excluding papers according to their title and abstract, the remaining 107 papers were then accessed in full and reviewed again for relevancy against the criteria for inclusion and exclusion. This section presents the inclusion and exclusion criteria, and justifies how each criterion related to the review aims and objectives.

2.4.1 Inclusion Criteria

Studies were included in this review if they met all of the following criteria:

- *Studies which explored or reported online cancer communities, forums or groups and their impact on people affected by cancer;*

Relevant studies needed to explore online cancer communities. Online communities were identified as applications which fit Roger and Chen's definition: "a group of individuals with a common interest or a shared purpose, whose interactions are governed by policies in the form of rules, rituals, or protocols; who have on-going and persistent interactions and who use electronic communication as the primary form of interaction to support and mediate social interaction and facilitate a sense of togetherness" (Rodgers & Chen, 2005). This definition was selected as it has been used in the context of cancer communities (Preece & Maloney-Krichmar, 2005). These communities needed to be used by people affected by cancer to be suitable for the aims of this review.

- *Studies published and conducted from 2008 onwards*

The development of this criteria was documented in section 2. 1 2 2. The internet environment has altered significantly as technology and internet access became more advanced and widespread. For instance, surveys across the western world have found that the advent of Broadband (high speed internet connection) has changed the way individuals use the internet, in addition to the rise of mobile technology and older populations' growing internet access (Zickuhr & Madden, 2012; Horrigan & Rainie, 2002). The figures suggested that in 2008 internet use amongst the western world changed and better reflected the use of the internet today (Office for National Statistics, 2008; Office for National Statistics, 2015a). As this review has sought to understand how support can be understood in contemporary online cancer community environments, it was decided that to include older published material would include outdated experiences of the internet. Outdated knowledge of the internet would make the results of this review and the subsequent investigation less applicable to society today. Where papers did not state the dates in which data were collected, those studies published after 2008 were included.

- *Studies which were high quality peer reviewed empirical published evidence*

Only primary peer reviewed published empirical evidence only was included in this review. This criteria was chosen to establish high quality findings and

ensure that current understanding of online cancer communities was informed by reliable evidence.

2.4.2 Exclusion criteria

Studies were excluded from this review if they met any of the following criteria:

- *Studies which did not focus on the use of online cancer support communities, forums or groups;*

When developing the search strategy, early results indicated that researchers have studied a variety of internet resources for cancer. For instance, studies have investigated cancer information available on the internet and programmes designed to provide other online resources such as coping tools or internet diaries for cancer survivors and families. However, it was not in the scope of this study to review the general effect of the internet or internet resources for those affected by cancer. Thus, only studies focusing on online cancer communities were included in the present review. In addition, several studies included training and online facilities, with online cancer communities being monitored as part of a research study. If the findings of these studies did not provide specific evaluations of the online cancer communities, they were considered irrelevant to the aims of this review.

- *Studies which did not focus on cancer survivors, family members, or carers as online cancer community users.*

This study focused on people living with a cancer diagnosis and their families due to their documented unmet needs for support. The publications of interest to this review were those concerned with cancer survivors and families, and their interactions with online cancer communities. Thus, those studies including other populations, such as other illness groups, or the professionals running the groups, were not included in the review.

- *Studies which did not explore or report the way online communities impacted people affected by cancer*

In recent years researchers have capitalised on the ability to access participants online. Online communities have been used as a research method

to collect the views and experiences of people affected by cancer on a variety of topics (Jones, 1998). However, those studies which did not explore the impact of using these groups as a supportive tool were considered irrelevant to the aims of this review. In addition, this search strategy identified papers which predicted or explored the likelihood of populations affected by cancer using online cancer communities. These studies did not provide evidence regarding the impact of using these groups, or the support available online. Therefore these papers did not meet the aim or objectives of this review. For this reason, these studies were excluded from the review.

- *Studies which were published in non-English Languages*

Due to financial constraints it was not possible to translate any documents into English for review purposes. It was recognised that this may have biased the literature review to focus on English speaking online cancer communities.

2.4.3 Overview of excluded papers

After accessing 107 full papers for screening, 82 papers were excluded from the final review. The most common reason for exclusion was if papers reported on data collected before 2008. These studies reported data from 1999 until 2008. The second most common reason for exclusion was if the paper was not a peer reviewed published empirical study, such as discussion paper, a thesis or dissertation, or a study protocol. A complete list of the reasons for study exclusion during full paper screening can be found in Table 1.

Table 1. Reasons for study exclusion during full text screening

Primary reason for exclusion	No. of papers
Studies which collected data before 2008	41
Papers which were not peer reviewed empirical published research	15
Studies which did not explore or report on how online cancer communities impacted people affected by cancer	11
Studies which did not focus on the use of online cancer support communities, forums or groups;	10
Studies which did not focus on cancer survivors, family members, or carers as online cancer support group users.	5

2.5. Study quality assessment

Quality assessment was important for this study. Health research has needed to be informed by high quality evidence, as the conclusions of health research studies can make a dramatic impact on the physical and emotional care of vulnerable people (Byers & Beaudin, 2001). There was a risk that studies conducted and reported with high levels of bias might affect the resulting understanding of online cancer communities, which may over or underestimate the impact that groups have on people affected by cancer (Krainowich-Miller, Haber, Yost & Jacobs, 2009). Therefore, the present study sought to reduce the possibility of drawing conclusions from misleading evidence and low quality studies were excluded from the present review. The following section will outline how quality was assessed in this review.

2.5.1 Assessment tool selection

25 papers were included in this review after full papers had been accessed and screened for inclusion. To undertake a consistent and thorough quality assessment, a standardised tool was used to direct the research student's evaluation of each study (Aveyard, 2010). The literature that had been collected consisted of studies that had used a wide range of methodologies and methods, from qualitative interview studies, to randomised controlled trials. Therefore, this review needed to use an assessment tool which accounted for the evaluation of a wide range of methods. A range of critical appraisal tools were considered for this study. For instance, GRADE was a method of study appraisal which has been highly advocated for systematic reviews of medical

evidence as it compares consistency of findings across different studies (Guyatt et al., 2011). However, this was considered inappropriate to the aims of this scoping review, which needed to highlight the gaps and nuances in studies in order to determine the most important question for empirical study in this PhD. Scottish Intercollegiate Guidelines Network (SIGN) guidelines were also considered for this review. These guidelines had been used in the development of Scottish public health policy (Ciliska, Thomas, & Buffet, 2010), and were considered because the present study had the potential to impact policy regarding supportive care for people affected by cancer. However, SIGN did not offer guidance for reviewing qualitative studies, and a large number of qualitative studies were included in this review.

The Critical Appraisal Skills Programme (or CASP) was ultimately selected as the most suitable appraisal tool for this study. CASP had been widely recommended as a critical appraisal tool within healthcare research due to its standardised format (Ciliska, Thomas, & Buffet, 2008; Polit & Beck, 2012). CASP standardised critical appraisal for a range of methods by providing checklist style questions, and sub-questions. CASP questions were used to probe the validity of each study, the results, and the usefulness of the findings. For example, an example of a main question and associated sub-question in critical appraisal guidance for qualitative research is:

- *Was the data collected in a way that addressed the research issue?*
 - *Consider if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?*

(CASP, 2010)

CASP had not developed specific guidelines for cross-sectional research, and cross sectional studies emerged in the present literature review. However, the Health Evidence Bulletin Wales identified a combined set of questions derived from the CASP cohort and case-control guidelines to create a set of suggested critical appraisal questions for cross-sectional designs (Weightman, Mann, Sander & Turley, 2004; Sanderson, Tatt, & Higgins, 2007). These

guidelines were included in this review for appraisal of cross-sectional research to enable a consistent CASP approach across the literature review.

2.5.1 Practical Quality Assessment

Each study was appraised individually using CASP questions and sub-questions. CASP has been criticised for lacking a scoring or rating system by which to compare the range in quality of the studies of a review. However, where there has been strong element of qualitative research, such as within this review, scoring systems often have not reflected the validity of the findings (Sanderson et al., 2007). Qualitative studies have been ranked as least methodologically rigorous in most scoring systems (Sandelowski & Barroso, 2002). This would not have allowed an in-depth analysis of the qualitative methods used in studies. Moreover, a scoping style review did not need to rank or grade the evidence based on its quality (Arksey & O'Malley, 2005). This was because the purpose of a scoping review was used to reveal the state of knowledge about a topic of study. It was noted that low quality studies could still provide interesting insights into the state of research and the difficulties faced by researchers in this field. Moreover authors have advised using common sense when excluding studies purely for methodological quality, as methodological insights could be lost from the review (Arksey & O'Malley, 2005; Sandelowski & Barroso, 2007). Nonetheless, less rigorously conducted studies could still introduce bias into the review. Therefore, CASP tools were used to assess the potential for bias in each individual study, rather than to compare and rank studies against one another.

Critical appraisal began with a comprehensive reading of each study. During the second reading of each study, a concise summary was written regarding how the CASP question and sub-questions could be answered based on the evidence in the article. If there was missing evidence, the study authors were contacted to obtain further information about how the study was conducted. This was a useful process, as it facilitated a detailed review of the research methods used in this field. An example of a summary for one study included in this review can be found in Appendix 2.1. CASP was designed to highlight the areas where the studies may have been biased. As the CASP appraisal questions were applied to each paper, several studies were found to have

demonstrated poor rigour and quality in the adhering to the study design, collecting and presenting data. As a result, five studies were deemed as potentially biased, and were excluded from the final review. An example of a CASP summary for one study excluded from this review can be found in Appendix 2.2.

2.6. Data extraction and organisation

A standardised approach was used to extract and compare key findings from each study. Data extraction tables were developed to ensure that similar aspects of the studies were identified. These were informed by Cochrane guidance for systematic reviewing (Higgins & Green, 2008), and by a similar systematic review of internet resources (Hong et al., 2012). Data extraction tables were useful for highlighting missing elements in study reporting. Authors were contacted for further information about methods and methodology where reports were sparse.

At this stage in the literature review process, it was deemed necessary to split the literature into two categories. There were five studies which investigated outcomes of online community use. The remaining 15 studies largely explored the content of online cancer communities, and used this content to draw inferences about the experience of processing this information. By comparing these studies in data extraction tables, it was discovered that these different categories utilised different study designs. They also, to some extent, seemed to explore different forms of online communities. Therefore it seemed prudent to review the literature in two separate categories to clarify what knowledge had been generated by the different study aims and designs. The data extraction tables were also split into these two factions of the literature to aid the critical review of findings. Data extraction tables can be found in Appendix 3.1 and Appendix 3.2 of this thesis.

2.7 Summary of the reviewing process

Twenty studies, which met the aims of this review, were identified from the academic literature. The strategic literature search process uncovered the relevant studies from a total of 1,449 potentially relevant papers. The papers were discovered through a combination of electronic and manual searching,

and using inclusion and exclusion search criteria. Figure 1.1 summarises how papers were attained, and how they were managed, to result in the final studies included in the review.

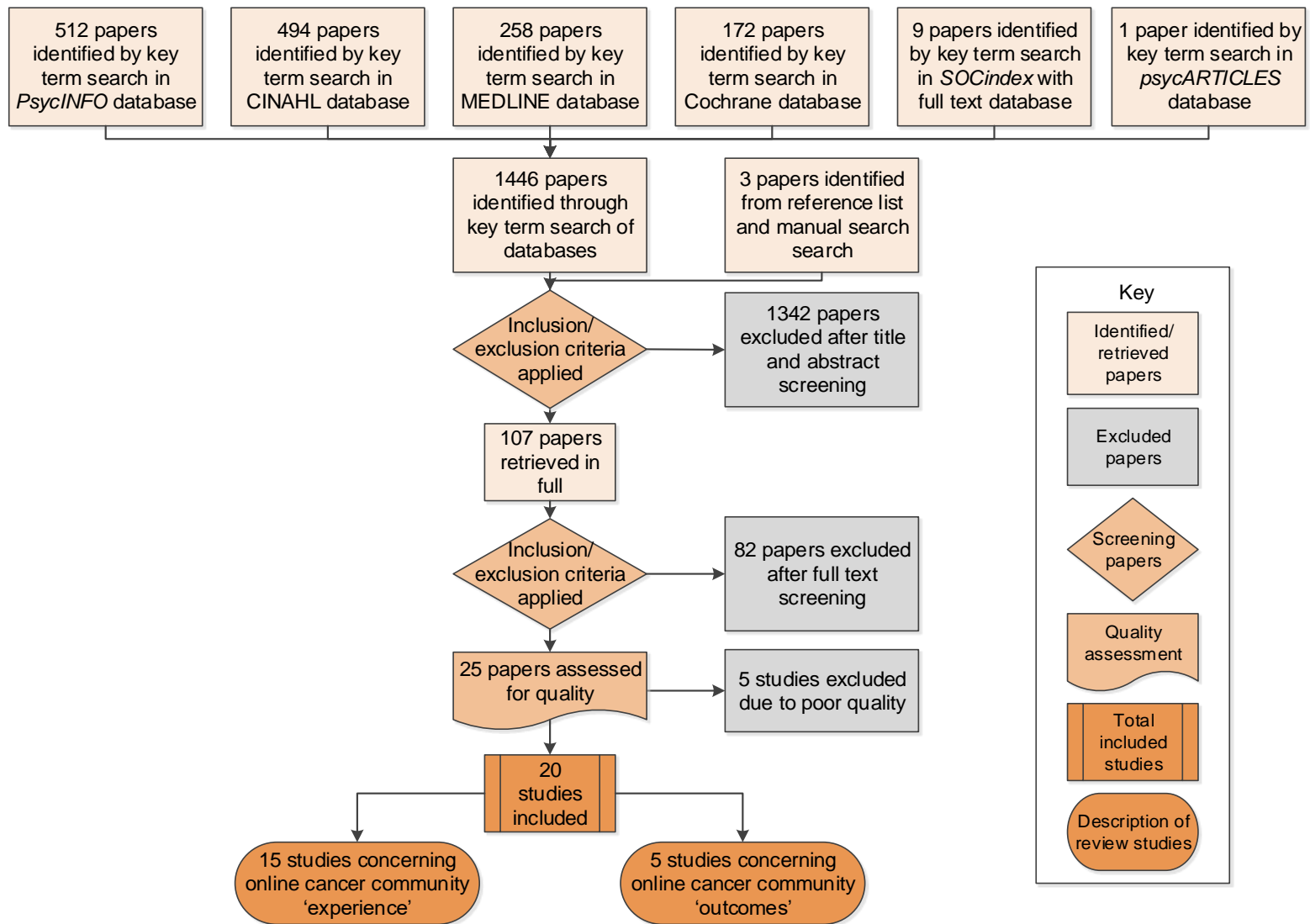


Figure 1. Flowchart illustrating literature review study retrieval and inclusion.

2. 8 Introduction to the literature review findings

This section presents the findings of the review. Firstly, studies included in the outcomes literature are described, and the findings of these studies are synthesised. Secondly, the experience related literature is described, and the findings are then synthesised. Scoping review guidance has suggested that the best way to demonstrate the breadth of knowledge about a topic is to present themes and divergences in the studies (Arksey & O'Malley, 2005; Levac et al., 2010). This approach has been advocated for reviews which need to determine what the state of evidence is, how studies have been conducted, and what findings have been generated from research (Armstrong et al., 2010). A thematic presentation style was adopted in this review, for both the outcomes and experience related literature. This was a logical approach for the experience related research, as these studies used qualitative designs which contained comparable themes. Outcomes and high quality quantitative evidence have often been reviewed using a statistical method of combining and comparing the study findings. However, the outcomes literature in this review was not suitable for a statistical comparison. The studies in this review explored different variables, covered a range of designs, and only two of the three randomised controlled trials (RCTs) retained their control group. Nevertheless, there were trends across outcomes studies and this provided some insight into online cancer communities. Additionally, the problems experienced in these studies offered an interesting view into conducting research in this area. Therefore, outcomes literature was synthesised using themes and subthemes. The themes identified in the outcomes literature were:

- **Satisfaction with participation**
- **Positive coping**
- **Participation and lurking**

The themes identified in the experience related literature were:

- **Support in online cancer communities**
 - Forms of support
 - Limitations of online cancer community support
- **The process of communication**

- Advice seeking and decision-making
- Exchanging experiences
- **Differences between user characteristics**
 - Gender differences
 - Family members
 - Lurkers

2.9 Description of the outcomes literature

Six papers were found to have reported outcomes of online cancer community use. Two papers reported on the same dataset, and it was decided that these papers should be considered as one study in the review (Kim et al., 2012; Kim et al., 2011), to prevent duplication and overemphasis of findings. This resulted in five studies being reviewed in this portion of the literature. Four of the included studies were conducted in the USA (Osei, Lee, & Modest, 2013; Klemm, 2012; Kim et al 2011, 2012; Seckin 2011) and one in Canada (Classen et al, 2013). The following sections describe the study designs, type of online cancer community and participants studied in this section of the literature.

2.9.1 Study designs

Three studies were designed as RCTs (Classen, et al., 2013; Klemm, 2012; Osei et al, 2013). The experimental arm of these three studies involved inviting and encouraging a sample of people affected by cancer to interact in an online cancer community. Outcomes were assessed by questionnaires testing the psychosocial wellbeing of participants at regular intervals. Klemm (2012) encouraged participants to interact in groups for 16 weeks, Classen et al's (2013) trial lasted 12 weeks and Osei et al (2013) investigated 6 weeks of community engagement. Klemm (2012) also tested the effect of the presence of a moderator on online community behaviours, and therefore the trial arm for this study included a moderated group, whilst the control arm required participants to communicate in an unmoderated group. The control arm of Classen et al (2013) and Osei et al (2013)'s studies both involved providing participants with paper information resources, and conducting the same tests applied to the experimental arm. However, Classen et al (2013) failed to recruit enough participants in either arm of the trial, and consequently the control group were also invited to participate in the experiment.

The remaining two studies in this section of the review were a cross sectional survey (Seckin, 2011), and a study with a design similar to a pre-post study (Kim et al, 2011; 2012). The survey correlated participants' online cancer community use with their psychosocial wellbeing. The pre-post style study explored a sample of participants using an online community, and investigated correlations between psychosocial wellbeing scores before and after the study, and the number of messages they posted and viewed in a community (Kim et al, 2011; 2012).

2.9.2 Form and format of online communities

Four of the five studies investigated online cancer communities which had been created and designed for the research study (Classen et al., 2013; Kim et al., 2011, 2012; Klemm, 2012; Osei et al, 2013). This meant the researchers controlled the design of the groups, and who was given access to the communities. The remaining study surveyed any individuals who used existing online cancer communities (Seckin 2011). Seckin (2011) had no control over what communities people had accessed, who they had communicated with nor what the participants' classified as an online cancer community.

Overall, three studies investigated communities which were moderated by professionals trained to support people affected by cancer (Classen et al., 2013; Kim et al., 2011, 2012; Klemm, 2012). Only one study included a synchronous online community in the investigation, but the participants largely focused on the more popular asynchronous board within this study (Classen et al., 2013). The remaining studies explored asynchronous communities.

Four of the five studies reported the sizes of the online cancer communities studied (Classen et al., 2013; Kim et al., 2011, 2012; Klemm, 2012; Osei et al., 2013). The three RCT studies investigated small groups of individuals interacting online, ranging from groups of 13 to 26 people affected by cancer. Kim et al (2012) investigated outcomes of participation in an online cancer community which contained 286 members, 177 of whom the authors considered active participants.

2.9.3 Participants

The majority of studies captured a sample of mainly white, degree educated participants with a relatively high income (Classen et al, 2013; Osei et al, 2013; Klemm, 2012; Seckin, 2011). The exception was Kim et al (2012) who targeted participants equal or below 25% of the poverty level in rural Michigan, USA. Furthermore, breast cancer was the most represented cancer in the study samples. Seckin (2011) surveyed people affected by different cancer diagnoses, though 75% of Seckin's sample were diagnosed with breast cancer. In contrast, Osei et al (2013) focused on men with prostate cancer, and Classen et al (2013) on women with gynaecological cancers. Not all studies reported the stage of cancer diagnosis. However, those which did report the participants' stage of cancer suggested participants were largely affected by early stage cancers; stage 1 or 2 (Classen et al., 2013; Kim et al, 2011, 2012; Klemm, 2012).

2.10. Synthesis of outcomes related findings

The outcomes literature investigated the impact of online cancer communities on a diverse range of psychosocial wellbeing measures. Studies aimed to explore psychosexual distress (Classen et al., 2013), quality of life (Osei et al., 2013), depression (Klemm, 2012), and coping and cancer concerns (Kim et al, 2011; 2012; Seckin, 2011). However, the three RCTs included in this study were underpowered due to inability to obtain the necessary sample sizes, and a high attrition during the trials. Therefore, findings were statistically inconclusive regarding how online cancer communities influence psychosocial distress, depression and quality of life. Thus, the interpretation of the following section of the review is based on the narrative trends in the RCT results, and findings from the cross-sectional survey and pre-post study (Kim et al., 2012; Kim et al., 2011; Seckin, 2011). In addition, other outcome measures used in the studies were comparable, such as satisfaction with online community participation.

2.10.1 Satisfaction with participation

Two studies measured satisfaction as a result of online cancer community use (Classen et al, 2013; Osei et al 2013). Results suggested that online community use had been a positive experience for participants. Classen

et al (2013) found that most participants were comfortable sharing their experiences online, including psychosexual concerns. Furthermore, the majority of participants in both studies indicated that they would recommend online communities to others affected by cancer. However, almost half of Osei et al (2013)'s respondents indicated that using online cancer communities had not met their needs, although there was no indication of which needs these were. This seemed to suggest that whilst online cancer communities seem satisfying, they may not provide meaningful support needed to cope with the challenges of cancer.

2.10.2 Effects on positive coping

There was evidence that using online cancer communities had an effect on participants' positive coping mechanisms (Kim et al., 2011, 2012; Seckin, 2011). Kim et al (2011; 2012) measured changes in wellbeing and coping characteristics of women after 12 weeks of using a community for breast cancer. This study found that individuals who received more support had less concerns about cancer, and those who provided more support experienced the greatest improvements in their positive reframing coping strategies. Similarly, Seckin (2011), in a survey of community user characteristics, found that positive coping styles could be predicted by increased use of online peer support. In both cases, the positive coping styles appeared to be mediated by personal coping ability, as coping strategies at the beginning of Kim et al's analyses (2011; 2012) predicted styles at the end. For Seckin (2011)'s sample, depressive symptoms appeared to mediate the effect of online community use on positive coping.

2.10.3 Participation and lurking

The definition of participation seemed to differ between research studies. Kim et al (2012) considered active participants those individuals who either wrote or read at least one message in the online community. Klemm (2012) posited that those women who posted three or less messages were 'lurking' members of the community. Lurking was defined as people who read messages and watched the community rather than participating in discussions. Classen et al (2013) considered those who posted at least 12 times to have received an 'adequate dose' of the group intervention. Furthermore, Seckin (2011) was the

only study to suggest that people affected by cancer can use more than one community. These findings demonstrated that studies have not defined what 'participation' in an online cancer community encompasses. Studies in this review also revealed that strategies could increase use of online cancer communities. Klemm (2012) found that moderation significantly increased the number of messages community members read. Kim et al (2012) found that providing and receiving support seemed to be reciprocal, wherein those who provided the most support received the most support from other community members.

2.11. Description of experience related literature

Fifteen papers explored the experience of online cancer support use. Five studies were conducted in the UK (Coulson & Greenwood, 2012; Foster & Roffe, 2009; Seymour-Mith, 2013; Sillence, 2010; Sillence, 2013), four in the USA (Blank, Schmidt, Vangness, Monteiro & Santaga, 2010; Durant, McCray and Safran, 2012; Lieberman, 2008; Love et al, 2012), four in Canada (Bender, Jimenez-Marroquin, & Jadad, 2011; Bender, Jimenez-Marroquin, Ferris, Katz & Jadad 2013; Stephen et al, 2013; Wiljer et al, 2011) one in Germany (Huber et al., 2012), and one was conducted in Japan (Sugawara et al., 2012).

2.11.1 Study designs

Studies exploring the experience of online communities used a variety of study designs. The majority of studies analysed the content of online cancer communities or community messages. A variety of techniques were used to review these sites. For instance, six studies used content analysis to explore websites (Bender et al., 2011; Bender et al, 2013; Blank et al, 2010; Huber et al., 2010; Lieberman et al., 2008; Love et al, 2012) and two studies used thematic analysis to determine the content of community messages (Coulson et al., 2011; Foster and Roffe, 2009). One study more generally described their methods as a qualitative analysis, and the study design reflected a thematic analysis of online cancer community messages (Sillence, 2013). In addition, two studies used discourse analysis to explore conversations (Seymour-Smith, 2011; Sillence, 2010) and two studies used network analysis to explore the frequency and intimacy of discussions between online community members (Durant et al., 2012; Sugawara et al., 2012). Two studies used interviews to

elicit the experiences of using online cancer communities (Stephen et al., 2013; Wiljer et al., 2011).

2.11.2 Form and format of online communities

The online cancer communities studied in the experience portion of the literature review were varied and diverse. Only two of the studies had developed online cancer communities specifically for the research study (Stephen et al., 2013; Wiljer et al., 2011). The remaining 13 studies explored existing communities on the internet. Furthermore, this literature studied online cancer communities in different formats. One study explored and categorised the different types of communities available on the internet for breast cancer, which covered forums and social media groups (Bender et al., 2013). Two studies focused on online communities in social media, exploring Facebook and Twitter respectively (Bender et al., 2011; Sugwara et al., 2012). Ten studies explored the content of existing forums for cancer.

Thirteen of the online cancer support groups focused on asynchronous communication. Two studies focused solely on synchronous communication, and the online support in these studies were provided in scheduled weekly sessions with a moderator present (Lieberman, 2008; Stephen et al., 2013). Only one study included both a synchronous and an asynchronous online community, but participants highlighted that they struggled to use the synchronous group (Wiljer et al., 2011). Six of the online cancer communities included a trained facilitator or a moderator (Bender et al., 2011; Coulson & Greenwood, 2011; Lieberman, 2008; Sillence, 2013; Stephen et al., 2013; Wiljer et al., 2013). The role of the facilitator was to guide and focus the discussions towards the therapeutic aims of the studies (Stephen et al., 2013), or to ensure that potentially harmful or non-productive discussions were avoided (Wiljer et al., 2011).

2.11.3 Populations studied

Only two studies in the experience literature selected a sample of participants to study (Stephen et al., 2013; Wiljer et al., 2011). These participants were largely female as Wiljer et al (2011) studied a sample of women living with gynaecological cancer. Stephen et al (2013) studied people affected by a range of cancers, but with approximately 52% of the sample were

living with breast cancer. The majority of studies in this review did not select a sample of participants to study. Rather, online cancer communities representing particular populations were studied. Five studies chose to examine communities which represented a mixture of cancer diagnoses (Blank et al., 2010; Durant et al., 2012; Foster & Roffe, 2009; Lieberman, 2008; Sugawara et al., 2012). Three studies explored online communities for people affected by breast cancer (Bender et al., 2011; Bender et al., 2013; Sillence 2013), and two studies explored prostate cancer communities (Huber et al., 2010; Sillence, 2010). Three studies also explored online communities for testicular cancer, young adults affected by cancer and families affected by childhood cancer respectively (Seymour-Smith, 2013; Love et al., 2012; Coulson & Greenwood, 2011).

2.12. Synthesis of experience related findings

Findings in the experience category of the literature have been organised into three main themes: support in online communities; the process of communication; and differences by user characteristics. A set of subthemes have been ordered within these themes to demonstrate the nuances in these findings. One notable finding in this synthesis influenced all themes. It emerged that there were few studies which had sought the perceptions and experiences of online communities from the visitors of the groups themselves. Two studies in this review used interview methods to understand online cancer community use, but these studies had several limitations. The sample size of Wiljer et al. (2011) was very small, and only included a select portion of participants who had agreed to interview after a RCT (Classen et al., 2013). It was likely that this study may have been subject to respondent bias, as less than half the participants of the original trial agreed to be interviewed for this study. The second interview study, Stephen et al (2013), transformed qualitative interview data into satisfaction scores, rather than providing insight into underlying reasons for satisfaction in the online cancer communities. Thus, comments have been made in throughout this portion of the literature review about the difficulties this limitation caused when understanding the experience of using online cancer communities.

2.12.1 Support in online cancer communities

Studies have posited online cancer communities as a resource that could potentially support people affected by cancer. Findings have been discussed in relation to two subthemes: forms of support; and limitations of online cancer community support.

Forms of support

Evidence suggested that online cancer community members used messages to convey social support to one another. The majority of the studies in the experience category of the review have identified forms of support in online cancer communities. Using an existing theory of support to guide analysis, one study found that support for members' emotional, information and self-esteem needs were particularly prevalent in online communities (Coulson & Greenwood, 2012). Other studies exploring the content of community messages developed their own coding schemes which were either based on the findings of previous online community studies, or based on emergent categories in the online community messages. In these studies, support was again a prominent theme of online community messages. For instance, Blank et al (2010) analysed 3203 messages in online communities and found supportive expressions in 81% of messages in prostate cancer forums, and 65% of messages in breast cancer forums. Love et al (2012) found that supportive expressions made up almost 50% of messages in a community for young adults living with cancer. Like Coulson and Greenwood (2012), Love et al (2012) found that support aided emotional, informational and self-esteem needs of people affected by cancer. Huber et al (2011) explored the questions posted to an online prostate cancer community, and found that 46% of questions were a direct request for emotional support. Support was a feature of online cancer communities in all formats including synchronous and asynchronous forums, Facebook and Twitter (Bender et al., 2011; Bender et al., 2013; Stephen et al., 2013; Sugawara et al., 2012), though support seemed to be relatively rare in Twitter messages about cancer (Sugawara et al., 2012).

Studies provided insight into how types of support were expressed online. Informational support was present in medical information, advice and

opportunities for learning which were shared between people affected by cancer online (Blank et al., 2010; Coulson & Greenwood, 2011; Foster & Roffe, 2009; Huber et al, 2010; Sugawara et al., 2013). Emotional support was exemplified in empathetic reactions to the statements of others, in displays of warmth and affection and in offers of physical affection such as 'hugs' (Blank et al, 2010; Foster & Roffe, 2009; Seymour-Smith et al., 2013). Self-esteem was supported by highlighting that the other users of the forum were not alone in their experiences, and encouraging their efforts to cope with the illness (Coulson & Greenwood, 2011; Love et al, 2012; Seymour-Smith et al., 2013).

Limitations of online cancer community support

Several studies identified limitations in the support offered in online cancer communities. Primarily, two studies found that there were certain forms of support that were less prevalent online. Coulson and Greenwood (2012) and Love et al., (2012) argued that tangible support was rare online, as they found limited evidence of members offering day to day assistance, loans, or offering to take over tasks for one another. This was unsurprising, as in online communities members were not personally familiar with one another and so could not offer support for their day to day lives. However, these findings suggest that individuals did not form face-to-face connections in order to offer their support beyond the virtual world.

Huber et al (2010) suggested that certain messages were less likely to receive supportive responses than others. For instance, if a member posted a question without providing their personal opinion and circumstances, they were less likely to receive a response from community members than those who provided a detailed account of their experiences. Similarly, Coulson and Greenwood (2012) reported an instance whereupon a family member of a child with cancer expressed her frustration and anger at receiving only one response to her post in a month. This individual highlighted her sense of growing isolation at having no support online, which compounded feelings of isolation she experienced offline. This suggested that this variation or a lack of response to messages posted online could be distressing and unhelpful to members of online cancer communities.

2.12.2 The process of communicating

Several studies in this review provided some insight into the process of online communication, identifying trends in discourse which may be supportive (Huber et al., 2011; Seymour-Smith, 2013; Sillence, 2010; Sillence, 2013). The process of communicating demonstrated how the communities might benefit people affected by cancer. These findings have been divided into three subthemes: advice seeking and decision-making; exchanging experiential information; and expressions used online.

Advice seeking and decision-making

Four studies in this review explored exchanges concerning advice and decision-making in online communities. Advice and decision-making processes were explored in communities for prostate cancer, breast cancer and testicular cancer. Messages in communities often sought advice from fellow group members on a variety of cancer related topics (Coulson & Greenwood, 2012; Foster & Roffe, 2009; Sillence, 2010; Sillence, 2013). Advice and recommendations concerning cancer treatments were the most prominent of these discussions (Huber et al., 2011; Seymour-Smith, 2013; Sillence, 2010; Sillence, 2013; Sugawara et al., 2012). There were no studies in this review which explored the validity of the advice offered online, though one study highlighted that the majority of forums did not moderate the accuracy of information in messages (Bender et al., 2013). Furthermore, there were no studies which explored whether the decisions which appeared to be made online were carried out, or taken to healthcare professionals. This was because, of the two interview studies in this review, no questions were asked of the medical changes that they may have enacted as a result of using online communities. However, studies offered an insight into nuances and patterns in soliciting and offering advice online which suggested that the process of this exchange may be supportive to those communicating.

Several studies suggested that a message soliciting advice is often posed to draw in like-minded people (Seymour-Smith, 2013; Sillence 2010; Sillence 2013). Sillence (2013) described this as a request for people 'in the same boat' to respond, which comprised 20% of the total advice soliciting

messages found in an online community. In response, the replies commonly demonstrated how the other group members were like-minded. Authors have theorised that this would establish a relationship between users, and provide the visitors with a sense of community (Foster & Roffe, 2009; Love et al., 2012; Sillence, 2010; Sillence, 2013). Thus, studies suggested that the purpose of advice exchange online was not primarily to obtain information, rather to pose a question that could receive a supportive response (Huber et al, 2010; Sillence, 2011; Sillence, 2013).

Studies suggested that the process of exchanging advice online may develop connections and deepen trust between group members. For instance, questions commonly received 'token' responses from group members stating they recognised and related to the emotive nature of the initial message (Seymour-Smith 2013). Group members also often responded to questions with their own personal narrative of experiences (Sillence, 2013). Sillence (2011) argued that this established how the experiences of the poster and their respondents were the same, and thus the advice they provided could be trusted. Furthermore, advice was often mediated by humour (Love et al, 2012; Blank et al, 2010) which may ease the concerns and worries of the original poster. In addition, advice was provided using 'hedged' expressions such as "maybe", or "it seems" (Sillence, 2013; Seymour-Smith, 2013) and commonly highlighted that the individual played the ultimate role in making a decision (Huber et al., 2011; Sillence, 2010; Sillence, 2013). It was argued that this encouraged individuals to decide whether they wanted to take on, or ignore advice. Thus, messages seemed to empower individuals to make their own decisions (Seymour-Smith (2013).

Only two studies offered insight into whether community advice influenced the decisions of people affected by cancer (Huber et al, 2010; Sillence, 2010). These studies analysed the messages between people affected by prostate cancer to explore any changes in the opinions expressed online by individual group members. Sillence (2010) only studied a small sample of online conversations, but argued that those posing questions were unlikely to change their opinions about a therapeutic choice in subsequent messages, regardless of the opinion of the replies they received. Rather, individuals were looking for

confirmation of their opinions, and supportive evidence which could ease feelings of uncertainty. Similarly, Huber et al (2010) found that most prostate community members studied responded to messages which confirmed, rather than refuted, their preconceptions. Ultimately, this evidence was limited because it did not demonstrate what decisions people enacted in their medical care. However, these studies suggested that decision-making may play a role in confirmation and reducing uncertainty rather than influencing the decisions made about cancer (Seymour-Smith, 2013).

Exchanging experiential information

Messages shared between people affected by cancer online often contained rich and detailed accounts of individuals' personal experiences, thoughts, and feelings about cancer. The previous section noted that this may establish trust and enhance acceptance of advice shared online. Several studies also suggested that sharing experiential information online might be therapeutically beneficial (Foster and Roffe, 2009; Love et al, 2012). Foster and Roffe (2009) theorised that writing about personal experience may allow the poster to confront their concerns regarding cancer, and to reframe what they had experienced. Similarly, Love et al (2012) discovered online messages which seemed to indicate that personal stories online had allowed young adult online community members to make sense of their self-identity and personal journey. Wiljer et al (2011) and Stephen et al (2013) also highlighted that contributing to a community of other people affected by cancer helped participants to discover a new sense of normality in their lives. Foster and Roffe (2009) suggested that this process may support people affected by cancers' ability to self-manage their cancer concerns, as people experiencing concerns and worries could reframe and negotiate a new understanding of their experiences online.

2.12.3 Differences by user characteristics

Studies highlighted variations in the ways individuals interacted with the online groups. For instance, some individuals posted messages with more informational than emotional support (Blank et al., 2010). Individuals expressed different types of negative emotions online (Lieberman, 2008). Furthermore,

some group members interacted with small numbers of groups members frequently, whilst others interacted with large groups of people infrequently (Durant et al., 2012). These variations in interactions were affiliated with group members' backgrounds and characteristics. This suggested that different groups of people tried to obtain different benefits from online cancer communities. These patterns are explained in the following subcategories: gender differences; family members; and lurkers.

Gender differences

Evidence suggested that men and women may use online communities differently (Blank et al, 2010; Lieberman, 2008; Seymour-Smith, 2013; Durant, 2012; Sugawara et al., 2013). Three studies proposed that there were gendered differences in communication online (Lieberman, 2009, Blank et al, 2010 and Durant et al 2012). Lieberman (2009) found that men and women expressed different negative emotions about the illness. Specifically, women expressed sadness and anger, while men expressed fear about death. Blank et al (2010) compared communication in prostate cancer and breast cancer forums, and found that men with prostate cancer communicated less emotional support and more informational support than women with breast cancer. Durant et al (2012) found that the connections individuals made with group members may differ amongst men and women, as women in breast and ovarian cancer communities formed smaller and more intimate connections than men in prostate cancer communities. The combined findings seemed to suggest that women used communities to form more intimate and emotional connections than men. Similarly, this suggested that men may receive less emotional support from online interactions than women. However, this conclusion seemed to be refuted by a study of online messages between men affected by testicular cancer (Seymour-Smith, 2013). Seymour-Smith (2013) used discourse analysis to explore the way men requested and responded to one another's requests for emotional support, and found evidence that men supported one another's emotional needs. This may indicate that whilst men and women sought different levels of support from online communities, they do not necessarily lack in informational or emotional support when using the groups. On the other hand, different norms of behaviour may simply develop in different online

communities. Durant et al (2012) found that melanoma communities, containing mixed genders, shared similar patterns of communication with breast and ovarian cancer forums, whereupon connections were intimate with a small network of people. This study also found that mixed gender renal cell online communities connected to other members in a similar way to prostate cancer community members. Thus, despite these groups containing a mixture of genders, these virtual communities formed patterns of behaviours attributed to either female or male forum use. Overall, evidence was unclear and contradictory as to whether gender differences in behaviour made a significant difference on the experience of online cancer communities.

Family members

Evidence demonstrated that families of people affected by cancer were the second largest population in online communities (Blank et al, 2010; Durant et al 2012). In Facebook groups, families comprised a significant number of group creators as 38% of groups were established to support the family member with cancer. There were also groups 'for anyone' which had been initiated by individuals with an afflicted friend or family member. These latter groups comprised of 19% of supportive Facebook cancer communities (Bender et al, 2011; Bender et al, 2013). However, most studies have given cursory attention to the presence of family members and friends in the online cancer communities. Therefore, there was little evidence to contextualise the experience of non-patient groups in survivor dominated forums. Only one study explored the use of online cancer communities for families affected by cancer. Coulson and Greenwood (2011) reviewed a forum for families of children with cancer and argued that the families could benefit more from online communities than patients as they have less direct contact with healthcare professionals. However, this conclusion was theoretical, as Coulson and Greenwood (2011) did not compare family members' experiences to people living with a cancer diagnosis.

Lurkers

Several authors highlighted one particular area for future research; research into the experience of those present but not communicating within the

forums, sometimes known as lurkers (Foster & Roffe, 2009; Huber et al., 2011; Seymour-Smith, 2013; Wiljer et al., 2011). Foster and Roffe (2009) and Huber et al (2011), both remarked upon the number of views a forum, thread, or post received compared to the replies it elicited. For Foster and Roffe's (2009) analysis, 89 messages were posted by 24 different people, and they received a total of 4440 views. Similarly, Huber et al found that 5% of all users of the online community contributed to 70% of all postings. This indicated that there may be a substantial number of lurkers in online communities. Only one study reported the experience of lurking in online communities (Wiljer et al., 2011). This was the reported experience of one woman who had not known how to post to an online community; this participant found support from reading online messages. However, with only one experiential account of this behaviour, this may not reflect the details of lurking and why it has been so prominent in online cancer communities.

2.13. Summary of the literature review

The literature review identified a large body of research that investigated internet support resources in cancer populations. However, only 20 studies were able to provide evidence about contemporary online cancer community use. The combined evidence demonstrated a rich wealth of knowledge about the content of online community messages, including messages in synchronous and asynchronous communities, in forums, and in social media groups. There was no reliable high quality evidence which found any conclusive outcomes after people used online cancer communities. This was caused by limited high quality quantitative studies investigating contemporary online cancer community use. Furthermore, there was surprisingly little representation of the perceptions of online communities from the users themselves. This section summarises the knowledge that was gained from reviewing this literature, whilst highlighting the gaps in current evidence. Following this, the limitations of this review are discussed. This section concludes by stating the rationale and aims for the study which emerged from the review.

Promising preliminary evidence was found which connect improved positive coping with online cancer community use. However, the studies which provided these findings did not use a control group, and therefore it was unclear

whether the communities affected any changes which were not simply adaptation to cancer over time (Kim et al., 2011; 2012; Seckin, 2011). This gap in evidence was also identified in a systematic review of online cancer community studies published between 1993 – 2010 (Hong, Pena-Purcell, & Ory, 2012). This systematic review was not included in the present review, as it discussed internet communication which was outdated and would not reflect contemporary online community use. However, by comparing the present review with Hong et al's (2012) findings, it emerged that there has been no conclusive evidence to suggest that online cancer communities can benefit or harm people affected by cancer. Healthcare recommendations must be informed by high quality rigorous research (Atkins et al., 2004). With a dearth of high quality research, it could not be determined whether cancer communities could become a recommended form of support for people affected by cancer.

Existing online cancer communities could inform the design of future high quality studies investigating online cancer community use. The RCT studies in this review suffered from low recruitment rates and high attrition. It was not clear why participation in RCTs was so low, but there was evidence from existing online communities that these groups could be very popular, used by large numbers of people. Therefore, this area could benefit by understanding what motivated people to use or leave online cancer communities, and which qualities of online communities people have appreciated. Moreover, this review also found that the definition and format of online cancer communities seemed to be wide and vague. Researchers investigating outcomes of online cancer communities largely controlled the format and content of the online groups. Analysis of existing online communities revealed that they could be open to the public or private, moderated or unmoderated, in forums and in social media. There was little indication about the most effective way to deliver support through online cancer communities and which formats were preferred by people affected by cancer. This gap in evidence was largely caused by a lack of studies exploring the views and perspectives of visitors to online cancer communities. However, the views of visitors to online communities could inform the design of future quantitative studies and the design of future online cancer communities to develop a more consistent approach to providing support online.

Finally, the lack of in-depth understanding about the experiences of visitors to online cancer communities posed a significant gap in how we understand these groups. On one hand, the content of communities seemed to be supportive and much of the evidence collected in this review suggested that posting activity might be therapeutic, could engender a sense of community, empowerment, and possibly support. On the other hand, it was unclear whether this was meaningful for people living with cancer. It was unclear how cancer survivors and caregivers might use the information they acquired online. One study highlighted that most online communities did not assess the validity of online messages, and there was no evidence to explore how this might impact people's trust or use of online advice and informational support. If this were known it may add a new dynamic to understanding the extent that the communities might benefit or harm users. Furthermore, there were various patterns of behaviours commonly observed online, such as lurking, men and women sharing different forms of support, and connecting with different sized networks online. The importance of these behaviours was unclear. Whilst we understood what has occurred in online groups, we did not know what this has offered people affected by cancer, nor whether it can support the cancer experience. In fact, one study suggested that an online community had not met people's needs (Osei et al, 2013), and another study highlighted that if people's messages did not receive a response people could feel increased isolation (Coulson & Greenwood, 2012). Ultimately, academic knowledge about online community use suggests interactions can be diverse, messages can be rich in meaning, and yet we have a significantly limited understanding of how people perceive these groups and how they impact lives.

2.13.1 Limitations of the review

This review had a number of limitations. The appraisal and analysis was conducted by one researcher (the research student), and so the focus of the review and the conclusions drawn may be subject to biases in the research student's worldview. Although findings have been discussed at length within the research team, this study did not have the resources of a full systematic review to independently extract the data amongst several researchers in order to validate findings (Higgins & Green, 2008). In addition, the conclusions were

limited to studies published after 2008. This was enacted to ensure that the findings were up-to date with the current experiences of the communities. However, many studies published after 2008 did not report the time of data collection and this criterion proved difficult to implement (e.g. Seckin, 2011; Blank., et al, 2010).

2.13.2 Rationale and aims for this study

To gain a clearer understanding of how online cancer communities have impacted the lives of people affected by cancer, future study in this area needed to explore the perceptions and experiences of the visitors to the communities. It was apparent that this could only be sought by gathering data directly from the online cancer community users. An in-depth study of experience would also provide a basis for understanding outcomes of online cancer community use, or the preferred designs of online communities. This insight would allow the development of more effective future research investigating outcomes in this field. The present study aimed to bridge this gap in knowledge, and increase insight into online cancer communities. Therefore the following aims and objectives were developed:

Aim:

To explore and understand the experiences and interactions of people affected by cancer who visit online cancer communities.

Objectives:

- To elicit in-depth experiential evidence about visitors experiences of online cancer communities;
- To clarify what people perceive as an online cancer community and online community use;
- To understand how people affected by cancer use and engage with online cancer communities;
- To explore how and why meanings are ascribed to online cancer support communities and community interactions;
- To understand the perceived consequences of online cancer community engagement from the perspectives of people affected by cancer.

CHAPTER THREE - METHODOLOGY

The previous chapter highlighted the main themes arising from academic knowledge of online cancer communities. A literature review outlined potential challenges of online cancer community use, and highlighted a need for in-depth research into the experience of contemporary online cancer communities. This chapter presents and justifies the philosophical and methodological approach this study took in order to address this gap in knowledge.

This chapter begins with an overview of the research paradigm and philosophical beliefs that underpinned the study. The second section of this chapter describes several relevant research methodologies which were considered relevant to this topic, and justifies why a constructivist grounded theory methodology was ultimately chosen for this study. Finally, grounded theory and the constructivist approach to grounded theory are described in further detail.

3.1. The research paradigm underpinning the study

The research paradigm was a framework of the perspectives that influenced the development of this study (Donmoyer, 2008). It was determined by the worldview of the researcher, and gaps in current knowledge about the studied phenomena (Blaikie, 2009; Lincoln, Lynham & Guba, 2011). The research paradigm influenced the way the study was designed, what elements of the findings seemed salient to the researcher and how the research has been presented (Salkind, 2010). Therefore, to ensure that the research was transparent and replicable, it was important to be explicit about the research paradigm used within a study (Creswell, 2007; Creswell et al., 2007). This section of the methodology chapter states four aspects of the research paradigm embedded in the present study (Crotty, 1998). The research student's ontology (beliefs about what reality is), epistemology (beliefs about how we know reality) and theoretical perspective (body of knowledge which have influenced this research) are outlined in this section of the methodology chapter. Finally, the methodology (beliefs about how to study reality) chosen for this study is explained, and this chapter will detail implications this methodology had on the research.

The ontological and epistemological assumptions of this research were relativism and constructivism. This study assumed that reality was a subjective experience, individual to each participant and determined according to individuals' personal nature, cultural background and past and present experiences (Schwandt, 1994; Schwandt, 2007; Smith, 2008). The related concept of constructivism stated that one can interpret reality by exploring the way it has been constructed in the human mind (Crotty, 1998; Holstein & Miller, 2006; Papert & Harel, 1991). This approach was considered appropriate for exploring, in-depth, the different experiences and interactions people have had with online cancer communities. The focus on subjectivity allowed the research student to obtain a rich description of the different experiences with online communities, which is an area missing from academic literature. Furthermore the focus on the mental construction of reality was considered an appropriate approach to understand a phenomena which is in a non-physical, virtual world.

Theoretical perspectives have been associated with sociological studies, as they focus on the meanings underlying social interactions and how social worlds work (Crotty, 1998; Grey, 2013). The present study aimed to explore the interactions within a relatively unexplored social world; online cancer communities. This social element of the research meant that it was considered important to state the theoretical stance of this study. Symbolic Interactionism (Blumer, 1969) was the theoretical perspective that best resonated with the ontological and epistemological beliefs of the research student (Annells, 1996; Blumer, 1969; Schwandt, 2007). Firstly, symbolic interactionism principles stated that the meanings that people gave to objects and other people determine the way they approach and act towards them. Secondly, meanings were derived from past and present social interactions. Thirdly, individuals' interpretations of objects, social interactions, and other people could be different depending on cultural, historical and social positions of those interpreting (Blumer, 1969; Blumer, 1980; Blumer, 1986). Moreover, symbolic interactionist researchers viewed individuals' experiences as important indicators of the society they were situated in (Annells, 1996; Davetian, 2005; Denzin, 1969). This approach was considered important for revealing people's individual

interpretations of cancer communities, and to obtain an overall understanding of the online groups.

An in-depth qualitative methodology was considered the most appropriate design to meet the aims of the study. This was primarily because there was a paucity of evidence regarding the importance of online cancer communities to people affected by cancer. A qualitative approach was suited to eliciting a range of experiences, and exploring the meanings behind interactions in-depth, which would address this gap in academic knowledge (Geertz, 1994; Holstein & Gubrium, 1998; Morse, 2011; Ponterotto, 2006). Qualitative work was also a natural methodological approach for the epistemological and theoretical perspective of this study. It allowed the research student to probe participants' different constructions or perceptions of online communities, and the factors which contributed to those perspectives. In addition, qualitative work allowed the research student to explore the symbolism in the online social interactions, as advocated by symbolic interactionism (Blumer, 1968). Furthermore, qualitative methodology in health research has been increasingly recognised as a means to providing substance and meaning to quantitative studies (Morse & Field, 1995). In the literature review, several longitudinal quantitative studies of online communities struggled with high attrition to their virtual communities (Classen et al., 2013; Klemm, 2012). An in-depth study of the significance of interactions in online communities was likely to shed light on these previous difficulties in quantitative research, and inform future studies in online cancer resources.

3.2. Selecting the qualitative methodology

Selecting a mode of qualitative enquiry was an important decision for this study. Qualitative methodologies have elicited different findings, depending on which design has been selected (Creswell, 2012; Guba & Lincoln, 1994; Lincoln et al., 2011). This section highlights several methodological designs which were considered appropriate for the study aim and objectives. It concludes with the chosen methodology, and justifies why this design was selected for this research.

3.2.1 Ethnography

Ethnographic methodology was developed to study and understand social groups and cultures (Griffin & Bengry-Howell., 2007; Hammersley & Atkinson., 2007). Data could be generated through a combination of observations, interviews and materials that might relate to the social group (Hammersley & Atkinson., 2007). An ethnographic researcher was expected to be reflective, and to discover the different worldviews and meanings of participating in a culture (Hamera, 2011). This qualitative enquiry has historically been associated with a symbolic interactionist perspective (Denzin, 1969; Rock, 2001), and thus was considered as a potential methodological enquiry for the present study. However, it was unclear in the literature whether online cancer communities constituted a complex social world for people affected by cancer. The literature review revealed that a significant number of people lurked in communities, rather than interacting with others in the online world. Therefore it was unclear whether the community aspects of this phenomena were relevant to all users of the groups, and required this specific social focus to understand the experiences of people affected by cancer. Thus, at the outset of this study it was unclear whether online cancer communities were suitable for ethnographic study.

3.2.2 Phenomenology

Phenomenological methodology has focused on exploring and highlighting the individual aspects of experiences (Creswell, 2007; Husserl, 2012). Phenomenological studies have sought individual accounts of an experience and deduced from this an essence of what it meant to participate in the phenomena studied (Husserl, 2012; Merleau-Ponty, 1996; Smith, 2007). A phenomenological qualitative approach was considered for this research because of the phenomenological focus on individual experiences, (Lavery, 2003). Furthermore, this approach has been considered valuable for exploratory research, where experiences are relatively unknown (Creswell, 2007). However, this approach was ultimately considered inappropriate for the present study. The community and technical interactions required for online cancer community use suggested that the most appropriate methodology should also be sensitive to wider structures of reality which could influence experience. For instance,

new social media groups had been relatively unexplored in the literature, but the different design of these structures may have caused variations in experiences online (Farmer et al., 2009; Koskan et al., 2014). Thus, to find an understanding of how individuals use online cancer communities, this research required a methodology that would appreciate the individual experience, but also account for wider structures in the interactions with the online social world.

3.2.3 Justification for a constructivist grounded theory approach

Constructivist grounded theory (Charmaz, 2006) was selected as the most appropriate methodology for this research. Grounded theory has been advocated as an excellent approach for conducting research in healthcare populations, particularly where there has been limited understanding of the perceptions and experiences of the phenomena (Glaser & Strauss, 1967; Hutchinson, 1993; Schreiber & Stern, 2001). This design involved collecting, analysing and presenting data whilst ensuring the interpretation was grounded in the experiences of participants (Glaser and Strauss, 1965; Glaser, 1978; Glaser and Strauss, 2009). Thus, this methodology would develop an in-depth exploration of a phenomena. It was understood that this would meet the study aim 'to explore and understand the experiences and interactions of people affected by cancer who visit online cancer communities'. Furthermore, constructivist grounded theory allowed study findings to move beyond a descriptive account of a phenomena, to explain how the phenomena interacted with wider constructs of experience, society, and culture. This meant that, using this methodology, findings could develop into a theory. It was decided that theoretical knowledge would be important in this field of study. As the introduction chapter highlighted, there has been significant growing interest in supporting people affected by cancer online (National Information Board, 2015). Thus, a theory of existing online community use was considered a valuable way to explore how this phenomena might influence a range of disciplines including knowledge about cancer support needs, use of healthcare resources, and wider societal trends of internet use.

Contemporary grounded theory has been considered a general method of enquiry because it has been used in a wide range of disciplines and the

methodology has become a recognised, effective, qualitative approach (Charmaz, 2012; Hussain et al, 2014; Morse, Stern & Corbin., 2008). There have been several different approaches to grounded theory, which have resulted in a variety of recommendations regarding how to apply grounded theory to research (Bryant & Charmaz, 2007; Corbin & Strauss, 1990; Cutcliffe, 2005; Glaser and Strauss, 1967). The following section will introduce the main elements of grounded theory research, and justify why the constructivist form of grounded theory was selected for this study.

3.3. Grounded theory and the constructivist approach

Grounded theory first developed during the 1960's when two sociological researchers collaborated; Barney Glaser and Anselm Strauss (1965; 1967). Glaser and Strauss argued that existing qualitative research had used unclear data collection and analysis techniques, and resultantly qualitative evidence had low credibility amongst the academic community (Charmaz, 2006; Glaser & Strauss, 1965). Thus, grounded theory was created as a way of applying explicit and reliable procedures to collect experiential information (Glaser & Strauss, 1967). However, Barney Glaser and Anselm Strauss considered research from two contrasting research paradigms (Charmaz, 2009; Glaser, 1991). On one hand, Glaser believed that the true nature of the world could be discovered by applying systematic procedures to collecting and analysing people's experiences. Thus, Glaser developed, taught, and published grounded theory strategies which could promote the discovery of the larger importance of experiences (Glaser, 1978). On the other hand, Strauss believed that individuals had different worldviews, and so would experience the world differently. Thus, Strauss, with fellow sociologist Juliet Corbin, refined grounded theory techniques to decipher and detail the individual aspects of experiences (Strauss & Corbin, 1990; Strauss & Corbin, 1991). Over the years, the two different approaches have been considered divergent ways of conducting grounded theory (Charmaz, 2009). In light of this, other epistemological schools of thought have evolved ways of conducting grounded theory (Bryant, 2002; Clarke, 2003; Morse et al, 2009). One contemporary and well cited modification of grounded theory has been Kathy Charmaz' (2006) constructivist grounded theory. Kathy Charmaz was a student of both Barney Glaser and Anselm

Strauss. Charmaz understood research through the philosophical position of constructivism, the stance taken in the present research. This meant that Charmaz expected qualitative research to elicit different experiences, due to people possessing unique world views. The constructivist approach also expected to find similarities in people's perceptions based on shared past and present experiences. Thus, Charmaz' constructivist grounded theory has advocated using practises from both Glaser's work (sometimes also referred to as classic grounded theory), and Strauss and Corbin's version of the methodology. In addition to this, Charmaz highlighted that previous grounded theory iterations had overlooked the role that the researcher played in interpreting findings (Charmaz, 2006). Therefore, this recent version of grounded theory has emphasised procedures which have highlighted and accounted for the impact of the researcher in a grounded theory study (Charmaz, 2009). This section introduces the grounded theory techniques used in the present study, and explains the constructivist justification for applying such techniques.

All grounded theory studies have been noted for the systematic approach to data collection and analysis; processes which take place simultaneously in this methodology (Birks and Mills, 2011; Charmaz, 2006). Grounded theory analysis has been guided by different stages of coding, from descriptively describing the data to exploring more abstract processes of experience (Glaser 2002). Furthermore, grounded theorists have been expected to constantly refer back to previous examples of coding, and to reflect on their analysis decisions in light of new data (Corbin & Strauss, 2008). This was known as 'constant comparison'. These procedures were clear and logical, and as a result grounded theory has been commonly considered the most repeatable and consistent approach to qualitative research (Reichert, 2010). A constructivist approach to grounded theory retained this emphasis on rigorous data analysis, whilst also proposing that the researcher's analytical worldview would impact on the study. Charmaz (2006) offered additional guidance to ensure that constant comparison involved reflection about the researcher's preconceptions and changing perceptions of the data. This approach resonated with the relativist and constructivist stance of this thesis; the research student expected to interpret the data based on her

own relative worldview and knowledge. Therefore, the present study found the constructivist approach to grounded theory particularly valuable, as this approach could challenge and expand the interpretive abilities of the research student.

Grounded theory methodology has been advocated due to its creative approach to data collection and analysis. Techniques known as theoretical sampling and abductive logic enabled this creativity (Charmaz, 2012; Davetian, 2005; Reichertz, 2010). Theoretical sampling involved selecting participants based on the knowledge that emerged during analysis and the knowledge that was needed for further in-depth understanding (van den Hoonaard, 2008). This ensured that the findings were driven by the experiences of participants. Similarly, abductive knowledge involved interpreting patterns and connections in individual participant's experiences, and applying this interpretation to new pieces of data as it was collected (Shank, 2008). This form of analysis allowed several levels of understanding to be generated directly from people's experiences; discovering descriptively what interactions took place online, and constructing theoretically what general impact this had on people affected by cancer (Burawoy, 2000; Charmaz, 2006). Finally, a constructivist approach has been valued as the most creative application of grounded theory. Charmaz (2006) recommended exploring the range of data analysis techniques offered by seminal grounded theory authors, and carefully considering which techniques could best expand knowledge for the present study. This approach was time consuming, and it required the research student to attain in-depth understanding of the various approaches to grounded theory data analysis. However, this approach allowed the research student to be flexible when constructing a theoretical interpretation of the data and this was believed to better honour the experiences of participants (Bryant & Charmaz, 2007; Mills, Bonner & Francis, 2006). The approaches which were considered and selected for data analysis are detailed in the Methods chapter section 4.4.

There are several noteworthy elements of grounded theory which have been particular to a constructivist approach. These defined the way this study was conducted and presented, and therefore influenced the knowledge that was produced about online cancer communities. Thus, it was important to highlight

these aspects of the methodological approach. The following sections describe the uniquely constructivist grounded theory approach to the literature review, and what a theory in grounded theory represents. A final section offers specific details about how a constructivist grounded theory demonstrates rigour in data collection, analysis, and interpretation.

3.3.1 The literature review in constructivist grounded theory

One key difference between a constructivist approach and other grounded theories has been the use of the academic literature review and existing literature (Charmaz, 2006; Corbin & Strauss, 1990; Thornberg, 2012). Glaser and proponents of classic grounded theory suggested that researchers approach a research study with a 'tabula rasa'. Latin for 'blank slate', a tabula rasa approach dictated that the researcher should not approach the academic literature until the field work (such as interviews) was nearing or had reached completion (Glaser, 1992, Thornberg, 2012). This was problematic for the present study, which conducted a literature review before determining that a qualitative grounded theory methodology was required. However, constructivist grounded theorists have taken a distinctly different approach to academic literature in a grounded theory study. Those in favour of the constructivist approach have argued that the separation of the researcher from their pre-existing knowledge was impossible (Charmaz, 2006; Morse et al., 2008; Thornberg, 2012). Constructivist grounded theory argued that the researcher arrived at the study with pre-existing knowledge based on their previous training and relative world experiences. Moreover, the tabula rasa approach discouraged the researcher from declaring their preconceptions (Dey, 2004), and reduced the researcher's sensitivity to the wide range of potential perspectives on the data (Bryant & Charmaz, 2007; Corbin & Strauss, 1990). Therefore, the literature review was considered important to the data collection, analysis and presentation of this study. Moreover the research student continued to consult the literature during the study to improve knowledge and enhance her analytical lens. This can be referred to as an 'informed grounded theory' (Thornberg, 2012).

3.3.2 Interpreting theory

Grounded theory can result in the development of an abstract theory of behaviours (Glaser & Strauss, 1965; Glaser, 2002; Reichertz, 2010). This theory has been perceived in one of two ways, and this perception was determined by the philosophical paradigm of a study. On one hand, most researchers using classic and straussarian versions of grounded theory have asserted that the methodology can lead to an objective theory (Corbin & Strauss, 1990; Glaser & Holton, 2007). An objective theory has been defined as a statement of the relationships between abstract concepts of experience (Charmaz, 2006). Researchers developing objective theories believed that they reflected the true experiences of the world, as experienced by all who interacted with a phenomena. On the other hand, Charmaz (2006) suggested that grounded theory produces an interpretive theory. The philosophies of a constructivist methodology have argued that researchers could not discover 'true' or universal processes in the world, but rather theories were interpretations created between the researcher and the participants (Annells, 1996; Blumer, 1969; Charmaz and Mitchell, 1996; Glaser, 2002; Melia, 1996). The constructivist methodology has offered ways to increase the researcher's sensitivity to the abstract processes in the data. However constructivist researchers ultimately argued that the theory which has emerged from a study was situated in the understanding of the researcher and the participants (Bryant, 2002; Bryant & Charmaz, 2007). The present study's philosophical worldview was in accordance with a constructivist approach to grounded theory.

There were advantages to this study acknowledging the interpretive nature of a theory. Methodologies which aimed to generate an objective theory did not acknowledge, and therefore did not explore, the factors that contributed to different perceptions of a phenomena (Charmaz, 2012). However, constructivist methodology has encouraged a rich exploration into how and why individuals can experience different constructions of the world (Bryant, 2002). Consequently, a constructivist grounded theory has encouraged greater in-depth insight into the meaning of online cancer communities to people affected by cancer (Charmaz, 2006). In addition, the development of an interpretive theory required the researcher to acknowledge preconceptions, and reflect on

how they may have impacted the research. By stating the researcher's potential impact on the research, the study offered transparency about the limitations of this approach (Thornberg, 2012; Charmaz, 2002) Thus, future studies would be able to evaluate this approach and consider alternative worldviews, or approaches, which could build upon or expand the application of these findings.

Interpretive theories have been developed to either represent a formal or a substantive area of study (Glaser & Strauss, 1965; Strauss & Corbin, 1994). Formal theories were those which have made inferences about behaviours which can be seen in a range of circumstances, populations, and sometimes in different fields of study. Alternatively, a substantive theory is one which has offered interpretations of specific instances, conditions, and causes (Adelman, 2010). This study aimed to explore a specific phenomenon and condition; the experiences of people affected by cancer using online cancer communities. Therefore, to meet the aims of this study, an in-depth substantive interpretive theory needed to develop from people's experiences and the study data. It was not in the scope of the study aims to develop a formal theory. However, by clarifying knowledge in this substantive area, this study has laid grounded work for a future work to develop a formal theory by comparing the present findings with other substantive areas such as other internet behaviours, health communication, or cancer survivors' interactions with other resources (Charmaz, 2006).

3.3.3 Criteria for rigour

Critics of grounded theory have argued that studies often have not adhered to the principles of the methodology when conducting and analysing a study (Bryant & Charmaz, 2007; Gasson, 2004). Grounded theory methodology procedures were developed to allow the researcher to consider data using theoretical lens (Glaser & Strauss, 1967). However, the methodology has often been misapplied in research by not following core tenants of the methodology, such as not collecting a breadth of different experiences about a topic (Mason, 2010). This then weakened the knowledge claims of the research as, for example, absent participant perspectives may result in missing significant nuances of experiences. Charmaz (2006) produced a set of four criteria for conducting and evaluating a grounded theory study which would guide the

research to follow the core principles of the methodology. This study adhered to Charmaz' (2006) recommended criteria as it needed to develop knowledge which could impact a range of fields, from knowledge about internet behaviours, to practice of supportive cancer care. Therefore, a strong, credible theory needed to emerge from this study. The following questions were asked of the data to ensure this study had credibility, originality, resonance, and usefulness:

For credibility:

- Has the research achieved intimate familiarity, a wide range of observations, and sufficient data to merit the knowledge claims?
- Have systematic comparisons been made between observations and emerging findings, and are the links logical and strong between the data and the analysis arguments?

For originality:

- Are the categories fresh, offering new insights?
- Is there social and theoretical significance of the work, and does it challenge, extend or refine current ideas?

For resonance

- Do the findings portray the fullness of studied experience, including liminal and taken for granted meanings?
- Do the findings make sense for participants or the study population, and are their links to larger collectives or institutions?

For usefulness:

- Can the findings be used in the everyday world, can it contribute to making a better world and does it spark work in similar areas?
- Do the findings suggest any generic processes and have the implicit assumptions in these processes been explored?

(Charmaz, 2006, pg 182-183)

The criteria for rigour needed to be applied throughout the research process. For instance, to achieve originality, this study needed to explore the perceptions of people affected by cancer in online communities, as these had been under explored in the existing literature. To produce a credible grounded theory, the research student needed to ensure she retained familiarity with online cancer community experiences throughout the study, and that all stages of the data interpretations were strong and logical. Additionally, to obtain resonance, this study needed to portray the fullness of the studied experience. Therefore, the research methods needed to collect data from the range of people interacting in online communities, and understand the potentially different experiences from these people. Finally, to demonstrate the usefulness of this study, a thorough research of relevant literature and policy was necessary during data collection, analysis, and writing up to ensure that these original perspectives were useful for cancer care. Thus, these criteria were regularly referred to during this study to ensure a consistent application of this methodology from the study design to the presentation and discussion of findings. For this reason, rigour will be referred to in the upcoming chapters, particularly in the methods when detailing the application of this methodology in data collection, and in the discussion chapter when reflecting on the quality of this grounded theory.

3.4. Summarising the study methodology

To ensure that this research would be clear and consistent, a philosophical approach was consistently used in this study (Creswell, 2012). A relativist and constructivist approach was used in this study. This meant that the research student expected to find variation in people's experiences of online cancer communities, with relative similarities based on similar past experiences and understanding. Furthermore, the sociological theoretical perspective of symbolic interactionism aligned with the research student's beliefs about social behaviours. This meant that the research student expected social behaviours to be symbolic and meaningful when interacting with online cancer communities. This paradigm of philosophical beliefs led the research student to consider three potential qualitative methodologies for this study; ethnography, phenomenology, and grounded theory. Ultimately, the constructivist approach to grounded theory

was selected as the best methodology to meet the study aims. This had a number of implications about how the study would approach the literature, the data, and the study methods, which have been discussed in this chapter.

CHAPTER FOUR - METHODS

The previous chapter discussed the theoretical paradigm underpinning this study, and justified the selection of a qualitative, grounded theory approach. The present chapter details how this methodology was applied using specific methods to collect and analyse the experiences of people affected by cancer visiting online cancer communities.

This chapter describes the study by following the logical order in which methods were selected. Firstly, the justification is provided for selecting in-depth interviews as a way to elicit data. Secondly, the sampling methods are described including the study population and the methods used to access and select participants. Thirdly, the interviews and data collection processes are described in further depth. Finally, this chapter will discuss the ethical considerations that were raised as this study was planned and conducted.

4.1. Interview methods

The aims and objectives of this study necessitated collecting rich and detailed data. A key finding of the literature review was that no previous studies had offered in-depth insight into the experience of using online cancer communities. Interviews have been cited as an excellent method for exploring overlooked perspectives and populations (Bowling, 2009; Geertz, 1994; Holstein & Gebrium, 1997). Moreover, the literature review revealed that there may be complex nuances to online interactions. For instance, lurking or non-posting behaviours may have had a different purpose or experience to posting behaviours. Therefore, interviews were chosen to allow the research student to explore the meanings associated with online interactions through in-depth, holistic discussions (Geertz, 1994; Kvale & Brinkmann, 2009; Rubin & Rubin, 2011). Individual interviews were selected over group interviews as the former were more informal, less structured, and allowed a greater rapport to develop between the interviewer (the research student) and the participants (Fontana & Frey, 2000; Gaskell, 2000). This was an advantage in the present study, as it allowed the researcher to gain a 'close' understanding of online communities from the perspective of the participants. Charmaz (2006) stated that this closeness should generate an insightful grounded theory, which resonates with the studied populations.

4.2 Sample

To achieve a rigorous grounded theory, this study needed to generate data which represented the fullness of experience in an online cancer community (Charmaz, 2006; Morse, 2010). Thus, a sampling strategy was essential to ensure that the appropriate people were recruited to the study (Browner & Mabel Preloran, 2006; Morse, 1991). This section explains the decisions that were made about the study population, and how a sample was selected for this study.

4.2.1 Population

The key population for this study were individuals, affected by cancer, who had visited existing online cancer communities. Studies have found cancer communities across a range of different internet platforms, and most recently have classified social media groups for cancer as supportive communities (Bender et al., 2013; Koskan et al, 2014; Moorhead et al., 2013). Additionally, Seckin (2011) found that an individual may use more than one online community. This study needed to explore what groups were considered 'online cancer communities' from the perspectives of people affected by cancer, and therefore did not place limits on what form of group the population had used.

The literature review, conducted for this study, demonstrated that online cancer communities were used by people living with their own diagnosis, and family and carers of cancer survivors (Bender et al., 2011; Coulson & Greenwood, 2011; Durant et al, 2012). These populations, with slightly different experiences of cancer, interacted with one another online. Constructivist grounded theory principles state that a credible application of the methodology should collect data from the range of individuals interacting with the phenomena of study (Charmaz, 2006). This would provide a comprehensive view into online cancer communities and contribute to a rigorous application of the theory (Charmaz, 2006). Thus, no limits were placed on the type of cancer that participants or their families had been diagnosed with. Additionally, to incorporate the experience of lurker behaviour, participants needed to have 'visited' the communities, rather than used them to post messages. Grounded theory principles have stated that as the data analysis unfolds, and the researcher gains insight into the phenomena, sampling may focus on the

emerging categories of experience. However, it was essential to be flexible and open to exploring different experiences at the beginning of the study. Therefore this study had two inclusion criteria for participants which can be found in Table 2.

For practical and ethical reasons, exclusion criteria were applied to exclude certain populations from participating in this research (for a full list see Table 2.). For instance, this research did not investigate the experiences of those under 18 years of age due to their vulnerability (Safeguarding Vulnerable Adults Act, 2006). In addition, major cancer forums in the UK (e.g. Macmillan Cancer Support and Cancer Research UK) have not allowed young adult cancer survivors to become members of their groups. The age limits in place ranged between different forums, but barred people from 14 years and younger to 18 years and younger from accessing communities. Therefore young adult cancer survivors were not expected to be amongst the populations interacting in general cancer communities in the UK.

This study did not include people without the mental capacity to consent for themselves. To avoid placing undue pressure on very ill individuals, this study did not include those who were residents in NHS hospitals, hospices or residential care homes at the time of study. The research student had a responsibility to conduct ethical research (Beauchamp & Childress, 2001; Seidman, 2012) and it would have been irresponsible to conduct a relatively time-consuming interview with individuals who were particularly ill (Smith, 2008; Ulrich, Wallen & Grady, 2002). Section 4.2.3 of this chapter details how participants were practically assessed for their eligibility to participate in this study, including how the research student assessed the potential participants' vulnerability.

Due to financial constraints, individuals who could not speak or understand the English language were excluded from the study sample. This was unlikely to have a pronounced impact on understanding contemporary online cancer community participation, as the large majority of public UK based communities were English language only. However, this may have caused a cultural bias in the development of a theory of online cancer communities.

The literature review revealed that there can be professional populations using online cancer communities, namely healthcare professionals or professionals involved with the development of the online sites (Bender et al., 2013; Durant et al., 2012). However, this study aimed to specifically explore the consequences of online community engagement on living with and experiencing cancer. Thus, healthcare employees, researchers, or board moderators were considered out of the scope of this study.

This study focused on online cancer community experiences for people affected by a cancer diagnosis treated in the UK. There were several reasons for this. Firstly, financial constraints meant that if this study were internationally focused, the research student would not be able to conduct face-to-face interviews with those living outside of the UK. Secondly, online cancer communities popular in the UK seemed to be nationally focused, and so this study began with the expectation that individuals communicate online with members of the same nationality. However, once the study was advertised, the research student was contacted by a potential participant who lived in Canada, but had been affected by a sister diagnosed with cancer in the UK. Thus, national online communities seemed to have a wider membership than anticipated. After consideration, it was thought that this study should focus on online community visitors who had experienced cancer which had been treated in the UK, to ensure that the theory which emerged remained relevant to the UK health and supportive care.

Table 2. The inclusion and exclusion criteria for participants of this study

Participant inclusion criteria:
People who have visited online cancer communities
People who self-identify as affected by cancer
Participant exclusion criteria
Online cancer community visitors under the age of 18 years
Online cancer community visitors unable to speak and understand English
Online cancer community visitors who do not identify as ‘affected by cancer’
Online cancer community visitors whose capacity to consent for themselves may be compromised
Online cancer community visitors who are residents in NHS hospitals, hospices or residential care homes
Online cancer community visitors who had been affected by a cancer which had not been treated in the UK

4.2.2 Sampling participants

The sampling strategy had a profound impact on the quality of this qualitative study (Coyne, 1997; Morse, 1991). For this grounded theory to be useful for people affected by cancer, it needed to account for the breadth of experiences with online communities (Charmaz, 2006). Guidance has differed on the number of participants needed for an in-depth qualitative PhD study (Mason, 2010). For instance, Cresswell (2012) argued that grounded theory requires 20-30 participants. Morse (1995) advised interviewing 30-50 participants to a grounded theory study. However constructivist grounded theory guidance has argued that a prescriptive number of participants would not necessarily elicit enough information to develop a theoretical understanding of a phenomena (Dworkin 2012; Patton, 1990; Charmaz, 2003). Instead, sampling and interview methods needed to focus on collecting data until the theoretical significance of this experience was discovered, and no new experiences emerged from the interviews (Charmaz, 2006). This was referred to as achieving data saturation, and the practicalities of this are described in section 4.4.2 of this chapter. The impact of this approach meant that this study needed to sample the range of relevant experiences in online cancer communities.

Therefore, a strategy was developed to firstly access a range of visitors to online cancer communities, and secondly to select participants who could contribute knowledge appropriate to the developing theory.

Accessing the study population

The first challenge in accessing participants was developing a way for this study to reach people affected by cancer who had visited online cancer communities. Many health studies have accessed people affected by an illness through healthcare professionals, or population databases (King & Horrocks, 2010). YliUotila et al (2013) found that individuals often did not disclose their online health behaviours to healthcare professionals. Therefore, it was unlikely that professionals could identify which patients had visited communities, and would be unable to recommend the study to relevant patients and their families. It was more suitable to directly target the organisations and individuals hosting online cancer communities in the UK. The aim was to advertise the study within the existing online cancer communities. However, solely advertising the study through online communities may have biased the study in favour of individuals who have had positive experiences of communities and remained using and visiting them. Consequently, the study also sought to access participants through offline cancer support groups, which may have contained individuals who had visited online communities but left them in favour of other support mechanisms.

Advertising the study online

To advertise within online cancer communities, the support of the hosting organisation was required. This was necessary because organisation hosts had the power to remove the study advertisement posted to the online community. Therefore, the research student sought the gatekeepers to online cancer communities (Mander, 1992). These were individuals with the ability to protect the community users, and the authority to co-operate by advertising the study and demonstrating their support for it in their forums, support groups, and social media. Studies have found that online media can be perceived to be more trustworthy to individuals when endorsed by trustworthy sources (Maddock, Lewis, Ahmad, & Sullivan, 2011; Miller & Bell, 2012). It was hoped that

gatekeepers' support would increase the credibility of this study and therefore the likelihood of participant accrual (Seidman, 2012). The advertisement provided a short summary of the study, and requested relevant participants for qualitative interviews. It was in the form of a poster which could be uploaded in a community. For communities which did not support an image or file posted online, text derived from the poster was provided to the gatekeeper. This advertisement can be found in Appendix 4.

Gatekeepers were mostly patient information managers at UK cancer charities, though several were specifically digital or online information managers. They were contacted by telephone where possible, and by email when telephone contact was not available. Gatekeepers were contacted from ten organisations which hosted online cancer communities. Organisations agreed to support and advertise the research through their online communities. One organisation declined to advertise the study. The online manager for this organisation reasoned that they had recently altered their online community and did not want to jeopardise the trust their community members were developing with the new site by promoting a research study in the group. Five contacts did not respond to requests. Table 3. details the organisations which were contacted, what types of cancer they represented, and where they agreed to advertise this study. Most organisations which responded demonstrated support for the study. Indeed, several organisations asked to receive a summary of the study findings in order to inform their practice running online cancer communities.

Several co-operating organisations agreed to advertise the study through their social media pages on Facebook and Twitter. Similarly, the research student shared the advertisement poster using a professional Twitter account. Increasing the reach of the study using social media will be explained in further detail in the section referring to the sampling strategies. However, it was evident that advertising the study through Twitter engaged the research student with a number of individuals particularly active on social media for cancer.

Table 3. List of organisations which advertised the study online

Organisation contacted	The cancer population represented	Place of advertisement
Anthony Nolan;	Blood & marrow transplants;	Public Facebook page;
Beating Bowel Cancer;	Bowel Cancer;	Public Facebook page and forum;
BRCA Umbrella;	Breast and Ovarian cancer and people with high genetic risk of cancer;	Forum;
Breast Cancer Care;	Breast cancer;	Forum;
British Skin Foundation;	Skin cancer;	Forum;
InBetweenEars;	Brain tumours;	Public Facebook and Twitter pages;
Macmillan Cancer Support;	Various cancer types;	MacMillan cancer voices social network and Twitter;
Maggie’s Cancer Centres;	Various cancer types;	Twitter;
Roy Castle Lung Cancer Foundation;	Lung cancer;	Public Facebook page and forum;
Target Ovarian Cancer;	Ovarian cancer;	Public Facebook page and Twitter

Advertising the study in offline support groups

This study needed data which contained nuanced experiences of online cancer communities. This would allow the various meanings and perceived consequences of online cancer communities to emerge. There was some concern that accessing individuals purely through online cancer communities would bias the findings to only explore people who had had positive experiences of the groups. Therefore this study was also advertised in face-to-face cancer support groups in the North West of England. This tactic aimed to recruit individuals who had sought online communities for support, but stopped using the groups. This was conducted by contacting the local support group leaders in the North West of England, and asking their permission to show the study poster advertisements during support group meetings. The response to this strategy was largely positive, and the study was advertised in nine support groups in the local area. These groups represented people affected by a range

of cancer types. Table 4. details the support groups contacted which agreed to advertise the study in offline settings, and the type of cancer support they offered.

Table 4. List of organisations which advertised the study offline

Organisation contacted	The cancer population represented	Place of advertisement
Bereaved Partners Support Group;	Partners affected by cancer;	Face-to-face support group;
Blackburn with Darwen Carers Service;	Carers;	Face-to-face support group;
Cancer Care (Lancaster and Kendal);	Various;	Face-to-face support group and advertisement in centre hall;
Cancer Help Preston;	Various;	Face-to-face support group and advertisement in centre hall;
Gentle Approach to Cancer;	Various;	Face-to-face support group;
Linden support Centre, Blackpool;	Various	Face-to-face support group;
Prostate cancer support Lancaster	Prostate cancer	Face-to-face support group;
Rosemere Cancer Foundation;	Various;	Advertisement in centre, word of mouth between nursing professionals;
Target Ovarian Cancer;	Ovarian cancer;	Advertisement in newsletter

Participant approach and recruitment

Once advertisements were sent to cancer support organisations, individuals who were interested in participation contacted the research student for further information. Potential participants emailed or telephoned the research student when making this initial contact. The research student requested those who made contact by email to then telephone the research assistant in order to assess their eligibility to participate (eligibility procedures are provided in further detail in section 4.2.3). Telephone contact was also requested because early interpersonal contact between researchers and participants has been found to increase the comfort of participants, and the subsequent depth of interview conversations (Spradley, 1979).

After having an initial conversation, and if individuals were eligible for the study, they were sent an information sheet and consent form. The information sheet was developed to fully inform all participants about the study including the aims, the researchers involved, and the types of questions asked during the interviews. This information sheet also informed individuals that a sampling strategy was being used in the research, and that it may not have been possible to interview all interested individuals. An example of this information sheet can be found in Appendix 5. Similarly, the consent form was created to ensure that the participants understood and consented to all aspects of the study including being audio recorded, and how to withdraw data from the research study. An example of this consent form has been provided in Appendix 6. The potential participants were given a minimum of 48 hours to read through the information sheet and consider participation. After this period, if the potential participants had not already contacted the research student, they were contacted again to ask if they would still like to take part. Willing participants were asked to return the completed consent form to the research student either by email with an electronic signature, or by post. Once the consent form had been returned, the research student contacted participants according to the sampling strategy, and arranged a time and place to interview.

4.2.3 Sampling strategies

Three sampling strategies were employed for this study. The first sampling strategy, convenience sampling, was dictated by the way study population was accessed. Patton (1990) described convenience sampling as selecting the individuals most ready, willing and able to participate in the study. The present study was advertised to visitors to online communities and the advertisement encouraged those interested to contact the research student. Therefore the initial sample of participants was self-selecting. This was suitable for the grounded theory methodology, which has been most commonly associated with theoretical sampling (Coyne, 1997; Glaser & Strauss, 1970). Theoretical sampling could not begin until the researcher was immersed in the experiential data, and had an understanding of which theoretical knowledge needed exploring (Glaser & Strauss, 1970; Charmaz, 2006; Chenitz &

Swanson, 1986). Thus, in the beginning, all individuals who contacted the research student and deemed eligible to participate were invited to interview.

The second sampling strategy used in this study was snowball sampling. This was employed alongside convenience sampling. Snowball sampling involved asking participants to refer the study on, either to potential participants or to other gatekeepers who could share the study further. This meant that the study advertisement was viewed by an accumulating, or snowballing, number of people (Biernacki & Waldorf, 1981; Patton, 1990). The main advantage of this technique was its ability to locate individuals who were not directly accessible to the researcher (Atkinson & Flint, 2001). The social media advertisements for this study were defined as snowball sampling, as social media allowed those viewing the advertisement to share it onwards amongst a new social circle. For instance, a study advertisement was shared amongst the research student's 77 Twitter followers. The poster was then retweeted (the tweet was shared further) by Twitter accounts for several leading cancer support organisations such as Target Ovarian Cancer, Cancer Care Local and a representative of MacMillan Cancer Support. This meant that the advertisement was shared amongst the organisation's approximately 6,500, 1,500 and 800 followers respectively.

The third sampling strategy was used once initial interviews had been conducted and analysed. The research student selected further participants using theoretical sampling methods. Theoretical sampling has been a core component of grounded theory methodology (Bryant & Charmaz, 2007; Corbin & Strauss, 1990; Glaser & Strauss, 1970). Theoretical sampling principles stipulate that the most appropriate participants would be those who could contribute to the categories of the emerging theory (Glaser & Strauss, 1970). Thus, key findings that developed in the initial interviews gave the research student clues about which potential participants could provide useful information and insight into communities. For instance, an early analytic code was 'keeping online behaviour from partner'. This emerged from two participants who had been living with their own diagnosis of cancer, and had struggled to communicate their online interactions to their family. Thus, the research student sought the insight of a family member to a person with cancer to participate in the study.

Strauss and Corbin (1990) advised conducting three types of theoretical sampling: open, relational and variational, and discriminate sampling. A combination of these strategies were used to select participants for this study, and to develop the theoretical understanding of this phenomena. Open sampling involved sampling those personas and situations with would provide the most relevant data about the phenomena. An example of this was the decision to explore the experiences of family members after discovering that people living with a diagnosis did not share their use of online communities. Relational and variational sampling involved selecting participants that would provide alternative views on key experiences to understand how far experiences could be generalised or limited. For instance, online community group rules, moderation and arguments seemed to be important to several participants. Therefore, the study sampled participants who were also group moderators, to understand how conflict and rules were perceived from this alternative perspective. Finally, discriminate sampling was used to investigate and verify the evolving process and storyline, and to fill in poorly developed categories. This form of sampling was utilised at towards the end of data analysis, when patterns evolving in analysis needed confirming. For instance, several participants had indicated a desire to move on and away from communities, and these participants were interviewed a second time to understand whether they had been successful in moving on.

Assessing eligibility and theoretical relevance

It was essential that the participants recruited to this study were able to cope with the physical and emotional demands of an interview. The interviews for this study were not developed to cause any stress or distress to participants. However, there were elements of the study design that may have been unsuitable for people vulnerable after a diagnosis of cancer (Israel & Hay, 2006). For example, the expected duration of the interviews was approximately 60 minutes. For those with severe illnesses, talking for this length of time could have been a burdensome task. The research student had a responsibility to ensure participants had the capacity to cope with an interview (Beauchamp & Childress, 2001). Unlike traditional routes of accessing participants, such as through healthcare providers and services, the sample for this research was

primarily self-selecting. As a result, this study did not have a professional screening procedure to determine individuals' physical and mental ability to participate. Therefore the research student was required to assess individuals for their eligibility to participate. This took place as the initial contact was made between the research student and an individual interested in the study. An eligibility screening guide was used to assess the individuals' eligibility to participate. The individual was asked a series of questions designed to highlight the challenges posed in an interview and probe about their current physical capacity to participate. The questions were based on the exclusion criteria presented in Table 5.

A set of additional questions were asked of potential participants who were deemed eligible to participate in this study. This action was taken in anticipation of the theoretical sampling strategy and aimed to record key characteristics of the willing potential participants. Participants were later selected based on the characteristics which seemed relevant to the emerging theory. The questions were predetermined before the study commenced. They were evidenced based, drawn from key issues that arose in the literature review. For instance, the literature review suggested that men and women may have had different experiences in online communities. Additionally, past studies have considered online communities as an activity for younger populations. The ages of potential participants were recorded to understand whether this made a significant impact on experience. The questions are exemplified in Table 5.

Table 5. Questions asked of potential participants to assess eligibility and theoretical relevance

Questions to assess eligibility to participate	Questions to record theoretical relevance
Is the individual able to speak and understand English?	How old is the potential participant?
Over the age of 18?	Is the individual male or female?"
Have they used forums, groups or discussion boards on the internet for cancer?	How have they been affected by cancer (personal diagnosis, or was a spouse/family member/friend diagnosed)?
Have they used online communities because they have been personally affected by cancer?	What type(s) of cancer have they been affected by?
Are they currently living at home, or in a place for medical reasons?	
The interview will involve a conversation that may go on for an hour? Some people might find this very tiring. Does the individual feel able to talk about online communities for this length of time?	

4.3. Data Collection

This section describes the data collection procedures in-depth. Once it was determined that the study would interview people affected by cancer, the methods needed refining to ensure that they were suitable for participants (Israel & Hay, 2006). The interviews needed to elicit in-depth relevant information about participants' experiences. They also needed to be conducted in a way which allowed participants to feel comfortable and willing to share in-depth information. Finally, data from the interviews needed to be recorded in a format which was suitable for in-depth data analysis, in line with constructivist grounded theory.

4.3.1 Semi-structured interviews

Semi-structured interviews were selected to elicit participants' experiences of online cancer communities. The interviews in this study needed to remain focused on online cancer communities, and therefore an interview

topic guide was developed (Kvale, 1987). However, Holstein and Gubrium (1995) argued that the more standardised the protocol or guide of the interview, the less freedom the researcher and participant have had to explore meanings within the discussion. This was concerning in the present study, as the study objectives centred on exploring the meaning of online cancer community interactions. A semi-structured approach to the interview guide was considered the most appropriate for several reasons. Firstly, as an early career researcher, the research student wanted a guide to support the interview process and the developing interview skills. Secondly, the interview guide was used with flexibility; there was no fixed order to the interview questions, nor requirements for participants to answer each and every question. This approach was beneficial as changing the order of questioning allowed both the research student and participants' freedom to explore meanings in a way that had not been previously conceptualised or described on the guide (Seidman, 2012). Thirdly, an interview topic guide seemed to suit the needs of several participants. Three participants asked to view a topic guide before the interview, stating that it would help them to prepare for the interview. This may have biased the focus of participants, but it also helped them to feel comfortable during the interview, which enhanced the relationship and trust between participant and interviewer.

Questions on the interview guide were used to engage the participant in conversation, and to guide the discussion to focus on online cancer communities. The guide included general questions, as these were useful for beginning conversations and prompting the participants to talk about online communities (Charmaz & Belgrave, 2002; Myers & Newman, 2007). For instance, the opening question used for most interviews included a confirmation that participants used communities, and a prompt for further information; 'So you have told me that you have used online groups for cancer. Can you tell me a little bit more about that?' The guide also included more focused questions about potential community interactions. For instance, 'When did you first use online communities?' often prompted participants to explain their motivation for using communities, in addition to how they found the groups. In keeping with constructivist grounded theory, probes were the most significant aspects of the

interviews, as they allowed the interviewer (the research student) to explore participants' expressions and meanings (Charmaz, 2006; Turner, 2010). Therefore commonly used probes were 'can you tell me more about' And 'what do you mean by...'. The original interview topic guide can be found in Appendix 7. As the interviews and analysis evolved, the interview guide adapted. For instance, the original interview guide used the term 'online cancer support group', as the literature had commonly referred to groups using this term. The term 'community' emerged as a more suitable name to many participants, and the interview questions were adapted accordingly. Finally, several participants were interviewed a second time to clarify details about their initial interview, or to ask questions confirming the emerging theory. These questions were much more specific and confirmatory compared to the open style of the initial interviews.

4.3.2 Interview setting

The participants of this study were affected by cancer. While many participants may have been living well following diagnosis and treatment, it was likely that some participants could have been physically affected by the illness, the effects of treatment, or had time restraints due to caring for a person with supportive care needs. The research student was responsible for ensuring the participants were in the most convenient setting to interview, particularly since they may have been recalling distressing memories (Israel & Hay, 2006; Seidman, 2012). Therefore, this study offered the participants a variety of interview formats. Participants were invited to face-to-face interviews, telephone interviews, or interviews using video call (e.g. Skype), depending on their preference. Furthermore, when participants indicated a preference for a face-to-face interview, they were arranged to take place in a setting mutually convenient to the participant and interviewer.

There were some potential advantages and disadvantages to offering several choices for interviewing. Face-to-face interviewing has been commonly considered the most suitable method for in-depth qualitative studies (Fontana & Frey, 1994; Novick, 2010). However, many participants in the present study chose to be interviewed via the telephone, which has been compared unfavourably to face-to-face interviewing (Davis, Bolding, Hart, Sherr & Elford,

2004; Fontana & Frey, 2000). Creswell (2012) noted that telephone interviewing has prevented researchers from recording participants' non-verbal expressions and interactions. This lack of non-verbal information may have prevented the interviewer from discovering and exploring nuances and context of peoples' experiential accounts. In addition, studies have suggested that a lack of nonverbal communication may have prevented rapport from developing between interviewer and participant (Robson & McCartan, 2016). However, Novick (2008) argued that there has been limited evidence to suggest that telephone interviews yield lower quality interview data. In fact, studies have suggested that telephone interviews have afforded participants a sense of anonymity, which has allowed them to feel increased comfort and willingness to share embarrassing or stigmatising experiences (Fontana & Frey, 2000; Holt, 2010; Sturges & Hanrahan, 2008). Furthermore, participants in the present study were likely to be accustomed to communicating with anonymity due to their online experiences. Therefore, telephone interviews were not perceived to be a significant challenge to participants, and may in fact have been preferable for this sample. A further challenge for this project stemmed from the option of interviewing through the video call software Skype. Evidence concerning the efficacy of Skype interviews is only in its infancy, and there has been a mixed reception of its feasibility as an interview tool (Bertrand & Bourdeau, 2010; Deakin & Wakefield, 2014; Weinmann, Thomas, Brilmayer, Heinrich & Radon, 2012). On the one hand, a Skype interview approach required participants to have existing technical equipment and expertise to participate; on the other hand this form of interview allowed the researcher to see the nonverbal expressions of participants during the conversation. Despite the limitations of electronic interviewing methods, it was ultimately decided to provide several options for interviewing. Sturges and Hanhran (2004) argued that research participation needed to be offered in a way that could maximise data quality whilst minimising imposition on participants. It was thought that the two electronic interview technologies could be conveniently accessed at home, and thus were suitable for a population who may not have the time, ability, or inclination to speak to the interviewer face-to-face. Finally, electronic interviewing was expected to be particularly relevant to a population familiar with using technology.

4.3.3 Demographic data collection

Constructivist grounded theorists have advocated collecting several forms of data (Charmaz, 2006). This has enriched researchers' knowledge of a phenomena by highlighting different meanings and directions for the emerging theory. This study recorded demographic data about the participants at the beginning of each interview using a simple tick box demographic sheet (see Appendix 8). This background information was recorded to understand how the present sample compared with other samples studied in the academic literature. When relevant, the demographic data was also used in the interviews to explore whether the participants' experiences differed according to their background. Information was recorded on participants' age, gender, ethnicity, marital status, education level, who had received the cancer diagnosis (themselves, a family member, or both) and finally the type or types of cancer they had been affected by. These were aspects of participants' backgrounds which appeared to be significant in the academic literature. For instance, the demographic sheet recorded the participants' relationship with cancer and type of cancer. This was included because literature rarely explored the experiences of online cancer communities with people affected by different cancers, and family members and cancer survivors. This data enabled the research student to explore and eventually evidence the generalisability of this grounded theory. Furthermore, demographic questions proved valuable in 'breaking the ice' with participants, and establishing a rapport with which to open the main semi-structured interview.

4.3.4 Interview data collection and organisation

The main data sources for this study were the transcripts from audio-recordings of interviews. There were several approaches to recording and analysing the different interviews for this study. Face-to-face interviews were conducted when the research student visited participant's homes or an agreed meeting place such as a private room in a local pub. These interviews were recorded on a dictaphone. The majority of interviews were conducted by telephone, and recorded using a dictaphone. Participants were comfortable talking about their experiences by telephone, and this allowed greater flexibility in data collection; participants were interviewed across the country, and in one instance, from a participant living in Canada. Telephone interviewing also

allowed several interviews to be conducted on the same day. However, on one occasion the telephone connection affected the quality of the recorded call. The option for video calling required the software Skype, which was the most widely used video software available (Weinmann et al., 2012). This form of interviewing required the research student and participant to have a working internet connection, and video and microphone hardware at the time of the call. Three attempts were made to interview via Skype, however the quality of the internet connection caused a major challenge to two of these interviews, and only so one interview was conducted entirely by Skype. A dictaphone was placed beside the computer supporting the Skype connection, and this recorded the Skype interview.

Audio recordings of each interview were transcribed. A transcript provided a thorough template of the actual interactions, including data such as participants' speech, laughter, and pauses. Transcripts were an essential requirement for the constructivist grounded theory approach to the study (Davidson, 2009; Oliver, Serovich, & Mason, 2005). As a novice researcher, transcription proved useful for improving the interview techniques used in the initial interviews (Gibson & Brown, 2009). The transcripts from the interviews were sent to the experienced supervisory team who commented and provided feedback to improve future interviews. The research student also used the transcripts to reflect on the questions used in the interview guide, to ensure they facilitated in-depth discussions. Moreover, transcription lessened the impact of the research student's preconceptions when interpreting the data (Hammersley & Atkinson, 2007; Hardy & Bryman, 2004). A verbatim transcript allowed the research student to analyse the data line-by-line, thereby analysing the data for the participants' meanings in each segment, as opposed to the research student selecting incidents to analyse (Charmaz, 2006).

The process of transcribing and reading the transcripts allowed the research student to become close to the data, particularly in the language used by participants (Charmaz, 1996). Transcription sensitised the research student to see, probe and understand implicit assumptions in experiences (Kvale & Brinkmann, 2009). For example, a commonly used phrase across the transcripts was 'dipping in and out' of online communities. In accordance with

principles of symbolic interactionism, language and words specific to social groups had additional significance and meaning (Blumer, 1980; Blumer, 1986). Therefore, the frequency with which 'dipping in and out' arose in the transcripts indicated that the research student needed to use this language in future interviews and to obtain further data about this phrase. To benefit from the advantages of transcription, the research student needed to analyse the majority of the interviews. However, for efficiency, the research student found that a university approved transcription service was required for several of the later interviews. This decision was made to allow the research student time to conduct in-depth analysis on the data as categories of the theory began to emerge and become saturated.

The research student transcribed the interviews using the qualitative computer software management programme QSR-Nvivo. The audio recorded interviews were firstly uploaded into QSR-Nvivo. They were transcribed using the transcription tool available in the software. The transcripts were then checked to ensure they were accurate, and they did not contain identifying features. Similarly, transcripts received by the university approved external transcriber were input into QSR-Nvivo and reviewed to ensure they were accurate and did not contain identifying features. A software management programme was necessary for several reasons. Firstly, the combined time of the interviews was in excess of 27 hours of data. This resulted in a large amount of data to be handled, which would have caused difficulties analysing the data by hand. Constructivist grounded theory analysis required an iterative back-and-forth analysis between interview transcripts, and QSR-Nvivo conveniently organised this data in one package. Secondly, QSR-Nvivo was developed to support grounded theory analyses (Gibbs, 2002; Hutchison, Johnston, & Breckon, 2010). This software offered features which were relevant to different levels of coding, and thus supported the data analysis procedure used in this study.

4.3.5 Field notes and memos

Field notes and 'memos' were recorded during the interview and analysis process. In accordance with constructivist grounded theory, this study treated field notes as a form of data produced during the interview process (Corbin &

Strauss, 1990). Charmaz (2006) argued that the thoughts and feelings of the researcher has impacted findings of a study, including the questions which are asked at interview and analysis. Field notes, or notes made during and directly after the interview, demonstrated what the research student found important, or needed further clarification from the interview (Kvale & Brinkmann, 2009; Altheide & Schneider, 2012). They were practically recorded on paper, and input into QSR-Nvivo following each interview. An example of a field note can be found in appendix 9.

Memos were the recorded thoughts of the research student which described the data analysis and interpretation (Eriksson & Kovalainen, 2008). Glaser suggested that memos should record each decision made with the data and they should include the description and justification of each decision (Glaser, 1965; Glaser & Holton, 2007). QSR-Nvivo supported memos, as this software allowed the research student to create and to attach them to significant codes or relationships identified between codes. An example of a memo can be found in appendix 10.1. Field notes and memos served an important function during the development of the grounded theory (Charmaz, 2006; Glaser, 1978; Glaser & Holton, 2007). This will be described in the following section of this chapter.

4.4. Data analysis

Constructivist grounded theory data analysis was used to transform the individual interview transcripts from descriptive data into theoretical findings about experiences in online cancer communities (Corbin & Strauss, 1990). A number of analysis techniques were employed to illuminate the actions and processes taking place in the data. Historically, grounded theory researchers have offered several different guidelines, perspectives and techniques for data analysis (Bryant and Charmaz, 2007; Morse et al., 2008). This section outlines the data analysis process that was chosen for the present study, and justifies why this approach was taken. This section will firstly detail the coding styles used to dissect and interpret the data. The following section will describe the logic that was employed to develop a theory from the analysis, and when the analysis was deemed complete.

4.4.1 The coding process

Coding in grounded theory was a process in which interview transcripts were dissected into labels, otherwise referred to as codes (Corbin & Strauss, 2008). Codes were then reassembled to represent common experiences and patterns of behaviours. There were several different types of codes that were applied to the data. They ranged from descriptive codes reflecting the meanings behind individual phrases, to interpretive codes reflecting common experiences and abstract processes in the data (Charmaz, 2006; Glaser & Strauss, 2009; Kelle, 2007). The present study employed a coding process which was advocated by Charmaz (2006) and which reflected the values of constructivist grounded theory. This involved initial coding, focused coding, and theoretical coding. These processes are briefly outlined below and, for the purpose of this thesis, they are described independently. In reality, coding was iterative as data analysis took place concurrently with interviewing, and subsequent interviews often provided new perspectives on previously analysed interview transcripts. Therefore, transcripts and coding processes were often revisited to explore different levels of meaning within the data.

Initial coding

Initial coding was employed to open the research student to the different experiences present in the data. This stage in the coding process was also referred to as open coding, as it required the research student to label each line with no reference to previous codes (Walker & Myrick, 2006). For this study, the research student employed line-by-line initial coding, a strategy suitable for fracturing detailed data (Charmaz, 2006). Line by line was a time consuming approach, as new codes were applied to every line in the data. This was often repetitive, resulting in many similar codes in one interview transcript. For example, during analysis of an interview transcript with participant one, several similar codes emerged which discussed the helping behaviours: 'helping when others are not'; 'helping by providing information'; and 'assuming a helping role'. This approach to coding was particularly useful for immersing the research student in the data, and allowing an open interpretation of many different meanings behind interactions with online communities (Charmaz, 2012).

Barney Glaser and Kathy Charmaz recommended labelling the initial codes as 'gerunds' (Charmaz, 2012; Glaser, 2002). Gerund, from the Latin 'gerundium', was defined as 'those to be carried out', or actions and intentions. Coding initial codes as gerunds allowed the research student to be sensitive to the actions and interactions participants had with online communities. Practically, this often involved coding the '-ing' processes described by participants, to highlight the active ways they considered and used online cancer communities. For example, codes that emerged from initial coding of the transcript for participant three included: 'constantly looking at the sites'; 'focusing on answers to questions'; and 'wanting a break from communities'. The gerund approach was essential in the process of theory development, as it prevented the analysis from becoming descriptive, highlighted the active elements of participants' experiences with online cancer communities, and encouraged interpretation of participants' intentions. Furthermore, fitting the codes with gerunds at this early stage in the analysis helped to keep the data interpretation close to the participants' experience. This was important to ensure the development of a rigorous grounded theory with resonance to people affected by cancer (Charmaz, 2006; Morse et al., 2010). To further ensure the data analysis was grounded in the experiences of participants, codes were also labelled with the participants' actual phrases where appropriate. This is otherwise known as in-vivo coding (Corbin & Strauss, (2008). For example, an in-vivo code which emerged from an interview with participant 17 was 'Navigating through cancer'.

Focused coding

Focused codes were the second set of codes applied to the interview transcripts (Charmaz, 2006). This stage involved reviewing the initial codes, and grouping those which appeared to be related or particularly meaningful to the participants. For example, the previous section of this chapter described three initial codes concerning helping online from participant one. These codes were eventually grouped under a focused code of 'becoming a source of help'. Codes which seemed to be contradictory or needed further exploration were also grouped and highlighted for further exploration in resulting interviews and analysis. The groups of codes that emerged during this focused coding process

were referred to as categories (Corbin & Strauss, 1990). Categories were labelled to reflect the codes and, where appropriate, repeated an in-vivo code. This ensured that the analysis remained reflective of participants' thoughts and experiences. Categories informed the questions to be asked in further interviews, and the theoretical sampling strategy (Morse, 2010).

Focused coding relied on constantly comparing new codes with previous codes in the each transcript, and with other transcripts in the study (Glaser, 1965). The field notes were also incorporated during this stage in the analysis. Field notes highlighted what aspects of the interviews had seemed pertinent to the research student, and how impressions changed over time. For example, a field note made during an interview with participant three highlighted that the term 'learning curve' had been used in that interview, and in the preceding two interviews. The research student made the note to probe further into the meaning of this notion during the interview, and to explore how this explanation might be similar or different to learning curve codes in the previous participants' transcripts. Emerging findings during focused coding often resulted in the research student returning to the original transcripts to adapt initial open codes, and to add new labels as a greater understanding of the communities emerged.

Theoretical coding

The final stage in coding involved exploring, and defining the theoretical significance of the data categories. The research student used various techniques to consider the theoretical processes in the findings. Strauss and Corbin (1990) proposed a form of coding known as axial coding, which required the research student to consider each category in the data from three perspectives; the conditions, the actions and the consequences of people's experiences (Bohm, 2004; Charmaz, 2006; Kelle, 2007). Strauss and Corbin (1990; 2008) also proposed a coding paradigm that expanded the axial coding system, and suggested specific questions which could be asked of the data such as; what were the wider societal conditions of the phenomena, or how do the participants' experiences fit within the structure of the specific social world of the phenomena? (Strauss and Corbin, 1990). Axial coding and the coding paradigm have received both criticism and praise as a data analysis technique

(Charmaz, 2006; Glaser, 1992; Kelle, 2007; Kendall, 1999). Glaser (1991) suggested that this technique forced data to be interpreted in a prescriptive framework, presenting the theory in a prescriptive shape and from a specific lens, rather than respecting the experiences as presented by participants. Charmaz (2006) advised researchers to consider Strauss and Corbin's (1990) coding techniques as a tool to encourage theoretical thinking. However, caution was needed with axial coding and the coding paradigm to ensure that the framework fit the experiences in the data. In the present study, when considering the theoretical direction of the findings, these techniques were applied to the existing codes. A diagram was developed to reflect the overall connections between emerging categories, and the research student labelled the categories which reflected actions, conditions, or consequences of experiences. This diagram can be found in Appendix 8.2. However, Strauss and Corbin's (1990) approach to rendering grounded theory data ultimately created a framework which detracted from the clear pattern of experiences that had emerged from participants (Kelle, 2007). For example, many actions participants' undertook with online communities were often also consequences of online experiences. Therefore selecting one label for these categories changed the way the categories were presented and perceived. After exploring and rejecting Strauss and Corbin's advised methods of coding, the research student decided upon Glaser's (1978) principles of theoretical coding to interpret this data.

Glaser's techniques for theoretical coding involved questioning and evaluating the nature of relationships between categories (Glaser, 1978; Kelle, 2007). The aim was to discover the abstract, rather than descriptive, nature of online cancer communities (Charmaz, 2006; Thornberg, 2012). Glaser (1978) developed a large body of 'coding families' for this process. Coding families represented general and abstract concepts that could be similar to the patterns in research data (Bohm, 2004). For instance, there was a coding family which described different types of processes; Stages, phases, phasings, transitions, careers, chains, sequences. There was also a coding family describing different ways that behaviours might constitute strategies; Strategies, tactics, techniques, mechanisms, management (Glaser, 1978). In accordance with constructivist

grounded theory, coding families were used in this study to challenge the way the research student considered patterns in the data (Thornberg, 2012). For example, the 'process' family allowed the research student to consider the different processes present in each category. Importantly, coding families were used as a guide to understand the data in abstract terms. They were not used to define the relationships between categories.

In practice, coding families were used as the research student reviewed diagrams and memos of the data. Buckley & Waring (2013) suggested that a visual representation of the relationships between categories drew attention to basic social processes. Similarly, diagrams were very useful in this study for presenting the different categories and their relationships. A key diagram used during theoretical coding has been provided in Appendix 8.2. The coding families were considered alongside this diagram, prompting the research student to question whether the findings resembled patterns described by Glaser (1978). The coding families which seemed most appropriate to this study were the process and strategy families, which have been previously defined in this chapter. The research student then returned to the memos which had been created during earlier data analysis, focusing on memos which explored or contradicted the presence of processes or strategies in the data. For example, one memo highlighted 'navigating' cancer and online communities as an abstract concept in participants' experiences. This memo reflected a pattern similar to a process or strategy in online communities, but which was evidenced in the data. This memo has been provided in Appendix 8.1. Moreover, this memo was influential because it highlighted why online communities were significant to participants in this study. As a result, the category 'navigating cancer' was eventually rendered to a theoretical code to best represent the theoretical importance of these findings, sometimes referred to as the 'core category' (Corbin & Strauss, 1990; Glaser, 2002). Thus, theoretical coding helped to construct and describe central the story of the findings. Navigating, as the core category, will be explained in detail in the findings chapter.

4.4.2 Data saturation

Participants continued to be recruited and interviewed for this study throughout the coding process. Grounded theory has traditionally stated that

data collection and analysis will be complete once a state of 'data saturation' has been reached. Strauss and Corbin (2008) argued that this was reached when no new information for each category can be identified during the interviews. The ability for studies to reach saturation has been challenged. Critics of grounded theory have argued that no study can capture the full range of experiences with a phenomena (Bowen, 2008). The researcher's worldview would often make them sensitive to particular insights, and insensitive to others, thus other researchers exploring the phenomena may develop different categories of experience (Dey, 2004; Morse, Stern, & Corbin, 2008). However, in the present study, the data analysis involved regular consultations with a multi-disciplinary doctoral supervision team. The coding decisions, and the logic and evidence for the emerging theory was discussed in and amongst this team, and insights were offered from professionals in nursing, public health, medical law and an international cancer researcher. These actions aimed to maximise the theoretical interpretations of the data, as well as challenging, confirming and supporting the findings.

Glaser (1992) stated that data saturation will occur when the theoretical categories have been completely defined. This had an important emphasis on the theoretical categories reaching data saturation. If the study had developed a framework of findings which were descriptive rather than theoretical, it was highly likely that future interviews could discover new and undocumented experiences or descriptions of online cancer communities (Birks & Mills, 2009; Glaser & Holton, 2007). In this field, for instance, technological advancements have rapidly changed the formats of online cancer communities, and it was likely that descriptive experiences of the groups would continue to change over time. However, this study placed an emphasis on discovering the theoretical importance of using the communities. Once theoretical categories were fully developed in properties, variations, and relationship, data saturation was reached (Birks and Mills, 2009; Glaser, 1992). This meant that if any future findings should discover unique descriptions of online cancer communities, the theoretical actions and experiences would demonstrate the same underlying theory constructed in this study (Corbin & Strauss, 2008; Charmaz, 2006). Moreover, to ensure that theoretical categories were saturated, several

interviews were conducted towards the end of the data analysis period which found no new theoretical significance in behaviours. Similarly, several participants were interviewed a second time to question the resonance of the theoretical interpretation of experiences, and the research student was satisfied that data saturation had been met for this study.

4.5. Ethical concerns and considerations

This study interviewed a potentially vulnerable population; people living with and caring for people affected by cancer. Therefore it was essential that precautions were taken to ensure that participants were respected and protected from harm during all involvement in the study. This was necessary from recruitment, data collection and once the study was complete and disseminated (Beauchamp & Childress, 2001; Israel & Hay, 2006). There were also risks to the research student in face-to-face interviewing outside of the university. The ethical considerations and precautions of this study are outlined in this section.

4.5.1 Ensuring confidentiality throughout the research

Participants in this qualitative research project had the right for their identities and contact details to remain confidential (Israel & Hay, 2006; King & Horrocks, 2010). This may have prevented participants from undue harm by allowing them anonymity free from judgement. This has been referred to as the ethical practice of non-maleficence and justice (Beauchamp & Childress, 2001). In the present study there were some challenges involved with maintaining confidentiality because the research student was required to use a transcription service for several interviews. In compliance with data protection requirements, the transcription service was approved by the university and the transcriber was under an agreement to assure confidentiality of the data. Following transcription, all identifying features were removed from the transcripts, and the transcripts were only reviewed by members of the research team once they had been anonymised. Additionally, it emerged that some participants were members of small online cancer communities with unique names, and this might have made participants identifiable. Therefore the names of online communities were also removed from interview transcripts.

Due to the online and new media aspects of this research and recruitment strategy there were some interesting contemporary challenges for ethical conduct. To ensure that the interviewee's involvement in the study remained confidential, no messages were left by telephone, either voicemail or with a person who was not the participant. Emails were exchanged between the research student and participant only, and all contact details, including Skype accounts, email addresses, phone numbers and postal addresses were deleted at the end of the study period, after the summary of the research had been sent to those who requested them. The study was advertised via Twitter, but potential participants were instructed to contact the researcher privately, by email or telephone. To ensure that the research student maintained professional appearance and personal safety, they communicated only by professional channels. For example, the Skype account used to call participants was a dedicated account created for the purpose of interviewing and the emails were sent from the university affiliated address only. Similarly, the Twitter account used to advertise the research project was a professional account, used to disseminate research.

4.5.2 Data confidentiality and storage

Storage of data was adhered to according to the requirements of the University of Central Lancashire. All documentation related to the project was kept locked away in a secure filing cabinet within a locked postgraduate base room. All participants' transcripts were checked to ensure identifying features were omitted and names were replaced with pseudonyms. Where external transcription services were used, they were affiliated by the University and interview audio data were sent and received via encrypted ZIP files. Any electronic data relating to the study was stored on the University secure server which was also password protected.

4.5.3 Sensitivity and participant distress

The interview and the interview questions were not designed to cause distress or offend participants in any way. The central focus of this study concerned the experience and use of online cancer communities. In this respect, it was considered unlikely that this focus for discussion would cause distress for participants. However, the study concerned experiences centered

around a diagnosis of cancer. The information they disclosed was of a sensitive nature and there was a risk that participants could recall distressing memories. Therefore, the research student took several actions to mediate and reduce any distress expressed by participants.

It was emphasised to participants that distress or sensitivity was understandable and acceptable and could be dealt with during interviews. Discussion about sensitive issues were guided by the SAGE and THYME communications format, widely used and recommended within health communications in the UK (Connolly et al., 2010). The research student received SAGE and THYME training, and also undertook training in interviewing methods to gain appropriate communication skills to support participants. The participants of this study were also fully informed that if they wanted to stop the interview at any time, they could do so without having to give any reason.

The participants were given 48 hours to consider full information of the study before being asked to consent, and consent from participants was sought written and verbally. This information was written in a lay format and reviewed by a lay and carer advisory board, to ensure that it was understandable. Information sheets and Consent forms used in this study can be found in Appendix 5 and Appendix 6. In addition, efforts were made to develop a relationship between the research student and the participant prior to the interview. This occurred when the potential participants first contacted the researcher to indicate their interest in the study, when they were assessed for their eligibility, sent study and consent information, and when they arranged to schedule an interview. Finally, in the event that a participant expressed distress, the research student was able to provide a list of resources which the participants might have wished to refer to, including phone lines for emotional support, cancer support and contacts for local cancer support centres.

4.5.4 Safety for the research student

Interviewing by telephone or video call posed less of a threat to the research students' personal safety than interviewing face-to-face. Interviewing in homes or other locations however did provide a threat to the personal safety of the research student. Evidence has argued that the risks of interviewing in an

individual's home are strongly outweighed by the advantages of participant comfort, privacy and confidentiality (Connolly et al., 2010; Seidman, 2012). Nevertheless a buddy procedure was enacted when the research student travelled to interview a participant. This involved providing the chosen 'buddy' (a supervisor) with a sealed envelope containing the destination of the interview. The research student text the buddy before entering the interview, and when it was complete. In the event that the buddy did not hear from the research student, they could open the envelope and try to make contact with the student. The envelope was destroyed when the buddy received each text after the research student returned from interviewing. Finally, to ensure safe practice when interviewing university risk assessment guidance was followed at all times.

4.5.3 Ethical Approval

This research study obtained ethical approval from the University of Central Lancashire STEMH (Science, Technology, Engineering, Medicine and Health) Ethics Committee. The letter indicating ethical approval can be found in Appendix 11.

CHAPTER FIVE - FINDINGS

The purpose of this chapter is to present the findings of the study through the lens of a constructivist grounded theory. This chapter opens by describing the participants who took part in this study and the types of online communities that were described in the data. Following this is a brief outline of the main categories in the theory and a description of how they were inter-related, illustrated by a visual diagram. The chapter then describes each category of the theory, beginning with the core category, followed by three categories that lead from the core. The categories include subcategories which provide a rich description of the findings.

Throughout this chapter, direct quotations and anecdotes from participants are used to illustrate key findings. At the end of each quotation the text enclosed in brackets indicates the participant number, their gender, the type of cancer they had been affected by and whether they, a member of their family member, or both had been diagnosed with cancer (e.g. 1/F/Sarcoma/Diagnosed).

This chapter marks a change in writing style. For the purpose of presenting the findings, I use first person pronouns where appropriate. In line with constructivist grounded theory principles, I have recognised that all individuals involved in the data collection and analysis process shaped the resulting findings (Charmaz, 2009). For instance, the participants discussed their experiences in the interviews, the interviewer chose the aspects of experiences to follow-up on, and the data analyst selected the nuances of meaning that appeared to be important. I have played the role of interviewer and data analyst in this study. As a result, my perspectives have inextricably shaped the development of this theory. It is important to acknowledge this, in order to demonstrate my impact on the research. In accordance with grounded theory methodology, I strived to immerse myself in the experiences of the participants during the data collection and analysis to view the world as participants have described it to me. I have also used a reflexive diary and memos to reflect on the impact of my worldview by understanding my own perspectives and stance on this topic. However, my impact as a research

student was unavoidable, and so I have used first person pronouns to emphasise my interpretations in the generation of the findings.

5.1. Participants

Twenty three individuals were interviewed for this study. Seventeen were conducted by telephone, four were conducted face-to-face and two were conducted on Skype. Eight of these participants were contacted on a second occasion to ask follow-up questions and seek additional clarification. Four participants were interviewed for a second time by telephone. A further four participants chose to answer follow-up questions by email.

The online recruitment strategy for this study was very effective. I was contacted by a total of 38 individuals interested in taking part in this study, though 15 were not included in the final study as they lost contact after the initial communication, or were unable to participate in the interviews. Of the participants included in this study, 17 were recruited after seeing a study advertisement online. Five participants were recruited after seeing an advertisement at a local support group. One participant was recommended this study by word of mouth from another participant.

Approximately 27 hours of audio recorded interview data was captured for this study. The average duration of the first interview with participants was 69 minutes, with the shortest interview being 43 minutes, and the longest interview being 123 minutes. Four participants were interviewed a second time and the average duration of these recordings was 20 minutes. All audio data was transcribed and, with the text from the four email follow up answers, all data was input into the data analysis software QSR-Nvivo for analysis.

The characteristics of the study sample are presented in Table 6. The majority of participants (n=18) had accessed online communities because they themselves had been diagnosed with cancer. Two participants accessed online communities because their family member had been diagnosed with cancer. Three participants accessed online communities because of their own and a family member's cancer diagnosis.

Participants had been affected by a range of different types of cancer. The most common diagnosis was melanoma, affecting seven participants. The second and third common diagnoses were ovarian (n=6) and breast cancer (n=5). The average age of the participants was 50 years, though participants ranged in age from 31 to over 70 years. The majority of participants were female (n=19), educated to undergraduate level or higher (n=15) and married or living with a partner (18). However, the study recruited both men and women, and the sample were educated to varying degrees, from GCSE level or equivalent, to post-graduate study. No participants identified as single, and the sample were mainly white British (n=22). Narratives have been created to describe the individual participants in greater detail. These can be found in Appendix 12.

Table 6. Characteristics of the study sample (n=23)

Characteristic	No. of participants
Who had been diagnosed?	
Self	18
Family	2
Both	3
Cancer location/type	
Skin	7
Ovary	6
Breast	5
Bowel	2
Prostate	2
Brain	1
Head and Neck	1
Lung	1
Non-Hodgkin's Lymphoma	1
Pancreas	1
Sarcoma	1
Thyroid	1
Age range	
<31	0
31-40	4
41-50	8
51-60	5
61-70	5
70>	1
Gender	
Female	19
Male	4
Highest educational attainment	
GCSE or equivalent	2
A-level	1
Vocational	2
Diploma	3
Undergraduate degree	11
Postgraduate degree	4
Marital status	
Single	0
Married/co-habiting	18
Divorced	4
Widowed	1
Ethnicity	
White British	22
Other	1

5.2. Online cancer communities

Many different online communities were discussed in the interviews. Participants had used a diversity of websites that facilitated interactions between people affected by cancer. In the early stage of the interview process, I needed to understand what participants referred to as 'online communities' for cancer. For example, several participants kept online blogs which broadcast their thoughts about cancer. These blogs were open for readers to make comments. Several participants also used microblogging websites, often referred to as Twitter. This allowed participants to broadcast 120 character messages about their thoughts. The vast majority of participants talked about their experiences in online forums and social media groups (such as Facebook, Google plus or Google groups). These were referred to as 'online communities'. Participants made an important distinction between online communities and blogging and/or microblogging. Communities were characterised by regular, sustained interactions between people affected by cancer. Blogging and Twitter were used by individuals to exercise their voice but not to form online relationships with other individuals. They were not used to create a sustained dialogue between people affected by cancer. Therefore, participants gained no sense of 'community' from blogs and Twitter. The sense of a community formed an essential element of the emerging theory. Given this important distinction, I decided that blogs and microblogs would not form the focus of this grounded theory.

"I think the blog is just me putting stuff out there. I do get people tweeting or commenting on the blog ... but it's all different people... So it's less of a community. Erm, and then on Twitter, it's the same. There are some Sarcoma groups but again, it's not really a community as such, no. But I think on [online community name], you know, it's a closed group, there's only us in it, you do feel like a little group, yes." (1/F/Sarcoma/Diagnosed)

It was noted that the phrase 'online support group' was not used by the participants in this study, and several participants were critical of this phrase when I used it to refer to the groups. I had taken this phrase from research articles which likened online communities for cancer to traditional face-to-face support groups. However, participants preferred to use the terms 'community',

'group', or 'network'. A 'community' was conceptualised as a group containing members who wanted to communicate with one another. Individuals felt that they could be understood and their views valued by their fellow community members. There was an expectation that if individuals in the community posted a message, they could receive an almost instant response. Henceforth, this thesis was amended to reflect the language of participants and refer to the phenomena of online support groups as online cancer communities or groups. Another important distinction was made by participants when describing public and private communities. The public and private groups had different qualities, different atmospheres, and were used for different purposes as described below.

5.2.1 Public and private communities

Public online communities were usually referred to as forums. These were usually hosted by cancer focused charitable organisations through the charity's website. The messages posted in these forums could be viewed by anyone visiting the webpages and could be found through a Google search. To post a message, participants usually needed to create an anonymous account. However, participants still considered this type of forum as public because the content they posted was in the public domain. These forums were usually large, aimed at as many people as possible. They were used by people affected by different cancer types, nationally and internationally. Examples of the forums accessed by participants were Macmillan Cancer Care's forums, Breast Cancer Care forums and Roy Castle Lung Cancer Foundation's forums.

Alternatively, private or secret groups were almost entirely hosted on the social media site Facebook. They were protected from the public, and therefore people could not find them by searching the internet; setting up a Facebook account and becoming a 'member' was required. Participants mostly found these groups through recommendations from fellow group members. Private groups were created and maintained by people affected by cancer, rather than an organisation focused on cancer support. They were usually smaller than public forums because they had specific requirements for membership. They were often devoted to one aspect of individuals' identities, for example there were groups for specific types of cancer, or for people under 50 years of age

with cancer. In order to preserve the anonymity of participants, I have withheld the names of all private groups that were described during interviews.

There were two types of privacy settings for Facebook groups. They were either closed or secret. Closed groups could be found through a search through the social media website Facebook, but the group messages were hidden or protected from non-group members. Secret groups could only be found and entered with an invite from a current member of the group. However, many participants did not fully understand the distinction between closed and secret groups. Therefore, for simplicity, this thesis refers to all protected groups under the homogenous term 'private groups'. The forthcoming sections of this chapter, sections 5.3, 5.4, 5.5, and 5.6, largely refer more generally to online communities and do not make finer distinctions. In this case, the communities are referred to as online or virtual communities, unless it is pertinent to draw attention to specific characteristics of forums or private groups. The different types of online communities did have a significant impact on the experiences of most participants. Thus, in section 5.7 I will present in further depth how the two different types of online communities were accessed, and how they affected visitors differently.

5.3. Introduction to the substantive grounded theory

Constructivist grounded theorists have stated that a theory is a representation of the patterns in a phenomenon. This representation helps to predict how the phenomena works (Charmaz, 2006). During data collection and analysis I uncovered many interesting and original insights into online cancer communities. Using the constructivist grounded theory method, I interpreted patterns in the data. I questioned whether wider abstract processes could explain the typical experiences and the variations in experiences that emerged. I found that the participants used online communities as a tool to 'navigate' the cancer experience. The concept of 'Navigating Cancer' was conceptualised as moving around and through the challenges participants encountered as a result of being affected by cancer. Participants used online communities to chart their progress with cancer, and to map their achievements as they lived with cancer. Therefore this theory is named 'Navigating Cancer using Online Cancer Communities'. An overview of the elements of this theory is presented in section 5.3.1.

The findings in this chapter have been presented as substantive grounded theory. I sampled different members of online cancer communities, explored commonalities and differences in their experiences and continued interviewing until no new theoretical information emerged. By analysing the data with theoretical intent, I explored what online communities symbolised to people affected by cancer, and the importance of interactions with communities. As a substantive theory, these theoretical interpretations offer insight into the perceptions and behaviours of people affected by cancer in online cancer communities. However, the findings could not be generalised to other populations or other phenomena such as other types of internet websites because this current theory was grounded on the evidence of this particular population.

5.3.1 Theory overview

The theory '*Navigating Cancer using Online Cancer Communities*' is presented visually in Figure 2.1. The diagram contains a framework of four categories (one core category and three main categories) and their related subcategories. To explain the way categories interact in this theory, I have labelled them using metaphors symbolising movement. In line with constructivist grounded theory methods (Charmaz, 2009), the metaphors were derived from the language participants used during the interviews.

Firstly, the largest and brightest yellow box represents the core category entitled *navigating cancer using online cancer communities*. This serves as the predominant category that emerged from the findings. The experience of navigating cancer was central to most participants in this study. The core category served as the driving force for participants' interactions with the groups. Above the core category title are three subcategories (in white boxes). These subcategories represent the motivating conditions which led participant to navigate cancer using online cancer communities (*experiencing a 'void'; experiencing change; wanting control*). There is an additional box before the core category title which represents the subcategory which mediated people's use of online cancer communities (*Familiarity with the internet*). Therefore, this core box demonstrates from top to bottom, the reasons why individuals wanted to navigate cancer, what influenced their use of online cancer communities in particular, leading to the core experience.

The core category provides direction for the further three main categories, shown as three lighter yellow boxes; *a journey to become informed*, *a journey to recreate identity* and *a journey through different worlds*. They each represent an important set of experiences participants encountered when they navigated online communities. As the term 'journey' indicates, participants' perceptions and behaviours could change over time as they became a part of online communities. Beneath each category are subcategories, presented in bullet points. These bullet points represent different features of each journey. For example, navigating cancer with online communities led participants to *a journey to become informed* (category

one). This journey could feature three key experiences; *embarking on a learning curve, gaining empowerment, and influencing the patient/provider relationship.*

For the purpose of clarity, the categories and subcategories have been presented and described separately. In reality, the categories were dynamic and participants could experience each category simultaneously. Therefore, it is inevitable that some elements of the categories overlap. For example, in category two '*a journey to recreate identity*', there is reference to participants *becoming part of a 'tribe'*. A tribe signified a close and inclusive group of people online, and this section discusses the impact being part of a tribe had on participants' identity. The section has similar elements to category three *a journey through different worlds, in being let into intimate communities*. This latter section discusses how participants find and are allowed to enter close inclusive online communities. The topics discussed are similar, but by keeping the subcategories separate I describe, and subsequently discuss, the different nuances of the experiences that were particular to each journey within the online communities.

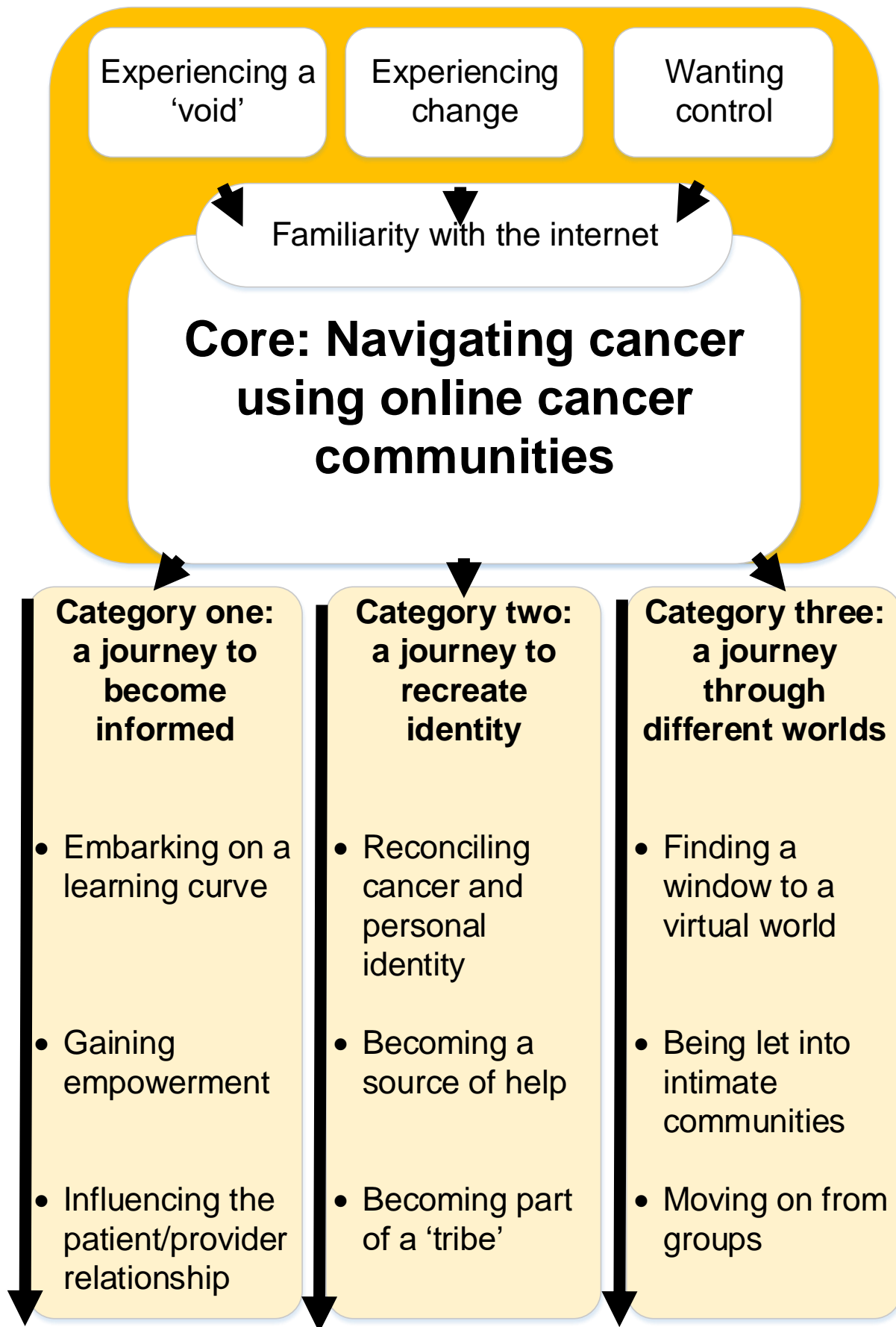


Figure 2.1 The key elements of the theory *Navigating Cancer using Online Cancer communities*

5.4. Core category: Navigating cancer using online cancer communities

At the centre of this theory was the core category entitled *navigating cancer using online cancer communities*. Navigating cancer was the key motivation for participants to seek and use online cancer communities. Navigating cancer was conceptualised as participants trying to move past particular barriers and challenges. For the majority of the participants, the cancer experience was perceived as a barrier or challenge to moving forward with their lives. Engaging with online communities was necessary because participants did not believe they had the skills or resources to move forward alone. Furthermore, online communities supported this sense of navigation, because they could be used as a tool or vehicle to travel past the challenges they faced. For many participants, the communities were a rich resource of information and support, and they enabled participants to plot changes they wanted to make, and to chart a course in their experience of cancer. Participants also navigated to different sections and different types of online communities in order to reach the support and information they required.

“...Interviewer: why were the communities so important to you?

Participant: to work out, to try and navigate our way through. Because you have to make a lot of quite big choices in a short period of time. And I think you're probably quite ill equipped to do so. I said at the time that, you know, I can spend months deciding what colour to paint my bathroom. And we were having to sort of go from one meeting to the next meeting and be making massive decisions about, about our future and so forth. And because of this big unknown in the middle, I did find it useful to kind of read about other people's experiential knowledge and how their, erm, how their sort of journey through had worked out” (17/F/Ovarian/Diagnosed)

“interviewer: why was the information you found [in online communities] so important?

Participant: well it was a combination of specifically how to navigate cancer and also the NHS and also practical stuff on what to have at home.”
(10/F/Pancreatic/Family)

The grounded theory core category acted as the organisational principle of the theory (Madill, 2008). It served to explain how the phenomena evolved for those who experience it, and this accounted for changes in perceptions or behaviours over time. A key consistent pattern in this data was the experience of movement or change. Participants experienced many instances of movement and change. For example, many participants believed their lives had moved from being stable to uncertain and unsettled after a cancer diagnosis. Several participants later moved on to finding a sense of calm through online community use. Participants also moved through communities. They found different groups as they spent more time in communities and many participants were drawn into forming relationships with the groups, or broke away from groups. These examples will be explained in more detail in this chapter, but I use them here to illustrate why I believed it was important to weave the metaphor of motion and guided movement into this theory. Furthermore, as I theoretically sampled and saturated the categories in this theory, I found that the movement could be defined into three journeys experienced by the participants using online cancer communities. These three journeys were *a journey to become informed*, *a journey to recreate identities* and *a journey through different worlds*. These journeys have been presented as three categories of this theory. A key challenge in the data analysis process was identifying the overarching principle, or core category that explained the three categories of experiences. I identified the core, *navigating cancer using online cancer communities* when I recognised that participants' movements in the communities were intentional. They steered their use of online communities based on which types of groups and interactions could improve their position with cancer. Navigating was also relevant in this context because it can be used to describe the act of moving around websites and learning to use internet technology.

Although it is usual to think of a journey as having a final destination, navigating cancer had no objective or measurable end point. Participants were particularly focused on moving away from negative experiences they encountered during their cancer pathway, or in the path they walked when caring for a family member. The experiences that motivated navigation have been described in finer detail in the subcategories to this core category. There

was no clear end to this navigation because it was guided by participants' subjective evaluation of how well they were moving past obstacles. These obstacles were sometimes, but not always, recognised medical processes and procedures. For example, several participants aimed to stop using online communities once they had reached a goal in their care and treatment pathway, such as when they stopped having biannual monitoring appointments. However, several participants had continued to use the communities after they completed active treatment, and so after the time they originally planned to leave the groups. Many participants encountered unforeseen psychological concerns after treatment was complete, such as anxiety about whether the cancer might recur. In these instances, participants evaluated these concerns, and many believed they still needed to rely on the communities to navigate these ongoing hurdles. The following quotations exemplify a participant who aimed to leave an online community based on their treatment pathway, and a participant who was past active treatment, and was using communities until he no longer felt emotionally affected by the experience of cancer.

“Interviewer: Can you see yourself continuing to use the groups in the future?”

Participant: I think I'll keep on them until I'm five years clear. So I keep getting the six months, six months, six months, until eventually, probably until then, yes. Maybe not so much but I'll definitely keep using them.” (12/M/Lung/Diagnosed)

“Interviewer: Can you see yourself continuing to use the groups in the future?”

Participant: Yes I don't know whether I'll be staying. I'm not sure whether I'll be staying in the groups forever. I mean I think I might move, well, I'm beginning to move away from it emotionally at least, as the experience of cancer is.” (2/M/Mal. Melanoma/Diagnosed)

Some participants found that online communities steered them to a position they did not want to be in with cancer. Using online communities required a very active approach to engaging with cancer information and resources. Participants' time was consumed by learning to use groups and searching through cancer related information. Many participants remarked that this kept cancer at the forefront of their mind. However, I interviewed several

participants who did not want to spend all their time focusing on cancer. They wanted to focus on other aspects of their life such as their family or hobbies. Hence, some participants used online communities for a time, but chose to move away from them to focus more time and energy on their family and friends. This concept is exemplified in the following quotation, in which the participant explains that she has temporarily left the online communities, referred to as her 'vehicle' to park the more emotional content of her cancer experience. This participant stopped navigating with online communities in order to focus on aspects of her life besides cancer. Nevertheless, she suggested that the emotional experiences of cancer sometimes had to be dealt with, and to do this she retained the option of returning to online groups. Moreover, there were participants who took a break from navigating with online communities, knowing that they could return to address particular cancer experiences.

"It's a real bugger actually because you end up dealing with life and death and all you want to do, you know, sometimes you just want to go to Tesco's, you know, do normal things and you don't want to deal with weighty issues but you know, it's the nature of having cancer and being involved in patient advocacy that [pause] and constantly going to hospitals and [pause] but, and it does become part of your life it does become become a feature and although I don't dwell on it because I'm, you know I sail my boats and I go off and I paint and I draw and do loads of great things, you know it is still something that comes up in everyday life and sometimes I have to deal with that sometimes I do need a vehicle to park the more emotional content that is that journey but I think not right now. I am focusing on other things" (5/F/Melanoma/Diagnosed)

Online communities were resources that allowed participants to navigate specific cancer experiences. I identified four key experiences which precipitated *navigating cancer using online communities*. These have been presented as subcategories of this theory. Three subcategories represented conditions which motivated participants to begin, and to continue, navigating journeys with online cancer communities. These subcategories are *experiencing a 'void'*, *experiencing change*, and *wanting control*. One additional subcategory mediated the relationship between participants being motivated to navigate

cancer, and using online cancer communities for this navigation; *familiarity with the internet.*

5.4.1 Experiencing a 'void'

Most participants acknowledged that they had been given information about their cancer when first diagnosed. However, this information had been provided at a distressing time and individuals had been unable to absorb and retain all the information. Most participants also struggled to understand the technical information they were given about different treatment and care regimes. Many participants turned to online communities when they returned home from a consultation. The communities helped to answer questions they had not asked, or had forgotten to ask, during consultations with healthcare professionals. The communities could be browsed at leisure, and participants could spend hours deciphering the meaning of medical terms and procedures. Furthermore, several participants printed information they found in the groups, allowing them to feel they had information to hand.

“Participant: It was just like, when my, like my CN [clinical nurse specialist] nurses sat down with me to tell me this before I started, it was like brain overload. It was hard to absorb all the information that they were telling you in one fell sweep. Even though my husband came with me, you know, you’re thinking, well did I interpret that right or shouldn’t I have been doing that? I know they were there to go back and ask questions again afterwards, but you felt, right I’ve got to, you know, really, really listen. As you were going through chemo, it got harder, your concentration just goes out the window. It’s like, you’re like a goldfish, it goes in and five minutes later you’ve forgotten what it was.

Interviewer: Did the communities help with that?

Participant: Yes, when you’re starting you’re asking about a different, like the different drugs and how it would be administered, how long it takes. They were some of the questions that I’d forgotten by the time I got home. ”

(13/F/Ovarian/Diagnosed)

Family members had fewer opportunities to be provided with information compared to those who had been diagnosed with cancer. Participants who were

family members struggled to have any one-on-one time with healthcare professionals. One participant, a twin sister to a woman with cancer, could not attend the healthcare consultations because she did not live geographically close to her sister. Another woman, a spouse to a man with cancer, attended consultations but reported that she did not want to ask healthcare professionals about the issues that were important to her. She believed it would have been disloyal to be given more information than her husband was willing to ask for. The family members of those with cancer perceived a gap in information provision, and they felt the internet was the only option for them to turn to.

“I could have asked him [consultant] more but I didn’t because I felt that was slightly disloyal going behind my husband’s back ...although we saw lots of health professionals of one sort or another, there weren’t that many opportunities for me to personally explore what was going to happen. And, therefore, going to various online communities seemed a sensible way. And there’s a lot of information out there” (10/F/Pancreatic/Family)

Being uninformed resulted in participants being unable to navigate cancer. Cancer was visualised as a void that participants could not move through or get around. Without information, participants did not know what course of action to take when they encountered a problem related to cancer. Participants could not make their own judgements about how to move forward because most did not fully understand their cancer, especially in relation to side effects of treatment and signs of recurrent disease. For example, many people experienced bodily reactions that they would have considered normal before cancer. However, after being diagnosed and undergoing invasive treatments, participants did not know how to react to their new body. A urine infection, for instance, could have a new and more sinister significance than before the cancer diagnosis. Participants did not know if a particular sign or symptom needed serious medical attention, or whether they should act as they would have before being diagnosed with cancer. Most participants in this study reacted to this ‘void’ by filling it with as much cancer related information as possible. They sought out different sources of information on the internet, and most commonly found online cancer communities. The communities were used to fill the ‘void’ by providing answers to questions that they currently had no

answers to. They looked for experiences reported by others and that they might encounter in the future, in order to visualise what might be in this void.

“You think 'okay where do I go from here' and this whole platform opens up of.. er like this void that you've never, this world opens up that you just think 'I've got to fill this suddenly with information'. I don't know what the hell I'm doing, I don't know what I'm up against, I don't know what it means so, that was the initial reaction...I couldn't wait to go online and then of course I scared myself half to death, looking at all the possible scenarios. Erm. I think like a lot of people in [community name] were the first hits that came up that. You know I gobbled those up and read everything I possibly could” (5/F/Melanoma/Diagnosed)

Most participants wanted experiential, tactile information such as what treatments would feel like, how their relationships would be affected and how to cope with the psychological impact of cancer. Participants believed that healthcare professionals could offer guidance for this, but they did not ‘really’ know what the experience would feel like or what was important to people affected by cancer. In addition, most participants suspected that healthcare professionals might not fully inform them about certain aspects of care and treatment or could make assumptions about what were priority needs. Participants’ believed that this was important because it could prevent them from adequately preparing for a particularly distressing or defining experience. In fact, several people found that healthcare professionals falsely assumed that certain experiences would have an emotional impact. For example, one woman reported that a doctor had assumed she would be distressed at losing her hair but this was not considered a priority in terms of importance by the participant. Hence, participants looked to people affected by cancer in communities to gain a fuller understanding of what experiences were important for people affected by cancer. They believed that people who had experienced cancer were in a better place to prepare them for the future.

“the nurse would tell you things, and I had this for radiotherapy, and the nurse would tell you something and as much as the nurse can give you advice, they don't know how it actually feels... so the Doctor said 'you will lose your hair with this' and I had long hair you see so, that's like the first thing he told me so I said

right okay. So my hair was down to here and I always had it nice and, he said erm, you will lose your hair. And I thought, oh I don't really care about that, and he was quite surprised that that was my response. And I said, oh nobody wants to be bald but if I've got to be I don't care but he thought that was the most important thing.” (1/F/Sarcoma/Diagnosed)

5.4.2 Experiencing change

Many participants expressed a sense of change, particularly a changed sense of self after the cancer diagnosis. Participants' lives and routines changed with a cancer diagnosis. Daily life suddenly centred on healthcare appointments, therapeutic treatments and other aspects of illness. Many participants also believed they needed to change their habits to promote better health, particularly by adopting a healthier diet and exercising. Other participants were also required to change their lifestyles including taking leave or retiring from work. This contributed to a feeling that cancer had caused participants lives to completely alter, and that they had become different people. Participants felt that their identities had fractured from who they had been, and they now faced a new identity. Many participants needed emotional support to move forward from these life changes. Online communities contained groups of people who were willing to offer support and guidance about how they had adapted to cancer, and this was valued by many participants in this study. For example, several participants were angry and frustrated about aspects of their lives that needed to change in response to being diagnosed and treated for cancer, such as healthy eating and leaving work or retiring early. They needed support to understand their changing priorities and to learn how to focus on certain aspects of their new life.

“I think it affects your identity quite a lot as well because it's the idea, your idea of yourself and, you know, who you are, I think can be challenged when you find out that there's quite a major medical issue that you're, that you have no idea of. And your sort of relationship between you and knowing your own body becomes quite fractured, that was quite a significant thing for me. ”
(17/F/Ovarian/Diagnosed)

“You think, I can’t do this because I’ve got cancer and I won’t be able to go on holiday because I’ve got cancer. And I’ve got to eat really, really correctly and I’ve got to, you know, I mustn’t over do things. And it just made me frustrated, I was eating food I didn’t like [laugh], I missed my chocolate [laugh]. And in the end I just thought, I’m not enjoying life, do you know what I mean?”

(6/F/Ovarian/Diagnosed)

“What some people want is just to go back to where it was before to forget all about it, but I don't think that, that's not necessarily the majority. There are some people who that's the way of dealing with it. But most of the people I've come into contact with you know do feel they've changed. They do want to change their life, they want to go in different directions they want to try different things. Things have become, certain things have become much more precious. Priorities have changed. You know, um so you, you're not the same as you were before. And that's difficult to deal with” (4/F/Non-Hodgkin Lymphoma/Diagnosed)

Participants came to understand online communities as a space to vent or exercise aspects of their personality that they needed to repress in real life. Many participants hid their new identity from friends and family. Several participants kept their cancer diagnosis a secret from all but their closest family members. Several participants notified close friends about their diagnosis, but kept their feelings about cancer to themselves. Participants kept their fears and anxieties a secret in order to protect their families. However, this compounded participants' feeling of change, because they could no longer use the support network they had relied on before cancer. Thus, participants strongly associated their new identity with cancer as isolating. Alternatively, the 'virtual' world of online communities became a place where many participants 'vented' their true feelings about cancer and were no longer isolated. Being 'virtual', this world was removed from their friends and family, and so they did not have to worry about upsetting their loved ones when they complained about cancer.

“One of the reasons that I did sort of start looking at the internet support groups because, erm, I tend to not cry in front of my husband, because he would get upset. Erm, and my friends didn’t really understand because, you know, as

much as they were there for me, none of them had been through it. And they were doing what they thought was right but, you know, there's not an awful lot that they can do to help.”(15/F/Breast/Thyroid/Both)

“It's more like a, erm, an escape environment. Sometimes you just, like your loved ones and your husband, you don't want to keep telling them the whole time that you're not feeling brilliant and whatever. Where sometimes, where it's more of a virtual, even though you've got to know very good friends and people, it's more like a virtual type of environment. That you can just let off steam and let some of like the anxiety out, knowing that you're not upsetting the people that are very, very close to you.” (13/F/Ovarian/Diagnosed)

I also interviewed three participants who asserted that cancer had not made a huge difference to their existence. These participants were not strikingly different from the rest of the sample in terms of cancer diagnosis or treatment. However, these participants referred to the cancer as 'like any other illness'. They treated the medical procedures as a necessity, but not a major barrier to their lives. These participants understood that they, unlike others, had not needed any assistance other than the readily available support of professionals and family, to move forward from the cancer diagnosis. I found there was a connection between these participants and their satisfaction with online communities. These participants had observed online communities but felt that the groups were not appropriate to them. Two participants, one with ovarian cancer and one with Hodgkin's lymphoma had worked with people affected by cancer. They both stated that these experiences had been a factor in how they addressed their own diagnosis. These participants were not shocked by the changes that cancer made in their lives, because they had seen them happen regularly to other people. A third participant with prostate cancer had been aware of his increased likelihood of developing cancer, as he had been observing rising PSA levels for a decade. These participants' attitudes toward cancer indicated that they did not need to use online communities to explore or discover a new identity. They had not felt displaced or the need to fundamentally change, having a familiarity with their condition that had accumulated over time based on previous experiences and expectations. Thus,

these participants needed no additional resources to move forward after their own cancer diagnosis.

“You realise that you can deal with it, you know, you can do it. But you don’t feel, not necessarily you feel as though the world is coming to an end. I didn’t feel that way. And I remember, I went home and I, or I phoned my wife, I said, erm, she said, how did you get on? I said, well it’s positive, I’ve got cancer. You, you come out of the hospital, nothing has changed. You’re still the same person. Buses are still going up and down the road” (8/M/Prostate/Diagnosed)

“I found that you know you can read, people like to share their stories or whatever. That didn’t help for me at all, it didn’t make it worse, didn’t make me feel I was going to die I just thought I don’t want to know that, I don’t need it. I am fine without it.” (7/F/Ovarian/Diagnosed)

5.4.3 Wanting control

Many participants associated using online communities with taking control of their lives following a diagnosis of cancer. The adjectives participants used to describe diagnosis were associated with feeling unpredictable movement; participants were in ‘freefall’, ‘a whirlwind’, a ‘rollercoaster’. Participants were keen to discover a sense of order in this perceived chaos. People living with cancer believed that the key to finding order and control was understanding the healthcare procedures they were undergoing and that they faced in the future. Similarly, families affected by cancer sought to understand and predict what their family member was experiencing, and would likely experience, so they could plan for their future. Online communities allowed participants to get involved, because they contained many other people affected by cancer willing to share the details of their experiences. Participants could draw up lists of what they might experience, and how to react if, or when, they also encountered those experiences. For example, people living with cancer could discover the potential side effects of a cancer treatment and look further at how people in online communities experienced and dealt with these side effects. For instance, a woman affected by sarcoma discovered that her chemotherapy caused her eyelashes to fall out and her eyes to water excessively, which affected her ability to drive. Following the guidance of

community members, she ensured that she carried a bottle of hydrating eye-drops and tissues with her to ease her discomfort. As the quotation below from participant 10 indicates, being able to plan for future healthcare experiences made participants feel in control.

“When I lost my eyelashes I was completely shocked, and with that your eyes constantly water, so it was at the point when I couldn't even drive because I couldn't see where I was going but I had read it on the [community name] so I constantly had eyedrops and constantly having tissues with me”(1/F/Sarcoma/Diagnosed)

*“It [using online communities] did make an impact because I felt I was sort of more in control. Rather than everything just happening and me having to react to it, I could plan for things and think about them and think of the best way”
10/F/Pancreatic/Family)*

Taking control using online communities was an intentional and active approach to the cancer experience. Taking control required participants to have a level of self-awareness about what they needed from online communities. Participants who benefitted from online communities emphasised the importance of appraising whether certain conversations, lines of enquiry or communities were benefitting or harming them. Without this appraisal, participants could become overwhelmed by the information rich communities. However, several participants did not initially have the resources to take control through the use of online communities. They spent a period of time ‘internalising’ or processing details of the diagnosis, and during this time they did not value online communities. These participants needed to accept the diagnosis before they could ask wider questions about how to navigate through the new situation. One such participant was a woman diagnosed with malignant melanoma. She discovered online communities at an early stage in her cancer journey, but chose to put aside the communities and wait until she had taken in the meaning of the diagnosis and what role it would have in her life. Until that time, she felt that she would not have been able to decipher the online communities.

“I would thoroughly recommend communities, providing people have a degree of self-awareness about, erm, what they’re looking for ... if you can take a deep breath and the times when things [in the community] go slightly astray, then you just have to put that in the context of, this amount of good, this is difficult. And then I suppose you have to decide, well, you know, do I want to, you know, do I want to change it, can I change it, do I need to change it”

(17/F/Ovarian/Diagnosed)

“I think you've got to internalise it [cancer] first and you've got to you know be able to sort of understand what you've been told because there were quite a few appointments close together sort of like, you know you went to one appointment, went to another one a week after, everything was hitting you at the same time, you know, quite quickly. So it was a lot to take in. Err, so finding a group at that point might have, you know I wasn't focusing on that I was focusing on what I was being told by the doctors really”

(16/F/Mal. Melanoma/Diagnosed)

5.4.4 Familiarity with the internet

Participants were all accustomed and familiar with using the internet long before their cancer diagnosis. Several participants had worked with information technology and all participants used the internet as part of their daily lives. Participants were also all aware of social media, though most participants did not regularly use this before the cancer diagnosis. Most participants understood what online forums were before being affected by cancer. Several participants had family members on Facebook, but had not used it before the diagnosis. Two participants had left Facebook before the diagnosis. Generally, participants believed that social media was a time consuming and trivial application. However, social media for communicating about cancer was viewed more favourably. It was perceived as having a function, which was to help people communicate about cancer. Several people joined or re-joined Facebook for the purpose of joining online cancer communities.

“Interviewer: Do you enjoy being part of the Facebook group?”

Participant: Yes [laugh], I do, I do. Erm, I wasn't actually an active Facebook user. I mean I had an account but I deactivated it back in 2007. Erm, so I only

reactivated it to join, specifically to join this group. Erm, and it is good, you know, as I say, it's helpful to be talking to people who understand what you're going through, who have been there.”(9/F/Breast/Diagnosed)

Participants believed that there was nothing unusual in referring to the internet in the face of a life threatening illness. Internet technology was an acceptable information source for participants, and in the present study this has been constructed as a mediating factor for participants turning to the internet in order to navigate cancer. The convenience of the internet meant that it was almost irresistible for participants to not search the internet for cancer related information. Participants had online access almost all day through various technology (e.g. ipads, mobile phones, laptops and desktop computers). Many participants referred to internet searching for health as 'doctor Google', and communities, particularly forums, seemed to be the most common item to be returned in a Google search. Therefore, online communities were readily available to participants. However, most participants were told by their healthcare professionals not to search the internet. The professionals had warned participants that cancer information online would be frightening and that online communities were not trustworthy. They emphasised that cancer experiences were unique to each individuals, and communities could mislead the participants because they did not contain information tailored to them. For some participants, this warning came too late; several participants found online cancer communities before they had been instructed not to look for them. Indeed, two participants found online communities before they had been given a formal diagnosis. These participants had used online communities to investigate whether their symptoms were similar to people living with cancer. Having already found communities, these participants continued to use them. In addition, several participants initially followed advice to ignore online communities, but could not resist the urge to search for other people affected by cancer in social media websites and search engines. It was described as a natural compulsion.

*“I just think it's anything that a normal woman would do in that situation.”
(7/F/Ovarian/Diagnosed).*

“If you could not access it everywhere, you would not be on there all the time (laughs).” (16/F/Mal. Melanoma/Diagnosed)

5.4.5 Summary of the core category

- ‘Navigating cancer’ was the key motivation for participants to seek and use online cancer communities. The communities were used like a tool, or vehicle, to move participants past barriers and obstacles, and towards a clearer understanding of cancer in their lives.
- Participants were driven to navigate cancer by four main experiences; *experiencing a ‘void’; experiencing change; taking control; and familiarity with the internet*. Figure 2.2 offers a recap of the relationships between this core category and subcategories.
- Cancer was perceived as a ‘void’ in participants lives, which could only be filled by gathering information about what was in the void, and how to move through it. Many participants believed that online communities were an information rich resource.
- Cancer caused many changes in participants’ lives and identity. Online communities were used as a place to express this new identity, and to understand holistically how to live as a person affected by cancer.
- Online communities allowed participants to take control over the experience of cancer. This required an active approach to cancer and the associated healthcare procedures.
- This sample of participants were well acquainted and comfortable using the internet. Moreover, they found it almost impossible not to use the internet in their cancer experience. This outlook mediated participants’ use of online communities as a resource to navigate cancer.

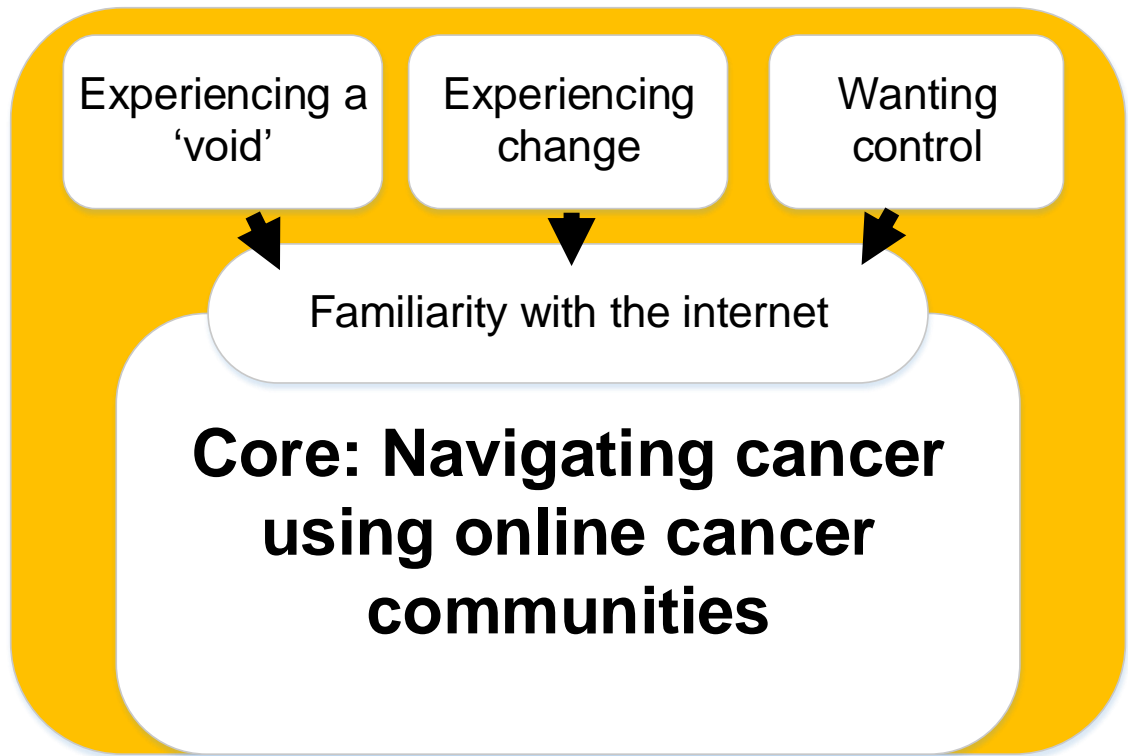


Figure 2.2 Recap of the core category *Navigating cancer using online cancer communities*

5.5 Category one: A journey to become informed

The core category, *navigating cancer using online cancer communities*, was described in the previous section. This section will now outline the first of three categories which represent the experience of 'journeys' in the data. These categories lead from the core category; participants' navigation with cancer led to three journeys with online cancer communities. This current section explains how people affected by cancer could become informed through online cancer communities. This experience formed a journey because most participants' intention was to use the groups to move from being in a position of limited knowledge, to become more fully informed.

"Interviewer: Did you use the online forums differently before compared to how you do now?"

Participant: Probably before it was more in the sense of, I'm not coping, what do I do, you know, messages like that, or oh my god, you know, does anybody know what happens for this? Whereas now I, you know, I'm a little bit more informed. Erm, I wouldn't say I know everything but I'm definitely more informed. I know where to get the information. And I can go on the group and get information from them." (16/F/Mal. Melanoma/Diagnosed)

Becoming informed was a process because most participants took steps to assimilate and use the huge wealth of information available within groups. Moreover, the information that participants needed to acquire changed over time. This was because participants accessed online communities for information as and when concerns arose. These concerns about cancer changed as their cancer pathway altered. Therefore, participants could pinpoint when and where on the journey they had needed specific knowledge. Some participants affected change in their cancer experience as a result of the information they found online. These participants could chart when they had needed and acquired information to enhance learning, and the ways that communities directly affected their treatment plan. One such example is given in the quotation below in which a woman affected by melanoma described discovering that she had choices about which healthcare professionals she could be treated by. In this example, becoming more informed actively changed her journey with cancer because she went on to change her treatment centre. Participants also recalled being preoccupied by

different topics at different time-points and found that over time their focus of interest changed. This was attested in the quotation below from a woman affected by Non-Hodgkin Lymphoma. This participant had once been interested in gaining information about the treatments she was undertaking, but later as her cancer pathways altered, looked into communities for information concerning exercise and cancer. The communities could be used flexibly for many different types of information, and so most participants travelled with the groups during their cancer trajectory.

“I've learnt so much about what to ask for, and things like, you know, like I say the doctors don't always tell you stuff and so I've [pause] you learn a lot from other people's experiences, like one of the main one of the main things that I've learned on this journey is that, you know you don't have to be treated by a certain person or at a certain hospital if you don't want to be. And I never, I never would've know that without erm, you know known it without this community” (3/F/Mal. Melanoma/Diagnosed)

“I think people, as they you know, as they continue on their cancer journey they may start to get interest in particular aspects of their life, or particular things that they might like to do “ (4/F/Non-Hodgkin Lymphoma/Diagnosed)

By becoming more informed about cancer, participants aimed to address and navigate away from the feelings described as *experiencing a void* in the core category. Not fully understanding cancer had been associated with anxiety and confusion. Most participants who were able to fill the void in their knowledge by acquiring information had found that their emotional experience of cancer improved. They felt calmer and more in control. Furthermore, participants tracked their informational journey in online communities according to the way it soothed their emotional experience of cancer.

“Being prepared and informed, [pause] you're not scrabbling around thinking, of god what do I do and then googling things and diagnosing yourself with another terminal illness, and then finding out you need to go to A and E [Accident and Emergency department]. Do you know what I mean, or phone your, phone your chemo nurse and stuff”(1/F/Sarcoma/Diagnosed)

Becoming informed was a subjective experience, and so naturally the length of this journey varied between participants. Nevertheless, I found some trends in how much information was required to feel informed. Participants who were family to a person with a cancer diagnosis seemed to feel informed with less information than people affected by their own diagnosis. Family members were inclined to focus on the scheduled cancer pathway when they looked for information. These participants searched for information directly related to what they had been told by healthcare professionals, or the information they had received from their family member. For example, family members often focused on online community messages that contained information about the specific type of cancer and the scheduled treatments. Participants affected by their own diagnosis also needed this information, and additionally asked hypothetical questions about the illness and potential alternative treatments. These latter participants used communities to explore what could go wrong in their cancer pathway, and how they might cope in that eventuality. For example, many participants had wanted to know about possible potential side effects of treatments before they experienced them. Thus, it seemed that people affected by their own cancer needed more complete information to feel informed than families affected by cancer. Indeed, this was expressed by a participant who had used communities for both her own and her mother's cancer diagnosis.

“Interviewer: was there a difference in the way you were looking at forums for your mum and forums for your diagnosis?”

Participant: I think there was something with the other diagnosis that I was much, much more ready to trust that the doctors would know what they were doing. Erm, so when, once I decided what type of thyroid cancer my mum had and what treatments were likely to happen to her, I didn't then really worry about, I didn't even think about side effects and all that good stuff. It just didn't cross my mind. I just, you know, I was concerned about the fact, she'd got this and they were going to treat it. How were they going to treat it? Great, so that's what's going to happen. Whereas for myself, almost all of the stuff that you're looking for is, so what's the worst thing that could happen? What are the side effects with this? Why haven't I been offered this? Erm, is there nothing they can do that's less intrusive or, erm, you know. It's all about side effects and

cosmetic effects and all that good stuff. Whereas for my mum, I just wanted to know, what's going to happen, OK let's get on with it."

(15/F/Breast/Thyroid/Both)

However, there was information family members sought that people affected by their own diagnosis usually avoided. In particular, information about death and dying had been very important to family members interviewed for this study. People affected by their own diagnosis tended to avoid this information and conversations that arose about dying. To become informed as a family member affected by cancer, participants needed to prepare for what might happen at end of life and how to act effectively as a carer. Family member participants were also focused on ensuring they were available to meet their families' needs in the final moments. Alternatively, to be informed as a person with a cancer diagnosis, participants preferred to focus on information that could help survival, such as potential treatments and clinical trials. Therefore, online conversations about dying were rare, and participants living with cancer stated that these topics were usually left unspoken until somebody became very ill or died. The following quotations demonstrate these two differing needs, firstly from a family member affected by cancer and secondly a participant living with cancer.

"She [sister diagnosed with cancer] was much more interested in living than she was about dying. It was me that was concerned about the dying part of it. I'm one of these people who always plans way ahead. And, err, so I was just, err, supporting her with information as much as I could and helping her make decisions about treatments. And understanding what tests were for and what results meant and that sort of thing. Err, but on my own I was looking into, down the road, how to help when we get to this other bit. And I just didn't know how far down the road it was, none of us expected her to last five years ... so the end of life issues were particularly helpful for me on that brain tumour, erm, forum, and it directed me into, you know, other sites, which dealt with end of life issues and what dying looked like and felt like. And what to expect and how to deal with it" (14/F/Brain/Family)

"They say that they're on borrowed time, you know, so I know they think like that as well. I don't think anyone actually puts it straight out in words, not

unless, erm, it's like I said, my friend, who unfortunately lost her fight. And, erm, she did say, you know, just before the, when it got really bad and she obviously knew it wasn't going to last, she did comment sort of, she wouldn't see her sons leave school and join, grow up and leave school.” (6/F/Ovarian/Diagnosed)

Not all participants were able to find the information they needed through online communities. Busy online cancer communities contained extensive information from group members who shared frank and detailed messages about their cancer experiences. Members also signposted to other information resources. However, participants found that messages about rarer cancer diagnoses and more unusual treatment plans were more difficult to find. Two participants were disappointed to find no relevant messages for their particular experiences. One participant had been diagnosed with a rarer form of ovarian cancer, of which she believed there was relatively little information available to enhance her understanding. The other participant had what she believed to be a rare treatment plan for her type of breast cancer. These two participants had specific questions about their prognosis, risks, and side effects. They were unable to find answers to these questions, because they could not locate community members with access to the specific information that was suited to them in terms of diagnosis and treatment plans. The latter participant believed that online communities could not help people affected by more uncommon cancers. As a result, both participants stopped searching for information in communities, effectively stepping off this information focused journey.

“There are questions that I wanted the answers to. Erm you know what what about the non-invasive implants that I've got. Has anyone got any experience of these? and what's happened has anybody died from this. And it's all little questions that I wanted the answers to that I feel like I never got.” (7/F/Ovarian/Diagnosed)

“I still think it's, as I say, a great tool, erm, for people who are going through more common routes. Erm, but I think, as with any of these support things, if you're slightly out of the ordinary, it can actually make you feel worse for not being the same as everybody else.” (15/F/Breast/Thyroid/Both)

The following subcategories present three main experiences of people affected by cancer on the *journey to become informed*. The subcategories detail how people used information, and what the journey to become informed felt like in the subcategory *embarking on a learning curve*, and *gaining empowerment*. They also highlight how online communities facilitated change in the lives of people who were able to become informed across *gaining empowerment*, and *influencing the patient/provider relationship*. A final section summarises this journey, and recaps the relationship between category one and the subcategories.

5.5.1 Embarking on a learning curve

Becoming informed by using online communities was described as 'a learning curve'. Most participants perceived that a large body of complex information existed in online communities but it was a steep and difficult task to acquire the information. Participants' knowledge base needed to be built from small bite sized pieces of information and simple facts, accumulating to build a knowledge base on more complex topics. There were several features of online communities that perpetuated this feeling of a learning curve, and allowed people to travel up the curve over time. These are explored below.

Online communities contained messages with many different facts, experiences and opinions about cancer. In the words of one participant, 'the world of cancer' seemed to be available upon first entering communities. This vast world stood in stark contrast to the participant's own limited knowledge, making the task of learning seem like a steep curve to climb. Each participant faced a personal and subjective learning curve. The curve consisted of information each participant believed they needed in order to navigate cancer. This could include technical information about cancer treatments, pathways and prognoses. It could also include information about emotional coping strategies and psychological support methods. Some participants focused on learning factual information, or coping, or both. It seemed that participants with more complex treatment plans and uncommon cancer diagnoses tended to closely focus on learning factual information. For example, a participant with an uncommon and life threatening form of breast cancer used communities to acquire specialist information about her cancer treatments. Similarly, a spouse to a man with late stage metastatic melanoma used communities to acquire information on alternative treatments for his cancer. Participants with less complex diagnoses tended to focus on coping method discussions in online communities. For example, a participant with early stage breast cancer used communities to discover how to control her anxiety. Similarly, several participants with melanoma explored coping methods for 'melanoia', a paranoia that melanoma has returned. Despite the content of the learning curve, participants evaluated this process as a monumental task.

“You ask me how has cancer affected my life? The learning curve you go through when you are looking at the group, in terms of what's going to happen to you and what path treatment takes that sort of thing ... it's a sort of like an ever escalating process shall we say” (3/F/Mal.Melanoma/Diagnosed)

“You do want to, to learn from others, you can learn a lot from other's experience, what to expect and that sort of thing.” (8/M/Prostate/Diagnosed)

A learning curve was evident in the way participants processed the information in online communities. Most participants chose to restrict the pace and amount of information they acquired. They structured their learning to take on information in a step by step, incremental process. In the early steps of this process, participants needed to learn the language and medical terminology used in online messages. For example, a participant affected by ovarian cancer found that messages often used phrases that she did not understand. By researching key words and phrases in online messages, participants became acquainted with the language that was commonly used by people affected by a similar cancer diagnosis. Learning these key and essential elements of the discussions allowed individuals to go forward and conduct wider research about their cancer diagnosis. In the instance recalled by the participant living with ovarian cancer, she moved forward to learn about specific blood test readings, and why these were important after chemotherapy. In this respect, online communities were used like a reference library. Participants built their knowledge from small manageable details, to gain knowledge of more complex subject areas.

“[describing messages] There's all words and new phrases, that a year ago, I wouldn't have known what my neutropenia reading would be and all these different things. And what the CA125 is. It's quite a learning curve.” (13/F/Ovarian/Diagnosed)

“I am quite good at just rummaging around and trying to sift out the information from these networking type sites. I tend to use the internet like I would do a library. You sort of go in and find something and then you check in the notes in the back and you might find something else [laugh].” (17/F/Ovarian/Diagnosed)

The design of online communities supported an incremental style of learning. Forums in particular had specific rooms (or 'threads') for different types of cancers, diagnostic stages and treatments. Participants' first step onto the learning curve was marked when individuals recognised rooms that were of direct relevance to them. In groups that were not delineated into rooms, participants needed to identify other group members who could offer the most appropriate information. Participants then plucked out information that could help them, ignoring extraneous facts and details. Participants often found information which was out of the scope of their own diagnostic stage. For example, participants in stages one or two of malignant melanoma did not want to see messages written by people diagnosed with later stage disease. The majority of participants concentrated on information relevant to 'the here and now'; the most current and pertinent details of the cancer diagnosis. They were often guided by the information they had been given by healthcare professionals, such as the name of the cancer or treatments. Furthermore, when participants received new information about their cancer care plan, they allowed themselves to take another step on the learning curve.

"If you're erm if you're diagnosed with cancer obviously you need to know what's going to happen immediately so you need information about all sorts of treatment and what - just what's going to happen as you jump, well hopefully people don't, but if you are unfortunate to go from stage 1 to stage 2 to stage 3 to stage 4 [pause] there is no stage 5, you need information as you go"
(5/F/Mal. Melanoma/Diagnosed)

"With me I sort of researched a certain amount and got as far as I did with that and then would stop because, the rest of it isn't isn't really always so meaningful" (3/F/Mal. Melanoma/Diagnosed)

When participants were in the early stages of a learning curve, they were often unsure what information was relevant or irrelevant to them. As a result, most participants initially focused on the information they had been given by healthcare professionals, or received from family members. Participants were keen to gain a balance between being well informed and being overwhelmed by information. The key to achieving this balance was pre-empting what

information should be focused on, and when to step away from irrelevant conversations and threads. However, I interviewed several participants who had been unable to find this balance. They had become obsessive when collecting extensive information about cancer, and preoccupied with filling the information void. As a result, these participants learnt about potential side effects and experiences that they later found to be irrelevant to their own experience. For example, whilst one participant was undergoing surgery for breast cancer she researched side effects she might experience later when treated with hormone therapy. She focused on the most negative experiences posted to communities, and became anxious and frightened about what she would experience in the future. She also later regretted that she had wasted so much time ‘over-preparing’ for her cancer.

“Erm, I just could not get enough information. I just wanted to keep, when I just got, just after being diagnosed and whatever, I just felt I had to throw myself in. I wanted to know loads and loads of stuff.” (6/F/Ovarian/Diagnosed)

“I think the one thing I’d sort of, you know, go back and speak to myself five months ago, six months ago, before I started looking in the forums, erm, is that it’s, I don’t think there is a way to do it. But not to try to find every single answer and work out every single scenario by going on and looking at what other people have said. Because, erm, a lot of what happened to me, erm, was nothing like what I was reading on the forums. ” (15/F/Breast/Thyroid/Both)

Participants implicitly learnt about cancer through online communities. Searching for relevant threads, messages and people required a thorough exploration of online forums. Participants described this process as ‘sifting’ ‘trawling’ and ‘ploughing’ through the communities. As participants sifted out the irrelevant sections of the community, they were implicitly learning about what did not relate to them. In some cases, participants accidentally picked up pieces of information which were wholly irrelevant to them. For example, several participants described online discussions detailing how to claim life insurance after cancer, but these participants did not have life insurance. In other cases, participants had absorbed information that became important at a later date when their situation changed and they experienced a different part of the cancer

journey. Despite not intending to learn about cancer progression, several participants found that they acquired information on this subject that enhanced their knowledge and was useful at a later date when their cancer recurred or progressed.

“Sometimes you don’t need it yourself and you just look at it. And I think, in your own little mind, the same as when at school, you’re told hundreds and hundreds of things, you don’t really listen. But when it comes to the exam, you suddenly find that bit of knowledge in the back of your brain.”

(6/F/Ovarian/Diagnosed)

5.5.2 Gaining empowerment

Participants gained a sense of empowerment as they became more informed by using online communities. Empowerment was a complex notion that was driven by *wanting control*, and influenced by feelings of *experiencing a void*, and *experiencing change* as outlined in the core category. Participants associated becoming empowered with the ability to be an agent in their own experience of cancer. I found a number of instances where unique features of online communities made participants feel more active and in control of their healthcare after being diagnosed with cancer.

Online discussions in relation to coping with cancer were largely empowering. Gaining knowledge on how to cope with side effects of treatment and other aspects of care provided participants with the tools to handle difficult situations as they arose. For example, a participant caring for her husband with terminal cancer made a list of tips other people had found helpful when caring for a dying family member. A specific example included the use of a children’s toothbrush and pineapple juice to clean her partner’s teeth when he was unable to care for his own oral hygiene. Creating this list, and having it to hand, gave this participant focus and allowed her to feel in control as her husband’s health declined.

“I certainly needed to know, I wanted to know what was going to happen and I wanted to know how to cope with it. So this particular lady [on the community] whose, erm, I think it was her father had died of pancreatic cancer, she included the most useful stuff. Everything to do with, you know, get a child’s toothbrush

in so you can offer them mouth care and this, that and the other, you know, all sorts of tips.

Interviewer: You picked this up by reading the forums?

Participant: Absolutely, in fact, I printed it off. And I went through the list and a month before he died, I made sure in the house I had the things that she had suggested, or access to them. And a lot of them were very useful”

(10/F/Pancreatic/Family)

Online communities encouraged and affirmed participants' practices of self-care. Most participants valued discussions which included many different tips for coping, even if the tips were contradictory. Participants selected the advice that best suited their needs and preferences. In this trial and error fashion, participants developed a sense of what was best suited for their personal needs. For example, a participant with ovarian cancer discussed messages about coping with an itching scalp after hair loss from chemotherapy. This participant presented her way of coping to the group and was supported by other group members. Similarly, she expected group members reading the messages to decide which particular methods and advice might work for them. The support of other group members seemed to give participants the confidence to form opinions about what they wanted and how to care for themselves.

“There’s a prime example at the moment. There’s a lady on there, her hair is growing back and she’s got, her head’s gone very, very sore. Erm, I was the same as her, my head actually went very, very sore when my hair grew back. And mine was more itchy than anything, more than sore. Erm, then there’s other ladies had it more when their hair was falling out, they had the soreness and the pain. And, you know, we’ve been talking, you know, chatting how we’ve dealt with it. Like I’ve put Aloe Vera gel onto my head to help cool it and soothe it. Yes, sometimes it’s just trial and error whether things work, but you get to know that you can choose, you know what works for you ... it’s up to the person whether they use what you post or not.”(13/F/Ovarian/Diagnosed)

“You could share that online with people about ways you had coped and what you’d achieved. And the response was always very, very supportive, you know

people would say you know that's really good, well done and things like that. So erm, I, you know, I felt it was very erm, confidence building you know and erm, yes supportive, concerning people and affirming people” (4/F/Non-Hodgkin Lymphoma/Diagnosed)

Seeking out information enabled participants to play a more active role in their cancer care. Online communities were particularly valued as an information source because they projected the impression that they were ‘at the cutting edge of information’. Participants were particularly impressed by the international cancer care news and clinical trials updates which were shared amongst group members. Several participants came across information that they perceived their own healthcare teams were unaware of. This was empowering because participants believed that by having this resource, they as individuals could be instrumental in finding answers for their future cancer care. Participants with later stage cancer found this aspect of online communities particularly comforting. They hoped they might be able to obtain information crucial to their own survival through messages about new scientific advancements and new clinical trials.

“It's all just information about what is happening in the world of melanoma in America and of course that's where a lot of our, the drug research comes from which is keeping people like me alive. So, you know it's been an incredible tool for me” (5/F/Mal. Melanoma/Diagnosed)

“There are very few options left for me. And if the chemo I'm having at the moment isn't working, then it's about knowing what my options might be. And so you're looking [on communities] and thinking, oh I've not heard of that drug before, when somebody's talking about what regime they're on. So you can go away and look it up” (11/F/Bowel/Mal. Melanoma/Both)

Participants were empowered by talking in detail about their cancer diagnosis and treatments with another person. For example, one participant, affected by an aggressive form of breast cancer, wanted to engage in a detailed discussion about the treatment plan proposed for her particular cancer type. She searched online communities and found group members who could provide relevant specialist information. This participant found that she was more

satisfied with her professional proposed treatment plan once she had the opportunity to discuss treatment options with a member of an online community. The fellow group member actually disagreed with the participant's recommended treatment, but the participant decided to accept the treatment plan that had been proposed by her healthcare professional. What was important for the participant was that she was able to discuss what concerned her and debate the issues with another person who spoke from an informed position before making any final treatment decisions.

"I talked about that [cancer treatment] with this lady [online]. Erm, I think, you know, she wouldn't have done that herself but she, you know, having a discussion with her, discussed it with my doctor again, erm, I understood his position and I didn't kind of seek a second opinion or anything. So that's the, you know, I went with him on that, on that, erm, on that occasion. But I felt that I'd made that decision on a much more informed basis. And we kind of, you know, worked it through and talked it through and I haven't just, I'm not the sort of person who just wants to kind of blindly, erm, follow a process without understanding why I'm going through it." (9/F/Breast/Diagnosed)

Online forums were often linked to specialist phone-lines which allowed participants to communicate with specialist nurses. Several participants used these phone lines to complement the information they acquired from communities. These telephone conversations also built participants' confidence which enabled them to engage in more detailed discussions with healthcare professionals. Participants wanted to verify information they had picked up in community conversations. Several participants felt empowered by their conversations with the independent specialists, because these experts assured participants that the information they had found was valid, or directed them to further information sources. Conversations with specialist nurses were also an opportunity to have an informal practice of the conversations participants wanted to have with healthcare professionals. However, the phone-lines described by participants were only available for limited daytime hours. Participants commonly described using online communities in the evening or during the night. Questions about cancer occurred to participants in unsociable hours 'when the house was quiet' because they had uninterrupted time to think

about their cancer. Moreover, at this time participants could not access the phone-lines for cancer specialists, and this was disappointing to the participants.

“Participant: I did have a conversation with one of the nurses on the helpline at [Bowel cancer charity with forum], particularly about what other treatments there might be.

Interviewer: Was that because you picked something up in the forum?

Participant: Yes that was because there were names of other drugs that I hadn't had and I didn't know as much about. And I, yes so we kind of went through a list of, you know, what other drugs there might be and where the information was on their website. And then I was able to go to my next oncology appointment with a list of drugs saying, well I haven't had these. Erm, and it was helpful to be prepared then to talk to the oncologist about options.”

(11/F/Bowel/Mal. Melanoma/Both)

“I mean what I will say is that obviously you've got helplines and then you've got erm [charity name] but they do close at 8 o'clock at night ... I did use the advice line, phone, but it shuts at 8 so obviously if you want it if you want that information or if you want somebody to talk to then you know I would I will search it online” (7/F/Ovarian/Diagnosed)

5.5.3 Influencing the patient/provider relationship

Information from online communities shaped many participants' relationships with healthcare professionals. This section has similar features to the previous subcategory *gaining empowerment* as the influence of information allowed participants to take greater involvement in their healthcare. However, the patient/provider relationship was particularly important to the participants of this study because they felt reliant on healthcare professionals for cancer care and, as several participants emphasised, for their survival. To emphasise the participants' perceived importance of online community use to influence the patient/provider relationship, I have presented these interactions as an independent subcategory. This allows presentation of the nuances of participants' behaviours within online communities that specifically influenced the relationship between participants and healthcare professionals.

Participants used information gained from online communities to be more alert and aware during healthcare consultations. Many participants were acutely aware of the precious and limited time they had available for discussion in healthcare appointments. In addition, they perceived themselves to be uninformed and overwhelmed at the outset, struggling to think of questions to ask healthcare professionals during the short time they had available during scheduled appointments. Most participants believed that if they already had a foundation of knowledge and understood the concepts that were being discussed by healthcare professionals, they could participate more fully in consultations. Online communities provided the means to discover this foundation of knowledge. Group members shared their experiences of healthcare professional interactions, and highlighted important information that had been useful to them when attending consultations. They also made suggestions as to what questions to ask during appointments, and shared their views on the information they wished they had acquired prior to consultations.

“If I'm already understanding what they're going to say and some of the terminology, that's helpful. Because it's not it's not all brand new to me, so I don't have to deal with the emotional side of what they're telling me, as well as the practical side, the practicalities. And then I feel like I'm in a better place to ask questions, or they don't have to maybe waste time repeating stuff that I already know.”(3/F/Mal. Melanoma/Diagnosed)

Many participants used online communities to demonstrate to healthcare professionals that they were well informed and equipped to deal with more complex information. Participants perceived that healthcare professionals were adopting a paternalistic attitude and were concerned that patients would be overwhelmed by too much detailed information. As a result, many participants believed that they were only provided with a limited amount of information. However, most participants were keen to acquire as much information as possible. Furthermore, the majority of participants highly respected healthcare professionals' opinions about cancer care and treatments and wanted more in-depth conversations. To generate such conversations, participants needed to persuade nurses and doctors that they could cope with in-depth information. They proved this by revealing their online community use and their level of

knowledge. By continually seeking information and going back to healthcare professionals to ask questions, some participants prompted a more sustained dialogue. For example, one woman opened up conversations about clinical trials with her consultant surgeon, who she perceived had assumed that she would not want to know about trials. By expressing her knowledge and sharing the information she had acquired from online communities, this participant engaged in a more productive discussion. Several participants influenced their patient/provider relationships in this way, and most participants were pleased with the changes they exacted over time.

“I think by the end, certainly by the end of, the process, the relationship I had with the surgeon was very different to the one I had at the beginning. I think I was very unsure at the beginning. Mind you, you know, I did not even know what was wrong with me really. Erm, but by the time I had my surgery in August I think we, the support that I’d had and the knowledge that I’d gained, the process I’d gone through, meant that I was much more comfortable and confident with him. And we, you know, I think we’ve got a really good relationship actually and very open and frank and able to talk to him quite well.”
(9/F/Breast/Diagnosed)

“My surgeon was quite good. He did eventually understand that I meant when I said that I want information.” (17/F/Ovarian/Diagnosed)

“The doctors don't necessarily voluntarily offer lots of information because they probably think well a lot of it might not happen. I did say to my doctor you know, why didn't you tell me about this? And he went, because it doesn't happen to everybody. and it may not have happened, and then he said but I know you're someone that wants to know all the possibilities so at least you're prepared”
(1/F/Sarcoma/Diagnosed)

Family members of people affected by cancer had fewer opportunities to obtain information from healthcare teams. The family member participants interviewed in this study had very little one-to-one time with healthcare professionals. Nevertheless, these participants had burning questions that they wanted to ask healthcare professionals privately. For example, two participants wanted to understand how to identify signs that their family member was dying.

This information would allow them to be effective carers and be with their family member in the last days or hours. However, the participants were only in contact with medical consultants and nurses in the presence of the family member, and could not speak about their family members' potential death in their presence. One participant highlighted that the only alone time she had with a healthcare professional was the short time when accompanying a nurse to her car after a home consultation. These participants could not influence, nor create a relationship where this conversation could take place. Thus, online communities became a vital source of information and support, particularly in relation to death and dying.

“We also had an NHS Macmillan Nurse, who started coming probably about a month and a half after the diagnosis. And came every week then up until the point of him dying. And she was superb and very helpful to us both. And I wasn't able to, I mean it was difficult, I couldn't always ask her personal stuff because we [participant and husband] were seen together, you know. So the only moment that I got to talk to her personally was as I escorted her out of the house to her car. Erm, but she was very helpful to both of us. District Nurses didn't really get involved until the last three weeks. And they were sort of, they were functionally helpful, practically helpful, but they didn't provide information.”
(10/F/Pancreatic/Family)

Online communities gave participants a tool by which to compare their experiences of care, clinicians, and treatment centres with other group members experiences. Several participants utilised this, and primarily focused on whether they were receiving compassionate care and being well informed by their healthcare team. Several participants realised after reading messages from the groups that they could become more informed and receive more compassion with different professionals or at different cancer centres. These participants became dissatisfied with the professionals caring for them. Several participants went on to research how to change the healthcare professionals who primarily treated them. Participants engineered a move to the same clinicians or cancer centres as their fellow group members, or alternatively sought a referral to other healthcare professionals.

“I wasn’t happy with my local hospital where I’ve been, where I was treated for various treatments and some other people were talking on their on their on the forum about how how great their doctor and you know this person was and that person was, and I’m thinking you know well hmm, you know I don’t really [pause] I’m not really having the same experience. So armed with that knowledge then I then went back to the internet and researched you know, like NHS patient choice so something and read a bit more about it erm, and then went back to the GP and sort of said look you know I’m not entirely happy can I be referred to... there’s basically a cancer site of excellence. So I have been referred now to the [hospital] in [city] which is a which is a definitely a centre of excellence for you know cancer treatment” (3/F/Mal. Melanoma/Diagnosed)

The vast majority of participants in this study were happy to work with healthcare professionals to make shared decisions about their care and treatment. However, I also found one case in which a participant found she could undermine medical processes by using online communities. A participant taking part in a clinical trial used online communities to un-blind herself and discover which arm of the trial she had been allocated to. She sought other group members who were taking part in the same trial, and engaged in speculative discussions about which arm they had been allocated (placebo or experimental). This participant was aware that this type of interaction would weaken the rigor of the clinical trial, but she feared she would die if she had been allocated the placebo arm. At the time of interview, this participant aimed to research how to obtain further treatment, should she be allocated to the placebo arm of the trial. On one hand, this case was unique amongst the interviews and so it may represent a particularly rare behaviour with online communities. On the other hand, I felt this was a poignant example of how people affected by cancer can use online communities to question and alter their prescribed care.

“What we can do as patients is if we club together we’ve realised as a group, if we online, pool our um symptoms, and our experiences when we are on clinical trials we can effectively unblind ourselves as to what is going on. And actually access and share information about the results of the clinical trial. Even before the scientists get their hands on it.” (5/F/Melanoma/Diagnosed)

5.5.4 Summary of category one

- *A journey to become informed* was characterised by three key subcategories; *embarking on a learning curve*; *gaining empowerment*; and *influencing the patient/professional relationship*. Figure 2.3 visually recaps the relationship between this category and the subcategories.
- Participants used online cancer communities to move from being in a position limited understanding about cancer, to become informed.
- Participants accumulated knowledge about cancer when they used online communities. They could take in information in a step by step process.
- Knowledge empowered people to engage in healthcare decision-making and gave participants confidence to have more in-depth discussions with their healthcare team.
- Individuals were keenly motivated to fill a perceived void in information, and so could become over prepared if they collected too much information.
- By making comparisons with other online group members, participants could make changes to their care, healthcare professionals and location of care.

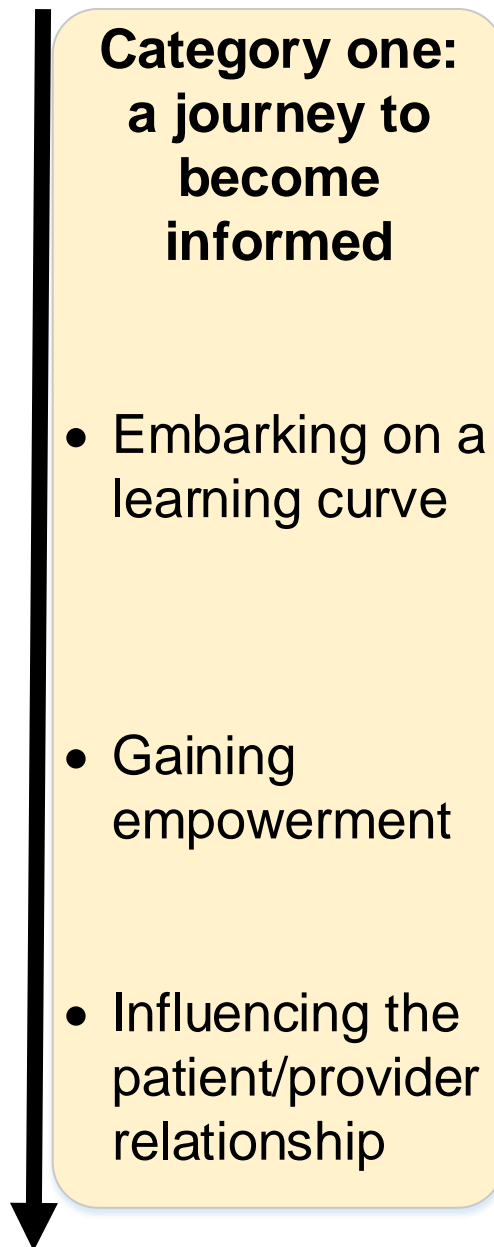


Figure 2.3 Recap of category one *a journey to become informed*

5.6. Category two: A journey to recreate identity

This section will now outline the second of three categories which represent the experience of ‘journeys’ in the data. This category highlights a journey in which participants recreated a sense of personal identity by using online cancer communities. Like the previous category, this experience leads from the core category *navigating cancer using online cancer communities*. In particular, this category stemmed from the feelings described in the core category of ‘experiencing change’. Participants used online communities to address the disparity they felt between their identity before cancer, and their lives following the cancer diagnosis. Online communities allowed participants to assert aspects of their personality that had been important before cancer, such as being in control. They also allowed participants to adapt their identity to suit the demands of their new lives. For participants living with cancer, this journey often involved making sense of their new self with cancer, and moving on to recreate a vision of their future. For families affected by cancer, this involved understanding how the roles they had previously had, such as spouse, daughter or sister, might change in light of the cancer diagnosis.

“I started, using the social media, the sites to try and work out, to try and make sense of my own feelings.” (17/F/Ovarian/Diagnosed)

“That was always my job as the, I was always the twin that perked her [sister with cancer] up when she was low, you know, right from being babies. We were sat on opposite ends of the pram and I could make her laugh. My parents tell me all the time that I would, I was always making her laugh. And that was just my job, so the forum helped me do that, keep her smiling.” (14/F/Brain/Family)

This experience formed a journey firstly because many participants’ identities altered through several consecutive interactions with the communities. Secondly, recreating an identity relied on participants connecting with other members of the online communities. Participants could look to group members to understand the beliefs, customs and experiences of ‘people affected by cancer’. In the earlier steps of the journey, participants gained a new ‘normal’ that was ingrained in the customs of the online communities they used. For many participants, this reliance on online communities could progress to make the

groups central to participants' lives. Moreover, participants looking back on this journey associated it with moving their lives from feeling abnormal and isolated, to becoming well-connected and supported.

"To summarise it was from isolation to European connection, well worldwide connection, through online resources" 5/F/Mal. Melanoma/Diagnosed)

"There's people from all walks of life, all ages, all over the country ... You meet older people, you meet younger people, but you meet everyone in all stages of the illness. And, you know, you can see people who've come through where you've just had the operation and you've just had your chemo, and you can see people who've come through it, come out and they're sort of six/seven years down the line. Or you can meet people who have sort of come through and it's come back sooner than later. But you can see that there is other things out there, rather than just, like I said, the initial isolation, which is what I felt."
(6/F/Ovarian/Diagnosed)

Not all participants ranked online communities as a major influence on their identity with cancer. A number of participants felt that the communities had been useful for feeling 'normal' and supported when undergoing cancer procedures, but they were not essential for their future identity. Alternatively, other participants felt the communities gave them a sense of purpose. The variations in these experiences were associated with the level of connectedness participants had with other members of online communities. Participants who developed deeper connections and friendships online were more likely to argue that the communities had influenced their sense of self. Moreover, there were certain participants who actively chose not to form friendships and connections online. These were participants who believed that their cancer experience would be short term, thus they often avoided making connections and friendships with other group members. Additionally, participants whose cancer treatments and experiences were rarer than others in the online groups felt a distinct lack of connection to other group members. Therefore participants, such as a woman with breast cancer who required no adjuvant treatment after surgery, wanted to return to 'normal' after the treatment was over. This also applied to families caring for a person affected by cancer. These participants

avoided committing to supporting other community members. They were less likely to be drawn into close-knit online communities. These participants were less likely to experience the full journey to recreate identity with online communities, as outlined in the subcategories below.

“I couldn’t join in the conversations. That actually made me feel more of an outsider... but I daily, daily I check the Macmillan and the Breast Cancer Care ones but I don’t actively participate in any of them. Erm, and I think that’s probably right for me now because I’m sort of coming through the tail end of treatment. And I just want to get back to that sense of normality”
(15/F/Breast/Thyroid/Both)

5.6.1 Reconciling cancer and personal identity

Online communities helped many participants to reconcile cancer as part of their new identity. Most participants believed their lives had altered as a result of cancer. Participants wanted to orientate themselves to this new life in order to overcome the isolation that accompanied ‘*experiencing change*’. Participants needed to learn what it meant to be a person affected by cancer. They also needed to establish how being affected by cancer would dictate their future, and change aspects of their lives that had been important to them. Many participants found value in reading about the experiences of other people affected by cancer because it helped to reconcile them to accept that changes may be part of a new ‘normal’. In addition, fellow community members were able to reassure participants that their lives were not entirely negative, despite the effects of cancer. The processes by which participants reconciled their identity with cancer are detailed in this section.

“[forum name] helped me reconcile myself to the fact that I was now retired. I might be in recovery but I was retired. Err, it was a bit premature, erm, it wasn’t what we, but it helped me learn to live with it.” (20/M/Head and Neck/Diagnosed)

Experiential information was a valuable feature of online communities and essential for participants who questioned their identity. Experiential information showed participants what it felt like to become a ‘person affected by cancer’. Factual and medical information from healthcare sources had given participants

little indication of how the cancer was going to impact on personal elements of their lives. Participants were concerned about the emotions they might feel, the impact of cancer on family and work relationships, hobbies and activities they enjoyed. For example, a participant affected by sarcoma wanted to know whether she would still be able marry her fiancé and enjoy the holidays they had planned. Medical consultants and nurses were perceived as ill equipped to offer this information as they had not lived through cancer. Online communities filled this gap because group members were explicit about how they had felt about cancer and the changes it produced in their lives. By reading about the experiences of other people affected by cancer, participants were better able to visualise their future. This reduced participants' feelings of uncertainty about their lives, and allowed participants to see themselves in the experience of cancer, establishing cancer as part of their identity.

"I did find it useful to kind of read about other people's experiential knowledge and how their, sort of, journey through had worked out."(17/F/Ovarian/Diagnosed)

"You don't have to talk, you can sit there and just read everything. And they [community members] talk about things that they've done or I've done this or that or the other, or I've managed to get back to work or, you know. And you could begin to see that there is life after cancer. And I mean though everyone says, oh you'll have to learn to live with cancer, it's what you kept being told. Well watching what other people [in communities] do and, you know, they go off here, they do this or they've raised so much money. And I thought, no, cancer can learn to live with me, if that makes sense. I'm going to keep my life exactly the same and cancer's going to have to work round me, rather than me working around cancer." (6/F/Ovarian/Diagnosed)

Being part of a group normalised the identity of being affected by cancer. Before entering communities, participants had been 'the odd one out', and 'abnormal' around their friends and family. Participants found their experiences were echoed in messages from other members of the online communities. When reading these messages, participants realised that their worries were normal for people affected by cancer. This altered many participants'

perspectives about the cancer experience. For example, several participants were pleasantly surprised to find that members of online communities shared jokes about their experiences. This so called 'black humour' lightened the tone of cancer conversations, making it easier for participants to analyse how cancer was affecting their lives. In addition, several participants emphasised how important it had been to be acknowledged by people affected by cancer in the communities. These participants posted messages to communities in order for their experiences to be validated by existing group members. Participants wanted group members to agree with them, and to recognise that they belonged to this group of people who were 'affected by cancer'.

"You're looking for reassurance that what you're going through is normal"(9/F/Breast/Diagnosed)

"It put perspective on a lot of things as well. I just wanted to speak to someone that I wasn't [pause] weird, being the odd one out." (6/F/Ovarian/Diagnosed)

"It is that needing to belong to something. And I suppose, you know, when I was going through all that emotional stuff, I didn't know what to do with myself. Erm, and it felt like being part of a secret group" (15/F/Breast/Thyroid/Both)

Belonging was an essential element of reconciling a cancer identity. When participants felt they belonged to an online community, they were happy to discuss elements of their cancer experience and explore how it had impacted their lives. On the other hand, several participants struggled to find a sense of belonging in online cancer communities. This caused participants to question their identity as a person affected by cancer. For example, one participant received no responses to a group message she sent asking for help. She questioned why no one had identified with her, and whether she might be abnormal compared to other cancer survivors. This experience also reinforced her feelings of isolation. The format of communities compounded this because she could see other messages with many responses and her own message with none.

"It's such a big thing in your life and when you put it out there and no one acknowledges. And you can see all these responses to other people's

questions, erm, that you've been looking at yourself. And there is something, you wonder, what is it about this and about me that people don't want to help or they're not interested in ... I think that's hard when you've put something on and you don't get any responses. It's almost like you feel there's, and there isn't, but it almost feels like a bit of a voyeuristic element or that people genuinely don't know what to say to you. And I think when you're faced with that anyway with all your friends and all that good stuff, it's just another factor to that that makes it, you know, just as hard ” (15/F/Breast/Thyroid/Both)

Participants' offline identities played a role in who people wanted to connect and communicate with. Participants followed threads, messages, and group members who were most similar to them in terms of their beliefs, culture, and personality. For example, participants overwhelmingly preferred communicating with people who were from their country of origin. Almost all of the participants were British cancer survivors. They noticed a stark cultural difference between American community members and themselves. American members used a dramatic style of communication, seemingly sharing only 'horror stories' about their experiences with cancer. The British style of communication gave relief from negative messages by using humour and promoting positive stories about cancer. The majority of participants did not stay in the American communities, instead they moved on in search of UK based groups. In some cases, participants preferred to focus on the most similar messages or most similar members to themselves because they provided the participant with the most relevant information learning opportunity. For example, family members tended to focus on messages provided by other family members affected by cancer. These members had the most relevant advice for caring for a person affected by cancer. However, several participants also asserted that they wanted to find group members who would assure them that they were right, and who would assert their worldview. Thus, many participants ignored conversations that contradicted their worldview. Participants also preferred to associate with group members who had a similar personality, as well as cancer diagnosis. For example, several female participants who considered themselves 'strong women' preferred communicating with other

'strong women'. Thus communities, allowed participants' to reinforce their existing sense of identity, as well as their new cancer identity.

"I think, it's like, erm, if you went out to a function, and I think this is like a forum, if you go out to a function and you don't know anyone there and you're standing there with your drink. You start talking to people and some people you think, oh yes, they're really interesting, I'd like to keep talking to them. Others you listen to and you think, ah, I wonder if I can escape, go to the toilet and join someone else? And I think that's like that in the forum. You can see, by the way people talk, you can see who you want to [pause] join in the, erm, thread more. And some threads you think, oh I can't be bothered to join in that thread [laugh]."(6/F/Ovarian/Diagnosed)

"Obviously we're all drawn to some characters more than others erm, I particularly like quite strong women who're erm you know quite out there [laugh] who've got quite forceful ideas and, like me, like to, you know, be movers and shakers. So I tend to be drawn to women who are setting about making a difference" (5/F/Mal. Melanoma/Diagnosed)

5.6.2 Becoming a source of help

Participants could take on a helping role in online communities. This marked a changing point in participants' attitudes towards cancer in their lives. It also marked a junction in which participants changed how they used online communities. Helping began when participants started to provide assistance and support to other community members. They answered the questions of other members and posted any items that might interest the community including pictures, information, or signposting to other websites. Most participants felt obliged to become a source of help when they had benefitted from the groups themselves. Several participants also wanted to 'give back' to charities that had supported them or their family, and so provided support in their online forums. Thus, participants took on this role when they had moved along the journey from seeking help (also referred to as 'using' the groups), to contributing help (also referred to as 'giving back'). Logging on to help people was not time consuming, nor physically demanding for individuals. This was important for those experiencing physical side effects after cancer, or those who

had time consuming caring responsibilities. Being a contributing member of the communities was a positive badge of identity for participants. They saw themselves, and the communities saw them, as a positive force and source of support in online communities.

To participants, helping people was evidence that they were successfully navigating cancer. In particular, participants benefitted when they shared their knowledge in communities. Sharing advice and tips displayed the skills participants had gained to navigate cancer. For example, several participants contributed to threads about continuing to work, full or part time, while undergoing cancer treatment, based on their own experiences. They offered advice about communicating with line managers, and coping with side effects of treatment while at work. Participants referred to the expertise they gathered as their 'knowledge base'. They often gained an identity within communities for having a particular area of knowledge. For example, a woman with breast cancer considered her knowledge base suitable for women going through diagnosis or in the first round of chemotherapy. A man with malignant melanoma considered himself the key source of information about an experimental treatment for malignant melanoma. The participants also gained status within communities as they continued to live well beyond the cancer diagnosis. Two participants who had survived for five and eight years respectively after a terminal diagnosis became a 'beacon of hope' in the communities. Participants became role models for newer members who did not, as yet, have the information and support they needed. Helping people allowed participants to reflect on their own experiences with a sense of achievement and boosted self-esteem.

"So when there's like new ladies coming along that are just going through diagnosis or first round chemo, that's where, you know, my skillset now is, if you can class it as a skillset, but my knowledge base is there to help."

(13/F/Ovarian/Diagnosed)

"Yes, I've sort of got more active over the years because I see myself being able to give some hope to people when they're talking about their diagnosis. Often in the early stages when they're quite concerned about what it might

mean, and I feel I can sort of pop in and say, well look, you know, here am I seven years on. And actually, nearly three years on from being told I'm incurable, you know, there are a lot of treatments out there.” (11/F/Bowel/Mal. Melanoma/Both)

Participants re-evaluated their experiences of cancer once they were in a helping role. The cancer diagnosis was now perceived in a more positive light; several participants found that they began to consider the illness as a 'blessing' because they could improve the lives of others and prevent people from experiencing some of the problems they had experienced with cancer. This particularly emerged when participants discussed sharing online the misunderstandings or problems they had encountered with the illness. They shared advice they wished they had been given. For example, a participant had suffered from burns after radiotherapy because she had not fully understood the implications of the treatment, nor how to prevent the burns. She warned and informed members of online communities about this experience, in the hope that other people would not make her mistakes. Supporting other people was a positive experience that could be balanced against the negative experiences participants had endured. Furthermore, in this stage of the journey many participants felt a responsibility to positively influence the lives of more recent cancer survivors.

“Participant: I kind of want to redeem my cancer diagnosis. I think I if I can assist or help in any way then I'm all for that.

Interviewer: what do you mean?

Participant: Well I just think... if what I've been through can help anybody else then that's got to be a blessing that's come out of it hasn't it? In the same way that people have helped me.” (23/F/Mal. Melanoma/Diagnosed)

“You feel you've accomplished something, you know. You think, yes, people are listening, they're not going to have to go through what I've gone through. And, you know, hopefully they'll be fine, sort of thing.” (16/F/Mal. Melanoma/Diagnosed)

“That's the type, that's my coping strategy. If I can help other people, it gives me sort of like a reason why it's happened to me. And I suppose it sounds daft but

[pause] I want, you sort of like, you want something good to come out of a bad situation.” (13/F/Ovarian/Diagnosed)

There was no definitive time point at which participants became ready to help other members of their communities. Several participants spent years using online communities for information only, before they decided to give back to communities. Other participants entered communities and soon ‘stepped over the line’ from using to contributing to communities. Contributing seemed to coincide with participants believing they had resources to help other people affected by cancer. It was important to have knowledge to share with other people, as discussed above. Knowledge about cancer was achieved over time. Participants also needed emotional strength to support others because it required them to consider and befriend people who were distressed. Many participants did not feel they had these resources soon after the diagnosis. When participants were acutely concerned about the cancer in their lives, they used their knowledge and emotional strength to focus on their own navigation of cancer. As participants became more settled and calm about the cancer experience, they became aware that they could attend to the needs of other community members.

“Interviewer: You said there was a point where you started to then support the newer people joining. Do you remember what was going on in your life when, or around that change?”

Participant: Erm, that happened quite rapidly after, erm, being diagnosed. Because I think the first sort of ones I was wanting to say, you know, support, were people who were saying, I think I might have cancer. And my instinct was to say, get it checked out, you never know. Erm, don’t be scared of going to your doctor, you know, so right from that point you start, just because you’ve tipped over the barrier from the fear of what if into, OK this is happening. You suddenly felt you were in a position of knowledge, you have some knowledge about something, erm, and could contribute something to the forums.”

(15/F/Breast/Thyroid/Both)

“Interviewer: Did something happen to make you think it is time to put a post up?”

Participant: I think, from memory, that I was sort of conscious that I was coming to a point where it was quite a natural time to, you know, to sort of say, OK, I can say this now. I don't think it was, I don't think it was overly complicated. It just, it just sort of got to the right point. It was just a point when it was quite, it felt right to do both. Erm, and I think, from memory, I think I had posted a couple of times, but they were just, erm, they were quite sort of inconsequential postings. You know, someone had been asking for information and I might have confirmed, prior to that on the Health Unlocked site, I might have confirmed, you know, the name of, it was more sort of factual. I hadn't posted a profile or said anything about my, about my, erm, personal experience. But, as I say, I'd always known that I would do at some point.” (17/F/Ovarian/Diagnosed)

5.6.3 Becoming part of a 'tribe'

Participants could form close connections with other online community members, and these influenced participants' identity with cancer. Many participants found pockets of intimate discussions taking place. In these pockets, the online community members had access to, and remembered, personal details about one another. They sought one another's messages online, and were particularly motivated to support each another. This sometimes developed into friendships. Participants believed that these intimate groups of people possessed a tribal, or a true 'community' spirit. This community spirit was associated with participants becoming more dedicated to helping in these communities, because they believed the other members were dedicated to helping them. Interacting with a known group of people defined what it felt like to be an individual with cancer because they promoted a feeling of 'ingroup vs outgroup'. The online groups contained members who were alike and who understood how to help one another. Alternatively, people in such intimate groups felt dissimilar to other less intimate groups of people online, and to their friends and family who could not offer this level of support. Being part of a tribe also changed participants' identity through several processes, these are explained in detail below.

“There is something about actually finding almost like a tribe. Erm, and you know these people will know, erm, not necessarily all the answers, but you believe or you hope. I think you believe rather than hope, hope and sort of

believe that they will understand exactly what you're going through and what it feels like. And, erm, to a certain point, that reinforces the fact that other people won't be able to have the same understanding.” (15/F/Breast/Thyroid/Both)

Participants were more likely to discuss difficult experiences in communities where group members knew each other well and understood each other's needs, compared to communities that were less intimate. Many participants shared experiences with intimate communities that they would not discuss with their families. These 'secret' issues were often aspects of their identity which were treated as taboo offline including sexual or mental health concerns. For example, one participant struggled with an eating disorder during her cancer treatment, but only felt comfortable sharing this journey with her online community. Similarly, one woman discussed concerns about her sexual relationship with her partner after ovarian cancer. She spoke about this online, as opposed to with her partner or a healthcare professional. Intimate online communities were treated as a safe space because the members understood enough information about one another to be familiar and trusting. This encouraged participants to feel safe and respected by the other members. However, the groups still existed in a virtual website, and so were removed from participants' 'real lives'. Participants were reassured because their disclosures could not be discovered by their family and friends. Moreover, discussions about the more challenging and taboo aspects of the cancer experience appeared to have a greater impact on participants' subsequent behaviours. In the example previously given of the participant affected by an eating disorder, having an online discussion about this was described as the most meaningful interaction of her online community use. It allowed this participant to accept and seek help for this part of her identity.

“Whilst I was going through the whole diagnosis and initial treatment stage, it [eating disorder] sort of started to resurface and I was panicking because I thought, gosh, I'm going to go on to medication, I've got to get this under control. Erm, because I had a number of years with bulimia. But I could not say that to my husband, he would have been absolutely terrified. Erm, and that was actually one of the best sort of interactions I had on one of the sites, because one person came back and said, I know exactly how you're feeling, I've been

there myself. And I just did not feel so abnormal at that point. Erm, so that was really useful in that sort of context.” (15/F/Breast/Thyroid/Diagnosed)

The previous section *becoming a source of help*, touched upon participants gaining status and influence in an online community. Participants were much more likely to gain status in an intimate online community than in communities where individuals were not known to each other. Regular contributors were recognisable to other members and people expected regular contributors to provide a swift response to their questions posted online. Therefore, participants who consistently and frequently provided support were valuable to the groups because they provided the most help. In addition, regular community members were offered roles as moderators of their groups (also referred to as administrators). This was an influential position within the groups. Moderators were members who enforced group rules, and removed violations. They assessed people who wished to join and participate in groups, and often introduced new members to the rest of the community. Moderators were noticed by other group members as they had a constant presence in the communities. They had a powerful influence; in group disputes, the moderators' decision was final. Their ultimate show of power was the ability to remove people from the communities. Interviews with participants who were not moderators revealed that this removal was perceived as a striking and 'brutal' move because removing people ostracised a group member from their support network. Individuals who had different opinions from the community moderators were closely watched for bad behaviour and the power differential between group members and moderators may have been cause for concern. This is exemplified in the following quotation from a moderator (participant 1) who closely observed the actions of a previously troublesome group member. In most groups, participants were not able to contest rules that were enforced. The quotation from participant 3 below is an example of a participant who believed that the moderators unfairly dismissed a group member. This participant seemed to express distaste at the group administrator for how they exercised their power. Thus, whilst some participants gained status in the groups, events such as enforcing the rules reminded other participants that they had a lesser level of control.

“Participant: last time I’d spoke about one of the ladies who’d been kicked out of the [social media community name]. Erm, she’d also been removed from [Facebook group name] because she appeared quite aggressive. Now she’s still in our group [a second Facebook group] and she hasn’t caused anything, so we’re comfortable with that. If she was to cause anything though, then obviously we’d take the same action.

Interviewer: Yes. Does she know how you feel?

Participant: Erm, yes [laugh] because, erm, there was an incident involving her however, she actually hadn’t done anything to contribute to the post ... to be fair, she actually hasn’t caused anything in our group, so we’re comfortable with her being there. But yes, she knows not to cross the line.”

(1/F/Sarcoma/Diagnosed)

“Participant: Two people were effectively, you know, let go from the site shall we say. It was all, it all got a bit unpleasant. Erm, and it was because [pause] the administrators felt that they [removed group member] were promoting alternative therapies and apparently that's one of the that's one of the rules of the website, of the forum. You know you can say what you like, you know, you can moan you can rant and all the rest of it and you can discuss, what the benefits might be of you know, oh I don't know of green tea or you know, smoking cannabis or whatever but you can't claim you can't make any claims that alternative therapies are a cure and that is one of the rules apparently.

Interviewer: How do you feel about that rule?

Participant: Erm, interesting question. Erm I wasn't aware that those people who were let go were making those claims shall we say, I didn't ever feel that anything they said was as strong as that. I wish they hadn't been removed, because it seems a bit extreme.” (3/F/Mal. Melanoma/Diagnosed)

Intimate communities could also have a detrimental effect on participants’ identity with cancer. It was inevitable that online cancer communities would experience many group members dying as a result of their disease. Reading about the deaths of group members in intimate communities was felt as a bereavement. Participants had made friends in communities, and were shaken to discover that their friends had died. In addition, in the previous sections I have described how participants came to understand their own

identity with cancer through other group members. Thus, when groups members died, or when they received news of their cancer progression, participants were reminded that they were also vulnerable. For several participants, this reignited fears about their cancer and caused feelings of anxiety. This was particularly pronounced when participants were similar to the late community member in terms of cancer prognosis, age, or personality. As a result, several participants questioned whether they wanted cancer communities to continue as part of their everyday lives. Several participants left online communities after the death of fellow members and this movement is charted in more detail in the next section of this chapter *a journey through different worlds*.

“It is an emotional drain and it, you know, it is awful to read about people suffering. Because, you know, you think well that could be me one day and it is horrible. So that's why, you know, it's difficult I suppose.” (3/F/Mal. Melanoma/Diagnosed)

5.6.4 Summary of category two

- *A journey to create identity* was characterised by three key subcategories; *reconciling cancer and personal identity*; *becoming a source of help*; and *becoming part of a ‘tribe’*. Figure 2.4 visually recaps the relationship between this category and the subcategories.
- Participants’ identity with cancer changed during the time they spent using online communities. This formed an experience of a journey to recreate their identity after a cancer diagnosis.
- Communities allowed people to reconcile cancer with their personal identity as they learnt the customs of being a ‘person affected by cancer’, and discovered ways of expressing aspects of their own culture and personality online.
- Participants could begin to feel more positive about the impact of cancer on their lives if they began to help other group members.
- Participants could find a close-knit intimate online community, and these groups offered a level of friendship that allowed participants to examine aspects of their identity with cancer.

- Participants were more likely to learn of group member's deaths in close-knit communities, and this unsettled participants and the positive identity which participants had created.

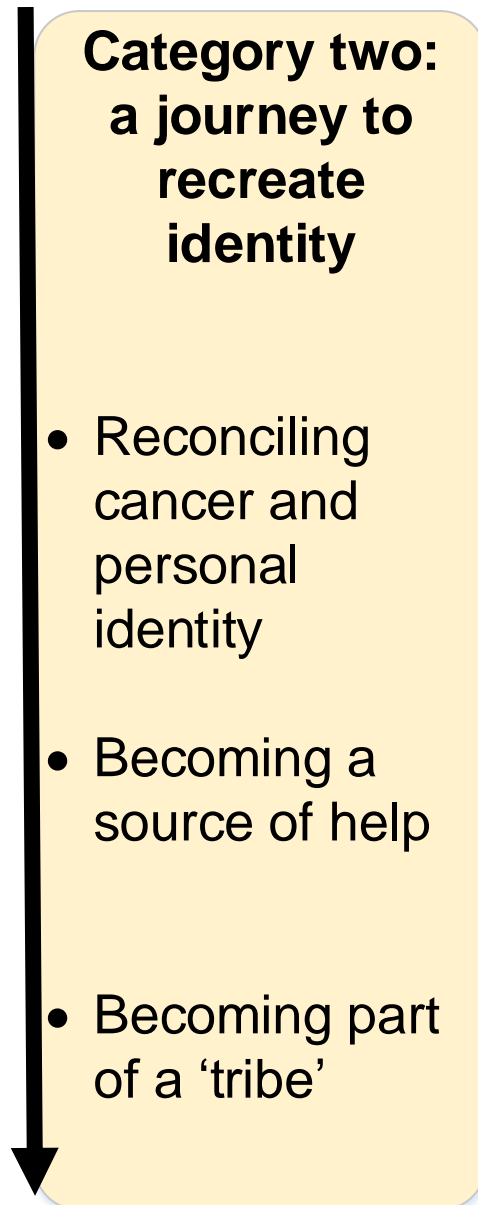


Figure 2.4. Recap of category two *a journey to create identity*

5.7. Category three: A journey through different worlds

This chapter will now outline the third and final category representing the experience of a 'journey' in the data. Like the previous two categories, this stems from the participants core intention to '*Navigate cancer using online cancer communities*'. In this category, I outline the main course that was charted through different online communities as participants sought to navigate cancer. Participants described this as moving through different worlds because they entered groups with unique members, rules, and operations. Furthermore, online communities represented a distinct world from participants' real lives because the interactions online possessed a 'virtual' quality. As described in the core category section *experiencing change*, many participants utilised the separation of the two worlds by expressing their thoughts about cancer online rather than sharing emotions and upsetting their friends and family in real life. Later in this category I will outline how participants, influenced by other community members, could break down this virtual barrier to form more realistic social connections. Participants discovered a different social world through the internet, and this journey evolved as it took participants deeper into different online cultures.

"It gave her an outlet, a little bit of a window on the world, erm, at least the world she was in. It was very different to the world she used to be in ... this was a moderated, err, interaction with the world that she could handle without over tiring her or stressing her out." (14/F/Brain/Family)

"I started using online communities, and then once I started that I then, I started branching out into other things. So I've met, I'd probably say there's about 30 people on my [Facebook group] that are either, I've met through sarcoma, I've got people on Twitter. So it really opened a lot of doors"
(1/F/Sarcoma/Diagnosed)

On the whole, participants' journeys followed a standard route. This began in online forums, and moved to private groups. The journey ended with participants moving on and out of communities. People affected by different cancers often started in different online forums, for example participants affected by breast cancer could initially find the organisation Breast Cancer

Care's online forums, whereas participants living with bowel cancer could begin in Beating Bowel Cancer's forums. Alternatively, several participants started in Macmillan Cancer Care's online forums because they were well known and catered for many different types of cancer. Despite these different starting points, the forums led participants to a different type of online community; private online groups. For participants, these latter groups had a more inclusive membership and only those who suited the membership of private groups were invited to be a part of them. For example, participants encountered a Facebook group for anyone affected by any cancer between the ages of 20-50, or a Facebook group for a cohort of women who began chemotherapy for breast cancer in the same month in 2014. Furthermore, participants had intentionally joined the initial communities to gather information and support, whereas in the private groups participants found a sense of gratitude and connection to their fellow group members. Using these experiences, participants mapped a clear progression in their journey through worlds. The final progression in this journey, moving on, was experienced when participants found that they no longer needed the groups as a tool to live with cancer. The subcategories of this journey have been organised to reflect this common pattern.

"When I first went on to, when I first used the networking sites for information I went on to [Ovarian cancer forum], which is an American forum. Erm, and the Macmillan site, erm, and Health Unlocked, [name of a forum within the website Health Unlocked website] which is, erm, specifically for women with ovarian cancer. And then since then, I've also become a member on two Facebook groups, one of which is closed, people can join but they have to be approved. And one which is a secret group, which is basically a group of women who met on the, on the Health Unlocked site and then have met in real life and have decided that they would like to stay in contact with each other ... I think it's probably quite a natural progression and much as one might if you met some people through work or college. And then you became, you had a connection with them and then you started going out or whatever. So, and certainly, some of the people who I know through the, who've sort of, I know through the Health Unlocked site and then the Facebook groups, and they've also become good

friends. So, you know, we meet in, you know, we meet up for coffee.”
(17/F/Ovarian/Diagnosed)

There were three participants whose journeys deviated from the common pattern. Unlike most participants, two were inspired to look directly in Facebook at the beginning of the journey. These participants sought groups using Facebook’s search feature; one seemingly by chance and the other participant had been informed of a Facebook group for women undergoing a hysterectomy, directing her to look for a cancer specific Facebook group. These two participants skipped the step of finding a forum. They then used their Facebook groups to both gather information, and to connect with others. These participants differed from the majority of participants because most had not known where to look for online communities, and so it was necessary for them to chart a path from forums to Facebook groups. In addition, the third participant who experienced a different path through online worlds witnessed the journey changing over time. This participant used an online forum in the mid 2000’s, before Facebook was widely used. After several years of being a community member, her once thriving online forum dwindled as members left to join Facebook. Thus, the emergence of new social media shaped this journey through different online worlds over time.

“I don’t know why I did it, no one suggested it, I don’t know why I did it, I was on Facebook and use Facebook a lot. And I found a lot of friends that I’d lost in the past through Facebook. And I thought, well I’ll type in Ovarian Cancer and see what happens. And it came up with a site, [Facebook group name]. So I thought, oh I’ll try that. And I went on there and the lady who had set it up, she’d done it herself because she’d been diagnosed at thirty two. And I suddenly found [laugh] I wasn’t the only one under the age of sixty five.”
(6/F/Ovarian/Diagnosed)

“Increasingly, as people struggled with, erm, trying to navigate the website, I think they turned more and more to some of the social networks like Facebook and, erm, things like that. So it did eventually, erm, lose some of its effectiveness for us.” (14/F/Brain/Family)

5.7.1 Finding a window to a virtual world

The first type of online community that most participants encountered were online forums. Several participants went directly to the websites of the largest charities in the UK. More commonly, participants sought an answer to a question about cancer using an internet search engine. Forums were public and searchable. Thus, search engines sent participants to online forums in which the search topic or phrase had been discussed. This often led participants to American and UK based forums. Participants often did not recall what they had initially searched. It seemed they had been navigating to a resource that might offer answers to many questions they had about living with cancer. Online communities differed from the other webpages online; they gave participants a glimpse into an interactive world of people affected by cancer. Participants' perception of this as a 'social world' seemed to be compounded by the isolation they felt as a person affected by cancer. Opening the webpage to an online forum allowed participants to see many other people with the same experiences, and this was like looking into a world that had been hidden from view. In the words of one participant, accessing the initial forum was like being given a 'bridge to a community'.

“Although the Internet's great, you're still at home as a little individual tapping away at your keyboard and through [charity name] I did find support services and I found an online forum [pause] and got talking to other people online about melanoma. And then I realised there were other patients out there which of course sound crazy but I didn't, I didn't know, you know, I don't know, I'd heard of malignant melanoma but you don't know how many people have found they're suffering from it, you don't know whether they're online, you don't know if they want to communicate” (5/F/Melanoma/Diagnosed)

“It's difficult to explain but I find it very easy to feel that I'm the only one going through what I'm going through. So it's good from that point of view to see other people and that they have got the same sort of mindset about things” (22/F/Bowel/Diagnosed)

Online forums had a number of unique technical features that defined this section of the journey. Firstly, participants did not usually need to create an

account to read the messages in the group, and this meant that no other members were notified when participants only looked into communities. Secondly, when participants did need to create an account, for a select few forums or if they wanted to post a message, they used an anonymous username. As a result, participants felt like they were unknown and often completely unseen in communities. They likened this online community use to looking through a window. This was also referred to as lurking and it gave participants a sense of safety in groups. Lurking was important to participants, because they were often apprehensive about social media and online communication, as detailed in the core category section *familiarity with the internet*. When entering communities, participants wanted to ensure that the groups could benefit them or their family. On one hand, participants were wary about sharing personal information in a public domain. Public communities were open for 'anyone' to read, including genuine people affected by cancer and hoax accounts. Indeed, several participants found 'scams' or hoax messages from people which aimed to cheat money from people affected by cancer. These messages were sent privately to several participants. They included a long message about how the person represented by the hoax account had been affected by cancer. The hoax aimed to persuade the participant to share their bank details. Participants were not convinced by this scam, and no participants in this sample imparted their bank details online. However, the presence of scams made participants re-evaluate how safe the forums were for vulnerable people. On the other hand, participants could also observe other group members receiving emotional support and uplifting messages in the online groups. This engendered a perception of communities as a positive environment. Thus, as participants lurked, they weighed up whether they trusted the groups and developed an understanding of how much personal information they wanted to impart in online messages.

"I'd never seen anything like that before. I'd never been involved in a forum. I'm not a social media junky, I'm really not into that kind of stuff. We were brought up very reserved and, erm, I wasn't sure it would do her [sister with cancer] good. I wanted to be convinced that it was a good place for her to be. And so I spent a while, first of all, just, I did not join but I just watched and listened, you

know, to see how things went with others, to see if it was going to be a positive and up-building experience.” (14/F/Brain/Family)

“I was on Macmillan once and a women was on saying she had, err, her husband was getting his lung out, his right lung out, which is what I had. She said she was very worried, so I replied, you know, explained how much it was, not to worry too much, you know, it’s not the end of the road. Then she wrote back asking if I’d be her friend, which I’ve not really got many friends on it, I just keep it on as normal threads, you know. But I didn’t like to refuse her, so I said yes. But then she was making out she had lots of money, her husband would have lots of money. She would give it to me but I would have to promise to give it to charity, etc, etc. And I knew then it was a scam ... It didn’t upset me. It makes me sorry somebody would come on cancer sites and do that. And, err, because there are some very vulnerable people on there, which, err, for that it makes me sad” (12/M/Lung/Diagnosed)

When participants initially entered online forums they were largely uninterested in the concerns of other group members. They looked into the groups with an inward focus on themselves, their own identity, and their own information needs. Lurking was particularly useful for this focus because participants could collect information without becoming beholden to other group members. Several participants had found they had not needed to post or ask the community questions to gather information. They could see other community members asking the questions and being provided with the information that participants were looking for online. One such participant was a woman married to a man diagnosed with terminal pancreatic cancer. This participant predominantly followed the messages provided by one online community member who had a similar experience as a family carer. The participant felt fortunate that she had not been required to post to the communities because it had allowed her to avoid making friends with other online community members, as exemplified in a quotation below. Several participants spent a long time lurking in online forums, with one participant lurking for as long as one year before introducing herself to a community. Other participants were not able to find the answers they needed simply by lurking, and needed to pose occasional questions to communities. These messages

were posed with a similar degree of detachment from the needs of others. Early messages were posted to generate information, rather than to make connections or friends.

“Interviewer: Were you ever aware of who certain people communicating in the forums were?”

Participant: No and I wasn't interested in that at all.

Interviewer: Why was that?

Participant: Well because I wasn't trying to make friends [laugh]. I just wanted to know information.”(10/F/Pancreatic/Family)

“It was quite a detached, erm, from my point of view, it was quite detached. I was just looking for information.” (17/F/Ovarian/Diagnosed)

“I think you're so insular, all you can just see is what's happening to you. Erm, and I think, I don't know, I think initially, I think you just feel a bit frantic. You know, you want to feel like, I guess contain, you know try and contain what's happening really.” (23/F/Mal. Melanoma/Diagnosed)

If participants did post to a community, initial posts were perceived as 'brave' but often 'despairing'. To expose oneself in front of a community, rather than remaining in the 'safe' lurking position, indicated that individuals were desperate for support and information. Participants who took on a helping role in communities considered these new members as the most vulnerable, with the most pressing concerns, and the most worthy of support. In addition, newer members were likely to post to online forums in the middle of the night. Several participants had used online communities when concerns about cancer prevented them from sleeping. The forums were open for 24 hours every day, and the most populated forums appeared to be active around the clock. These populated forums contained international group members, and they logged on at hours in which most UK members would be asleep. For example, one participant used forums from Canada and believed it was her job to support UK members who were distressed in the middle of the night. In this respect, the 'sun never set' over the forums, and they could support members around the clock. However, in less populated forums those posting in the night could be left for hours without receiving a response. Several participants were concerned

about the wellbeing of such group members because they seemed particularly desperate in the middle of the night.

“That was when I’d just joined and I was desperate for support, just wanted, you know, someone to help me and, erm, you know, be there.”

(1/F/Sarcoma/Diagnosed)

“I think the people, people who make initial posts are sometimes in quite dark places and quite despairing ... a first post is quite a brave step”

(9/F/Breast/Diagnosed)

“They were the most likely to come in at some ungodly hour in the morning, they’d be desperate. They’d be in tears, erm, they’d have a partner who was, err, just been diagnosed and they’d just found the website” (16/F/Mal.

Melanoma/Diagnosed)

5.7.2 Being let into an intimate community

Participants received invitations to different online communities if they began communicating in online forums. Posting gave participants a presence in the online community. This presence left them open to be approached by other community members. In other words, when participants posted to communities they were no longer looking into a window; the groups became a door to a social world. Many participants were shown paths to access private cancer communities, often on Facebook. Features of Facebook facilitated an inclusive and supportive atmosphere between group members in ways that public forums often did not. Thus, many participants were tempted to move over to, or spend more time in Facebook groups. Two other participants managed to find pockets of inclusive conversations in online forums, and these acted in a similar way to private Facebook groups. These two participants were assimilated into regular conversations between approximately 10 community members. These forum members formed a deeper connection with one another than with other members of the forums, and this was described with a similar feeling of intimacy as Facebook group connections. However, several other participants noted that the intimate groups in forums were small and difficult to become a part of once they had been established. On the other hand, features of Facebook allowed more people to be welcomed into a network. The common factor across these

types of communities was that other community members drew participants into an intimate subgroup of people affected by cancer.

“I was invited to join by following a conversation I had on one of the main groups ... I think I got talking to somebody on one of the other sites and then we had a private message and then they invited me to join. I did feel a bit like I'd been asked into the sixth form common room [laugh]. But then I met, and then I met, somebody organised a get together, so I met a lot of the women at that face-to-face.”(17/F/Ovarian/Diagnosed)

“Through that forum, somebody contacted me after a post I'd made, to let me know about the Facebook group that I've since joined.” (9/F/Breast/Diagnosed)

“And it wasn't until, as I say, one of the ladies on, a couple of ladies, I kept hearing them talking about it on the breast cancer site. They kept on about this secret network, this secret network that was on Facebook for younger people ... whereas with the other sites [referring to forums], I can see these communities on them, but I certainly haven't really been able to get into them or, you know. I think I'd have to be quite proactive to try to nudge my way into some of the ones that have sort of evolved on the sites. It's more to me about asking a question and then providing support by being able to try to answer other people's questions, rather than a sense of a network..” (15/F/Breast/Thyroid/Both)

In intimate communities, participants learned details about the people they were communicating with. This paved the way for relationships to develop between members and created an atmosphere in which participants were comfortable returning personal details about their own lives. This was possible in forums and in Facebook groups. However in forums, with anonymous usernames and very few identifying features, participants struggled to know details about many of the other members of the communities. Small numbers of very regular posting members became familiar to one another, but participants were unlikely to remember the username of an individual who posted infrequently. Alternatively, Facebook group members provided their real names and usually a picture attached to each post. This information was more memorable to the participants than seemingly 'random' usernames. Moreover, real names and pictures revealed implicit information about community

members to one another; in a picture participants might have identified the gender and ethnicity of other community members. This was described as 'putting a face to a name' to fellow community members. Most participants believed they had a better understanding or more complete image of the people they were communicating with when they had more information about them. For example, one participant moved into a Facebook group with another member of the forum she had used. Through Facebook profile pictures, this participant realised that the member who had used irritating expressions on the forum was younger than her. This participant forgave and sympathised with the member's style of writing because she believed she understood more about her personality. Thus, participants cared more about fellow members of communities when they understood, or believed they understood, who they were.

"I think those [Facebook] connections are different to say the connections you might meet when you're on an online forum. And, you know, there's a person with a, you know, with a username, you know, it might be, you know, I don't know, fluffy cloud or whatever ... [on Facebook] you will care about some of them, all of them, more so than if they're just usernames on a website"
(17/F/Ovarian/Diagnosed)

"The lady with the liver cancer, I never knew how old she was and then she joined the Facebook group and it was like ah right, so you're only in your twenties, so you're only really young, it makes sense now I understand why you are the way you are. She was quite giddy ... and she was quite excited to be part of this group and I used to think oh good god, it's not exciting to be a part of this group, it's like the worst thing you, you don't want to be part of it. But then when I seen her on her Facebook page I realised what kind of person she was. It all made sense then so it didn't irritate me when certain kinds of messages came through because I was like this is the kind of person she is and you have to accept that" (1/F/Sarcoma/Diagnosed)

Intimate communities were portrayed as more conversational than the online forums participants initially encountered. Initially, participants posted in order to have their questions answered and to probe for cancer related

information. Intimate communities still contained questions about cancer but they were also more likely to contain casual conversations. For example, participants found intimate groups sometimes singled out how a regular contributor had been doing or wished luck for future healthcare appointments. In intimate communities, conversations developed that were not necessarily cancer related. Participants asked about people's families or holidays. They shared jokes and created names for one another. This jovial atmosphere was likened by two participants to a 'virtual bar', and it benefitted many participants. For example, one participant had used online communities with her sister, and fellow group members referred to them as 'Sooty and Sweep' because the two were twins. The sister living with cancer had become bedbound by her illness, and the communities allowed her to be part of a lively social world. The communities also had a dramatic positive impact on the participant's relationship with her sister because they had friends in common. Furthermore, the sisters could enjoy conversations with one another towards the end of life that were not about the negative progression of the illness, instead they chatted about their friends and online conversations.

"Participant: There were times when she was feeling a little bit better that we'd play little games on there, you know, like has anybody seen Sooty? And then Sweep would write something naughty and, erm, you know. So we used it, erm, in a number of ways. Erm, it was very helpful to us. ...

Interviewer: You said that this buoyed her up?

Participant: Yes, absolutely, because it was people we knew in common. It was like being kids again. We had friends in common, which we hadn't had actually for many years, with us being in different continents." (14/F/Brain/Family)

"You felt very, made very welcome with people, you know. People like seemed to chat to you and help you through. They're the type of communities, they haven't seen you online for a couple of days, you know, there was a post, you know, hi, how are you doing? Erm, have you got any questions? And as I was going through treatment, it was nice to reach out to some of the other ladies." (13/F/Ovarian/Diagnosed)

Participants also highlighted that technical and social features particular to Facebook groups had nurtured friendly and personal conversations. These features were not available in forum conversations. Firstly, Facebook group moderators introduced new members to the communities with a brief description of the new member's experience with cancer. This encouraged fellow group members to welcome the newcomer, and gave information which could be used to strike up conversations. Participants found that a welcoming entrance gave them a sense of the group as a homely and familial environment. Secondly, Facebook groups allowed individuals to share inspirational pictures they sourced online or 'like' the posts of other members¹. This allowed participants to have a presence and be contributing members of groups, without needing to impart cancer information or expertise. This made conversations accessible for members who had expertise to share, and for those who had little to say but wanted to offer support. Moreover, Facebook 'likes' were a small but significant feature for participants looking for support. Several participants received only a few replies to messages, but many 'likes' from the community members. This was a simple symbol that showed participants other members were reading, appreciating and supporting their experiences. Alternatively, many forums allowed members to count how many people had viewed their messages without leaving a reply. Several participants felt that this feature made forums seem voyeuristic, as though they were being watched and judged, rather than supported.

"In the Facebook group, it's much more about somebody who you've had ongoing conversations with and you know quite a lot about them. You know, we know each other's family names. I know the ones that work, what they do. Erm, so, erm, you know, if somebody posts to say, they're having a rubbish day, erm, other people might, you know, might say, yes so am I [laugh] and that might be all you say. Whereas, I think on the Forum, it doesn't kind of work that way."(15/F/Breast/Thyroid/Both)

¹ A feature of Facebook where group members can show they 'like' other members messages. Messages can accrue many 'likes'.

“You felt like you’d stepped through the door of, you know, someone’s house and everyone was sort of saying hi to you ... and it’s got all the additional stuff that, you know, Facebook can do. So if someone’s having a bad day, erm, or someone’s achieved something, people click ‘like’. And it’s so stupid but, you know, when you see someone has got a hundred and twenty five ‘likes’ because they’ve finished chemo or, erm, I think that’s a big thing.”

(15/F/Breast/Thyroid/Both)

Communicating regularly set many participants on a course to meet or enhance their relationship with online community members. Participants could add members of their cancer-related Facebook group as a ‘Facebook friend’, giving the members access to their entire profile. Similarly, some participants shared their phone numbers with particular group members. These actions symbolised a growing friendship between members, because they let members into a friendship circle that included their ‘real’ or ‘pre-cancer’ friends. These actions also marked the point in the journey when online communities reached across the ‘virtual- real’ divide that participants had placed between their online and real interactions. For some participants, online community members had made a dramatic and vivid impact on their lives by reaching across the virtual barrier to help them. For example, one participant had moved to the UK shortly before being diagnosed with cancer. She and her family had no local friends, and she was distraught at the process of arranging her daughter’s birthday party. She believed this might be the last birthday she shared with her daughter, and yet could not find any children to attend the party. The online community ‘saved the day’, as members in the local area attended with children who were the same age as the participant’s daughter. This participant was in tears when relaying this story, because the communities had made such an impact when she had no alternative friends to turn to.

“It was so, you know, sad to me to think, this could be my daughter’s last birthday party that I’m alive for and she would only have three guests to come. And so I posted on the local one and I said, you know, if anybody is free this weekend, please feel free to come and bring your kids or grandkids, erm, to my daughter’s birthday party. And don’t worry about bringing presents or anything, just we’re pleading for people to show up. And the main organiser of the group,

erm, she contacted some of her friends that she knew had children around my daughter's age to come. And this other really nice lady, I'll just, I don't even remember her surname. Erm, she had a daughter around my daughter's age, so she got like ten of her friends to bring their kids. And so, you know, they ended up really saving the day, her birthday party. So we ended up having about twenty guests show up and, you know, it was really heart-warming."
(21/F/Breast/Diagnosed)

Intimate communities occasionally arranged to meet one another. In anonymous forums, this seemed to occur if the organisation hosting the community arranged a patient advocacy event in the UK. These events were often promoted and discussed in the communities, and several participants arranged to attend and meet those they regularly communicated with. In Facebook, group members often arranged social events or 'meet ups' in pubs around the country. These events were sometimes open for anyone from the group to attend. In other cases, participants identified particular group members to meet with one on one. For example, one woman met with another woman affected by breast cancer who lived nearby, and another man living with melanoma travelled to meet a friend he had made a particular connection with. Participants noted that meeting other members face-to-face bridged the relationship from a virtual to a real connection. After meeting, participants were much more committed to supporting those they had met. Furthermore, they were much more susceptible to being bereaved if their friends died. However, face-to-face meeting was not accessible to all participants. Those who were unable to travel could not attend the meeting events. Thus, those who were caring for their family, or who experienced physical limitations as a result of cancer struggled to meet with those they communicated with. One such participant was both caring for her husband, and too ill to attend an event herself, and was disappointed not to meet her online friends.

"Interviewer: How did you feel, not being able to meet up with your group?

Participant: I was disappointed but there was, you know, there were a few different factors. It was a distance to travel, erm, my husband probably wouldn't have been able to come with me. So if I had gone, I didn't want to go on my own because I knew that, erm, you know, I was still having chemotherapy and

there was a chance of not being well. So, you know, trying to find somebody who could go with me, you know, could my son go with me? So given those sorts of complications, I was disappointed that I couldn't go but at the same time quite relieved because I was a bit worried about, erm, making that journey on my own or with somebody who, you know, if I'd gone with my husband I would have been more concerned about looking after him. Erm, there wouldn't have been anybody had I needed to be looked after. I think it would have been London, so it would have been probably train and tube. And there would have been, I mean you know what it's like going from the train to the tube, it can be quite a long walk and my husband is not good at walking long distances. So I would have been concerned if he had gone, you know, just for the moving around. But yes, I was disappointed not to go, it would have been an interesting day and good to meet up with some of those people who, err, you've kind of got to know in a forum." (11/F/Bowel/Mal. Melanoma/Both)

As online communities played more of a 'real' and less of a 'virtual' role in participants' lives, they had a more significant impact on the participants. Participants referred to the intimate communities as having 'a flipside' which signified that as participants cared more, they became more vulnerable to being upset by the online communities. There were several reasons communities had a negative impact on participants. Firstly, arguments were more likely to occur in intimate communities. Members left candid messages to the groups about their feelings towards cancer, healthcare and charities. Unfortunately, this could spark arguments between members with differing opinions. Arguments soured the 'positive' atmosphere of a group for those involved in the arguments and for those observing them unfolding. Furthermore, as messages were conveyed in writing, participants found their opinions could easily be misconstrued as something more controversial than intended. Secondly, intimate community members had regular personal contact, and so the groups were informed when member's health declined or when members died from cancer. Participants felt bereaved when their online friends passed away. Thirdly, Facebook groups encroached onto participants' 'real' friends and family. Group membership was sometimes visible on Facebook. Participants who met with group members in real life found that they needed to explain to their friends and family who their

new friends were. As outlined in the core category *experiencing change*, several participants had attempted to hide their diagnosis from friends and family. Connecting with community members could 'out' participants as a person affected by cancer to their 'real life' social circle.

"Friends have busts up, you know, people, people misunderstand others. And I think one of the downsides of a written discussion, and it is that tone of voice isn't there. And things can be misconstrued" (9/F/Breast/Diagnosed)

"I was worried that, you know, through posting on that site or even joining the group, that I would kind of be outed on my Facebook feeds to all my friends and family, which, you know, I did not even tell my family that I had cancer until three months after I started chemo, just because, you know, I was worried about how they would react." (21/F/Breast/Diagnosed)

5.7.3 Moving on from groups

Several participants reached, or could foresee, a time when they needed to 'move on' from online communities. The groups had represented a time when participants needed assistance to navigate cancer. The communities imparted many participants with enough knowledge about cancer to feel in control. With enough knowledge and experience, participants did not need to continue to regularly refer to communities. This was particularly expressed by participants who had completed active treatment, and saw their future with cancer as stable. For example, a woman affected by malignant melanoma completed surgery and spent time seeking online support for 'melanoma' or paranoia that the melanoma might return. When she felt she had her concerns under control, and understood that she required no additional information, this participant considered moving on from online communities. At this juncture, participants began to turn their attention to other aspects of their lives, such as their family, friends, work, or hobbies. However, online communities could hinder participants' efforts to think less about the role of cancer in their lives. Membership in online communities caused participants to receive daily updates of the groups through Facebook or by email. These updates, which had once seemed like an outlet for participants' concerns about cancer, came to remind participants of the presence that cancer had in their lives. One participant

likened communities to watching the news of a tragic event. They caused people to stay engaged in the experience of cancer. Participants relived negative emotions they had once felt when they identified with the messages of other newer members in communities. Other participants felt desensitised to the help others needed, and wanted to move out of the groups in order to forget about the other people affected by cancer.

“You're constantly looking to see what people have put up and what's going on ... constantly looking at the website as well. It's reinforcing the whole thinking about it and dwelling on it as well. It's a difficult one and, you know, I've often thought as well I should take a break from it so that I'm not [pause] it's like watching the news about something isn't it. If you stop watching it, you know, it's like I remember when when the twin towers happened all them years ago, I was just watching the news all day long about it, so you never stop thinknig about it, it's like that with these. You know when you're constantly constantly looking onto a website and reading it keeps it in your mind.” (3/F/Mal.

Melanoma/Diagnosed)

“I stopped being so proactive on it and, erm. And it's awful but as you go through the sort of treatment cycle, you realise it's just a big monster, the wheels turn and the next batch of people are coming in. And all the stuff that they're terrified of is the stuff that you sort of come to terms with yourself. And that horror of the, you know, diagnosis and waiting for test results and all that horrible stuff that you really need help with. Erm, when you're just a bit further on, your immediate desire is to go back and help them and say, look, it's going to be OK. And then as you sort of are coming further out of that, I personally just started to feel a little bit sensitised to it. I knew that the support was going to be there for them because there was that wave who were slightly behind where I am now. Erm, but I just, I think I didn't feel so engulfed by cancer, as I've sort of gone through and made a bit more sense of what's happening.”

(15/F/Breast/Thyroid/Both)

Not all participants expressed a need to move on from groups. I interviewed a range of participants at different times in their navigation of cancer. For example, I interviewed several participants who were using groups

to collect information and connect with community members. The majority of these participants had not decided how long they would remain in the groups. The concept of moving on seemed to occur to participants who had been living with cancer for longer periods of time. These participants had gathered enough resources to live without communities. Moreover, the longer participants used communities for, the more likely they were to encounter the 'flipside' of online community participation, as outlined in the previous subcategory '*Being let into an intimate community*'. Participants weighed up the pros and cons of their participation, and when they had less to gain from communities, often decided to move on. If their circumstances changed and participants required more information, several participants expected that they would return to the groups. For example, one participant highlighted that she was slowly moving out of a group, but that she would return immediately if she received news of her husband's cancer spreading or needed information for new treatments. In addition, several participants had used online communities for many years after their diagnosis before they needed to move on. The longest period of use was over eight years for one participant. These participants highlighted that over time the communities themselves could change to make participants no longer beneficial to the groups. For example, a participant became expert in knowledge and experience of a particular experimental drug for melanoma treatment. However, over time newer people to the groups were being given different drugs and his expertise was no longer required.

"I suspect that, erm, as long as my, I think as long as my medical situation is fairly stable and I don't have any, you know, additional, you know, additional challenges, then I think I would use them less and less. But I'd be quite quick to go back on to them if there was an issue. So, for example, if, you know, if I had a scan and it showed up as being, you know, there was, you know, x showed up on my scan, I think the first thing I would do would automatically go [laugh]"
(17/F/Ovarian/Diagnosed)

"I don't know whether I'll be staying. I'm not sure whether I'll be staying in the groups forever. I mean I think I might well, I'm beginning to move away from it emotionally at least because erm, I mean it's partly, it's twofold. It's partly a personal thing that, you know, the drive to get on with living erm but it's also

partly that as the newer treatments come online I've got no experience of those to offer" (2/M/Mal. Melanoma/Diagnosed)

It emerged that several participants struggled to leave a community immediately. Often, participants seemed to contradict themselves by explaining that they had moved on but also continued to 'dip in and out' of the communities. Participants explained that they no longer frequently committed time to online communities but checked in irregularly to pick up snippets of information or to offer words of advice. This occurred as participants transitioned from forums to intimate groups. It also occurred when participants were deliberating about leaving communities altogether. Dipping in and out was important to participants because they had come to see online communities as a valuable source of cancer information. By keeping the groups at hand, participants used communities like a 'security blanket' if they were to have any recurring fears about cancer. At this time, the groups symbolised an indulgence rather than a necessary tool to navigate cancer. Participants explained that even when feeling largely in control, they still had 'weak moments' of fear and anxiety, during which they needed support. Moreover, participants had become accustomed to relying on communities, and leaving them altogether was like walking alone with cancer.

"I do actually, I'm still linked to it, erm, but I don't have it come up in my news feeds. It's one that I will just dip in to occasionally, to have a look to see if there's anything new." (13/F/Ovarian/Diagnosed)

"I still pop over, have a look and see if there's anything in the other forums" (11/F/Bowel/Mal. Melanoma/Both)

"As you like start to move on with your life, you're still there and you want it, it's like a little bit of a security blanket because you've met some nice friends and things like that" (13/F/Ovarian/Diagnosed)

Many participants struggled to leave online communities entirely because they continued to feel a duty to fellow members of the groups. Participants living with cancer stated that cancer would always be a part of their lives, and so they could always identify with other cancer survivors. Several participants leaving

intimate communities acknowledged that as they moved on some of the members left behind would pass away. They felt guilty that they would not support these members to the end of life. On the other hand, I found that leaving online communities was less difficult for several family members affected by cancer. These participants saw cancer as a temporary fixture in their lives, and they could return back to 'normal' after cancer stopped affecting them. Returning to normal occurred for two participants whose family member with cancer was stable and well, and two participants whose family member died. When cancer was no longer an influence on the lives of family members, these participants could no longer relate to other members of the communities, and so these participants felt no longer able to offer their support.

"I met a thirty nine year old lady locally, in the same sort of position as me. And she said she was thinking about leaving the group because she needed to move on emotionally. But she felt really guilty because she felt like she owed it to the new people coming on to give back what she got when she joined and the support that she got. So she actually, mentally for herself she thought the right thing to do was to leave. But her sense of obligation was that she felt really she should stay because she needed to pay this back, in terms of her knowledge and experience" (15/F/Breast/Thyroid/Both)

"I have also left them both [two online forums] and the reason for that was that I went along and I met them, and they were all very nice people, but I was no longer surrounded by people that were in the same situation as me. I needed to be normal." (10/F/Pancreatic/Family)

For most family members, there was relatively little difficulty moving on from the groups. Alternatively, people living with cancer could take a long time to leave groups completely. One such participant underwent a process of leaving and re-joining the groups on a number of occasions. An initial interview with this participant had revealed that she was trying to reduce her time in communities. At a second interview six months later, she had managed to leave online communities. This participant's experience is exemplified below, with a contrasting family member participant account. Despite different degrees of difficulty leaving the groups, moving on accompanied a sense of relief and

achievement. This was also conveyed in both of the following accounts of moving on. Leaving signified that the participant had been able to navigate, and were moving on from a particular time of crisis.

“But it was, something that was special from them [community members] at that time in their lives. Err, because once that crisis was over, they all went their separate ways and attempt to, erm, rekindle, erm, those friendships never really worked after that because we’d all moved on in different directions to different places. And so, err, we would never have attempted, for example, to have a reunion because it would have been totally inappropriate to do that. We were just all in that very dark place all at the same time and we just made the best of it and recognised the support that we gave each other. It was very special.”
(14/F/Brain/Family)

“Interviewer: we spoke several months ago about you wanting to leave the group. Are you still a member now or did you leave?”

Participant: Only about two weeks ago [time of second interview in April]. It took a long time to do it. I kept thinking about it. And, when did we last speak? About October, so. No, and I mean it took a long time, and in the end, and I tried cutting back on it and not leaving as such, but without leaving the group completely erm, I still kept erm looking (laughs) so no it did not. I had to sort of you know, take myself off as a member in order to leave it properly ... I have felt just so much less stress and anxiety worrying about other people since I left”
(3/F/Mal. Melanoma/Diagnosed)

5.7.4 Summary of category three

- *A journey through different worlds* was characterised by three key subcategories; *finding a window to a virtual world*; *being let into an intimate community*; and *moving on from groups*. Figure 2.5 visually recaps the relationship between this category and the subcategories.
- Most participants followed a common route through different types of online communities. This could draw people into richer and more intimate online social worlds.

- Over the course of using online communities, participants could move from interacting with the communities as though they were a one-way window, to entering a door to a social world.
- Intimate communities could only be accessed when individuals had been invited in. People who continued to lurk in communities were not invited to this part of the journey.
- Moving away from communities was easier for families affected by cancer than people with their own cancer diagnosis because they did not feel a strong affinity and sense of duty to people affected by cancer.
- Moving away from communities gave participants a sense of relief and signified moving on from a crisis in participants' lives.

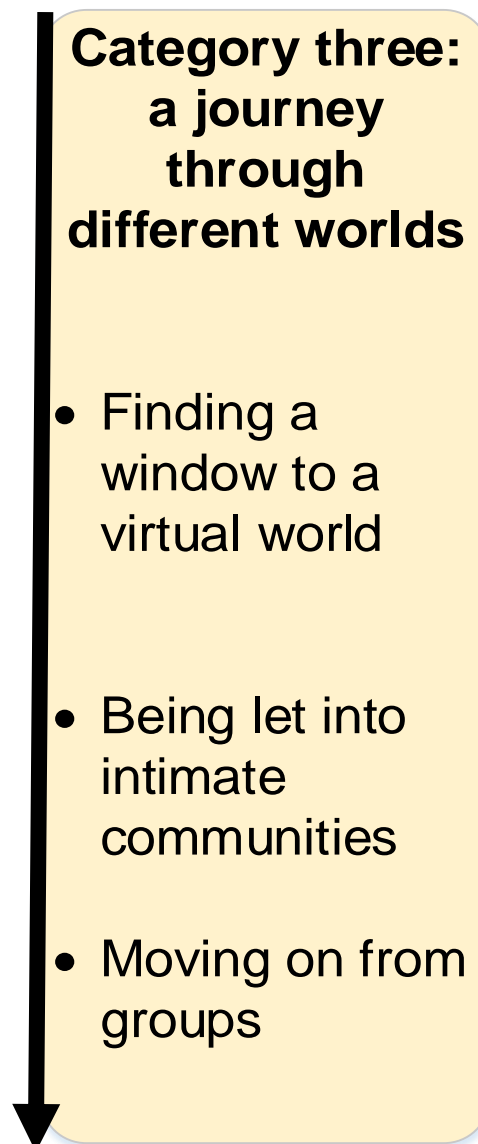


Figure 2.5 Recap of category three *a journey to through worlds*

5.8. Summary of the findings

Constructivist grounded theory methodology allowed rich experiential data to emerge from interviews with people affected by cancer, and a theory to develop about online cancer community use. A core category was developed and labelled *Navigating cancer using online communities*. Participants used support in online cancer communities to navigate challenges they faced with cancer. The navigation individuals made with the communities resulted in three categories of experience online. Firstly, the advice of community members and information in online groups set participants on a *journey to become informed*. Secondly, participants were cast into a *journey to recreate identity* as they connected and formed friendships online. Thirdly, participants navigated a *journey through different online worlds* to the most relevant and often hidden communities, and these virtual groups became closer to people's real lives and social networks.

CHAPTER SIX – DISCUSSION

This study aimed explore and understand the experiences and interactions of people affected by cancer who visit online cancer communities. The objectives of this study were to elicit in-depth experiential accounts of online communities from visitors affected by cancer, and to understand the perceptions, interactions, meanings, and consequences of these online cancer communities. The aims and objectives were met by developing an in-depth, theoretical understanding of how the online communities have been used in the lives of people affected by cancer. This is the final chapter in the thesis and presents an interpretation of the study findings. The findings are discussed in terms of the relevance and potential applications of this theory in academic knowledge, healthcare practice and the design of online cancer communities.

This chapter is divided into four sections. The first section discusses the relationship of key findings to existing literature. The second section examines the originality, strengths, and limitations of the study. The third section details the implications this study has on healthcare practice, policy, and internet research. The fourth section offers recommendations for future research in this field. The final section of this chapter summarises the main conclusions about this thesis.

6.1. The theory in context

This was the first qualitative study to explore the impact of online cancer communities in the lives of people affected by cancer. By utilising constructivist grounded theory methodology, experiences have been examined on a number of levels (Burawoy, et al., 2000; Charmaz, 2006). The study findings highlighted interactions that individuals made with groups, including previously unknown interactions such as the use of secret online communities. Grounded theory also allowed the importance of these experiences to be examined (Charmaz, 2003), presenting online cancer communities as valuable because they helped people to navigate cancer. These insights had important consequences for how we might utilise online cancer communities in supportive care, and how we should consider online communities in research. This section discusses the most pertinent findings in relation to existing knowledge and implications for the health and wellbeing of people affected by cancer. This is presented in relation

to the categories which emerged from the data, beginning with the core category which explained the overarching theory (*Navigating cancer using online cancer communities*), followed by the three categories which led from this core (*a journey to become informed; a journey to recreate identity; and a journey through different worlds*).

6.1.2 Navigating cancer using online cancer communities

This study offered a unique definition of what has constituted an online cancer community. This was an objective of this study, in order to have a clearer understanding about the existing online peer support available to people affected by cancer. Previous taxonomies of online communities have included personal websites, blogs, video diaries, Twitter, Facebook, and forums as part of a homogenous set of groups (Chui & Hsieh, 2012; Hwang et al., 2013; Im, 2011; Koskan et al, 2014; Preece & Maloney-Krichmar, 2006; Sillence & Mo, 2014). These have interchangeably been referred to as online communities, internet support groups, self-help groups, or social media. Alternatively, the present study found that a sense of community was particularly experienced in groups which focused on and facilitated interactions. Sites such as personal websites and blogs were not considered communities because they were centred on promoting individuals' own views, rather than interactions. This seemed to support Rogers and Chen's (2005) definition of online communities, which was used in the literature review of this study. Roger and Chen defined online communities as internet groups with a shared interest, shared rules, on-going and persistent interactions, and a sense of togetherness. However, this study has suggested that a caveat is needed in this definition to lessen the emphasis on persistent interactions. Lurking, or reading but not interacting with the community, was a valuable and significant part of using the groups in the present study. Seminar sociologist Benedict Anderson (2006) proposed that communities did not require every day face to face interactions for individuals to feel a sense of membership. Moreover, Somerville (2011) defined community as a sense of connectedness amongst individuals, and this was present in the way participants engaged with online communities in this research. Therefore this thesis has asserted that there was a particular sense of membership in interactive social media groups and forums online which may not be as easily

identified in blogging and personal websites. As the following sections of this chapter will address, online community had a unique impact on living with cancer.

In this study, online cancer communities were revealed as resources which helped people to navigate the impact of cancer on their lives. A Dictionary definition of navigation was “the process or activity of accurately ascertaining one’s position and planning and following a route” (Oxford Dictionaries, 2016). Similarly, in the present study online cancer communities were resources which allowed participants to determine their position with cancer, and plan how to manage present and future treatment decisions, side effects, and caring responsibilities. It was not surprising that participants were compelled to navigate cancer, as the conditions that motivated use of the groups represented common cancer concerns. *Experiencing a ‘void’, experiencing change, and wanting control* indicated that participants needed information, and felt uncertain and lacking in control. These experiences have been frequently reported amongst people affected by cancer (Miller, 2012; Rutten et al, 2005) and, without support, have led to greater emotional distress and lower quality of life after a cancer diagnosis (Arora et al., 2002; Mast 1998; Sammarco, 2001). Importantly, participants in the present study expressed a strong need to influence cancer experiences, and often sought online communities without or against the advice of healthcare professionals. This suggested that information, control, and uncertainty were a priority for people affected by cancer, and greater attention in supportive care may be needed to address these unmet concerns. These findings are informative, as in recent years healthcare has been striving to offer personalised care, or care which attends to the priorities of people affected by cancer (NHS England, 2014; Peterson, Knudsen & Vinter, 2015; Wensing et al, 1998). Thus, this study contributed to literature about patient centred care by highlighting that lacking information, control, and uncertainty or experiencing changes can be distressing, and lead people to require and seek support additional support.

Navigation was an active, participatory, approach to living with cancer. It encouraged a greater relationship between individuals and their perception of cancer, influenced interactions with healthcare professionals, and it encouraged

active decision-making in cancer care. This was an encouraging finding, as publications from the NHS England have suggested that patient and lay carer involvement with healthcare decisions can improve in reported service quality, care outcomes and general population health (Longtin, Sax and Piditt, 2010; NHS England, 2013; NHS England, 2014). In the UK, an active participatory approach to living with and adapting to cancer has been referred to as 'self-management'. Furthermore, cancer self-management programmes have been found to improve psychological and emotional concerns of people affected by cancer (McCorkle, et al., 2011). This has included improved depressed mood, uncertainty, anxiety and distress (Lewis, 2006; McCockle, 2009) and increased self-confidence and confidence in cancer knowledge (Braden, 1998; Lewis 2006). De Silva (2011) suggested that self-management can be supported in four ways: by supporting self-efficacy in taking control of care; teaching technical skills to care for oneself; providing information to ensure people feel informed; and encouraging behaviour change to influence healthy behaviours. Similarly, the present study found that online cancer communities allowed many people to believe that they could personally navigate, or self-manage, their care because they had access to a resource which kept them informed, supported their sense of identity, and connected them to a supportive network. This built on work in the literature review which suggested that communities might be suitable for active self-management of cancer concerns (Foster and Roffe, 2009; Kim et al, 2011; Kim et al, 2012). Moreover, self-management has been a key focus of cancer care research in the UK (Davies & Batehup, 2010), and thus the theory proposed in this study could inform the design of future self-management interventions. Specifically, this theory justified the inclusion of online cancer communities in self-management research on the basis that it may allow people to navigate cancer.

As an active approach to cancer, online community use may have been inappropriate for individuals who wanted to avoid cancer-related information, and to take a passive approach to the illness. Studies have found that many people affected by cancer have preferred to delegate decisions about their cancer care to healthcare professionals, and to avoid cancer related information (Degner & Sloan, 1992; Case et al., 2005; Miller, 1995). Cancer survivors have

taken this passive approach to cancer as a coping strategy (Manuel et al., 1987; Roth & Cohen, 1986; Steptoe et al., 1991). Passive, or avoidant, coping has involved avoiding information and experiences related to a stressor in order to avoid dwelling on negative thoughts and concerns. Surveys have reported that approximately 30% of cancer survivors have not wanted involvement in treatment decisions or additional cancer related information (Benbassat, Pipel, & Tidhar, 2010; Chewing et al., 2012). However, it is noteworthy that this figure has been found to vary considerably between different stages in the cancer trajectory, and different cancer types (Beaver et al., 1996; Luker, Beaver, Lemster & Owens, 1996). The participants in the present study were highly motivated to collect and obtain information. Furthermore, to access the social interactions in online communities, participants needed to implicitly learn information about cancer to understand which communities, threads, messages, and group members were most appropriate and relevant to them. Therefore, online cancer communities involved implicit and explicit engagement with information. Thus, online communities may have been unappealing or even detrimental to individuals affected by cancer with an avoidant approach coping style. After all, cancer information on the internet has been found to ease the anxiety of people affected by cancer wanted to engage with their care, whilst causing anxiety for individuals who did not want information (Friis et al., 2003; Sabel et al., 2005). Moreover, a recent study of online cancer communities found that individuals who took an active approach to address the emotional impact of cancer were more likely to benefit from online cancer communities than those who took a less active approach to cancer (Batenburg & Das, 2014). Thus, online cancer communities may address a particularly active style of coping, and may not be suitable for people who employ a more avoidant approach to cancer.

Participants in this study turned to online communities partly because they were familiar with and habitually used the internet. This seemed to suggest that people who have been unfamiliar with the internet would not seek out and use online communities. This study did not make direct comparisons between online community users and non-internet using cancer survivors. However, this would be an important area of future study as there has been a digital divide in

the UK which could perpetuate health and support inequality (Saveloy et al., 2009). A 2015 survey found that 14% of adults in the UK were not regular internet users (Office for National Statistics, 2015a). Additionally, a higher proportion of non-internet users were people living with a disability, compared to able people (Office for National Statistics, 2015a). These findings did not indicate which disabilities these non-internet users were living with, not whether people living with particular disabilities were more or less likely to use the internet. Nevertheless, being offline meant that these populations were less likely to be familiar with using the internet and therefore may not consider using online communities to support a cancer diagnosis (Debronski & Hargittai, 2006). Moreover, people living with disabilities have been found to have high needs for social and emotional support (Shultz, & Deck, 1985; Tuffrey-Wijne, Bernal, Jones, Bulter, & Hollins, 2006). If supportive care increasingly moves online, in accordance with objectives for the future strategy of the NHS (National Information Board, 2015), there may be a proportion of people needing but being unable to access support. Thus, this research has provided evidence that encouraging more of the population to use the internet, and supporting disabled populations to get online, may provide them with better opportunities for support. It was also important to also note that there will always be people unable or unwilling to use internet technology for support, and thus support services should always be available offline for people affected by cancer.

6.1.3 A journey to become informed

The present study found that people could feel better informed about cancer when they used online communities. This could be a significant finding for populations affected by cancer. The patient and family benefits of having information about cancer have been well documented; information has increased cancer survivor satisfaction (Iconomou, Vanenakis, & Kalofonos, 2001), alleviated feelings of uncertainty, loss and fear, and allowed people to feel increased control over their future (Hours et al, 1991; Jefford and Tattersall, 2002). However, studies have consistently found that people affected by cancer have experienced unmet needs for information (Sanson-Fisher et al, 2000; Rutten et al, 2003). The present findings suggested that online communities may meet and support these informational needs. This supported evidence

identified in the literature review which suggested that many communities contain high levels of informational support (Blank et al., 2010; Coulson & Greenwood, 2012; Huber et al., 2011; Love et al, 2012). Thus, online cancer communities could be perceived as a valuable informative resource for people affected by cancer.

Online community use gave participants the opportunity to build their cancer knowledge incrementally; at first viewing and researching small elements of messages, and later using the knowledge gained to explore more complex concepts. This 'learning curve' style of information provision contrasted dramatically with the traditional approach of providing large amounts of information in a single sitting at healthcare consultations (Ardern-Jones, Kenen, & Eeles, 2005; Fujimori & Uchitomi, 2009). Moreover studies have found that this latter approach has resulted in cancer survivors and family forgetting details of health information, and feeling uncertain about the illness (Jolles, Clark, & Braam, 2012; Watson & McKinstry, 2009). Alternatively, online communities gave participants in the present study the opportunity to reinforce the information they had gained from professionals. Furthermore, participants of the present study stated that other members of the communities were often instrumental to the knowledge they gained, as they could ask questions and be directed by others to useful resources. This process was consistent with 'scaffolding learning', a learning method which posited that individuals could reach a further level of knowledge about a topic when they took steps to build their knowledge, and when they were aided (Butler & Winne, 1995; Kozulin, 2003). This scaffolding learning theory has had a major influence on education, and has more recently been posited as a guide to educating adults about medical conditions and treatments (Biswas et al, 2012; Daniels et al, 2007; Kazimeirczak et al., 2013). Thus, these findings suggested that online cancer communities offered people affected by cancer a valuable learning opportunity.

Most participants felt empowered as they became informed through online cancer communities. Empowerment has been an important notion in recent healthcare policy and practice. In the UK, the growing population and rate of cancer survival has been steadily causing an increased demand on cancer services (Maddams, Utley, Møller, 2012). Thus, policy in recent years

has been placing a greater emphasis on patients' responsibility for their personal wellbeing (National Information Board, 2015). Studies have shown that people affected by cancer have needed to feel empowered and able to affect changes in order to feel motivated for cancer self-management (Anderson & Funnell, 2005; McCorkle et al., 2011). People affected by cancer have also needed to understand practically how to self-manage their or their family member's cancer care, including physiological and psychosocial needs (Kuijpers, Groen, Aaronson, & van Harten, 2013). In the present study, use of online cancer communities generated knowledge about how to manage concerns, increased confidence, increased self-esteem, and promoted the view individuals were capable of managing their care. Thus, online cancer communities could be a valuable resource for empowering people affected by cancer, enhancing the ability for individuals to self-manage their cancer concerns.

The present study found that online cancer communities had particular advantages for families affected by cancer. Firstly, the online communities were a readily accessible source of support, whereas families struggled to find the appropriate time to communicate and consult with professionals. This could address families' information needs, as studies have commonly found that families have difficulty contacting healthcare providers, yet have shown significant need for information (Harris, 1998; Adams et al, 2009). Secondly, online cancer communities allowed families to access information about cancer without feeling guilty or disrespectful to their family member, particularly information about death and dying. This was a significant finding, as studies have argued that more needs to be done to inform lay carer givers how to provide care and support at the end of life (Huson, 2006; Loke, li, & Man, 2013). Furthermore, studies have shown that families' bereavement after cancer can be exacerbated by feeling that they failed to care for their family member (Koop & Strang, 2003) and prolonged grief could lead to families requiring additional post-bereavement support (Schultz et al, 2006). Thus, the present study supported the assertion in the literature review that online communities might be a particularly valuable resource for carers and family of people living with cancer (Blank et al., 2010; Coulson and Greenwood, 2011), and these groups

may be particularly valuable for delivering support to people caring for dying cancer patients.

The findings of this study addressed concerns that people affected by cancer may be misled if they rely on online communities as a source of information. Studies have found that health information shared online was frequently inaccurate, incomplete, and this could mislead healthcare service users (Eysenbach, 2008; Eysenbach, Powell, Kuss, & Sa, 2002). This has also been a primary concern in surveys of healthcare professionals' opinions of online peer communication (Ferguson, 2006; Hughes, Joshi, & Wareham, 2008). However, participants in the present study did not rely on online communities as their sole source of information. The groups became an information hub used for querying experiential aspects of the illness, conducting further research, and for gaining confidence and skills to communicate with healthcare professionals. Furthermore, this study largely supported findings that healthcare professionals have been peoples' primary and most trusted source of health information (Ryhanen et al., 2012; Satterlund et al., 2003). Therefore, the present study has posited that online communities were a useful tool for engaging people affected by cancer with information. Moreover, participants discussed the information they found online with their healthcare professionals. It was not in the scope of this study to explore healthcare professionals' perceptions of discussions about online community information. Nevertheless, it might be useful for future research to evaluate these discussions, as they seemed to be a useful opportunity for professionals to refute or correct any misleading information that had met the attention of people affected by cancer. Moreover, this shared conversation could facilitate active decision-making, which Charles, Gafenu, and Whelan, (1997) argued occurs when both healthcare professionals and patients to contribute information to the healthcare discussion.

Several participants in the present study struggled to manage the wealth of information in communities, and subsequently became overwhelmed by information. This was an important finding because studies have found that overwhelmed cancer survivors can struggle to make treatment-related decisions (Leydon et al, 2000; Ubel, 2002; Ubel, & Loewenstein, 1997). The solution to

this, presented by the participants in this study, was to develop a better strategy for sifting through online groups. This strategy needed to clarify which communities, messages, and group members may or may not be relevant for their personal experiences. For instance, key terms and phrases related to the individuals' personal treatment plans were a useful starting point for discovering online messages and threads. However, participants received little guidance from professionals about their use of online cancer communities. In fact, several participants were advised not to use the groups. This was not surprising, as there has been no published policy or guidance advising professionals how to communicate about online health behaviours. Nevertheless, advising on strategies for using online communities seemed to be a key opportunity for individuals to be directed to the most accurate sources of information. A European survey of cancer related internet use found that people would feel less overwhelmed or confused if they were directed to the most appropriate sites by their healthcare professionals (Maddock et al, 2011). Similarly, McMullan (2006) suggested that if professionals acknowledge and discuss a patient's search for knowledge online, they can guide them to more accurate sources and conclusions (McMullan, 2006; Bradway, Arsand and Grottnland, 2015). Thus, this study has demonstrated that healthcare professionals could offer advice for online cancer community use, and this might support online navigations by reducing the likelihood of people feeling overwhelmed.

6.1.4 Journey to recreate identity

This study found that participants' personal and social identities altered as a result of online community interactions. This was a significant finding for cancer populations, as studies have found that many experience identity crises after the diagnosis (Mathieson & Stam, 1995; Zebrack, 2000; Deimling, Bowman & Wagner, 2007). Cancer has been considered 'stigmatising' because it is associated with progressive illness and dying, and individuals have struggled to discuss their fears and seek support (Crocker, Major, & Steele, 1998; Greene and Banerjee, 2006). The treatments and related side effects of cancer often altered individuals' working lives, day to day capabilities, and personal relationships (Matthieson & Stam, 1995). These have been important elements of an individuals' identity (Weinreich & Saunderson, 2003). Moreover,

studies have found that the way individuals consider their relationship with cancer can influence their wellbeing and quality of life (Deimling, Bowman & Wagner, 2007; Park, Zlateva & Blank, 2009). Evidence has shown that an identity as a cancer 'survivor', one which emphasises an active involvement in surviving the illness, can promote better quality of life than an identity as a 'patient' or 'victim' (Morris et al, 2014; Zebrack, 2000). In the present study, many participants considered their interactions in online communities as evidence that they were personally overcoming, or surviving, challenges they associated with cancer. This was particularly pronounced when participants become a positive source of information and help for newer members of online communities. Thus, online communities could be considered useful tools for helping people affected by cancer to achieve a more positive outlook on their lives with cancer.

This study found that people experienced pronounced personal benefits when they began helping other members of the online cancer communities. This phenomena reflected the helper-therapy principle (Greidanus, & Everall, 2010; Reissman, 1965). Reissman (1965) proposed that helping, supporting, and providing assistance resulted in the helper experiencing psychosocial benefits. Roman et al (1999) investigated this principle in community health workers, and found that supporting others in their professional capacity benefitted healthcare workers' personal sense of self, and belonging. Similarly, studies in the literature found that posting messages could improve cancer survivors' ability to positively reframe cancer (Foster and Roffe, 2009; Kim et al, 2012; Seckin 2011). In the present study, participants who helped other community members were often proud of their actions, expressing a feeling of 'redeeming' the negative experiences of the cancer diagnosis. Thus, these findings implied that people affected by cancer could benefit from encouragement to contribute to online communities (Sears, Stanton, & Danoff-Berg, 2003). However, a recent study found that encouraging prosocial or helping behaviours in online communities caused an increase in depression and anxiety amongst people affected by cancer (Lepore et al, 2014). The theory proposed in the present study may explain Lepore and colleague's findings, as this study emphasised that participants needed to be on the correct stages of

their identity journey in order to support people affected by cancer. Lurking, or non-posting and non-helping behaviours, had an important function for people affected by cancer, and this is discussed in further depth in the following section of this chapter. In summary, this study has found that posting behaviours have been beneficial to people affected by cancer, but specifically when people have felt able to reflect on and respond to the needs of other people affected by cancer.

When using online cancer communities, participants aligned their identity to group members, threads and messages. In some cases, individuals found comfort from messages which allowed themselves to assert salient aspects of their previous identity, such as being a 'strong woman'. In other cases, individuals' experiences became normalised as they found that members online shared similar thoughts and feelings about cancer. This was consistent with the social comparison theory (Festinger, 1954). Social comparison theory posited that individuals evaluated their own opinions and abilities by comparing themselves to others. Through this comparison, individuals altered how they defined themselves. Social comparison has been well documented in people's perception of their health and wellbeing (Buunk, Gibbons, & Buunk, 1997). Studies have suggested that the greater an individual identified with a health support group or community, the more psychosocial benefits they were likely to experience (Cruwys et al, 2014; Jetten, Haslam, & Haslam, 2012; Wakefield, Sani, & Bickley, 2013). Moreover, online communities proved a particularly valuable resource for social comparison, because the participants of this study struggled to meet face-to-face with people they could compare and evaluate their experiences with. People connected based on various aspects of their identity, such as age, family and marital status, in addition to cancer type and treatments. Thus, comparisons with online community members allowed people to develop of holistic understanding of life with and after cancer.

Participants benefitted when they found people like themselves in cancer communities. In contrast, being unique and different to other community members was isolating. This was also consistent with the social comparison theory; groups that strongly identified have been found to form stereotypes based on shared experiences and values (Hogg, 2000; Tajfel, & Turner, 2004;

Turner, Hogg, Oakes, Reicher & Wetherell, 1987). Sarnoff and Zimbardo (1961) argued that social comparison resulted in individuals who could not fit into the stereotypes feeling excluded, and sometimes ostracised, from groups. In the present study, having a rarer cancer or treatment path resulted in people stepping off the online cancer navigation journey, preventing them from experiencing social support online. This was concerning because studies have found that a lack of social support can have a direct effect on individuals' ability to self-manage their personal care (Macmillan, 2013). Furthermore, a recent report has suggested that being people diagnosed with a rarer cancer have a less positive experience with cancer care and services compared to people diagnosed with the 'big four' cancers (breast, lung, bowel and prostate cancers) (Smith, 2015). Thus, people affected by rarer cancers may have greater support needs, but online communities may be less suitable to offer these individuals in-depth support. However, the connection between rarer cancer and lesser online support was not a definitive finding amongst this sample. There were several participants living with a relatively rare cancer in this study, such as melanoma, ovarian cancer, or sarcoma, and these participants found people like themselves in online communities. In order to better understand the support needs of people affected by less common cancers and treatment plans, it may be prudent to conduct further work in this area.

This study found that when online group members died, people affected by cancer became distressed, bereaved, and their identity and perceptions of cancer altered. There has been limited attention in the literature to the impact of other people's deaths on people living with cancer. Studies exploring people's attitudes to death have found that younger people, in the general and in healthcare populations, have a greater anxiety about death and dying than older people (Maxfield, 2007; Robinson & Wood, 2007). Authors have theorised that as people have aged, they developed a greater acceptance of dying (Hall, Longhurst, & Higginson, 2009). The sample interviewed in the present study were relatively young, and it might be unsurprising that they were concerned about dying. However, the death of friends online was particularly upsetting for participants in this study as it reignited fears about their own mortality, and it prevented people from coping with these fears. This was a concerning finding

because death anxiety in health populations can be detrimental to psychosocial wellbeing and adaptation to illness (Gonan et al, 2012; Serman, Norman, & McSherry, 2010). For instance, Gonan et al (2012) found that people affected by cancer concerned with death and dying were also more likely to experience depression and anxiety. Thus, there seemed to be a significant need to support the bereavement experiences of people visiting online cancer communities.

6.1.5 Journey through different worlds

This study found that people tailored their journey through online worlds to discover communities, threads, and messages that would meet their needs. This was often related to where individuals were in their cancer trajectory. This seemed to reflect principles of personalised health information systems. Personalised health information systems have been created to deliver information tailored to people's specific cancer trajectory. Most recently, these systems have investigated the efficacy of connecting online health records recorded and updated by health professionals, with internet information services delivered to cancer survivors (Bental, Cawsey, & Jones, 2002; Cawsey, Jones, & Pearson; Noar, Benak & Harris, 2007). Thus, personalised health information systems have delivered information via the internet, which has been specifically relevant to people's cancer journeys. However, healthcare services have reported difficulties delivering personalised health information and support (DiMarco et al., 2006; Duffy, 2007; Watson et al., 2012). Studies have found that people affected by cancer's needs for information and support have changed and adapted as they lived longer after cancer (Aranda et al., 2005; White et al., 2012). Moreover, it has been difficult to determine how much information and support individuals need, as needs can also differ from person to person. In online communities, many participants tailored their search of information and support to meet their own needs. This may be a beneficial feature of online cancer communities because access to personalised information has been found to reduce cancer survivors' feelings of anxiety and support learning about the disease (Jones et al, 1999; Jones et al, 2006). However, unlike studies which have investigated personalised or tailored health information systems, visitors to online cancer communities needed to identify their own path through online communities to relevant information. It might be

prudent to combine future personalised health information systems with online communities, in order for visitors to communities to have a reputable guide for what information they might need to seek and discuss online.

This study demonstrated that lurking online had a valuable function for people affected by cancer. Lurking behaviours have been understudied in cancer communities and in other healthcare communities (Setoyama et al., 2011; Preece et al., 2004; Nonecke, 2000). Early internet researchers separated lurkers from active participators of online groups, arguing that the former were 'social freeloaders' who used online communities for information, with little regard or attention paid to the social environment (Kollock & Smith, 1996). Alternatively, this present study supported more recent assertions that lurking was an active and responsive process, in which individuals were listening members of communities (Crawford, 2011; Lee, Chen and Jiang, 2006, van Uden-Kraan et al., 2012). The present study also highlighted that people lurked in communities when they were considering leaving online communities by slowly reducing their posting activity, or dipping into the groups less frequently. Studies exploring lurking have produced inconsistent findings in terms of measurable psychosocial improvement for people affected by cancer. On one hand, one study of lurkers in communities for breast cancer, fibromyalgia and arthritis found that lurkers reported significantly lower social wellbeing than posters (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). On the other hand, a recent study of cancer survivor lurkers found that lurking resulted in group visitors feeling more enhanced quality of life after using online communities for three months ((Han, Hou, Kim, & Gustafson, 2014). Setoyama, Yamazaki, & Namayama, (2011) found that both lurkers and posters in a cancer community experienced beneficial peer support, but posters experienced more pronounced support. This study could explain this diversity in findings by suggesting that lurkers were not a homogenous group of people, and individuals may have lurked more than others at different times in their cancer journey, or journey with online communities. Thus, these apparent differences in lurking scores may have been due to the need to understand more about the individuals lurking in the communities, for instance whether they were at the beginning of their use of online communities or at the end, and

whether they had found alternative online communities. The literature review in this study identified two RCTs in which non-posting behaviours was discouraged (Classen et al., 2013; Klemm, 2012). On the contrary, the present study findings have suggested that lurking group members should be respected and encouraged. Similarly, the findings of this study demonstrated that future high quality online cancer community research should encourage both lurking and posting behaviours.

A significant finding in this study was that people could join a meaningful social network online. Sociologists have debated whether an online community can be likened to a face-to-face community (Bauman, 2013; Castells, 2011; Delanty, 2010). For instance, early internet theories suggested that because the internet lacks facial, conversational, and tonal cues, groups of people could not form meaningful connections online (Barak & Suler, 2008; Suler, 2004; Wilson & Peterson, 2002). The theory presented in this study refutes this concept, as many participants showed a sense of kinship, shared experience, and commitment to their online communities. This was important, because a report of cancer survivors in the UK found that one in four felt social isolation during their treatment and recovery (MacMillan, 2013). Furthermore, participants demonstrated signs of developing social capital as they used online cancer communities. Social capital has been defined as the features of social groups which facilitated collective group action such as support and healthy behaviours (Kawachi & Berkman, 2000; Putnam, 2001; Putnam, 1993). In cancer populations, social capital between peers affected by cancer has been found to improve stress and depression, and increase engagement with coping behaviours (Beaudoin & Tao, 2007; Beaudoin & Tao, 2008). Moreover, the if participants in the present study perceived their online interactions as part of a 'community', they expressed greater commitment towards group members. This indicated greater feelings of social capital in such communities. These findings suggested that reported friendship style communities could be valuable for isolated people affected by cancer.

This study has provided original insight into differences between public and secret groups available online for people affected by cancer. Participants in the present study stated that their expressions in public communities were not

as open and honest as their expressions in private and secret communities. Participants reasoned that when they could see others' true identities, they had greater rapport with others. This was a surprising finding, as theories of online behaviour had suggested that anonymous communication elicited open and uninhibited discussions (Suhler, 2004; White & Doorman, 2001). The findings in the present study could have a significant impact on internet research, particularly methods which have used transcripts or select messages from online communities as data (Hookaway, 2008; Keeling, Khan, & Newholm, 2013; Walther & Boyd, 2002). Studies have argued that it has been beneficial to collect data from online communities because these groups reflect honest and relatively natural conversations which have not been influenced by the presence of researchers (Liang and Scammon, 2011; Kozinets, 2011). However, this study identified important behaviours which would not register with these data collection methods; lurking, and the use of highly private or secret groups. Furthermore, this study highlighted that people have elected to post more informational, or more emotional content depending on the group they used. Therefore, research which has chosen to use freely available information in online communities should be aware of the nuances in online behaviours.

6.2. Evaluating this study

This section reflects on the quality, repeatability, and applicability of this study by evaluating the benefits and limitations of the methodological approach and the methods. Firstly, the original contribution this study made to knowledge is outlined. This section then describes the measures that were taken to ensure that rigour was evident in the present study findings. Following this, the background, training and potential bias of the research student will be highlighted, to consider how this may have influenced the development of the findings. Finally, this section will discuss the limitations of the study methods and how they might have impacted the findings.

6.2.1 Original contributions to knowledge

This study has made a unique contribution to several bodies of knowledge. Firstly, this study has illuminated the in-depth views of visitors to contemporary online communities. These understudied perspectives offered original insight which has increased knowledge about using online communities,

highlighted the presence of secret social groups, and refined what constitutes an online cancer community. Secondly, this study has revealed how people discover, use, and which features people value from groups. This contributed knowledge to the design and implementation of current and future online cancer communities. Thirdly, this study added insight into the potential impact of policy literature regarding supportive resources, which have a distinct lack of specific attention to internet peer communication. Fourthly these findings have extended current knowledge about the support needs of people affected by cancer. Participants used online cancer communities, often with very little guidance, and therefore their actions demonstrated people's priorities and concerns when living with cancer. Finally, this study has contributed to the growing field of internet research methods. Primarily, this study demonstrated that experiential information can provide a richer insight into the value of online resources for their users, compared to online data collection or content analysis of websites. Additionally, this study demonstrated the effectiveness of online recruitment techniques, which have been rarely utilised in psychosocial research. Advertising in forums, Twitter, and Facebook allowed this study to reach relevant potential participants across the country, and also had an international reach.

6.2.2 Reflecting on rigour

Charmaz (2006) stated that a rigorous grounded theory was one which adhered to the principles of the methodology and the theoretical paradigm in which it was developed (Creswell & Miller, 2000; Golafshani, 2003). Charmaz (2006) provided four criteria which needed to be followed to ensure that the research project rigorously explored and rendered the study data in the development of theory. Firstly, the findings needed to be credible in terms of the connections and relationships that were presented, and accurately reflected the field of study. Secondly the findings needed to make an original and significant contribution to the field. Thirdly the grounded theory needed to resonate with the study population. Finally, the study needed to produce useful findings and insight, which could make an impact on health and supportive care practices. This section now details the actions that were made to make this grounded

theory a transparent, valuable, in-depth and honest interpretation of visitors' experiences with online cancer communities.

To achieve credibility the study attempted to achieve intimate familiarity with online cancer communities and participants' understanding of them. The research student observed publically available online forums to develop background knowledge of their key features. The research student also contacted managers of different online cancer forums to discuss their perceptions about the groups and about those who communicated within them. This included managers of large online communities such as Breast Cancer Care's forums, Roy Castle Lung Cancer Foundation's communities, and also managers for newer and smaller online forums such as Anthony Nolan's forums for people who have had a bone marrow or stem cell transplants. In addition, the research student collected a wide range of empirical observations, and gathered sufficient in-depth data to support the knowledge claims (Charmaz, 2006). This was ensured by using theoretical sampling techniques during the interviews, and interviewing until data saturation was reached. To ensure that the conclusions were logical, the research student presented the emerging evidence and analysis amongst the research team. Furthermore, in line with constructivist grounded theory methods, deductions and arguments made during data analysis were asked and tested in subsequent interviews. For instance when defining the concept of community, the research student tested the preliminary definition of a sense of 'community' by questioning participants, and adapted the working definition of community until it matched the experience described by participants.

Originality was an essential component of the PhD process, in addition to the development of grounded theory. Thus, the original contributions this study made to knowledge were distinctly highlighted in the previous section of this chapter. Primarily, it should be noted that this substantive theory has been the first in-depth exploration of how people have used contemporary online communities to affect changes in their lives with cancer.

The resonance of the findings of this study was explored in a number of ways. The findings of this study have been presented in several forms to

different audiences. The findings were summarised and sent to the participants by email, and a copy of this summary can be found in Appendix 13. Participants were invited to comment on the conclusions made in the study to ensure that they were an accurate representation of experiences, and no changes were recommended by participants during this process. Online community managers have also been sent a summary of the findings of this study and, through telephone and email conversations, they have offered their opinions about the perceived implications of this study. An example of a summary sent to online community managers can be found in Appendix 14. This action helped to understand the importance of the findings and revealed, for instance, that several online managers did not have protocols about how to react when an online community member died. Moreover, this helped to understand what this theory meant for populations involved with online communities, and illuminated potential implications for practice. Thus, this touched upon the final criteria for a grounded theory, the usefulness of the findings. The usefulness of this grounded theory has been further outlined in the implications section of this chapter.

6.2.3 Reflecting on the impact of the research student

A core understanding in this constructivist grounded theory was that the findings of a study were expected to be influenced by the worldview of the research student (Holstein and Gubrium, 1995; Charmaz, 2006). Whilst the participants provided the insight into online cancer communities, they answered questions devised by the research student, who chose what areas of interest to probe, analyse, and report. For example, the research student chose to present the findings using the metaphor 'navigation'. This term, and related terms of 'journeys', were taken directly from the data (Charmaz, 2006). However, there were other metaphors present in the data, and the decision was made to represent the findings using the term that resonated with the research student's perception of the phenomena. Whilst measures were made to immerse the research student in the perspectives of the participants, this influence of the research student could not be removed from the study. For transparency, it was important to highlight the worldview of the research student and how this may have influenced the findings.

The research student highlighted in the methodology chapter that this study would be conducted using the theoretical lens of symbolic interactionism. Symbolic interactionism posited that social interactions have shaped the way people view the world (Blumer, 1969). Therefore, this study explored participants' experiences with the assumption that social interactions were meaningful, and would shape experiences and perceptions. The resulting findings of this study outlined how different interactions produced different perceptions of the world, for example, interactions with information online allows people to feel informed and empowered. However, pursuing this area of study through a different theoretical lens may have emphasised different aspects of participant experience.

Secondly, the research student studied undergraduate psychology prior to conducting this research. Though reading about this topic covered a diverse area of disciplines, the student began this study particularly familiar with psychological theories of behaviour. This may have influenced the worldview that drove this study. In addition, the research student had no clinical background. This could be perceived as a disadvantage, as the research student may have been less familiar with aspects of online communities that could have an important impact on clinical practice in cancer care. However, this can also be considered a strength of this study. The research student brought few preconceptions to this study about the clinical utility of online cancer communities, and represented what people affected by cancer valued about the groups, rather than how they could benefit practice.

6.2.4 Reflecting on the study methods

This section reflects on the methodology, recruitment technique, sample, and methods used in this study. Particular considerations are given to the study limitations as this forms a basis for a discussion about the applicability of the research, and informs recommendations for future work in this field.

Reflecting on the methodology and methods

This grounded theory methodology produced valuable and original insights into individuals' experiences of online cancer communities. However, on reflection, this study would have also been suitable for an ethnographic approach. Ethnographic approaches have been used to understand the

relationship between culture and behaviour (Hammersley & Atkinson, 2007). This study demonstrated that cultures have certainly developed online, as groups developed rules for appropriate behaviour, and members of online groups could have different roles and responsibilities. These were two examples of cultural behaviours (Frake, 1982; Griffin & Bengry-Howell, 2007). An ethnographic approach might have combined different pieces of data, for instance interviewing with observations of online communities, to produce a great analysis of the interactions that occur between members (Hammersley & Atkinson, 2007). Observation in online communities has been a contested method in research ethics (Carpurro & Pingel, 2002; Eysenbach & Till, 2001). In the present study, participants who were group moderators invited the research student to join secret online communities. After some consideration, this offer was declined. This decision was made because the emerging findings suggested that the 'secret' groups had an emotional significant for many of the participants in the present study, who perceived them as a safe and non-voyeuristic space in which they could share their experiences openly. Therefore, it did not seem ethical to enter private or secret groups to watch behaviours without receiving ethical approval from all participating members. Thus, this was eliminated as a potential data collection method in this study. Nevertheless, if this study was redesigned, it might have been useful to have developed and observed an online cancer community with full informed consent of group members. This may have provided greater insight into the formation and development of culture in online cancer communities.

This study explored online communities through interviews with people affected by cancer. There have been a few limitations to this method that may have biased this study. For instance, the study relied on participants recalling their experiences, and there was a risk that some participants may have provided inaccurate or incomplete memories of a past event (Hassan, 2006). This was possible in this study, as several participants had used online communities for many years, and in the case of one participant, up to eight years. Recall bias could have meant that this study missed the nuances of experiences that individuals felt at the moment of entering an online community or posting a message. Despite this recognised limitation of interview studies,

the research student believed that the participants offered honest accounts of their experiences.

Interview methods may have influenced the study because they were relatively time consuming, with some interviews lasting approximately two hours. The potential length of interviews was highlighted in the study advertisements and information sheet, to ensure participants were fully informed. However, this may have resulted in individuals who had particularly strong opinions of online communities to contact and consent to be interviewed. Alternatively, individuals who had less clear or strong opinions about communities may not have felt eligible to contribute an hours conversation to this study.

Reflecting on the study sample

The sampling strategy used in this study was beneficial to the aims of this research. Sampling online reached people who had a range of experiences using online cancer communities. During recruitment, attempts were made to keep track of how widespread the advertisements were sent and received. This was recorded by observing the number of views adverts received in forums and how many times they were shared in Facebook and on Twitter. It emerged that this was not an effective approach for recording the reach of the recruitment poster. Several individuals found the study in places the research student had not anticipated, for example on the social network Google Plus and in private and secret groups. This suggested that the snowball sampling did indeed snowball when advertisements were posted online; interested individuals had found the advertisement and sent it on to an additional network of friends and potential participants. Online recruitment techniques have received limited attention in the literature, and therefore this reach of the study was initially surprising to the research student (Baltar & Brunet, 2012). However, in light of the findings of this study, it was not surprising that this advertisement was shared amongst private communities, in which sharing current cancer news of research was valued, and in groups which could become important networks for people affected by cancer. Thus, this generated important lessons about the lack of control and reach of online snowball sampling methods. Future

researchers may not be able to record the effectiveness of their online recruitment strategy if it is taken into private online spaces.

This sample was limited by over-recruitment of certain demographics and under-recruitment of others. Firstly, there were a surprising number of requests to participate from people affected by melanoma and ovarian cancer. Melanoma was the fifth most common cancer in the UK, whilst ovarian cancer was the 15th most common cancer in the UK (Cancer Research UK, 2016). These cancers were significantly less common than the four most diagnosed cancers in the UK, (breast lung, prostate, and bowel), which together account for approximately 53% of UK cancer diagnoses (Cancer Research UK, 2014). People affected by breast, ovarian, prostate, and bowel cancer were interviewed in the present study, but far fewer people affected by these cancers indicated interest in the study than those affected by melanoma and ovarian cancer. The prevalence of people affected by melanoma was interesting, and could suggest that communities were particularly utilised by groups of people affected by melanoma. Alternatively, the prevalence of people affected by melanoma in this study could have been caused by the online recruitment strategy. Several participants contacted the researcher from the same secret online community for melanoma, and it emerged that an advertisement had been shared in this group. The lack of control of the online snowball sampling strategy may have resulted in the study advertisement not being distributed amongst a representation of the different groups available to people affected by cancer online. This did not seem to make a significant difference to the findings of this study. This grounded theory did not intend to present a representation of the different cancer populations in the online groups, but rather a representation of experiences with the online cancer communities generally (Charmaz, 2012). Moreover, the theoretical categories in this substantive theory seemed to be experienced across people affected by different cancers. However, future research using an online recruitment strategy should be aware that research shared online may oversample particularly active private individuals from private online communities.

The sample in this study were mostly white British. Ethnic minority groups have been commonly under-represented in research in the UK

(Hussain-Gambles, Atkins & Leese, 2004; Samsudeen, Douglas & Bhopal, 2011). Studies suggest that this may have been due to negative cultural perceptions of research, or language and literacy barriers preventing the study being accessed and understood by non-English speaking populations (Hussain-Gambles et al., 2004; Lloyd et al, 2008). This may have caused the lack of cultural diversity in the present study, as this research was only advertised in English, and through English language only online cancer communities. Alternatively, online cancer communities may have a greater appeal to people with a white British background. Studies of American online cancer communities have found that people with a white ethnic background were significantly more likely to use online communities than populations living with cancer from Asian, African American, or Hispanic backgrounds (Fogel et al., 2008; Im & Chee, 2008; Im, Chee, Lee, 2011). Im, Lee, and Chee (2010) suggested that Asian communities felt marginalised in mainstream, white dominated online communities. Fogel et al (2010) suggested that African American cancer survivors might mistrust online communities, or prefer a culture specific community. There have been no studies which have explored online community use by minority ethnic communities in the UK, and so it is unclear what might have caused the lack of representation in this research. However, a key finding highlighted in this discussion was that stereotypes around common experiences could form in online cancer communities, and participants felt excluded if their experiences were rare in the groups. Therefore, it may have been possible that people from ethnic minorities were less likely to use UK national online communities as they felt marginalised by the groups, and thus they were not recruited into this study. Unfortunately, it was not possible to explore this in the present study. Only one participant in this study was not white British and this participant did not raise her ethnicity as a factor affecting her experience of online cancer communities. This single experience was not enough to represent the experiences of diverse groups of ethnic minorities in online cancer communities. Therefore, it may not be possible to generalise the theory presented in this thesis to the experiences of people from ethnic minority backgrounds. Further research is needed before online cancer community use can be recommended to people from ethnic minority backgrounds in the UK.

The sample of participants had an average age of 50 years, which was relatively young for a population of people affected by cancer. There may have been several reasons for this finding. For instance, studies have found that younger populations have been more responsive and capable in terms of technology and internet communities. Indeed, a motivating factor for participants using online communities was their familiarity with the internet. A report in 2015 found that in the UK only 33% of people over 75 years were using the internet (Office for National Statistics, 2015a). Thus, there may have been a greater number of younger populations in online communities and willing to participate in this study. In addition, studies have suggested that younger cancer survivors were more likely to want to take an active role cancer experience, whereas studies reported that a significant number of cancer survivors over the age of 70 still preferred to take a passive patient role (Elkin, Kim, Casper, Kissane, & Schrag, 2007; Maly, Unezawa, Leake, & Silliman, 2004). Online cancer community use was notably an active engagement with the experience of cancer, and therefore it may have been a particularly appealing resource to younger populations. However, studies have argued that training older populations to use digital health media has increased active participation in their healthcare, and was acceptable for elderly populations (Arif, Emary, & Koutsouris, 2014; Lam & Chung, 2010). Moreover, evidence has shown that each year older members of the UK population are increasingly using the internet (Office for National Statistics, 2015a). The theory presented in this study may be increasingly applicable as the population ages, becomes increasingly digital, and increasingly active in their approach to healthcare.

This study sample was highly educated, as most participants had an undergraduate degree. Studies have suggested that people with less formal education have been more likely to take a passive, rather than an active role in their healthcare and cancer journey (Davis, Koutandtji, & Vincent, 2008; Levinson, Kao, Kuby & Thisted, 2005). Studies have also found that people with less formal education have been less likely to use the internet in their health behaviours (Fogel, Albert, Schnabel, Ditkoff & Neugut, 2002). Therefore, this study may have struggled to recruit participants with less formal education if the groups did not appeal to a passive approach to cancer. However, this study

revealed that online communities required a level of literacy that may have made them inappropriate for people with limited education or with intellectual difficulties. Navigating cancer in online communities involved a range of skills, from discovering the groups through search engine research, to sifting through groups for information and learning to use different platforms and different online communities. Moreover, the use of online communities seemed to require competency in interpreting complex medical terms shared online, and communicating by composing in-depth messages. This suggested that people required a degree of education and intellectual competency to unlock and access the support in online communities. Thus, the theory presented in this thesis suggested that online cancer communities may not be an appropriate form of support for people with less formal education.

6.3. Implications of the findings

The theory proposed by this study offered original insight into how visiting online cancer communities could impact use of healthcare services, healthcare professional and patient interactions, and perceptions of charity led online forums. Given the rise of internet access and online behaviours in the UK (Office for National Statistics, 2015b), it was necessary to outline how use of online communities might be affecting the practice of cancer care, or could affect changes in the future. Additionally, it emerged that key adaptations in practice and policy might improve people's experiences of online cancer communities, and could potentially benefit health service resources. These implications are highlighted in this section.

6.3.3 Implications for UK government policy

To date, no online cancer communities have been endorsed by the UK NHS to be recommended to people affected by cancer. The findings of this study suggested that the resources of the health service could benefit from offering and recommending online communities to people affected by cancer. This study found that communities met well documented information, identity, and social needs of people affected by cancer. Moreover, this study demonstrated that communities could play a role in mobilising peoples' active self-management of cancer care. This could reduce pressure on health resources to meet the supportive needs of the growing number of cancer

survivors in the UK. Furthermore, there has been precedence for offering health service endorsed online communities for psychosocial wellbeing. In the US, there has been a project spanning two decades which had offered online cancer resources and communities to people through health centres (DuBenske et al., 2014; Gustafson et al., 2012; Gustafson et al., 1994). Studies have found that this CHESS (Comprehensive Health Enhancement Support System) system has improved cancer survivor and family quality of life and reduced demand on health professionals' time (Gustafson et al., 1999; Pingree et al., 2010). Furthermore, NHS endorsed online communities have proven effective and valuable for mental health interventions (Christie, 2013; Treanor, Abrar, Harris, Morris, & Carson, 2010). The Big White Wall is an online community for people requiring mental health support, and which has been approved for use by the NHS. This service has been offered to people through General Practice (GP) referrals as a 'social prescription' (Friedli, 2009; Christie, 2013; National Information Board, 2015). According to reports from the Big White Wall organisation, this online community has been effective at reducing depression and isolation for users, and supported many to self-manage their mental health (Christie, 2013). Moreover, health service endorsement of these online services have made them accessible to a wide range of populations including people with different ethnic backgrounds, different ages, and people with different socioeconomic backgrounds (Dosani, Harding, & Wilson, 2014). Similarly NHS endorsed online cancer communities may help to improve peoples' access to these supportive resources, whilst benefitting the resources of the health service (Hunt, Kotayko, & Gunter, 2015).

In recent years a number of UK policy reports have emphasised the need for healthcare users to become digital, and to provide digital healthcare services (NHS England, 2014; National Information Board, 2015). One successful and ongoing project entitled the Tinder Foundation has been working with NHS England to teach people across the country how to use the internet for health searching behaviours. (The Tinder Foundation, 2015). The foundation has supported approximately 235, 000 people to learn basic digital health skills in two years of the programme. These skills are likely to have enabled people to access the internet, online health information, and online communities.

However, there has been relatively little activity in teaching people more detailed internet literacy skills, such as how to navigate an online cancer community. This study has demonstrated that the online community world is complex, and that certain benefits, such as discovering secret groups, cannot be attained until people have posted messages or engaged with other community members. Moreover, participants of the present study expressed fears about trusting online groups, which they balanced against their need to communicate. Overall, this study found that journeys through online cancer communities may have benefitted from guidance on how to use the communities to more efficiently find relevant communities, threads, messages and other group members. Rather than simply focusing on getting people online, UK policy should now focus on increasing the skills of the digital population, to ensure that people can gain the available benefits from existing supportive websites.

6.3.1 Implications for healthcare practice

The theory proposed in this study offered insight into what an empowered, confident and educated patient population may be looking for, and how they use the internet to influence their cancer care. In particular, this study has demonstrated that individuals approach healthcare professionals with internet information in order to solicit more in-depth or different professional information. It seemed that internet and online community involvement in healthcare was likely to continue, and to become embedded in how patients and families interacted with healthcare professionals. The digital revolution has given people greater access to informative and educational materials, and this will increasingly influence healthcare as the population becomes digitally literate (Neter & Brainin, 2012). Therefore, healthcare professionals should be prepared to have conversations with cancer survivors about their health-related internet activities. However, participants in the present study initially received discouragement from using the internet or specifically online cancer communities. Similarly, surveys of healthcare professionals have found that internet information is mistrusted and may be discouraged by many professionals (Ferguson, 2006; Hughes, Joshi, & Wareham, 2008). In the present study, discouragement seemed to be unhelpful, as participants used

the internet regardless. Instructing people not to use the internet may prevent people from discussing what they find online with professionals, who could in the best position to redirect individuals' to more accurate conclusions or sources of information. Thus, a key conclusion from this study was that healthcare professionals should participate in conversations about information which patients have sourced online and in communities.

Healthcare professionals might be in a unique position to support peoples' navigation with online cancer communities. This study found that the communities had the potential to upset or overwhelm people affected by cancer. Individuals also became bereaved after the death of an online friend. This study found that there may be a need to support these negative experiences, as they caused considerable distress for some participants of this study. Healthcare professionals in the UK responsible for the supportive care of people affected by cancer have had no guidance regarding online cancer support (National Cancer Action Team, 2010; NICE, 2004). This may explain why participants did not initially have conversations with professionals about their online community use, or were dissuaded from using the groups. However, healthcare professionals had the most accurate personalised knowledge regarding which key medical terms are associated with individuals' diagnosis, and could have highlighted which keywords to seek out or to ignore in online communities. Additionally, this study demonstrated that people can use a range of different groups during their cancer experience, but their healthcare team, for instance a clinical nurse specialist or a general practitioner, will be available to people affected by cancer throughout the cancer journey. Therefore, these professionals will be in a position to offer advice or make a referral to bereavement support services for individuals who are struggling as a result of online cancer community use.

6.3.2 Implications for hosting online communities

This study found that there were particular features of online communities which could be categorised as either supporting social interactions, or supporting information use and exchange. The following features were conducive to participants experiencing a sense of community in online interactions; a private, peer-led, welcoming group, which shared aspects

of peoples' identity and allowed people to share pictures, and 'like' messages. Several of these findings have been supported in previous studies of social media. Having more Facebook friends and receiving more Facebook likes has been found to correlate with experiencing social capital (Ellison, Steinfield, & Lampe, 2007) and social capital has increased over time using Facebook (Steinfield, Ellison, & Lampe, 2008). Additionally, photo sharing on a national cancer charity Facebook page was found to increase public engagement (Strekalova & Krieger, 2015). These findings could be used to guide the design of online cancer communities which aim to facilitate a companionship style virtual community. Alternatively, studies which aim to produce an online community for information provision might benefit from using the following features: providing anonymous online communities, the ability to lurk, and credibility that the information is trustworthy.

This study identified a number of opportunities for organisations hosting online communities to support use of online cancer communities. For instance, online communities belonging to UK charitable organisations were often the first groups visited by people affected by cancer, often soon after diagnosis, and they were associated with a search for information. However, Bender et al (2013) revealed that most public cancer forums did not assess the quality of information posted to online forums. This might be concerning, because soon after a cancer diagnosis people have reported being particularly alarmed by new information (Randall & Wearn, 2005), and have been vulnerable to being misled. Furthermore, studies have found that untrustworthy information sourced online could reduce the credibility of the source website (Banes, Romania, Ahmed and Hopson, 2005). Thus, misleading information in a community could impact the reputation of the associated cancer charity. Therefore it should be a priority, for the wellbeing of visitors and the organisation, to provide easily available links from communities to reputable sources of information. Additionally, organisations hosting online communities could provide instructions for assessing the quality of information shared in online communities. Cline and Haynes (2001) suggested that peoples' internet information evaluation skills should be a public health priority, as the ability to appraise information online reduces the likelihood of people being misled.

Furthermore, learning information evaluation skills might serve to enhance individuals' feeling of empowerment and perceived ability to care for oneself after cancer (Zeibland, 2004).

This study found that support for bereavement may be needed for many visitors to online cancer communities. This was a complex issue, as participants' expressed both bereavement, and renewed personal fears about cancer after the death of an online friend. Moreover, several participants highlighted that they kept their virtual interactions separate and sometimes secret from their friends and family. Therefore friends and family were not available as a source of support for these bereavement experiences. Alternatively, online community members could contact members of the UK charitable organisations hosting the communities. After all, participants in the present study valued the use of a support phone line when they were present in online communities. However, in private communications with online community managers, the research student has found that there may be no formal protocol or procedure in place to support the bereavement of people interacting online (Personal communication, 9 March 2016). This issue was complicated further as findings demonstrated that people seemed to be more likely to feel bereavement in private and hidden Facebook groups. Online cancer organisations had no commitment to support the activities in Facebook groups, as they were often peer-led. This meant that there was a gap in support provision for online interactions after death and bereavement online, and further work in this area may be prudent to support the experiences of people affected by cancer.

6.3.4 Implications for using the internet in research

This study had several messages for research using or concerning the internet. Firstly, studies collecting information from public online forums should be aware that there have been limitations concerning what people share in public forums. It would be naive to claim that public online communities reflect a naturalistic conversation online (Hookaway, 2008; Walther & Boyd, 2002). This study has revealed that different online communities (whether private or public) prompted different levels of trust and openness from people affected by cancer. Secondly, this study has emphasised that there may be ethical issues regarding

whether researchers should access private online communities for data. Rodham & Gavin (2006) highlighted that some private online communities are easy to access, requiring only a password and username to view all the messages within. However, this study has revealed that people placed greater trust in private online communities, and were more open in sharing their intimate and vulnerable experiences. This study has argued that it would be unethical to use data from private online communities without obtaining informed consent for every member of a private group. Specifically, using data private groups without permission would contravene the ethical principles of respect for autonomy (Beauchamp & Childress, 2001). Group members would not have autonomy in any research which has used private community data without asking permission, as individuals would be unable to make an informed decision about participating and their level of participation in the research.

The findings of this study suggested that online cancer communication has the potential to make a significant impact on healthcare research, particularly the blinding procedures of RCTs. Recent authors have argued that Twitter could be used to increase enrolment and engagement in medical clinical trials (Sedrack, Cohen, Merchang & Shapira, 2016; Thompson, 2014). However, this study observed an instance of a participant using online communication to contact other members of a blinded RCT. Blinding has been a significant feature of research trials and contributes to RCTs being considered the gold standard of evidence (MacKenzie & Grossman, 2005). If trial participants can contact, communicate, and compare experiences with one another, they could un-blind themselves to the trial conditions that have been assigned to. They may then be able to regulate their behaviour or cancer care, which can influence the findings of RCTs. This may be a growing challenge for RCT research as the internet becomes increasingly utilised by people affected by cancer. Furthermore, this study has suggested a need for caution when recruiting participants for blinded clinical trials using online communities in which people may be able to see and contact fellow group members.

6.4. Recommendations for future research

One key limitation of this study was that this small scale qualitative approach could not offer definitive predictions about online cancer community

use amongst the general populations affected by cancer. Future study is needed to determine conclusively whether there are benefits of online cancer community use for people affected by cancer (Hong et al., 2012). Before policy can advocate and recommend the use of particular online communities, there must be reliable evidence to show that the communities will benefit people affected by cancer (Atkins et al., 2004). Therefore addressing this gap in knowledge should be a significant priority for future research. Several approaches are required to investigate the effects of online cancer community use on cancer populations. Primarily, this study has suggested that online cancer communities support navigation of the cancer experience, particularly enhancing self-management skills and abilities. Thus, future investigative research should focus on investigating any relationship between online cancer community use and cancer self-management abilities. In addition, studies would benefit from focusing on specific subtypes of cancer when investigating how people have been supported online. This study demonstrated that there may be different experiences for people affected by more common cancers, compared to less common cancers when communicating online. Studies exploring the benefits of online community use may be more successful if they focus on people affected by more common cancers, such as breast, prostate, colorectal and lung cancer. There has been work underway to investigate this, as a study protocol has been recently published indicating that there will be a future systematic review into online community use for people affected by breast cancer (McCaughan, Parahoo, Heuter, & Northhouse, 2015). Similarly, investigating the experiences of people affected by rarer cancers and online support might be beneficial. This study found that people with particularly rare cancer experiences may have struggled to find the information and support they needed online. This might perpetuate unmet needs for support and information, and an offline supportive approach may be needed for these populations. Finally, online cancer communities may be particularly beneficial for families affected by cancer. These populations have been typically unable to access cancer information and support (Harris, 1998; Adams et al, 2009). Therefore future work should investigate the acceptability and feasibility of online cancer community use for families affected by cancer, as it may be a convenient and supportive way to meet the needs of this population.

6.5. Conclusions

This study has provided a detailed view of the ways people affected by cancer experience online communities. Moreover, this study discovered how and why communities have been valuable for supporting peoples' journeys as they live longer with cancer. This insight has been particularly timely, as an increasing majority of people in the UK have been accessing the internet and communicating via social media. The increasing prevalence of existing online cancer communities may have a benefit for both people affected by cancer, and wider demands on NHS resources. If online cancer communities can enhance people's abilities to manage their cancer information and social support needs, there may be a reduced demand on healthcare professionals' time. Consequently, online support is a field which has received increasing interest from health researchers and policy makers, whom have published a significant amount of papers and public documents since the inception of this study. Therefore, this study has made a significant contribution to this burgeoning field by highlighting the complexity and potential of existing social online communication to improve the lives of people living with cancer.

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APPENDICES

Appendix 1: Example of literature review key word search strategy

Search no.	Searches	Results (n of references)
1	exp Neoplasms/	2488170
2	exp Computer Communication Networks/	59856
3	internet discussion forum.mp.	8
4	internet forum.mp.	33
5	on?line support.mp.	249
6	on?line forum.mp.	88
7	exp Communications Media/	221026
8	social support.mp.	58332
9	exp Self-Help Groups/	8592
10	forum*.mp.	9343
11	internet support group.mp.	23
12	on?line support group.mp.	63
13	on?line services.mp.	105
14	2 or 3 or 4 or 6 or 7 or 11 or 12 or 13	283156270010
15	5 or 8 or 9 or 10	74209
16	1 and 14 and 15	453
17	limit 16 to yr="2008 -Current"	228

Appendix 2.1: Example of a study included after qualitative CASP study appraisal

<p>Study reference</p> <p>Seymour-Smith, S. (2013). A reconsideration of the gendered mechanisms of support in online interactions about testicular implants: a discursive approach. <i>Health Psychology</i>, 32(1), 91</p>
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CASP question	Summary of study response
Is there a clear statement of the aims of the research?	Aims to analyse posts to an online community for testicular cancer, and analyse the mechanisms of support in the messages. Good literature review, framed the importance of the study and the unique approach and knowledge that this study would generate.
Is a qualitative methodology appropriate?	Strong justification of both the methodology and methods. Discursive methodology selected to analyse written word. Suggests consistent approach to data collection and analysis.
Was the research design appropriate to address the aims of the research?	See above. The rationale for analysing messages and using a discursive approach is justified and explained well. Clear description of the underpinnings of the methodology. Moreover, the focus of this design suits the study aims.
Was the recruitment strategy appropriate to the aims of the research?	No recruitment strategy per se. Selection of online communities and messages was clearly described. The testicular cancer communities were relevant to the study aims, though three of the four were from the US which may not provide directly comparable evidence for this UK based study.
Was the data collected in a way that addressed the research issue?	The four longest threads in communities about prostheses were chosen. It is not clearly defined why the longest threads were selected, presumably this was to analyse the interactions between individuals. It might also have been interesting to explore why discourse might be shorter in other threads. However, collecting the longest threads suits the general aims of the study, therefore this was not a major concern.

Has the relationship between researcher and participant been adequately considered?	There was no relationship as the researcher collecting existing public community messages.
Have ethical issues been taken into consideration?	The members of online communities were not informed of this study. There was a discussion about the ethics of this form of research, and conclusions were made that the communities were public, and therefore the data was publically accessible without requiring informed consent from community members.
Was data analysis sufficiently rigorous?	The data analysis was well detailed and there was an adequate description of the coding process and the lens of the researcher. There was supporting evidence for the findings, including in depth descriptions of the main findings and contradictory was discussed and explained. The techniques used to assess rigour of the findings were also clearly outlined. The analysis and findings were assessed between a team of researchers.
Is there a clear statement of findings?	Yes. The themes were clear, logical and couched in the language of the participant/ online community members which conveyed a sense of their original meaning when posting messages. The findings were suitable to the study aim.
How valuable is the research?	Very relevant and valuable study. Addresses a gap in knowledge about testicular cancer experiences, in addition to knowledge about the use of online cancer communities. The discursive approach was suitable for an online community study. This was a unique rendering of online cancer community 'experiences' and has provided some insight into the message and conversation compositions in testicular cancer groups.

Appendix 2.2: Example of a study excluded after qualitative CASP study appraisal

<p>Study reference</p> <p>Nicholas, D. B., Chahauver, A., Brownstone, D., Hetherington, R., McNeill, T., & Bouffet, E. (2012). Evaluation of an online peer support network for fathers of a child with a brain tumor. <i>Social work in health care</i>, 51(3), 232-245.</p>

CASP question	Summary of study response
Is there a clear statement of the aims of the research?	Aims to evaluate the effectiveness of an online community for fathers affected by cancer, ascertain participant experiences and perceptions, and identify the benefits and limitations of an online network. These aims are appropriate for several different study designs.
Is a qualitative methodology appropriate?	NB this study was not purely qualitative, as the aims indicated. Several types of data were presented in this study. However this mixed methods study did not describe how the study findings were combined. Therefore it was not possible to evaluate the mixed method approach of this study. I was also not able to get in contact with the research to obtain this data, Therefore the different elements of the data were appraised independently. A qualitative approach did appear to be appropriate for ascertaining the experiences and perceptions of fathers in this study. The type of qualitative design selected was not justified, nor was it explained how it would impact the findings.
Was the research design appropriate to address the aims of the research?	There was limited justification for the research design but it appeared to be suitable for evaluating an intervention.
Was the recruitment strategy appropriate to the aims of the research?	It was not clear how participants were selected firstly for the intervention, and then the subsample of 14 participants for the interviews. This was a potential area of bias.
Was the data collected in a way that addressed the research issue?	There was limited description of the data collection setting, thus it was unclear how soon after the study the interviews were conducted. Content analysis of

	communities were also collected, but there was no description of this data, There it was unclear how long ago this community interacted, how frequently and detailed messages were and how the messages related to the interviewed participants.
Has the relationship between researcher and participant been adequately considered?	There was no discussion about the relationship between researcher and participant. It was not clear who conducted the interviews.
Have ethical issues been taken into consideration?	Ethical approval was obtained.
Was data analysis sufficiently rigorous?	A limited description of the analysis was provided. It was described as qualitative content analysis and themes were assessed for reliability between several reviewers. However, it was unclear whether the data from the communities and interviews were analysed together or separately, or whether the content analysis was inductive or deductive. This report mentioned the use of negative case analysis to establish trustworthiness, but does not provide examples of this in the text to determine the negative cases against the main findings. In fact presents no quotes in the findings to demonstrate the key themes. This is a concern as quotations demonstrate the logic used in studied, which has not been evidenced in the qualitative portion of this study.
Is there a clear statement of findings?	There is no clear statement of the findings, either across the data sets or within the two qualitative analyses. The themes do not provide in-depth insight into experiences.
How valuable is the research?	A valuable area of work, however missing elements of the reporting in this paper mean there can be limited evaluation of the study design and reporting. There were no quotes provided to exemplify the qualitative finding, which may have resulted in researcher bias in analysis and selection of findings. Furthermore, it was unclear how the participants were selected for interview from the main intervention sample. The findings were also general statements of use of communities, rather than exploring

	the perceptions nuances in perceptions and experiences of this online community. Unfortunately these combined areas for bias mean that I will exclude this study from the final review.
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Appendix 3.1. Literature review summary table – Studies investigating outcomes

Source; Location	Type of online community	Target population; Participant cancer type/stage/treatment.	Aims,	Study design; Intervention type; Measures	Recruitment ; Sampling	Overview of findings
Classen et al, 2013; Canada	Private and facilitated online community for gynaecological cancer survivors. This involved a 12 week asynchronous forum, with one additional synchronous board held for 90 minutes.	Women experiencing psychosexual distress as a result of gynaecological cancer; The gynaecological cancers were of the cervix (14 women), of endometrium/ uterus (9 women) and of the ovary (4 women); The majority of the women had stage 1 cancer; There were a wide range of treatments including pelvic radiation therapy (20 women), surgery (18 women), chemotherapy (15 women) and brachytherapy (10 women)	To determine feasibility and rates of participation in an OCSG for women with gynaecological cancer and to explore how the OCSG addresses the psychosexual concerns of the women.	RCT; 13 women were assigned to a 12 week OCSG intervention, 14 were assigned to a wait-list control; Participation rates measured by number of posts to the OCSGs. Psychosocial measures at baseline and the end of the intervention measures female sexual distress, anxiety and depression, illness intrusiveness and satisfaction.	Recruited from two gynaecology outpatient clinics; Twenty seven women participated.	Low numbers in recruitment meant that the control group were recruited into the experimental arm following a waitlist. Greater participation was found in the control group, arguably because they were given more support in using the OCSGs. Small effect size changes found in intimacy concerns and sexual distress.

<p>Klemm 2012; USA</p>	<p>Moderated and peer-led asynchronous online breast cancer support groups</p>	<p>Women with breast cancer; The majority of women had stage 1 or 2 breast cancer; The majority of women had experienced surgery (48 women), followed by chemotherapy (32 women) and radiation (32 women). 15 women identified 'other' treatment; Twenty eight women perceived their cancer cured, 17 perceived it controlled, and 16 perceived it treated. Only 1 perceived the cancer terminal.</p>	<p>To evaluate the effects of different formats of online group support (moderated vs peer led) on depressive symptoms and the extent of participation in women with breast cancer</p>	<p>RCT; 24 women participated in moderated OCSGs, 26 participated in the peer-led OCSGs; Participants' extent of participation was measured by number of messages, and depression scored at baseline and during the 16 week intervention.</p>	<p>Recruited online and offline by several methods including advertising through flyers, local media and approaching a private cancer centre; Fifty women participated and were randomised into moderated or peer-led groups.</p>	<p>Attrition over the course of the study meant that the two arms of the trial were not sufficiently powered to detect an effect size with confidence. Moderation enhanced participation in posting and reading messages in the forums. There appeared to be no differences in depression scores for either condition from pre to post tests.</p>
<p>Kim et al, 2012; Kim et al, 2011 USA</p>	<p>CHESS</p>	<p>Underserved women with breast cancer; 68.4% of women had early-stage breast cancer (0,1 or 2), while 31.6% of women had late stage breast cancer (3,4 or inflammatory).</p>	<p>To better understand the process and effect of social support exchanges within computer-mediated social support (CMSS) groups for breast cancer patients</p>	<p>Cohort study There was no control group; Participation was measured by the type of messages posted and the number read. Psychosocial measures investigated health self-efficacy, perceived availability of social support, coping with breast cancer, emotional support, and positive reframing.</p>	<p>Recruited women participating in the CHESS (Comprehensive Health Enhancement Support System); 177 women were included in the analyses. 19695 posts from 4 months of the OCSG were analysed.</p>	<p>Participants who were younger, white and living alone were more likely to post messages. Less likely to post were those with higher levels of social support offline. Participants were more likely to send supportive messages if they were more positively adjusted and with lower levels of self-blame. Providing and receiving emotional support appeared to occur in a reciprocal relationship. Positive reframing was predicted by reframing scores at pre-test and support giving.</p>

Osei et al, 2013; USA	Prostate cancer private asynchronous online community. Facilitation unknown.	Prostate cancer patients received diagnosis within past five years; Demographics relating to the prostate cancer were not collected.	To use a randomized controlled trial to explore the effect an online support system has on quality of life among men diagnosed with prostate cancer.	RCT; 20 participants were assigned to an 8 week OCSG, and 20 assigned to a waitlist control; Quality of life was measured in perceived health, life satisfaction and perceived spousal characteristics.	Mailed 1000 survivors from one cancer registry in California; Forty survivors participated. These were matched in pairs based on demographic information and randomised to each condition.	Some changes were seen from baseline to 6 weeks; the control group dropped on measures of perceived health, life satisfaction and negative perceived characteristics of their spouse. The experimental group score rose in perceived urinary irritation, sexual health and hormonal health. However all scores returned to baseline at 8 weeks.
Seckin, 2011; USA	Online peer support groups	Female users of online cancer support groups; 75% of the sample were diagnosed with breast cancer. Each of the other diagnoses were 5.5% or less (including lung, kidney, ovarian and bladder)	To examine whether older women with cancer have different perceptions about, and are influenced to a different extent by, online peer support than younger women	Cross-sectional survey; Women were surveyed by measures of depression, coping, perceived benefits of OCSGs, medical measures, and patterns of participation in OCSGs. Age based comparisons were made.	Recruited by online postings to websites; 255 female cancer survivors participated. Women were analysed by age; 143 were 50 years and younger, 112 were 51 years and older.	Older age group participated in more support groups, sought online support more frequently, for longer months and reported more benefits than younger women. As physical severity of symptoms increased the older age group also increased the number of support groups they participated in. For younger women, when severity increased they increased the length of time spent in support groups. Positive coping styles appeared to be predicted by receiving more benefits from online peer support and also age; stage of cancer at diagnosis; perceived severity of physical symptoms and depression

Appendix 3.2 Literature review summary table- Studies exploring experiences

Source; Location	Type of online community	Target population	Aims, purpose.	Methods	Recruitment; Sample; Dates of message analysis	Overview of findings
Bender et al, 2011; Canada	Facebook groups affiliated with breast cancer. Asynchronous and moderated by creator of group.	Breast cancer support groups	To characterise the purpose, use, and creators of Facebook groups related to breast cancer	Content analysis was used to develop a classification scheme of groups and reasons for creation and the types of creators. Categories were counted to explore the distribution and activity within support groups.	Searched Facebook using keyword: 'breast cancer'; 620 groups related to breast cancer found in total; Search conducted in 2008	Of 620 groups, the majority were created for fundraising and awareness-raising, with only 7% for support. Of the supportive groups, 49% were created for general support for people affected by breast cancer, with an additional 38% to obtain support for a specific person. Of the general support groups, 19% were created by a person affected by cancer.
Bender et al, 2013; Canada	All online communities available for people affected by breast cancer.	Online communities available for people affected by breast cancer.	To identify the characteristics and levels of use of online communities for people affected by breast cancer	Content analysis used to categorise of online peer resources; Websites were categorised based on characteristics of purpose, affiliation and initiator, launch dates, forms of communication,, moderation and level of activity.	Searched for breast cancer online communities using Google, developed inclusion and exclusion criteria for the websites to be included; 111 websites supporting online communities were included in the final analysis.	Many sites supported multiple online communities, notably Facebook with over 600 breast cancer communities. 68% of sites that were specifically created for breast cancer online peer support were likely to have been created by a person affected by cancer or their loved one. The majority of sites were moderated. Only one site appeared to screen for accuracy of information in messages before allowing them to be posted.
Blank et al, 2010;	Two public websites each	People who contribute to	Who most commonly posts	Content analysis was used to develop a classification	Websites for breast and prostate cancer selected	More women posted to the sites than men.

USA	hosting breast and prostate asynchronous online communities. Facilitation/moderation unknown.	breast and prostate cancer forums	messages, and how do different types of message content differ between breast and prostate cancer groups?	scheme of messages and users. They used this to numerically explore the distribution and activity within support groups.	based on their popularity; A complete month's postings for both breast and prostate cancer forums (3203 posts in total) downloaded for analysis; Dates unknown	Messages are posted primarily by cancer 'survivors' (i.e. not newly diagnosed), followed by spouses. The most common category of content addressed in messages was support, occurring in 70.4% of messages combined, followed by medical content in 32% of the messages. Comparing breast with prostate cancer forums, there were significant differences in the type of content shared within the messages.
Coulson and Greenwood, 2011; UK	Three public moderated and asynchronous boards for families affected by childhood cancer	People who contribute to forums for families affected by childhood cancer.	To explore the role of online support groups in supporting families affected by childhood cancer.	Qualitative design; Thematic analysis based on a social support typology identified in the literature.	Randomly selected 91 conversation threads; 487 messages retrieved for analysis; Retrieved messages from 2006-2010.	Emotional and informational support was exchanged most frequently. Emotional support was the most prevalent. Information support was also prevalent. Less prevalent but present were support for esteem and support by being connected to a network of people. The forums were less able to offer tangible support.
Durant et al, 2012; USA	Six asynchronous cancer forums. Unknown whether private or public, moderated, facilitated or none.	People who contribute to forums for melanoma, renal-cell, prostate, testicular, ovarian and breast cancers.	To determine if different gender-preferred social styles can be observed within the user interactions at an online cancer community	Quantitative social network analysis of communication (by number of messages) between user types.	Reasons for selection of online forums unknown; Analysis of posts online. This involved a total of 8388 users, 5385 threads and 27450 posts analysed. Posts from 2001-2010 analysed.	Breast and ovarian survivors show significantly more intimate connections than prostate, renal-cell and melanoma cancer survivors. Ovarian cancer patients connect in clusters or dyads of groups of people, and are statistically more likely to form bonds with other patients or survivors than others within the forum. The breast cancer forum is full of smaller 'sub-networks' of people. The prostate cancer forum is more likely to forum large networks connecting to many other people.
Foster and Roffe, 2009;	UK online mixed cancer asynchronous	People who contribute to forums for	To describe and categorise the content of	Qualitative thematic, inductive analysis.	Selected the most popular thread at the time;	Emotional support was prevalent and exchanged by representations of physical affection, individual and group compliments

UK	discussion forum. Facilitation/moderation unknown.	mixed cancer diagnoses.	contributions to an online discussion board as a resource for supporting self-management.		89 posts retrieved. Date of retrieved posts unknown.	and expressions of wonder/ appreciation of others abilities/gains. Informational support was also prevalent through hints, tips and links to further information. The forums were considered a place for contributors to 'sound' their own thoughts.
Huber et al, 2010; Germany	Public asynchronous German online community for prostate cancer. Facilitation/moderation unknown.	Newly diagnosed contributors to forums for prostate cancer.	Investigation into patient-to-patient communication online where communication discusses decision - making for localised prostate cancer.	Content analysis to identify content of messages and the activity of responses. Conclusions made from inferential analyses of the distribution of the forum activity	Largest German forum was selected; Thread selected based on inclusion and exclusion criteria; Retrieved posts from between May 2006-December 2008.	Threads which gained the most responses were threads on emotional support, treatment-related side-effects and further diagnostics. People commonly requested therapy recommendations, information on the course of treatment and emotional support. Messages were more likely to receive a response if they stated an opinion or position on a topic and invited discussion as opposed to open questions about subjects.
Lieberman, 2008; USA	4 professionally facilitated mixed diagnosis synchronous cancer chat rooms	People who contribute to a mixed cancer diagnosis forum.	To analyse and compare gendered negative emotional expression in the chat groups, particularly negative expressions directed towards cancer and treatment, and to identify whether men express more fear and apprehension than women	Quantitative content analysis; Content analysis guided by by 3 text analysis programmes, and compared with participant demographics to identify trends in communication styles.	Recruitment strategy unknown (of either selection of the website used or the participants in the groups); Participants drawn from 4 professionally moderated groups. 35 women and 11 men included. Patients with gender-related cancer diagnoses excluded. Date of retrieved posts unknown.	Women express significantly more anger and sadness than men. Men indicate higher levels of anxiety concerning death and mutilation in messages.
Love et al, 2013;	Asynchronous adolescent and young adult	People who contribute to forums for	To assess what types of messages related to psychosocial	Content analysis of the types of talk exchanged in the forums. Categories based on	Strategy for selecting the forum unknown,	16 types of talk could be identified in messages within the forum.

USA	OCSG. Public/private status unknown, facilitation/moderation unknown.	adolescent and young adult cancer.	needs are being shared within an AYA community	deductive typologies, with descriptive numerical data of the category frequency within the posts	posts randomly sampled; 350 posts selected to analyse for 'speech events'; Posts retrieved from 2007-2010	These were five main categories of talk: exchanging support (which appeared in 47.91% of the total messages), coping (in 24.94% of the messages), describing experiences (in 10.81 % of the messages), enacting identity (in 9.1 % of the messages), and communicating membership (in 7.37 % of the messages). Adolescents and young adults appear to negotiate normality and create a community in the forums.
Seymour-Smith, 2013; UK	Four public testicular cancer OCSGs sampled from, three US based and one UK. Seemingly asynchronous, facilitation/moderation unknown.	People who contribute to selected forums for testicular cancer, and are considering a testicular implant	to examine support mechanisms that men employed when deciding whether or not to have a testicular implant	Discursive analysis of discourse found in online cancer communities.	Internet sites searched through Google. Four largest threads from results were sampled from; Number of posts retrieved and analysed unknown; Date of posts retrieved unknown.	The men frequently expressed emotional feelings, for themselves and in response to others. Support is commonly provided by, 'me too' types of responses, reviewing the other's situation positively, providing humour, providing information and sources or suggestions of what to ask doctors.
Sillence, 2010; UK	An asynchronous prostate cancer forum. Public/private and facilitation/moderation unknown.	People who contribute to prostate cancer forums.	To explore the resources and associated social practices involved in asking for and offering advice in the context of an online message forum discussing PC	Discursive analysis of discourse found in online cancer communities.	Strategy for selecting the forum and messages is unknown, Two threads of messages selected to analyse in detail. Date of posts retrieved unknown.	The online medium seems to support decision-making processes. Decision-making in messages seemed to reinforce pre-existing beliefs about treatment and illness factors, such as beliefs about how to react to the diagnosis, how to treat and put faith in doctors, and how side effects are considered.
Sillence, 2013;	A public asynchronous	People who contribute	To examine the way ways in which peers exchange advice	Design description was vague.	The forum was selected because it was publically accessible	Advice consists of over 40% of the exchanges. Nearly 60% of the responses to these messages contain advice.

UK	moderated breast cancer forum	forums for breast cancer.	within an online health forum in order to better understand online groups as a resource for decision-making	Qualitative examination of advice solicitations based on two pre-existing theories. This was combined with descriptive numerical data of the frequency of the categories of advice.	and appeared to be active; Sampled all messages from one month, 425 messages retrieved; Messages retrieved from Jan-Feb 2011	People exchange their own experiences frequently in the messages. The types of advice most sought are 'problem disclosure' (35%), closely followed by request for opinion or information (34%) and for a response from the 'same boat' (20%).
Stephen et al, 2013; Canada	Private facilitated synchronous OCSGs. 19 groups held for breast cancer, 19 for caregivers and 17 for mixed diagnosis cancer survivors. This involved groups held online for 90 minutes for 10-12 weeks.	Survivors of mixed diagnoses and caregivers who participate in private online support groups.	To assess the overall satisfaction of the participants with OSGs and their perspectives on beneficial outcomes they might have experienced related to information gains, behavioural changes, or emotional changes, so as to determine whether OCSGs yield psychosocial benefits	Semi-structured telephone interviews with participants of the groups held. The data was analysed with principles of 'interpretive description' to transform the data into three themes of satisfaction. The themes were quantitatively compared using descriptive numerical data.	Recruitment of participants in a scheme known as CancerChatCanada. Original recruitment into the scheme unknown. Interviews were conducted with a purposive sample of the people affected by cancer using the scheme; 102 interviews were conducted; initially all users were invited, as saturation was reached purposive sampling was used to target unrepresented groups; 2010	Most participants were rated at having high or moderately high satisfaction from their experience communicating in the groups. Among the 102 interviewees, 44% were rated as "very satisfied" or having "high benefit"; 45%, as "moderately satisfied" or having "moderate benefit"; and 11%, as "dissatisfied" or having "no benefit".
Sugawara et al, 2012; Japan	Public Twitter users affiliated with cancer.	Cancer patients who communicate about their	To examine Twitter usage in Japan and evaluate its role in the lives of today's	Social network analysis; Design description was vague. The design appears to use	Searched Twitter for profiles identifying with a variety of different cancers. Selected 'most influential' accounts	Some Twitter accounts had more followers and were more influential than others. Influential accounts by cancer type appeared to be in the order of: breast cancer, leukaemia,

		experiences on Twitter	“wired” cancer patients	quantitative content analysis to analyse the types of user’s identified with cancer in Twitter (the type of cancer, and accounts for those diagnoses themselves, or relatives etc). Additionally, they appear to employ quantitative social network analysis of communication (by number of messages) between user types.	(with the most ‘followers’) to analyse their activity; 731 Twitter accounts with cancer terminology found. 51 ‘influential accounts’ identified. The account with the most followers selected for activity review; The search was conducted in spring and summer of 2011.	colon cancer, cancer of the uterus and malignant lymphoma. Conversations from the accounts identified with cancer were not commonly about cancer. However, where the tweets did concern cancer they represented psychological encouragement, greetings or reports from the hospital wards, updates on physical condition and advice for treatment.
Wiljer et al, 2011; Canada	Private and facilitated OCSG for gynaecological cancer survivors. This involved a 12 week asynchronous forum, with one additional synchronous board held for 90 minutes.	Women with psychosexual distress due to gynaecological cancer who participate in private online support groups.	To examine the feasibility and efficacy of a structured online support group for women with gynaecological cancers experiencing sexual distress post treatment	Qualitative design; Semi-structured telephone interviews conducted at the end of 12 weeks of using OCSGs.	Part of a wider study on internet resources for cancer people affected by cancer. Sample recruited into the 12 week OCSG by approaching two outpatient clinics. Participants invited to participate in interviews at the end of the 12 week period. 44% of original sample participated; Semi-structured interviews with 12 women;	Women found that the format of the asynchronous forums were not difficult to access. However they struggled to use the fast paced synchronous forum and one woman did not understand how to post. Positive themes of support emerged, and it was indicated that some members were particularly willing to provide support to others.

Appendix 4. Poster study advertisement

Have you or a loved one been affected by cancer?

Have you used internet forums, discussion boards, groups or communities for cancer?

If so, I would really like to hear about your experiences

My name is Lydia Harkin. I am a PhD student at the University of Central Lancashire. I am looking for participants to take part in the following study:

“Exploring Visitors’ Experiences of Online Cancer Support Groups”

If you are interested in this study I can provide you with a detailed study information pack and answer your questions by post, telephone or email:

Lydia Harkin (PhD student)
Post: **Brook Building, University of Central Lancashire, Preston, Lancashire, PR1 2HE**
Tel: **07875723380**



What is this study about?

Internet communities for people affected by cancer can be used to communicate with other people, or to read messages of information and support.

I want to find out what people affected by cancer face when they use these internet communities. How do they affect your life?

How can I help?

If you are over the age of 18, have been affected by cancer in some way, and you have used internet communities to write messages or to read about issues concerning cancer, **I would like to talk to you.**

What will the study involve?

I would like to interview you and ask you to share your experiences of online cancer communities and how they have impacted various aspects of your life.

Appendix 5. Participant information sheet

“Exploring Visitors’ Experiences of Online Cancer Support Groups”

Research team: Lydia Harkin, Professor Kinta Beaver, Professor Paola Dey, Dr Kartina Choong

You are being asked to take part in a research study. To help you decide if you would like to be involved in the study, please take some time to read the following information carefully. The study is being conducted as part of a research degree at the University of Central Lancashire.

If you have any further questions after reading the information and would like to discuss them further, please do not hesitate to contact me. You should be fully satisfied that you have all the information you need before you decide to be involved with the study.

Why is this research being conducted?

Increasing numbers of people are using internet discussion groups, forums, or Facebook groups for information and support about cancer. This could be called an online community.

Online communities allow people ‘in the same boat’ to discuss experiences, share tips and ask questions. But they also involve sharing difficult and sometimes distressing information.

We don’t know how important these online communities are for people who have been affected by cancer. This is because we don’t understand how people might use the forums to help with problems they face because of cancer. We also don’t know whether the cancer communities on the internet are helpful, or unhelpful.

The findings of this study will provide important information to healthcare professionals who do not understand whether online communities should be recommended to people affected by cancer.

The findings of the study will also be helpful for the charities and organisations that 'host' the online groups. The findings may help these people to better meet the needs of the people who use their online communities.

Why have I been sent this information?

- Have you been affected by cancer? Either from your own diagnosis or a diagnosis of a loved one?
- Have you used an online cancer community?
- Are you aged eighteen or over?

If your answers to these three questions are yes, then you might be able to provide us with some valuable information for this study. We'd like to talk to you about your experiences with online communities.

What is involved?

You will be invited to take part in a face-to-face interview at a mutually convenient place and time. The interview will take place between you and the researcher, Lydia Harkin. This could take place in person, by telephone or a video call (e.g. Skype), depending on which you would prefer. It is expected that the interview will last about 60 minutes, but this can be shorter or longer depending on you.

With your permission, I (Lydia) will start the interview by asking you some brief questions about your background including your age, ethnicity, your marital status and the level of education you have received. I will also ask you what type of cancer you or your loved one has been diagnosed with. This information will be asked as it may help us to understand how people's experiences of online communities might differ because of their different backgrounds. Following these brief questions, I will ask you about your experience of using online communities. With your consent, you may be contacted again to clarify comments that you may have made in your interview. If this takes place it will be to check on or gain a bit more information about some of the points you have made or to ask you if you have anything more to say about your experiences. This will usually take place by telephone.

We would like to invite up to 25 different people to interview and I will be selecting participants who have a range of different experiences. If more people indicate their interest in being interviewed, I may not be able to interview everybody who gets in contact. If this is the case then I apologise for the inconvenience but thank you for your interest in this study.

What are the possible benefits of my participation?

There are no direct benefits to taking part in this study. The person who carries out your interview (Lydia) will ask you questions about your experiences. You

may find that discussing your experiences is helpful to you. However, the person carrying out your interview is a researcher based in a university and not a health care professional so she will not be able to answer any health related questions.

What are the possible risks of my participation?

There are very few risks associated with the interviews. This is because we will make sure that we arrange the interview in a location that you feel safe and comfortable in. However, it is appreciated that during the course of the interview you may recall some negative experiences or trigger negative emotions. If you do feel upset at any point during our conversation, I will ask if you would like me to stop the interview. The interview can be stopped if you feel unable to continue for any reason at all. This can be until you feel ready to continue, or we can end the interview at that point. I can also give you the contact details for appropriate support groups and organisations if you feel that this would be helpful.

What if I consent to be interviewed but then change my mind?

You are under no obligation to take part in an interview. Even if you provide consent to be interviewed, if you change your mind then you are free to withdraw from the study.

If we go ahead with the interview, you may find that there are questions that you do not want to answer. You do not have to answer any of the questions and you can ask for the interview to be stopped at any time.

You may decide that you would like to withdraw your information from this study after you have been interviewed. You are free to request your information to be withdrawn up until April 2015. After this date the information will be processed and made anonymous. At this point it will not be possible to remove your information, as it will have been merged with information from other interviews.

If you decide you wish to withdraw from this study, you will not have to give a reason for why you choose to withdraw.

Will what I say during the interview be treated as confidential?

Yes, please be assured that all the information that you provide will be strictly confidential. With your permission, each interview will be recorded. All recordings will be securely stored within password protected files at the University. If you agree to your interview being recorded, you can ask for the recorder to be stopped at any time during the interview or you can ask for any part of the recording to be deleted. You will have a unique identification number (ID number) for the study. Therefore, if any comments that you make are used in written

reports about the study, the ID number will be used. Any information that may directly identify you will not be used.

Your interview will be transcribed (typed up) by a professional transcriber. Any details of your experience that could identify you (e.g. place of work or names) will be deleted from the transcript. The transcriber will sign a declaration to not discuss or transfer recording and notes to unauthorised personnel.

Some organisations hosting online communities may ask to see a summary of the findings of the project. Please be assured that no identifying information will be contained within any reports of this research, and the organisations will not be told of the identity of any of our participants.

What information will be held about me after the study?

At the end of the study, your interview recording will be destroyed and any other information, such as your transcript, will be safely stored in a secure archive for five years in keeping with standard research practice at the University. At the end of this period all your data will be destroyed in a secure manner. This is in accordance with University of Central Lancashire's storage of data policy.

Can I discuss this study with friends or family before I agree to take part?

Yes, of course. If any members of your family or friends have any questions they would like to ask about the study I will be happy to answer them, with your permission.

If I have to travel to the place of interview, will I have my costs reimbursed?

Yes. If we arrange a mutually convenient place to meet that requires you to travel, before the interview we can arrange for reasonable expenses to cover the cost of your travel.

Who has reviewed the study?

This research study has obtained ethical approval from the University of Central Lancashire STEMH (Science, Technology, Engineering, Medicine and Health) Ethics Committee.

Do I need to consider any further information about this study?

After the interview you may wish to ask me some questions about the interview or research study. You will have plenty of time to ask any questions and I will also leave my contact details in case you think of anything else you would like to ask at a later date.

If you have any questions that you feel need to be asked right away, I have provided my contact details and my supervisor's contact details at the end of this page.

If I decide to be interviewed, what should I do?

48 hours after you have received this information pack, I will contact you again to ask if you have any further questions about the study.

If you are satisfied that you have enough information and feel happy about taking part, I will ask you to please fill in and return a consent form to me. You can do this by email or by post. A copy of the consent form has been sent to you in this information pack.

If you have been sent the information pack by email but would like to post your consent form to me, please tell me so when I contact you. I will send you a stamped addressed envelope so that you don't have to pay for postage. If you have received your information pack by post, this pack will contain the stamped addressed envelope but I can also email your consent form to you if you would prefer.

If you provide me with a completed consent form, we arrange a mutually convenient time for you to be interviewed.

However, if after speaking to me you decide that you would like to have a little more time to think about taking part in the study, I can arrange to contact you a couple of days later when you have had more time to think about it.

What do I do if I have any concerns or issues about this study?

I would like to listen to your experiences and to what you feel you would like to share with me. However, I would like to emphasise that I am a researcher and not a healthcare professional. Because of this, I will not be able to deal with any complaints you may have about the professional care you or your loved one has received.

If you have any concerns about this study that you feel I or my supervisor will be unable to resolve, you can contact the University Officer for Ethics at officerforethics@uclan.ac.uk. They will ask you to provide the study name, investigator name, and the details of the complaint. The concern will be sent to the chair of the STEMH ethics committee within two working days.

Thank you for taking the time to read this information sheet.

If you have any further questions about the project please contact:

Lydia Harkin (PhD student)

School of Health, Brook Building, University of Central Lancashire, Preston PR1
2HE

Email: ljharkin@uclan.ac.uk Tel: 07875723380

Professor Kinta Beaver (Project Supervisor)

School of Health, Brook Building, University of Central Lancashire, Preston PR1
2HE Email: KBeaver@uclan.ac.uk Tel: 01772 893715

Appendix 6 Participant consent form

Participant Consent Form

Exploring Visitors' Experiences of Online Cancer Support Groups.

Participant copy:

This consent form is your copy. Please complete this and keep it for your records.

To complete, please place your initials against each box that you are happy to consent to:



1	I confirm that I have read and understood the Participant Information Sheet version 2 dated 29.07.2014 about the above study. I have had the opportunity to ask questions and I am satisfied with the answers to any questions I may have asked.	
2	I have had enough time to think about whether I want to be interviewed or not.	
3	I understand that I am under no obligation to agree to being interviewed and that taking part is voluntary.	
4	I understand that I am free to withdraw from this study without giving reason for doing so.	
5	I agree to my interview being recorded with written notes and a digital recorder. I understand that I can ask for the recording to be stopped at any time.	
6	I agree that some of my comments from the interviews may be used in written reports about the study, but my name or any other identifying features will not be used.	
7	I understand that I may be contacted again by the researcher after my interview if there are any questions about the information that I have provided. I understand that I am under no obligation to provide any further information if I am contacted again.	
8	I understand that I do not have to answer any of the questions, can stop the interview at any time and that if I wish to withdraw my data from the study, this will only be possible up until final analysis has been undertaken (April, 2015).	
9	I agree to being interviewed as part of the above study.	

Name of Participant	Date	Signature

Name of researcher	Date	Signature

Appendix 7. Original interview topic guide.

Interview and Topic Guide / Probe Examples

So you have told me that you have used online groups for cancer. Can you tell me a little bit more about that?

Prompts/probes:

- What was the cancer diagnosis?
- When did this happen?
- What were you looking for?

What drew you to online groups/communities?

- Which online communities have you used? Why?
- How did you first find them?

Have you used cancer communities to send messages to other people?

- **Why? Can you tell me more about that?**
- What kind of things have you said?
- Is there anything you haven't been able to say about your experience with cancer online?

Can you tell me a little about reading messages in online communities?

- What kinds of things do you like to read? Why is that?
- Is there anything you don't like to see online?

Have you ever made 'friends' with anyone as a result of using online cancer support groups?

- If not, why not?
- If so, how did that happen? Can you tell me a little more about that?

Have you found anything about online support groups that are helpful?

- What do you like about them?

Have you found anything about online support groups to be unhelpful?

- What do you dislike about them?

How important have the groups been to you?

- Have you continued to use online groups/ communities? If so, why? If not, why not?

Additional prompts/probes:

- **What do you mean by...**
- **Can you tell me anything more about...**

Appendix 8. Participant demographic information sheet

Demographic Information Sheet

Title of study:

“Exploring User’s Experiences of Online Cancer Support Groups”

<p>Participant ID Number: _____</p> <p>Researcher Name: _____</p>

Age (years): _____

Gender: _____

Ethnic group (tick all that apply):

- | | | | |
|-------------------|--------------------------|-----------------|--------------------------|
| Bangladeshi | <input type="checkbox"/> | Black - African | <input type="checkbox"/> |
| Black – Caribbean | <input type="checkbox"/> | Black - Other | <input type="checkbox"/> |
| Chinese | <input type="checkbox"/> | Indian | <input type="checkbox"/> |
| Pakistani | <input type="checkbox"/> | White | <input type="checkbox"/> |

Marital Status (tick all that apply):

Married/co-habiting/civil partnership Widowed
Divorced/separated Never
married

Education/qualifications (tick all that apply):

No formal qualifications Vocational qualifications
O level/GCSE Certificate/Diploma
A level University degree

Would you like to receive a summary of the findings once they have been prepared?

Yes, please

No, thank you

You have been affected by a diagnosis of cancer. Was the person diagnosed...

(tick all that apply)

Yourself A spouse or partner
A family member A friend

What type(s) of cancer have you been affected by?

Appendix 9. Field notes recorded during data collection

Shorthand key:

Black text: Participant's words

Red text: Instruction for interviewer

*** Can I probe for more information?

Q. Ask additional question

Participant 15 interview 1

Used online epilepsy online groups for husband

Used online thyroid cancer groups for mum *** Follow this up- Q. how different to own use?

Joined group at first symptom but didn't post. Q. Why not?

Joined literally at the point of diagnosis

initial post 11.39PM, 12 responses, 517 views *** how does this feel?

Voyeuristic. Q. What does this mean?

'A lot of people were very American'- Q what does this mean?

Eating disorder *** Follow up for more info on how this was supported online

Facebook - very much more immediate. Real. **Community.** Q- what does this feel like?

Groups like a TRIBE *** Follow up for more info

Desensitised to people *** Follow this up for more info on why

Not Active? *** Probe what could this mean?

Appendix 10.1 Memo recorded during data analysis

Decision: To name the core category and theory 'Navigating cancer'

Description & Reasoning

The main message of the interviews was that participants had been or were currently engaged in actively adapting to cancer. In this study, virtual communities formed a valuable resource to help with this. As people engaged with the communities, they also developed styles of using them which improve their lives with cancer. By applying Glaser's coding families to the data, it seemed that the descriptors best described online community interactions as strategies OR processes from the coding families. Initially, strategies were considered suitable for this study as participants have used motivations, management techniques and tactics as strategies that people affected by cancer employ with online cancer communities. For instance, the groups were accessed because many participants had a strong need for information (experiencing the information void ID5). People left or took a break from online communities when they became overwhelmed or wanted to focus on other aspects of their lives. People dipped in and out of groups that were no longer useful for them. These actions were all purposeful, enacted to support the cancer experience.

Upon review of participant 21, 22, and 23's audio recordings I was reminded that not all aspects of online cancer communities are strategical. Participants are drawn or pulled into online cancer communities when they start to engage with people and feel a sense of intimacy with them. A process begins by which they move from keeping a virtual distance from other people, to being pulled 'into the 6th form common room' ID15. However, process was not suitable to experiences either, as process denotes less free will, and rather a stable and continuous experience. There was no stepping in and out of the groups to suit needs in a process. Therefore, I returned to the data to observe the previous descriptions of overall perceptions of the groups, or beliefs about online communities.

"...Interviewer: why were the communities so important to you?"

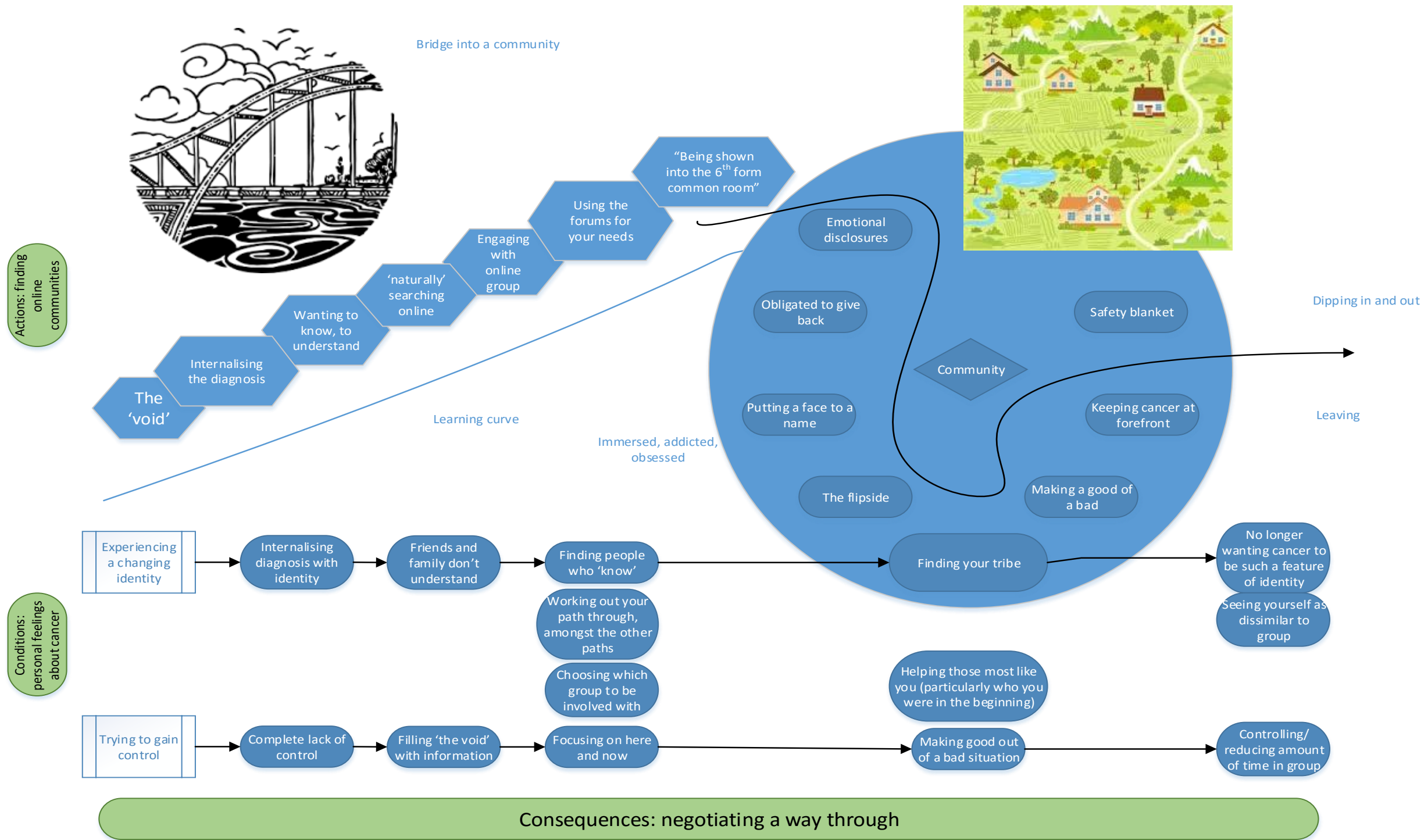
*Participant: **to work out, to try and navigate our way through.** Because you have to make a lot of quite big choices in a short period of time. And I think you're probably quite ill equipped to do so. I said at the time that, you know, I can spend months deciding what colour to paint my bathroom. And we were having to sort of go from one meeting to the next meeting and be making massive decisions about, about our future and so forth. And because of this big*

unknown in the middle, I did find it useful to kind of read about other people's experiential knowledge and how their, erm, how their sort of journey through had worked out" (ID17)

The gerund 'navigating' leapt out after rereading the transcripts. This incorporated the feeling that the individuals were steering or charting a course through online cancer communities, in order to move their selves to a place of greater understanding and emotional stability, Furthermore, the metaphor seemed to be suitable for other descriptive used in participants' experiences. 'The void'(ID5) for example, which described the feeling of having no information and dealing with a cancer diagnosis, could be navigated with the correct information resources. The attempts that could be made to navigate could consist of journeys. Moreover, the key emerging categories which have been described in the diagram (Appendix 10.2) could be described as these journeys. Individuals stepped into the different virtual world as a journey, they tried to become informed by collecting information and learning (learning curve), and the also explored a journey with their identity as they found tribe like people, but rediscovered fears when their friends passed away. For this reason, navigation has been selected as the best descriptor for these findings.

Appendix 10.2 Diagram created during data analysis

Considering core concepts: finding your path; processes; strategies.



Appendix 11 Ethical approval



12 August 2014

Kinta Beaver / Lydia Harkin
School of Health
University of Central Lancashire

Dear Kinta / Lydia

Re: STEMH Ethics Committee Application
Unique Reference Number: STEMH 248

The STEMH ethics committee has granted approval of your proposal application 'Exploring Visitors' Experiences of Online Cancer Support Groups'. Approval is granted up to the end of project date* or for 3 years from the date of this letter, whichever is the longer.

It is your responsibility to ensure that

- the project is carried out in line with the information provided in the forms you have submitted
- you regularly re-consider the ethical issues that may be raised in generating and analysing your data
- any proposed amendments/changes to the project are raised with, and approved, by Committee
- you notify roffice@uclan.ac.uk if the end date changes or the project does not start
- serious adverse events that occur from the project are reported to Committee
- a closure report is submitted to complete the ethics governance procedures (Existing paperwork can be used for this purposes e.g. funder's end of grant report; abstract for student award or NRES final report. If none of these are available use [e-Ethics Closure Report Proforma](#)).

Yours sincerely

A handwritten signature in black ink, appearing to read "G Thomson".

Gill Thomson
Vice Chair
STEMH Ethics Committee

* for research degree students this will be the final lapse date

NB - Ethical approval is contingent on any health and safety checklists having been completed, and necessary approvals as a result of gained.

Appendix 12. Profiles of the participants

1

Participant 1 was a 32 year old woman who had been diagnosed with soft cell sarcoma three years prior to the interview. One year before the interview this participant had a recurrence of her cancer.

This participant had used several forms of online cancer support groups. Shortly after her diagnosis she opened a blog with the aim of keeping her friends and family informed of news about her treatment and cancer care experiences. At this early stage she also found Macmillan's cancer forums, which she found unhelpful. She began using a forum associated with the charity Sarcoma UK. She used this forum regularly but had misgivings about it. With two other women, she set up a private Facebook group, and also used one other Facebook group. Facebook was the format she preferred.

Participant 1 was interviewed a second time around seven months after the first interview. She highlighted that she had stopped regularly using the forums, and spent more time in the community she had helped to set up on Facebook.

2

Participant 2 was a 67 year old man with advanced stage malignant melanoma. He reported being given only months to live. After several experimental treatments, he had been living with cancer for five years and described his condition as stable.

Participant 2 began using Macmillan forums, which he criticised. He moved on to a Facebook group on the suggestion of a number of the members of the Macmillan forum whom he respected. In this group he became a moderator or administrator, a role that involved monitoring who has asked permission to enter the site, making decisions about who was allowed to join the group and removing 'troublesome' members.

Despite being an administrator, participant 2 used the groups out of his own personal interest in the information provided, and a sense of belonging.

However, he indicated that he was emotionally moving away from the groups, and suggested that he may not continue to use them.

3

Participant 3 was a 50 year old woman who was diagnosed at the beginning of 2014 with an early stage of malignant melanoma. At the time of interview she was effectively cured with no evidence of recurrent disease. She felt that the impact of cancer had been 'all consuming'. Participant 3 shared very little of her cancer experience with her friends and family and felt she could not talk to her husband about her cancer at all.

Participant 3 used a Facebook group for people affected by melanoma. She confessed to being reliant on the forum, and addicted to using it. She expressed a desire to leave the forums, but the one instance she took a break she quickly returned upon finding a potential symptom of cancer.

This participant was interviewed for a second time around six months after the initial interview. She indicated that after trying to leave the groups for six months, she had finally managed to leave two weeks before the interview.

4

Participant 4 was a 64 year old woman and had been diagnosed with Non-Hodgkin's Lymphoma. In the five years since her diagnosis she reported that she had constantly been in treatment.

She encountered two kinds of online forums during her experience with cancer. One of the online forums she experienced was operated by Macmillan as part of a trial of patient information sharing. She felt that the structure of this group was beneficial, and it was interesting to take part. However, after the trial ended the group was no longer available for use. Participant 4 had also used a forum associated with the charity Penny Brohne. This forum was not helpful for her. She struggled to find people with the same experiences, and she did not receive many responses. This participant was happy with the social support she received in an offline support group. In this offline group she rarely recommended online communities to the other attendees.

5

Participant 5 was a 59 year old woman. She had advanced stage malignant melanoma. She used a huge range of different cancer forums. Her main goal in using the internet was to seek, gather and share information and she dipped in and out of different websites to meet this need. This included national and international forums. Participant 5 also used forums when she wanted to have a 'rant' about cancer. Participant 5 was passionate about being a part of a community of people affected by cancer, as she felt that patient advocacy was powerful, and can change the way medicine works. She did not feel that there was any one site which adequately met her needs, hence her use of different sites. However, she recently stopped using one Facebook group due to the deaths of several group members she was close to.

Participant 5 also had her own blog and Facebook page, which she used to share how her treatment was progressing.

6

Participant 6 was a 50 year old woman with ovarian cancer. When initially diagnosed, she felt isolated by the fact that the only other ovarian cancer patients she met in hospitals and centres were a generation older than her. She found a Facebook group simply by typing ovarian cancer into Facebook one day. Eventually she was so active in the forum that she was asked to become a moderator or administrator for the group. She stated that her administrative duties mainly included letting people into the group when they applied for access. She used the communities to communicate with people similar to her. These were usually younger patients with children. She enjoyed sharing pictures or cartoons in the groups and receiving 'likes' from them. She met people in the group offline, particularly at ovarian cancer awareness events and had also experienced the death of a friend from the forum.

7

Participant 7 was a 32 year old woman living with what she described as a relatively rare form of ovarian cancer. She used the internet to find information about her specific type of cancer, and found that there was very little information

available. In searching the internet she came across a number of forums. Participant 7 did not find the forums helpful. She did not find anyone who had shared her particular experience on the forums. She did not post, but had searched forums for group members with similar experiences. Participant 7 found that she looked at the forums regularly, particularly on her lunch break as something to do. She still wanted more information as she was aware that her cancer may return and she needs to be monitored.

8

Participant 8 was a 67 year old man with prostate cancer. His PSA (prostate specific antigen) levels had been monitored for years and levels had eventually risen to a level which caused concern and subsequently led to a diagnosis of prostate cancer. He was not surprised when he received the diagnosis. Participant 8 used the internet to research treatment for prostate cancer and to assist the decision-making process. Participant 8 was aware of online communities but distrusted them and social media in general. He felt that social media was akin to standing on the top of a hill and shouting to the world. He concluded by stating that he did not need the online communities, as he did not feel significantly changed after his diagnosis

9

Participant 9 was a 42 year old woman who was diagnosed less than a year before the interview with an aggressive type of breast cancer. She joined internet communities fairly soon after her diagnosis. Initially she joined an online forum hosted by a breast cancer charity. In this forum she was told about a Facebook group for her specific type of cancer. The charity forums contained threads for each treatment (chemotherapy, radiotherapy, hormone treatment) and she was able to join a chemotherapy group specifically for people who had started chemotherapy in the same month as her. Within this group a member set up a new Facebook group and participant 9 was invited to join. The Facebook groups were perceived as having more 'real' friendly interactions. However, people were more likely to post when they were having bad days, and were more likely to have arguments with other group members. Ultimately, she felt that the Facebook group gave her the chance to give back to the community

who had helped her, and made a positive of the terrible year she had experienced by helping others with more recent experiences. Therefore, she aimed to stay active in the Facebook groups, and to use the breast cancer forums less and less.

10

Participant 10 was a 59 year old woman who was widowed after her husband died from pancreatic cancer. When her husband was ill for two years they would 'interrogate doctor Google' together on their ipads. He was subsequently diagnosed with advanced pancreatic cancer. Participant 10's husband stopped using the internet after his diagnosis. However, she needed to make practical preparations for her husband's end of life care. Participant 10 looked for this information in the forums, though she never posted at the time. She wanted to understand what it was like when a person died, how to recognise when her husband was dying and what to have ready. She reported that she was unable to get this information from healthcare professionals

Since her husband's death, Participant 10 had been volunteering for Marie Curie's newly established online forum. She was asked to be a founding member. She had been posting about the experiences that were particularly important and challenging.

Participant 10 was interviewed a second time three months after her first interview. She had not visited the Marie Curie forum since the last interview and did not foresee using the groups again.

11

Participant 11 was a 52 year old woman who had been living with bowel cancer for over eight years. Her husband was diagnosed with malignant melanoma two years ago. Both illnesses were metastatic. She began using forums for her own diagnosis, and used Macmillan forums. She looked into one forum for bowel cancer, and occasionally looked at a secondary cancer forum. She also used a melanoma Facebook group with her husband. She found the melanoma group after being introduced to it from a Macmillan forum.

12

Participant 12 was a 60 year old man who had been diagnosed with operable lung cancer 18 months before the interview. He was aware of forums before his surgery, but with the speed of the diagnosis and surgery, did not begin to use them until after treatment. He used the forums to understand his new body without a lung by sharing experiences with others. Participant 12 also felt that using the forum could be his way of giving back that did not require money or mobility.

Participant 12 used a number of forums, particularly one affiliated with a charity he supports. He also used an American site and Macmillan's forums. Originally he wanted to use sites he had heard of, but when another forum member linked him to the American site he began using that site as well. He states that he is not 'tech savvy', and has been unable to use Cancer Research UK's forums since he lost his password.

13

Participant 13 was a 43 year old woman who was diagnosed with ovarian cancer. After she was required to have a hysterectomy, a colleague suggested she join a hysterectomy Facebook group. This introduced her to the idea that there might be cancer support groups online. She searched and found an American and an English website. She found the American site frightening, with clear cultural differences to the UK site. She used the UK group regularly and became a group moderator or administrator. At the time of interview, participant 13 was starting to spend less time on the forum as she wanted to think less about cancer.

14

Participant 14 was a 63 year old woman who had used communities for her sister who had been diagnosed with a terminal brain tumour. She lives in Canada, though her sister lived and was treated in the UK. Her sister lived for five years from diagnosis and had died before the time of interview.

Participant 14 found forums when searching for information. As a family member living abroad, she wanted to help the family by understanding the treatment regimes and helping to make informed decisions. She introduced her sister to forums as a way of giving her additional support. They initially used the forums together and then, when her sister became too ill to use the laptop, participant 14 continued supporting others in the forum until her sister's death. By using the communities the sisters gained friends in common and a topic to talk about that was not cancer. They gave participant 14 a community too, as there were other international members of the group.

15

Participant 15 was a 40 year old woman who had been diagnosed with breast cancer a year before the interview. Her cancer was diagnosed at an early stage and at the time of interview participant 15 stated that there were no clinical signs of recurrent disease.

Participant 15 has used health related forums before, for her husband's diagnosis with epilepsy, for her mother's cancer and for her own. She felt that her own cancer forum use had been much more involved, questioning the information she got about treatments, and looking at what types of treatments she needed and why.

She found the forums when googling her symptoms, whilst waiting for her diagnosis. After joining the forum, she saw a number of people talking about a Facebook group for younger people with cancer, and joined this group. She felt that this group was something different, the Facebook format allowing it to develop a new community. However, her treatment path was very different from others, and she felt that she did not fit into the group. At the time of interview she had stopped using the Facebook group regularly but continued to use the forums.

16

Participant 16 was a 41 year old woman who had been diagnosed with early stage melanoma. She had no clinical signs of recurrent disease at the time of

interview, but struggled with feelings of anxiety about cancer recurrence. She also kept her diagnosis a secret from many of her friends and family.

The first community she found was an American forum. She felt unhappy with the attitudes of the American group members. She went back on the Macmillan site and found Macmillan's forum, where she was later invited into a Facebook group. She much preferred the format of the Facebook group and used that predominantly at the time of interview.

Participant 16 used the communities to gather new information and to catch up with friends she made online. She also kept an eye on international forums (US and Australia based) for any news updates on melanoma research. She was trying to restrict how much she used the forums at the time of interview, as she felt it became an addictive activity.

17

Participant 17 was a 43 year old woman who had been diagnosed with early stage ovarian cancer. She began using the internet to learn about her cancer and this led her to online communities. She primarily used communities for information until she began chemotherapy. During this time, she began to feel socially and emotionally isolated. She lurked in the forums, following people similar to her and using their experiences to help her feel normal.

After chemotherapy participant 17 felt it was appropriate to tell her personal Facebook friends about her cancer, and also to open up to the forum about her experiences. Comments then led her to be invited to join two private Facebook groups. She later met up with people from the community in real life.

At the time of the interview participant 17 had been using forums less and less, but saw the Facebook group as more of a personal friendship group. Therefore she intended to continue to use the Facebook group.

18

Participant 18 was a woman over 70 who had been diagnosed with breast cancer approximately 10 years ago. She found online forums when she was searching for information about the side effects she experienced from cancer

treatments. Participant 18 had a personal blog which she used to comment on the NHS and cancer treatments. She used online communities to research new perspectives or drugs and she would post this information on her blog.

19

Participant 19 was a 50 year old woman who had been diagnosed with breast cancer eight years before the interview. Participant 19 had not used online communities, but had read blogs which were posted to a website for a breast cancer charity. She was recruited as part of a theoretical sampling strategy when exploring how similar or different blogs were to online communities. This participant had read but never created a blog post. She had used them in the early stages of her cancer diagnosis. She found comfort from them when she had initial concerns. However, she never interacted with the creators of blogs, nor wanted to create blogs herself.

20

Participant 20 was a 62 year old man who had been diagnosed with a head and neck cancer. He found online communities when he was searching for information about his cancer. Participant 20 reported that he found the online communities too soon after his cancer diagnosis, as he felt frightened and depressed by what he read in the communities. He returned to the communities later when he felt he could focus only on people with his type of cancer. Participant 20 wanted to participate in the communities because he felt helping other people would be an act of support for the charity who had supported him during his experience with cancer.

21

Participant 21 was a 33 year old woman who had been diagnosed with breast cancer shortly after moving to the UK, and had no friends or family to support her. She found the Macmillan forums through their websites but felt they did not offer a support network. Through the forums participant 21 found a UK wide Facebook group. On a flyer in her GP surgery she also found information about a local Facebook support group. Participant 21 had not informed the majority of her family about the cancer diagnosis and was worried that joining a Facebook

group would 'out' her as a person affected by cancer. However, after several months she felt very isolated, so joined the Facebook communities. She received social support that changed her experience of cancer, but at the time of interview was trying to reduce her use of communities as she felt she had spent too much time online.

22

Participant 22 was a 70 year old woman who had been diagnosed with bowel cancer. She found Macmillan communities soon after her diagnosis. At the time, she felt they were too depressing for her to use, and she was not in a stable emotional condition that would allow her to support other community members. She spent time away from the communities. After having a colostomy, she recalled a colostomy online forum advertised by the Macmillan forum members. She began to use this forum to find information on colostomy management, but had received conflicting information from her GP. Therefore at the time of interview she was considering leaving the community.

23

Participant 23 was a 41 year old woman with malignant melanoma. She wanted information after her diagnosis and found Macmillan Cancer Care's forums in her search. After engaging with the forums she was introduced to a Facebook group for melanoma. At the time of interview she felt she no longer needed to use communities for information. She helped other people search for information and support. Participant 23 felt that this action was helping her to balance her negative experiences with cancer.

Appendix 13. Participant findings summary

Exploring Visitors Experiences of Online Cancer Communities

Background

We wanted to find out what online communication can bring to the cancer experience and how people affected by cancer feel about using online cancer communities, forums and social media groups.

What did we do?

To find out about how people use online cancer communities, we needed to speak to the people who have visited them. People affected by cancer who were willing to take part in this study were interviewed. We spoke to people affected by a range of different cancers, and to current patients, cancer survivors and families. We recorded the interviews, and compared peoples' experiences to find out how what the important experiences were.

What did we find out?

We found out that online cancer communication can be used to support peoples' experience of cancer. People share many facts and tips for coping with cancer online. This can help people to feel more informed, and in more control with their cancer experience. Some people can also find a new sense of 'normal' after they have talked to other people online. They can form friendships, and sometimes they meet face to face. However, sometimes people affected by rarer cancers, or with uncommon treatment experiences can struggle to find people like themselves. This can be isolating, and confusing. People also feel upset if their online friends have a cancer progression or pass away.

Conclusion

Online cancer communities can give people access to cancer information, and are a way to connect with lots of other people affected by cancer. However, not all people can benefit from the groups, and because of this, extra support could be offered to people who visit online cancer communities.

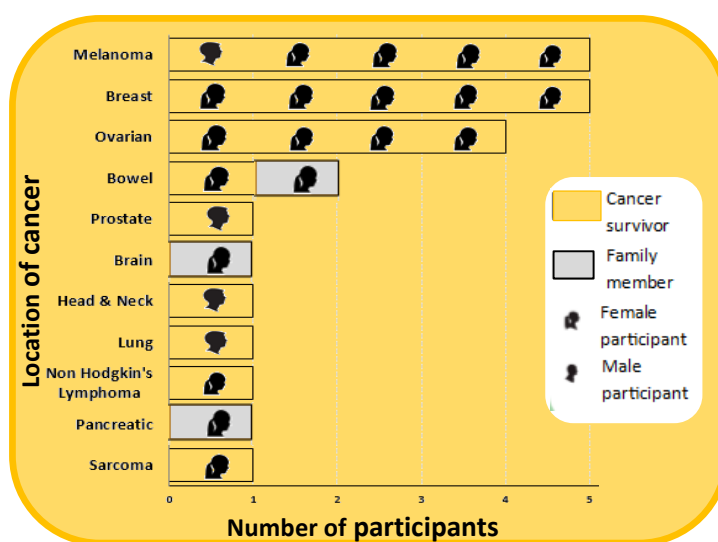
Appendix 14. Summary of findings for online community managers

Study aims and methods

One in four people affected by cancer feel isolated and lacking in social support (Macmillan, 2013). Online communication and peer communities might be a convenient alternative source of social support, as approximately 85% of people affected by cancer participate in online health behaviours (Girault et al, 2005). However, we have a limited understanding of how people experience existing online cancer communities, and so we do not know whether online communities make a supportive impact on living with cancer.

This study aimed to understand the experiences of visitors to online cancer communities

A qualitative research study was conducted. We interviewed 23 people affected by cancer who had visited online communities. The sample included a range of cancer types, and people who were affected by their own cancer diagnosis or a family member's cancer.



The sample contained 4 men. The range of participants sampled is presented in figure 1.

The interviews were semi-structured, and conducted face to face, by telephone or through Skype. Data was analysed using principles of constructivist grounded theory.

Key findings

This study found that online communication could be very useful for people affected by cancer. Most participants used online cancer communities to 'navigate cancer' and the challenges they experienced whilst living with cancer. They also used a variety of online groups simultaneously. There were three key ways the communities supported the participants; they allowed people to

become informed, to recreate their identity, and to discover and move through different social worlds.

Becoming informed

- Busy online communities were perceived as a rich source of cancer information.
- Most participants learnt felt empowered and engaged in their own care after learning through online communities. Family members felt better equipped to support and care for their loved ones with cancer.
- However, it was possible for individuals to become anxious if they read too much irrelevant information. This was known as ‘over-preparing’ for cancer.
- Public, anonymous communities supported becoming informed. In these groups participants were able to focus on gathering information, rather than becoming concerned about the needs of other group members.

“I couldn't wait to go online and then of course I scared myself half to death, looking at all the possible scenarios. Erm. I think like a lot of people in [community name] were the first hits that came up that. You know I gobbled those up and read everything I possibly could” 5

Recreating identity

- The messages online demonstrated the impact cancer could have on people’s personal lives. Reading this helped participants to recreate a new sense of ‘normal’.
- Participants took pride in helping others online, and this often became a new and positive part of their identity.
- Many participants formed friendships online, particularly if they identified with group members’ personality or lifestyle.
- However, participants with rarer cancers or uncommon treatments struggled to find ‘people like me’ and relevant information online. This increased participants’ feelings of isolation.
- Private communities which showed features of member’s identities were valuable for this experience. Private communities seemed more trustworthy. With features of identity including a real name and a picture, group members more sympathetic and relatable.

"I couldn't join in the conversations. That actually made me feel more of an outsider" 15

"I started, using the social media, the sites to try and work out, to try and make sense of my own feelings" 17

Different worlds

- Online communities were initially treated as a 'virtual' world which could be kept separate from people's day to day lives. Participants were wary of the communities and often only read messages, rather than interacting with group members.
- If participants posted to a community, they opened the door to allow other group members to interact with them. As a result, community use became more personal and intimate.
- Once a rapport was established between group members, participants were introduced to other online communities. These were often 'secret' or private Facebook groups.
- Groups with features which indicated solidarity such as Facebook 'likes' and sharing pictures were associated with a shared network of support. However, groups which indicated the number of views a message received seemed voyeuristic.
- As individuals used communities more frequently and personally, the virtual affected participants' offline lives. For instance, participants felt bereaved when 'online' friends died and this reignited fears for their own future.

"I don't like to read the ones where people are struggling because, it's awful and you can't help but think 'that could be me'" 3

Appendix 15. Abstract, presentation and publications from this study

Published abstracts

Harkin, L., Beaver, K., Dey, P., & Choong, K., (2016) Meet me at the virtual bar: cancer survivor and family experiences of online cancer communities. *Psycho-oncology*, 25(1)18

Harkin, L., Beaver, k., Dey, p., Choong, K., (2015) Experiencing online cancer communities - a qualitative study. *European journal of cancer* (s134)

Harkin L, Beaver K, Dey P, Choong K., (2014) Do online support groups benefit people affected by cancer? *Psycho-oncology* 23(1), 9

Seminars and presentations

Harkin, L., Beaver, K., Dey, P., & Choong, K., (2016) Online Support for People Affected by Cancer – UCLan Cancer Studies Seminar (*Upcoming on 6.04.2016*)

Harkin., L., (2016) 'Not All Those Who Wander Are Lost': Navigating Cancer using Online Cancer Communities – semi-final shortlisted presentation as part of the Three Minute Thesis Competition (*Upcoming 27.04.2016*)

Miscellaneous

Harkin., L., (2014). Student Spotlight: Lydia Harkin, University of Central Lancashire. *Published in British Psychosocial Oncology Society (BPOS) newsletter*, 3-5