eHealth and the burden of cancer survivorship

By

Anna Clare Cox

Submitted in fulfilment for the degree of Doctor of Philosophy

Faculty of Health and Medical Sciences

School of Health Sciences

Supervisors:
Professor Emma Ream
Professor Roma Maguire

September 2016

Declaration of originality

This thesis and the work to which it refers are the results of my own efforts. Any ideas, data, images or text resulting from the work of others (whether published or unpublished) are fully identified as such within the work and attributed to their originator in the text, bibliography or in footnotes. This thesis has not been submitted in whole or in part for any other academic degree or professional qualification. I agree that the University has the right to submit my work to the plagiarism detection service TurnitinUK for originality checks. Whether or not drafts have been so-assessed, the University reserves the right to require an electronic version of the final document (as submitted) for assessment as above.

The work is submitted on the basis of published papers in accordance with the regulations of the University of Surrey

Anna Clare Cox

September 2016

Abstract

Cancer survivorship is increasing year on year due to an aging population and improvements in cancer screening and treatments. The experience of survivorship can be challenging; individuals living with and beyond cancer can face a *burden* of survivorship. Cancer survivors not only experience *symptom burden* (the severity and impact of biopsychosocial consequences of disease and its treatment), there is also evidence that individuals living with chronic conditions experience *treatment burden* (the 'work' required of them in managing their condition and its symptoms). Traditional clinic-based approaches to relieving the burden of cancer survivors may not be sustainable or the most beneficial. eHealth interventions are developing exponentially and there is an expectation that they can improve the experience of cancer survivorship. This thesis considers the impact of eHealth supportive care interventions on the burden of those living with and beyond cancer, reporting the experience of adult cancer survivors and the perceptions of health care professionals (HCPs). Five publications form the body of this thesis. The first publication indicates that while most cancer survivors want to be fully informed many do not receive sufficient information in all areas (e.g. psychosocial issues), thus supporting the consideration of alternative approaches to providing cancer survivors with supportive care. Two publications report positive impact of a telephone follow-up intervention on the burden of survivorship. Two publications consider HCP perceptions of remote symptom monitoring and internet care plans. These papers report that HCPs perceive eHealth interventions to increase burden for specific groups of cancer survivors depending on individual patient factors, the context of their care, and the content of the intervention. This body of work supports the potential of eHealth to alleviate the burden of cancer survivors but acknowledges that the complexity of for *whom* and *how* these benefits occur warrants exploration through further research. Involving cancer survivors and HCPs in the development of eHealth supportive care interventions is key to creating and implementing sustainable effective solutions to relieving the burden of future cancer survivors.

Acknowledgements

I would like to thank my supervisors Professor Emma Ream and Professor Roma Maguire for their support and guidance.

Professor Sara Faithfull and Professor Dame Lesley Fallowfield were the principal investigators on the majority of studies on which the included publications report. I am forever grateful for the opportunities and expertise they offered to me.

Thank you also to Professor Ann Gallagher for her support on this journey and for believing in me.

Financial support from the University of Surrey is gratefully acknowledged – with particular thanks to Professor Nora Kearney who kindly gave me the time I needed to focus and the encouragement I needed to complete.

I acknowledge all my colleagues and co-authors who played a part in producing the publications included within this thesis.

Many thanks to the nurses, patients and doctors who participated in these research studies - without whom this body of work would not have been possible.

I would like to thank my mother for demonstrating so perfectly the importance of caring for others and the skills that it requires. Mum - it is my privilege to show you all I learned from you now that you need my support, you are my inspiration.

Thank you to all of my dear friends who have allowed me a year of self-absorption, I promise I will stop talking at you about my PhD from this point forward!

Finally, thank you to Darren, Henry, Reuben and Freya for allowing me to step in and out of family life for a year in order to write this thesis. I have missed you all but I hope I have made you proud.

Table of Contents

Appendix 1 - Main publications (including poster presentations)

P1   Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. (2006) 'Information needs and experiences: An audit of UK cancer patients.' European Journal of Oncology Nursing, 10 (4), pp. 263-272.
Poster presentation of P1

P2   Cox A, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. (2008) 'Nurse led telephone follow up in ovarian cancer: A psychosocial perspective'. European Journal of Oncology Nursing, 12 (5), pp. 412-417.
Poster presentation of P2

P3   Cox A, Illsley M, Knibb W, Lucas C, O'Driscoll M, Potter C, Flowerday A, Faithfull S. (2011) 'The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer.' Palliative Medicine 25 (7), pp. 675-681
Poster presentation of P3

P4   Cox A, Faithfull S. (2013) "They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information.' Supportive Care in Cancer, 21 (9), pp. 2491-2497

Poster presentation of P4

P5   Cox A, Faithfull S. (2015) 'Aiding a reassertion of self: an Interpretative Phenomenological Analysis of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up.' Supportive Care in Cancer 23(8):2357-64.

136

Poster presentation of P5

Appendix 2 - Supporting publications (including some poster presentations)

S1   Catt S, Fallowfield L, Jenkins V, Langridge C, Cox A. (2005) 'The informational roles and psychological health of members of 10 oncology multidisciplinary teams in the UK.' British Journal of Cancer: 93 (10), pp. 1092-1097.

S2   Jenkins V, Fallowfield L, Cox A. (2005) 'The preferences of 600 patients for different descriptions of randomisation.' British Journal of Cancer: 92 (5), pp. 807-810.

Poster presentation of S2

S3   Cox A, Fallowfield LJ, Jenkins VA. (2006) 'Communication and informed consent in phase 1 trials: A review of the literature.' Supportive Care in Cancer, 14 (4), pp. 303-309.

S4   Fallowfield L, Atkins L, Catt S, Cox A, Coxon C, Langridge C, Morris R, Price M. (2006) 'Patients' preference for administration of endocrine treatments by injection or tablets: Results from a study of women with breast cancer.' Annals of Oncology, 17 (2), pp. 205-210.

Poster presentation of S4

S5   Cox A, Fallowfield LJ. (2007) 'After going through chemotherapy I can't see another needle.' European Journal of Oncology Nursing, 11 (1), pp. 43-48.

168

Appendix 3 - Curriculum Vitae

Tables

Figures

Regulations for research degrees on the basis of published works

University of Surrey Academic Year 2014/15

Section 10 - Within twelve months of confirmation of candidature, a candidate is required to submit a thesis which consists of:

1. An introductory chapter which will: provide a literature review setting the research in context; demonstrate how the research and resultant publications have contributed to the advancement of the field

2. Copies of the published works on which the submission is based. Co-authored papers will be accompanied by a statement declaring the contribution of the candidate.

3. A concluding chapter which will draw together the themes of the submission and propose areas for further research

4. Appendices – any additional publications which do not form a part of the submission but which may illustrate how the candidate's research has developed over time. Candidates may also wish to submit a full CV.

Publications on which the submission is based

This submission to the University of Surrey for the award of Doctor of Philosophy is based on five first author peer reviewed journal articles [Papers P1-P5]. The research work and subsequent publications were completed between 2006 and 2015. I joined the University of Surrey in April 2007 and currently hold a permanent contract as a Research Fellow in Health Sciences within the Faculty of Health and Medical Sciences. Four publications report on projects conducted at the University of Surrey and one publication reports on a project conducted at the University of Sussex. As lead author on each paper I led the analysis and writing of all publications (details of my contribution are given within the manuscript). None of the submitted papers have formed part of a submission for any other Degree.

The published works reflect my interest in cancer survivorship and innovative approaches with the potential to improve the provision of supportive care. My interest in this area was stimulated by my early work demonstrating that information about psychosocial well-being is not routinely provided to cancer survivors in the UK [P1]. Within other research projects, and their resulting publications [P2-P5] I have considered innovative approaches to providing cancer survivors with such information and support. Five additional publications support this submission [S1-S5].

Main publications

P1   Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. (2006) 'Information needs and experiences: An audit of UK cancer patients.' European Journal of Oncology Nursing, 10 (4), pp. 263-272.

P2   Cox A, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. (2008) 'Nurse led telephone follow up in ovarian cancer: A psychosocial perspective.' European Journal of Oncology Nursing, 12 (5), pp. 412-417.

P3   Cox A, Illsley M, Knibb W, Lucas C, O'Driscoll M, Potter C, Flowerday A, Faithfull S. (2011) 'The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer.' Palliative Medicine 25 (7), pp. 675-681.

P4   Cox A, Faithfull S. (2013) "They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information.' Supportive Care in Cancer, 21 (9), pp. 2491-2497.

P5   Cox A, Faithfull S. (2015) 'Aiding a reassertion of self: an Interpretative Phenomenological Analysis of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up.' Supportive Care in Cancer 23(8):2357-64.

Supporting publications

S1   Catt S, Fallowfield L, Jenkins V, Langridge C, Cox A. (2005) 'The informational roles and psychological health of members of 10 oncology multidisciplinary teams in the UK.' British Journal of Cancer, 93 (10), pp. 1092-1097.

S2   Jenkins V, Fallowfield L, Cox A. (2005) 'The preferences of 600 patients for different descriptions of randomisation.' British Journal of Cancer, 92 (5), pp. 807-810.

S3   Cox A, Fallowfield LJ, Jenkins VA. (2006) 'Communication and informed consent in phase 1 trials: A review of the literature.' Supportive Care in Cancer, 14 (4), pp. 303-309.

S4   Fallowfield L, Atkins L, Catt S, Cox A, Coxon C, Langridge C, Morris R, Price M. (2006) 'Patients' preference for administration of endocrine treatments by injection or tablets: Results from a study of women with breast cancer.' Annals of Oncology, 17 (2), pp. 205-210.

S5   Cox A, Fallowfield LJ. (2007) 'After going through chemotherapy I can't see another needle.' European Journal of Oncology Nursing, 11 (1), pp. 43-48.

Personal reflection

As a Research Fellow, I have worked on a broad spectrum of projects within health and social care. I was fortunate enough to begin research within psychosocial oncology in 2004 working for Professor Dame Lesley Fallowfield at the University of Sussex. Survivorship was not routinely referred to at this time; survival rates were increasing but cancer was yet to be situated within a chronic condition framework as it is now. Within Professor Fallowfield's group I was involved in an audit of the information needs, decision making preferences and information experiences of cancer patients. I was interested in the fact that cancer patients were not routinely provided with information on psychosocial issues. It struck me that there was a discord between wanting to be involved in decisions regarding their care and the level of information and support patients were given to facilitate involvement in their future health and well-being.

In 2007, I joined the School of Health Sciences at the University of Surrey, an evolving hub of research on eHealth and cancer care. Between 2007 and 2010, I worked with Professor Sara Faithfull on three projects designed to evaluate eHealth interventions in the field of supportive care in cancer. These interventions spanned use of the telephone, hand-held technology and the internet. It has been exciting to watch the field of cancer survivorship evolve and to be involved in projects considering the potential of eHealth to support cancer survivors. My interests lie in improving the patient experience of long-term conditions, ensuring the provision of information and support, and recognising the importance of developing and maintaining collaborative and supportive relationships between individuals and health care professionals. I believe it is possible for eHealth to support cancer survivors in managing the consequences of their disease and its treatment whilst potentially reducing their workload. However, these benefits cannot be assumed. The impact of eHealth supportive care interventions on the experience of cancer survivorship needs to be explored within robust studies, which are informed by both cancer survivors and health care professionals, so that the potential benefits of eHealth can become a reality within cancer survivorship.

1.0 Introduction

1.1 Overview

The profile of cancer is changing. In the 1970s, the median survival time following a diagnosis of cancer was only one year (Macmillan Cancer Support, 2015). In 2010-2011, 50% of adults diagnosed with cancer in England and Wales were predicted to survive 10 or more years (Cancer Research UK, 2015). Currently, there are 2.5 million people living with a cancer diagnosis in the UK and this is predicted to increase to 4 million by 2030. The term 'cancer survivor' is used to encompass all individuals living with cancer 'from the time of diagnosis and for the balance of life' (National Coalition for Cancer Survivorship, 2015).

The profile of cancer has changed both in terms of the expected trajectory of those diagnosed with cancer and the model of care provided to them. In a time of increasing numbers of cancer survivors and reduced budgets it is not economically viable or sustainable for health care professionals (HCPs) to be solely responsible for managing supportive care. The scope of supportive care is broad, commonly defined as 'the provision of the necessary services as defined by those living with or affected by cancer to meet their physical, informational, practical, emotional, psychological, social, and spiritual needs' (Hui, 2014) (p372). The onus is now being placed on cancer survivors to play an active role in managing their care (McCorkle et al., 2011) and there is a drive to transfer the care of cancer survivors from hospital to a community setting (Macmillan Cancer Support, 2014b) both of which may impact on the provision of supportive care.

There is increasing focus on improving the experience of living with and beyond cancer and reducing the 'burden' of cancer survivors. A vast body of literature has identified that cancer survivors experience symptom burden: the severity and impact of biopsychosocial consequences of their disease and its treatment (Macmillan Cancer Support, 2013). There is also a growing body of evidence that suggests individuals living with chronic conditions such as cancer experience treatment burden: the 'work' required of them in managing their condition and its symptoms, and its impact on functioning and well-being (Tran et al., 2015).

eHealth interventions are developing exponentially and there is an expectation that they can increase the quality and sustainability of healthcare generally (IoM, 2009) and specifically within the field of cancer (Department of Health et al., 2010, Independent Cancer Taskforce,

2015, Macmillan Cancer Support, 2014b). The number of reviews and meta-analyses considering both the effectiveness and cost-effectiveness of eHealth interventions for many conditions (including cancer) has substantially increased in recent years. Systematic reviews of these papers report that in the majority of cases there is evidence to suggest that eHealth is effective/cost effective (Ekeland et al., 2010; Elbert et al, 2014). However, an evidence synthesis of 141 randomised controlled trials using eHealth in chronic condition management concluded the evidence base to be 'on the whole weak and contradictory' (p219) (Wootton, 2012). High quality evidence for the efficacy of eHealth interventions is lacking and a need to conduct research which focuses on the perspectives of patients has been identified (Ekeland et al., 2010). A meta-synthesis of qualitative studies exploring user experience of eHealth in the management of chronic obstructive pulmonary disease highlighted the positive (reassurance and empowerment) and negative (dependency and burden) aspects of eHealth (Brunton et al., 2015), the potential for ehealth to cause both benefit and burden needs further exploration.

This thesis considers the impact of eHealth supportive care interventions on the burden of adult cancer survivors and demonstrates the contribution of the publications [P1 – P5] which form the body of this thesis. The following introduction is presented in 3 parts: 1) The burden of cancer survivors; 2) Expectations of eHealth; and 3) Impact of eHealth supportive care interventions on the 'burden' of cancer survivorship – considering both the experience of cancer survivors and the perceptions of health care professionals.

1.2 The burden of cancer survivors

Cancer survivorship has been described as a positive side effect of more successful cancer treatment (Moser and Meunier, 2014). Screening, new drugs and more personalised multi-modality treatments account for the rapidly increasing numbers of cancer survivors. However, success has come at a cost in terms of the challenges experienced by individuals living with and beyond cancer.

The challenges facing cancer survivors are increasingly referred to as burden. 'The Cambridge Dictionary defines 'burden' as 'something difficult or unpleasant that you have to deal with or worry about' (http://dictionary.cambridge.org/). It is acknowledged that the appropriateness of this term warrants question; while cancer is something many individuals have to 'deal with or worry about' the experience of doing so should not be assumed to be consistently 'difficult or unpleasant'. There are many accounts where a cancer diagnosis is reported to have a positive

effect on life in terms of 'opportunity, empowerment, and social connection' (p200) (Andrykowski et al., 2008) and encouraging appreciation of the value of life and relationships (Wise et al., 2009). However, the term burden has been adopted in cancer survivorship literature and will be used accordingly within this thesis to represent the challenges faced by individuals living with and beyond cancer. Professor Jane Maher, Joint Chief Medical Officer, Macmillan Cancer Support recognised that many cancer survivors experience a burden of survivorship in her statement 'We can now see the long-term burden of cancer and the knock-on effect it has on a person's health' (Macmillan Cancer Support, 2014a) (p.11). The concept of burden has two interconnected components – symptom burden and treatment burden (Gapstur, 2007, Sav et al., 2013b).

1.2.1 The symptom burden of cancer survivors

The concept of symptom burden has been defined as 'the subjective, quantifiable prevalence, frequency, and severity of symptoms placing a physiologic burden on patients and producing multiple negative, physical, and emotional patient responses' (Gapstur, 2007) (p.673). Symptom burden encompasses both the severity of symptoms and the patient's perception of the impact of symptoms (Cleeland, 2007). The importance of improving the experience of survivorship is increasingly recognised and subsequently symptom burden is commonly used as a patient-reported outcome in cancer clinical trials (Cleeland and Sloan, 2010). Health related quality of life (HRQoL) is a broader construct within which symptom burden is usually one aspect (Burkett and Cleeland, 2007). Most HRQoL measures evaluate the severity of some symptoms. For example, The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) (Aaronson et al., 1993), the Functional Assessment of Cancer Therapy (FACT) scale (Cella et al., 1993), and the Short Form (36) Health Survey (Ware and Sherbourne, 1992) include measures of pain, nausea, fatigue and depression. Symptom burden is inversely related to a cancer survivor's quality of life (Deshields et al., 2011).

Symptoms commonly experienced by cancer survivors include *physical* symptoms such as fatigue (Hofman et al., 2007) and pain (van den Beuken-van Everdingen et al., 2007), *psychological* symptoms such as anxiety (Mitchell et al., 2013) and *psychosocial* symptoms such as sexual dysfunction (Bober and Varela, 2012). Symptoms rarely occur in isolation; most likely they occur together and interact (Lemanska et al., 2014).

Evidence for the prevalence of symptom burden in cancer survivors can be drawn from both qualitative and quantitative research. A cross-sectional survey of 1,569 cancer patients in America who were receiving chemotherapy and/or radiotherapy (or had done so within the last 12 months) used the Functional Assessment of Chronic Illness Therapy fatigue scale and the Brief Symptom Inventory to assess the prevalence of cancer treatment-associated side effects (Henry et al., 2008). The majority of patients (88%) reported at least one side effect of their treatment; the most commonly reported side effects were fatigue (80%), pain (48%) and nausea/vomiting (48%). More recent research corroborates that 90% of cancer survivors experience at least one symptom but highlights that the number/type of symptoms experienced vary by cancer type (Deshields et al., 2014). A synthesis of qualitative research exploring the symptom experiences of cancer survivors post-treatment reports that symptoms most frequently fall within the categories of 'feeling tired or fatigued' or feeling 'worry, anxiety or fear' (Bennion and Molassiotis, 2013). Cancer survivors report feeling unprepared for the symptoms they experience post-treatment (Lubberding et al., 2015).

Symptom measures, including those within HRQoL questionnaires, are only able to indicate the presence of a symptom, and not whether it is a problem which requires support. Subsequently, supportive care needs assessment tools have been designed to assess the *needs* of cancer survivors, an example of which is the Supportive Care Needs Survey (SCNS) (Bonevski et al., 2000). The SCNS includes assessment of need regarding symptoms, for example pain, fatigue and anxiety. A systematic review of the unmet supportive care needs of people living with cancer reported unmet needs were highest and most varied during treatment, but more cancer survivors reported unmet needs post-treatment than at any other time (Harrison et al., 2009). A prospective longitudinal survey of supportive care needs post cancer treatment reported that that while only a minority (34%) of cancer survivors experienced moderate to severe (≥5) unmet needs at the end of treatment, for the majority of these individuals (60%) their unmet needs did not decrease over the following six months (Armes et al., 2009). At both time points the most frequently reported unmet needs were psychological (e.g. fear of recurrence, anxiety).

Living with cancer requires survivors to cope with, and adapt to, their symptoms and endeavour to minimise their burden. In doing so, they require information and support. However, a multi-centre audit of 394 cancer survivors in the UK (Cox et al., 2006) [P1] indicated that individuals living with and beyond cancer did not report receiving information on all areas of their health

and well-being. While all cancer survivors reported receiving information from HCPs about their diagnosis and surgery, fewer recalled information to aid their sexual (37%), social (47%) or emotional well-being (58%). Recent research demonstrates that this picture of information provision has not improved over the last 10 years. A large, multi-centre, cross-sectional study in Germany reported that 72-88% of cancer survivors perceived they had been well informed regarding their diagnosis, prognosis, treatment and side effects, but only 39% reported having been informed regarding psychological support (Faller et al., 2016). Fear of recurrence is one of the main concerns of cancer survivors (Harrison et al., 2009), it is essential that cancer survivors are given necessary psychological support to manage their fears and other symptoms such as anxiety and depression.

The right approach to alleviating the symptom burden of cancer survivors requires consideration. The Living with and Beyond Cancer report (National Cancer Survivorship Initiative, 2013) emphasised the need for provision of supportive care from the point of diagnosis, through active treatment and beyond into later stages of survivorship. The Supportive Care Framework (Fitch, 2008) states that in order to be effective, supportive care has to be personalised to the unique needs of the individual. The increasing number of cancer survivors raises the question of how current models of care will be able to follow these recommendations and alleviate symptom burden. One approach to meeting the information needs of cancer survivors is through application of eHealth interventions which can provide either general or personalised information/support targeted to the individual. While recognising that there are other approaches to meeting the information needs of cancer survivors, including the face to face provision of information in clinic, this thesis is focused on the role of eHealth interventions on reducing the burden of cancer survivorship – through for example, more effective provision of information.

1.2.2 The treatment burden of cancer survivors

An additional 'burden' is increasingly referred to within the chronic conditions literature – treatment burden, however, there is a lack of consensus on the dimensions of treatment burden and its definition. A concept analysis and review of the chronic illness literature conceptualised treatment burden as having four dimensions: the physical side-effects of treatment, the financial burden of treatment, the time burden of obtaining, managing and administering treatment, and the personal/psychosocial aspects of burden (Sav et al., 2013b). This conceptualisation

overlaps with the concept of symptom burden, which already encompasses the physical side-effects of treatment. A clearer way of distinguishing between symptom burden and treatment burden is to consider treatment burden as the 'work' of managing a chronic condition (May et al., 2009b).

The concept of treatment burden with regard to managing conditions is not new. As long ago as 30 years, sociologists (Corbin and Strauss, 1988) were exploring the different kinds of work required of those living with chronic illness. Recently, the work involved in managing a chronic condition, as well as its impact on functioning and well-being, has been termed the *burden of treatment* (May et al., 2014). Understanding the work involved in managing a chronic condition has mainly been informed by Normalisation Process Theory (NPT) (May et al., 2009b). NPT was developed as a framework to understand the implementation, embedding, and integration of tasks or practices into everyday life (May and Finch, 2009) and can be applied to the work/practices required in managing a chronic condition (Gallacher et al., 2013a).

NPT has been used to inform data collection (Eton et al., 2012) and analysis (Demain et al., 2015, Gallacher et al., 2011, Gallacher et al., 2013b) within qualitative studies exploring the treatment burden of individuals living with chronic conditions. Examples of patient work identified by these studies and a larger multi-country web-based study of treatment burden which included cancer survivors (Tran et al., 2015) support the four constructs of NPT (figure 1):

Sense-making - seeking information about one's health condition, how to manage it, and the available treatments including their potential consequences (Eton et al., 2012, Gallacher et al., 2011, Gallacher et al., 2013b, Tran et al., 2015);

Cognitive participation - engaging with others to manage one's condition (Eton et al., 2012, Gallacher et al., 2011, Gallacher et al., 2013b, Tran et al., 2015);

Collective action - preparing for and attending appointments, organizing and preparing medicines, monitoring one's own health, and adopting a healthy lifestyle (e.g. dieting, and exercising) (Eton et al., 2012, Gallacher et al., 2011, Gallacher et al., 2013b, Tran et al., 2015); and finally,

Monitoring - reflecting on the management of one's condition and appraising treatments (Gallacher et al., 2011, Gallacher et al., 2013b).
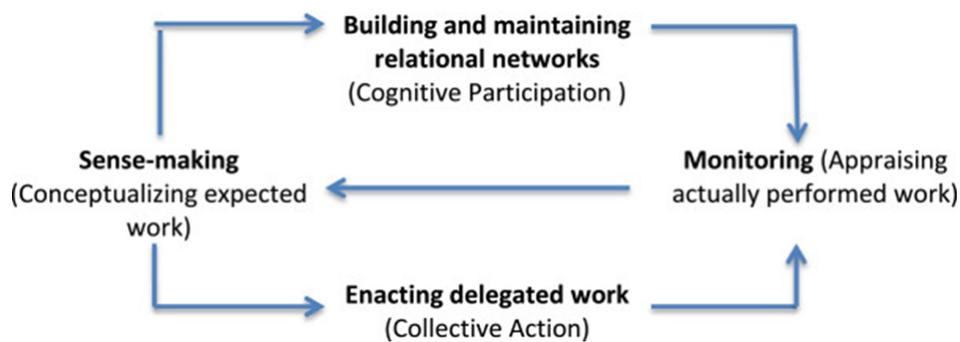
Figure 1: Constructs of Normalisation Process Theory

[May et al. BMC Health Services Research. 2014, 14:281]

The following factors have been identified by patients with chronic conditions to exacerbate treatment burden:

- Systemic obstacles of health care delivery, including fragmented/poorly organised care lacking in continuity (Eton et al., 2012, Gallacher et al., 2011, Gallacher et al., 2013b, Tran et al., 2015);
- Poor communication (both with and between health care professionals) (Gallacher et al., 2011, Gallacher et al., 2013b, Tran et al., 2015);
- Poor information provision (Eton et al., 2012, Gallacher et al., 2013b);
- Challenges regarding medications and appointments (Eton et al., 2012, Gallacher et al., 2011, Tran et al., 2015);
- Barriers to accessing services/insufficient time with health care professionals (Gallacher et al., 2011, Gallacher et al., 2013b, Tran et al., 2015);
- Relational problems and social activity limitations (Eton et al., 2012, Tran et al., 2015);
- Financial challenges (Eton et al., 2012, Tran et al., 2015);
- Personal beliefs about one's condition and treatment (Tran et al., 2015); and
- Situational factors; out-of-routine situations (Tran et al., 2015).

Interventions targeted at reducing treatment burden need to consider these factors in their design. Research suggests that patients with chronic conditions are seeking an organised and convenient system of care which provides improved levels of information and communication. The use of technology has been reported to be beneficial in supporting the organisation of care

and enabling contact with health care providers (Ridgeway et al., 2014). 'Minimally disruptive medicine' has been suggested to relieve treatment burden; the provision of effective treatment and care with the smallest workload for patients and care-givers (May et al., 2009a). This potentially requires a redesign of health care services to become more patient-centred in their delivery, for which May et al. propose the key question to be 'what kinds of changes are necessary to improve patient experiences of complex and cumulative burdens?' (May et al., 2009a) (p9). eHealth is considered one potential solution (Heckman et al., 2015) and cancer survivors, health care providers and policy makers are looking to eHealth to facilitate and improve supportive care in cancer (Aaronson et al., 2014). The expectations of eHealth will be considered in section 1.3.

1.3 Expectations of eHealth

1.3.1 Broad expectations of eHealth

The concept of eHealth has been around for almost a century. In April 1924, an edition of the Radio News carried a front page headline "The Radio Doctor – Maybe!" The accompanying image made reference to remote diagnosis using television and audio. The doctor interviewed patients remotely and a prescription was automatically printed. At the time of publication this was science fiction, but eHealth is no longer the future: its moment is now. Health care has lagged behind other sectors in adoption of technological innovations but it is currently at an intersection fuelled by increasing numbers of people living with chronic disease, economic pressures, and a shift in the model of care towards self-management (Gammon et al., 2015).

At a time when developments in information and communications technology are rapidly expanding, expectations of eHealth are high. eHealth is seen as an effective way to increase the quality, safety and sustainability of health care systems globally (Institute of Medicine, 2009, World Health Organization, 2005). A survey of health care opinion leaders in America reported that 67% of respondents believed that accelerating adoption of eHealth would improve health care (Shea et al., 2007); a view which is shared by the UK eHealth industry, who state that 'eHealth is better healthcare and a healthier life through digital technology' (eHealth Industries Innovation Centre, 2015). Further support for this vision is found within the Five Year Forward View for the NHS (NHS England, 2014) and within the European Union (European Commission, 2012):

'To ensure that in the future all EU citizens have access to a high level of healthcare, anywhere in the Union, and at a reasonable cost to our healthcare systems..[..].. we must make use of solutions offered by information technology'

[Toomas Hendrik Ilves, Chairman of the EU Task Force on eHealth]

1.3.2 Definition of eHealth

There is no standard definition for eHealth; a systematic review published in 2005 identified 51 different definitions (Oh et al., 2005) and these have likely increased in number over the past 10 years in line with increasing developments in technology. Previously known as 'telemedicine', the term eHealth evolved through recognition that other technologies were involved in healthcare (de Lusignan, 2015). The World Health Organization offers an all-encompassing definition of eHealth which will be adopted for the purpose of this thesis. They define eHealth as 'the use of information and communication technologies (ICT) for health' (World Health Organization, 2015).

The many broad definitions of eHealth and the varying categorisations of its interconnected components reflect the ever evolving nature of the field. Within chronic conditions management, the components of eHealth can be broadly categorised into: use of the Internet for health information; social networking; telehealth; mHealth (including wearable devices); electronic health records (EHRs); and electronic personal health records/patient portals (PHRs) (Gee et al., 2015).

<u>1.3.3   Expectations of eHealth within cancer supportive care</u>

eHealth is expected to support changes in the model of care provided to cancer survivors. The National Cancer Survivorship Initiative Vision (Department of Health et al., 2010) proposed that the shift to supported self-management could be facilitated in part 'using support, through telephone, text and e-technology' (p29). Similarly, a key factor in the process of providing effective care in the community is claimed to be 'improved communication and technology' (Macmillan Cancer Support, 2014b).

The Independent Cancer Taskforce (Independent Cancer Taskforce, 2015) makes three recommendations within the domain of digital technologies for the next five years in order to improve the outcomes and experience for people affected by cancer:

- Recommendation 57: From confirmation of a diagnosis, all consenting patients should have the ability to access all test results and other communications involving secondary/tertiary care providers online (extending to include all GP records thereafter);
- Recommendation 58: NHS England should partner with charities or commercial partners in commissioning the development of a smartphone app which patients can use to collate all their diagnosis and treatment related information and correspondence in one place;
- Recommendation 59: NHS England should undertake a strategic review of how digital technologies might be used to drive improvements in patient experience, for example in the coordination of their care. This should include assessing how digital technology can be used to link to harder to reach groups.

It could be argued that consideration of how technology may impact on patient experience is essential (recommendation 59) and should precede investment in the development of interventions (recommendations 57-58).

In short, there are great expectations for eHealth, not only in terms of reducing healthcare costs but also as a mechanism for improving the experience of patients. However, in some areas the development of eHealth interventions is outpacing the research which is necessary to provide evidence of efficacy. Mobile applications (apps) serve as an example of this point. Speaking at the recent NHS Innovation Expo in Manchester, the Health Secretary, Jeremy Hunt challenged the NHS to embrace technology to empower patients to manage their own

healthcare needs. The Health Secretary intends to mobilise 15% of all NHS patients to routinely access NHS advice, services and medical records through 'apps' by the end of the next financial year (Gov.uk 2015). Health applications are a rapidly developing market, with over 100,000 applications registered on my health apps (http://myhealthapps.net), but questions remain as to whether they have been appropriately tested. A systematic review conducted by Bender et al. (2013) sought to identify evaluations of cancer-focused smartphone apps. While the search strategy yielded 594 articles related to cancer and mobile technology, none of them provided an evaluation of a cancer-focused smartphone application (Bender et al., 2013).

Evaluation is a key component in developing interventions (Craig et al., 2008) and the impact of eHealth must be explored prior to implementation. Section 1.4 will consider current evidence for the impact of eHealth supportive care interventions on the burden of cancer survivors.

1.4 Impact of eHealth on cancer survivor burden

The impact of eHealth supportive care interventions on the burden of cancer survivors will be considered within the following sub-sections:

1.4.1 Impact of eHealth supportive care interventions on the symptom burden of cancer survivors

1.4.2 Impact of eHealth supportive care interventions on the treatment burden of cancer survivors

1.4.3 Perceptions of health care professionals on the impact of eHealth interventions on the burden of cancer survivors

1.4.1 Impact of eHealth supportive care interventions on the symptom burden of cancer survivors

Recent reviews have sought to synthesise the findings of studies reporting on the impact of eHealth interventions on cancer survivors (Table 1). These reviews have considered eHealth within the following domains: web-based self-management support interventions (Kim and Park, 2015); supportive telehealth interventions (Agboola et al., 2015); online support and

Author and year	Title	Aim of study	No. studies	Symptoms considered	Conclusion
Agboola et al. (2015).	The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials	To systematically review the literature on the effect of supportive telehealth interventions on pain, depression, and quality of life in cancer patients	20	Pain Depression	Telehealth has the potential to improve outcomes in cancer care - more rigorous research is required.
Dickinson et al. (2014)	Using technology to deliver cancer follow-up: a systematic review	To evaluate evidence for the effect of using telemedicine and telehealthcare in cancer follow-up on the clinical safety, patient acceptability, cost effectiveness and impact on quality of life	13	Fatigue Anxiety Depression Pain Sexual dysfunction	Cancer follow-up can include technology without increasing psychological distress, impairing quality of life or compromising patient satisfaction or safety – more rigorous research is required.
Hong et al. (2012)	Outcomes of online support and resources for cancer survivors: a systematic literature review	To systematically review literature on health outcomes of online cancer support and resources	24	Pain Depression	On-line cancer support shows promise for achieving positive effects – more rigorous research is required.
Kim &. Park (2015).	Web-based self-management support interventions for cancer survivors: A systematic review and meta-analyses.	To identify the characteristics of web-based self-management support interventions for cancer survivors and assess the effects of these interventions	37	Fatigue Depression Anxiety	Web-based self-management support interventions demonstrated small to moderate effects on symptoms of fatigue, depression, and anxiety.
McAlpine et al. (2015	A systematic review of types and efficacy of on-line interventions for cancer patients	To examine outcome-focused literature surrounding interactive online resources for cancer patients	14	Depression Anxiety Pain Fatigue	Online interventions for cancer patients show promise but the small number of studies which are rigorous in analysis report mixed efficacy
Okuyama et al. (2015).	Psychosocial telephone interventions for patients with cancer and survivors: a systematic review	To review the efficacy of randomized controlled trials (RCTs) of psychosocial telephone interventions for cancer patients	20	Anxiety Depression	Telephone interventions hold promise for psychosocial outcomes in cancer care but more robust research is required to establish efficacy.

Table 1: Reviews providing evidence for impact of eHealth supportive care interventions on symptoms

resources (Hong et al., 2012), interactive online resources (McAlpine et al., 2015), psychosocial telephone interventions (Okuyama et al., 2015); and technology in the delivery of follow-up (Dickinson et al., 2014).

Within these reviews, studies have considered the impact of eHealth interventions on the following symptoms (as well as other outcomes, e.g. quality of life, patient satisfaction, social support and coping): fatigue (Dickinson et al., 2014, Kim and Park, 2015, McAlpine et al., 2015); anxiety (Dickinson et al., 2014, Kim and Park, 2015, Okuyama et al., 2015, McAlpine et al., 2015); depression (Agboola et al., 2015, Dickinson et al., 2014, Hong et al., 2012, Kim and Park, 2015, Okuyama et al., 2015, McAlpine et al., 2015); pain (Agboola et al., 2015, Dickinson et al., 2014, Hong et al., 2012, McAlpine et al., 2015); and sexual dysfunction (Dickinson et al., 2014).

All six reviews conclude that eHealth supportive care interventions demonstrate potential for cancer survivors. Interventions were generally evaluated in terms of whether they had a positive impact on symptoms (or other measured outcomes). However, when evaluating the use of eHealth in the delivery of cancer follow-up, interventions were reported in terms of equivalence of care rather than seeking improvement. This suggests that within this area the main incentive for the service change may be economical, and evaluations are conducted to ensure that care is not compromised by being provided remotely. To date, studies considering alternative approaches to providing follow-up to cancer survivors have been dominated by the use of the telephone. This is reflected in the review of technology in the delivery of follow-up (Dickinson et al., 2014), where the telephone was involved in 7 out of 13 randomised controlled trials (RCTs). Providing follow-up remotely using technology did not significantly increase psychological distress or reduce quality of life.

Although symptom improvements were reported in five of the reviews, there was little consistency within and across them regarding the impact of eHealth on symptom burden. The systematic review of web-based self-management support interventions included a small number of articles in meta-analyses. Small to moderate effect sizes were found on fatigue, depression and anxiety compared to usual care (Kim and Park, 2015). The review of supportive telehealth interventions did not corroborate the efficacy of eHealth interventions in reducing depression (only 4 out of 9 studies focusing on depression reported significant effects) but did suggest benefit in terms of reducing pain (2 out of 3 studies on pain control reported significant

effects). Reviews considering online resources reported varied efficacy (Hong et al., 2012, McAlpine et al., 2015); many studies reported positive effect but these were often marginal, not sustained, and inconsistent with other studies within the review.

As the most mature component of eHealth, psychosocial interventions have been delivered over the telephone for the past 25 years. The review by Okuyama et al. (Okuyama et al., 2015) focused purely on RCTs of telephone based psychosocial interventions; 9 of the 20 studies reviewed reported statistically significant or marginally significant effects, but they were mainly modest effects and were not robust across time points or studies.

While evidence suggests that eHealth supportive care interventions have the potential to reduce symptom burden, firm conclusions cannot be drawn from these reviews. The reason for this may lie in methodological limitations. Few evaluations of eHealth supportive care interventions employed an RCT design, and small sample sizes precluded firm conclusions (Dickinson et al., 2014, Hong et al., 2012, Okuyama et al., 2015). Further, short follow-up limited evaluation of the potential longer-term effects of eHealth interventions (Hong et al., 2012, Okuyama et al., 2015, McAlpine et al., 2015). There is also a disproportionate inclusion of women with breast cancer within studies of eHealth supportive care interventions (Agboola et al., 2015, Hong et al., 2012, Kim and Park, 2015, Okuyama et al., 2015, McAlpine et al., 2015). Evidence may not be transferable to other cancer types or gender; men may express different supportive care needs and preferences regarding delivery of support (Børøsund et al., 2013).

Further, studies evaluating eHealth interventions have inadequate inclusion of individuals from ethnic minorities or low socioeconomic groups (Okuyama et al., 2015, Hong et al., 2012). This however reflects the population for who most eHealth interventions have been designed for, and utilised by. A review of Internet Cancer Support Groups (ICSGs) conducted in 2005 (Im et al., 2005) indicated that out of the 546 internet cancer support groups reviewed, only 24 were designed for ethnic minorities. Reviews of ICSGs in particular suggest that the most likely demographics of users are: younger, highly educated, high income, white, women, in early stages of cancer who consider themselves active participants in their health care (Im, 2011, Im et al., 2005). While most on-line interventions have been designed and evaluated in English to date, this is not the primary language for the fastest growing on-line populations (China &

India) (Hong et al., 2012). It is important that the cultural appropriateness of interventions utilised by populations outside of those they were designed for is considered.

It is difficult to consider evidence of efficacy across interventions due to a lack of consistency in outcome measures (Okuyama et al., 2015, McAlpine et al., 2015) and the use of investigator-designed ones (Hong et al., 2012). This is supported by a review of supportive eHealth programmes in cancer care (Ventura et al., 2013) which synthesised information on the design of interventions. The review included 28 articles reporting on 16 eHealth supportive care interventions, and found that only the Functional Assessment of Cancer Therapy (a quality-of-life measure) (Cella et al., 1993) and the Speilberger State Trait Anxiety Inventory (a measurement of anxiety) (Spielberger et al., 1983) were consistently used as outcome measures across studies.

In addition to inconsistent outcome measures, conclusions are also limited by sparse reporting of theoretical underpinnings for eHealth supportive care interventions (Hong et al., 2012, Ventura et al., 2013, McAlpine et al., 2015). Employing theoretical models will enable an understanding of changes in behaviour and any resulting impact on symptoms in order to guide future intervention development and evaluation (Ritterband et al., 2009).

Reviews of eHealth interventions are limited by poor reporting of trial information in included studies. For example, frequent omissions relate to recruitment and follow-up information, sample size calculations and the effect sizes for primary and secondary outcomes (Okuyama et al., 2015). The Consolidated Standards of Reporting Trials (CONSORT) group provide criteria for reporting information about randomized clinical trials (Altman et al., 2001, Begg et al., 1996). Due to the challenges in accurately reporting eHealth trials (e.g. difficulty in reporting accurate recruitment numbers when inviting participation over the Internet), CONSORT guidelines were reviewed with relevance to eHealth research and subsequently found to be beneficial (Baker et al., 2010). A checklist extending these guidelines with specific relevance to eHealth interventions has also been developed - CONSORT-EHEALTH (Consolidated Standards of Reporting Trials of Electronic and Mobile HEalth Applications and onLine TeleHealth). This checklist aims to ensure sufficient details of eHealth interventions are reported to enable replication and theory-building (Eysenbach, 2011). The next generation of eHealth research needs to consider relevant CONSORT guidelines at each stage of the research

process, including the design, delivery and evaluation of the intervention. The reporting of these details may enable stronger conclusion to be drawn across studies.

More rigorous research is required to draw firm conclusions regarding the impact of eHealth supportive care interventions on the symptom burden of cancer survivors. Whilst this review of evidence suggests there is potential benefit, future interventions could be strengthened by theoretical underpinnings, standardised outcome measures, and samples diverse in ethnicity and cancer type. There is a need for more robust evidence for *whether* eHealth supportive care interventions relieve symptom burden in cancer survivors and to understand the mechanism of *how* and *why* they relieve this burden.

1.4.2 Impact of eHealth supportive care interventions on the treatment burden of cancer survivors

1.4.2.1 Background

Treatment burden is an emerging concept within the chronic conditions literature (Mair and May, 2014) but is currently under-investigated in cancer survivors. Consequently, the impact of eHealth cancer supportive care interventions on treatment burden has not been the specific focus of research studies to date. A questionnaire which measures the treatment burden of patients with multiple chronic conditions has been developed in France (Tran et al., 2012) and validated for use in English (Tran et al., 2014) but has yet to be used with cancer survivors so this section cannot consider the impact of eHealth supportive care interventions on treatment burden using quantitative data. However, qualitative data reporting the experience of adult cancer survivors who have engaged with eHealth supportive care interventions can be considered within a framework of treatment burden to shed light on the impact of eHealth on this aspect of survivorship.

For the purposes of this thesis, telehealth (one component of eHealth which incorporates three of the five papers which form the body of this thesis) will be considered as an exemplar of eHealth supportive care inteventions. Telehealth is a subset of telehealthcare which refers to the use of technology to provide remote personalised healthcare to patients (McLean et al., 2011, Sood et al., 2007). Telehealth interventions allow remote exchange of data and communication between patients and health care professional/s (Barlow et al., 2012).

This section reports a theoretically informed framework synthesis of cancer survivor experience of telehealth interventions conducted to explore the impact of telehealth on treatment burden. Framework synthesis has developed from framework analysis (Ritchie and Spencer, 1994, Ritchie, 2013), a highly structured method of synthesis which uses a pre-defined framework to extract and synthesise findings (Barnett-Page and Thomas, 2009). Qualitative work on treatment burden has been heavily informed by Normalisation Process Theory (NPT) [see section 1.2.2] which encompasses the domains of work, the processes, involved in the incorporation of patient work into everyday life. NPT provides a framework for the synthesis of qualitative data (May et al., 2015, Mair et al., 2012, Gallacher et al., 2013a).

1.4.2.2   Aim

The aim of this review was to systematically identify and synthesise qualitative research evidence on the experience of adult cancer survivors who have engaged with a telehealth intervention, using NPT as a theoretical framework, in order to consider the impact of telehealth on treatment burden.

1.4.2.3   Search strategy

A comprehensive search strategy was developed with the intention of identifying all studies which met the criteria. The search strategy was developed for Medline (PubMed) and then adapted and applied to PsychINFO, CINAHL (Cumulative Index for Nursing and Allied Health Professionals), Embase and Cochrane Central Register of Controlled Trials. These databases were chosen to encompass nursing, medicine, social sciences and psychology. To retrieve other relevant publications, the reference lists of selected publications were hand searched and articles considered against the eligibility criteria. Non-research publications and 'grey' literature were excluded. The search was conducted on 14.08.2015.

Search terms were split into 3 categories: cancer survivors (population), eHealth (intervention), and survivor experience (outcome). Each category included medical subject headings (MeSH) and keywords using truncation (*) within title or abstract fields (see table 2 for full Medline search strategy). The search terms were informed by previous systematic reviews of eHealth (Darlow and Wen, 2015, Ross et al., 2015) and database thesauri. Boolean terms 'OR' and 'AND' were used to combine searches within and between categories respectively. The search was restricted to papers published in English between 2006 and 2015.

Cancer survivors	"Neoplasms"(MH) OR "Oncology Nursing"(MH) OR "Radiation Oncology"(MH) OR "Medical Oncology" (MH) OR "Oncology Service, Hospital" (MH) OR Cancer (TI) OR Oncology (TI)
eHealth interventions	"Management Information Systems"(MH) OR "Decision Making, Computer-Assisted" (MH) OR "Therapy, Computer-Assisted" (MH) OR "Medical Records Systems, Computerized" (MH) OR "Technology" (MH) OR "Remote Sensing Technology" (MH) OR "Technology Assessment, Biomedical" (MH) OR "Telecommunications"(MH) OR "Telephone" (MH) OR "Cell Phones" (MH) OR "Electronic Mail" (MH) OR "Videoconferencing" (MH) OR "Telemedicine" (MH) OR "Telenursing" (MH) OR "Computers, Handheld" (MH) OR "Mobile Applications" (MH) OR "Remote Consultation" (MH) OR "Computer Communication Networks" (MH) OR "Attitude to Computers" (MH) OR "Internet" (MH) OR App (TI) OR Apps (TI) OR Device* (TI) OR M-health (TI) OR Mhealth (TI) OR Mobile* (TI) OR Phone* (TI) OR Smartphone* (TI) OR Telephone* (TI) OR E-health (TI) OR Ehealth (TI) OR Web* (TI) OR On-line (TI) OR Online (TI) OR Smartphone (TI)
Survivor experience	"Patient Acceptance of Health Care" (MH) OR "Patient Satisfaction" (MH) OR "Patient-Centered Care" (MH) OR Experience* (TI) OR Accept* (TI) OR Satisf* (TI) OR Perception* (TI) OR Perspective* (TI) OR View* (TI) OR Attitude* (TI) OR ((Patient* or User*) AND (Experience* OR Accept* OR Satisf* OR Perception* OR Perspective* OR View* OR Attitude*)) (ABS)
Combination	Cancer survivors AND eHealth interventions AND survivor experience
Limiters	1) English language only 2) Last 10 years (1/1/2006 – 31/8/2015) 3) Adult only 4) Human

Table 2: Search strategy eHealth and treatment burden

1.4.2.4   Screening

The initial search was not limited by research method, papers which contained qualitative data were identified during the screening process. During screening, only eHealth interventions fitting the definition of telehealth were included. In keeping with the expectations of a doctoral thesis, screening, quality appraisal, data extraction and analysis were conducted independently by the candidate only.

Articles were included if they met the following inclusion criteria: published in English in the last 10 years (1/1/2006 – 31/7/2015); reported on adults with a diagnosis of cancer, regardless of age, sex, tumour type or co-morbidities; incorporated participants who had experienced a telehealth intervention; reported qualitative data on cancer survivor experience of a telehealth intervention (including data collected through interview, open text and open-ended survey questions); and reported qualitative data that had been analysed with themes identified and examples given. Articles were excluded if they included data from individuals with conditions other than cancer without reporting findings by disease type or included data from carers/family members without reporting findings by population.

1.4.2.5   Quality assessment

Quality checks were conducted using the Critical Appraisal Skill Programme (CASP) Checklist for Qualitative Research (Critical Appraisal Skills Programme, 2015) to determine methodological rigour and ethical standards of studies. In studies which collected qualitative data using an open question on a survey tool, the checklist was adapted to consider the appropriateness of the question used to gather the data. Reflexivity was not reported in many of the studies so understanding of the impact of the researcher's role on data collection and analysis is limited. On the whole, auditable processes were reported and studies provided adequate information about samples to generate transferability. Only one study was considered to provide limited transferability due to a small sample size (Chan et al., 2013). All studies fulfilled the critical appraisal criteria and were considered sufficiently methodologically sound to have confidence in their findings (Table 3).

Article	Clear aims	Appropriate methodology & design	Recruitment explained	Appropriate data collection	Researcher role examined	Ethical approval sought	Rigorous analysis	Clear findings
Beaver et al., 2010	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Chambers et al., 2015	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Chan et al., 2013	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Cox et al., 2008	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Cox & Faithfull, 2015	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Fergus et al., 2014	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Head et al., 2011	Yes	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes
Hoberg et al., 2013	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Hoberg et al., 2015	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Kearney et al., 2006	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
McCann et al., 2009	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Williamson et al., 2015	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes
Zheng et al., 2013, China	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes

Table 3: Quality appraisal of articles using Critical Appraisal Skills Programme (2015)

1.4.2.6 Data extraction

Details of sample, telehealth intervention, HCP, time point of data collection, data collection method, and data analysis were extracted for each article to set the context for the paper. Themes and quotations were extracted from the results section of each article.

1.4.2.7 Analysis

This synthesis is unique in that data was coded and analysed using the four core constructs of NPT - sense-making; cognitive participation; collective action; and monitoring – as a framework to consider the impact of telehealth interventions on the treatment burden of cancer survivors. Themes, and an example quotation to illustrate the meaning of the theme, were coded to the relevant construct. There was no limit to how many themes from each paper could be

coded to one construct. Themes which did not fit within a construct were not forced into the framework. Each theme was given equal weight within the framework.

1.4.2.8 Results

A total of 2,776 articles were identified (Medline – 775; PsychINFO – 175; CINAHL – 298; Embase – 1,212; Cochrane Central Register of Controlled Trials – 316; Hand searching – 4). Duplicate articles (565) and those not meeting the inclusion criteria [see 1.4.2.4] (2,198) were removed – 13 articles were included.

Table 4 details the 13 articles which analysed and reported on qualitative data (reporting themes and examples) relating to cancer survivor experience of telehealth between 2006 and 2015. Notably, there is a paucity of qualitative studies relating to cancer survivor experience in an area with considerable research activity. Nine papers focused on survivors from a specific cancer type: breast (Beaver et al., 2010, Fergus et al., 2014), ovarian (Cox et al., 2008, Cox and Faithfull, 2015), haematological (Högberg et al., 2013, Högberg et al., 2015), lung (Chambers et al., 2015), head and neck (Head et al., 2011), or colorectal (Williamson et al., 2015); 3 papers included cancer survivors with a range of cancer types (Chan et al., 2013, Kearney et al., 2006, McCann et al., 2009) and 1 paper reported on cancer survivors returning home with colostomies (Williamson et al., 2015).

The majority of papers reported on studies conducted within the UK (Beaver et al., 2010, Cox et al., 2008, Cox and Faithfull, 2015, Fergus et al., 2014, Kearney et al., 2006, McCann et al., 2009, Williamson et al., 2015). This may be in part due to the search strategy being restricted to papers published in English language only, but there were few papers published from other English speaking countries such as the USA (Head et al., 2011) or Australia (Chambers et al., 2015).

Telehealth interventions are intended to remotely connect patients and health care professionals. In 11 of the 13 papers cancer survivors were connecting with nurses (Beaver et al., 2010, Chan et al., 2013, Cox et al., 2008, Cox and Faithfull, 2015, Head et al., 2011, Högberg et al., 2013, Högberg et al., 2015, Kearney et al., 2006, McCann et al., 2009, Williamson et al., 2015, Zheng et al., 2013). This may reflect the economic driver for eHealth and the anticipated cost effectiveness of nurse involvement in comparison to oncologists, or it may be an acknowledgement of the communication skills demonstrated by cancer nurses.

Telehealth interventions within these papers most frequently used the telephone either in terms of telephone follow-up (Beaver et al., 2010, Cox et al., 2008, Cox and Faithfull, 2015, Williamson et al., 2015, Zheng et al., 2013) or telephone delivered intervention (Chambers et al., 2015). As previously discussed, the telephone is the most mature component of eHealth and its dominance within telehealth may simply reflect this, which may change as other components of telehealth become more accessible and normalised over time. Papers included in this framework synthesis also consider cancer survivor experience of engaging with online interventions incorporating remote monitoring and/or communication (Chan et al., 2013, Fergus et al., 2014, Högberg et al., 2013, Högberg et al., 2015), remote monitoring and communication using hand-held computers (via a telephone line) (Head et al., 2011, Kearney et al., 2006), and remote monitoring and communication via mobile phone (McCann et al., 2009).

Table 4: Studies analysing qualitative data on cancer survivor experience of telehealth

Article	Sample -Qualitative element	Telehealth intervention	Health Care Professional	Time point of data collection	Data collection method	Data analysis
Beaver et al., 2010, UK	28 women with breast cancer	Telephone follow-up	Breast care nurse specialist	End of a randomised equivalence trial (mean length of intervention across all participants - 24 months)	Interview	Thematic content analysis
Chambers et al., 2015, Australia	22 lung cancer patients who commenced the intervention; 9 lung cancer patients who did not commence the intervention	Telephone delivered cognitive behavioural intervention	Psychologist	At 3 month follow-up	Interview	Thematic analysis
Chan et al., 2013, Singapore	4 patients receiving first chemotherapy for lung, breast or colorectal cancer	Daily online symptom care and management system (and at least 2 videoconference consultations)	Nurse	After 4 cycles of chemotherapy	Questionnaire (adapted from Kearney et al., 2006); 1 open ended question	Thematic content analysis
Cox et al., 2008, UK	52 women with ovarian cancer received intervention (46 returned questionnaire, 35 completed open question)	Telephone follow-up	Nurse specialist	After study period of up to 10 months	Experience of care questionnaire - 'general views' section had open responses	Thematic content analysis
Cox & Faithfull, 2015, UK	11 women with ovarian cancer	Telephone follow-up	Nurse specialist	After at least 3 years	Interview	Interpretive phenomenological analysis
Fergus et al., 2014, UK	10 women with breast cancer and their partners	Online coping and adjustment intervention including 'dialogue room' for facilitator and the couple to have 3-way conversations	Mental health practitioner with oncology expertise	After completion of entire program	Questionnaire (including open ended questions) and a telephone interview	Thematic analysis

Head et al., 2011, USA	44 patients with head or neck cancer	Simple monitoring and messaging device 'Health buddy' - connected via land-line.	Nurse	Participants had used the device for an average of 71 days before data collection	Interview	Thematic analysis
Hoberg et al., 2013, Sweden	11 haematological cancer patients and 6 family members	Web-based communications channel to nurse, could submit written questions and receive written responses within 3 days	Nurse	After 4 months	Interview	Thematic analysis
Hoberg et al., 2015, Sweden	10 haematological cancer patients	Web-based communications channel to nurse, could submit written questions and receive written responses within 3 days	Nurse	After 3 months of being given access to service	Interview	Thematic analysis based on Gadamer's approach to hermeneutics
Kearney et al., 2006, UK	18 patients with lung or colorectal cancer and 9 HCP consented to participate (11 patients and 9 HCP retuned a post-evaluation questionnaire - reported separately)	Handheld computer - symptom monitoring	Nurse	After 2 cycles of chemotherapy	Questionnaire (including open ended questions)	Thematic content analysis
McCann et al., 2009, UK	12 patients with breast lung or colorectal cancer	Mobile phone based remote symptom monitoring system	Nurse	After 5 cycles of chemotherapy	Interview	Thematic content analysis
Williamson et al., 2015, UK	21 colorectal cancer patients	Telephone follow-up	Specialist nurse	All participants had received at least 1 telephone follow up (4 patients had received 2) prior to data collection	Interview (20 by telephone; 1 face-to-face)	Thematic ontent analysis
Zheng et al., 2013, China	11 colostomy patients (author confirmed all had a diagnosis of cancer)	Telephone follow-up	Enterostomal nurses	Completion of telephone follow-up (2-3 telephone follow-up calls within 1 month of discharge)	Telephone interviews	Thematic content analysis

The experience of cancer survivors was mainly elicited after a relatively short period (up to 10 months) of engagement with telehealth, the exception being two papers reporting on telephone follow up (Beaver et al., 2010, Cox and Faithfull, 2015). In the paper reporting on nurse-led telephone follow-up of women with breast cancer, survivors had received a mean of 24 months of the intervention prior to interview (Beaver et al., 2010), and the Cox and Faithfull study reported on the experience of women who had received at least 3 years of telephone follow up after treatment for ovarian cancer (Cox and Faithfull, 2015) [P5].

Table 5 groups themes reported within the 13 identified articles against the four core constructs of NPT - sense-making; cognitive participation; collective action; and monitoring. It is not a 'truth' but merely one way of considering the impact of telehealth on survivor burden. It is acknowledged that many themes span more than one construct, for example, cognitive participation mainly includes themes relating to the relationship cancer survivors have experienced with a HCP, but this relationship/engagement may also enable the cancer survivor to gain information which helps them to make sense of their situation (sense making) or benefit the management of their health (collective action).

Table 5: Cancer survivor experience of telehealth - themes and examples coded within Normalisation Process Theory framework

Article	Themes	Sense making	Cognitive participation	Collective Action	Monitoring
Beaver et al., 2010, UK	Convenience, Continuity, Normalising, Structure, Putting a face to the voice	Structure: *'She [BCN] asked about families and how the rest of your family had dealt with it and you might not have even thought of that so in between times if the question came up again you might have reflected on it or even spoken to some of the family and got their views on it. So it was good that she asked me the same question again'*	Continuity: *'She [BCN] always had the time to talk you through it and I found her very reassuring right from the start so I think it's the continuity'* Putting a face to the voice: *'You need to see her face. I think if you can picture her face whilst you're having…telephone consultation…because she could be asking you an awful lot of intimate details'*	Convenience: *'I'm self employed and I travel all over the county…and it's difficult to be at a hospital at a certain time so that was good'* Normality: *'It is much more relaxed to know that you don't have the alien thing of the hospital. You can have it in your home [telephone follow up]. You can have it at work. You can have it on your mobile if you want sat in the car'*	
Chambers et al., 2015, Australia	Therapeutic relationship, Self-management of distress, Family relationships	Family relationships: *'The psychologist, she was really good, because she sort of told me [daughter's name] point of view too..[..]..that helped me to look at my daughter's point of view a bit more than what I had'*	Therapeutic relationship: Described as independent, empathic and supportive *'it's just good to talk it through with somebody totally independent'* , *'she was supportive and it's not gonna go away'*	Self-management of distress: *'She [the therapist] told me what to do and she even sent me some letters to explain, you know the way I gotta do the breathing and the way when I get depressed like to relax'*	
Chan et al., 2013, Singapore	Reassurance, Self care advice, Simple and user friendly,	Self care advice: *'It is educational in the sense that I have an overall view about the side effects of chemotherapy'*	Reassurance: *'the most helpful thing: can see and talk with the nurse'*	Simple and user friendly: *'It is too tiring after work and time consuming'*	
Cox et al., 2008, UK	Relationship with the nurse & Convenience		Relationship with the nurse: *'able to establish a very close relationship with the nurse over the telephone'*	Convenience: *'Not having to go to the clinic and wait a long time'*	

Cox & Faithfull, 2015, UK	Somebody was looking out for me, It's just reassurance, Time was never an issue	It's just reassurance: *'I think I would probably phone [nurse 2] first and say do you think I should go to my doctor because I feel that she's the expert'*	Somebody was looking out for me *'knowing that someone was going to be phoning me and I had a little query about something and I could pass that over was almost a feeling of relief really, whoever I spoke to never questioned why I asked that..[...]..it was a support I had not expected.*	Time was never an issue. *'I was never conscious that I was over running my time which was a good thing and I hadn't thought about that until about the second one in, when I put the phone down and I thought 'oh my gosh I've been on there 10 minutes, I wonder if that was too long' and I think I mentioned that next time to [Nurse 3] or whoever phoned, I said 'do you have a time limit here' and she said 'NOT at all' and it was very definite 'NOTATALL' and that made you relax again, because you weren't being rushed.*
Fergus et al., 2014, UK	Reasons for participating; Program satisfaction; Program facilitation and website usability; Program convenience; Program limitations;		Program satisfaction: *'My husband and I are feeling more connected to one another. We have learned to communicate and express ourselves better'* Program facilitation and website usability: *'The fact...that there was feedback from a health care professional'*	Program convenience: *'We have very limited free time available and found it difficult to finish the lessons within a week, particularly the ones that needed to be started immediately'*
Head et al., 2011, USA	Provided needed information; Improved my self management during treatment	Provided needed information *'it gave me information on what could be expected from treatment'*		Improved self-management: *'It reminded me to take my meds and exercise'*

Hoberg et al., 2013, Sweden	Preferences and characteristics of the individual; A clear context of web-based support; An incorporated use of web-based services	A clear context of web-based support: *'Is this question suitable for the web-based function or is it not?'*	An incorporated use of web-based services: *'If I should share my innermost thoughts, I'd probably like to have some kind of relation with the person I'm writing to. Otherwise, I need to know exactly what I'm asking for...'*	Preferences and characteristics of the individual: *'It is very easy to send your question when it suits yourself, instead of sitting and waiting for a telephone'*	
Hoberg et al., 2015, Sweden	A space to have their say; A consolidation of a matter; An extended caring relationship; Access to individual medical assessment; An opportunity for emotional processing.	A space to have their say: *'...It has been difficult to decide when to call...so often, I've saved things until I meet someone...but they usually have no time for all questions either, they take the most important. I see this as a chance to get a space I was missing'* A consolidation of a matter: *'It has also been nice getting a written response. You can read it several times'*	An extended caring relationship: *'To be able to write and tell someone who knows you, who knows that I exist and a bit how I am...you know who to write to, then it's easier than calling because then it is just a stressed voice than answers that might as well be sitting in Pakistan.... As a patient, I get good 'Coaching' off the nurses here..but when I leave the hospital, I meet the whole world and I am suddenly all alone.. Now I know, even if no one saw me when I left, that there is still someone I can communicate with'*	Access to individual medical assessment: *'It's nice to be able to check or question...should you really be this tired?...I have received massage, could it have been dangerous?'* An opportunity for emotional processing: *'Sometimes it may be better to have some written communication, you have to think through a little bit what the problem is, or so...to 'write it off' is also a way to sort yourself out in a way'*	
Kearney et al., 2006, UK	Knowledge and confidence; Self-care behaviour and symptom management; Communication and support	Knowledge and confidence: *'Made it easier to understand some of the problems experienced'.* Self -care behaviour and symptom management: *'Made me more aware of the likely problems'*	Communication and support: *'The nurse at the hospital can reach me better'*		

McCann et al., 2009, UK	Initial thoughts and feelings about the study; Training and familiarization of the handset; Length of data collection; Daily routine; Symptoms; The alerting facility; Reassurance; Overall experience of the study; Future use and development of the system.			Daily routine: '*Well I made it useful by doing it at the same time as I took my pills…so, I set an alarm and I did it at the same time as taking my pills so that wasn't difficult'.* The alerting facility: '*It wasn't until afterwards I thought, well that was really good, that was good, because as I say you could sit all day maybe and wait for somebody, your GP to get back in touch, but that was like only about 10, 15 minutes after I closed the thing down'.* Reassurance: '*It was quite positive. It was quite reassuring, you did feel that you were being monitored. You didn't think if you put in those symptoms that you would slip through the…[..]..Somebody would have picked it up'*	
Williamson et al., 2015, UK	Accessible and convenient care; Personalised care; Relationship with the specialist nurse.	Personalised care: '*She [CNP] was able to tell me sort of little details. Like how much of the bowel they'd removed, and how far the cancer had gone. And of course I wouldn't have asked things like that, but she offered the information…'*	Relationship with the specialist nurse: *She was a very caring person and she's a person who listened to your problems…her personality still came hard over the phone. She spoke to me like a friend… It was her whole attitude seemed to be…. I just felt I was able to talk to her'*	Accessible and convenient care: '*I haven't got a car so I'd have to take two buses you see to go to the hospital. When I get to the hospital I have about an hour and a half wait in the waiting room. And I go see the doctor, 2 min and I'm out again'*	

| Zheng et al., 2013, China | The pleasure of receiving calls; Timely problem solving; Instructions for resuming a normal life; Psychosocial support; High acceptance of the telephone follow-up | | The pleasure and assurance of receiving calls: *'I felt safe and reassured because the hospital staff followed up with me like a kite in their hand, so that I would not fly away'*

Psychological support: *'I was depressed and cried all day after surgery and didn't want to face reality. The enterostomal nurse's call pulled me out of the shadows at this critical time'* | Timely stoma problem-solving: *'She [the enterostomal nurse] pointed out the correct way for me, so I wouldn't need to take so many detours'*

Instructions for resuming a normal life: *The enterostomal nurses' calls are just like a guideline for my daily life, which lets me know what I can eat and what I can do'* | |

<u>Sense making</u>

Sense-making encompasses seeking information about a health condition and how to manage it. Within most of the telehealth interventions, cancer survivors were connected remotely (via differing means and for differing purposes) with a nurse. The themes within these articles indicate that cancer survivors experienced these interventions as offering personalised care (Williamson et al., 2015) and the opportunity to connect to a nurse with the expertise to offer reassurance (Cox and Faithfull, 2015). These factors create a culture conducive to information seeking and sense making. Questions initiated by the nurse triggered reflection and (further) information seeking (Beaver et al., 2010) but also allowed cancer survivors 'space to have their say' (Högberg et al., 2015). Survivors felt they could ask questions they wanted to in the way they wanted to using web-based communication, without worrying about disturbing or burdening the nurse, or allowing a two-way conversation to lead them away from what they wanted to ask.

> *'...It has been difficult to decide when to call...so often, I've saved things until I meet someone...but they usually have no time for all questions either, they take the most important. I see this as a chance to get a space I was missing'*
> (Högberg et al., 2015) (p148)

Telehealth interventions, particularly those which are mobile or web-based, can utilise written communication, which brings an awareness of permanence that is not commonly an issue in telephone or face to face communication (unless the consultation is recorded). This sense of permanence could both benefit and hinder sense making. For example, in the earlier study by Hogberg et al (Högberg et al., 2013) survivors found the definitiveness of writing down their questions to the nurse intimidating, and felt they needed to know exactly what they were allowed to ask. However, in their later study (Högberg et al., 2015) cancer survivors expressed the benefits of receiving a written response as it allowed them to read it again. The factors affecting whether written information is experienced positively are unclear.

<u>Cognitive participation</u>

Cognitive participation refers to engaging with others to manage a condition. Telehealth interventions provide remote engagement, usually with an identified HCP, and the benefits of this for cancer survivors in terms of cognitive engagement were consistent throughout the themes. Most themes within this construct emphasised the quality of the engagement that the

telehealth intervention enabled. This relationship with a HCP (most commonly a nurse) did not just provide a platform for information exchange to facilitate sense making. Rather, the quality of the relationship in terms of its continuity (Beaver et al., 2010), empathy, and independence from existing support (Chambers et al., 2015) enabled a valued relationship with the HCP (Chan et al., 2013, Cox et al., 2008, Högberg et al., 2015, Zheng et al., 2013) and the sense that 'someone was looking out for me':

> *'It was, it was consistency, it was um…the feeling that I was being looked after, that somebody was looking out for me, because it is scary, you do go to a scary place then and you, you, and….the feeling that it could, you know it could happen again or you know, something like that, it takes a while to go away and it's knowing somebody that you feel you trust um…and who understands you, I feel that's very important.'*
> (Cox and Faithfull, 2015) (p2360)

For some cancer survivors there is a suggestion that a remote relationship with a HCP could be strengthened by other means. For example, relationships with HCPs over the telephone could benefit from 'putting a face to the voice' (Beaver et al., 2010), and cancer survivors engaging with HCPs through written interactions expressed they may benefit from 'some kind of relationship with the person I'm writing to' (Högberg et al., 2013). An online coping and adjustment intervention facilitated by a mental health practitioner with oncology expertise (Fergus et al., 2014) indicated that telehealth interventions can also benefit engagement between cancer survivors and their partners.

Collective action

Collective action is practical in nature; it is the actions of the individual and their network in monitoring and managing their health and implementing any changes in lifestyle. This includes preparing for and attending appointments and organising and preparing medication. The remoteness of telehealth offers obvious practical advantages to relieving the burden of collective action as by its very definition telehealth replaces the journey to and from HCPs. This benefit was recognised in the themes of many papers; the convenience of telehealth interventions was cited by survivors across a range of telehealth mediums: telephone (Beaver et al., 2010, Cox et al., 2008, Cox and Faithfull, 2015, Williamson et al., 2015), mobile phone (McCann et al., 2009) and web-based communication (Högberg et al., 2013). Replacing clinic-based contact with a HCP with remote connections did not only relieve the burden of travel,

the need to park, and lost hours waiting in clinic for an appointment, it also offered the potential for a greater sense of normality for cancer survivors (Cox and Faithfull, 2015). Hospitals and clinics can have negative associations for cancer survivors and stimulate stress and anxiety (Allen, 2002). Connecting with HCPs remotely can avoid this negativity and permit more relaxed interaction, potentially enabling survivors to look forward to their future rather than dwell on their past:

> *I am sure there are lots of people like me that return to normality. It's a thing of the past. You have a full life. You function. You're working. You're living. You have a social life. You're doing everything. It is much more relaxed to know that you don't have the alien thing of the hospital. You can have it in your home [telephone follow up]. You can have it at work. You can have it on your mobile if you want sat in the car'*
> (Beaver et al., 2010) (p2919)

Remote connections also blind cancer survivors to the time pressures which the HCP may be facing. In clinic, it is very evident if many other people are also waiting, which can inhibit cancer survivors from feeling able to express their feelings (Cox and Faithfull, 2015) and limit collective action.

The burden of collective action was not only relieved in terms of convenience or the removal of negative associations and time pressures, telehealth was also felt to support cancer survivors in managing their own health. Advising the cancer survivor remotely of the best way to manage symptoms and side effects (Chambers et al., 2015), reminding them to take their medications (Head et al., 2011), and facilitating timely problem solving all supported individuals in the tasks involved in living with and beyond cancer (Zheng et al., 2013).

Not all of the papers presenting themes within collective action reflected a relief of burden. Online interventions could also serve to add to the burden of collective action particularly if experienced as another task to complete at the end of a busy day (Chan et al., 2013, Fergus et al., 2014).

<u>Monitoring</u>

The construct of monitoring refers to an individual's reflection on the management of their condition. Reflection was necessary in order for survivors to indicate the impact of telehealth on sense making, cognitive participation and collective action, but it is notable that none of the studies suggested that telehealth had aided reflection. This is in contrast to an eHealth intervention in which self-monitoring without connection to a HCP facilitated reflection (Patel et al., 2012). Breast cancer survivors who were given a personal health information management tool (HealthWeaver - a website and a companion mobile phone application) reported the benefits of being able to consistently collect and reflect on their data, using patterns in the data to investigate symptoms and monitor their health. For example, participants took comfort in owning the monitoring process and the routine it provided, and used the data to communicate about their symptoms during their clinic appointments.   It is possible that when a cancer survivor feels they are being monitored by a HCP, they assume the responsibility for appraisal is with the professional. This is supported in the Cox et al (Cox and Faithfull, 2015) study within the theme 'It's just reassurance'. Women relied on the nurse to monitor even subtle changes in their well-being: *'She'll know…if you say such and such and such and such she will know that there is a problem'* (p2361). Within the construct of cognitive participation, the quality of the relationship established through telehealth has been emphasised. It is possible that this relationship enables cancer survivors to feel that they are being monitored externally without the pressure to use telehealth interventions to appraise the management of their condition themselves. This warrants further investigation in future studies of cancer survivor experience of telehealth.

In summary, NPT has been used in this section as a framework for the synthesis of qualitative data on cancer survivor experience of engaging with telehealth. This synthesis highlights the potential for telehealth interventions to relieve the treatment burden of cancer survivors by:

- Facilitating the provision of focused, personalised and uninterrupted information;
- Establishing relationships which are valued in terms of their continuity, independence, empathy and support;
- Providing convenient health care which can facilitate a sense of normality, and the potential to offer regular personalised support for self-management.

This qualitative synthesis has demonstrated how the factors identified in section 1.2.2 as exacerbating treatment burden can be addressed by telehealth interventions. For example, in terms of poorly organised care – telehealth seems to have provided the continuity which was lacking as well as improving communication between patient and HCP. There is suggestion that the challenges of taking medication and attending appointments can be reduced and barriers to accessing HCPs may also be alleviated.

1.4.3 Health care professional perceptions - the impact of eHealth supportive care interventions on survivor burden

Within the large body of research considering the impact of eHealth supportive care interventions on the burden of cancer survivors, only a small minority of publications report HCP engagement (Darlow and Wen, 2015). This is in line with eHealth interventions more broadly, where a lack of user engagement is cited as a weakness of research in the area (Mair et al., 2012).

The few studies which have sought HCP perceptions of eHealth supportive care interventions have reported them to be positive. Although mainly based on small samples, there is evidence that HCPs perceive eHealth supportive care interventions to have potential to relieve both symptom and treatment burden. Remote symptom monitoring systems that communicate data from patient reported outcome measures to HCPs are consistently perceived to relieve survivor burden (Dubenske et al., 2008, Kearney et al., 2006, Maguire et al., 2015, McCall et al., 2008). Some perceptions of benefit are broad:

> *'if employed, it will no doubt result in improved patient care'*
> (McCall et al., 2008) (p430)

More specifically, HCPs perceive remote symptom monitoring systems could relieve the symptom burden of cancer survivors by facilitating earlier detection of and intervention for problematic symptoms (Dubenske et al., 2008, Kearney et al., 2006, Maguire et al., 2015):

> *'Immediate contact may reduce fear' (staff nurse)*
> *'Symptoms can be monitored immediately and acted upon if necessary' (Staff nurse)*
> (Kearney et al., 2006) (p748)

In addition, HCPs report that symptom monitoring systems potentially empower cancer survivors to improve their own symptom management whether they are monitored remotely by

a HCP (Kearney et al., 2006, Maguire et al., 2015) or provided automatically generated personalised feedback and supportive care without connection to a HCP (Duman-Lubberding et al., 2015).

HCPs using eHealth interventions to connect remotely with their patients (telehealth) perceived the interventions to reduce the treatment burden of cancer survivors. HCPs using telephone (Beaver et al., 2010, Williamson et al., 2015), email (Cornwall et al., 2008), or teleconferencing (Sabesan et al., 2012) reported perceptions that these approaches were more convenient for cancer survivors. The work of being a cancer survivor was perceived to be easier as a result of not having to travel to clinic and the associated costs, for example time, money and disruption. The quality of communication was also perceived by HCPs to have improved using these mediums. Less interruptions, less evident time pressures and anonymity were felt to benefit cancer survivors (Beaver et al., 2010, Cornwall et al., 2008):

> *'Sometimes the anonymity of the telephone enabled patients to say more than they might have done in clinic, particularly because they weren't feeling rushed' (Breast Cancer Nurse)*
>
> (Beaver et al., 2010) (p2920)

However, the medium of eHealth is not perceived by HCPs to facilitate relief of burden in all cancer survivors; individual survivor characteristics affect HCP perceptions of the appropriateness of eHealth supportive care interventions. For example, HCPs reported feeling 'protective' of individuals receiving palliative care. A study which aimed to evaluate the support provided by a computerized assessment tool post palliative radiotherapy for lung cancer reported that access to patients was denied (Cox et al., 2011) [P3]. While the HCPs involved in Cox et al.'s (2011) study acknowledged the potential benefits of remote symptom monitoring from both a patient and practice perspective, they questioned the appropriateness of using eHealth with palliative care patients. HCPs considered these patients may be too old, with too rapidly deteriorating a condition to be invited to participate in a study involving technology. Recognising the burden experienced by palliative care patients, HCPs sought to simplify the process and protect them from what they perceived to be an additional burden of eHealth. One HCP who participated in this study summarised this sentiment:

> *'Well it's just an emotional, ethical. . .you know they've already got such huge burden, why burden, how do we dare burden them with anything else'*
>
> (Cox et al., 2011) (p679)

This sentiment is supported by a large qualitative study of HCP experiences of telehealth for people with long-term and complex conditions (MacNeill et al., 2014). Telehealth was considered to cause unnecessary stress for the severely ill:

> *'there is a point where telehealth is quite stressful, if you're at that end stage, you know, you don't really need that'*
>
> (MacNeill et al., 2014) (p403)

Paradoxically, HCPs in the MacNeill et al. (2014) study also felt remote clinical surveillance was inappropriate for patients with less advanced conditions. Telehealth was considered to burden individuals who were currently still 'active and healthy'; they felt that monitoring would cause these individuals needless anxiety without offering any benefit. HCPs have questioned the benefit of eHealth interventions for other individuals, including those with limited eHealth literacy skills, a lack of motivation, and older age (Duman-Lubberding et al., 2015, Haase and Loiselle, 2012).

Naturally, HCP perceptions are also affected by the *content* of eHealth supportive care interventions. eHealth interventions can provide cancer survivors with a wealth of information, potentially personalised to their own disease and treatment experience. Whilst cancer survivors may receive guidance from HCPs towards certain sources of information, ultimately they access remote information independently. Consequently, the content of eHealth interventions is as worthy of consideration as the medium by which it is delivered. HCPs recognise the potential benefits of personalised information provision using eHealth interventions. For example, HCPs perceived a virtual navigation tool to relieve treatment burden by directing cancer survivors to information on line which they could use to make sense of their condition (Haase and Loiselle, 2012):

> *'I think it [the tool] gives the patient more chance of knowledge. And I think knowledge is power and that can make people feel a sense of control..' (Dietician)*
>
> (Haase and Loiselle, 2012) (p398)

However, not all eHealth interventions are supported by HCPs due to the content of the information which they provide. Research exploring UK HCP perceptions of a US-created web-based survivorship care plan tool highlighted several content-related concerns (Cox and Faithfull, 2013) [P4]. HCPs did not support provision of information regarding potential future

consequences of treatment for cancer survivors. Not only did they consider there to be insufficient evidence of physical or psychological *benefit* to cancer survivors but they felt there was a potential *detrimental effect* of providing this information. HCPs expressed concern that causing survivors to think negatively about the consequence of their treatment and their future health status may hinder their current physical and mental health – reflecting a perceived consequence of adding to cancer survivor burden rather than relieving it. Similarly, HCP perceptions were sought during the development stage of a remote monitoring intervention for individuals living with head and neck cancer (Duman-Lubberding et al., 2015). Whilst the quality of information provided was mainly perceived to be beneficial for cancer survivors, engaging with HCPs enabled concerns regarding the inclusion of abstract terminology and comprehensibility and repetition issues to be addressed.

There is a suggestion that HCP perception of impact, with regard to eHealth interventions, is affected by their professional role. Nurses have been reported to express a greater positivity towards eHealth interventions in cancer care than doctors (Dubenske et al., 2008). A study comparing nurse and physician perceptions of an eHealth intervention, which included online access to laboratory results, reported greater positivity from nurses both pre- and post-intervention (Rodriguez et al., 2011). This is supported by the MacNeill et al. (2014) study in which most nurses perceived telehealth to benefit both the patient and their own development, while GPs perceived telehealth to increase their workload and undermine their autonomy (MacNeill et al., 2014). The impact of eHealth interventions on workload is a concern for HCPs (Haase and Loiselle, 2012) and should be considered when developing interventions.

A small body of published research has suggested that HCP's perceptions of eHealth supportive care interventions are in line with the reported experiences of cancer survivors. HCPs perceive that for some cancer survivors, eHealth supportive care interventions can improve symptom management and relieve symptom burden, this supports Section 1.4.1 which summarised that eHealth supportive care interventions have the potential to reduce symptom burden based on studies focusing on cancer survivors. The potential for eHealth supportive care interventions to relieve the treatment burden of some cancer survivors has also been recognised by HCPs in keeping with the reports of cancer survivors in section 1.4.2. HCPs and cancer survivors consider telehealth (one component of eHealth) has the potential to relieve treatment burden. The convenience of telehealth and the limited disruption on a cancer survivor's life in

comparison to attending clinic appointments has been identified by both HCPs and cancer survivors.

However, there are caveats to the benefits perceived by HCPs. Firstly, HCPs do not expect all cancer survivors to benefit from eHealth supportive care interventions. HCP hold preconceptions regarding which cancer survivors will experience a relief in burden and which will experience increased burden as a result of using eHealth interventions. These preconceptions are important to eHealth developers and researchers as they identify areas which require further exploration. It may be true that certain populations are less willing to use eHealth. Literature suggests that it is harder to recruit palliative care patients who are older, with poor health status or lacking familiarity with technology to studies involving eHealth (Maguire et al., 2015, White et al., 2008, Williams et al., 2006). However, HCPs should not shield these populations from 'perceived' burden by limiting invitation to eHealth interventions. Some individuals may not benefit from eHealth based on individual factors such as age or stage of disease, but this is unclear and warrants further investigation. Without further exploration the preconceptions of HCPs could lead to health inequalities with certain groups of cancer survivors being excluded from the benefits of eHealth without sufficient evidence.

The second caveat to HCP perceptions of benefit is regarding the content of the intervention. HCPs express concern regarding certain aspects of the content of eHealth interventions perceiving it to increase the burden of cancer survivors. The focus of eHealth has to be on improving clinical care and patient experience; HCP guidance on the provision of safe and effective care is vital to eHealth development and implementation (Hannan and Celia, 2013). Seeking HCP advice on the content of eHealth supportive care interventions will inform the development of eHealth interventions which relieve rather than increase the burden of cancer survivors.

Having considered evidence for the impact of eHealth supportive care interventions on the burden of cancer survivors (from both cancer survivor and HCP perspectives), section 2 will present the abstracts for the five publications [P1-P5] which form the body of this thesis and highlight the contribution of each publication to the advancement of knowledge in this field.

2.0 Published works

This thesis is based on the following five papers which are included in full in appendix 1. The contribution of each paper to the field of work presented within this thesis is identified in bullet points beneath each abstract:

2.1 Abstracts of submitted papers

P1 Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. (2006) **Information needs and experiences: An audit of UK cancer patients**. European Journal of Oncology Nursing, 10 (4), pp. 263-272.

As part of a multi-centred UK study evaluating multidisciplinary team communication, the information needs, decision making preferences and information experiences of 394 cancer patients were audited. A majority of patients (342/394, 87%) wanted all possible information, both good and bad news. Assuming that all clinicians had equal skill, the majority of patients (350/394, 89%) expressed no preference for the sex of their doctor. The largest proportion of patients (153/394, 39%) wanted to share responsibility for decision making, preference was significantly influenced by age ($X^2 = 17:42$, df = 4, P = 0:002) with older patients more likely to prefer the doctor to make the decisions. A majority of patients reported receiving information regarding their initial tests (313/314, 100%), diagnosis (382/382, 100%), surgery (374/375, 100%) and prognosis (308/355, 87%), fewer recalled discussions concerning clinical trials (119/280, 43%), family history (90/320, 28%) or psychosocial issues, notably sexual well-being (116/314, 37%). Cancer patients want to be fully informed and share decision making responsibility, but do not report receiving sufficient information in all areas. Multidisciplinary cancer teams need to ensure that where appropriate, someone provides patients with information about clinical trials, familial risk and psychosocial issues. Regular audits highlight gaps and omissions in the information given to patients.

Contribution of publication to the advancement of the field:
- Identified HCPs require support to ensure cancer survivors have complete and comprehensive information, specifically in areas of psychosocial well-being.
- Suggested that HCPs should support cancer survivors to be as informed as they would like to be in decisions regarding their treatment and care.

P2 <u>Cox A</u>, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. (2008) **Nurse led telephone follow up in ovarian cancer: A psychosocial perspective**. European Journal of Oncology Nursing, 12 (5), pp. 412-417.

Survivorship is a relatively new concept in ovarian cancer due to improvements in diagnosis, surgery and chemotherapy. As more women require long term follow up for ovarian cancer the pressure on these services is increased and the question of how best to care for these women needs to be addressed. This paper considers the results of a pilot study of nurse led telephone follow up in ovarian cancer from a psychosocial perspective. Fifty-two women received telephone follow-up over a 10-month period; one aspect of this intervention was the opportunity for women to discuss psychosocial concerns with the clinical nurse specialist. A nurse database held records of patient discussions, and patient feedback regarding the service was collected using FACT Ovarian quality of life questionnaire, plus the satisfaction and experience with follow-up questionnaire. Thirty-three women were recorded as discussing psychological concerns with the nurse, 42% discussed feelings of anxiety or depression and 33% discussed fear of disease recurrence. Thirty-nine women were recorded as having discussed social concerns with the nurse, 56% discussed their family (husband, children, etc.), 51% discussed work and/or finances, and 41% discussed sexual intimacy. The majority of women (73%) expressed a preference for nurse led telephone follow up, the main advantages were reported as the relationship and discussions between the patient and the nurse, and the convenience of having follow up appointments over the phone instead of attending clinic. This pilot study suggests that nurse led telephone follow up offers an acceptable opportunity for psychosocial support for women with ovarian cancer.

Contribution of publication to the advancement of the field:
- Demonstrated that specialist nurses have the skillset to deliver remote follow-up for women with ovarian cancer;
- Indicated that telehealth offers opportunity for cancer survivors to receive psychosocial support from HCPs;
- Highlighted the importance of convenient healthcare for cancer survivors;
- Reported that the majority of women expressed a preference for the telehealth intervention.

P3 Cox A, Illsley M, Knibb W, Lucas C, O'Driscoll M, Potter C, Flowerday A, Faithfull S. (2011) **The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer** Palliat Med 25 (7), pp. 675-681

E-technology is increasingly used in oncology to obtain self-reported symptom assessment information from patients, although its potential to provide a clinical monitoring tool in palliative care is relatively unexplored in the UK. This study aimed to evaluate the support provided to lung cancer patients post palliative radiotherapy using a computerized assessment tool and to determine the clinical acceptability of the tool in a palliative care setting. However, of the 17 clinicians identified as managing patients who met the initial eligibility criteria for the study, only one clinician gave approval for their patient to be contacted regarding participation, therefore the benefits of this novel technology could not be assessed. Thirteen key clinicians from the centres involved in the study were subsequently interviewed. They acknowledged potential benefits of incorporating computerized patient assessment from both a patient and practice perspective, but emphasized the importance of clinical intuition over standardized assessment. Although clinicians were positive about palliative care patients participating in research, they felt that this population of patients were normally too old, with too rapidly deteriorating a condition to participate in a study using e-technology. In order to encourage acceptance of e-technology within palliative care, emphasis is needed on actively promoting the contribution of technologies with the potential to improve patient outcomes and the patient experience.

Contribution of publication to the advancement of the field:

- Identified HCP concerns regarding the burden of telehealth for cancer survivors receiving palliative care;
- Highlighted the importance of involving HCPs in the design of interventions to facilitate successful implementation;
- Suggested the need for research considering the impact of telehealth on the burden of cancer survivors according to individual factors and the context of care in order to address the preconceptions of HCPs.

P4 <u>Cox A,</u> Faithfull S. (2013**) 'They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information**. Support Care Cancer, 21 (9), pp. 2491-2497

Purpose: The concept of providing personalised care plans for cancer survivors is receiving increasing attention; a recognised element of a care plan is to provide an indication of the risks and consequences of treatment. This paper reports health care professional (HCP) response to providing cancer survivors with information on potential late effects of their cancer treatment.

Methods: Eighteen HCPs from five cancer centres and three general practices in the UK completed semi-structured interviews which were digitally recorded, transcribed and qualitatively analysed using framework analysis.

Results: HCPs' view of health care was that it is currently focused on acute care and needs are responded to as they may arise, including those which are late effects of cancer treatments. The concept of pre-empting a discussion of potential late effects during the survivorship phase was felt to be discordant with this approach and could impact on adjustment to life after cancer treatment.

Conclusion: Providing cancer survivors with information on potential late effects requires further consideration. Evidence for survivor preference for late effect information and the benefit afforded to survivors who receive it could inform the practice of HCPs. If a culture of proactivity is to be encouraged regarding discussions of future potential risk, HCPs may need support in considering ways of presenting survivors with reality whilst being mindful of their need to retain hope during the survivorship phase.

Contribution of publication to the advancement of the field:

- Identified that eHealth interventions providing information considered contrary to the approach of the existing healthcare system may not be supported by UK HCPs;
- Suggested that research is required to explore cancer survivor preference for the provision of information on potential late effects of their cancer treatment;
- Highlighted the need to support HCPs with approaches to presenting cancer survivors with reality whilst supporting their need to retain hope.

P5 <u>Cox A,</u> Faithfull S. (2015) **Aiding a reassertion of self: an Interpretative Phenomenological Analysis of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up** Support Care Cancer DOI: 10.1007/s00520-014-2578-4

Purpose This study explored the views and experiences of women following treatment for ovarian cancer who had received long-term (at least 3 years) nurse-led telephone follow-up. Exploring the long-term experiences of follow-up for women with ovarian cancer provides important information regarding the coping processes of cancer survivors that can inform the development of innovative and patient-centred approaches of cancer follow-up. Methods This is a qualitative study approach using interpretative phenomenological analysis (IPA). Eleven women were identified by a clinical nurse specialist as having received nurse-led telephone follow-up for a period of at least 3 years. These women were interviewed in person or over the telephone using a semi-structured interview schedule; interviews were audio-recorded and transcriptions were analysed using IPA. Results Nurse-led telephone follow-up was felt to support a reassertion of self and a rejection of patient identity. Three core themes emerged regarding the positive impact of nurse led telephone follow-up: 'Somebody was looking out for me' highlights the perception of increased psychosocial support; 'It's just reassurance' includes both the deep trust in the expertise of the nurse and the reassurance of the continued blood tests; and 'Time was never an issue' presents the perception of relaxed follow-up appointments with time to talk and the perceived practical benefits of this approach. Conclusions Nurse-led telephone follow-up was broadly recommended for women following treatment for ovarian cancer, particularly for those later on in the survivorship trajectory when focus may move from biomedical aspects of cure to holistic approaches to well-being. Remote interventions which provide a perception of a consistent and constant source of medical/psychosocial support may support adaption to cancer survivorship by enabling a reassertion of self and a rejection of patient identity.

Contribution of publication to the advancement of the field:

- Indicated nurse-led telephone follow-up is positively received by cancer survivors who remain on this approach long-term;
- Suggested the need to conduct longitudinal studies which explore the views and experiences of cancer survivors who are referred back to clinic-based care.

2.2 Contribution of Anna Clare Cox to co-authored works

		RQ formation/ design	Lit. review	Data collection	Co-ordination management	Data analysis	1st draft author	Draft/revise intellectual content	Published version approval
P1	**Cox A**, Jenkins V, Catt S, Langridge C, Fallowfield L. (2006) 'Information needs and experiences: An audit of UK cancer patients'. European Journal of Oncology Nursing, 10 (4), pp. 263-272.	--	--	✓✓ (Member of core team)	✓✓ (Member of core team)	✓✓ (Member of core team)	ACC	✓✓ (Member of core team)	✓✓ (Member of core team)
P2	**Cox A**, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. (2008) 'Nurse led telephone follow up in ovarian cancer: A psychosocial perspective'. European Journal of Oncology Nursing, 12 (5), pp. 412-417.	✓✓✓ for secondary RQ on which publication reported	✓✓✓ for secondary RQ on which publication reported	Secondary analysis	Secondary analysis	✓✓✓	ACC	✓✓✓	✓✓✓
P3	**Cox A**, Illsley M, Knibb W, Lucas C, O'Driscoll M, Potter C, Flowerday A, Faithfull S. (2011) 'The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer.' Palliative Medicine 25 (7), pp. 675-681	✓✓✓for secondary RQ on which publication reported	✓✓✓for secondary RQ on which publication reported	✓✓✓	✓✓✓	✓✓✓	ACC	✓✓✓	✓✓✓
P4	**Cox A**, Faithfull S. (2013) "They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information.' Supportive Care in Cancer, 21 (9), pp. 2491-2497	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✓✓✓	ACC	✓✓✓	✓✓✓
P5	**Cox A,** Faithfull S. (2015) 'Aiding a reassertion of self: an Interpretative Phenomenological Analysis of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up' Supportive Care in Cancer 23(8):2357-64.	✓✓✓	✓✓✓	✓✓✓	✓✓✓	✓✓✓	ACC	✓✓✓	✓✓✓
	RQ: Research question; ACC: Anna Clare Cox; ✓: small contribution; ✓✓: medium contribution; ✓✓✓: large contribution.								

Table 6 Contribution of candidate to co-authored works submitted in fulfilment of the degree of Doctor of Philosophy

2.3 Statements declaring the contribution of Anna Clare Cox to co-authored works.

Statement declaring the contribution of Anna Clare Cox

_____

The thesis herein contains five peer-reviewed publications. Table 6 indicates the contribution of Anna Clare Cox to these publications. Professor Sara Faithfull was co-author on four of these publications and principal investigator on three of the projects on which they report.

In signing below, Professor Sara Faithfull confirms the extent of the candidate's contribution to the publications submitted; confirms agreement to the submission of the publications and confirms that the article in question is not the subject of another (current or completed) dissertation.

8th February 2016

Professor Sara Faithfull   Date

Statement declaring the contribution of Anna Clare Cox

_____

The thesis herein contains five peer-reviewed publications. Table 6 indicates the contribution of Anna Clare Cox to these publications. Professor Dame Lesley Fallowfield was principal investigator on the audit of UK cancer patients and co-author on the resulting publication.

In signing below, Professor Dame Lesley Fallowfield confirms the extent of the candidate's contribution to the publication submitted; confirms agreement to the submission of the publication and confirms that the article in question is not the subject of another (current or completed) dissertation.

26th January 2016

Professor Dame Lesley Fallowfield   Date

3.0   Conclusion

The following conclusion will summarise and draw together the findings of this thesis, highlight the limitations, detail dissemination and evidence of impact in the field, and make recommendations for future research.

3.1   Summary of findings

This thesis has presented a unique approach to considering the impact of eHealth on cancer survivors, using the concept of burden.   Conceptualising burden as being broader than biopsychosocial symptoms (symptom burden), this thesis is novel in recognising the work required of cancer survivors in managing their condition (treatment burden). Whilst the symptom burden of cancer survivors has been frequently reported, the concept of treatment burden has to date been relatively unexplored within cancer survivors (Henry et al., 2008, Tran et al., 2015).

Cancer survivors require information and support to improve the experience of survivorship and relieve burden (Hui, 2014). The initial paper presented within the body of this thesis [P1] (Cox et al., 2006) highlighted that traditional clinic-based approaches to meeting the supportive care needs of cancer survivors do not provide sufficient information in all areas of care, particularly regarding psychosocial issues.

Having suggested the need to consider alternative approaches to addressing the burden of cancer survivorship, the body of this thesis presented four papers which explored eHealth solutions to providing supportive care to cancer survivors [P2-P5] (Cox et al., 2008, Cox and Faithfull, 2013, Cox and Faithfull, 2015, Cox et al., 2011) and considered these papers in terms of the impact of the eHealth interventions on cancer survivor burden.

Two submitted publications provided evidence that a telehealth intervention offered women with ovarian cancer relief from treatment burden [P2 & P5] (Cox et al., 2008, Cox and Faithfull, 2015). In addition to providing an acceptable opportunity for psychosocial support, women reported that nurse-led telephone follow-up was more convenient and enabled a valued relationship with a clinical nurse specialist to be developed. These identified benefits have been corroborated by other research (Beaver et al., 2010, Chambers et al., 2015, Williamson et al., 2015). The introduction to this thesis is novel in that it has further extended understanding of the impact of telehealth on treatment burden by systematically identifying and synthesising qualitative accounts of cancer survivor experience of telehealth (including P2 and P5). This

theoretically informed qualitative synthesis suggested that telehealth can relieve treatment burden by a) providing cancer survivors with focused and personalised information to help make sense of their condition and how to manage it, b) establishing supportive relationships with HCPs, valued for their continuity, and c) providing convenient health care which can be accommodated into life and facilitate a sense of normality. These results are supported by a recent review of telehealth interventions for individuals with long-term conditions (Vassilev et al., 2015) which highlighted the importance of 'relationships' and 'fit'. This study concurs that telehealth has the potential to develop and extend relationships with HCPs and provide convenient care by fitting into existing routines.

This thesis has made an important contribution to understanding the longer-term experience of cancer survivors who engage with telehealth interventions and the impact of telehealth on burden. The majority of papers identified within the introduction of this thesis report the experience of cancer survivors after a relatively short period of engagement with telehealth. This thesis includes a paper reporting the experience of women who had received at least 3 years telephone follow-up after treatment for ovarian cancer (Cox and Faithfull, 2015) [P5]. Women broadly recommended nurse-led telephone follow-up, particularly for those later on in the survivorship trajectory. This telehealth intervention was perceived to provide a consistent and constant source of medical and psychosocial support which supported adaption to cancer survivorship by enabling a reassertion of self and a rejection of patient identity. The only other study of telephone follow-up which reported longer-term experience of intervention (mean of 24 months across participants) supported the convenience and continuity of care provided by this approach (Beaver et al., 2010).

While improving the experience of care for cancer survivors is unquestionably important, the cost-effectiveness of eHealth interventions is crucial to health service adoption. The 'burden' of cancer also exists at a societal level, the financial cost of providing cancer treatments and the cost of lost productivity (Luengo-Fernandez et al., 2013, Guy et al., 2013, Elting and Shih, 2004). Escalating numbers of cancer survivors are placing mounting economic pressure on society, and many predict this will render traditional approaches to care unsustainable and necessitate the redesign of supportive care services (Howell et al., 2012). It is therefore essential that available resources to support people living with and beyond cancer are used effectively and the costs associated with alternative approaches to providing supportive care are considered.

Evaluating the economic impact of eHealth is complex. In terms of the nurse-led telephone follow-up intervention evaluated within this thesis [P2 & P5], the costs associated with delivering the intervention were in addition to existing clinical practice (Thomas et al., 2006). Both the additional labour and telephone costs associated with the intervention need to be considered. For example, during the study, the nurse specialist spent 33 hours and 2 minutes on telephone consultations with cancer survivors and 1 hour 51 minutes on the telephone to a consultant. The additional cost to the health service was calculated to be £1,895.66. However, although the costs were higher for the intervention there are other economic benefits: (i) Indirect travel savings for cancer survivors amounting to £2,072.80; (ii) Additional capacity in clinic without allocating further resources to extending clinic time; and (iii) Reduced risk of crisis management which could result in unplanned admissions to hospital. This evaluation is supported by an economic evaluation of a randomized clinical trial of hospital versus telephone follow-up after treatment for breast cancer (Beaver et al., 2009) in which the authors conclude that although telephone follow-up for breast cancer may reduce the burden on busy hospital clinics and offer savings to cancer survivors, it does not necessarily lead to cost or salary savings.

In addition, this thesis has made a valuable contribution to understanding HCP perceptions regarding the impact of eHealth interventions on the burden of cancer survivors. HCP perceptions of eHealth interventions are vital to successful implementation (Greenhalgh et al., 2004) but previous studies reporting the development and evaluation of eHealth interventions rarely include HCPs (Darlow and Wen, 2015, Mair et al., 2012). The content of interventions is as important as the medium by which it is delivered (Fleisher et al., 2008) as are the protocols and algorithms employed in the provision of personalised information and support, each of these factors require careful consideration during development of future eHealth interventions (Stacey et al., 2012). Two publications submitted within the body of this thesis report HCP perceptions of eHealth interventions and highlight concerns that they could increase both the symptom burden and treatment burden of cancer survivors [P3 & P4] (Cox and Faithfull, 2013, Cox et al., 2011). In the context of palliative care patients, the work of engaging with a remote symptom monitoring system was considered 'an added burden for them rather than a benefit' [P3] (Cox et al., 2011) (p5). The content of an online care plan tool which presented cancer survivors with information on potential late effects was perceived to be detrimental to the physical and mental health of cancer survivors and impact on their adjustment to life after cancer treatment [P4] (Cox and Faithfull, 2013). Gatekeepers are vital within health care

research to protect potentially vulnerable people (Holloway and Wheeler, 2002). HCP perceptions that eHealth interventions may increase cancer survivor burden can thus lead them to limit the participation of their patients in research. Including HCPs in the development of eHealth interventions and research protocols may reassure HCPs regarding the impact of the intervention and offer a solution to unnecessary gate-keeping.

The impact of eHealth interventions on the burden of HCPs also requires consideration. Remote interventions can provide cancer survivors with the perception of consistent and constant medical and psychosocial support (Cox and Faithfull, 2015). While this may relieve the burden of cancer survivors, an expectation of constant monitoring and support may add to the workload of HCPs (MacNeill et al., 2014; Wildevuur et al., 2015). If web-based information is sought and accessed independently by patients, they may subsequently seek an interpretation of the information from their clinician which could add pressure to NHS resources (Cox and Faithfull, 2013, Hesse et al., 2010). It is important that clear boundaries are set when implementing remote monitoring and/or communication to ensure that HCPs are not over-burdened.

This thesis has demonstrated that eHealth interventions have the potential to alleviate the burden of cancer survivors. However, the complexity of realising this potential should not be overlooked. Key stakeholders need to be involved in all stages of eHealth development and evaluation to ensure interventions evolve in line with the needs and recommendations of both cancer survivors and HCPs and are successfully implemented in practice. Future research should not focus exclusively on *whether* eHealth supportive care interventions relieve the burden of cancer survivorship; research needs to be designed to address the question of *who* benefits, and to understand the mechanism of *how* burden is relieved.

3.2 Limitations of research

The limitations of this thesis will be considered within the categories of *scope* and *methodology*. Within *scope*, the limitations of the thesis as a whole will be considered. Within *methodology*, both the methodological limitations and the steps taken ensure rigour will be presented and discussed with regard to the five submitted publications [P1-P5].

<u>3.2.1 Scope</u>

The scope of this thesis has been the impact of eHealth interventions on the burden of adult cancer survivors, as reported over the last 10 years. Within cancer care there are other burdens which need to be acknowledged; societal burden and HCP burden have already been discussed within the conclusion of this thesis but the burden of those individuals who support cancer survivors also requires consideration, as does research on children and young adult cancer survivors. These limitations are considered below.

Burden is not limited to individual cancer survivors. The members of their social network also participate in the workload required (Sav et al., 2013a). Within the constructs of normalisation process theory, family and friends may seek information to make sense of a diagnosis (sense making), engage with others to gain information and advice (cognitive participation), collect medications and organise clinic appointments (collective action), and monitor symptoms for signs of recurrence or to appraise the impact of lifestyle changes (monitoring). This thesis has only considered burden from a cancer survivor perspective but studies suggest the potential impact of eHealth interventions on alleviating carer burden (DuBenske et al., 2014) which needs further consideration.

The scope of this thesis is also limited by its focus on adult cancer survivors. In 2016, children and adolescents have grown up in a world with fast-paced computer games and high quality graphics and expect instant and remote connections. There is evidence that children and adolescents respond positively to eHealth (Gibson et al., 2009), reporting high satisfaction and demonstrating high adherence to remote monitoring interventions which are game-based (Stinson et al., 2013). The telephone is the most mature component of eHealth and as discussed within this thesis, it currently holds dominance within telehealth. The social relations, information provision and remote monitoring enabled by the telephone pale in comparison to the opportunities made available by mobile health and the Internet – which the children and adolescents of today are already familiar with and may embrace without reservation. 'Digital natives' (children born after 1980) may counteract the reticence of 'digital immigrants' and drive the development and implementation of eHealth (Prensky, 2001).

In addition, only literature published over the last 10 years was reviewed within this thesis as this spans the period during which the articles which form the body of this thesis were

published. It is acknowledged that there was already a substantial body of research within eHealth prior to 2006, particularly related to using the telephone. For example, in 2003 Professor Karen Cox published a review of literature evaluating the impact of nurse led follow-up in cancer care, with particular focus on the acceptability and feasibility of telephone interventions (Cox and Wilson, 2003).

3.2.2 Methodology

In considering the limitations of the submitted publications, it is important to acknowledge that rigour is assessed and described differently for quantitative and qualitative methodologies (Mays and Pope, 2000). The traditional criteria for assessing the rigour of research stem from quantitative (positivist) paradigms which assume a realist ontology (i.e. there is an objective reality - fact is fact). Quantitative research is considered in terms of its 'validity' (internal validity – whether the results of the study can be accurately drawn from the data, external validity –whether the results of the study are generalizable to other contexts, populations, or settings) and 'reliability' (whether the intervention or measures would produce similar results in different circumstances) (Roberts et al., 2006).

In comparison, qualitative (constructivist) paradigms reject the concept of universal truth. Consequently, it is questioned whether the same criteria for assessing the quality of quantitative studies can be applied to qualitative research (Rolfe, 2006). Whereas the rigour of quantitative research is considered in terms of validity and reliability it is suggested that qualitative research is considered in terms of its 'truth value' (whether it clearly and accurately presents participant perspectives and acknowledges potential bias), 'consistency' (the auditability of processes undertaken), 'neutrality' (acknowledging that findings are linked to the researchers experience/perspective) and 'applicability' (consideration of whether findings can be applied to other contexts, populations, or settings) (Noble and Smith, 2015).

The methodological limitations of the five submitted publications as well as the steps taken to ensure rigour within these studies are considered below under the categories of design, sampling, sample, data collection and data analysis. It is important to note that the studies on which the submitted publications are based were appraised by relevant research ethics committees to judge whether the overall design and proposed conduct of each study was ethically justifiable – favourable ethical opinion was received for each study with minor amendments.

3.2.2.1 Design

P1 reports on an audit of UK cancer patients. A limitation of the design of this study was that it reported on the *perceptions* of information provided to patients, it did not collect objective measures of consultation content. Although it is still meaningful to consider subjective measures as if a patient cannot recall information being given to them then its provision could be considered ineffective.

P2 reports on a pilot study which had a quasi-experimental design. Measures of quality-of-life and satisfaction and experience of follow-up were taken before and after ($\leq$10 months) a telephone follow-up intervention. A limitation of this pre- post-test design is minimal internal validity – the extent to which a causal relationship can be assumed. This study design cannot conclude that the improvements in quality-of-life scores are a direct result of the intervention rather than due to naturally occurring improvements over time as there was no comparison group. Randomised controlled trials (RCTs) are considered the 'gold standard' for determining causality (Bench et al., 2013) and have been used to evaluate telephone follow-up in other studies involving cancer survivors (Beaver et al., 2009, Beaver et al., 2012). In addition, the use of a questionnaire design in answering the third research question– 'what are the benefits of telephone follow-up from a patient perspective' – limited the quality of the data. Richer data could have been elicited through interviews (as later used in a subset of this population in P5). The design of P2 limited the assessment of intervention fidelity, if a percentage of telephone follow-up calls had been recorded the fidelity of the intervention could have been assessed (Badr et al., 2015). Audio-recording the intervention would also have enabled confirmation that the content of nurse-patient discussions had been accurately reported on the database.

3.2.2.2 Sampling

The studies submitted as part of this thesis used non-probability sampling. The researcher/s or clinician/s invited participants to take part based on convenience (e.g. the population in clinic) or purposively to include participants most suited to the study purpose.

Within a quantitative paradigm, non-probability sampling approaches are questioned in terms of external validity. In the study described in P2, the clinician approached women with ovarian cancer to take part in the trial of nurse-led telephone follow-up. It is possible that she invited

the women who she felt to be most receptive to this intervention, which could introduce bias and impact the generalizability to other women with ovarian cancer.

P4 reports a snowball sampling technique to identify a sample of HCPs with a known interest in cancer survivorship. Within a qualitative paradigm this purposive sampling can be considered to have enabled the selection of participants who were able to offer insightful responses to the concept of providing survivorship information. Similarly, a non-probability sample was used within P5 – only views and experiences of women who had received long-term telephone follow-up were explored. It is acknowledged that the views and experiences of these women may not be representative of all women with ovarian cancer but they do provide a unique insight into the experience of long-term telephone follow-up. Women who remained on telephone follow-up without requiring/requesting referral back to clinic-based follow-up may have had a more positive appraisal of the service but these comparisons cannot be made in this study. In keeping with expectations of rigorous qualitative studies, both P4 and P5 consider 'applicability' within their limitations, i.e. whether findings can be generalised to other cancer survivors/HCPs.

3.2.2.3 Sample

Quantitative data was collected from participants via questionnaire in P1 and P2. The audit of the information needs and preferences of UK cancer patients [P1] recruited all patients who were eligible and willing to participate, a response rate of 66% resulted in a sample size of 394 participants. Power calculations are not required to determine adequate sample size for a pilot study [P2] (Leon et al., 2011), but a response rate of 73% resulted in recruitment of 56 women, and 46 participants completed both pre- and post-measures.

Qualitative research methods were used to explore the views and experiences of participants in P3, P4, and P5. Qualitative research seeks to obtain rich information about a phenomenon from relevant stakeholders; the sample sizes within these three papers all permitted this to be achieved. Malterud et al. recently proposed that the concept of information power should inform the sample sizes of qualitative studies rather than formulae or perceived redundancy (saturation) (Malterud et al., 2015). The greater information power the sample has, the smaller the sample size required. Information power is determined by five factors: the aim of the study, sample specificity, use of established theory, quality of dialogue, and analysis strategy. The three qualitative studies included within this thesis are all considered to have narrow study

aims, to have included participants who were highly specific to the study aim, and to have gained rich and focused interview data. With these factors considered, it is felt that the sample sizes of 11, 13 and 18 participants were sufficient to have confidence in study findings.

The studies including cancer survivors recruited predominantly female participants. This is explained by two papers reporting on an intervention for women with a diagnosis of ovarian cancer [P2, P5], and the auditing of predominantly gynaecology and breast multidisciplinary teams [P1]. Women and men may report different information experience (Faller et al., 2016) and may use eHealth interventions differently (Børøsund et al., 2013) which could limit the generalizability of findings, however recruiting a more homogenous group may enable more accurate conclusions for the specific group considered. It is also important to note that the ethnicity of participants have not been reported in these publications, which limits consideration of the effect of ethnicity on the needs and experiences of cancer survivors.

3.2.2.4 Data collection

The data reported in P1 and P2 was collected via questionnaire. P1 used a survey tool designed specifically for the study; this enabled the reporting of the information needs and experiences of participants but may limit comparison with other studies which have collected the information using a different tool. Further, the tool has not been subjected to psychometric testing therefore the validity and reliability of the measure cannot be claimed. P2 collected data using the Functional Assessment of Cancer Therapy–Ovarian questionnaire, a reliable and valid assessment of the quality of life of women with ovarian cancer (Basen-Engquist et al., 2001), and the satisfaction and experience with follow-up questionnaire which has been piloted and validated in a number of other cancer studies (Avis et al., 1995, Faithfull et al., 2001, Thomas et al., 1996).

Data in P3, P4 and P5 were collected via interview. Semi-structured interview schedules were developed to provide questions to explore key areas (Gill et al., 2008). These questions were all designed to be open-ended - further probing, summarising and clarification questions ensured the richness of data for subsequent analysis. The use of semi-structured interview schedules and the audio-recording and full transcription of each interview in studies P3, P4 and P5 strengthen the 'accountability' of the data collection process.

3.2.2.5 Data analysis

Statistical analysis [P1, P2] was checked and corroborated by members of the research team to ensure rigour. Results were clearly presented and reported association between variables [P1] and compared pre-post intervention data [P2] using appropriate statistical tests (e.g. X^2 tests to assess association between patient variables and information needs/experiences [P1] and T-tests to compare pre-post intervention data [P2]).

Framework analysis (Ritchie and Spencer, 1994, Ritchie, 2013) was used in P3 and P4. Framework analysis was suited to these studies as it is an established approach for the analysis of semi-structured interview transcripts (Gale et al., 2013). Framework analysis is a highly structured auditable approach which can demonstrate consistency of analysis. Justification for the use of interpretative phenomenological analysis (IPA) (Smith et al., 2013) is detailed within P5. While framework analysis provides a structure to check sufficient evidence for a proposed theme within a matrix, IPA is phenomenological in that it seeks to explore events and experiences as they are perceived by the individual rather than attempting to offer an objective account of reality. IPA recognises that a researcher makes sense of a participant's experiences based on their own conceptions – it is interpretative. Reflexivity was employed within the qualitative studies and prior assumptions and expectations were bracketed to limit the effect of the researcher on analysis. The rigour of qualitative analysis can be strengthened with analyst triangulation (Patton, 1999) - using multiple analysts to review findings – a co-author (SF) verified the qualitative analyses within the submitted publications and confirmed them to be systematic and transparent. Member checking is one way to ensure study validity; a summary of findings were offered to participants from the qualitative studies and feedback encouraged in order to check if results were in keeping with participant experience.

3.3   Dissemination and evidence of impact in the field

Two approaches to disseminating knowledge generated by a research study are publication in a journal and presentation at conference. Table 7 indicates where each of the five publications, which are submitted as the body of this thesis and the five supporting publications were published (and the impact factor of the journals they were published in). Citations are one way of considering the impact of a publication on subsequent research studies. The number of academic publications which have cited the submitted publications are given in Table 7. Table 8 highlights where the findings from the five submitted publications have also been presented at conference. Social media is an increasingly embraced approach to raising the impact of research. All ten publications submitted as part of this thesis can be found on ResearchGate, a social networking site for scientists and researcher to share papers, discuss research and build collaborations.   In addition, a podcast discussion of the article 'After going through chemotherapy I can't see another needle' [S5] was recorded by the International Program of Psycho-Social Health Research (IPP-SHR), and was available on the Central Queensland University (CQU) website in Australia.

Dissemination to study participants is also important. Within the studies on which the submitted publications are based, study participants were offered the opportunity to receive a summary of the main findings of the study and/or a copy of the publication. Participant feedback on summaries is a valuable way of ensuring validity of findings, known as member validation. Feedback on the results of these studies was positive, indicating that the findings were a good representation of member experience.

		IF	CITATIONS*
P1	Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. (2006) 'Information needs and experiences: An audit of UK cancer patients'. European Journal of Oncology Nursing, 10 (4), pp. 263-272.	1.43	109
P2	Cox A, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. (2008) 'Nurse led telephone follow up in ovarian cancer: A psychosocial perspective'. European Journal of Oncology Nursing, 12 (5), p412-417.	1.43	30
P3	Cox A, Illsley M, Knibb W, Lucas C, O'Driscoll M, Potter C, Flowerday A, Faithfull S. (2011) 'The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer'. Palliative Medicine 25 (7), p675-681	2.86	11
P4	Cox A, Faithfull S. (2013) "They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information.' Support Care Cancer, 21 (9), p2491-2497	2.36	3
P5	Cox A, Faithfull S. (2015) 'Aiding a reassertion of self: an Interpretative Phenomenological Analysis of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up' Support Care Cancer 23(8): p2357-64.	2.36	2
S1	Catt S, Fallowfield L, Jenkins V, Langridge C, Cox A. (2005) 'The informational roles and psychological health of members of 10 oncology multidisciplinary teams in the UK.'. Br J Cancer, England: 93 (10), p1092-1097.	4.84	57
S2	Jenkins V, Fallowfield L, Cox A. (2005) 'The preferences of 600 patients for different descriptions of randomisation.'. Br J Cancer, England: 92 (5), p807-810.	4.84	10
S3	Cox A, Fallowfield LJ, Jenkins VA. (2006) 'Communication and informed consent in phase 1 trials: A review of the literature'. Supportive Care in Cancer, 14 (4), p303-309.	2.36	42
S4	Fallowfield L, Atkins L, Catt S, Cox A, Coxon C, Langridge C, Morris R, Price M. (2006) 'Patients' preference for administration of endocrine treatments by injection or tablets: Results from a study of women with breast cancer'. Annals of Oncology, 17 (2), pp. 205-210.	7.04	86
S5	Cox A, Fallowfield LJ. (2007) 'After going through chemotherapy I can't see another needle'. European Journal of Oncology Nursing, 11 (1), pp. 43-48.	1.43	18

Table 7: Publications and citations

*Information from Researchgate on 13/1/16

	Conference presentations
P1	British Psycho-Social Oncology (BPOS) Conference 2005
P2	European Cancer Conference (ECCO 14) 2007 Festival of Research (University of Surrey) 2007- Winner of academic award
P3	British Psychosocial Oncology Society Conference 2009 Festival of Research 2010, University of Surrey.
P4	10th Acta Oncologica Symposium: European Cancer Rehabilitation & Survivorship Symposium 2012, Copenhagen Festival of Research 2012, University of Surrey.
P5	Festival of Research 2016

Table 8: Conference presentations

3.4   Recommendations for future research

This thesis has proposed that eHealth interventions can relieve treatment burden in cancer survivors. This is important as the impact of eHealth cancer supportive care interventions on treatment burden has not been explicitly researched in studies to date. In order to develop this area, research is required which explores treatment burden from the perspective of cancer survivors and considers the consequences of this burden. Only one study to date has reported qualitative data on treatment burden based on a sample which included cancer survivors (Tran et al., 2015). This study analysed written responses to open-ended questions from a survey tool which considered the experience of managing chronic conditions in everyday life. It is recommended that future research in this area collects data using interview, allowing the researcher to probe or explore responses to gain richer data. Within an interview it would be possible to explore the factors which may protect cancer survivors from a sense of burden. The interview schedule could include probes to consider environmental factors such as social support and financial constraints, and internal factors such as health literacy and self-efficacy. A deeper understanding of the treatment burden experienced by cancer survivors and the factors which can protect or minimise burden could inform the development of eHealth interventions designed to alleviate cancer survivor burden. This research recommendation is in keeping with Medical Research Council guidance on developing and evaluating complex interventions which highlights the importance of qualitative research with stakeholders to develop a theoretical understanding of the expected impact of an intervention (Craig et al., 2008).

Knowledge could be extended regarding the impact of eHealth supportive care interventions on treatment burden based on existing literature reporting the experience of cancer survivors. The introduction to this thesis included a synthesis of qualitative data exploring cancer survivor experience of telehealth interventions. In keeping with the expectations of a doctoral thesis, this work was conducted independently by the candidate, which has implications for the rigour of a review. Subsequently, a recommendation is that this qualitative synthesis is developed utilising a systematic team-based approach to ensure firm conclusions can be drawn to inform the development and application of telehealth in the future. Funding has been awarded to Anna Clare Cox and a team of researchers by the Faculty of Health and Medical Sciences at the University of Surrey to enable the development of this synthesis.

The funded qualitative synthesis is using an adaption of the search strategy developed by Anna Clare Cox: it has refined inclusion criteria - qualitative analyses which did not provide second order themes will be included to ensure the full breadth of research in this area inform conclusions. In order to limit bias, all aspects of screening, data extraction, quality appraisal and data analysis will be conducted by at least two team members, with a third member of the team resolving any disagreements. The funded qualitative synthesis will use Thematic Synthesis (Thomas and Harden, 2008), an approach developed to conduct reviews that address questions relating to intervention acceptability. This is necessary because the synthesis presented within this thesis used a framework approach and there is a concern that a priori frameworks risk forcing data inappropriately and limit interpretive creativity (Dixon-Woods, 2011). Thematic Synthesis combines elements from meta-ethnography and grounded theory, and allows synthesis of methodologically heterogeneous studies. The quality of each paper will be appraised using an amended version of the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Critical Appraisal Skills Programme, 2015) to ensure reporting of reliable conclusions. Future qualitative syntheses are also recommended to explore the impact of other aspects of eHealth (e.g. on-line peer support) on the treatment burden of cancer survivors and to explore the impact of eHealth on the treatment burden of children and adolescents with cancer.

Other recommendations for future eHealth research include the design of studies which evaluate outcomes against individual characteristics. It cannot be assumed that eHealth interventions will be understood and experienced in the same way by all. There is currently a disproportionate focus on small heterogeneous samples of cancer survivors (Hong et al., 2012,

Kim and Park, 2015, Okuyama et al., 2015, Agboola et al., 2015, Hoey et al., 2008, Ventura et al., 2013). Future eHealth interventions must be evaluated in populations who are representative in terms of ethnicity, gender, cancer type and stage of disease in order to determine who benefits. This will permit future interventions to be targeted to appropriate populations as well as highlighting where alternative strategies for providing supportive care are needed. Involving cancer survivors in the co-design of eHealth interventions could ensure that user needs and experiences inform development and implementation (Robert et al., 2015).

Future research evaluating eHealth interventions need longer time frames than have been reported by most studies to date. Cancer survivors may experience eHealth interventions differently over longer periods, but currently only few studies provide any evidence regarding the long-term experience of eHealth supportive care interventions (Cox and Faithfull, 2015, Beaver et al., 2010). The perceptions of those individuals who choose not to take part in eHealth intervention studies also need to be explored, to determine if perceived burden is a barrier to engagement.

This thesis recommends that future eHealth interventions need to be developed and evaluated with theory as a foundation. Too many studies report benefit without a mechanism for understanding why or how the benefit occurs. eHealth research needs to follow the Medical Research Council recommendation that interventions should be developed systematically 'using the best available evidence and appropriate theory' (Craig et al., 2008) (p.8). Without being able to demonstrate a theoretical rationale for eHealth interventions and the expected benefits, it is difficult to understand the success or failure of interventions or implement them in practice (Gammon et al., 2015).

Finally, the interconnection of symptom burden and treatment burden needs exploration in cancer survivors. Clinical and social factors interact and may increase burden (Shippee et al., 2012). High symptom burden can cause a greater workload. Individuals who perceive their workload as demanding are less likely to adhere to their treatment plans (World Health Organization, 2003). This in turn may lead to an increase in symptom burden, which may require further treatments, thus increasing treatment burden. In short, both the efficacy and 'adhere-ability' (Demain et al., 2015) of eHealth interventions require consideration and the potential impact of burden on cancer survivors needs to be explored in future studies.

3.5 Final words

This thesis has demonstrated that cancer survivors and HCPs recognise the potential of eHealth supportive care interventions to relieve the burden of survivorship, but has acknowledged that the complexity of for *whom* and *how* these benefits occur warrants exploration through further research. However, these conclusions are drawn from the experience of cancer survivors and HCPs over the last 10 years. eHealth is developing exponentially and the future experiences of cancer survivors may be different. As the health care system embraces 'connected health', the 'internet of things' and utilises 'big data' to seek sustainable, personalised and proactive health care, we need to ensure that the concept of burden is considered in its broadest sense. Not only evaluating eHealth in terms of the relief it may provide to the economic burden caused by increasing numbers of cancer survivors, but also measuring the impact of eHealth interventions on the burden of those living with and beyond cancer. eHealth is not a 'one size fits all' solution. Involving cancer survivors and HCPs in the development of eHealth interventions is key in creating and implementing sustainable personalised solutions that relieve the burden of cancer survivorship.

References

Aaronson, N. K., Ahmedzai, S., Bergman, B., Bullinger, M., Cull, A., Duez, N. J., Filiberti, A., Flechtner, H., Fleishman, S. B., De Haes, J. C. & Et Al. 1993. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst,* 85**,** 365-76.

Aaronson, N. K., Mattioli, V., Minton, O., Weis, J., Johansen, C., Dalton, S. O., Verdonck-De Leeuw, I. M., Stein, K. D., Alfano, C. M., Mehnert, A., De Boer, A. & Van De Poll-Franse, L. V. 2014. Beyond treatment – Psychosocial and behavioural issues in cancer survivorship research and practice. *European Journal of Cancer Supplements,* 12**,** 54-64.

Agboola, S. O., Ju, W., Elfiky, A., Kvedar, J. C. & Jethwani, K. 2015. The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials. *Journal Of Medical Internet Research,* 17**,** e65-e65.

Allen, A. 2002. The meaning of the breast cancer follow-up experience for the women who attend. *Eur J Oncol Nurs,* 6**,** 155-61.

Altman, D. G., Schulz, K. F., Moher, D., Egger, M., Davidoff, F., Elbourne, D., Gotzsche, P. C. & Lang, T. 2001. The revised CONSORT statement for reporting randomized trials: explanation and elaboration. *Ann Intern Med,* 134**,** 663-94.

Andrykowski, M. A., Lykins, E., & Floyd, A. (2008). Psychological Health in Cancer Survivors. Seminars in Oncology Nursing, 24(3), 193–201.

Armes, J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., Ream, E., Young, A. & Richardson, A. 2009. Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey. *J Clin Oncol,* 27**,** 6172-9.

Avis, M., Bond, M. & Arthur, A. 1995. Exploring patient satisfaction with out-patient services. *J Nurs Manag,* 3**,** 59-65.

Badr, H., Smith, C. B., Goldstein, N. E., Gomez, J. E. & Redd, W. H. 2015. Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer,* 121**,** 150-8.

Baker, T. B., Gustafson, D. H., Shaw, B., Hawkins, R., Pingree, S., Roberts, L. & Strecher, V. 2010. Relevance of CONSORT reporting criteria for research on eHealth interventions. *Patient Educ Couns,* 81 Suppl**,** S77-86.

Barlow, J., Hendey, J. & Chrysanthaki, T. 2012. Scaling-up remote care in the United Kingdom: Lessons from a decade of policy intervention. *In:* GLASCOCK, A. & KUTZIK, D. (eds.) *Essential Lessons for the Success of Telehomecare - Why It's not Plug and Play.* IOS Press.

Barnett-Page, E. & Thomas, J. 2009. Methods for the synthesis of qualitative research: a critical review. *BMC Medical Research Methodology,* 9**,** 1-11.

Basen-Engquist, K., Bodurka-Bevers, D., Fitzgerald, M. A., Webster, K., Cella, D., Hu, S. & Gershenson, D. M. 2001. Reliability and validity of the functional assessment of cancer therapy-ovarian. *J Clin Oncol,* 19**,** 1809-17.

Beaver, K., Campbell, M., Williamson, S., Procter, D., Sheridan, J., Heath, J. & Susnerwala, S. 2012. An exploratory randomized controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer. *Colorectal Dis,* 14**,** 1201-9.

Beaver, K., Hollingworth, W., McDonald, R., Dunn, G., Tysver-Robinson, D., Thomson, L., Hindley, A.C., Susnerwala, S.S. & Luker, K. 2009. Economic evaluation of a randomized clinical trial of hospital versus telephone follow-up after treatment for breast cancer.*Br J Surg*. Dec;96(12):1406-15

Beaver, K., Tysver-Robinson, D., Campbell, M., Twomey, M., Williamson, S., Hindley, A., Susnerwala, S., Dunn, G. & Luker, K. 2009. Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial. *BMJ (Clinical Research Ed.),* 338**,** a3147-a3147.

Beaver, K., Williamson, S. & Chalmers, K. 2010. Telephone follow-up after treatment for breast cancer: Views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing,* 19**,** 2916-2924.

Begg, C., Cho, M., Eastwood, S., Horton, R., Moher, D., Olkin, I., Pitkin, R., Rennie, D., Schulz, K. F., Simel, D. & Stroup, D. F. 1996. Improving the quality of reporting of randomized controlled trials. The CONSORT statement. *Jama,* 276**,** 637-9.

Bench, S., Day, T. & Metcalfe, A. 2013. Randomised controlled trials: an introduction for nurse researchers. *Nurse Res,* 20**,** 38-44.

Bender, J. L., Yue, R. Y., To, M. J., Deacken, L. & Jadad, A. R. 2013. A lot of action, but not in the right direction: systematic review and content analysis of smartphone applications for the prevention, detection, and management of cancer. *J Med Internet Res,* 15**,** e287.

Bennion, A. E. & Molassiotis, A. 2013. Qualitative research into the symptom experiences of adult cancer patients after treatments: a systematic review and meta-synthesis. *Support Care Cancer,* 21**,** 9-25.

Bober, S. L. & Varela, V. S. 2012. Sexuality in adult cancer survivors: challenges and intervention. *J Clin Oncol,* 30**,** 3712-9.

Bonevski, B., Sanson-Fisher, R., Girgis, A., Burton, L., Cook, P. & Boyes, A. 2000. Evaluation of an instrument to assess the needs of patients with cancer. Supportive Care Review Group. *Cancer,* 88**,** 217-25.

Børøsund, E., Cvancarova, M., Ekstedt, M., Moore, S. M. & Ruland, C. M. 2013. How User Characteristics Affect Use Patterns in Web-Based Illness Management Support for Patients with Breast and Prostate Cancer. *Journal of Medical Internet Research,* 15**,** e34.

Brunton L, Bower P, Sanders C. The Contradictions of Telehealth User Experience in Chronic Obstructive Pulmonary Disease (COPD): A Qualitative Meta-Synthesis. PLoS One. 2015;10(10):e0139561.

Burkett, V. S. & Cleeland, C. S. 2007. Symptom burden in cancer survivorship. *J Cancer Surviv,* 1**,** 167-75.

Cancer Research UK 2015. Cancer Statistics for the UK. *http://www.cancerresearchuk.org/health-professional/cancer-statistics accessed June 2015.*

Cella, D. F., Tulsky, D. S., Gray, G., Sarafian, B., Linn, E., Bonomi, A., Silberman, M., Yellen, S. B., Winicour, P., Brannon, J. & Et Al. 1993. The Functional Assessment of Cancer Therapy scale: development and validation of the general measure. *J Clin Oncol,* 11**,** 570-9.

Chambers, S. K., Morris, B. A., Clutton, S., Foley, E., Giles, L., Schofield, P., O'connell, D. & Dunn, J. 2015. Psychological wellness and health-related stigma: a pilot study of an acceptance-focused cognitive behavioural intervention for people with lung cancer. *European Journal of Cancer Care,* 24**,** 60-70.

Chan, M.-F., Ang, E., Duong, M. C. & Chow, Y. L. 2013. An online Symptom Care and Management System to monitor and support patients receiving chemotherapy: a pilot study. *International Journal Of Nursing Practice,* 19 Suppl 1**,** 14-18.

Cleeland, C. S. 2007. Symptom burden: multiple symptoms and their impact as patient-reported outcomes. *J Natl Cancer Inst Monogr***,** 16-21.

Cleeland, C. S. & Sloan, J. A. 2010. Assessing the Symptoms of Cancer Using Patient-Reported Outcomes (ASCPRO): searching for standards. *J Pain Symptom Manage,* 39**,** 1077-85.

Corbin, J. & Strauss, A. 1988. *Unending work and care : managing chronic illness at home,* San Francisco, Jossey-Bass Publishers.

Cornwall, A., Moore, S. & Plant, H. 2008. Embracing technology: patients', family members' and nurse specialists' experience of communicating using e-mail. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society,* 12**,** 198-208.

Cox, A., Bull, E., Cockle-Hearne, J., Knibb, W., Potter, C. & Faithfull, S. 2008. Nurse led telephone follow up in ovarian cancer: a psychosocial perspective. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society,* 12**,** 412-417.

Cox, A. & Faithfull, S. 2013. 'They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information. *Support Care Cancer,* 21**,** 2491-7.

Cox, A. & Faithfull, S. 2015. Aiding a reassertion of self: a qualitative study of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up. *Supportive Care in Cancer,* 23**,** 2357-2364.

Cox, A., Illsley, M., Knibb, W., Lucas, C., O'driscoll, M., Potter, C., Flowerday, A. & Faithfull, S. 2011. The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer. *Palliative Medicine,* 25**,** 675-681.

Cox, A., Jenkins, V., Catt, S., Langridge, C. & Fallowfield, L. 2006. Information needs and experiences: an audit of UK cancer patients. *Eur J Oncol Nurs,* 10**,** 263-72.

Cox, K. & Wilson, E. 2003. Follow-up for people with cancer: nurse-led services and telephone interventions. *J Adv Nurs,* 43**,** 51-61.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I. & Petticrew, M. 2008. Developing and evaluating complex interventions: new guidance.

Critical Appraisal Skills Programme 2015. CASP qualitative checklist http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf accessed 2015.

Darlow, S. & Wen, K. Y. 2015. Development testing of mobile health interventions for cancer patient self-management: A review. *Health Informatics J.*

De Lusignan, S. 2015. Unleashing the power of e-Health requires the development of an
evidence base for interventions that improve care. *J Innov Health Inform,* 22**,** 143.

Demain, S., Goncalves, A. C., Areia, C., Oliveira, R., Marcos, A. J., Marques, A., Parmar, R.
& Hunt, K. 2015. Living with, managing and minimising treatment burden in long
term conditions: a systematic review of qualitative research. *PLoS One,* 10**,** e0125457.

Department of Health, Macmillan Cancer Support & Nhs Improvement 2010. National
Cancer Survivorship Initiative Vision http://www.ncsi.org.uk/wp-
content/uploads/NCSI-Vision-Document.pdf accessed 2015.

Deshields, T. L., Potter, P., Olsen, S. & Liu, J. 2014. The persistence of symptom burden:
symptom experience and quality of life of cancer patients across one year. *Support
Care Cancer,* 22**,** 1089-96.

Deshields, T. L., Potter, P., Olsen, S., Liu, J. & Dye, L. 2011. Documenting the symptom
experience of cancer patients. *J Support Oncol,* 9**,** 216-23.

Dickinson, R., Hall, S., Sinclair, J. E., Bond, C. & Murchie, P. 2014. Using technology to
deliver cancer follow-up: a systematic review *BMC Cancer,* 14**,** 311.

Dixon-Woods, M. 2011. Using framework-based synthesis for conducting reviews of
qualitative studies. *BMC Med,* 9**,** 39.

Dubenske, L. L., Chih, M.-Y., Dinauer, S., Gustafson, D. H. & Cleary, J. F. 2008.
Development and implementation of a clinician reporting system for advanced stage
cancer: initial lessons learned. *Journal Of The American Medical Informatics
Association: JAMIA,* 15**,** 679-686.

Dubenske, L. L., Gustafson, D. H., Namkoong, K., Hawkins, R. P., Atwood, A. K., Brown,
R. L., Chih, M. Y., Mctavish, F., Carmack, C. L., Buss, M. K., Govindan, R. &
Cleary, J. F. 2014. CHESS improves cancer caregivers' burden and mood: results of
an eHealth RCT. *Health Psychol,* 33**,** 1261-72.

Duman-Lubberding, S., Van Uden-Kraan, C. F., Jansen, F., Witte, B. I., Van Der Velden, L.
A., Lacko, M., Cuijpers, P., Leemans, C. R. & Verdonck-De Leeuw, I. M. 2015.
Feasibility of an eHealth application "OncoKompas" to improve personalized
survivorship cancer care. *Supportive Care In Cancer: Official Journal Of The
Multinational Association Of Supportive Care In Cancer*.

Ekeland, A.G., Bowes, A., & Flottorp, S. 2010. Effectiveness of telemedicine: a systematic
review of reviews. *Int J Med Inform.,* Nov;79(11):736-71.

Ehealth Industries Innovation Centre 2015. What is eHealth?
http://www.ehi2.swan.ac.uk/en/what-is-ehealth.htm accessed 2015.

Elbert, N.J., van Os-Medendorp, H., van Renselaar, W., Ekeland, A.G., Hakkaart-van Roijen, L., Raat, H., Nijsten, T.E., & Pasmans, S.G. 2014. Effectiveness and Cost-Effectiveness of eHealth Interventions in Somatic Diseases: A Systematic Review of Systematic Reviews and Meta-Analyses. *J Med Internet Res.,*16(4):e110.

Elting, L. S. & Shih, Y. C. 2004. The economic burden of supportive care of cancer patients. *Support Care Cancer,* 12**,** 219-26.

Eton, D. T., Ramalho De Oliveira, D., Egginton, J. S., Ridgeway, J. L., Odell, L., May, C. R. & Montori, V. M. 2012. Building a measurement framework of burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Relat Outcome Meas,* 3**,** 39-49.

European Commission 2012. eHealth Task Force Report – Redesigning health in Europe for 2020. Luxembourg.

Eysenbach, G. 2011. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. *J Med Internet Res,* 13**,** e126.

Faithfull, S., Corner, J., Meyer, L., Huddart, R. & Dearnaley, D. 2001. Evaluation of nurse-led follow up for patients undergoing pelvic radiotherapy. *Br J Cancer,* 85**,** 1853-64.

Faller, H., Koch, U., Brahler, E., Harter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Boehncke, A., Hund, B., Reuter, K., Richard, M., Sehner, S., Szalai, C., Wittchen, H. U. & Mehnert, A. 2016. Satisfaction with information and unmet information needs in men and women with cancer. *J Cancer Surviv,* 10**,** 62-70.

Fergus, K. D., Mcleod, D., Carter, W., Warner, E., Gardner, S. L. & Cullen, K. I. 2014. Development and pilot testing of an online intervention to support young couples' coping and adjustment to breast cancer. *European Journal of Cancer Care,* 23**,** 481-492.

Fitch, M. I. 2008. Supportive care framework. *Can Oncol Nurs J,* 18**,** 6-24.

Fleisher, L., Buzaglo, J., Collins, M., Millard, J., Miller, S. M., Egleston, B. L., Solarino, N., Trinastic, J., Cegala, D. J., Benson, A. B., Schulman, K. A., Weinfurt, K. P., Sulmasy, D., Diefenbach, M. A. & Meropol, N. J. 2008. Using Health Communication Best Practices to Develop a Web-Based Provider-Patient Communication Aid: The CONNECT™ Study. *Patient education and counseling,* 71**,** 378-387.

Gale, N. K., Heath, G., Cameron, E., Rashid, S. & Redwood, S. 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol,* 13**,** 117.

Gallacher, K., Jani, B., Morrison, D., Macdonald, S., Blane, D., Erwin, P., May, C. R., Montori, V. M., Eton, D. T., Smith, F., Batty, G. D. & Mair, F. S. 2013a. Qualitative systematic reviews of treatment burden in stroke, heart failure and diabetes - methodological challenges and solutions. *BMC Med Res Methodol,* 13**,** 10.

Gallacher, K., May, C. R., Montori, V. M. & Mair, F. S. 2011. Understanding patients' experiences of treatment burden in chronic heart failure using normalization process theory. *Ann Fam Med,* 9**,** 235-43.

Gallacher, K., Morrison, D., Jani, B., Macdonald, S., May, C. R., Montori, V. M., Erwin, P. J., Batty, G. D., Eton, D. T., Langhorne, P. & Mair, F. S. 2013b. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. *PLoS Med,* 10**,** e1001473.

Gammon, D., Berntsen, G. K., Koricho, A. T., Sygna, K. & Ruland, C. 2015. The chronic care model and technological research and innovation: a scoping review at the crossroads. *J Med Internet Res,* 17**,** e25.

Gapstur, R. L. 2007. Symptom burden: a concept analysis and implications for oncology nurses. *Oncol Nurs Forum,* 34**,** 673-80.

Gee, P. M., Greenwood, D. A., Paterniti, D. A., Ward, D. & Miller, L. M. 2015. The eHealth Enhanced Chronic Care Model: a theory derivation approach. *J Med Internet Res,* 17**,** e86.

Gibson, F., Aldiss, S., Taylor, R. M., Maguire, R. & Kearney, N. 2009. Involving health professionals in the development of an advanced symptom management system for young people: the ASyMS-YG study. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society,* 13**,** 187-192.

Gill, P., Stewart, K., Treasure, E. & Chadwick, B. 2008. Methods of data collection in qualitative research: interviews and focus groups. *Br Dent J,* 204**,** 291-295.

Greenhalgh, T., Robert, G., Bate, P., Kyriakidou, O., Macfarlane, F. & Peacock, R. 2004. *How to Spread Good Ideas: A systematic review of the literature on diffusion, dissemination, and sustainability of innovations in health service delivery and organization. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*, University College.

Guy, G. P., Ekwueme, D. U., Yabroff, K. R., Dowling, E. C., Li, C., Rodriguez, J. L., De Moor, J. S. & Virgo, K. S. 2013. Economic Burden of Cancer Survivorship Among Adults in the United States. *Journal of Clinical Oncology*.

Haase, K. R. & Loiselle, C. G. 2012. Oncology team members' perceptions of a virtual navigation tool for cancer patients. *International Journal Of Medical Informatics,* 81**,** 395-403.

Hannan, T. J. & Celia, C. 2013. Are doctors the structural weakness in the e-health building? *Internal Medicine Journal,* 43**,** 1155-1164.

Harrison, J. D., Young, J. M., Price, M. A., Butow, P. N. & Solomon, M. J. 2009. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer,* 17**,** 1117-28.

Head, B. A., Keeney, C., Studts, J. L., Khayat, M., Bumpous, J. & Pfeifer, M. 2011. Feasibility and Acceptance of a Telehealth Intervention to Promote Symptom Management during Treatment for Head and Neck Cancer. *Journal of Supportive Oncology,* 9**,** e1-e11.

Heckman, B. W., Mathew, A. R. & Carpenter, M. J. 2015. Treatment Burden and Treatment Fatigue as Barriers to Health. *Curr Opin Psychol,* 5**,** 31-36.

Henry, D., Viswanathan, H., Elkin, E., Traina, S., Wade, S. & Cella, D. 2008. Symptoms and treatment burden associated with cancer treatment: results from a cross-sectional national survey in the U.S. *Supportive Care in Cancer,* 16**,** 791-801.

Hesse, B. W., Moser, R. P. & Rutten, L. J. 2010. Surveys of Physicians and Electronic Health Information. *New England Journal of Medicine,* 362**,** 859-860.

Hoey, L. M., Ieropoli, S. C., White, V. M. & Jefford, M. 2008. Systematic review of peer-support programs for people with cancer. *Patient Education And Counseling,* 70**,** 315-337.

Hofman, M., Ryan, J. L., Figueroa-Moseley, C. D., Jean-Pierre, P. & Morrow, G. R. 2007. Cancer-Related Fatigue: The Scale of the Problem. *The Oncologist,* 12**,** 4-10.

Holloway I, Wheeler S: *Initial steps in the research process*. Qualitative Research in Nursing. Edited by: Holloway I, Wheeler S. 2002, Oxford: Blackwell Publishing.

Högberg, K., Sandman, L., Nyström, M., Stockelberg, D. & Broström, A. 2013. Prerequisites required for the provision and use of web-based communication for psychosocial support in haematologic care. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society,* 17**,** 596-602.

Högberg, K. M., Stockelberg, D., Sandman, L., Broström, A. & Nyström, M. 2015. The Meaning of Web-Based Communication for Support. *Cancer Nursing,* 38**,** 145-154.

Hong, Y., Pena-Purcell, N. C. & Ory, M. G. 2012. Outcomes of online support and resources for cancer survivors: a systematic literature review *Patient Education and Counseling,* 86**,** 288-296.

Howell, D., Hack, T. F., Oliver, T. K., Chulak, T., Mayo, S., Aubin, M., Chasen, M., Earle, C. C., Friedman, A. J., Green, E., Jones, G. W., Jones, J. M., Parkinson, M., Payeur, N., Sabiston, C. M. & Sinclair, S. 2012. Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence. *J Cancer Surviv,* 6**,** 359-71.

Hui, D. 2014. Definition of supportive care: does the semantic matter? *Curr Opin Oncol,* 26**,** 372-9.

Im, E.-O. 2011. Online Support of Patients and Survivors of Cancer. *Seminars in Oncology Nursing,* 27**,** 229-236.

Im, E. O., Chee, W., Tsai, H. M., Lin, L. C. & Cheng, C. Y. 2005. Internet cancer support groups: a feminist analysis. *Cancer Nurs,* 28**,** 1-7.

Independent Cancer Taskforce 2015. Achieving world-class cancer outcomes a strategy for England 2015-2020
https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf accessed 2015.

Institute of Medicine 2009. Health Literacy, eHealth, and Communication: Putting the Consumer First: Workshop Summary. Washington, DC.

Kearney, N., Kidd, L., Miller, M., Sage, M., Khorrami, J., Mcgee, M., Cassidy, J., Niven, K. & Gray, P. 2006. Utilising handheld computers to monitor and support patients receiving chemotherapy: results of a UK-based feasibility study. *Supportive Care In Cancer: Official Journal Of The Multinational Association Of Supportive Care In Cancer,* 14**,** 742-752.

Kim, A. R. & Park, H. A. 2015. Web-based Self-management Support Interventions for Cancer Survivors: A Systematic Review and Meta-analyses. *Stud Health Technol Inform,* 216**,** 142-7.

Lemanska, A., Cox, A., Kirkby, N. F., Chen, T. & Faithfull, S. 2014. Predictive Modelling of Patient Reported Radiotherapy-Related Toxicity by the Application of Symptom Clustering and Autoregression. *International Journal of Statistics in Medical Research***,** 412-422.

Leon, A. C., Davis, L. L. & Kraemer, H. C. 2011. The Role and Interpretation of Pilot Studies in Clinical Research. *Journal of psychiatric research,* 45**,** 626-629.

Lubberding, S., Van Uden-Kraan, C. F., Te Velde, E. A., Cuijpers, P., Leemans, C. R. & Verdonck-De Leeuw, I. M. 2015. Improving access to supportive cancer care through an eHealth application: a qualitative needs assessment among cancer survivors. *J Clin Nurs,* 24**,** 1367-79.

Luengo-Fernandez, R., Leal, J., Gray, A. & Sullivan, R. 2013. Economic burden of cancer across the European Union: a population-based cost analysis. *Lancet Oncol,* 14**,** 1165-74.

Macmillan Cancer Support 2013. Throwing light on the consequences of cancer and its treatment http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationr eports/Throwinglightontheconsequencesofcanceranditstreatment.pdf accessed 2015.

Macmillan Cancer Support 2014a. Cancer's unequal burden http://www.macmillan.org.uk/Documents/CancersUnequalBurden_2014.pdf accessed 2015.

Macmillan Cancer Support 2014b. Working together: Challenges, opportunities and priorities for the UK's cancer workforce http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/Weareaforceforc hange/Workforcediscussiondoc.pdf accessed 2015.

Macmillan Cancer Support 2015. The Changing Story of Cancer http://www.macmillan.org.uk/Documents/AboutUs/Research/TheChangingStoryofCa ncer.pdf accessed 2015.

Macneill, V., Sanders, C., Fitzpatrick, R., Hendy, J., Barlow, J., Knapp, M., Rogers, A., Bardsley, M. & Newman, S. P. 2014. Experiences of front-line health professionals in the delivery of telehealth: a qualitative study. *Br J Gen Pract,* 64**,** e401-7.

Maguire, R., Ream, E., Richardson, A., Connaghan, J., Johnston, B., Kotronoulas, G., Pedersen, V., Mcphelim, J., Pattison, N., Smith, A., Webster, L., Taylor, A. & Kearney, N. 2015. Development of a novel remote patient monitoring system: the advanced symptom management system for radiotherapy to improve the symptom experience of patients with lung cancer receiving radiotherapy. *Cancer Nurs,* 38**,** E37-47.

Mair, F. S., May, C., O'donnell, C., Finch, T., Sullivan, F. & Murray, E. 2012. Factors that promote or inhibit the implementation of e-health systems: an explanatory systematic review. *Bull World Health Organ,* 90**,** 357-64.

Mair, F. S. & May, C. R. 2014. Thinking about the burden of treatment. *BMJ*, 349: g6680, p83.

Malterud, K., Siersma, V. D. & Guassora, A. D. 2015. Sample Size in Qualitative Interview Studies: Guided by Information Power. *Qual Health Res*.

May, C. & Finch, T. 2009. Implementing, Embedding, and Integrating Practices: An Outline of Normalization Process Theory. *Sociology,* 43**,** 535-554.

May, C., Montori, V. M. & Mair, F. S. 2009a. We need minimally disruptive medicine. *BMJ,* 339**,** b2803.

May, C., Rapley, T., Mair, F. S., Treweek, S., Murray, E., Ballini, L., Macfarlane, A., Girling, M. & Finch, T. L. 2015. Normalization Process Theory On-line Users' Manual, Toolkit and NoMAD instrument http://www.normalizationprocess.org accessed 2015.

May, C. R., Eton, D. T., Boehmer, K., Gallacher, K., Hunt, K., Macdonald, S., Mair, F. S., May, C. M., Montori, V. M., Richardson, A., Rogers, A. E. & Shippee, N. 2014. Rethinking the patient: using Burden of Treatment Theory to understand the changing dynamics of illness. *BMC Health Serv Res,* 14**,** 281.

May, C. R., Mair, F., Finch, T., Macfarlane, A., Dowrick, C., Treweek, S., Rapley, T., Ballini, L., Ong, B. N., Rogers, A., Murray, E., Elwyn, G., Legare, F., Gunn, J. & Montori, V. M. 2009b. Development of a theory of implementation and integration: Normalization Process Theory. *Implement Sci,* 4**,** 29.

Mays, N. & Pope, C. 2000. Assessing quality in qualitative research. *BMJ : British Medical Journal,* 320**,** 50-52.

McAlpine, H., Joubert, L., Martin-Sanchez, F., Merolli, M. & Drummond, K. J. 2015. A systematic review of types and efficacy of online interventions for cancer patients. *Patient Educ Couns,* 98**,** 283-95.

McCall, K., Keen, J., Farrer, K., Maguire, R., Mccann, L., Johnston, B., Mcgill, M., Sage, M. & Kearney, N. 2008. Perceptions of the use of a remote monitoring system in patients receiving palliative care at home. *Int J Palliat Nurs,* 14**,** 426-31.

McCann, L., Maguire, R., Miller, M. & Kearney, N. 2009. Patients' perceptions and experiences of using a mobile phone-based advanced symptom management system (ASyMS) to monitor and manage chemotherapy related toxicity. *European Journal Of Cancer Care,* 18**,** 156-164.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K. & Wagner, E. H. 2011. Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA Cancer J Clin,* 61**,** 50-62.

McLean, S., Protti, D. & Sheikh, A. 2011. Telehealthcare for long term conditions. *Bmj,* 342**,** d120.

Mitchell, A. J., Ferguson, D. W., Gill, J., Paul, J. & Symonds, P. 2013. Depression and anxiety in long-term cancer survivors compared with spouses and healthy controls: a systematic review and meta-analysis. *Lancet Oncol,* 14**,** 721-32.

Moser, E. C. & Meunier, F. 2014. Cancer survivorship: A positive side-effect of more successful cancer treatment. *European Journal of Cancer Supplements,* 12**,** 1-4.

National Cancer Survivorship Initiative 2013. Living with and beyond cancer: taking action to improve outcomes.

National Coalition for Cancer Survivorship 2015. NCCS Mission http://www.canceradvocacy.org/about-us/our-mission/ accessed 2015.

Nhs England 2014. Five Year Forward View https://www.england.nhs.uk/ourwork/futurenhs/ accessed 2015.

Noble, H. & Smith, J. 2015. Issues of validity and reliability in qualitative research. *Evidence Based Nursing,* 18**,** 34-35.

Oh, H., Rizo, C., Enkin, M. & Jadad, A. 2005. What is eHealth?: a systematic review of published definitions. *World Hosp Health Serv,* 41**,** 32-40.

Okuyama, S., Jones, W., Ricklefs, C. & Tran, Z. V. 2015. Psychosocial telephone interventions for patients with cancer and survivors: a systematic review. *Psychooncology,* 24**,** 857-70.

Patel, R. A., Klasnja, P., Hartzler, A., Unruh, K. T. & Pratt, W. 2012. Probing the benefits of real-time tracking during cancer care. *AMIA Annu Symp Proc,* 2012**,** 1340-9.

Patton, M. Q. 1999. Enhancing the quality and credibility of qualitative analysis. *Health Serv Res,* 34**,** 1189-208.

Prensky, M. 2001. Digital Natives, Digital Immigrants. *On the Horizon,* 9**,** 1-6.

Ridgeway, J. L., Egginton, J. S., Tiedje, K., Linzer, M., Boehm, D., Poplau, S., De Oliveira, D. R., Odell, L., Montori, V. M. & Eton, D. T. 2014. Factors that lessen the burden of treatment in complex patients with chronic conditions: a qualitative study. *Patient Prefer Adherence,* 8**,** 339-51.

Ritchie, J. 2013. *Qualitative Research Practice,* London, Sage.

Ritchie, J. & Spencer, L. 1994. Qualitative data analysis for applied policy research. *In:* BRYMAN, A. & BURGESS, R. (eds.) *Analysing Qualitative Data.* London: Routledge.

Ritterband, L. M., Thorndike, F. P., Cox, D. J., Kovatchev, B. P. & Gonder-Frederick, L. A. 2009. A behavior change model for internet interventions. *Ann Behav Med,* 38**,** 18-27.

Robert, G., Cornwell, J., Locock, L., Purushotham, A., Sturmey, G. & Gager, M. 2015. Patients and staff as codesigners of healthcare services. *BMJ,* 350.

Roberts, P., Priest, H. & Traynor, M. 2006. Reliability and validity in research. *Nursing Standard,* 20**,** 41-45.

Rodriguez, E. S., Thom, B. & Schneider, S. M. 2011. Nurse and physician perspectives on patients with cancer having online access to their laboratory results. *Oncol Nurs Forum,* 38**,** 476-82.

Rolfe, G. 2006. Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Journal of Advanced Nursing,* 53**,** 304-310.

Ross, J., Stevenson, F., Lau, R. & Murray, E. 2015. Exploring the challenges of implementing e-health: a protocol for an update of a systematic review of reviews. *BMJ Open,* 5**,** e006773.

Sabesan, S., Simcox, K. & Marr, I. 2012. Medical oncology clinics through videoconferencing: an acceptable telehealth model for rural patients and health workers. *Internal Medicine Journal,* 42**,** 780-785.

Sav, A., Kendall, E., Mcmillan, S. S., Kelly, F., Whitty, J. A., King, M. A. & Wheeler, A. J. 2013a. 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia. *Health & Social Care in the Community,* 21**,** 665-674.

Sav, A., King, M. A., Whitty, J. A., Kendall, E., Mcmillan, S. S., Kelly, F., Hunter, B. & Wheeler, A. J. 2013b. Burden of treatment for chronic illness: a concept analysis and review of the literature. *Health Expectations,* 18**,** 312-324.

Shea, K., Shih, A. & Davis, K. 2007. Health care opinion leaders' views on the quality and safety of health care in the United States http://www.commonwealthfund.org/usr_doc/1047_Shea_HCOL_quality_safety_data_brief.pdf?section=4039 accessed 2015

Shippee, N. D., Shah, N. D., May, C. R., Mair, F. S. & Montori, V. M. 2012. Cumulative complexity: a functional, patient-centered model of patient complexity can improve research and practice. *Journal of Clinical Epidemiology,* 65**,** 1041-1051.

Smith, J., Flowers, P. & Larkin, M. 2013. *Interpretative Phenomenological Analysis: Theory, Method and Research*, SAGE Publications Ltd.

Sood, S., Mbarika, V., Jugoo, S., Dookhy, R., Doarn, C. R., Prakash, N. & Merrell, R. C. 2007. What is telemedicine? A collection of 104 peer-reviewed perspectives and theoretical underpinnings. *Telemed J E Health,* 13**,** 573-90.

Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P. R. & Jacobs, G. A. 1983. *Manual for the State-Trait Anxiety Inventory.,* Palo Alto, CA: , Consulting Psychologists Press.

Stacey, D., Bakker, D., Ballantyne, B., Chapman, K., Cumminger, J., Green, E., Harrison, M., Howell, D., Kuziemsky, C., Mackenzie, T., Sabo, B., Skrutkowski, M., Syme, A. & Whynot, A. 2012. Managing symptoms during cancer treatments: evaluating the implementation of evidence-informed remote support protocols. *Implementation Science: IS,* 7**,** 110-110.

Stinson, J. N., Jibb, L. A., Nguyen, C., Nathan, P. C., Maloney, A. M., Dupuis, L. L., Gerstle, J. T., Alman, B., Hopyan, S., Strahlendorf, C., Portwine, C., Johnston, D. L. & Orr, M. 2013. Development and testing of a multidimensional iPhone pain assessment application for adolescents with cancer. *J Med Internet Res,* 15**,** e51.

Thomas, H., Faithfull, S., Cockle-Hearne, J., Toms, E. & Knibb, W. (2006). *Evaluation of a telephone follow-up service for women with ovarian cancer* (Unpublished final report). University of Surrey, Guildford.

Thomas, J. & Harden, A. 2008. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol,* 8**,** 45.

Thomas, L. H., Mccoll, E., Priest, J., Bond, S. & Boys, R. J. 1996. Newcastle satisfaction with nursing scales: an instrument for quality assessments of nursing care. *Qual Health Care,* 5**,** 67-72.

Tran, V.-T., Barnes, C., Montori, V., Falissard, B. & Ravaud, P. 2015. Taxonomy of the burden of treatment: a multi-country web-based qualitative study of patients with chronic conditions. *BMC Medicine,* 13**,** 1-15.

Tran, V.-T., Harrington, M., Montori, V. M., Barnes, C., Wicks, P. & Ravaud, P. 2014. Adaptation and validation of the Treatment Burden Questionnaire (TBQ) in English using an internet platform. *BMC Medicine,* 12**,** 1-9.

Tran, V.-T., Montori, V. M., Eton, D. T., Baruch, D., Falissard, B. & Ravaud, P. 2012. Development and description of measurement properties of an instrument to assess

treatment burden among patients with multiple chronic conditions. *BMC Medicine,* 10**,** 1-10.

Van Den Beuken-Van Everdingen, M. H., De Rijke, J. M., Kessels, A. G., Schouten, H. C., Van Kleef, M. & Patijn, J. 2007. Prevalence of pain in patients with cancer: a systematic review of the past 40 years. *Ann Oncol,* 18**,** 1437-49.

Vassilev, I., Rowsell, A., Pope, C., Kennedy, A., O'Cathain, A., Salisbury, C. & Rogers, A. 2015. Assessing the implementability of telehealth interventions for self-management support: a realist review. *Implementation Science* 10:59

Ventura, F., Ohlén, J. & Koinberg, I. 2013. An integrative review of supportive e-health programs in cancer care. *European Journal Of Oncology Nursing: The Official Journal Of European Oncology Nursing Society,* 17**,** 498-507.

Ware, J. E., Jr. & Sherbourne, C. D. 1992. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care,* 30**,** 473-83.

Wildevuur, S.E. & Simonse, L.W. 2015 Information and Communication Technology–Enabled Person-Centered Care for the "Big Five" Chronic Conditions: Scoping Review. *J Med Internet Res*;17(3):e77

Williamson, S., Chalmers, K. & Beaver, K. 2015. Patient experiences of nurse-led telephone follow-up following treatment for colorectal cancer. *European Journal of Oncology Nursing,* 19**,** 237-243.

Wise, M., Marchand, L., Aeschlimann, E., Causier, D., & Cleary, J. 2009. Integrating a narrative medicine telephone interview with online life review education for cancer patients: lessons learned and future directions. *Journal Of The Society For Integrative Oncology*, 7(1): 19-25.

Wootton R. Twenty years of telemedicine in chronic disease management--an evidence synthesis. Journal of telemedicine and telecare. 2012 Jun;18(4):211-20.

World Health Organization 2003. Adherence to long-term therapies: Evidence for action http://apps.who.int/medicinedocs/pdf/s4883e/s4883e.pdf accessed 2015.

World Health Organization 2005. WHO eHealth Resolution: A resolution on eHealth adopted at the 58th World Health Assembly http://www.who.int/healthacademy/news/en/ accessed 2015.

World Health Organization 2015. Health topics: E-Health http://www.who.int/topics/ehealth/en/ accessed 2015.

Zheng, M.-C., Zhang, J.-E., Qin, H.-Y., Fang, Y.-J. & Wu, X.-J. 2013. Telephone follow-up for patients returning home with colostomies: Views and experiences of patients and enterostomal nurses. *European Journal of Oncology Nursing,* 17**,** 184-189.

Appendices

Appendix 1 - Main publications (including poster presentations)

P1   Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L. (2006) 'Information needs and experiences: An audit of UK cancer patients'. European Journal of Oncology Nursing, 10 (4), pp. 263-272.

Poster presentation of P1

P2   Cox A, Bull E, Cockle-Hearne J, Knibb W, Potter C, Faithfull S. (2008) 'Nurse led telephone follow up in ovarian cancer: A psychosocial perspective'. European Journal of Oncology Nursing, 12 (5), pp. 412-417.

Poster presentation of P2

P3   Cox A, Illsley M, Knibb W, Lucas C, O'Driscoll M, Potter C, Flowerday A, Faithfull S. (2011) 'The acceptability of e-technology to monitor and assess patient symptoms following palliative radiotherapy for lung cancer.' Palliative Medicine 25 (7), pp. 675-681

Poster presentation of P3

P4   Cox A, Faithfull S. (2013) "They're survivors physically but we want them to survive mentally as well': health care professionals' views on providing potential late effect information.' Supportive Care in Cancer, 21 (9), pp. 2491-2497

Poster presentation of P4

P5   Cox A, Faithfull S. (2015) 'Aiding a reassertion of self: an Interpretative Phenomenological Analysis of the views and experiences of women with ovarian cancer receiving long-term nurse-led telephone follow-up' Supportive Care in Cancer 23(8):2357-64.

Poster presentation of P5