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**The On-going Care of Patients with Cancer:
What is the Appropriate Balance of Cancer Care
between Specialist and Primary Care?**

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General Practice and Primary Care

College of Medicine, Veterinary and Life Sciences

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Abstract

Background: Mortality rates have fallen resulting in people living longer with cancer. However, cancer survivors can face significant treatment related physical and psychosocial issues including comorbidities. Treatment related side effects can persist in the long-term or may occur many years later. There is now a focus on the best way to provide appropriate care to people who have survived cancer and its treatment.

Aim: The aim of this study is to explore the appropriate balance of cancer care for patients following diagnosis and treatment between specialist and primary care.

Methods: Semi-structured interviews with a purposive sample of 40 oncologists, CNSs and GPs across Scotland. Data are analysed in a systematic fashion using constant comparison.

Findings: Many patients face significant health care issues after a diagnosis of cancer. Professionals often play a pivotal role during follow-up by identifying and managing patients' physical and psychosocial needs and by sign posting to address the challenges that arise. Psychosocial needs, long-term and late effects are sometimes not addressed. Oncologists are leaders of the cancer care process. CNSs often play a central role in survivorship both in specialist and primary care. GPs' roles are seen to span the full spectrum of survivorship care, although this is largely opportunistic in nature. Communication between specialist and primary care is a key issue. Professionals perceived that there is insufficient contact across the interface in terms of understanding others' viewpoints about the nature of their work. Efforts are needed to improve the timeliness and detail of letters to primary care. Successful primary care follow-up may require development of nurses' roles in general practice and the community. It is perceived that GPs could attend specialist care for survivorship education or become cancer specialists in general practice. Cancer Care Reviews are considered useful tools in terms of allowing GPs to engage with their patients. Improvements to technology and further research are considered central to optimal cancer care.

Conclusion: Considerable barriers exist with the current system of follow-up. After the treatment phase, GP survivorship care is largely opportunistic and driven by patients' needs. Based on the findings from this study, strategies of care could potentially be planned to facilitate the role of primary care. However, research supporting these practices is needed.

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Fiona Jane Elizabeth Smith BSc (Hons) MPH

Definitions/Abbreviations

UK	United Kingdom
HRQoL	Health Related Quality of Life
GPs	General Practitioners
QoL	Quality of Life
SIGN	Scottish Intercollegiate Guidelines Network
NICE	National Institute for Health and Care Excellence
CEA	Carcinoembryonic Antigen
CT scan	Computer Tomography
MRI	Magnetic Resonance Imaging
WW	Watchful Waiting
PSA	Prostatic Specific Antigen
AS	Active Surveillance
DRE	Digital Rectal Examination
RP	Radical Prostatectomy
CNS	Clinical Nurse Specialists
NHS	National Health Service
NCSI	National Cancer Survivorship Initiative
NCRI	National Cancer Research Initiative
RCGP	Royal College of General Practitioners
STF	Scottish Task Force
TCAT	Transforming Care After Treatment
EBM	Evidenced Based Medicine
RCTs	Randomised Controlled Trials
ICT	Information Communication Technology
GRADE	Grading of Recommended Assessment Development and Evaluation
MESH	Medical Subject Headings
US	United States
CaPSURE	Cancer of the Prostate Strategic Urologic Research Endeavour
COPD	Chronic Obstructive Pulmonary Disease
ESMO	European Society for Medical Oncology
IOM	Institute of Medicine
SCP	Summary Care Plan
NCAT	National Cancer Action Team
QoF	Quality Outcomes Framework
BWoSCC	Beatson West of Scotland Cancer Centre
SPRCN	Scottish and Primary Care Research Network
IHTAB	In-house Trials Advisory Board
OSOP	One Sheet of Paper
MDT	Multidisciplinary Team Meeting
MCN	Managed Clinical Network
SCAN	South East Scotland Cancer Network
GSF	Gold Standards Framework
GMSC	General Medical Services Contract
SCI Gateway	Scottish Care Information Gateway
EPR	Electronic Patient Record
PICC Lines	Peripherally Inserted Central Catheters

DRH	Derby Regional Hospital
IA	Indigenous Australians
Appendices	
SR	Systematic Reviews
>	Greater than
<	Less than
FP	Family Physician
SCEs	Serious Clinical Events
SaAC	Satisfaction and Accessibility scale
HADS	Hospital, Anxiety and Depression Scale
ASFMI	Attentional Focus Symptom Management Intervention
BCEI	Breast Care Education Intervention
STAI	State-Trait Anxiety Inventory
GHQ	General Health Questionnaire
COPD	Chronic Obstructive Pulmonary Disease
CVD	Cardiovascular Disease
SGRQ	St George Respiratory Questionnaire

1. Introduction

This chapter aims to introduce the thesis and to give the context in which the research is situated. Cancer is an important public health issue. In 2008, cancer contributed to 27% of all deaths in the UK (Jayatilleke et al. 2011). Whilst mortality rates have fallen, survivors of cancer may face a myriad of treatment related physical and psychosocial issues that could significantly impact on their Health Related Quality of Life (HRQoL). There is consensus that the traditional model of oncologist and cancer centre follow-up is not sustainable and must be re-structured to meet the needs of the survivorship population (Howell et al. 2012). Primary care professionals may be equipped to care for patients during the survivorship phase. However, there is a need for a better understanding about the involvement of General Practitioners (GPs) in cancer care follow-up.

1.1 Cancer incidence, survival and prevalence

In the UK, in 2011, 331,487 individuals were diagnosed with cancer. In particular, breast, prostate, lung and colorectal cancers were the most commonly diagnosed cancers, which accounted for over 54% of the cancer burden (Cancer Research UK 2014a). In the UK, in 2014, 49,936 females (4,578 in Scotland) and 349 males (30 in Scotland) were diagnosed with breast cancer. In that same year, in the UK, 47,736 males (2,817 in Scotland) were diagnosed with prostate cancer. In the UK, in 2014, 19,693 females (2,495 in Scotland) and 23,770 males (2,601 in Scotland) were diagnosed with lung cancer. In that same year, in the UK, 13,076 females (1,248 in Scotland) and 14,279 males (1,440 in Scotland) were diagnosed with colorectal cancer (Cancer Research UK 2014b).

Survival rates for most cancers in the UK have improved over time. In breast cancer, for example, five-year survival rates have increased from 52% in 1971-1975 to 85% in 2005-2009 (56% in 1971-1975 to 85% in 2003-2007 in Scotland). Similarly, five-year survival rates for prostate cancer have increased from 31% in 1971-1975 to 81% in 2005-2009 (36% in 1971-1975 to 85% in 2003-2007 in Scotland). For both males and females, five-year survival rates for colorectal cancer have increased from 22% in 1971-1975 to 55% in 2005-2009 (26% in 1971-

1975 to 54% in 2003-2007 in Scotland) (ISD Scotland 2000). However, for males and females in the UK, five-year survival rates for lung cancer have altered very little over time, only increasing by 10% (8% in Scotland) (Cancer Research UK 2014c). Poor survival rates for lung cancer may in part be due to challenges associated with its diagnosis. For example, patients with suspected lung cancer, often present when the cancer is at an advanced stage, making treatment more problematic and therefore, reducing the chance of survival (Imperator et al. 2009).

In the future, it is likely that cancer prevalence will increase largely due to changing incidence and mortality rates, a growing and ageing population and early detection of cancer (WHO 2010). Currently, in the UK there are over 2,000,000 cancer survivors, which are set to increase to 4,000,000 by 2030. In Scotland it was estimated that at the end of 2010 there were 190,000 cancer survivors, which will most likely increase to 350,000 by 2030 (Macmillan 2013a). In 2008 in the UK and Scotland it was estimated that breast and prostate cancers were the most prevalent cancers followed by colorectal and lung cancers (Maddams et al. 2009).

1.2 Survivorship issues and quality of life

‘Cancer survivorship’ is a term that has emerged to represent the process of living following a cancer diagnosis. Individuals may have active disease or they may be living beyond cancer (NCRI 2013). Many survivors of cancer are at risk of developing significant physical and psychosocial issues as a result of the cancer itself or because of cancer treatments (Brem and Kumar 2011). Some treatment related symptoms occur immediately, whilst other symptoms can occur many years later. Challenges will be individual to each cancer patient and will be underpinned by a combination of circumstances, for example: site and stage of the cancer; treatments given; age of the patient; genetic predisposition; personal traits and social circumstances (Stein et al. 2008). The next section highlights some of the treatment related complications for breast, colorectal, prostate and lung cancers and their potential impact on Quality of Life (QoL).

Breast cancer patients can experience physical effects from treatments, for example: fatigue; hot flushes; night sweats; vaginal discharge; breast sensitivity; pain and sleep disturbances (Ganz et al 2002; Cappiello et al. 2007). After treatments, survivors of breast cancer can live with the fear of a cancer recurrence. In addition, patients may feel vulnerable as they move from regular visits with their oncologist to less frequent visits, perhaps heightening their anxiety regarding their future. Withdrawal and changes in family support can leave patients feeling depressed as women may be expected to resume their normal lives at pre-cancer level of functioning (Ganz et al. 2004).

Patients with colorectal cancer both stoma and non-stoma patients are troubled by pain and difficult bowel symptoms and often have to follow a strict dietary plan. Compounding these issues are fatigue and weight loss, which can persist for many years (Arndt et al. 2004; Knowles et al. 2013). Many patients are anxious about their cancer returning, despite the knowledge that they had successful treatment (Taylor et al. 2011). Indeed, patients with stomas seem to have an overall lower QoL, poor body image and less social activity (Cotrim and Pereira 2008; Marventano et al. 2013).

Prostate cancer patients can experience a number of physical and psychosocial difficulties associated with their treatments. Most treatments impact on sexual and urinary function, which often develop immediately after treatment. Although recovery from treatments can occur up to two years, this is less likely after three years (Huang et al. 2010; Simon 2013). Physical issues such as these can limit activities of daily living and social functioning including psychological wellbeing and QoL (Reeve et al. 2013).

After treatments for lung cancer, patients can endure physical symptoms such as fatigue and nausea including pain and dyspnoea. These effects can impact on the patient's cognitive and social ability including their overall wellbeing (Win et al. 2005). Lung cancer patients who survive in the long-term can develop symptoms such as a persistent cough and chest pain including haemoptysis (coughing of blood). These symptoms increase as patients become more unwell with their disease (McCannon and Temel 2012). The impact of treatments or from the lung cancer itself is often profound and leads to more functional impairment when compared with other cancer patients (Dhillon et al. 2012).

1.3 Current recommendations for follow-up of breast, colorectal, lung and prostate cancers

Table one shows the current follow-up pathways for breast, colorectal, lung and prostate cancers according to the Scottish Intercollegiate Guidelines Network (SIGN) and the National Institute for Health and Care Excellence (NICE) including Cancer Research UK. Largely, the focus is on surveillance practices for detection of recurrent cancer and management of treatment related complications including late effects.

Table one: Current pathways of follow-up care

Breast cancer pathway	Colorectal cancer pathway	Lung cancer Pathway	Prostate cancer Pathway
SIGN134 (2013) Cancer Research UK (2012a)	SIGN 126 (2011)	SIGN 80 (2005)	NICE Pathways (2014)
Post Surgery/Treat.	Post Surgery/Treat	Post Surgery/Treat	Risk stratification
Specialist follow-up for up to 10 years.	Specialist follow-up at Intervals	Surgical follow-up for management of symptoms.	Watchful Waiting (WW) ¹ -not curative intent- Follow-up primary care Prostatic Specific Antigen (PSA) levels yearly.
Screening programme Mammography yearly - 3-5 years (Cancer Research UK 2012a).	Screening programme Carcinoembryonic Antigen (CEA) Computer Tomography (CT) scan Colonoscopy - 5 yearly MRI		Active Surveillance (AS) ² Low risk (Enrolment AS- Magnetic Resonance Imaging (MRI) (During AS- PSA -3-4 monthly) (Year 1 AS - Digital Rectal Examination (DRE) 6-12monthly) (Year 2-4 AS - PSA 3-6 months, DRE-6-12months) (Year 5 and after AS - PSA 6 months, DRE 12 monthly)
If possible, premenopausal women administered with Tamoxifen - 5 years.			Immediate risk - Offer Radical Prostatectomy (RP) or radiotherapy. Consider AS if men with immediate risk localised prostate cancer do not wish to have RP or radiotherapy.
If possible, postmenopausal women administered with Aromatase inhibitors after 2-3 years of Tamoxifen - 5 years. For men -same regime as women - no Tamoxifen			High risk- Offer RP or radiotherapy to men with high-risk prostate cancer, if, there is a realistic prospect of a good prognosis. Do not offer AS

¹ Watchful **Waiting** is not curative in intent. Monitoring of asymptomatic prostate cancer, which is not causing symptoms. If symptoms begin treatment will be offered (Prostate Cancer UK (2012) Watchful Waiting [Internet], Available from: <http://www.cancerresearchuk.org> [Accessed 12 May 2014]).

² **Active Surveillance** is one method of managing prostate cancer, which aims to avoid or delay unnecessary treatment in men with aggressive cancer (Cancer Research UK (2014d) Treatment options for prostate cancer [Internet], Available from: <http://www.prostatecanceruk.org> [Accessed 12 May 2014]).

1.4 General Practitioners and Clinical Nurse Specialists' involvement in cancer care

Patients with suspected cancer often present with symptoms, in the first instance, to their GP (Campbell et al. 2002). Often, the GP has the difficult task of unravelling an assortment of signs and symptoms, which might or might not be related to cancer (Rubin et al. 2011). These factors together with the few cases of cancer that GPs see may mean that GPs delay referral for a consultant's opinion (NHS 2010a). In Scotland, for example, an individual GP might consult with about seven to eight new cases of cancer per year- based on an average list size of 1,500 patients per GP. Furthermore, a GP practice is likely to see on average four to five new cases per year of patients with each of the most common cancers (lung, breast and colorectal cancer). An individual GP might only see one new patient affected with either cancer of the bladder, kidney or oesophagus (NHS Scotland 2013). GPs in the pre-diagnosis phase are involved in cancer prevention and education including screening and referral (Emery et al. 2012). GPs in the survivorship phase provide substantial cancer specific follow-up that focuses on: detection of recurrence; assessment of treatment related side effects; screening for new cancers; addressing psychological issues and management of comorbid conditions (Grunfeld 2005).

Clinical Nurse Specialists (CNSs) are acknowledged as integral to improving the delivery of cancer care across the UK. Their role largely involves coordination of care and provision of information including physical and psychological support for patients with cancer (Department of Health 2007; The Scottish Government 2008). Despite the national emphasis on CNSs, there remain variations in care in terms of access both in number and cancer type (Trevatt et al. 2010). This in part may be explained by their developing roles and responsibilities (Macmillan 2011). Macmillan in partnership with the Department of Health provides funding to support the positions of CNSs with the intention to improve the delivery of services. However, the worry is that austerity measures might constrain further expansion and development of these posts (Royal College of Nursing 2010).

1.5 UK policy initiatives

Historically, in the UK, cancer survival has been poor compared to other European countries. This was thought to be due to underinvestment in the National Health Service (NHS) infrastructure. This led to the 1995 publication of the Calman-Hine report, which focussed on improving health outcomes and reducing inequalities in NHS cancer care (Rosen et al. 2006). Integrated care between primary care and cancer centres including cancer units were proposed to harmonise practice and provide quality care for all patients across the UK. Multidisciplinary management and teamwork were seen as essential (Department of Health 1995).

Whilst the Calman-Hine report served as an important first step in providing a vision for cancer services, development and implementation of these policies were not uniformly addressed. Consequently, some regions within the UK focussed on cancer centres, whilst others concentrated on networks of care or accreditation of services (Haward 2006). The Department of Health (2000) published the NHS Cancer Plan, which aimed to build on efforts from the Calman-Hine report. The Cancer Plan proposed that extra resources were to be deployed into cancer networks based around specialist cancer centres. Strategies focussed on were: prevention of cancer; extending cancer screening services; new waiting times for diagnosis and treatment; workforce expansion and improving facilities (Elwood and Sutcliffe 2010). An evaluation of the Cancer Plan found that considerable progress had been made in reducing mortality rates, yet more emphasis was needed in terms of cancer networks and partnership working (Department of Health 2005).

In order to build on the progress over the last decade and to meet the challenges that remain the government developed the Cancer Reform Strategy, which set out the plan for delivering cancer services in England. The Cancer Reform Strategy - endorsed by the Improving Outcomes Strategy for Cancer (Department of Health 2011) aimed to establish a new approach to cancer care services. Key aspects of this included prevention and treatment including early diagnosis and living with cancer (Department of Health 2007). The National Cancer

Survivorship Initiative (NCSI) was introduced to improve survivorship outcomes in relation to personalised care planning (Richards et al. 2011). The NCSI set out five key areas in the approach to care and support for people living in the survivorship phase (Department of Health 2010a).

Table two: NCSI shifts in survivorship care.

Table two: Five key shifts to improve survivorship outcomes	
1.	A cultural shift in the approach to care and support for people affected by cancer-to a greater focus on recovery, health and well being after cancer treatment.
2.	A shift towards assessment, information provision and personalised care planning. This is a shift from one size fits all approach to follow-up to personalised care planning based on assessment of individual risks, needs and preferences.
3.	A shift towards support for self-management. This is a shift from a clinically led approach to follow-up care to supported self-management, based on individual needs and preferences and with the appropriate clinical assessment, support and treatment.
4.	A shift from a single model of clinical follow-up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease.
5.	A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome Measures.

Integral to the work of the NCSI is the research work stream, one of seven work streams, which aimed to map the survivorship journey of people affected by cancer. Part of this work also involved establishing knowledge about best practice (Neate 2009). Priorities for research on survivorship identified many potential problems for cancer survivors in terms of unmet physical and psychosocial needs, which contrasted markedly with the lack of quality evidence about potential solutions to these problems (Department of Health 2010b). More recently, the National Cancer Research Initiative (NCRI) consensus conference on cancer survivorship highlighted the need for: development of risk stratification tools; patient-centred choice and empowerment; assessment of stepped care (progression to intensive care if required); the development and testing of needs assessment tools and improvements in ICT infrastructure between cancer networks with primary care leading service delivery (NCRI 2010).

In 2012, the Royal College of General Practitioners (RCGPs) selected cancer as its first 'enduring priority' - a five-year programme, which aimed to develop optimal practice models and guidance supported by educational resources. These priorities also include embedded educational improvements within the GP curriculum (Cancer Research UK 2012b).

1.6 Scottish policy initiatives

Responsibility for health care was, in the main, devolved to the Scottish Parliament under the terms of the Scotland Act 1998 (Robson 2011). A number of publications within Scotland have emerged in relation to cancer services. The Commissioning Cancer Services publication set out recommendations for genetic screening services in Scotland (SCCAC 1996 and 1997). Additionally, the 2001 Cancer Scenarios: An Aid to Planning Cancer Services in Scotland documented trends in cancer incidence and mortality in terms of future actions and strategies (The Scottish Government 2001). In that same year, the 2001 Cancer in Scotland: Action for Change published recommendations about quality assurance regarding cancer services. Proposals were also made with regard to the provision of cancer treatments and advice for genetic screening across Scotland (The Scottish Executive 2001) and outwith Scotland - the Calman-Hine report (Department of Health 1995). These publications were central to the development of cancer services within Scotland.

The 2008 the Better Cancer Care: An Action Plan publication proposed the modernisation of cancer services. Key actions focussed on were: prevention of cancer; early detection of cancer; genetic testing; referral and diagnosis; treatment issues; living with cancer and service delivery (The Scottish Government 2008). In response, the Scottish Task Force (STF) established a survivorship working group to oversee implementation of the Cancer Plan and its actions and to maintain the NCSI focus (Macmillan 2009). For example, the Transforming Care After Treatment (TCAT) programme was set up by the Scottish Government in partnership with Macmillan Cancer Support to meet the needs of cancer survivors. The TCAT is a work stream of the STF and assessment and care planning is a major feature of the NCSI programme (The Scottish Government 2013).

1.7 Outline of the thesis

This study consists of seven chapters and is presented as follows:

Chapter two describes the literature on survivorship care. Firstly, to explore the evidence regarding best practice for follow-up care. Secondly, to understand professional and patient roles during cancer care follow-up by drawing on the available systematic reviews and meta-analyses where they exist.

Chapter three details the aim and research objectives.

Chapter four describes the design and methodology of the study. This section also includes ethical considerations and reflections about the reliability and validity of the study.

Chapter five presents the studies findings. This chapter explores professionals' perceptions in relation to: the organisation of cancer care; patients' physical and psychosocial needs; professional roles in follow-up; communication practices between specialist and primary care including optimisation of primary care.

Chapter six begins by considering the main findings in relation to the wider literature. Next, the strengths and weaknesses of the study are discussed. This is followed by implications for policy and practice. The chapter will conclude with a conceptual model of care and recommendations for further research.

Chapter Seven presents the conclusions.

2. Literature review

2.1 Introduction

The purpose of this literature review is to establish the context and rationale for this thesis by identifying the wider literature on cancer care follow-up. Currently, patients with cancer receive their follow-up care within specialist care. However, the efficacy of this model is questionable as it fails to meet all survivors' needs. Research suggests that other models of survivorship care may be effective and acceptable to cancer survivors. The Calman-Hine report recognises the value of primary care in survivorship care; however, this remains very poorly defined at present.

2.1.1 Historical development of the hierarchy of evidence

Sackett et al. (1996) described Evidence-Based Medicine (EBM) as the conscientious and explicit decision to use the best available evidence to inform clinical practice. Advocates of EBM have increasingly used various types of 'hierarchies of evidence' to assess the quality and strength of research. Generally, systematic reviews and meta-analyses of Randomised Controlled Trials (RCTs) are at the top of the hierarchy, followed by individual RCTs, observational studies and lastly expert opinions (Gao Smith et al. 2006).

Until recently, these hierarchies of evidence were a widely accepted system, particularly in terms of guideline recommendations. However, it has become apparent that the quality of systematic reviews is only as good as the quality of the studies contained within them (Merlin et al. 2009). Therefore, the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) approach was developed to address the shortcomings of the present hierarchical system and to further inform future decision-making (Barbour and Miller 2001). GRADE proposed that the *quality* of evidence be judged by its design, conduct and analyses and the extent to which this might reduce bias. The highest grading of evidence is currently offered to RCTs; however, this rating can be downgraded if there are limitations and bias within the design. Although observational (cohort, case control and cross-sectional) studies begin with a low quality grading, they

can be upgraded if the treatment effect is significant and if the findings cannot be explained by other plausible biases (Guyatt et al. 2008). Similarly, the *strength* of the evidence needs to be assessed in terms of whether the benefits of the evidence outweigh the risks, harms and costs. If this is the case, then strong recommendations are awarded (Gao Smith et al. 2006; Booth et al. 2012). Conversely, uncertain or low quality evidence should be offered a 'weak' recommendation (Guyatt et al. 2008). The approach in this thesis is to present systematic literature reviews and meta-analyses where they exist. If these types of studies are unavailable, RCTs, cohort and case-control studies will be presented. For aspects where there is limited research, there may be a need to present other types of studies too. The quality and strength of studies examined in this literature review will be presented in (Appendix1).

A literature review can be described as an objective, thorough summary and critical analysis of the available literature on a specific topic (Hart 2009). A literature review is often approached either narratively or systematically with or without meta-analyses or meta-synthesis. Narrative reviews, for example, have many benefits in that they can summarise the literature and are useful for obtaining a broad overview of a given topic, particularly in the hands of an experienced researcher. However, narrative reviews can be susceptible to bias because they are less likely to use systematic methods to select and appraise the evidence (Klassan et al. 1998).

Systematic reviews, on the other hand, have a more rigorous and well defined approach to searching and use explicit methods to identify, select, appraise, synthesise and detail the research evidence (Khan et al. 2011). If it is reasonable to do so, a meta-analyses may accompany a systematic review, which can increase the power and precision of estimates of a treatment (Akobeng 2005). Whilst meta-analyses of well-conducted RCTs might be considered one of the highest levels of evidence (Garg et al. 2008), its mathematical results should be interpreted with caution. For example, investigators conducting meta-analyses of individual studies may have a tendency to choose published studies over unpublished or small studies, especially if they identify significant results. This type of publication bias has the potential to exaggerate or misrepresent the true effect size and as a consequence may invalidate the conclusions (Mueller et al. 2013).

Whilst meta-analyses are concerned with aggregating data to reach conclusions, meta-syntheses are about combining evidence from individual qualitative studies to produce results (Korhonen et al. 2013). A key advantage of meta-syntheses is its potential to generate comprehensive theory as well as providing further insight into existing systematic reviews and in doing so may facilitate policy and practice (Noyes et al. 2008). Meta-syntheses of qualitative research has been criticised, however, because they can be underpinned by a particular philosophical stance and could be presented in different ways, therefore, making it difficult to produce a congruent syntheses (Zimmer 2006).

There are numerous benefits in undertaking a systematic review, however, conducting this type of search can make certain demands on students. Often a team of experienced researchers are required to assist with the reading and analysis process. So, while a systematic review has not been done, the student has drawn from these principles and used a 'systematic approach' to searching, which are evidenced both in the conduct and presentation of this literature search and embodied in the principles and guidelines of a systematic review. The rationale for using this ordered approach is based on the need to conduct a comprehensive search of the literature and as a consequence produce more worthwhile and believable review findings that are less prone to bias (Booth et al. 2012).

2.1.2 Approach to literature searching

In this chapter, literature relating to the aim of this thesis is reviewed. The first section describes the evidence in terms of best follow-up practices for survivorship care. The second section reviews the literature regarding professional roles in service delivery.

The systematic approach for this literature review involved: identifying search terms; finding suitable databases; using specific research techniques and collating the results. Firstly, key terms and synonyms were identified using the Medical Subject Heading (MeSH) database (US NLM 2014). MeSH searching resulted in key terminology, such as: 'cancer', 'survivors', 'follow-up', 'family

practice’, ‘general practice’, ‘primary health care’, ‘general practitioner’, ‘physician’, ‘hospital’, ‘clinics’ and ‘initiated.’ The Cochrane, Embase, Medline and CINAHL databases were used, largely because they seemed most relevant to the topic of survivorship. The decision was made to start with the Cochrane Library as this database concentrates on systematic reviews and meta-analyses and was considered highly systematic with explicit quality criteria (The Cochrane Library 2013).

Having identified the potential terminology and databases, the next stage of the literature search involved employing the use of specific research techniques to widen and improve the quality of the search. This included the use of truncation symbols to obtain plural and other forms of key words, for example, surviv\$, which was likely to include studies about survival, survivors and survivorship. Connectors such as ‘OR’ and ‘AND’ were used to combine key terms and phrases into sets for searching. Full documentation of the approach to the search strategy can be viewed in (Appendix 2).

After the database search was completed, the next step of the searching process involved a citation and hand search of the literature, which examined key papers and their reference lists. As a result of this procedure, the list of journal articles increased substantially, identifying a wider range of articles for review. Studies prior to 1996 were excluded because the student was of the viewpoint that much of the work in this thesis originated after the 1995 Calman-Hine report. Studies that related to patients undergoing active cancer treatment and those that related to palliative care were excluded unless they were considered key to the research aim. The decision was made, however, to include studies regarding patients who were undergoing adjuvant therapy, as it was perceived that this phase of care could extend for a number of years; therefore, patients would most likely need some form of follow-up support. The types of articles included for review were best practice interventions for patients who had breast, lung, prostate and colorectal cancer. The decision was made to choose these cancers because they were the common cancers in terms of prevalence. Additionally, the evidence consistently demonstrated that there was a lack of research about the most effective model of cancer care. Whilst these four cancers were the main cancer sites focussed on, other studies that provided evidence for other cancer sites were also examined and included if relevant.

Reference Manager 10 was used to export and manage the journal citations appropriately. Collation of the results and characteristics of the included studies for this thesis are described in (Appendix 3).

2.2 Disease focussed models for delivering survivorship care

Historically, the major focus of survivorship was to monitor care after treatment and to check for recurrent cancer (Hewitt et al. 2006). Cancer surveillance can be described as a numerical portrait of cancer and its determinants in specific populations. Broadly, the aim of cancer surveillance is to measure cancer incidence, morbidity, survival and mortality. Cancer surveillance also includes: assessment of genetic predisposition; environmental and behavioural risk factors; screening surveillance and overall quality of care from prevention to palliative care. Cancer surveillance informs us about ways in which the cancer burden can be reduced, which in turn generates further research, prevention and control (National Cancer Institute 2010). For the purpose of this thesis, however, the evidence regarding cancer surveillance will focus primarily on surveillance after the treatment phase, rather than screening of the overall health of populations. The following sections summarise surveillance practices in relation to breast, colorectal, prostate and lung cancer.

2.2.1 Breast cancer

The practice of surveillance has been most comprehensively assessed in breast cancer. A recent Cochrane review conducted by Rojas et al. (2012) included four of the most influential RCTs in the breast cancer area. Two studies compared traditional care with intensive care and found no differences in overall survival. In the RCTs that compared specialist care with GP follow-up, no differences were found in time to detection of recurrent cancers or depression. Patients were also found to be more satisfied with care from their GP. It is important to acknowledge, however, that some studies in Rojas's work had a 10% loss-to-follow-up, which may have had the potential to impact on the strength of the studies findings (Dumville et al. 2006). This review also raised

questions about representativeness. For example, two of the trials were conducted in the early 1990's when knowledge and treatments about breast cancer surveillance may have been different to current practice today.

In the Grunfeld et al. (1996) and Grunfeld (2006) RCTs, it was found that GP follow-up for women with breast cancer did not contribute to more recurrence-related events, anxiety or reduce HRQoL compared to women who were followed up by specialist care. Frequently, the women themselves detected recurrences before their visit to the GP, irrespective of their attendance at the specialist.

Such seminal studies as these are important forerunners in our understanding of surveillance practices, particularly in relation to shifting the focus of care from specialist to primary care.

2.2.2 Colorectal cancer

The search revealed three systematic reviews regarding colorectal cancer and surveillance practices. Renehan et al's (2005) meta-analysis of five RCTs demonstrated that intensive surveillance in colorectal cancer improved detection of recurrent cancer and survival. Similarly, Figueredo et al. (2003) in their review of the same studies, in addition to a subsequent sixth RCT (Secco et al. 2002) found that intensive surveillance contributed to a reduction in mortality. Since then, Jeffrey et al's (2008) Cochrane review has supported both Renehan's and Figueredo's conclusions. Based on the same RCTs, the authors also found that intensive follow-up care in colorectal cancer improved survival. Furthermore, no differences were found between intensive and usual care in terms of patient satisfaction, psychological functioning or QoL. However, the findings must be interpreted with caution as some authors described intensive interventions as a comprehensive set of visits and tests, whilst others considered the intensive intervention to be a clinical review, a yearly colonoscopy and intermittent x-rays. As with the breast cancer studies, the authors made reference to the age of some RCTs and questioned their relevance to current practice.

2.2.3 Prostate cancer

Traditionally, follow-up care for prostate cancer has been hospital based under the guidance of clinicians in urology and oncology outpatient departments. However, as the prevalence of prostate cancer continues to increase and specialist care resources face pressure, other forms of care are now being considered (Rose and Watson 2009). Nurse-led interventions involving prostate cancer, for example, have been found to be comparable to that of specialist care - these studies are discussed in more detail in 2.3.3.

A systematic review of international guidelines on the management of prostate cancer was undertaken to determine best practice for primary care. The authors sought to find key components of current models of survivorship care to establish a framework for evaluating future complex interventions. The results showed that most guidelines did not provide sufficient information from which to appraise the accuracy of the recommendations. Moreover, there was disagreement regarding the extent to which primary care should be involved (McIntosh et al. 2009). Unclear guidelines in primary care - with respect to prostate survivorship, may cause variations in care or cause patients to be lost to follow-up. Uncertain guidelines may also explain why some patients with prostate cancer have unmet psychosexual needs (O'Brien et al. 2009; Watson et al. 2011a).

Recently, NICE (2008) recommended that men with stable prostate cancer be offered their care in primary care according to the WW regime. Complementing the WW guidelines are PSA testing and psychosocial care.

2.2.4 Lung Cancer

Lung cancer follow-up is not well understood. Searches for systematic reviews including studies of lesser evidence yielded little. The NCCC (2011) in their review of lung cancer studies identified three retrospective interventions, which compared various surveillance practices. In Virgo et al's (1995) study, the authors compared intensive follow-up (outpatient visits, CT scans, bio measures, x-rays, bronchoscope screening, sputum tests) with non-intensive follow-up (follow-up which met none of the criteria for intensive follow-up) in patients

with lung cancer. It was found that intensive follow-up did not significantly impact on time to detection of recurrence or survival. In Younes et al's (1999) study, the authors compared strict follow-up (regular physical examinations, x-rays, bio measures) with symptom based follow-up (less than three consultations per year) and found no difference in early detection of recurrence or survival. Finally, in Nakamura et al's (2010) lung cancer study, the authors compared follow-up by a thoracic surgeon (regular physical examinations, chest x-rays) with follow-up by chest physician (CT scan every 6 months). The results indicated that follow-up by a thoracic surgeon increased hazard of death compared to chest physicians. Although these studies provided some insight into surveillance practices for lung cancer, the results must be questioned as the comparison groups were weighted differently. This was particularly noticeable with respect to comorbid conditions. Other studies had low numbers of patients in each follow-up group, therefore, preventing a detailed analysis. These factors made it difficult to draw firm conclusions about the most effective follow-up strategy.

2.2.5 On going research

Research in breast, colorectal, prostate and lung cancers will continue to facilitate our understanding of follow-up surveillance. In breast cancer, for example, a large multi-site RCT aims to compare standard follow-up (clinical examination and mammography including a questionnaire at five years post diagnosis) with alternative follow-up (mammography and questionnaire at five years post diagnosis) (Dunn et al. 2009).

Colorectal studies such as the COLOFOL trial aim to determine whether intensive imaging (every 6 months for 36 months) or less intensive imaging (at 12 and 36 months) is the best strategy (Akin et al. 2012).

In the United States (US), management of patients with prostate cancer has changed considerably. The Cancer of the Prostate Strategic Urologic Research Endeavour (CaPSURE) study is a web-based reporting system that allows clinicians to submit data. Similarly, patients contribute their information to the database at regular intervals and after their treatments. This system facilitates clinician knowledge around prostate cancer (Cooperberg et al. 2004).

Finally, studies around lung cancer were generally found to be limited. Lack of high quality evidence around this specific cancer seemed inescapably linked with its poor survival rate (Furman et al. 2013). Research is needed to understand the impact of treatment related side effects in order to provide optimal care.

2.2.6 Summary

This section has examined disease focused models for delivering survivorship care. These studies provided an outline of some of the key texts regarding surveillance for breast, colorectal, prostate and lung cancers. For patients with breast cancer, the evidence suggested that it is not advantageous to attend specialist care for follow-up. Yet, for patients with colorectal cancer there were advantages in attending specialist care for reasons related to detection of recurrent cancer and survival outcomes. For prostate cancer, primary care seems to have a greater involvement in follow-up care; yet, barriers persist to best practice. Finally, on-going studies around surveillance for lung cancer were limited.

2.3 Nurse-led models and survivorship care

2.3.1 Nurse-led care and breast cancer

The search revealed two systematic reviews in relation to nurse-led care and breast cancer. In Taggart et al's (2012) systematic review of five RCTs, the authors compared standard care (routine clinical review) to nurse-led care (point of need access via the nurse specialist). The results showed no differences between the groups in terms of HRQoL, detection of recurrence, psychological functioning and time to death. In one study, patients' satisfaction with their care was found to be greater in the nurse-led group. The authors acknowledged that some studies failed to meet the sample sizes they had originally calculated, which may have influenced interpretation of the findings.

In Galway et al's (2012) Cochrane review, three RCTs compared nurse-led interventions (telephone - education and supportive therapy) with usual care. Breast cancer patients who were assigned to the nurse-led intervention had small but positive effects in physical functioning and QoL. The authors also found that nurse-led care improved knowledge and mood as well as reduced stress levels. Whilst these results suggest that nurse-led psycho-educational strategies may improve patient care, the variation between interventions made it difficult to draw firm conclusions.

2.3.2 Nurse-led care and colorectal cancer

The search revealed three RCTs, which examined nurse-led interventions after surgery for colorectal cancer. In Beaver et al's (2012) study, comparisons were made between a nurse-led telephone intervention (physical and psychological assessment including bio measures) and usual care. The results showed no differences between groups in terms of time to detection of recurrence or resource usage. Furthermore, there were no differences in measures of anxiety and mental health. In the nurse-led intervention, it was reported that patients discussed their health concerns more frequently, conceivably linked to their increased satisfaction. A strength of this study was that the researcher analyst was blind to the study group allocation, perhaps reducing the potential of bias in

the treatment effect estimates. On the other hand, the nurse that delivered the usual care appointments also delivered the nurse-led telephone appointments. The nurse may have inadvertently contaminated the usual care group by applying the nurse-led intervention (Keogh Brown et al. 2007).

In Young et al's (2013) RCT, nurse-led telephone support (needs assessment relating to physical and psychosocial functioning) was compared with usual care. Colorectal cancer patients receiving the nurse-led intervention did not report any significant benefits regarding: unmet needs; experience of care coordination; unplanned readmissions; emergency department presentations; distress and QoL. However, in this particular study, unmet needs were consistently low in both groups. An RCT conducted with individuals with considerably more needs may report different findings.

In Strand et al's (2011) RCT, comparisons were made between nurse-led care (abdominal examinations, bio measures and x-rays) and surgical follow-up (same as nurse-led) after surgery for colorectal cancer. The authors found no differences between groups in terms of medical safety or patient satisfaction. Key strengths of this study were its randomised design and low attrition rate and that both groups indicated high patient satisfaction, highlighting the potential of nurse-led care. The authors acknowledged that the sample size was relatively small, making it difficult to detect any differences in aspects of medical safety.

2.3.3 Nurse-led care and prostate cancer

The search revealed three RCTs in relation to prostate cancer. In Helegeson et al's (2000) study, the authors compared a nurse-led telephone intervention (every six months or patient initiated contact) with usual care. The authors found no differences between groups in terms of: detection of recurrence; reporting of symptoms; psychological morbidity; patient satisfaction; resource utilisation and access to services. This study emphasised that for patients with prostate cancer, nurse-led care has the potential to make a demonstrable contribution to patient experience and safety. Whilst the authors reported on the numbers of those lost to follow-up, it was unclear if the characteristics of the remaining respondents differed from the original sample. This may have led

to attrition bias - overestimates of the effectiveness of the intervention (Dumville et al. 2006).

In Faithfull et al's (2001) prostate cancer research, a comparison was made between nurse-led telephone follow-up (initial clinical assessment, followed by point of need access) and usual care. The study showed that there were no differences in symptom scores between both groups. Moreover, men who received the nurse-led intervention were more satisfied with care and valued the continuity of the service. Finally, service costs were lower in the nurse-led group largely due to nurses being cheaper to employ than the clinicians. A caveat to these findings, however, was that the authors were unable to meet the sample size they had previously calculated, which might have had some impact on the interpretation of the findings. For example, one particular cancer centre, which had been expected to participate in the study, did not in the end enter respondents.

In Giesler et al's (2005) prostate cancer study, the authors compared a computer based, nurse-led telephone intervention (monthly educational support for six months) with usual care. Patients who were assigned to the nurse-led intervention had greater improvements in sexual outcomes, increased satisfaction with their care and less cancer related worries. Depending on the level of baseline depression, some respondents experienced less bother with urinary dysfunction. A particular strength of this study was its focus on individual care, perhaps relevant and useful for most cancer sites and other chronic diseases. However, the study had several limitations. Firstly, the accrual rates were not as high as previously anticipated, perhaps impacting on the research findings. Secondly, the sample of respondents was primarily Caucasian and relatively well educated, which may not be representative of the wider population.

In Devine and Westlake's (1995) meta - analyses of 116 RCTs, three studies involved prostate cancer. Patients were assigned to nurse-led interventions, for example, (home visits over three months - Benor et al. 1998) or (at home videotapes and books - Clotfelter 1999) or (self-selected audio tapes - Zimmerman et al. 1999) or usual care. The results showed that interventions of these types reduced pain intensity and increased knowledge in patients with

prostate cancer. Whilst this appears encouraging, conclusions drawn from this research must be tempered by worries about the methodological quality of some of the studies.

2.3.4 Nurse-led care and lung cancer

Follow-up models for lung cancer remain largely unknown. The search revealed one systematic review (Schmidt-Hansen et al. 2012), which compared various follow-up strategies for patients with lung cancer. Of the four included studies, three were observational and related to surveillance practices and were discussed in 2.2.4. The final study, an RCT, compared nurse-led follow-up (monthly assessment by telephone or in a nurse-led clinic) with GP follow-up. A key part of nurse-led care was to provide the patient with information and signpost to other services where necessary. Patients who were randomised to the nurse-led intervention had less severe symptoms, for example, dyspnoea and peripheral neuropathy and were more satisfied with their care. The authors also found no discernible differences in survival rates between the two groups, perhaps indicating the potential of nurse-led follow-up for patients with lung cancer (Moore et al. 2002).

2.3.5 Nurse-led care for cancer and other chronic diseases in the primary care setting

In the primary care context, relatively few studies have examined nurse-led interventions for survivorship care. However, there is a plethora of primary care based, nurse-led strategies for other chronic diseases, which seemed highly relevant in terms of follow-up cancer care. Individuals with chronic diseases seemed to concurrently share common symptoms (pain, fatigue, constipation, anorexia and depression) with people who have cancer, perhaps reflecting their universal illness pathways (Solano et al. 2006). Therefore, the decision was made to present both the available cancer studies and studies relating to other chronic diseases according to their quality and appropriateness to this thesis.

The search revealed one RCT in relation to nurse-led cancer care, and three systematic reviews concerning chronic disease. In Verschuur et al's (2009) RCT,

the authors compared nurse-led home visits with surgical follow-up in patients with oesophageal cancer. It was found that nurse-led home visits had small, but positive effects on mobility, usual activity, pain, anxiety, depression and satisfaction with care. The authors suggest that this type of intervention may be an alternative to usual care, which in turn may help to reduce waiting lists in hospital. A limitation of this study, however, was its small sample size, perhaps impacting on the estimates of the effectiveness of the intervention.

In Ram et al's (2004) systematic review of four RCTs pertaining to Chronic Obstructive Pulmonary Disease (COPD), the authors compared nurse-led care (hospital at home schemes) with inpatient care. The results showed no significant differences between groups in terms of rates of readmissions to hospital or mortality.

In Laurant et al's (2005) Cochrane review of 16 studies, the authors aimed to evaluate the impact of doctor-nurse substitution in primary care. In three of the 16 studies the nurse assumed responsibility for first contact and on-going care of all presenting undifferentiated patients. No significant differences were observed between clinicians and nurses in terms of patients' health status, objective measures or satisfaction with care. The findings suggest that nurses might be able to provide care for some patients with enduring conditions and in doing so may reduce clinicians' workloads. A limitation of this study, however, relates to nursing roles. For example, the literature review only considered nurse-led studies that were concerned with first contact or management of chronic conditions. It is suggested that nurses in their line of duty might provide a far wider range of care.

Recently, Keueth et al's (2013) Cochrane review compared nurse versus physician-led care for the management of asthma. Of the five RCTs that were identified, two studies related to nurse-led care and primary care follow-up. In Pilotto et al's (2004) study, the authors compared nurse-led asthma clinics (based in general practice) with usual medical care (GP follow-up, but not in the asthma clinics). The results showed that for patients who followed the nurse-led regime there were fewer absences from work and no differences in QoL or lung function. In Van Son et al's (2004) RCT, the researchers compared nurse-led care in primary care (review visits including spirometry, inhalation techniques,

training and psychosocial support) with usual care by the GP. Nurse-led care was found to improve patients' knowledge of asthma with no differences between groups in terms of lung function. The authors acknowledged that based on the evidence from these few studies; nurse-led care may have some potential as a strategy for patients with well-controlled asthma.

2.3.6 On-going nurse-led research

On-going research is now testing the effectiveness of nurse-led interventions for patients with cancer. In primary care, the PROSPECTIV pilot trial aims to compare a nurse-led psycho-educational intervention (telephone - tailored advice at different time points) with usual care in patients with prostate cancer. In this intervention, nurse-led support is key in terms of facilitating patients to self-manage aspects of their care. The outcome of interest is prostate-cancer-related QoL (Watson et al. 2014).

Currently, Jefford et al. (2013) reports on an on-going RCT for colorectal cancer, which aims to compare a SurvivorCare intervention (nurse-led care with educational materials and individualised care plan) with usual care. Outcomes of interest include psychological distress and unmet needs including QoL. The authors suggest that the SurvivorCare intervention may reduce patient suffering and burden on specialist services through engagement with primary care. The study aims to conclude in 2015.

2.3.7 Summary

On the basis of the evidence included in these systematic reviews, nurse-led interventions (telephone on demand; home care outreach programmes; doctor-nurse substitutions and nurse-led clinics) may offer benefits across a range of health domains. However, some of the studies identified in this research varied considerably in terms of their methodological rigour.

2.4 Professional and patient roles during cancer follow-up

2.4.1 Oncologists' roles in risk reduction and shared care

Traditionally, oncologists' roles have focussed primarily on cancer treatments and managing patients with established cancer (Zon et al. 2009). Key aspects of their role include surveillance for cancer recurrence and vigilance for the development of new cancers (Edgington and Morgan 2011). The European Society for Medical Oncology (ESMO) announced that oncologists were well positioned to reduce the incidence of cancer by avoiding an individual's exposure to risk factors (immunisation) and by detecting cancer at an early stage (screening) when treatment is more effective (Baselga and Senn 2008). Chlebowski et al. (1992) surveyed oncologists to assess their attitudes toward cancer prevention and early detection and found that they were already conducting risk reduction measures and expected to be routinely conducting screening and risk reduction/genetic counselling in their practices over the next few years.

The literature search identified a small number of studies, which focussed on oncologists' risk reduction practices in relation to lung cancer. In Warren et al's (2013) observational study it was found that oncologists do not provide smoking cessation advice to their patients because of pessimism and lack of confidence regarding their ability to encourage patients to stop smoking. In Lancaster's (2011) review of smoking cessation evidence, it was found that if doctors were provided with more support to signpost patients to other services, they might feel more inclined to deliver risk reduction strategies to patients.

It is now recognised that cancer patients are at risk for the development of comorbid conditions. These include diabetes, cardiovascular disease, osteoporosis, obesity, dyslipidaemia, menopause, decreased bone mass, hypertension, and hypothyroidism (Hamilton and Peters 2007; Edgington and Morgan 2011). The transition of a patient with cancer to a cancer survivor has been acknowledged as a 'teachable moment' when oncologists have an opportunity to advise patients of their increased risk of developing second primary cancers and comorbid conditions (Zon et al. 2009).

After completion of cancer treatments, cancer survivors often return to their GP for their care. For this transition to be optimal, GPs must be given information and management strategies to care for patients' treatment related problems (McCabe and Jacobs 2012). In the US, the Institute of Medicine (IOM) have recommended the introduction of individualised Survivorship Care Plans (SCPs) to be developed by the oncologist and shared with the patient and the GP (Earle 2006). Care plans often include information about: surveillance for recurrence; management strategies for physical and psychosocial issues; surveillance guidelines for new cancers and health promotion (McCabe and Jacobs 2012).

In Grunfeld et al's (2011) RCT of patients with breast cancer, the authors compared a comprehensive SCP (personalised treatment summary, the Canadian guidelines and supportive care resource) with a control (standard discharge visit and letter to the primary care physician - no SCP). Outcomes of interest were cancer related distress, patient satisfaction, health status and continuity of care. The researchers concluded that the standard discharge visit achieved similar findings as the comprehensive care plan.

The NCSI initiative has introduced the 'recovery package' a combination of strategies, which intends to improve coordination of cancer care and health outcomes in patients living with and beyond a cancer diagnosis (NCSI 2014). The treatment summary plan is to be developed by the oncologist and shared with the GP and their patient. Key to the treatment summary plan was information about symptoms and potential treatment related toxicities including late effects (NCSI 2013a). The treatment summary plan was evaluated into test communities across England and was generally well received in both specialist and primary care. 80% of GPs found the treatment summary useful and wanted it to continue. Oncologists found it helpful to concisely record cancer patients' care (Smith and Thompson 2014).

2.4.2 Nurse-led roles and improving the cancer experience

The 2007 Cancer Reform Strategy identified the importance of CNSs. Emphasis was placed on extending CNSs' roles to include: coordination of care; technical support; information provision; symptom management and emotional care (Department of Health 2007). Varied job titles and lack of role clarity pose

barriers to the integration of CNSs' roles (Raja-Jones 2002; La Sala et al. 2007; Kendall et al. 2010).

Extending nurses' roles and responsibilities to take on some functions of clinicians has been widely promoted in cancer care, largely because of the lack of medical staff, the need to improve service provision and to reduce costs. Nurse specialists as care coordinators were seen as potential solutions to these issues (Corner 2003). The nurse coordinator role has emerged in the last few years to improve patient satisfaction with service provision, facilitate access to services and decrease the length of hospital stays. Despite these potential benefits, the scope of their coordinating role remains relatively unclear (Nutt and Hungerford 2010).

In Sussman et al's (2006) prospective longitudinal cohort study, the authors investigated whether a community based specialist nurse influenced patients' supportive care needs. Key roles of the nurse specialist involved assessing needs and coordinating care to other services, for example, professional counselling. The findings indicated a reduction in patients' psychological and informational needs at four weeks, which continued at eight weeks. The need for physical support lessened and continued to improve over time. Interestingly, respondents also indicated that the nurse specialist was instrumental in helping them achieve their positive health outcomes. Given the limitations of the observational design, a RCT might be warranted to estimate more precisely the benefits of this particular nurse-led intervention.

Studies have also confirmed CNSs' roles as providers of information. In Koutsopoulou et al's (2010) critical review of diverse cancer diagnoses, the authors found that nurses provide information to patients about the management of their treatment related symptoms.

The following section emphasises nurse-led care in relation to the management of other long-term conditions. The focus on extending CNSs' roles to include chronic diseases other than cancer is not new. There is a wealth of research in domains such as respiratory health, diabetes and heart disease. In Caird et al's (2010) systematic review, the authors identified 32 systematic reviews of nurse-led studies, which involved other chronic conditions. Nurse-led care was found to be beneficial across a range of settings and health domains. The remaining

two studies involved breast and lung cancer. In Eicher et al's (2006) breast cancer review, the authors examined six RCTs, which found that nurse-led care improved anxiety, depression and coping, but not physical recovery or pain control. In Sola et al's (2004) lung cancer study, the authors identified nine RCTs relating to lung cancer, which found that non-invasive interventions delivered by specialist nurses improved psychological functioning and reduced breathlessness. The studies identified in Caird's review highlight the potential of nurse-led survivorship care. However, there was an overlap between systematic reviews, which meant that some reviews had included studies that were found in other studies, which may have had the potential for bias in terms of double counting.

2.4.3 On-going nurse-led research

A number of strategies outwith the field of cancer care are examining nurse-led coordinated care. In Arendts et al's (2014) on-going RCT, the authors aim to compare nurse-led care (multiple strategies - nurse/practitioner-led, care planning, clinical pathways, hospice care and family education) with usual care (discretion of the GP). Outcomes of interest are QoL and hospitalisation rates amongst people living in care homes. The nurse will coordinate care with the GP in a shared care arrangement. A particular strength of this study is that each of the multiple strategies used in the intervention have been previously proven to be clinically effective and beneficial in terms of QoL. It may be difficult, however, to identify which part of the intervention might be responsible for the outcome or effect. Despite this study relating to care homes and not directly to cancer care, the findings may enhance knowledge in this area considerably.

2.4.4 GPs' roles in survivorship care

As previously discussed survivors of cancer are likely to develop significant physical and psychological health problems often as a result of their disease and its treatments (Hewitt et al. 2006). Whilst GPs are currently involved in caring for cancer survivors, their role at present is unclear (Hamilton and Peters 2007). For GPs to provide optimal cancer care, however, there needs to be a change in emphasis to more proactive and structured care (Watson et al. 2011b). The NCSI

model, for example, intends to ensure that individuals living after a cancer diagnosis get the best available care and support they need to lead optimal lives. Part of the shift from traditional based care to primary care management is likely to include shared care and supported self-management. The following section outlines GPs' roles within a shared care approach, including patients' roles in supported self-management.

The search revealed one systematic review and two RCTs. In Lewis et al's (2009) systematic review of five RCTs, two studies involved GPs and shared care interventions. In Nielsen et al's (2003) study, the researchers compared a shared care strategy (comprehensive discharge summary as well as oncologists' expectations regarding GP input) with usual care (discharge summary with no formal guidelines). A central aspect of this study was active patient involvement. Patients, on receipt of the discharge summary letter were encouraged to contact their GP on demand. Patients found that the shared care intervention facilitated cooperation between oncologists and GPs. Indeed young patients in the intervention group were of the viewpoint that GPs were significantly more knowledgeable about their cancer. No differences were found between groups in terms of QoL. This study highlighted the potential of team working with involvement from patients. However, it also showed that oncologists and patients had specific roles, whereas GPs' roles seemed more reactive to patients' needs, rather than being a clear delineated role.

In Johansson et al's (2001) RCT, the authors compared intensified primary health care (nutritional and psychological support including education and supervision for GPs and home care nurses) with a control (no follow-up contacts to GPs or home care nurses). The results showed that older patients in the intervention group used fewer specialists' services and had reduced hospital admissions including days spent in hospital. The authors concluded that older patients' utilisation of specialist care may be lessened by intensified primary health care services.

Other research shows GPs' roles around management of symptoms. In Kousgaard et al's (2003) RCT, the authors aimed to compare GPs' assessment of a structured oncology information pack (discharge letter, available contacts, patient information about their cancer and treatments including potential side

effects) with a control group (standard discharge information). GPs in the intervention group had improved oncology knowledge, which enabled them to provide advice to patients about their symptoms. This in turn increased GPs' satisfaction with their role. The authors acknowledged, however, that there is a need for further research into the area of communication and cooperation between specialist and primary care.

Harrison et al. (2012) informed that patient discharge from hospital is a key time point in the cancer trajectory to receive input from primary care. In Rutherford and Burge's (2001) RCT, GPs conducted visits and telephone calls at the point of discharge. The intervention also included a discharge summary letter (patient diagnosis, individual management plans and educational materials about treatments). The findings showed no differences in patient satisfaction or confidence with GPs' supportive care. GPs valued this contact in terms of meeting patients' information needs.

The US, UK, Danish and Scandinavian studies inform of potential strategies to facilitate communication and supportive care practices between specialist and primary care as described in sections (2.4.1 and 2.4.4). Since 2004, Cancer Care Reviews have been introduced in primary care to improve communication and supportive care practices between GPs and their patients (Watson et al. 2011). The Quality and Outcomes Framework (QoF) stated that patients should receive a Cancer Care Review from their GP within six months of a cancer diagnosis. However, studies have indicated that Cancer Care Reviews have been conducted opportunistically and as a result of this patient experience has varied (Adams et al. 2011).

2.4.5 Patients' roles in supported self-management

Key to the NCSI shift in cancer survivorship is supported self-management. This emphasises that patients could actively participate in their recovery, rehabilitation or on-going survivorship care. Part of supported self-management involves initiatives to assist patients to overcome challenges associated with treatment related physical and psychosocial symptoms (NCSI 2013c).

The search revealed one literature review of RCTs. In McCorkle et al's (2011) review of 16 self-management interventions, two RCTs examined supported self-management strategies for survivorship care. In Stanton et al's (2005) breast cancer study, researchers compared psycho-educational interventions (a combination of print materials, workbooks, videos and sessions with a trained educator) with a control (National Cancer Institute print material). The results showed that fatigue and energy improved in those patients that received the intervention. Furthermore, the educational component of the intervention reduced cancer-specific distress.

In Cimprich et al's (2005) breast cancer research, the authors evaluated the Taking CHARGE self-management intervention, which aimed to facilitate patients' transition to survivorship after treatments. The study involved nurse-led group meetings and individualised telephone sessions. A particular focus of the study was to provide information and education to patients so that they may take on some aspects of their care. Patients randomly assigned to the Taking Charge intervention found the programme to be timely, relevant and useful in terms of dealing with physical and psychosocial issues after treatments. In order for supported self-management interventions to become a central part of survivorship care, however, patients must make decisions about the extent of their involvement in their care. Similarly, clinicians need to consider what level of involvement is appropriate for different people (Steurer-Stey et al. 2010; McIntosh and Shaw 2010). Some progress has been made in supporting patients to self-manage their care. However, few studies have addressed self-management interventions in follow-up cancer care, indicating a need for further research (McCorkle et al. 2011).

2.5 Chapter summary

This chapter has dealt with the literature on cancer care follow-up. This literature search is aimed at providing context for the experiences and perspectives of oncologists, CNSs and GPs. The literature asserts that GP follow-up for patients with breast cancer does not reduce QoL or contribute to increased recurrence related events or anxiety. Conversely, there are survival advantages for colorectal patients to attend specialist care regularly. Although

primary care currently manages some patients with prostate cancer, barriers persist to optimal practice. More research is needed around surveillance practices for patients with lung cancer.

Examination of the literature regarding professional roles show that oncologists' deliver cancer treatments and monitor for cancer recurrence including new cancers. Oncologists seem well placed to drive forward risk assessment advice, but may lack the necessary support to signpost patients to the appropriate services. The IOM recognises oncologists' roles in terms of delivering care plans to primary care.

Nurse-led models in various settings involve a number of interventions and have been shown to improve physical and psychological functioning. These consist of: telephone on demand; home care outreach programmes; doctor-nurse substitutions and nurse-led clinics. CNSs/nurses also show their potential as coordinators of care and providers of information including education.

GPs are well placed in terms of caring for cancer patients' physical and psychosocial needs, yet their role is unclear. For GPs to provide optimal cancer care, however, there needs to be a focus on structured care. Care plans, for example, provide information to GPs about surveillance practices and management of patients' treatment related symptoms. However, more research is needed regarding their specific benefits. Treatment summaries are considered useful by oncologists and GPs. Cancer Care Reviews assist GPs to engage with their patients.

A central tenet of the NCSI model is supported self-management. This model encourages patients to participate in their survivorship care. Examination of the literature regarding supported self-management informs that psycho-educational strategies, for example, may reduce fatigue and increase energy in cancer patients. Furthermore, nurse-led group meetings may assist and support patients to deal with their treatment related physical and psychosocial issues.

3. Aim and research objectives

3.1 Aim

The overall aim of this study is to explore the appropriate balance of care for cancer patients between specialist and primary care.

3.2 Research objectives

- To explore oncologists', CNSs' and GPs' perceptions about patients' physical, psychological and social needs and how these might be applied to future models of care
- To describe oncologists', CNSs' and GPs' perceptions in relation to professional roles and cancer care follow-up
- To illustrate oncologists', CNSs' and GPs' viewpoints regarding communication practices and how these could be enhanced
- To explore oncologists', CNSs' and GPs' viewpoints about the ways in which the role of primary care could be optimised.

4. Methodological perspectives

4.1 Introduction

The first section of this methods chapter discusses the key philosophical issues in the context of this research. This is then followed by the rationale for the research and the studentship plan. Next the research design and process is described, which includes the sample, the fieldwork materials, the interview process and finally analysis.

4.2 Theoretical perspectives in the context of this research

Van Krieken et al. (2000) described ontology as the beginning of all research after which epistemological and methodological positions follow. Ontological perspectives are assumptions about the nature of reality; they are perspectives about what really exists in the world. Ontology is often described in terms of objects, whether concrete or abstract, existent or non-existent, independent or dependent. Ontology can be made up of units, which make up reality, for example, relations, dependencies and predictions. What we see often depends on what we have experienced. Whilst a sociologist and a psychologist, for example, might observe a similar phenomenon, the former may focus on social reality and the latter on interpersonal differences. Within the ontological perspective there are two different streams of thought, these are objectivism and constructionism. It is important for researchers to be clear about their theoretical assumptions prior to the design and data analysis stages of a research project (Bowling 1999).

4.2.1 Objectivism and constructionism

Objectivism is an ontological position, which suggests that social reality exists without outside influence/s. Objectivism usually refers to a reality, which is measurable, often seen as the foundation for scientific work (Van Krieken et al. 2000). Constructivism theory argues that there are multiple perceptions of reality, whereby social phenomena are produced by social interactions and are forever changing (Van Krieken et al. 2000). Ontological positions underlying

health care, for example, are likely to be different, which could impact on the way that health professionals organise and conduct their working practice (Hansen 2006).

4.2.2 Epistemology, positivism and interpretivism

Epistemology is concerned with the theory of knowledge with respect to methods, validation and the ways of gaining information from individuals and groups about their social realities. Epistemology relates to what researchers essentially claim about what is assumed to exist and how it can be shown (Van Krieken et al. 2000). There are two broad epistemological positions - positivism and interpretivism (Bowling 1999). In the positivist approach, the researcher is independent from the research participants. Usually, values and biases are held in check whilst objectivity is strived for. Knowledge is obtained using a deductive process and the emphasis is on discrete, specific concepts (Mason 2005). Researchers who work from the positivist stance explain in quantitative terms how social realities interact and cause specific outcomes (Lincoln and Guba 2000).

Conversely, the interpretivist paradigm involves the researcher interacting with the research participants and the findings are the result of that interactive process. The idea of emerging subjectivity and values are sought. Knowledge is obtained using an inductive process and the focus is on gleaning narrative information through participant experiences, often a central tenet of qualitative research (Abercrombie et al. 2000; Van Krieken et al. 2000; Ritchie and Lewis 2008). Whilst objectivity may be possible in the positivist approach, objectivity is strived for in the interpretivist paradigm, usually through the use of reflexive techniques. Furthermore, the positivist paradigm seeks generalisations, whilst the interpretivist approach seeks transferability across research settings (Ritchie and Lewis 2008).

4.2.3 Approaches to health and social care research

The terms quantitative and qualitative describe groups of methods commonly used in research practice. The quantitative approach is based on positivism, whereby the researcher aims to study behavior under controlled conditions in

order to isolate the effect and strength of single variables (Hansen 2006). Usually this type of method is numerical in nature and can involve large groups of individuals (Van Krieken et al. 2000). Qualitative research, on the other hand, is characterised by its aims, which relate to understanding peoples' social reality and its methods, which come in the form of words rather than numbers (Mason 2005). Both positivist (quantitative) and interpretive (qualitative) researchers hold the viewpoint that human actions and behaviors may be patterned and regular. Whilst positivists see this in terms of cause and effect, interpretivists identify such patterns around evolving belief systems that individuals generate as they socially interact with others (Neuman 2003). From its inception, this study focussed on understanding the belief systems and experiences of oncologists, CNSs and GPs in relation to cancer care follow-up (Merriam 1998). Therefore, this required a qualitative approach in order to generate a detailed description of health professionals' beliefs and perspectives in terms of: patients' physical and psychosocial needs; professional roles; communication practices and ways in which the role of primary care might be optimised.

Some research studies use more than one approach. Mixed methods research, for example, is commonly understood to include both quantitative and qualitative approaches within a single study. Researchers who use mixed methods often work from an objective (quantitative) or subjective (qualitative) perspective, which guide the data collection and analysis procedures (Tashakkori and Teddlie 2003). Mixed methods research can be characterised by the collection of quantitative evidence (surveys and diagnostic tests) or qualitative evidence (observations and interviews). The mixed method approach has the potential to provide a better understanding of research problems and complex phenomenon, rather than one approach alone (Creswell and Plano Clark 2010). In this study, interviews aimed to provide depth to the research inquiry, whilst the case note audit and the patient survey intended to provide breadth to the research, therefore, providing information about different aspects of survivorship care. The challenges with respect to using the mixed methods approach for this thesis are described in section 4.4.1.

4.2.4 Traditions of qualitative research

Qualitative research has developed over the years and a number of different schools of thought have emerged. Most notable are ethnography, phenomenology and grounded theory (Ritchie and Lewis 2008). Ethnography studies social interactions between individuals and groups of people. It sets out to describe peoples' perceptions, actions, sights and sounds and the location they inhabit through the collection of data, using methods such as in-depth interviews and observations. It is often customary and necessary for ethnographers to have repeated access to respondents so that time can be spent in the research field (Reeves et al. 2008). Using ethnography as a methodology for this thesis seemed problematic. Following ethnographic research in its truest sense may have meant that the student would have had to shadow consultants for months in follow-up clinics, which may not have been practical. Furthermore, ethnographic research may have had ethical consequences in terms of informed consent. For example, researchers can become deeply integrated into the research setting. Friendships are formed, which may blur the boundaries between the researcher and respondents. Participants may disclose information that they do not recognise as pertinent to the research but which the researcher considers to be so. Indeed, this raises questions about the extent of prior consent and if this justifies the use of such acknowledgements as data (Murphy and Dingwall 2007).

Phenomenology, on the other hand, is about understanding the constructs that people make in their everyday lives. Researchers who use the phenomenological approach study social reality from the viewpoint of the experiencing person (Ritchie and Lewis 2008). Data collection usually involves approaches such as semi-structured and in depth interviews including focus groups (Hansen 2006). A particular strength of this approach is its effectiveness in bringing to the fore perceptions of individuals (Lester 1999). Whilst the student could have explored the patient's lived experience regarding their survivorship care, the aim of this this thesis was to understand professionals' perceptions about the balance of cancer care between oncologists, CNSs and GPs.

Glaser and Strauss (1967) introduced grounded theory as a formal methodology in their book *'The Discovery of Grounded Theory'* (Goulding 1999). Grounded theory methods comprise an entire approach to collecting and analysing qualitative data with the goal of developing theories that are grounded in real life experiences (Mason 2005). This is achieved through simultaneous data collection, as well as comparative analysis of the data (Hansen 2006). A key element of pure grounded theory is the notion that the researcher should have no preconceived ideas prior to the research and would essentially remain a passive actor, therefore, allowing theories to emerge naturally grounded in the data (Jones and Alony 2011). Much has been made of Glaser and Strauss's claim that the researcher in traditional grounded theory should be able to enter the field of research as a blank slate, therefore, facilitating the development of emerging theories legitimately. It is argued, however, that a researcher might find it difficult to conduct field research as an empty vessel. The literature suggests that a researcher who is sensitive to emerging theory is more likely to be able to immerse themselves in the data (Barbour 2000; Heath and Cowley 2004; Mills et al. 2006).

In the 1990s, Strauss joined Corbin to take grounded theory to a new level, for example, acknowledging the importance of preconceived ideas and semi-structured questions (Jones and Alony 2011). More recently, however, Charmaz (2006) described grounded theory in terms of an interpretive approach towards research design, suggesting that grounded theory should now acknowledge the role of the researcher and be more relaxed in structure (Allen 2010). Charmaz was of the opinion that researchers need to position themselves as co-producers of the research; there is a need to delve beyond the surface in order to understand participants' values beliefs and ideologies (Mills et al. 2006). Whilst grounded theory is relatively popular with qualitative researchers as a method for collecting and analysing data (Chiovitti and Piran 2002), it is not without its critics. Bryant (2002) cautioned that whilst grounded theory can be used as a constructivist and interpretivist analytical tool, essentially it is derived from positivism and objectivism, which are commonly associated with quantitative research. Glaser (2005) argued that grounded theory is indeed intended for different paradigms and that researchers should use grounded theory within the context of their own research.

Diverging concepts around the grounded theory approach have created confusion for qualitative researchers (Greckhamer and Koro-Ljungberg 2005). Consequently, different versions of grounded theory have emerged to meet research needs. Common elements from the original version of grounded theory include theoretical sensitivity, sampling, constant comparative method and theoretical memos (Bulawa 2014). Whilst this thesis has been informed by grounded theory, it is not grounded theory. This work draws on an adaptation of grounded theory, for example, constant comparison. Concepts and categories were iteratively compared and fed back into the data in order to identify patterns, similarities, variations and emergent theory (Cooper et al. 2009).

4.3 Placing this study in context of other research

Previously, it was identified that cancer policy had called for a reform of cancer services to improve health outcomes and reduce inequalities. Consequently, cancer services have evolved through reconfiguration of facilities and personnel. The survivorship literature shows that clinical practice has largely focussed on treatment and on-going surveillance for the management of cancer. Yet, cancer services have now become unsustainable, particularly for patients in the survivorship phase. Other research around survivorship care shows that cancer survivors have significant physical and psychosocial needs, which were not always met. Whilst health professionals appeared critical to the delivery of follow-up care, the question of responsibility for the care of cancer patients remains unclear. Therefore, the perspectives of oncologists, CNSs and GPs would be useful and new. The most appropriate method to draw on these experiences was the qualitative approach.

4.4 Summaries of the studentship plan

The purpose of this studentship was to explore the appropriate balance of cancer care between specialist and primary care as perceived by health professionals. The initial plan was to conduct a mixed-method study, which involved a retrospective review of case notes and qualitative interviews including a patient survey. The case note review intended to identify the content and timeliness of letters between the Beatson West of Scotland Cancer Centre (BWoSCC) and primary care in relation to diagnosis, type of treatment

and psychosocial issues. The qualitative aspect aimed to explore professionals' viewpoints regarding their current practices and roles as well as models of care and ways in which the role of primary care could be optimised (reported in this thesis). The aim of the third study was to conduct a patient survey at the BWoSCC, in particular, investigating patients' viewpoints regarding management of their care from diagnosis to follow-up.

4.4.1 Rationale for not including the quantitative studies

The rationale for not including the case note review and the patient survey related to timeliness and ethical issues. Whilst the data collection phase for the case note review was completed according to schedule, recruiting respondents for the qualitative study took considerable time. Additionally, appreciable time was spent travelling to hospitals and GP practices across Scotland. The amount of qualitative data generated and the time taken to conduct high quality analysis meant that the analysis phase of the case note review slipped.

Recruitment restrictions outlined by the ethics committee meant that the student was not permitted to distribute the patient survey and had to rely on the clinic nurses at the BWoSCC to do this. However, questionnaires were not being distributed to patients consistently; rather they were given out occasionally. Furthermore, other patient related trials were being carried out at the BWoSCC and there was the perception that patients would get confused between these. This reduced the feasibility of recruiting patients for the patient survey. Indeed the student hadn't anticipated the other trials and couldn't compete with these. These factors impacted on the response rate. In the four months of the study, only 150 responses were obtained (the target had been 500). As a result of these issues, the student and supervisor made the decision to halt the questionnaire study and concentrate on the qualitative analysis.

4.4.2 Weaknesses and strengths of excluding the quantitative studies

The decision to exclude the quantitative studies in this thesis resulted in a number of weaknesses and strengths. Excluding the case note review may have hindered understanding and knowledge about the content of letters between specialist and primary care. Moreover, the patient survey may have provided insight into the patient's experience of cancer care follow-up, rather than just relying on health professionals' perspectives. The quantitative studies may have provided stronger evidence for a conclusion, through convergence and corroboration of findings (Burke et al. 2004). Despite the disadvantages of not using the mixed method approach, the student was able to spend considerable time immersed in the data during the analysis phase.

4.5 Methodological design and process considerations

This section of the thesis presents the research design and the process used in sampling and data collection including analysis. The chapter concludes with a discussion on ethical considerations.

4.5.1 Sampling design

It is a general feature of social research to design and select samples for a study. When sampling strategies for research are discussed, a distinction is usually made between probability and non-probability samples. Probability sampling is often associated with quantitative research and involves randomly selecting units as a way to draw statistical robust generalisations from the sample to the population (Ritchie and Lewis 2008). Probability or random sampling is generally used for RCTs and is often considered the gold standard for research in terms of judging the effectiveness of an intervention (Barton 2000).

Non-probability sampling consistent with qualitative research does not involve randomisation. Respondents are selected based on their accessibility to the researcher or because of particular features or characteristics, which allow the researcher to study the phenomenon in greater detail (Mason 2005). Non-probability sampling does not intend to be statistically representative or

estimate effect; rather the focus is on its transferability to other settings (Ritchie and Lewis 2008). Whilst the student appreciated that probability sampling is the preferred method for sampling in statistical research, as a rule it is inappropriate for qualitative research (Ritchie and Lewis 2008). Justification for using the non-probability sampling method was based on the need to explore health professionals' opinions about survivorship care, rather than attempt to make statistical inferences about the sample being studied. Additionally, these groups of health professionals were likely to have expertise in different cancers and therefore, different perspectives.

There were a number of non-probability sampling strategies that the student could have used. Convenience methods, for example, entail sampling the most convenient or accessible individuals. These methods are considered inexpensive and advantageous in terms of time and effort (Marshall and Rossman 1999).

Snowball sampling, an example of convenience sampling, requires that respondents refer to other participants who might meet the study's eligibility criteria. This type of sampling is often used in research where individuals have specific traits or who are difficult to identify (Hansen 2006). Convenience sampling did not seem an appropriate strategy for this thesis for a number of reasons. Firstly, the student was concerned about convenience sampling in terms of under-representation or over-representation of cancer types and or cancer centres. Secondly, the type of sample chosen may have been atypical to that of the population (Marshall 1996; Marshall and Rossman 1999) and may have led to bias and poor data quality. Finally, convenience sampling seemed risky, as this method does not allow the researcher to have any control over the typicality of the sample (Van Krieken 2000).

Theoretical sampling and purposive sampling are often considered similar, but with some important distinctions. In theoretical sampling, sampling is generally not determined before, but is directed by emerging theory, often considered the hallmark of pure grounded theory methodology (Draucker et al. 2007). The researcher seeks out respondents in order to collect, code and analyse data iteratively with the goal of generating theory, which is then fed back into the data (Silverman 2010). Further, individuals may be sought out in order to

confirm the previous findings or to generate further theory (Goulding 1999). This process is continued until the researcher reaches a point where no new insights are obtained (Ritchie and Lewis 2008).

Purposive sampling is generally decided beforehand and the researcher may select respondents based on specific criteria, for example, type of knowledge, uniqueness or transferability (Ritchie and Lewis 2008). Some authors argue that theoretical sampling does initially involve purposeful selection of respondents. After this phase, however, it is then termed theoretical because emerging theory controls it. Justification for using the purposive sampling method was based on the student's need to encapsulate a range of perceptions, similarities and differences as experienced by oncologists, CNSs and GPs in survivorship care. Additionally, the intention was to generate meaningful and diverse data in order to facilitate constant comparative analysis, which would then translate to the research findings.

In purposive sampling, there are no firmly established criteria for sample size. Sample size is largely judged by the aim, rationale and the informational needs of the research (Marshall 1996; Bowling 1999). Additionally, judging the size of a purposive sample should be determined by data saturation, for example, sampling until no new information emerges (Hansen 2006). In general, sample sizes should not be too large so that it becomes challenging to extract data from the research. Conversely, the sample size should not be too small so that it is difficult to achieve saturation (Onwuegbuzie and Leech 2007). This research aimed to recruit 60 respondents, 20 each from oncologists, CNSs and GPs.

4.5.2 Sampling process – settings and sampling frames

The first stage in the sampling process was to purposively select the specialist cancer centres in Scotland. These were the BWoSCC in Glasgow and the Edinburgh Cancer Centre including the Ninewells hospital in Dundee and the Aberdeen Royal Infirmary. These particular cancer centres were included because they were the main cancer treatment centres and hubs for cancer units to feed into. These sites were also chosen because of their potential usefulness in this context to generate data.

It made sense to commence sampling at the BWoSCC as it offered oncology services to large sectors of the population both within and out with Glasgow. The site was also geographically accessible and the student was familiar with the oncology department having previously conducted a case note review there. Furthermore, the then Clinical Director of Medical Oncology at the BWoSCC was also the student's co-supervisor and provided the student with the sampling frames of oncologists and CNSs currently employed at the BWoSCC including the names of the clinical and nurse leads at the remaining cancer centres.

The student then aimed to retrieve the sampling frames from the clinical and nurse leads at cancer centres out with Glasgow. In the first instance, the student mailed the Expression of Interest Form (Appendix 4) to the relevant leads. This form outlined the purpose of the research and requested their interest in participation in the research. If interested, the leads usually contacted the student by telephone or email to discuss the study and if appropriate, provide the student with a list of potential participants. If the leads did not respond to the Expression of Interest Form, the student followed through with a telephone call or email message two weeks after the initial mail out.

General practices were identified through the Scottish and Primary Care Research Network (SPCRN) at the University of Glasgow. There were 271 general practices located within NHS Greater Glasgow and Clyde, 124 in NHS Lothian and 57 in NHS Forth Valley (University of Glasgow 2011). These particular health boards were selected because they had diverse characteristics, in particular, varied socio-economic differences. Furthermore, the student confined the number of health boards to three because of time and resource constraints set by the research project.

The Carstairs DepCat Scores³ were used to locate the most affluent and deprived practices (McLoone 2004). The SPCRN database was also used to identify

³ Carstairs Depcat scores measure socioeconomic deprivation or affluence according to material disadvantage. These are measured by variables, which include: unemployment, lack of car ownership, overcrowded housing and the household being in social class IV or V. Depcat 1 is the most affluent while Depcat 7 is the most deprived. McLoone, P. (2004) Carstairs scores for Scottish postcode sectors from the 2001 Census Glasgow, Public Health Research Unit, University of Glasgow.

practices if they were fairly large (greater than five GPs per practice) and of a similar size. The intention was to choose practices with the most GPs in order to maximise the possibility that each GP might see at least seven new cancer patients in one year. This breaks down to an average of one case each of breast, lung, bowel and prostate cancer including an average of three cancers of different types (Cancer Research UK 2012c). The sampling frame were GPs employed in these particular general practices.

4.5.3 Sampling process - participant inclusion

Having decided on the settings for the study as well as obtaining the sampling frames of oncologists, CNSs and GPs, the next step in the process was to decide which respondents were suitable to be included in the study. Oncologists, for example, were purposively sampled based on the need to ensure that the sample included those who looked after patients with the main cancers (breast, lung, bowel and prostate). It was acknowledged by the student that it was not possible or needed to sample all the oncologists with an interest in all cancer sites. CNSs were chosen based on their area of expertise - breast, lung, bowel and prostate and because they worked alongside oncologists at the major cancer centres. There were 26 oncologists and 23 CNSs who were potentially available to be included in the study.

GPs were selected from the general practice community in which they worked. Of particular importance was the need to include GPs with a specific interest in cancer. The student considered that these GPs might be able to provide additional insight regarding cancer care in primary care practice. Overall, there were 18 GP practices with approximately five to ten GPs per practice who were potentially eligible to participate in the research. Of these 18 GP practices, three GPs had a special interest in cancer.

4.5.4 Sampling process – recruitment of oncologists, CNSs and GPs

The first step in the recruitment process was to enlist eligible oncologists and CNSs from the BWoSCC. Although the student had secured the sampling frame from the Clinical Director, this did not confirm their participation in the research. To address this issue, it was planned that the student would attend the In-House Trials Advisory Board (IHTAB) meeting at the BWoSCC, with the aim of introducing the research to the oncologists and CNSs. After this meeting, eligible oncologists and CNSs were mailed the Expression of Interest Form. If professionals did not reply to the form, the student approached potential participants by telephone or email two weeks after the initial mail shot.

Next eligible oncologists and CNSs were purposively recruited from cancer centres out with Glasgow. This involved mailing the Expression of Interest Form to oncologists and CNSs. If respondents showed an interest in the research, they usually contacted the student electronically or by telephone. If professionals did not respond to this form, the student contacted potential participants by telephone or email two weeks after the initial mail shot.

Eligible GPs were contacted by approaching the practice manager at each general practice with copies of the Expression of Interest Form. After one week, the student contacted each practice and enquired if any GPs had agreed to participate in the study.

When the student was in receipt of the Expression of Interest Form, eligible oncologists and CNSs were sent information packs via the conventional mail shot or email. GP information packs were hand delivered to the practice manager. The pack consisted of a Covering Letter (Appendix 5A, 5B, 5C) and an Information Sheet (Appendix 6A, 6B, 6C) outlining the purpose of the project. The pack also included a Form for Reply document (Appendix 7) with a pre-paid envelope, which identified respondents' availability for contact.

Respondents who agreed to participate in the study returned the reply form in the pre-paid envelope using the conventional mail shot or by electronic means to

General Practice and Primary Care at the University of Glasgow. During the recruitment phase, six oncologists were unable to be contacted, three declined because they were unavailable at the time of the research and one was available but declined at the last minute due to work commitments. Of the CNSs, three had work commitments and two were on secondment out with Scotland. The remaining two CNSs were unavailable for contact. At the end of the recruitment phase, the student had recruited 16 oncologists and 15 CNSs. After completion of the GP recruitment, the student had recruited nine GPs. Tables three; four and five show the characteristics of the sample of oncologists, CNSs and GPs.

Table three: characteristics of the oncologists included in the study

Oncologists	Sex	DISCIPLINE	CANCER CENTRE	TIME IN POST (Years)
Spec 01	F	Lung	Beatson, Glasgow	6
Spec 02	M	Prostate	Beatson, Glasgow	6
Spec 03	M	Breast	Beatson, Glasgow	25
Spec 04	M	Gynaecological	Beatson, Glasgow	30
Spec 05	M	Prostate	Beatson, Glasgow	20
Spec 06	F	Colorectal	Beatson, Glasgow	Unknown
Spec 07	M	Lung	WGH, Edinburgh	9
Spec 08	F	Lung	WGH, Edinburgh	7
Spec 09	F	Oesophageal	WGH, Edinburgh	4
Spec 10	F	Colorectal	WGH, Edinburgh	5
Spec 11	M	Breast	WGH, Edinburgh	6
Spec 12	M	Head and Neck	Ninewells, Dundee	6
Spec 13	M	Breast, Upper GI	Ninewells, Dundee	25
Spec 14	M	Urology, Lung	ARI, Aberdeen	20
Spec 15	M	Prostate	ARI, Aberdeen	20
Spec 16	M	Head, Neck	ARI, Aberdeen	5

Table four: characteristics of the CNSs included in the study

CNSs	Sex	DISCIPLINE	CANCER CENTRE	TIME IN POST (Years)
CNS 01	F	Gynaecological	Beatson, Glasgow	20
CNS 02	F	Haematology, Breast	Beatson, Glasgow	15
CNS 03	M	Urology	Beatson, Glasgow	7
CNS 04	F	Clinical trials	Beatson, Glasgow	4
CNS 05	F	Head, Neck	WGH, Edinburgh	25
CNS 06	F	Oesophageal	WGH, Edinburgh	5
CNS 07	F	Breast	WGH, Edinburgh	4
CNS 08	F	Lung	WGH, Edinburgh	8
CNS 09	F	Colorectal	Ninewells, Dundee	7
CNS 10	F	Breast	Ninewells, Dundee	15
CNS 11	F	Urology	Ninewells, Dundee	10
CNS 12	F	Prostate	Ninewells, Dundee	12
CNS 13	F	Head, Neck	Beatson, Glasgow	7
CNS 14	F	Breast, Colorectal	ARI, Aberdeen	15
CNS 15	F	Neuro-oncology	ARI, Aberdeen	Unknown

Table five: characteristics of GPs included in the study

GP Respondent	Sex	AGE	Health Board	Approx. Practice size ⁴	Time in post (Years)	DEPCAT Score of practice ⁵
GP 01	M	45-55	Glasgow	1,614	20	7
GP 02	M	45-55	Glasgow	6,600	23	2
GP 03	M	35-45	Glasgow	5,909	17	7
GP 04 Cancer interest	M	40-50	Forth Valley	4,564	20	2
GP 05 Cancer interest	M	55-65	Forth Valley	No affiliated practice	25	-
GP 06 Cancer interest	M	40-50	(Lothian Unscheduled Care Service)	Not practice 840,000	15	1-7
GP 07	F	30-40	Edinburgh	5,270	8	5
GP 08	M	40-50	Glasgow	4,044	14	5
GP 09	M	45-55	Glasgow	6,004	15	7

4.5.5 Reflections about the sample size

Recruiting oncologists' and CNSs' respondents was achieved with relative ease. The Clinical Director at the BWoSCC and the clinical and nurse leads out with Glasgow facilitated this process. GP recruitment proved more difficult largely due to their working schedules. This meant that GPs had less time to participate in this research. By this time, however, the student had gathered 40 interviews, which is a large qualitative study. Therefore, the student and supervisor judged this to be an opportune time to complete the recruitment process. If it had been necessary - during the analysis phase, for example, the student would have done extra mail outs going past the research network.

4.5.6 Data generation - design

The main methods of data generation in qualitative research are observational studies, focus groups and interviews. In observational studies, the researcher

⁴ ISD Scotland (2011) GP practice populations [Internet], Available from: <http://www.isdscotland.org>

⁵ McLoone, P. (2004) Carstairs scores for Scottish postcode sectors from the 2001 census [Internet], Available from: <http://www.mrc.ac.uk>

collects data through observation of a group or setting (Bowling 1999). Simply observing oncologists, CNSs and GPs in their research setting did not seem an appropriate method for this research because the student wished to attain a full explanation from respondents about their perceptions and experiences regarding cancer care.

Focus groups capitalise on communication between individuals, particularly in a group setting. If a group works well, trust develops and the group can explore solutions to particular issues (Kitsinger 1995). Whilst it would have been advantageous to organise a focus group involving oncologists, CNSs and GPs, practically this may have proved difficult. Furthermore, preformed relationships between colleagues might have impacted on what they said during the focus group and therefore influenced research findings. Finally, the student was worried that some people may dominate the focus group, which may have controlled the theme of the discussion (Hansen 2006).

Interviewing can include three main approaches, for example, unstructured, semi-structured and structured approaches. The unstructured interview has particular advantages in that it allows complete freedom in terms of structure, content, wording and order (Kumar 2014). The questions are not pre-determined; rather they rely on the social interaction between the researcher and the respondent (Minichiello et al. 1990). Whilst unstructured interviewing seemed plausible in terms of its ability to highlight new concepts and themes, its lack of structure, may have made it difficult for the student to discuss specific aspects of survivorship.

In a structured interview, the researcher asks a set of pre-determined questions using the same wording as specified in an interview schedule. Questions are often open-ended or closed and are thoroughly pre-tested and evaluated (Kumar 2014). A key advantage of this type of interviewing is that it provides uniform information, however, the strict format of the questions makes it difficult to explore complex issues (Hansen 2006). This type of interviewing seemed more useful with surveys, rather than qualitative research (Lichtman 2010).

The semi-structured method of interviewing appeared to be the most helpful method for this thesis. This method allows new ideas and concepts to emerge

(flexibility) during the interview as well as incorporating the student's need to focus on specific aspects of survivorship care (structure). Therefore, the interview process in this study followed a semi-structured approach.

4.5.7 Data generation process – topic guide

Central to the design of the semi-structured interview was the topic guide, which was not a priori because it was not created or derived independent of experience. Rather, the topic guide emerged as a result of knowledge based on facts from the survivorship literature including experiences from the student's supervisors.

The topic guide was designed in three sections. The first section gave a brief statement about the aim and objectives of the research. Next, participants' perceptions were sought about historical follow-up practices and factors influencing change. Respondents were then questioned about their reasons for conducting survivorship care including the barriers they thought might impede optimal practice. The middle section explored health professionals' opinions regarding patients' needs including the extent to which these needs were met. Asking participants about professional roles in relation to survivorship care led to discussions about communication practices across the interface. The final section focussed on respondents' perceptions about models of care and the role of primary care in survivorship. The student had intended to follow the topic guide as discrete sections. However, the diversity and speciality of the individual oncologists, CNSs and GPs meant that new topics of interest emerged out with the topic guide. The topic guides can be viewed in Appendices 8 A, B and C.

A pilot study was conducted with two GPs who were recruited from the University of Glasgow. The purpose of this exercise was to test the clarity and correctness of the topic guide. After suggestions from the GPs, changes were made to the topic guide.

4.5.8 Data generation process - interviews

Interviews with oncologists CNSs and GPs were carried out during 2008 to 2009. Individual interviews were conducted in a private room within the hospital or

general practice. At the start of the interview, the student asked each respondent if they had received a copy of the information sheet and if they were aware of the aim of the research. Participants were then asked if they had any questions regarding the study. Next, the student produced the consent form - described in Appendices 9 A, B and C, which was relevant to his or her individual status. If agreeable, the consent form was signed and dated by each oncologist, CNS or GP and witnessed by the student. All interviews were recorded onto an Olympus digital recorder. The student then assigned each recording with a coded number. A professional transcriber then transcribed the audiotapes with the coded number verbatim.

The intention of this study was to conduct 15-20 interviews with each group of professionals; however, interviews with oncologists, CNSs and GPs were completed at 16,15 and nine respectively. This was because the themes and categories in the interviews became repetitive and did not reveal any new perceptions or insights. The student and the supervisor felt that a broad and diverse sample had been collected from oncologists, CNSs and GPs. This was also supported by recurring codes and categories in NVivo, the qualitative software package.

4.5.9 Data generation process - field notes

Observational and theoretical field notes were recorded during the course of each interview. Observational notes, for example, described the date and time of the interview, including the demographics of each participant and their specialism. Additionally, the student used the Gibbs reflective model (Burns and Bulman 2000) to describe personal feelings about how the interview progressed and what could be improved prior to the next interview. Field notes were taken on all the interviews and interpretive attempts were made to attach meaning to the more common and different responses. Field notes were used in the analysis phase to assist the student's understanding and interpretation of the data.

Generally, each interview lasted from 25 minutes to 60 minutes with the average being approximately 35 minutes. One interview was considerably shorter because the oncologist had an emergency request to attend to a sick patient.

4.5.10 Reflections on the methodological design and process

4.5.10.1 Temporal ordering of the interviews

Interviews were completed consecutively starting at the BWoSCC in Glasgow and finishing at the Aberdeen Cancer Centre. Pragmatically, it was thought useful to organise the interviews this way because of time and cost issues. The clinical lead in Aberdeen, however, requested that interviews be conducted over the course of one day. The opportunistic nature of this request meant that the student could conduct multiple interviews over a relatively short time period. However, this experience proved both challenging and tiring and may have impacted on the quality of the final interviews.

GP interviews both within and out with Glasgow were organised according to GP availability. This meant that the student often conducted interviews at varying geographical locations in order to achieve the required number of interviews.

4.5.10.2 Rationale for not interviewing surgeons and patients and how the studentship plan constrained this idea

Surgical intervention is often one of the main treatments for cancer. Indeed many surgical teams work alongside oncologists in the care of cancer patients; however, their role is largely concerned with surgical intervention, rather than survivorship. Furthermore, interviewing surgeons may have made for a very large sample and as a consequence of this, the student may have had to narrow down the number of types of oncologists and CNSs. Importantly, the emphasis in this thesis was on follow-up cancer care; therefore, information about adjuvant therapy, for example, may not have been a significant part of the surgeons remit.

The rationale for not interviewing patients was based on the aim and objectives of this research. The intention was to explore professionals' perceptions about the balance of cancer care between specialists and primary care. Not conducting the patient survey or utilising interviews to explore patients' experiences about survivorship constrained potential insights and perspectives. However, this was

a different question - so it may be beneficial to include this work as a separate piece of research.

4.5.10.3 Introducing the patient voice through professional interviews

As previously discussed, this research did not intend to introduce the patient voice or patients' needs. Nevertheless, health professionals when discussing their professional roles linked this directly to cancer patients' needs. Therefore, the decision was made to include this aspect within the topic guide. It must be recognised, however, that this is not a true patient voice. The purpose of this thesis was to obtain a professional voice - but interesting and important that the professionals seemed unable to discuss current and future follow-up practices without relating it to patients' needs.

4.5.10.4 Rationale for not addressing a raft of issues relating to individual cancer sites versus considering all cancers together

Whilst it may have been helpful and appropriate to explore in depth issues around individual cancers, the aim of this research was to understand general issues around cancer care follow-up as it was felt that this was most appropriate from a primary care perspective. However, specific issues relating to individual cancers emerged when speaking with specific groups.

4.6 Analysis

4.6.1 Design

As previously discussed in section 4.2.4, the student used constant comparison as an approach adapted from grounded theory. The framework method of analysis as described by Ritchie and Lewis (2008) seemed a useful fit for this phase of the research.

The framework method of analysis can be described as an analytic method, which facilitates data management in a hierarchical systematic manner. It allows the researcher to iteratively move back and forth across all stages in the analytical hierarchy. The thematic framework classifies and organises key themes, concepts and emergent categories, therefore, allowing researchers to make sense of the data (Ritchie and Lewis 2008). Five key stages in the

framework method of analysis include: familiarisation with the data; identifying a thematic framework; indexing; charting; mapping and interpretation (Ritchie and Spencer 1994). Srivastava and Thomson (2011) suggest that the framework method of analysis is a useful tool for research that uses a pre-determined sample and questions within a limited time frame. Both the topic guide and the framework method of analysis provided direction and facilitated the emergence of theory in relation to survivorship care.

4.6.2 Analysis - process

The first step in the analysis process was to transcribe each narrative verbatim and remove any identifying information. Next, each transcript was read in conjunction with its audio recording. Observations, demographics and comments from the field notes were then matched to each narrative, which classified and verified each participant. This was a helpful exercise as it assisted the student to check for errors and understand interpretations regarding initial conclusions.

Following this process, the student aimed to make interpretive sense of the data and to build explanations and debates (Mason 2005). Firstly, a small number of transcripts were chosen according to their characteristics and circumstances. The aim of this task was to read each transcript thoroughly (familiarise) and become immersed within the data set (Ritchie and Spencer 1994). Next, the student created a thematic framework by applying codes, themes, ideas and perspectives to the corresponding text (indexing) (Ritchie and Lewis 2008). Once completed, the thematic framework was applied to the remaining transcripts.

The next step was to programme the transcripts and thematic framework including its associated codes, themes, and categories onto NVivo, the qualitative software package. Particular attention was paid to new ideas or emerging themes generated by the participant interviews.

Finally, the student copied the codes and themes from NVivo and placed them onto a chart under associated headings and subheadings (charting) (Ritchie and Spencer 1994). The chart used in this thesis was the 'One Sheet of Paper' (OSOP) method (Ziebland and McPherson 2006). The OSOP method was a useful strategy in this thesis, as it allowed relationships, patterns, commonalities and emergent issues to arise from the data. This task was iterative in nature and required a

systematic and comprehensive approach. Using the OSOP method in this way generated an extremely large and unwieldy piece of paper.

4.7 Ethical considerations

At the time this study was conducted, research with health professionals required NHS Ethics Committee approval. Therefore, ethics approval was sought and gained from (MREC, 03/09/08, Appendix 11) and (NHS approval letter from Glasgow RD, 08/09/08, Appendix 12). Management approval was also sought and gained from each health board, for example, (NHS Lothian, 04/12/08, Appendix 13), (NHS Highland, 10/10/08, Appendix 14), (NHS Grampian, 08/10/08, Appendix 15) and (NHS Tayside, 26/09/08, Appendix 16).

There were two main ethical principles guiding the conduct of this research. These were informed consent and confidentiality. Mason (2005) states that informed consent is an ethical guideline that requires researchers to inform respondents of possible risks and benefits from their participation in the research. In section 4.5.8, the student described the process of informed consent prior to the commencement of each interview. Confidentiality was maintained by ensuring that transcripts and field notes were anonymised. All raw and processed data were securely stored in a locked filing cabinet or password protected.

4.8 Reliability and validity of the research

Mays and Pope (1995) suggest that in order to establish rigour in qualitative research, there must be a systematic approach underpinning the foundation, design, data collection and analysis processes of the study. In particular, qualitative researchers should detail the methods chosen, therefore, facilitating transferability to other research situations. Indeed, the results must reflect as much as possible, the explanations and meanings given by the respondents (Lincoln and Guba 2000). Therefore, the student thought it appropriate to discuss the concept of trustworthiness in relation to reflexivity and the audit trail.

4.8.1 Rigour and the audit trail

The development of an audit trail is a guideline from which to demonstrate that research should be conducted with due care (Seale 1999). The audit trail allows the reader to see into the research process and to follow key elements of the research practice (Ritchie and Lewis 2008). For the duration of this thesis, a site file was developed and maintained. Files and documents were stored in chronological order under subject headings, therefore, allowing an auditor or second party to identify the research procedures as well as the rationale for specific research decisions.

4.9 Chapter summary

This chapter has detailed the design and process of this research. The sample of oncologists, CNSs and GPs were recruited from cancer centres across Scotland via clinical directors and lead nurses. GP respondents were identified using the SCPRN database at the University of Glasgow and by the health board areas in which they worked. This particular sample of participants was chosen to reflect health professionals who care for patients with cancer during the follow-up phase. A total of 16 oncologists, 15 CNSs and nine GPs were recruited to the study. Data were generated with semi-structured interviews using a topic guide. A structured qualitative analysis approach was used, which involved an adaptation of the constant comparative method used in grounded theory.

5. Findings

5.1 Introduction

This chapter presents the findings of the research. Analysis of the results are organised around the research objectives and the key themes that emerged from the analysis. Themes were examined using the OSOP method. This detailed and secondary method of coding improved the student's understanding of the issues around survivorship care. Major themes were classified as: organisation of cancer care; patients' needs; professional roles; communication practices and optimisation of primary care. Sub-themes on the OSOP emerged from the major themes. For reference purposes, the next section will describe the practical application of the OSOP method in relation to communication practices. This is also described in detail in Appendix 10.

1. The first step in the OSOP method was to obtain all the issues that were relevant to communication practices. This involved retrieving the 'extracts of transcripts' and their codes, which were previously verified by the student and the supervisor. Supplementing the extracts was the NVivo coding report and the student's field notes, which provided the first iteration and analysis. The OSOP method allowed for deeper analysis.
2. The student, in the first instance, described these issues in a summary format. This allowed commonalities, patterns and differences to emerge.
3. As a result of these highlighted issues and codes, the student was then able to link the codes with one another, therefore, facilitating broader themes and meanings. For example, some codes showed that specialists used a standard letter to communicate to GPs. Codes from GPs' transcripts identified that letters from specialist care were delayed because of scarce secretarial resources. The student followed this iterative process throughout the analysis phase.

Table six presents the final version of the coding framework.

Table six: final version of the coding frame

Traditional practices	Barriers to practice	Patients needs	Professional roles	Communication practices	Communication barriers	Communication enhancement	Optimisation of primary care
Historical practices	Traditional model of care unsustainable	Rationale for follow-up	Oncologists' leadership roles in specialist care	Mode of communication	Professional relationships	Develop professional relationships	CNS acting as an intermediary
Factors influencing change	Patients' preference for care	Meeting patients' needs	CNSs supportive care roles in specialist care	Method of communication	Access to professionals	Improve discharge letter	CNSs - general practice
Current practice	Access to care	Individuality of cancer	CNSs' roles acting as an intermediary		Lack of understanding regarding professional needs	GP leads - specialist care	CNS - community support
Policy	Primary care follow-up opportunistic		GPs provision of survivorship care		Detail of letters	ICT	Cancer Care Review
Guidelines	Organisation of cancer centres				Timeliness -letters		Research evidence
	Lack of available resources				ICT challenges		GP clinics
	Professional attitudes						GP cancer leads
	Lack of education training						
	Lack of research evidence						

5.2 Organisation of cancer care

The first key theme to emerge around survivorship care was discussions about historical and contemporary practices. Oncologists were asked to provide their perspectives on historical follow-up practices. Traditionally, the setting for follow-up cancer care was carried out in specialist care.

“They [the patients] would come up to the hospital every three months and see a specialist. Then it was realised that it wasn’t helpful, in terms of hospital time and resources, or in terms of how well supported the individual patients were.” (SPEC01, Lung)

Specific to the development of oncology, this oncologist described changes from radiotherapy to the specialism now known as clinical oncology.

“The radiotherapy department, it was never oncology. At that time it was sort of developing into the speciality of clinical oncology.” (SPEC08, Lung)

Comparisons were made regarding the different types of specialisms. This respondent differentiated radiotherapy to that of the academic speciality of medical oncology.

“I went into the specialty that was then known as radiotherapy oncology. When you become a consultant, you can practise both radiation therapy and deliver chemotherapy.” (SPEC04, Gynaecological)

The following extract by this GP highlights changes to traditional practice in terms of the former dominant roles of doctors. Although this quote seemed to relate to medicine in general, cancer services and oncology as a speciality have changed within this context, so that as the generalist physician has disappeared from view, so too has the generalist oncologist. This quote encapsulates the degree of change within specialist care.

“I started in general practice, as a registrar in 1984, so I’ve seen some cataclysmic changes, including the virtual demise of the secondary care generalist. The general physician has disappeared off the face of the planet.” (GP04-cancer interest)

The same GPs described that follow-up cancer care might not remain the domain of specialist care. It was hinted that primary care might have an increased role in cancer care follow-up.

“There are a greater number of people living with cancer. There are traditional models of follow-up for bringing patients back up to hospital-based clinics. I think that these follow-up models are out-dated. There are times when patients are going back for reviews, when they don’t need to attend a hospital.” (GP04-cancer interest).

GPs agreed that the setting for follow-up cancer care was and is to some extent largely the responsibility of specialist care, whilst GPs had less formal involvement.

“As far as their cancer itself is concerned, we generally don’t have a lot to do with them. They are seen by the hospital. They have their treatment and review instigated by the hospital.” (GP09).

Oncology nursing has also evolved; there was the inference that it had not really existed in its current form until the development of the CNS. It was also suggested that CNSs’ roles have developed in different ways often in response to health demand and service need.

“The CNS, as a generic role has evolved in different ways in just about every post that’s ever been established, and a lot of it has been to fit in with what the service needs were at that time.” (SPEC01, Lung)

Throughout the interviews it was common for respondents to talk about CNSs in terms of advanced practice developments. Participants discussed these changes in practice around clinical care.

My roles changed dramatically. There is more of an emphasis on sort of advanced practice. You’re seeing more people that are being diagnosed or being treated with chemotherapy using new adjuvant therapies.” (CNS02, Haematological, Breast)

5.2.1 Multidisciplinary Team Meetings and Managed Clinical Networks

Multidisciplinary Team Meetings (MDTs)⁶ were frequently advocated in this research, particularly from the perspective of ensuring that patients received optimal cancer care. However, emphasis was often placed on the working practices of MDTs, rather than their impact on health outcome/s. Policy documents such as the 1995 Calman-Hine report (Department of Health 1995)

⁶ Multidisciplinary team meetings (MDT) in cancer care was introduced to ensure that care delivery is consistent with the best available evidence. Patkar, V., Acosta, D., Davidson, T., Jones, A., Fox, J., Keshtgar, M. (2011) Cancer Multidisciplinary Team Meetings: evidence, challenges and the role of the clinical decision support technology. *International Journal of Breast Cancer*.

and the 2000 NHS Cancer Plan (Department of Health 2000) mandated cancer centres to establish MDTs. The following participant described the nature and process of MDT meetings.

“Every single cancer patient is discussed at an MDT, the MDT then discusses the diagnosis and the protocol they fit into. That then will allow us to know what the plan is for them.” (CNS11, Urological)

Some respondents described MDTs as a tool to facilitate collaborative management of cancer. This quote gives an example of how MDT practice has influenced the care of patients with colorectal cancer.

“Colorectal cancers used to always get surgery, and now because of multidisciplinary teams, a patient with colorectal cancer is discussed in that team. The radiologists will be involved in how best to manage it, whether to get adjuvant chemotherapy to immediately shrink that cancer down, so the surgeons got a much better chance of completely removing it or keeping it controlled.” (CNS02, Haematological, Breast)

GPs also favoured MDTs. This particular GP discussed the importance of MDTs in terms of meeting the physical and psychosocial needs of younger patients with cancer. This extract described how professionals from different disciplines aim to provide support for cancer patients.

“I try and ensure that every teenager with cancer is considered, both by a specialist MDT, looking to make sure they get the best treatment by the best specialist, but also an MDT that has psychosocial input, so that there’ll be people there with psychology input, social workers, and educational specialists taking an interest.” (GP05-cancer interest)

Managed Clinical Networks (MCNs)⁷ were first introduced in the 1998 Acute Services Review, which recommended that patient care should be underpinned by partnership working across boundaries, rather than care provided in isolation. The aim of MCNs was to maximise resources for the benefit of large numbers of patients (Carter 1998; Kunkler 2000). One particular GP described his role in the development of an MCN.

“We did it through a re-design process. We got GPs, district nurses, oncologists, clinical nurse specialists, radiology and pathology involved. Then just started what was the patient journey for this particular cancer.” (GP04-cancer interest)

⁷ MCNs are described as a linked group of health professionals from primary, specialist and tertiary care working together, unconstrained by existing professional and health board boundaries. The aim of MCNs is to provide high quality, clinically effective service. NHS Greater Glasgow and Clyde (2014) NHSGGC: what is a Managed Clinical Network? [Internet], Available from: <<http://www.nhsggandc.org.uk>> [Accessed 4 March 2014].

Respondents often described the benefits of MCNs in terms of facilitating collaborative working practices between specialist and primary care. For example, some GPs - with the support of MCNs, were able to care for patients with prostate cancer during the survivorship phase.

“Through the Managed Clinical Network many of the GPs have agreed to support patients in their follow-up. For patients who have had radiation prostatitis, we would advise them to contact their GP. We would want those GPs to examine them. If that symptom is not settling, refer to us.” (CNS03, Urology)

5.2.2 Policy, protocols and guidelines

Respondents displayed their understanding of how policy might influence change. Strategies outlined in the 2008 Better Cancer Care document placed an emphasis on shared care between health providers, with a particular focus on care being delivered close to the patient’s home (Donnelley 2008).

“The Better Cancer Care strategy mixes local follow-up and specialist treatment where needed. There is an emphasis on follow-up care as close to the patient’s home as possible, whether that means in the hospital setting closest to their home or whether it means in primary care.” (SPEC04, Gynaecological)

Some urological oncologists talked about prostate cancer in terms of AS and WW protocols that were shared between hospital specialists, oncologists and primary care. Although respondents did not refer to policy driving this type of follow-up care, it is suggested that these prostate directives may have been influenced by the NICE clinical guidelines (NHS NICE Clinical Guidelines 2008).

“Some of them will have shared care between me and/or the surgeon and/or the GP. The active surveillance patients do need regular monitoring PSAs and regular biopsies. The proposal is that this should be done as shared care with GPs. Whereas, the watchful waiting patients, the principal there is you’re not going to do anything unless there’s a problem to treat. So those patients are best managed by their GP because they don’t have any active issues.” (SPEC02, Prostate)

Oncologists with colorectal expertise informed that when patients were categorised into CNS clinics, their cancer care followed guidelines developed by

SIGN (SIGN 2011). Furthermore, the South East Scotland Cancer Network (SCAN) (NHS Scotland 2011) implements the SIGN guidelines via protocols.

“Once they’ve completed their adjuvant chemotherapy, if they’ve curative cancer, then we refer them to a nurse-led follow up clinic, and they’re followed up as per a standardised SCAN network, a protocol for follow up, with CT scans, columns, and CEA tests, as dictated by the policy, under the nurse-led follow up clinic.” (SPEC10, Colorectal)

For some GP respondents, there was a semblance of change with regard to the QOF (NHS Employers 2011). GPs were of the viewpoint that the QOF had impacted on their practice, particularly around management of care.

“We have got the contract and cancer care is part of that. So we need to review our patients within six months of a diagnosis of cancer.” (GP07)

Other evolutionary changes in primary care practice related to palliative care, rather than follow-up cancer care, nevertheless considered important in the context of change. This GP described how his surgery became involved with the Gold Standards Framework (GSF), which was designed to improve care for cancer patients nearing the end of their life. Patients with advanced disease were placed on the palliative care register from the point of diagnosis, therefore, ensuring continuity of care (NHS Scotland 2007).

“We got involved with the Gold Standards Framework; we were one of the pilot practices in the second stage. We started putting cancer patients onto our palliative care register, at diagnosis. And so we became aware of them and we stayed aware of them.” (GP03)

5.2.3 Barriers to the organisation of follow-up cancer care

GPs considered that the traditional model of care has become unsustainable. It was highlighted that patients often received their care in specialist care regardless of their health and or cancer type. This together with an ageing population and that patients are surviving many years after a cancer diagnosis, have placed considerable demand on the NHS. The literature has recognised the challenge with regard to inadequate follow-up regimes and unmet needs (Evans 1996; Ferlie and Shortell 2001; The Scottish Government 2003; Hall et al. 2011). The following quote encapsulates the challenges regarding the old model of cancer care.

“The old model of follow-up where you reviewed everyone annually from the time of their diagnosis and treatment until the day that they died is no longer applicable, particularly for people who are either cured of their cancer or who are going to live for many years.” (GP04-cancer interest)

“We’re still dealing with systems that are based on cancer services 40 years ago, when the outlook was: most people will die and are not going to live very long. But that system is not going to cope, it was never setup to deal with these problems.” (GP05- cancer interest)

Some oncologists offered patients’ preference for care as barriers to follow-up. It was suggested that relatively few patients wish to be discharged and preferred follow-up to be within the hospital system. The idea that specialist care should be responsible for follow-up cancer care is debatable, particularly because of changing historical practices and unsustainable care (Grunfeld et al. 1995; Rojas et al. 2012).

“Whenever you ask a patient, do you want to be discharged or do you want to come back next year, they always say I want to come back next year. There are relatively few patients who want to be discharged not for several years down the line.” (SPEC07, Lung)

Oncologists and CNSs were seen as the ‘specialists of cancer care’ compared to GPs. The following extracts help explain why some patients prefer the specialist setting for their care.

“We have found that a lot of outpatients... they see us as the specialists. So they’re quite reluctant to contact the GP if they’re unwell. They don’t have a huge amount of confidence in their GP.” (CNS06, Oesophageal).

“One of the things that we encounter is the lack of trust that some patients have in primary care. But I think that it is a feature of some patients’ attitudes.”(SPEC01, Lung)

It was also expressed that not all patients preferred specialist care for their follow-up. Respondents suggested that patients’ preference for care were roughly split into thirds, with some patients feeling comfortable with primary care follow-up, whilst others preferred either specialist or a combination of care between sectors.

“Some people will be quite happy seeing me; some people will want to see much more of the oncologist and some people want it generally split down the middle.” (GP03)

The fear and worry of a cancer recurrence also encouraged patients to seek oncological attention. These findings were consistent with other studies (Hewitt et al. 2007; Humphris and Ozakinci 2008; Jefford et al. 2008). The following extracts highlight patients' preference for care in relation to cancer recurrence.

“The patients want reassurance that the breast cancer hasn't come back. Most patients, I have to say, prefer to go back to see their specialist, they prefer to see the consultant who looked after them.” (SPEC03, Breast)

“It varies from patient to patient, but I think they want somebody they can contact if they are worried because the majority of patients are worried about recurrent disease. They will often refer patients back to us anyway.” (CNS07, Breast)

Social class was often discussed in terms of equitable access to care. Respondents considered that patients who belonged to less affluent groups were less likely to utilise voluntary services compared to those from affluent groups. Research around breast cancer finds that these particular individuals have difficulties accessing services because of: perceived personal risk; difficulties identifying breast cancer symptoms; concerns about money; comorbid conditions and family issues (Woods et al. 2005).

“There are a lot of facilities available, they've got Thistle Foundations.⁸ We've tried to catalogue all of these available resources and to ensure that people are getting equitable access to them. Patients who get them are the higher-earning social class, better educated, there's an inequity in it. I think that education and social class is a big barrier to access for a lot of people.” (SPEC11, Breast)

It was perceived by CNSs and oncologists that patients with head and neck cancer invariably belonged to less affluent backgrounds, which influenced their decision to seek out information. The following extracts reflect respondents' viewpoints.

“From my experience and speaking to other specialists throughout the UK, it isn't only a Scottish issue. It's through Europe. Historically it's been found that head and neck cancer sufferers come from lower socioeconomic backgrounds and literacy rates are not that good, so they won't seek out the information.” (CNS13, Head, Neck)

“For the most part, head and neck cancer patients here in Scotland and Tayside are no exception; they are usually a socially deprived group anyway.” (SPEC12, Head, Neck)

⁸ The Thistle Foundation is a Scottish Charity, which supports people with disabilities (Thistle Foundation 2012).

Respondents also linked lung cancer with social deprivation, which influenced their help-seeking behaviours. These findings were confirmed in other reports (Alberts et al. 2003; Metcalfe et al. 2005; Yu et al. 2007; Shack et al. 2008).

“The demographics from lung cancer are that many patients are from backgrounds where they are more deprived. They are less able to access support in terms of Cancerbackup,⁹ Macmillan¹⁰ and Maggie’s Centres¹¹ where you might go to seek out information or patient support.” (SPEC08, Lung)

Traditionally, lung cancer patients have not found they’re way to any of these resources, and they therefore look to the specialist for most of the information.” (SPEC01, Lung)

This particular GP suggested that some individuals from deprived areas do not seek help for their cancer because their expectations about their health are not a priority, perhaps influencing their motivation to seek out assistance.

“There are a couple of people who are not doing well with their cancer and don’t really want to see anybody. We give them a wee ring and say, do you want to come in? They’re actually okay just getting on with things. I think that’s part of maybe working in quite a deprived area, and stuff like that, people’s expectations are maybe not that high.” (GP03).

Several participants viewed guidelines as a benefit to follow-up. However, there was an awareness in some accounts that guidelines were non-existent. For patients with gynaecological cancer, for example, it was unclear who should provide follow-up cancer care. Some GPs considered that even if guidelines were followed, this does not necessarily mean that patients will receive their care if there was a lack of capacity in the service.

“The follow-up was very ad hoc. The patients were seen too often. There were no guidelines as to when, how, who should follow the patients up.” (CNS01, Gynaecological)

“I think there’s a lack of capacity in the service. If I refer somebody and there is a long waiting list, it’s because the service is full.”(GP03)

⁹ Cancerbackup has merged with Macmillan Cancer Support. Its aim is to provide cancer information. The nurse help-line provides emotional, physical and practical support for patients (Macmillan 2014)

¹⁰ Macmillan Cancer Support is the largest cancer care and support charity in the UK. Macmillan offers practical support and funds to build cancer centres (Macmillan 2013b).

¹¹ Maggie’s centres provide practical, emotional and physical support for cancer patients (Maggie’s 2013).

5.3 Survivorship and specialists' perceptions of patients' needs

This second theme reports on oncologists', CNSs' and GPs' perceptions about patients' physical, psychological and social needs and how these might be applied to future models of care.

As previously highlighted in chapter 4.5.10.3, this study did not intend to explore patients' needs. This theme emerged as part of professional roles. The student has acknowledged that using the professional voice to describe patients' needs was not the best way to understand patients' experiences.

5.3.1 Rationale for follow-up

CNSs and oncologists were of the viewpoint that treatment related side effects were a significant challenge for patients to bear and therefore, a reason for follow-up. The following extracts reflect the viewpoints of many.

“If they've got symptoms after their treatments, these symptoms have to be managed, that's primarily the biggest problem for the patient.” (CNS02, Haematological, Breast)

“The first thing is the side effects of treatment and monitoring that. The biggest problem we have in prostate cancer is radiation proctitis. Very few people actually manage that well. There are one or two colorectal surgeons in the region who do seem to contribute and do a good job at keeping it under control.” (SPEC05, Prostate)

Respondents in this study highlighted that a key purpose of follow-up care was to detect recurrent cancer. Although it was felt that early disease detection was of little value if all treatment options had been exhausted. Some oncologists expressed the opinion that metastatic disease was likely to occur between visits, therefore, increasing the importance of monitoring for recurrence regularly.

“The prime reason for follow-up is picking up early recurrence and then you can do something about it. If you haven't got any more active therapeutic options, I don't really see the point of seeing patients regularly. Traditionally, just a month after finishing treatment, we'd see them at fairly regular intervals.” (SPEC16, Head, Neck)

“Have they got any evidence of recurrence? Most metastatic disease comes back in-between visits in the second year.”(SPEC03, Breast)

Another oncologist with oesophageal expertise described late effects as a reason for follow-up.

“The cure rates for cancers I treat are sufficiently low that they’re not looking for late effects, which is the other reason to follow-up to look at late effect cancer treatment. In the sarcoma practice, you’re following up people for late effect treatment. That’s well recognised in cancer.” (SPEC09, Oesophageal)

Some professionals considered a reason for follow-up was to see the long-term side effects of new drugs and treatments in order for medicine to progress satisfactorily.

“I like to follow them up because it’s very helpful to see the long-term side effects of your treatment. The treatment of cancer is changing so much in terms of new drugs, different ways of delivering radiotherapy and its incumbent upon us as a profession to know what we’re doing to people in terms of long-term morbidity.” (SPEC12, Head, Neck)

Less was said in specialist care about the management and monitoring of co-morbid conditions as reasons for follow-up.

“Now for those patients [prostate], there may be a need for them to be seen by their GP in that six months, depending if they have any other conditions that require them to go to their GP.” (GP06-cancer interest)

Psychological issues were also considered a reason for follow-up. This GP described the uncertainty and worry that patients face regarding a potential cancer recurrence.

“The question that always seems to be on the top of their minds is has the cancer come back? Has it re-occurred? You often have to deal with that.” (GP07)

GPs often talked about social worries as a rationale for follow-up. It was perceived that patients suffered considerable stress after a cancer diagnosis often exacerbated by financial concerns. Respondents considered that benefit coverage were a significant issue. Financial concerns in cancer patients have been detailed elsewhere (Donnelley 2008; Neal 2008).

“I think the other thing that you don’t forget is the social aspect of cancer, making sure their benefits are in place and making sure that they have everything that they possibly need to cover them through a stressful period in an undefined period, because you don’t know how long it’s going to last for.” (GP07)

5.3.2 Treatment related physical side effects and comorbidities

Reasons for follow-up were closely linked to patients' treatment related physical, psychological and social needs. Usually respondents discussed treatment related side effects in terms of their own expertise. Some CNSs, for example, identified memory deficits and hemiplegia in head and neck patients, whilst others spoke about the impact of chemotherapy on haematological patients.

“A lot of complex problems. They're often left with memory deficits, hemiplegia, a lot of significant problems after treatments.” (CNS15 Head and Neck)

“They've had the cancer removed so to speak, and then we give them chemotherapy and make them unwell.” (CNS02, Haematological, Breast)

Respondents in specialist care considered that patients were likely to suffer physical symptoms, for example, nausea and fatigue as a result of their chemotherapy treatments. The association between cancer treatments and side effects have been well documented (Grunfeld 2005; Donnelly et al. 2007).

“It's just treating all the various side effects that they have from their chemotherapy, whether it happens to be their nausea or their fatigue.” (CNS10, Breast)

This GP highlighted the myriad of treatment related issues a patient can face as well as the risk of neutropenic sepsis. The literature indicates that patients often attend primary care for management of these conditions (Campbell et al. 2002; Grunfeld 2005).

“There are physical symptoms that cancer patients often get that you have to be alerted to. You have to think about bowel care, constipation, diarrhoea, vomiting and sick. You have to deal with fluids. Their hair falls out; you need to be able to support them. They can often get skin and mouth care problems. Neutropenic sepsis is a big worry. You can often get nerve damage from chemotherapy.” (GP07)

Oncologists often talked about the side effects of hormonal treatments. For example, an oncologist with breast expertise discussed hormonal treatments in relation to menopausal related symptoms.

“Hormonal side effects, the menopausal symptoms are the main ones. So it's everything that goes with that, irritability, hot flushes, night sweats, feeling tired, aching, sexual problems and vaginal dryness.

Patients get on-going problems from the operation, pneumatic pains and chest wall pains.” (SPEC03, Breast)

There is the suggestion that treatments can lead to complex issues. This oncologist identified that patients with head and neck cancer can suffer from disfigurements after their treatments. Therefore, these patients may require more intensive follow-up compared to patients with other types of cancers. Challenges with regard to speech, eating and respiratory problems including the psychological impact this has on body image has been raised in other research (Larsson et al. 2003; Humphris and Ozakinci 2008).

“Head and neck cancer is very disabling and very obvious. The treatments are there on display for everybody to see. They can have problems with speech, swallowing, all the activities required for them to be normal. So, their needs are complicated.” (SPEC12, Head, Neck)

Health professionals also acknowledged that cancer should now be thought of as chronic illness because patients were living longer after a diagnosis of cancer. Cancer survivors, however, were considered at risk for treatment related issues. Other studies conclude that long-term cancer care, particularly relating to treatment therapy should occur on a continuum throughout the cancer journey (Tritter and Calnan 2002; Rowland 2008).

“Cancers becoming looked upon more of a chronic illness for patients who can be kept alive and well for a number of years, so that raises concerns about survivorship issues and long-term is usually related to their therapy.” (CNS02, Haematological and Breast)

Professionals also discussed the issue of comorbidities. Research suggests that for some cancer patients their cancer care constitutes a small part of their medical history (Campbell et al. 2002; Earle and Neville 2004; Nord et al. 2007). The following extracts show the effect of comorbidities on cancer patients.

“Most patients have a lot of on-going issues that are not specifically related to their cancer.” (SPEC10, Colorectal)

“We kept him alive, he’s not in bad shape really, but it’s just his head and neck cancer, it comes on the end of heart problems and a couple of strokes previously, due to lifestyle.” (SPEC16, Head, Neck)

5.3.3 Meeting short-term treatment related side effects

Some respondents reflected on whether needs were being met. It was felt that physical short-term treatment related side effects were met satisfactorily and were addressed as much as possible, particularly within the time constraints of patient clinics.

“I think most of the physical needs are met fairly well, as in symptom control. We’re very good, I think, at controlling nausea, vomiting, diarrhoea and all those kinds of physical manifestations.” (CNS04, Clinical trials)

Respondents also discussed meeting patients needs in relation to a collaborative working and categorisation of care model. In this example, professionals designed a standardised follow-up plan - patients were categorised according to their particular health needs to either CNSs, surgical, oncology or primary care follow-up. Part of the NCSI (2013d) vision focuses on stratification of care, whereby the clinical team decides on the best form of survivorship care based on the level of care needed including the ability of the patient to self-manage aspects of their care.

“We were seeing them one week and the surgeons seeing them the following, and it was a waste of patients and our time. So the surgeons, nurses and the oncologists designed a joint, standardised follow up. Group A patients would get referred to the nurses for follow up. Groups B and C, if they were seen by oncology, would be treated within oncology and then transferred to the community unless there were issues that made that inappropriate.” (SPEC10, Colorectal)

Developments within nursing were viewed by this particular oncologist as a significant factor in meeting treatment related needs.

“I think probably better now because we have nurse-led follow-up. Their appointment times are significantly longer. I think they do spend a little longer with each patient and probably, therefore, explore each issue a little more.” (SPEC10, Colorectal)

It was previously reported that patients attend primary care for management of their treatment related symptoms. Patients also present to primary care for management of their co-morbid conditions (Campbell et al. 2002). For patients with prostate cancer, for example, it was estimated that each full-time GP would have about ten men on their register of who only a small proportion will

die of the disease. Furthermore, patients with prostate cancer can have high levels of co-morbidity, often considered more serious than their prostate cancer (Neal 2008). Similarly, patients with breast cancer can suffer from shoulder and hand pain and can often have lower mood profiles unrelated to their initial cancer and its treatments (Pavlic et al. 2009). The following extracts encapsulate GPs' viewpoints in relation to comorbid conditions.

“Often they have a lot physical symptoms that were not related to their cancer.” (GP07)

“You know the rest of the time people are living their lives. You are seeing them for other things; you’re just giving them a general medical service for all the other things that may arise. You know they still have their sick lines to come and get. They come for respiratory infections, dermatology you know all the gamut of problems.” (GP02)

“We are caring for a cohort of people with multiple co-morbidity, and probably a degree of cognitive impairment.” (GP03)

Respondents in primary care often described meeting needs in relation to the hierarchical structure of the medical model.¹² For example, physical symptoms such as pain were prioritised as an immediate need, whereby; psychological issues were dealt with more latterly.

“Yes, absolutely, the medical model is based on the perception of a hierarchy, which puts the physical ahead of the emotional and psychological. We get very agitated if the patient is in pain.” (GP06-cancer interest)

Respondents consistently discussed the value of the voluntary sector in terms of meeting treatment related needs. The following extracts highlight two different sources of voluntary support.

“We use Cancerbackup. They’ve got cancer support services and local hospices. There’s a whole variety of different things; there’s not one thing that we consistently use.” (SPEC06, Colorectal)

“We’re very fortunate now, we have Maggie’s Centres and specialist nurses and I can’t imagine not having that support there.” (GP05-cancer interest)

¹² The medical model is based on the biological causes of disease. The focus is on physiology, pathophysiology, pharmacology, biology, histopathology and biochemistry. Often a cure is sought through the applications of medications and/ or surgery (Germov 2002).

CNSs and GPs often worked collaboratively with the voluntary sector and referred patients for advice and information.

“We’ve got a day hospice, it is a drop-in information centre. It is fairly relaxed, with the Maggie’s Centre approach. We would do a full day really, myself and another clinical nurse specialist, we work with dieticians and OTs and an information officer.” (CNS14, Breast, Colorectal)

“We will see them and we will advise them and we will phone them up and get advice for them or whatever. Just by chance on Monday we had a meeting with the Macmillan Cancer Information and Support Service, they just phoned to open up in this area from March [respondent shows a pamphlet] to offer a service which is going to be of great benefit.” (GP02)

5.3.4 Psychological needs throughout the cancer continuum

Participants when discussing their perceptions about patients’ psychological needs explained these in terms of the whole cancer trajectory, rather than just survivorship alone. The following extract shows how psychological needs can peak and trough during the cancer patient’s pathway.

“Psychological issues will change throughout a patient’s journey. At the beginning of the journey there will be the diagnosis, the uncertainty, their fear of treatment. The biggest problem with cancer care is you can come through radiotherapy on a daily basis and chemotherapy and then suddenly you’re left on your own.” (CNS02, Haematological, Breast)

Fear of recurrent cancer appeared to be at the heart of psychosocial concerns. The following participant described how patients might feel when faced with the possibility of a cancer recurrence.

“The problem is, a lot of them panic and think it’s the cancer, it’s going to flare because they are so tired and it must be that the cancer it’s working its way through the body.” (CNS11, Urology)

GPs also described that for some cancer patients, a cancer diagnosis may re-awaken mental health issues. The literature informs that distress and worry regarding a cancer recurrence can extend from worry to true depression, which can be disabling (Pascoe et al. 2004). Fear of cancer recurrence was ubiquitous amongst cancer patients (Lee-Jones et al. 1997; Humphris and Ozakinci 2008; Jefford et al. 2008).

“There are two levels of psychological. One is the fact that the patient is worried they’ve got cancer and then it’s the fact of what we do when they’ve been told they’ve got cancer.” (SPEC07, Lung)

“It may be that the diagnosis reawakens mental health issues or they’re susceptible to depression. They may have to be considered for antidepressant medication.” (GP08)

Some respondents described psychological challenges with regard to female and male cancers. Treatment for gynaecological cancer, for example, was thought to cause embarrassment and stigma particularly in relation to how other individuals viewed their sexuality. Studies report that surgery for gynaecological cancer can have a significant disruption on body image including perceived stigmatisation, which in turn impinges on theirs and others perceptions of themselves (Anderson and Hacker 1983; Butler et al. 1998; Hamilton 1999). The following extracts demonstrate the challenges that patients with gynaecological cancer can face.

“Gynaecological cancers are still in the minority. It’s a bit of an embarrassing, shameful diagnosis and we do see a lot of women who are scared and concerned about telling people where exactly their cancer diagnosis is. Things come back about promiscuity, their sexual habits and things like that and that stigma stays with the patient and that is very difficult to try and dispel.” (CNS01, Gynaecological)

“There’s the psychosexual as well, particularly the gynaecological cancer patients. When they’ve gone through the menopause, removal of the ovaries and womb, it does have a psychological impact and they need support in coming to terms with that.” (SPEC04, Gynaecological)

Participants were of the perception that patients with breast cancer also had significant psychological needs after completion of their treatments. Loss of hair and weight gain, for example, altered perceptions of their body image.

“At the end of chemotherapy there are lots of psychological issues relating to changes in body image, hair loss and weight gain.” (SPEC11, Breast)

Several respondents described the emotional consequences of treatments. Treatments for cancer of the prostate, for example, can contribute to physical problems such as loss of sexual function, which has the potential to impact on sexual relationships. Research shows that lack of sexual function in men with prostate cancer can lead to depression (Heriot et al. 2005; Kennedy and Rizvi 2009; Letts et al. 2010).

“You can tell a [male] patient [after prostate cancer] all the potential problems and discuss things like sexual dysfunction. Once treatment is finished, six months down the line it becomes more of an issue when they maybe have relationship problems with their partner, they’re trying to get their life back together.” (CNS02, Haematological, Breast)

Some oncologists identified a psychological need associated with information about the treatment process. It was suggested that patients could suffer from anxiety in their quest for knowledge concerning type and time to treatments. The need for information was entirely dependent on individuals and could vary throughout the cancer process. Other studies conclude that some patients actively seek out information in order to reduce their anxiety, whilst others avoid information about their disease. It was thought important to account for these differences in requirements, particularly in relation to patient care (Skalla et al. 2004; Vivar and McQueen 2005).

“The main psychosocial need is for information and knowing what the treatment is. There is a high degree of anxiety about when the treatments going to be. The level of information does differ from one person to another and changes over time with the patient. Some patients want to know everything the first time they see you, some of them want to know very little.” (SPEC02, Prostate)

Respondents described that some patients had the potential to form strong bonds with staff in specialist care. These relationships offered guidance, support and encouragement for the patient, which were often severed after the treatment phase. It was expressed by these respondents that patients suffered feelings of isolation and loneliness after their discharge from specialist care. The following extracts show the difficult transition for patients after specialist input and their re-adjustment to life.

“They sometimes struggle emotionally with having got this awful illness, having had very intense input from the specialist and suddenly they’re just flung out there and they’re on their own.” (SPEC09, Oesophageal)

“Many patients, when they come for chemotherapy form a bond not just with the medical staff, but with the nurses giving chemotherapy. There are patients, who during treatment do become very attached to clerical staff; the phlebotomist, whatever.” (SPEC04, Gynaecological)

5.3.5 Meeting cancer patients' psychological needs

Participants used varied methods to support patients' psychological needs. Oncologists often reported that the medical consultation offered an opportunity to assess the emotional status of the cancer patient. The literature reports that interviews conducted by health professionals, which were based on informed decision making including open directive questioning were viewed as ways to enhance emotional disclosure in cancer patients (Ford and Hall 2004).

"I think that we're quite good at picking up distress and depression. We try to ask people what they've been up to. What have they been doing? Have you been out of the house to do anything other than go to specialist since I last saw you? We don't do a formal assessment." (SPEC09, Oesophageal)

After assessing patients' needs, oncologists often sign posted patients to the appropriate services for support and care. Psychologists were considered an available resource for patients to access.

"Usually the first port of call is the specialist psychologist; it's attached to the oncology unit but it's here in Forth Valley, that's usually where I'd think of sending them first off." (SPEC05, Prostate)

Other oncologists sign posted cancer patients to CNSs for emotional and financial support. CNS would then refer patients to the voluntary sector.

"Regarding emotional and financial support, the CNS tends to pick up that side of things a lot more and is able to make referrals to Macmillan for grants or to the social department." (SPEC16, Head, Neck)

Oncologists often favoured the use of exercise to support patients through their psychosocial issues. It was thought that there were associations between exercise and relief of physical symptoms including psychosocial emotions. These findings were reflected in other studies, which found that exercise interventions improved physical function and psychosocial wellbeing (Stevinson et al. 2004).

"There are such strong associations between fatigue, mood and exercise." (SPEC09, Oesophageal)

"I am interested in the role of exercise programmes and things like that in getting people back to normal. From the physical end, I think it helps psychologically as well." (SPEC06, Colorectal)

The data also show that part of the identification of psychological need was about the CNS getting alongside the patient during their treatment phase, therefore, being in a direct position to detect emotional distress.

“I usually get to know them quite well. I mean, if somebody’s very depressed, you’d hopefully pick that up when you first meet them.” (CNS05, Head, Neck)

CNSs were integral in terms of practical support for patients with anxiety and uncertainty issues. The following extracts show how CNSs offer support.

“We do a lot of individual counselling and psychological support. They have a lot of anxiety and uncertainty in that process. We can discuss with patients the different tests, trying to allay their fears.” (CNS08, Lung)

“And checking that the people understand what they’ve been told. So, it’s about checking that they are reiterating information. It’s a lot of information giving and just providing emotional support.” (CNS06, Oesophageal)

As in specialist care, GPs informally assessed the psychological wellbeing of the patient during their consultations.

“I think you get that feeling. I mean you pick up on the non-verbal as well. Well I have been here for 23 years; you really do know the patient. When they walk in, you just know if the patient is not themselves.” (GP02)

Some GPs sign posted patients with psychological needs to either the cancer centre or to the CNS. This was largely because local services were less than optimal.

“Obviously you can refer patients to local counselling services and they will vary enormously from one area to another. And access is patchy. Generally, one would tend to rely on the Edinburgh Cancer Centre and probably rely on the clinical nurse specialists.” (GP06-cancer interest)

The implementation of the 2004 General Medical Services Contract (GMSC)¹³ introduced changes to follow-up in primary care. Part of that contract was the QoF,¹⁴ which offered points to general practices for quality care and

¹³ The GMS contract is a UK wide contract introduced to provide a more flexible delivery of services, improved quality and modern infrastructure. It aims to promote better quality and more responsive GP services. At the same time it provides a level of remuneration with incentives for enhanced care (Department of Health 2013)

¹⁴ QoF was introduced as part of the GMSC. The QoF is a voluntary incentive scheme for GP practices in the UK rewarding them for how well they care for patients (NICE 2013)

management of patients. This voluntary scheme encouraged general practices to produce a register of patients diagnosed with cancer including a recorded review of patients seen within six months of their cancer diagnosis (NHS Employers 2011). The Cancer Care Review offered scope for improving cancer care practice (Adams et al. 2011). This GP described how the Cancer Care Review allowed cancer patients an opportunity to discuss their psychological worries.

“Part of our Cancer Care Reviews are to make sure that they have their psychological needs taken care of. Making sure they get an opportunity to talk through their worries, their fears, their difficulties, their anger almost a grief reaction.”(GP07)

5.3.6 The impact of cancer in relation to social needs

Cancer and its resulting social issues were found to be a significant theme in this thesis. The following extracts show how oncologists and CNSs acknowledge the patient’s need for financial support.

“Financial problems are a big issue.” (CNS14, Breast, Colorectal)

“Some problems are financial. So I try to and give advice that I think will impact from that point of view.” (SPEC11, Breast)

Some patients needed financial support because it became difficult to continue working. This presented a problem for some self-employed patients, as they were often the sole breadwinners for the family. Worries about remaining employed, particularly during cancer treatments was commonplace amongst cancer patients (Jefford et al. 2008).

“We get a lot of self-employed people like taxi drivers, as patients. And, it’s a huge thing. They’re the main breadwinners and they’re being told that they’ve got this cancer and they’re not going to be able to work. And, that is one of their first questions. What am I going to do for money? Particularly if they’ve got a young family and the wife doesn’t work. You think it’s your health. But, for some people it’s a real issue. Being able to point people in the right direction and sorting out things can be a huge relief to them.” (CNS06, Oesophageal)

This particular GP described the importance of identifying economic and social needs first as these factors were likely to have a significant impact on the cancer patient’s psychological health.

“I am looking more at psychosocial how they’re doing. Is it affecting their employment? How they’re doing at home? How it’s affecting them mentally? I find often people who have been cured for cancer, this has a major long-term impact on their psychological status.” (GP02)

Social needs were also discussed in relation to cancer groups. Patients with head and neck cancer, for example, often presented to oncology with a multitude of problems often compounded by their less than affluent backgrounds, inadequate social networks and habitual health behaviours, resulting in poorer health outcomes.

“Head and neck cancer patients have lots of problems, very poor psychosocial set ups, smoking and drinking. Some of these characters have to change their habits. They have difficulty coping with what we’ve done to them. The family can’t cope either.” (SPEC16, Head, Neck)

Although the majority of respondents identified social needs from a financial perspective, there was discussion around the needs of the family. It was perceived that some relatives of patients looked to the oncologist to meet their needs, which if not met, created a measure of tension between the patient and the oncologist. Studies informed that meeting the cognitive and emotional needs of the family facilitates patient care (Wingate and Lackey 1989; Wagner et al. 2010).

“There are lots of social needs from the family and they are quite different. Quite often the partner who comes with the patient has different needs from the patient themselves and that’s quite difficult because my prior responsibility is with the patient. Sometimes there can always be some resistance from the patient for the needs of the partner to be met.”(SPEC02, Prostate)

Social needs also included respite care for elderly cancer patients. Often, lack of access to a nursing home or similar meant that older persons with cancer had to wait some months in specialist care.

“Some elderly patients are often stuck in hospital and needing a placement, they are not fit enough to look after themselves, so they have to wait for a nursing home or care home, they have to wait for months.” (SPEC08, Lung)

There was the perception that some cancer patients had social needs relating to re-housing. Patients with aggressive forms of cancer who had previously coped at home may need support that only sheltered housing can provide.

“There are social needs, re-housing sometimes is an issue, social support. You know a patient may have no social physical needs right now but you know that they are going to be developing those very quickly. So, if someone knows they have a nasty cancer and they are going to deteriorate quite acutely.” (SPEC02, Prostate)

5.3.7 Meeting cancer patients’ social needs

Central to meeting financial needs was alleviation of financial constraints. It was recognised that receipt of benefits was an immediate worry and cause for concern for most patients.

“Benefits are a huge issue for any individual receiving any form of treatment, but you find it more so in head and neck because I think a lot of them don’t have anything.” (CNS06, Oesophageal)

“I mean benefits must be probably the biggest concern people have. Getting that sorted out, along with the other services.” (GP03)

Oncologists reported encouraging patients to continue working during their treatments. It was felt that patients who worked during this time fared better psychologically, perhaps alleviating some financial issues.

“I try to encourage my patients to continue to work during chemotherapy. I think those that do are psychologically much better, just being active, getting out and about. Some problems are financial, so I try and give advice that I think will impact from that point of view.” (SPEC11, Breast)

Additionally, oncologists offered support by signing documentation relating to the DS1500. The DS1500 was designed to speed up the payment of the Disability Living Allowance, Attendance Allowance or Incapacity Benefits (Simon 2008a).

“Well, if DS1500 are appropriate, then I tend to instigate that with a letter to the clinical nurse specialists here, saying get on with it. For folk who are far from DS1500, but whom have significant financial worries, it tends to be through Macmillan that they’d be pointed.” (SPEC14, Urology, Lung)

CNSs often sign posted patients for their financial worries to the voluntary sector or patient accessible help lines.

“I use the Macmillan and Citizens Advice Bureau that’s a very good service.” (CNS15, Neuro-Oncology)

“We utilise Maggie’s Centre, Macmillan nurses, various telephone help lines, Cancer Concern and Backup and stuff that patients could access.” (CNS09, Colorectal)

CNSs also highlighted the value of Maggie’s Centres in terms of one-to-one individual support.

“A lot of our patients use the Maggie’s Centre, from the point of view of what they offer and the one-to-one support they get.” (CNS10, Breast)

Some GPs described the benefit of CNSs in terms of supporting patients to re-integrate into society and the workplace, whilst ensuring that patients have access to supportive services.

“I think the benefit of using clinical nurse specialists is that they can start to explore some of the softer issues in follow-up, like how the cancer is affecting that person’s ability to re-integrate into society, including their social functioning in their workplace. Perhaps, looking at the financial impact of the cancer on the individual and whether or not they’ve got access to the right support and resources that they may need.” (GP04)

GPs often provided advice for cancer patients in conjunction with the benefits agency and social work department.

“We can get them advice regarding financial help with the benefits agency, disability living allowance and social help through the social work department.” (GP08)

5.3.8 Meeting needs and the individuality of cancer care

The individuality of cancer in terms of patients’ needs care was a key issue in this thesis. This was discussed in relation to: type of cancer; stage of cancer; differences across and between cancers; coping skills and varied working practices. The following extracts highlight specialists and GPs perspectives on the individuality of follow-up.

“It depends on the stage of cancer, type of cancer and the treatment needed.” (SPEC15, Prostate)

“Each individual patient has an individual condition and responds to it in an individual way.” (GP08)

Other respondents provided examples as to how follow-up might be different across tumour types and gave examples of breast, prostate, bowel and lung cancer.

“I think that the purpose of follow-up is different from one tumour site to another, it’s appropriate for the timing, schedule, and the intensity of follow-up to be different. Breast cancer patients may walk away after treatment while lung cancer patients most of whom will be dead within a year of diagnosis.”(SPEC01, Lung)

“The follow up of patients with a new diagnosis of cancer is that it isn’t one size fits all, particularly when you take into account different diagnostic groups. I think if you look at your breast cancer or prostate cancer or bowel cancer, or even rarer cancers, there are specific needs. I think we should be thinking in terms of those groupings rather than cancer being one disease. Clearly, it isn’t.”(GP06-cancer interest)

Oncologists highlighted the individuality of cancer within the same tumour types. For example, the timing of follow-up can be different for patients with breast cancer because of their individual needs.

“The follow-up starts at a different place. So for some patients who have an operation, they will be 18 months further on. Some will have gone on a follow-up phase for a year, others won’t have started follow-up-yet because they’re still on active treatment.” (SPEC03, Breast)

Coping with cancer and its subsequent follow-up was dependent upon the individual and their coping skills. Some patients were able to cope effectively with the emotional stressors and strains of a cancer diagnosis/treatments, whereas other patients for varying reasons were unable to cope at all. Additionally, some patients required significant support during this phase whilst others preferred to just get on with it.

“Some have very intense needs, because they have a great deal of difficulty coping with the whole diagnosis and treatments. Some have few needs and are very robust in their ability to get on and to deal with it and to cope with it.” (SPEC10, Colorectal)

“Their psychosocial needs are hugely varying depending on which patient you’ve got in front of you. Some people in terrible situations can appear to cope very well. Some people who are in relatively benign situations can have huge amounts of psychological morbidity, from the fact that they’ve had pre-malignant condition in their breast. And even though their life expectancy is excellent, they can be dreadfully taken down by the psychological impact of the diagnosis.” (SPEC13, Breast)

GPs and specialists also spoke about the importance of being aware and sensitive to each cancer patient's needs and wants.

“When patients are first diagnosed, the system overloads them with people. It may be more sensitive to stand back and allow the patient to decide what they want to be done. Do they want to be left alone or do they want all that psychological input and nursing support etcetera? It does vary from patient to patient. I think patients find it very difficult to say no when some caring professional comes along and says ‘I’m this specialist, Nurse X or Doctor Y, and I’m here to do whatever.’ They may not actually feel they need any more help. I think we have to be careful we don’t impose more than we should on patients.” (GP08)

“I think the important thing is to sort out the ones that actually need financial help or something significant done for them and those that aren’t and then refer them on if appropriate.” (SPEC05, Prostate)

Although uncommon, some respondents described the individuality of cancer care in terms of different working practices and protocols used within each cancer centre/unit.

“It’s very much site-specific in terms of the follow-up that they receive. In terms of oncology, each site has very different follow-up protocols.” (CNS12, Prostate)

The previous section highlighted that both specialist and primary care used a combination of methods, which aimed to meet cancer patients’ physical and psychosocial needs. There was considerable agreement, however, that needs were not addressed satisfactorily.

“I don’t think we’re meeting any of these needs nowadays. I don’t think there’s time in the system to do it properly. Whether you’re a survivor of cancer, or dying of cancer, or got dementia, or got COPD, or are depressed, or just have a miserable and rotten existence.” (GP03)

“What we’re not good at the psychological distress of the whole process.” (SPEC12, Head, Neck)

5.3.9 Barriers to meeting cancer care needs

Mandelblatt et al. (1999) informs that health care systems and their providers can impede optimal delivery of health services. This research identified a number of barriers to follow-up, for example: organisation of the cancer centres; lack of resources; professional attitudes; paucity of research and an absence of communication training.

The organisation of cancer centres was introduced in the interviews in terms of their geographical locations. Some patients out with centralised care had to travel considerable distances to receive their support. Long travelling time was often compounded by time spent waiting to see their oncologist. This was considered inappropriate in light of some patients who had less time to live.

“I think one of the frustrations for patients, is the amount of time they waste in travelling and hanging about even when they do have specialist appointments, it’s not a good use of their time. The patient’s time is very valuable.” (SPEC01, Lung)

“But people who are travelling to a regional service for a five minute consultation may feel that is a bit too much.” (GP03)

Respondents often talked about the lack of flexibility in the system, which impacted on working practices. It was suggested that specialists and GPs often work according to set working practices and principles specific to their environment. For example, patients attending specialist care were reviewed systematically according to a routine timed schedule. On the other hand, the principle in primary care was not on a timed basis; rather, the emphasis was mostly patient-led according to their cancer and non-cancer needs. GP06 expressed the opinion that specialist care had problems because of the rigidity of its appointment system. If patients became ill between appointments, it was difficult to re-schedule consultations because of bureaucracy. Differences in working practices across settings have been documented elsewhere (Kvamme et al. 2001; Wadmann et al. 2009).

“The principle of contact with the GP is that it is patient led. They’re offered treatment for any condition and cancer is no different. The principle in primary care is come back and see me if you’re not better. The principle of follow up in secondary care is a routine for following these patients who come back in three months. If a patient gets an appointment [in specialist care] in three months, what could they do if they had a

problem in eight weeks' time? They can't bring their appointment forward without bureaucracy." (GP06-cancer interest)

In contrast, some respondents expressed the viewpoint that the appointment system in specialist care was transparent and fluid. It was perceived that patients found it fairly simple to contact CNSs for advice and support, compared to the bureaucracy of engaging with their GP. The following extracts highlight some CNSs and oncologists' perceptions regarding GP availability.

"I think that patients think there is no way they can easily speak to their GP, well as much as they would like to. But patients can speak directly to us, that's an advantage." (CNS02, Haematological, Breast)

"Oh no, I've never seen him [the GP], can't get an appointment. So the patients are obviously struggling with how we're managing to see them perhaps fairly frequently in the clinic, but we don't see much input in GP land, which is disappointing." (SPEC16, Head, Neck)

Resource barriers were seen to impact on the delivery of cancer services. This particular specialist spoke about the lack of funding and staff shortages and the impact this had on the delivery of services.

"The level of service has varied over the years; sometimes it's been good. It's also been plagued by shortages due to mortality, maternity leave and difficulties in funding." (SPEC04, Gynaecological)

It was described how lack of financial resources had impacted on psychology services

We don't have great psychologists. Sometimes getting a referral can take some months before they can be seen." (CNS10, Breast)

"It's not as good as the actual availability of the service, which I think you'll probably find in clinical psychology, there's just not enough people in the speciality are there? So it's just funding issues." (SPEC16, Head, Neck)

Difficulties were also encountered in terms of CNS availability and time, which was thought to impact on meeting patients' needs.

"We probably are missing a few needs because of lack of resources, lack of time, and perhaps if maybe more patients had the opportunity of seeing a CNS on the day they came to the clinic." (SPEC04, Gynaecological)

Whilst some GPs described their interest in sharing care with specialist care, it was thought that this practice might create additional workloads for GPs. Other

barriers referred to were lack of available resources. The following extracts show GPs' financial concerns about conducting follow-up in primary care.

“I enjoy looking after people with cancer and I have an interest in cancer. I would be happy to do more co-work with people with cancer. General practice is also responsible for many other different conditions. There is a greater workload within primary care than there ever was. Certainly we would need to look into what are the resources needed, what are the education requirements?” (GP04-cancer interest)

“Another huge risk is that if any service finds itself a little bit overwhelmed, it can do less with all the patients that it sees. What was that government paper about? Living for Health? It allows you to delegate out from the acute service, which is struggling to meet demand. General practice is really pretty full now and so there isn't the capacity to do all of this follow-up.” (GP03)

Professional attitudes in terms of ownership issues were also seen as barriers to care. Respondents in specialist care felt uncertain about relinquishing a patient's care to primary care because of fears concerning inappropriate or ineffective follow-up. Other studies have also acknowledged similar concerns particularly in terms of whether GPs have the necessary skills to conduct follow-up care (Somerset et al. 1999; Greenfield et al. 2009). The following extracts highlight this issue.

“Sometimes the problem in healthcare is ownership issues, whether it comes from nurses or medical teams. They [the oncologists] don't want to relinquish the care of their patient. They're frightened that somebody else won't manage them as effectively as they will.” (CNS02, Haematological, Breast)

“That it seems to be like most of them, like the GPs are thinking, okay, you just take control, I'm happy because I've got heaps of work and you just don't want to let go of the patient. I can sense that there is that tension there. They just don't feel comfortable that the GP can sort of take hold of office, but if GPs have got an interest in it, that changes everything because then they [the oncologists] do feel more comfortable.” (GP04-cancer interest)

Some GPs considered the notion of oncologists' professional relationships with their patients. It was perceived that a desire on the part of the oncologist to follow the cancer patient throughout their journey was a barrier to care in primary care.

“Healthcare professionals develop a relationship with a patient, particularly when you have looked after someone who has gone through a tough period in their life. You have seen them come out the other end and you've

developed a professional relationship. I think professionals like to be able to see what's happening to the patient and there is perhaps a need from the professional point of view to bring the patient back just to find out what's happening and I think that is a barrier." (GP04-cancer interest)

Oncologists had concerns about whether GPs were interested in conducting follow-up care. Other studies report that GPs are happy to provide follow-up care; yet had worries about the lack of evidence informing best practice (Del Giudice et al. 2009; Greenfield et al. 2009).

"I'd have to say that on the whole we have found that GPs are not desperately happy about follow-ups for breast cancer patients." (SPEC03, Breast)

"Some people will have very good GPs and some people have GPs who don't want to look after cancer patients." (SPEC07, Lung)

"It never fails to surprise me that they don't appear to take more of an interest in their patients. I find that strange that GPs don't take a more active role." (CNS15, Neuro-oncology)

Some specialists reported that they lacked training around communication practices, which impeded their ability to communicate effectively with their patients. This issue was compounded by busy clinics.

"We're also perhaps not especially good at teasing out this information, partly because we may not be trained to do it and partly because the clinics are too big and too busy. You've got a clinic with 25 to 30 people and you know that if you delve too far, you might open Pandora's box and suddenly half an hour has gone and you can't really afford that." (SPEC04, Gynaecological)

GPs also described difficulties in communicating with their patients about their sexual attitudes and sexual functionality.

"We've been very bad about having discussions with patients about the impact [of cancer] on their sexual attitude or their sexual function. We're very slow to get into that whole area. But we need to extend this to all aspects of the patient's life; what is the impact of their disease on their life. For some patients, it's minimal. For others, there may be great anxiety associated with their cancer, which is having an adverse effect on their lives." (GP06-cancer interest)

Oncologists highlighted that the current evidence base in terms of survivorship and its outcomes was deficient. Other studies also confirm the paucity of evidence in this area (Pascoe et al. 2004; Allgar and Neal 2005; McIntosh et al. 2009).

“I don’t think we have a good enough evidence base for what actually is optimal follow-up and what the benefits of it are and probably what we really need is more randomised studies and different follow-up. I suspect a lot of the follow-up we do is utterly pointless and we are often doing it to satisfy ourselves and to be seen to be doing something.” (SPEC02, Prostate)

“Until we know how and what sort of strategies we should apply and advise, GPs aren’t going to know specifically what to look for, and when to look for it. So I think we need to do more research in that area to define what would be the best long-term follow-up.” (SPEC06, Colorectal)

Respondents from specialist care pointed out that a lack of evidence impacted on implementation of guidelines within specialist and primary care.

“There was no systematic follow-up; there were no guidelines to when, how, who should follow the patients up.” (CNS01, Gynaecological)

“So, asking them to commit to a follow-up arrangement, which probably GPs could do, but unless we know what that follow should be, it is difficult to advise a GP on what that should be.” (SPEC06, Colorectal)

5.4 Professional roles and cancer care follow-up

This section reports on the third theme to explore oncologists', CNSs' and GPs' perceptions in relation to professional roles and cancer care follow-up. The results will be presented for each group of health professional.

5.4.1 Oncologists' roles in follow-up cancer care

Professional roles were clearly linked to patients' needs. The issue of patient individuality was a constant theme in oncologists' accounts. Oncologists described how their role diversified depending on the patient and the type of cancer they were dealing with.

“It depends on the cancer and the patient, and where they are, and everything else.” (SPEC05, Prostate)

“I think you should design the role to suit the patients you're seeing.” (SPEC13, Breast, Upper Gastro-Intestinal)

Oncologists' roles were also discussed in terms of ensuring that each patient was satisfied with the approach to their care.

“My role is to ensure that I see every one of these individuals. I make sure that the appropriate follow-up is available and then I try to make sure that patients are happy with what has been given to them.” (SPEC14, Urology, Lung)

In this study, part of oncologists' roles was to provide direct leadership in the management and care of cancer patients. Oncologists regularly used terms, such as, 'gatekeeper' or 'team leader' to describe their leadership roles.

“I am the gate keeper in terms of what is appropriate, which will depend very much on what the likely outcomes, short or long-term for that individual patient is. Then it is very much a discussion with the patient. So my role, if you like is the team leader.” (SPEC14, Urology, Lung)

“Well, again, their role [oncologists] is, really, dealing with side effects, checking for recurrence with these patients; making sure we're not missing anything; and that if there are any problems that come up, then we can issue treatments for them speedily.” (CNS10, Breast)

Respondents were of the opinion that oncologists' roles also involved management of acute treatment related side effects. This was often dealt with

opportunistically, for example, dealing with side effects as they arose. However, it was debatable whether acute toxicities can be viewed as part of the follow-up process as this could be construed as an effect of on going treatments. Nevertheless, other research confirms oncologists' roles in terms of monitoring for early toxicities (Wood and McWilliam 1996). The following extracts highlight the perspectives of oncologists, CNSs and GPs.

“Well, as oncologists, the only follow-up is to deal with issues that arise. For example, ones that are complicated, a symptom like toxicity.” (SPEC11, Breast)

[Discussing the specialist's role] “It's very much dependent on the situation, but absolutely. Again, it depends very much on the disease site, the expectation, or if there are complex symptoms to be managed.” (CNS03, Urology)

“They're there for any chemotherapy or oncological side effects or complications.” (GP07)

Oncologists' roles also included managing patients after surgery. It was explained that patients with colorectal cancer, for example, often have challenging bowel symptoms, which required oncology support. The following extracts described oncologists' roles in relation to colorectal and pancreatic cancer.

“I think, because quite a lot of these patients have had bowel surgery, and so they have bowel issues, stoma issues, some of them. I think there is a certain benefit in being seen by a specialist team.” (SPEC10, Colorectal)

“The people that I see have had sufficient surgery but they're quite symptomatic forever. For people who've had an operation on the pancreas, they've got symptoms for the rest of their lives.” (SPEC09, Oesophageal)

The possibility of side effects from hormonal treatments was frequently discussed. Oncologists with breast cancer expertise expressed the opinion that patients having endocrine therapy were likely to endure challenging symptoms. Often patients would seek oncological support in order to relieve these symptoms. If symptoms were not alleviated, patients were likely to cease their hormonal therapy. Indeed research suggests that side effects such as hot flushes, vaginal discharge and dryness were common reasons for women to discontinue their hormonal therapy (Cella and Fallowfield 2008).

“The patient will return to see us for any side effect issues of the on-going endocrine therapy, and that’s quite a common issue. We know that one in four drop out of endocrine, adjuvant endocrine therapy” (SPEC11, Breast)

Management of cancer can involve surgery or may include additional treatments such as hormone therapy, chemotherapy and or radiotherapy. The aim of these treatments is to potentially cure patients, therefore, increase their longevity or in the case of palliative patients improve their quality of life. It is well known that after cancer treatments there is the potential for recurrent cancer either locally or in distant areas of the body (Feuerstein and Ganz 2011). In section 5.3.1, it was highlighted that a key reason for follow-up was to detect for recurrent cancer, therefore, an integral part of oncologists’ roles. Other research reflects these findings (Wood and McWilliam 1996; Greenfield et al. 2009). The following extracts symbolise the importance and need for oncologists to detect and manage recurrence.

“For patients who have had potentially curative treatment, my role, I think, is to detect early relapse.”(SPEC15, Prostate)

“If they do have a recurrence during that follow up period of three to four years, depending on the cancer, they’re referred back to oncology, or to surgery, depending on which is most appropriate. So that’s for your curative ones.” (SPEC10, Colorectal)

Oncologists were of the perception that they were less responsible for the detection of recurrence if relapse wasn’t curable.

“From our perspective, if relapse isn’t curable, it’s much less so. From the patients’ perspective, picking up early relapse is important. I don’t think that we really try to address that difference. They don’t ask us why they should be followed up and people who relapse are often angry if they perceive that they’ve not been followed up adequately.” (SPEC09, Oesophageal)

It was also perceived that part of oncologists’ roles in relation to recurrence was to select which patients require intensive follow-up compared to those who don’t.

“I think it’s trying to select out those that may need a bit more intensive follow-up and those that can be managed less intensively.” (SPEC04, Gynaecological)

GPs and oncologists discussed the importance of oncologists' roles around provision of information, particularly regarding helping patients understand their cancer and its treatments. Oncologists also provide health promotion and nutritional advice.

“They [oncologists] have a role at the beginning, at treatment and at the end of treatment, to give patients information about their cancer and prognosis and the likelihood of recurrence.” (GP04-cancer interest)

“To inform patients what is available. To make sure they get the best quality of specialist care. To give patients all the information that is required.” (SPEC08, Lung)

“And it's to give advice and reassurance to patients, as well as secondary prevention, life-style advice, etc. Stopping smoking is really important; a healthy balanced diet is too.” (SPEC15, Prostate)

Some respondents suggested that oncologists should manage adverse events of treatments and emerging toxicity including detection of secondary primary cancers.

“There is also role in the monitoring of adverse events of treatment, later emerging toxicity. We often discharge them from the follow-up at 5 years, but nonetheless that is a role. As a sort of foot note, there is also a role in detecting secondary primaries.” (SPEC02, Prostate)

CNSs were clear about the role of the oncologist in terms of managing long-term side effects. The following extract expressed an opinion from a CNS with breast expertise.

“For some people the treatments can often have longer-lasting side effects. So we feel that's part of what we're seeing them for. Or if they've developed lymphedema, so there are lots of things that we can bring them in for, not just diagnosis or recurrence.” (CNS02, Haematological, Breast)

Most oncologists perceived that management of late effects from cancer treatments was not part of their remit. It was suggested that these patients should receive their on-going supportive care needs out with the hospital setting, specifically in primary care or the voluntary sector. Other studies confirm these findings (Donnelly et al. 2007). There was considerable debate, however, regarding respective roles in cancer care teams (Greenfield et al. 2009; Grunfeld and Earle 2010).

“I think a lot of them need on-going support through either the GP or through our Maggie’s Centre, or through other groups who can help deal with what they’ve been through. I don’t see that as the role of the specialists.” (SPEC10, Colorectal)

This particular oncologist considered the importance of monitoring for treatment related, secondary malignancies. Yet it was also felt that this risk this was relatively low.

“I think yes, [on discussing their role] because most of the time these things are not going to happen. The likelihood of some of these late effects in terms of secondary cancers or heart disease or whatever, is relatively low.” (SPEC09, Oesophageal)

Some oncologists felt that they provided limited benefit to patients after the first few years of follow-up care.

“After the first couple of years, I’m not sure that we [oncologists] provide any added benefit. I am not sure that we do, but early on I think oncologists follow up is probably important.” (SPEC09, Oesophageal)

When GPs discussed the role of the oncologist, this was usually in relation to detection of recurrence and management of treatment related side effects including assessment of treatment effectiveness. It was not specifically stated by this group of health professionals that the oncologist had a role in management of long-term or late effects.

“The role of the specialist, I suppose, is to ensure that they haven’t had any significant side effects from the treatment, to assess how beneficial the treatment has been, to determine if they need any follow-up courses of treatment in the future. And to appropriately monitor the patient for signs of recurrence.” (GP08)

CNSs and GPs felt that part of the oncologist’s role was to assess the patient’s psychosocial status. It was thought that this should be conducted around the time of the medical consultation. Respondents felt that patients derived considerable benefit from seeing their oncologist, particularly around a truthful and realistic prognosis.

“They [specialists] know how to be straight to the point and honest, and not give the patient the impression that perhaps this will be fine, when really they know it’s not. So, I do think the oncologist has a vital role for these cancer patients, they need to be seen by a cancer specialist.” (CNS11, Urologist)

“I think the patients get a huge benefit from seeing their specialist. Even if it’s just to say, yeah, you’re doing fine. And, do you have any concerns? Do you have any problems? I think there’s a lot to be gained for patients from seeing the consultant of their choice, repeatedly. It can be reassuring.” (GP03)

Oncologists also discussed their role in terms of psychosocial needs. Often this involved acknowledging the patient’s need for psychological support and provision of reassurance.

“One of the things that they require is on-going support, and reassurance, which is psychological.” (SPEC01, Lung)

“I suppose questions and reassurance would come into that. If they’ve got breast pain after conservation treatment, we can reassure them.” (SPEC13, Breast, Upper Gastro-Intestinal)

Oncologists showed that they were aware of the patients’ potential financial worries and were key in terms of signposting patients to CNSs, social workers, Maggie’s Centres and Macmillan nurses.

“The main psychosocial needs are financial worries. Work. What’s going to happen to their families? Those that need benefits should have had that arranged. You know a lot of it is provided in hospital with support groups. Maggie’s is another support base for them. I would try to get the family involved with clinical services, for example, Columbus, which provides a huge service including Macmillan nurses.” (SPEC08, Lung)

Few oncologists alluded to or acknowledged their particular role in provision of practical, psychosocial support. This oncologist prioritised physical needs over other patient needs. Other studies confirmed that oncologists perceived their role around physical support, rather than psychosocial supportive care (Greenfield et al. 2009).

“I think they’re very much focusing on the physical aspects of care. I think the oncologist is about surveillance, looking at symptoms. It’s a busy clinic, so they [the patients] don’t really ask questions.” (CNS09, Colorectal)

It was also highlighted by respondents that physical symptoms can act as catalysts for psychosocial distress. In section 5.3.4, it was described that sexual dysfunction can have a detrimental effect on a patient’s physical and psychological wellbeing. Some CNSs perceived that specialist and primary care professionals could become more involved in provision of support for these patients.

“Sexual dysfunction is a huge issue. It’s not something that’s managed properly. And it’s something that patients don’t really look at during treatment, but it can cause enormous problems for them both physically and psychologically and socially. And that’s something that the specialist can do, but primary care people can certainly become much more involved in that.” (CNS02, Haematological, Breast)

5.4.2 CNSs’ roles in specialist care

In section 5.2, it was described that oncology nursing had not really existed until the development of CNSs’ roles. Historically, doctors had more responsibility and greater domain over patient care. Currently, however, there seems to be a shift toward equal sharing of patient care, particularly in cancer care. The following extracts highlight the changes in nursing roles.

“My particular role is an expanded role in as much as we do what would normally have been done by a doctor previously.” (CNS07, Breast)

“There are a couple of clinical nurse specialists around here who do follow up clinics, but basically their role is the same as the medical staff role.” (SPEC03, Breast)

“I think the patients won’t often see consultants in the follow-up, unless there were issues. In the main, it’s xxx nurse specialist who arranges their optimum follow-up clinics.” (SPEC11, Breast)

This particular GP highlighted the significance of CNSs’ roles in terms of development.

“The future’s bright for clinical nurse specialists. I mean they have clearly got a huge role and ever increasing role, in some ways I think that is really super.” (GP03)

Most CNSs felt that it was important to oversee patient care from the beginning of the cancer patient’s pathway in order to understand their needs and to provide supportive care. The following extracts give an insight into CNSs’ roles from diagnosis.

“The most important thing is that she fully understands what the patient’s needs are. She’s there at diagnosis, at the MDT, to know what the follow-up is and to be involved in that decision.” (CNS11, Urologist)

CNSs frequently described their role as patients' advocate as well as a coordinator of care within the hospital environment.

"I see the clinical nurse specialist as the patient's advocate. I see the nurse specialist as the coordinator. She is at the hub." (CNS11, Urology)

"It's [the CNSs role] is very much a lynch pin." (CNS05, Head, Neck)

CNSs were considered a key contact for patients. The following extracts were indicative of CNSs' and GPs' responses.

"The patient has got a contact number, so that the patient knows if there's a problem, or if it's actually for an appointment, they can contact the nurse specialist." (CNS11, Urology)

"I think it's important as a nurse specialist, that we're there for advice and backup for patients, so that there's a contact, and for signposting if they've got problems. You build quite a relationship with patients and it's important that they know where to turn afterwards, for backup." (CNS03, Urology)

"They become the key contact, the main support that the ladies have with breast cancer." (GP05)

CNSs were also considered to have a key role working alongside oncologists. The following extracts show how CNSs provide support to oncologists.

"In terms of follow-up, [CNSs] they work alongside us, and have ready access to us." (SPEC06, Colorectal)

"They see and assess the patient, manage side effects of treatment. I am not sure they can order mammograms but they can certainly write out the forms. If you're looking for a simple check-up, for example, prostate patients who are treated by radical radiation or surgery- they're in for a five minute chat and maybe a rectal examination and a PSA, which can be dealt with by a nurse specialist." (SPEC03, Breast)

The following extracts show that CNSs provide a link between consultants to keep them informed of their patients.

"But more importantly, the nurse specialist can keep all the consultants informed." (CNS11, Urology)

"Well, the clinical nurse specialist with whom I work in my lung cancer practice is absolutely invaluable, because what she does is provide the fairly crucial link between primary care, the respiratory team and myself in oncology." (SPEC01, Lung)

Throughout the interviews CNSs perceived that a significant part of their role was to organise patient care within nurse-led clinics. The following extracts highlight the diverse nature and responsibility of their working practice within cancer clinics.

“I work in new patient clinics and assess patients that are referred. I do three new patient clinics a week and two follow-up clinics a week and those are the patients who are referred to follow-up.” (CNS07, Breast)

“Some of them have been put into the oncology clinics, some work at the prostate clinics.” (CNS12, Prostate)

“I think the roles pretty diverse. I do a radiotherapy review clinic by myself, but our main clinic is multidisciplinary.” (CNS15, Neuro Oncology)

CNSs discussed their professional roles around the individuality of cancer care. It was reported that CNSs adapted their role to suit the individuality of patients' needs.

“Part of what we do is on-going support. The side effects, for some people can last quite a long time, some people sail through it, others really do struggle with some of the treatments.” (CNS10, Breast)

“A lot of our patients have bowel dysfunction, sexual dysfunction... so providing advice and support for that.” (CNS09, Colorectal)

CNSs also recognised their role in relation to the individuality of cancer patients' psychosocial needs. Some patients, for example, required considerable supportive care, whilst others needed very little input. The following extract reflects the viewpoints of many.

“There's the psychological support aspect, not only for them, but for their families. Some people need very little support, whereas other people need a lot of psychological support, because they have complex issues.” (CNS09, Colorectal)

CNSs were considered integral to getting alongside patients and families and helping them to accept their cancer diagnosis and prognosis.

“We do lot of counselling and psychological support. A lot of time is spent talking to patients and families and helping them come to terms with diagnosis and prognosis. And, making sure they understand what the treatments are.” (CNS06, Oesophageal)

It was common for GPs to discuss CNSs' psychosocial roles around emotional support. It was perceived that CNSs established rapport with patients, therefore, allowing them the freedom to ask questions that they may not ask their oncologists.

“That’s getting on the side of the patients and getting closer to them emotionally and asking questions which they may be afraid to ask the specialist.” (GP01)

“The CNS can enhance the quality of care, she can develop relationships and she can be easily accessible. There may be fewer barriers than speaking with the oncologist. I think the relationships that nurses develop with patients are similar to relationships that GPs develop with the patients, which has the potential to enhance care.” (GP02)

CNSs often provided support for patients and families to deal with their financial issues. CNSs regularly conducted practical administrative tasks so that cancer patients would receive their benefits and disabled badges.

“Making sure patients have got the benefits they’re entitled to. Applying for the blue disabled badges for cars. Writing letters for other benefits, or grants. So, a lot of it is a practical thing that we’re involved with.” (CNS06, Oesophageal)

“We do the physical and holistic things too, including support for financial and family issues. That can be a much longer process for some people than others.” (CNS14, Breast, Colorectal)

CNSs roles were also described out with specialist care. These narratives appeared to contribute more towards the optimisation of primary care; therefore, will be included in section 5.6.

5.4.3 GPs' roles in follow-up cancer care

GPs in their survivorship role were considered key contacts for patients after their treatments. GPs were seen as crucial in terms of providing on-going medical care to the patient (Simon 2008b).

“I think it’s central, so the GPs the lynchpin in my view. Once the patient’s completed their specialist therapy, the GP is effectively the first port of call for the patient (SPEC11, Breast)

“We’re the first port of call if any symptoms recur, like pain or vomiting. The patient would come to us first for treatment and assessment.” (GP08)

CNSs expressed the opinion that GPs were ideally placed to act as a first point of contact for patients with prostate and head and neck cancers, for example. The following extracts show how CNSs encourage patients to contact their GP for management of their treatment related symptoms.

“GPs very often are the first point of contact for the patients. For patients who have had radiation prostatitis, we would advise them to contact their GP first of all.” (CNS03, Urology)

“The GP is very much there to be contacted, if there are any problems.” (CNS05, Head, Neck)

GPs appeared to actively participate in the follow-up of patients with prostate cancer.

“If somebody has currently finished with oncology and they’re in a bit of watching and waiting, let’s see how they get on.” (GP03)

GPs also reported that a significant amount of their practice related to holistic care. In particular, care of the cancer patient’s physical and psychosocial needs.

“My role as an individual general practitioner is to make sure that I am assessing the patient’s holistic needs. Are the patient’s physical, psychological and psychosocial things been taken care of?” (GP07)

GPs were acutely aware about the risk of a cancer recurrence. Part of this role; however, was deciding if the patient had a cancer recurrence or if their symptoms were related to another health issue.

“Because they have had a history of cancer- an awareness of the possibility of the cancer returning, we often have to determine the possibility of that, or if it’s just a simple condition that we treat.” (GP08)

“People who’ve had radiotherapy and thinking about the problems they might have with bones and stuff like that, or whatever in the future; that sort of thing. Yes, I think we’ve got a role there.” (GP03)

Specialists considered that if GPs were suspicious about the possibility of a recurrence, part of their remit included reporting this to specialist care.

“I think they (GP) have a remit in maintaining and reporting any specific concerns in terms of toxicity or relapse.” (SPEC06, Colorectal)

Other respondents felt that a key role of the GP was to monitor and assess patients for signs of disease progression.

“I spend quite a lot of time on the telephone to GPs about various issues very often the first point of call, when a lot of the disease related problems arise or progress between appointments, which often present to the GP. Sometimes a patient will phone here and we’ll ask them to see the GP to make an assessment. So I think that is one of their key roles.” (SPEC02, Prostate)

Oncologists also discussed GPs’ roles in terms of comorbid conditions. Some oncologists felt that they do not possess the skills to manage the cancer patient with co-morbid conditions because of their involvement with cancer related issues. An international and UK study compared the roles of GPs and oncologists in cancer care and found that most GPs managed co-morbid conditions, whilst oncologists were less involved in these roles (Klabunde et al. 2009; Khan et al. 2010).

“I think the GP is their primary carer. We’re dealing with the specialist problems related to cancer. We can’t be used to deal with all the medical problems.” (SPEC12, Head, Neck)

“I think the GP has to continue to look at the [patients] general health. Our knowledge is less than a general practitioners who sees lots of disorders over time.” (SPEC06, Colorectal)

GPs also highlighted their role in relation to psychological need. The following extract shows how this particular GP empathises with patients about their suffering and allows them to feel comfortable to discuss their distress.

“Witnessing people suffering, I would say that’s a key role for general practice. People who just come in and they go, blah. Just agreeing with them that it is miserable and it is rotten. And I think it’s a place where people can come and be emotional, without it being frowned upon.” (GP03)

Central to GPs working practice in terms of psychological need was managing the cancer patient’s fear of recurrence. Uncertainty and a fear of a cancer recurrence was ubiquitous amongst cancer patients (Corner and Wagland 2013)

“What are we trying to do with follow-up? You could say that our role is to reassure the women, but the evidence shows that women, particularly in breast cancer, become very, very, anxious in the weeks leading up to follow-up, but the reassurance they get from follow-up is probably false.” (GP05-cancer interest)

“But they want to know whether the disease has recurred or not. They have all sorts of concerns, which they think they should bring to a doctor. For some patients, it’s minimal. For others, there may be great anxiety, which is having an adverse effect on their lives.” (GP06-cancer interest)

GPs described the Cancer Care Review as part of their practice. In particular, it was identified that these templates allowed GPs to provide formal care within six months of a cancer diagnosis. The literature informs that the Cancer Care Reviews have given GPs a structured role in cancer care follow-up. However, further research is needed in terms of how they are regarded by patients and the primary care team (Watson et al. 2010).

“There are quite good principles within the Quality and Outcomes Framework about how you meet the patient within six months of their diagnosis. You know patients with a new diagnosis should have a cancer review by their GP within six months.” (GP06-cancer interest)

Most respondents’ saw the Cancer Care Review as an opportunity to cover the patient’s individual health needs, however, after this time care by the GP would be opportunistic in nature.

“No, I would have to say that it [follow-up] is really just after the first initial diagnosis that the system is in place [Cancer Care Review]. We would see them after their diagnosis to see what is going to happen with them to get an idea of their care. We do that as a matter of course, but we don’t as a matter of course necessary follow beyond that, as it would be opportunistic.” (GP02).

Other GPs described that follow-up care was often patient initiated. Rose and Watson (2009) acknowledged that many patients, particularly those with breast and prostate cancer, for example, were likely to continue with their treatments for several years after the primary treatment. GPs, therefore, were likely to have responsibility for monitoring the impact of these treatments.

“I don’t have much to do with the formal follow-up of cancer patients, but I do follow-up patients more on an ad hoc basis that is determined by the patient themselves.” (GP04-cancer interest)

Many of the respondents described GPs' roles in relation to the organisation of patient care. Other research has also found that GPs seem well positioned to take on the responsibility of survivorship care (Cheung et al. 2009).

“Once the patient has finished treatment, the GP is in charge of their care.” (CNS06, Oesophageal)

Other key elements fundamental to GPs' coordinating role include information provision. Many GPs described their role in terms of managing the exchange of information between specialist and primary care.

“An important role is when cracks appear in the system and patients fall through the net. What's the follow-up? Often results don't appear and we sometimes have to ensure that we telephone or write to the doctors involved.” (GP08)

This role extended further with some GPs providing information to patients about their illness. This involved informing and educating patients with the intention of helping them understand their physical and psychological issues.

“Sometimes we have to have an educational role or a supportive counselling role to get the patients informed.”(GP08)

“We've got a role in trying to help people make some sense of what's going on. Partly in a practical sense of who's doing what to them and why.”(GP03)

Some GPs were less positive about their role in survivorship because of gaps in their knowledge. This was particularly noticeable after the patients had been referred to the oncologist. GPs were keen to be kept informed of the patient's health status.

“The GP hands the patient over to the oncologist and then hears nothing. I've always advocated real time communication, so that we can be kept in the loop about what's happening with the patient.” (GP05- cancer interest)

5.5 Communication between primary and specialist care

This section reports on the fourth theme to explore oncologists', CNSs' and GPs' viewpoints regarding communication practices and how these can be enhanced.

5.5.1 Mode and type of information across the interface

Oncologists reported that the commonest method of communication to primary care was the traditional letter. Often letters, which included treatment plans, were sent to GPs after MDT meetings and clinic consultations. A fairly recent study of MDT coordinators found that letters was the most commonly used method by oncologists to communicate to primary care (Soukop et al. 2007).

“On a weekly basis we send out a record of each patient that is discussed at MDT, so that they’re aware of the treatment plans and what the focus is.” (CNS09, Colorectal)

“I think as a team we communicate with primary care quite well. In that every time they’re seen here, the GP receives a copy of the letter, they’re seen here during the treatment once a week.” (CNS05, Head, Neck)

Telephone calls were sometimes used to communicate information to GPs. Often oncologists used this method to highlight a health issue or to proactively glean advice from the GP.

“It is not uncommon after a clinic to have an issue that you want to make phone calls to the GP, sometimes about patients that I have given bad news to, or I have just started them on something like Warfarin.” (SPEC10, Colorectal)

“We do get telephone calls; sometimes the consultants will ask my opinion. I may know the patient much better than they do, they might ask what I think about a particular course of action.” (GP01)

Whilst oncologists used letters and the telephone to communicate to GPs, GPs on the other hand, often used a combination of methods to communicate to oncologists. For example, telephone, emails and faxes.

“I get phone calls from GPs and I’m quite happy with them. I get emails from GPs and very quickly we get the patient sorted out.” (SPEC14, Urology, Lung)

“I often get faxes through from GPs saying that so and so is not well.” (SPEC08, Lung)

“We now have a form that they use. They can get it off the computer package, they actually have to fill it in and give us the information they want by using a form.” (CNS07, Breast)

According to oncologists, information from GPs was usually about their patient's treatment related symptoms or disease progression.

“We get letters from GPs, about problems their patient's having with treatment. So we'll generally get a letter saying this person's having trouble, they've been having hot flushes, vaginal discharge.” (SPEC13, Breast, Gastro-Intestinal)

“GPs communicate back to us. We will sometimes get letters if the patients have got issues they think needs further investigation. Should they have a bone scan because it may be metastatic disease?” (SPEC03, Breast)

Most GPs were of the perception that primary care was more technologically advanced than specialist care and that it would be less usual for primary care to employ traditional methods of communication.

“We're very lucky in primary care in that we moved to computerisation much earlier than other sectors in the health service. It is unusual to have a letter sent through the post or faxed other than for emergency referrals normally sent through SCI Gateway.”¹⁵ (GP06-cancer interest)

Not all oncologists were convinced that GPs used electronic methods to communicate information to specialist care. Some oncologists considered that GPs could be doing more to include email technology in their working practices. Evans et al's (2001) work found that hospital doctors used email more than GPs, although this was for social reasons rather than transferring clinical data.

“I would hope that in the next few years, more of the GPs will learn that email is probably the most efficient way of getting things done promptly and appropriately. There are a lot of GPs who just haven't embraced that at all.” (SPEC14, Urology, Lung)

“GPs can bleep here, they often don't like to bleep here and very rarely they email you.” (SPEC08, Lung)

5.5.2 Barriers to communication practices

Respondents frequently discussed professional relationships as a barrier to optimal communication. For one particular CNS, this was described in terms of traditional hierarchies and the differences between nurses and GPs.

¹⁵ SCI Gateway is a national portal for clinical communications between and within healthcare organisations as a product of the eHealth Strategy in Scotland. SCI Gateway facilitates the secure and reliable exchange of patient-based clinical data (NHS 2011).

“When I first started it was you’re the nurse and I’m their doctor - don’t tell me what to do kind of thing.” (CNS08, Lung)

Particular emphasis was placed on the need to improve cooperation between oncologists and GPs.

“We need a feeling of co-operation, which we don’t have at the moment. Every time I ask a GP to do something, they probably think oh God, am I going to have to do that?” (SPEC08, Lung)

Some GPs reminisced about the regular contact they had with consultants. The productive nature of these meetings was seen to create a semblance of unity between professionals. Lack of regular contact has meant that some older GPs, for example, were unsure of who the younger consultants were.

“We don’t see each other often. I think it’s a shame; we would have frequent meetings with local consultants. Another function of these things would be to get to know the consultants. To get GPs and consultants to mix and to know each other, which I think has been lost a wee bit. In my area I think I know many of the consultants who are sadly about my age, but I don’t know any of the younger ones which is becoming a disadvantage.” (GP01)

Oncologists also suggested that routine contact from primary care is non-existent except when solutions were required for particular problems or issues. There is a sense here that oncologists would like more frequent contact with the GPs regarding cancer patients.

“Routine communication from GPs is non-existent, we get no letters from GPs to us to say if the patients have seen them. Sometimes the patient comes up and we find out they’ve had a whole series of visits with GPs, we get no communication from them.” (SPEC03, Breast)

“Most of the time I hear from a GP because there is a problem, rather than because there isn’t a problem.” (SPEC02, Prostate)

Oncologists’ perceptions that GPs do not communicate effectively were reflected in GPs’ responses. Some GPs, for example, perceived that a key part of their communication was to refer patients to the oncologist. After this phase, however, the expectation was that the oncologist was responsible for the exchange of information to the GP.

“I think the predominant flow of information is going to be from secondary to primary care, but again the tradition or primary care is that we write a letter at the point of referral or if we’re referring a patient back. There isn’t a system for communicating information between times.” (GP06-cancer interest)

“ There is the expectation of, for instance, when patients start treatment that there is communication from the GP.” (GP06-cancer interest)

GPs also reported that they were required to know what was happening during the patient’s treatment phase. In some GPs experiences, it was perceived that oncologists do acknowledge letters, yet when GPs have issues with regard to patient care; there was no acknowledgment of that specific letter.

“If I have written to colleagues in secondary care, they will acknowledge it. But I have written to colleagues in secondary care saying prior to seeing this patient or whatever, there are a few issues that have arisen and there is a clinical need just now, there is no acknowledgment of that letter at all.” (GP07)

Some GPs described that they were left out of the communication loop when consultants were conferring. Whilst GPs were copied into letters between specialists, any requests for information did not include the GP. Therefore, GPs found it difficult to comment on aspects of the patient’s care because enquiries were directed to the specific consultant involved.

“So, I am finding more and more that letters go between consultants, usually oncologists, physicians or surgeons and GPs are copied into this. It often means that I can’t act on letters, because the questions are for the oncologists that actively see them. It does immediately concern me in terms of acting on things.” (GP01)

Finally, some GPs considered the impact of communication on the workload of oncologists.

“If we started writing to the consultants every time we saw somebody with condition X, they would really get a lot of letters. (GP03)

CNSs generally felt that it was difficult to get access to the correct GP because patients often had a number of health professionals involved in their care. Compounding this problem was that some patients were unsure of who their GP was.

“I give that information as soon as I get hold of a GP. But the difficulty sometimes is because there are four or five GPs; it could be more than one person that is seeing this patient. And patients often say to me - well my doctors meant to be such-and-such, but I never see him. I often see so-and-so and someone else.” (CNS08, Neuro-Oncology and Lung)

Specialists also encountered difficulties when attempting to contact the GP by telephone. Often the gate-keeping role of the receptionist impeded communication from oncologists to GPs. This is not to infer that receptionists prevent communication from oncologists to GPs, but rather the frustration that oncologists feel about GPs unavailability. Other studies around gate-keeping roles suggest that inflexible attitudes or uncooperative behaviours can be a significant barrier to effective communication (Wood 1993).

“You often get met with receptionists who say they are in surgery, while we are quite happy to be disturbed, they are sacrosanct when they are in their surgery, which is annoying.” (SPEC07, Lung)

“It is always a pain getting through to GP practices and getting the GP and they’re out on calls blah, blah, blah.” (SPEC10, Colorectal)

Similarly, some GPs had difficulties when attempting to telephone the oncologist. At times, access was difficult because of oncologists varied working practices, which was seen to impact on the timeliness of communication.

“I think it is very difficult to communicate by telephone. The oncologists can be at five or six different hospitals in one week so that is difficult. And often if you have had to communicate you can phone first on the Monday and it can be Thursday till you hear from them.” (GP02)

The quotes described above highlight the communication difficulties between oncologists and GPs. Some oncologists confirmed their lack of understanding around GPs’ communication needs.

“I think the barriers are the realisations of what others want, or the perceptions of what others want. The GP perception is that they want a letter after every clinic visit. My perception is that is what they don’t want.” (SPEC03, Breast)

One CNS however, identified what was a key issue:

I don't think anybody has actually gone to the GPs and said what do you want to know?" (CNS12, Prostate)

The literature suggests that GPs would like to be able to contact the relevant specialist should problems arise (Babington et al. 2003; Del Giudice et al. 2009). Similarly, oncologists wished to receive feedback from primary care (Berendsen et al. 2009).

Oncologists often described the timeliness of letters as a barrier to communication across the interface.

“We are very poor at communicating because we have a backlog on all our letters and our typing. I will dictate things and even when they are flagged up as urgent it will be weeks later before the GPs get those letters.” (SPEC01, Lung)

“The problem is that the turnaround for letters can be 4 to 6 weeks, in an ideal world you would want the letter delivered that week but it is not always the case.” (CNS02, Haematological, Breast)

These reflections from oncologists and CNSs were often recounted in the interviews by GPs. GPs acknowledged that the delay in receipt of letters was a significant issue for them. The cause of the delay in correspondence was thought to be secretarial speed and differences between consultants and cancer units.

“I think sometimes letters take a long time to come which is a secretarial issue. A letter will come, but letters from hospital take a notoriously long time to come.” (GP01)

“Time lag can be very much an issue. I think it depends from unit to unit and consultant to consultant.” (GP09)

Respondents often described communication difficulties around electronic information systems. Oncologists were of the opinion that the current email system was an unsatisfactory vehicle from which to transfer confidential information across the communication interface. Participants feared that their patient's medical records might be compromised. Even within these groups there was confusion about security and confidentiality issues.

“I think we are not meant to email patient details, specific information back and forwards to primary care.” (SPEC01, Lung)

“Due to confidentiality and security issues, we’ve never been able to find a way to make the Excelicare¹⁶ system transmit information to general practice.” (SPEC04, Gynaecological)

Some respondents referred to the Information Communications Technology (ICT) mismatch between specialist and primary care and the impact this has on communication efforts.

“Well hospitals: they’ve all got their own patient management systems, but that tends to be about appointments. But what they don’t have is one clinical system where all the clinical notes go. Some of them are doing it. But with us [primary care], we never see a case file. Never, ever do I see a case file on my desk. The hospitals are behind in their Information Technology services. That’s why you can’t get information and that’s not good” (GP05- cancer interest)

5.5.3 Enhancement of communication practices across the interface

Respondents considered that regular contact across the interface might facilitate communication links between specialist and primary care.

“I think the single thing that would make communication better would be more clinical time. I think it would be great if we had the time to...maybe routinely is putting it too strongly, but time on both sides, both on acute and ourselves, to facilitate discussions.” (GP03)

Oncologists were keen to describe methods for improving professional relationships as a way of creating a link between settings. This was seen to involve face-to-face meetings.

“I think actually meeting with people and discussing things across specialists is useful because I think you hear the other person’s points of view. We had the GP cancer lead at our clinical board meeting and it’s very important to get their feedback.”(SPEC10, Colorectal)

Respondents saw the structured discharge letter as a method to facilitate communication across settings and to meet professionals’ needs.

¹⁶ Excelicare is an application that allows clinical systems to communicate with other clinicians across the healthcare spectrum. It incorporates telecommunication, multi-media and the Electronic Patient Record (EPR) framework (Axsyst 2010).

“I think if we had better communication in terms of written communication towards meeting our needs and I am sure they would say the same from our side. If we met their specific needs then that should improve things.” (GP02)

“I think if we can do it as a shared approach with primary care, in a structured fashion that enables communication swiftly backwards and forwards, then again I think that’s got to be an improvement.” (SPEC01, Lung)

GPs described in considerable detail their requirements regarding the format of the immediate discharge letter. It was thought that specific headings with appropriate text would facilitate specific actions for the GP.

“Actions for the GP, because the letter has got so many purposes. If there was something specifically the specialists wanted to tell me, put under comments for the GP.” (GP07)

“I would much rather see something with these basic headings, some appropriate free text. I don’t need War and Peace. I just need something that’s appropriately detailed and preferably legible as well, which can be a problem with immediate discharge letters that are handwritten.” (GP08)

Information, which GPs highlighted as important to receive include: staging of disease; available treatments; potential side effects; prognosis and follow-up plans. The findings from this study echo those of other studies. GPs specific requirements include diagnosis and treatment options including prognosis (Bado and Williams 1984; Tattersall et al. 1995; Wynn and Hindley 2004; Kripalani et al. 2007), and side effects (McConnell et al. 1999; Kripalani et al. 2007).

“I am more interested in the diagnosis, what’s the stage, the likely prognosis, what treatments are available, for example, whether they are having adjuvant chemotherapy or adjuvant radiotherapy. What are the potential things to look for, adverse reactions to it and what are their plans for follow-up.” (GP02)

“The bits that the GP needs to know. Are they having another cycle of chemotherapy? Did you feel the disease had progressed?” (GP07)

GPs frequently talked about the importance of being aware of the patient’s medication status, investigations and results. Recent research concerning GPs’ preferences for discharge letters found that medications and changes to medications were considered important aspects of care (Kripalani et al. 2007; Frew et al. 2010).

“Say that it’s been started, [medications] say that it’s been stopped and why, because quite often some of these patients when they are acutely ill, you put them in hospital. You find that their medication has been stopped. Action points for GP’s, fine, but are they reasonable action points.” (GP09)

“It should have a list of medications and notification of any changes in medications and why medications has been discontinued. It should have information about important investigations that were done and the results.” (GP08)

GPs also considered the need to have an understanding about follow-up plans. Emphasis was placed on management plans and the shape of follow-up.

“So I’d like some quite specific information about the on-going follow-up and what the management is going to be and the role of that follow-up.” (GP04-cancer interest)

Some GPs perceived that it would be beneficial to include information about patients’ knowledge of their illness. A study of discharge letters found that GPs wanted information about what the patient was told at the clinic consultation including what they knew about their disease. In particular, how the patients were coping (Farquhar et al. 2005).

“What are the patients being told, what is their understanding of it, what have any carers been told, has the prognosis been discussed with the patient, all of those would be extremely useful. (GP06-cancer interest)

“The other thing that is very important is what they have been told.” (GP02)

More recently, the SCP has been introduced, which, summarises the patient’s diagnosis, treatment and aspects of their on-going follow-up care. Treatment summaries, which form a part of the SCP were evaluated by NCSI/Macmillan and were well received by health professionals across settings (Watson et al. 2011b).

Respondents often discussed the potential of a secure email system, which was seen as a method to improve clinical access and data transfer between oncologists and GPs. Research around email systems have found that electronic codes and passwords may help to encourage the use of email and dispel concerns about confidentiality (Evans 2001). Developing email systems for appropriate information exchange is an important vehicle from which to meet standards of care and should be considered a high priority for research and development

(Kvamme et al. 2001; Richards et al. 2005; Grunfeld 2008; Aiello Bowles et al. 2008).

“I think if you had a secure email system you might use that more often. But then you then might not phone the GP.” (SPEC10, Colorectal)

“I think there needs to be more access through things like computers. If only I could email somebody.” (CNS08, Lung)

Electronic communication was also discussed in terms of SCI Gateway. In particular, it was thought that SCI Gateway could be used as a two-way communication tool from which specialist and primary care could transmit data.

“[SCI] Gateway is literally that, a gateway between primary and secondary care. It has up until now only been used for referrals for secondary care, but it is capable of two-way transmission of data. And there are now pilots on the way in different transport areas to look at two way access traffic through Gateway.” (GP06-cancer interest)

Some respondents discussed the potential of a computer based management system that would hold information about the patient. This model may facilitate and inform the patient about their condition and follow-up care.

“They can phone in, they can document the toxicity. I think if you have a central place for patients to phone, which could be managed by a computer. So that whenever a patient phones in, you’ve got all the details, it’s all on computer and so whatever information you’ve given that patient, or the management, it’s documented.” (CNS02, Haematology)

In section 5.5.2, oncologists and GPs described their difficulties in gaining access to other professionals when using the telephone. Largely this was due to professional availability at the time of the call. Some respondents considered that designated numbers at specific time points might be a solution in terms of overcoming telephone access issues. The following extracts highlight the viewpoints from both specialist and primary care.

“I think easy access by telephone from both sides. Telephone communication is without doubt the most effective way of getting things sorted quickly.” (SPEC01, Lung)

“If they wanted to speak to us [by telephone], they could give us time options of when they particularly wanted to speak, and we could pick a time when we are also going to be free. That would be useful, because if you want to contact somebody, you are not going through a receptionist who says they are not here today. Maybe even on the GP’s heading there could be contact times.” (CNS07, Breast)

“There was a conventional educational thing with the British GPs and Danish GPs. One of the things that the Danes do is that their society wants and expects telephone consultations. The first half hour of the morning is when you phone your GP if you want to have a chat. And they’re all sitting around actually phoning.” (GP03)

Respondents discussed the issue of research and investment as a way to improve ICT across the interface. Emphasis was placed on the importance of telemedicine.

“We need innovation. We need a lot of research. Some investment. I think if you had to put money in at the moment, it would be into Information Technology because of telemedicine.” (GP05)

5.6 Optimising the role of primary care

The final section of this thesis reports on the fifth theme to explore oncologists', CNSs' and GPs' perceptions in relation to the optimisation of primary care.

5.6.1. CNSs acting as an intermediary across settings

As previously suggested in 5.4.2, CNSs' roles appeared to be key in terms of optimisation of primary care. For example, some CNSs informed they had the potential to act as intermediaries across the interface. Part of this role included informing and updating GPs about changes to treatments and potential adverse effects.

“Well, I think by making sure that we keep the GPs informed of what's happening with their patients, and whether we have to do update sessions with GPs so that we keep them aware of what the changes are with treatments, and what things they should be looking out for.” (CNS10, Breast)

CNSs were also considered a dedicated point of contact for GPs, particularly relevant for patients who required immediate access back into the specialist system.

“The GP can also contact me. I write to the GP formally letting them know treatment is finished. A lot of GPs will contact me directly and I will slot the patient in to the appropriate clinic accordingly.”(CNS01, Gynaecological)

Respondents also perceived that CNSs provided a link between specialist care, patients, district nurses and the voluntary sector. This involved provision of information and advice to patients and referring onto the voluntary sector. A key aspect of their work was supporting nurses and GPs to provide optimal care.

“Have they [the patients] had test results, heard about appointments? They know [the patients] to contact us if they've got any questions or queries. Providing information and advice and referring on to Macmillan and Maggie's or social workers for benefits advice. We also act as a resource for the girls who work in the community. They [GPs] often phone us and say, we've got this patient, and we've tried this. Can you suggest something else?” (CNS09, Colorectal)

CNS-led telephone support was considered essential in terms of assessing a patient's health status and providing support for patients who were worried about a cancer recurrence. Other reports also suggest that the nurse-led telephone

model may be an efficient way of providing patient care (James et al. 1994; Sardell et al. 2000; Faithfull et al. 2001; Davies and Batehup 2009). The following extracts highlight how the telephone model might reduce the number of hospital visits.

“Other neuro-oncology nurses use this model. There was a great neuro-oncology nurse who used telephone consultations. It is easier to check things over the phone and to stop people coming back and forth to the clinic.” (CNS15, Neuro-Oncology)

“The model that they were exploring would be telephone follow up with the clinical nurse specialist, that could also be face to face contact. But you don’t need a breast surgeon to see a woman who’s had breast cancer three years ago, who is worried about a recurrence.”(GP06- cancer interest)

Other CNSs discussed the potential of nurse-led clinics in general practice. In particular, bringing expertise out with specialist care into the community, with the broad goal of avoiding hospital visits.

We could come out and do clinics in the surgery area, and we can tell the patient the diagnosis in their own surgery, rather than them coming to the hospital, and it will allow the patients to avoid the hospital visits.” (CNS10, Breast)

GPs also talked about the value of CNS-led clinics in general practice. The CNS was seen to provide psychological support for cancer patients in the early stages of their cancer journey.

“We have got a CNS who is our early cancer support nurse. She is attached to us. She will see all cancer patients at the early stages and give quite a lot of support, psychological support particularly.” (GP07)

GPs and oncologists considered that CNSs could extend their roles to include nurse-led clinics in community hospitals or local health centres. The potential for CNSs to be involved out with specialist care and in the community setting was recognised in the Commissioning Support for London stakeholder event (NHS 2010b). The following extracts highlight the potential of CNS-led clinics in the community for patients needing less intensive follow-up.

“I think there are great benefits of clinical nurse specialists, but I don’t necessarily think that follow-up has to be always within the hospital. We may be able to utilise clinical nurse specialists within a community setting to follow-up some cancer patients. I think that would probably suit a lot of patients. If they can get followed-up in a local community hospital or a

local health centre, perhaps using the expertise of the clinical nurse specialist, then I think that would be really useful for a small proportion of cancers.”(GP04- cancer interest)

“There may well be clinics run by nurses. And that may well be the way that they can take on a lot of the routine follow-up for patients who are leaving our services. I guess that will be the biggest step that we’ll see over the next five to 10 years.” (SPEC14, Urology, Lung)

A CNS with head and neck expertise talked about the success of a CNS-led model in Dumfries. For example, a tracheotomy nurse from specialist care provided home support for patients with tracheostomies, whilst up skilling district nurses in the community.

“One of the models they’ve used in Dumfries, a long time ago was to have a tracheotomy liaison sister, she deals with, the people with tracheotomies in the hospital, but she goes out to their homes and trains all the district nurses.” (CNS05, Head, Neck)

CNSs also provided an educational programme to the community on management of Peripherally Inserted Central Cather (PICC) lines.¹⁷

“So education about the new treatments as they come out and how to deal with symptoms. When we moved a lot of patients had PICC-lines put in, which the community hadn’t worked with, so there had to be an education programme on PICC lines.” (CNS04, Clinical Trials)

Supported self-management was considered by respondents to be part of CNSs’ roles. The following extract described a collaborative partnership between the CNS and the patient, which empowered the patient to take on some aspect of their care.

“If the patient phones up and say they’re on a drug that causes hypertension, quite often we would get them to monitor their blood pressure at home. If it was something that we knew was related to the drug, which the GP wouldn’t know anything about, we would tend to deal with that.” (CNS04, Clinical trials)

¹⁷ PICC-lines are a method of administering chemotherapy in the ambulatory setting, therefore, reducing the need for peripheral venous cannulation (Molloy et al. 2008).

5.6.2 GPs and optimisation of primary care

GPs were considered essential in terms of optimisation of primary care. Some respondents were of the viewpoint that GPs' had the potential to act as an interface between care settings. Part of this role involved dealing with medical issues, which oncologists may not always address.

“I see the GP in terms of offering advice, dealing with problems and acting as an interface between the hospital and the patient. In many circumstances dealing with general medical issues that oncologists don't always take heed of.” (SPEC15, Prostate)

This particular GP talked about the specialisation of cancer and what that could mean for general practice, perhaps suggesting that GPs include specialised cancer leads in their practice. Other studies suggest that challenges exist when developing models for primary care because of the diversity of cancer, clinicians and health services (Brennan and Jefford 2009).

“We are seeing increasing specialisation within group practices, and that may be one way forward.” (GP06-cancer interest)

Some oncologists suggested the possibility of cancer leads in general practice. This particular respondent cited examples, of diabetes, asthma and cardiovascular disease. It was felt that cancer care follow-up could parallel the models used in other chronic diseases.

“I think it would be helpful if there was somebody in each practice who took an interest in it. If you go into an average practice these days, there'll be somebody who has an interest in diabetes, in asthma and cardiovascular disease. There won't just be somebody who does the whole thing, and I think cancer overall, could be looked on in a similar sort of way. If there was one person in each practice to deal with cancer, it would be a lot easier.” (SPEC05, Prostate)

Cancer leads in general practice were also thought to be beneficial in terms of organising access to professional education and to facilitate communication.

“We could have a lead cancer GP in each practice, who maybe does have a bit more education, or could come up here for a morning programme of education, so that you could salvage a link. You know that someone will be in a practice that may be able to facilitate better communication.” (SPEC06, Colorectal)

Some respondents referred to the English Polyclinic¹⁸ as a model of care. It was thought that GPs were well placed to take on the role of cancer lead or coordinator of community run clinics with support from specialist care. The following extract discusses oncologists' viewpoints regarding the polyclinic.

“The polyclinic is an English phenomenon. I don't think we're getting them up here. They're a little bit like an ambulatory drop-in centre that will be run by GPs. We may have 20 or 30 GPs running these polyclinics. You could envisage some cancer specialists being employed to work, not full-time but to have some sessions in a polyclinic where they could work with the GPs.” (SPEC04, Gynaecological)

“I think there could be GPs with a cancer interest in the community, who could run a cancer clinic dealing with problems. GPs could take on a bit more of that in the community. I think there is much more scope for GPs in the community.” (SPEC08, Lung)

This GP proposed that for some groups of patients - those with less intensive needs, community follow-up was a viable option, irrespective of the type of health professional.

“There will be a group of patients where there will be more community follow-up, but that may not mean GP follow-up, but it will be with the appropriate health care professional within the community and that might mean a district nurse, it might be a CNS, it might be a practice nurse, or it might be a GP.” (GP04-cancer interest)

GPs in this research suggested that patients might benefit from supported self-management strategies, particularly during the survivorship phase. For example, patients deemed at 'low risk' would have less frequent follow-up at specialist cancer centres. A caveat to this, however, was the need to ensure that patients were aware of potential symptoms and knew how to access specialist care if required. A key commitment of the NCSI (2013c) supports a shift towards supported self-management, which involves a collaborative partnership between patients and health professionals, therefore, empowering patients to take on some aspect of their care.

“I think it will change, first of all, to more patients' involvement with their management and supported self-care so that patients who don't need follow-up aren't getting follow-up; that they are aware of what to look out

¹⁸ Polyclinic: A clinic often independent of a hospital, whereby , medical care is provided by a range of specialists (Imison et al. 2008).

for and they're aware of how to get back into the system. So for that group of people there won't be intensive follow-up from anyone, whether it be a nurse, a GP or a hospital consultant."(GP04-cancer interest)

Previously in section 5.4.3, it was described that Cancer Care Reviews were used as tool for GPs to engage with their cancer patients to provide optimal cancer care. Furthermore, Cancer Care Reviews are helpful in terms of facilitating GPs to sign post their patients to the necessary services, for example, benefits advice (Torjesen 2011).

Both oncologists and GPs alluded to the role of research evidence as a marker for best practice. Central to research practice, however, was the need for careful evaluation.

I think you need to find out what is optimal care is and to optimise follow-up you really have to do randomised studies to demonstrate what is better. It almost certainly has to be validated to be any use at all, but I think that is what you actually need to do. You need to get the evidence base." (SPEC02, Prostate)

"They can improve things as long as they are evaluated and they are evaluated properly. The reports should come back saying what the successes are. What things are not working as good? Let's keep monitoring them."(GP02)

Professionals also considered the potential of research evidence to inform guidelines, which support GPs to provide best practice.

"We need to pass on guidance as to what the general practitioner should be doing in that area. Because it is not well defined as to how often you'd be doing, what tests you should be doing." (SPEC06, Colorectal)

"I think we need to look at what we do and we need to look at the evidence for what we do, and then we need to decide if we can do it better." (GP06-cancer interest)

5.7 Chapter summary

Traditional practice had evolved due to changing roles and specialisms. Participants considered that cancer treatments could cause short and long-term effects, which could persist for years. Cancer patients could also endure psychosocial problems, comorbid conditions and late effects. Specialists endeavoured to meet patients' needs at the time of the clinic consultation and

by getting alongside the patient. Involvement of primary care in survivorship was often opportunistic in nature and driven by the patients themselves.

Oncologists were responsible for overseeing patient care. Their roles largely revolved around management of treatment related symptoms and surveillance practices. CNSs were perceived as a key contact and coordinator of care including patient advocate within the hospital environment. CNSs often acted as an intermediary across settings. This was seen to involve: key contact across sectors; provision of information and advice to GPs; physical and psychosocial support and supported self-management. GPs' roles in survivorship involved: management of treatment related symptoms; detection for recurrent cancer; management of comorbid conditions and provision of psychosocial support.

Oncologists communicated information to GPs about clinic consultations or to ask for advice. GPs often sought the advice of oncologists about treatment related issues or problems requiring further investigation. Barriers impeding communication were considered as: weak professional relationships; access difficulties; less than optimal detail and timeliness of letters including a mismatch of ICT services across settings.

Participants perceived that regular contact between professionals could establish links across settings and therefore, facilitate communication. GPs described how the content and quality of letters might be improved. Furthermore, the telephone was seen as way to improve access between professionals. Development of ICT was considered important in terms of email and telemedicine. Respondents considered the importance of investment in research.

GPs considered several methods to optimise the role of primary care. These include: CNS-led clinics in general practice; CNSs supportive roles in the community; GP cancer specialists in general practice and the community; GP education; Cancer Care Reviews and further research.

6. Discussion

6.1 Introduction

This chapter begins with a reflection of the main findings in relation to the study's objectives and considers how the findings contribute to the literature in this area. Next, a methodological evaluation will reflect on the design and methods of the research. The main strengths and weaknesses of the study are then discussed, followed by implications for practice including research and policy.

6.2 Main findings

This study set out to explore the on going care of patients with cancer and to consider what is the appropriate balance of cancer care for patients between specialist and primary care. The main findings will now be considered in relation to the objectives described in chapter three.

6.2.1 To explore oncologists,' CNSs' and GPs' perceptions about patients' physical, psychological and social needs and how these might be applied to future models of care

Participants described in detail that cancer treatments (surgery, chemotherapy, radiotherapy and hormonal therapy) could result in side effects, which can impact on a patient's physical wellbeing. Treatment related effects were also discussed in terms of long-term effects (persisting after treatment ends) and late effects (emerging years later). Comorbidities were thought to present additional physical challenges.

Participants in this research felt that short-term treatment related physical side effects were met satisfactorily. Whilst respondents acknowledged the importance of being aware of long-term or late effects, less was said about meeting these specific needs.

Respondents described that psychological issues were endured throughout the whole cancer trajectory, rather than survivorship alone. Patients faced feelings of isolation at discharge, fear of a cancer recurrence, worries about physical symptoms, for example, bowel and urinary incontinence including sexual dysfunction. For some patients, cancer treatments caused severe disfigurement and disablement, which impacted on their ability to cope.

In this study, participants described meeting patients' psychological needs at the time of the clinic consultation and by sign posting to the appropriate services. However, professionals informed that lack of clinical time and professional expertise were barriers to meeting these needs.

Professionals reported financial needs as a key subject of patients' concerns. This was most prevalent in individuals who were unable to work during their treatments. In this study, patients from less affluent backgrounds required more social support because of multiple health problems, weak social networks and poorer health outcomes. Other social needs related to the family and respite care for the elderly including re-housing for patients needing sheltered support.

Professionals described meeting financial needs by encouraging patients to continue working during their cancer treatments. Respondents also supported patients by signing documentation designed to facilitate payment of incapacity benefits. Often patients were sign posted to the social work department and the voluntary sector for financial assistance and support.

In this study, individuality was a key theme in terms of delivering care that was appropriate to individuals' needs, preferences and circumstances. Commonly, respondents described individuality in terms of coping with the psychological aspects of cancer. Some patients were able to cope with the emotional stressors and strains of cancer, whilst others were unable to cope at all.

Respondents also described patient individuality in relation to information needs. It was perceived that follow-up cancer care should not be a 'one size fits all' approach. Information support should suit the patient if and when it was useful for their particular needs.

6.2.2 To describe oncologists,' CNSs' and GPs' perceptions in relation to professional roles and cancer care follow-up

Oncologists were considered the leaders of the cancer care process. Their role involved management of treatment related side effects and surveillance. Professionals did not refer to their role in terms of management of long-term and late effects. Whilst oncologists provided information and advice to patients, practical support for psychosocial issues was usually sign posted to CNSs.

CNSs were critical to survivorship care both within and out with specialist care. Key aspects of their role included oncology support and patient advocate within the hospital setting. CNSs were also considered to have a much broader field of influence. In particular, acting as an intermediary between specialist and primary care and support for self-management.

GPs were considered by respondents to be well positioned to accompany patients throughout the whole process of their cancer care because they already offered support for physical and psychosocial issues including comorbid conditions.

6.2.3 To illustrate oncologists,' CNSs' and GPs' viewpoints regarding communication practices and how these could be enhanced

Oncologists communicated to GPs via the telephone or by letter. Often this was to ask GPs for advice or to inform GPs about the outcome of MDT meetings or clinic consultations. GPs, on the other hand, used a combination of methods to inform oncologists about symptoms or issues, which needed further investigation.

Participants reported several issues with respect to optimal communication. It was expressed that there was little understanding regarding each other's communication needs. Consequently, the content of letters between professionals was often variable in quality and at times over complex for GPs' needs. Resource issues in specialist care meant that letters to primary care were

often delayed. Other problems were weak professional relationships, access difficulties and ICT problems.

Participants described several ways that communication could be enhanced across the interface. These include: regular contact between professionals; improvements to the quality and content of letters; telephone access and ICT development.

6.2.4 To explore oncologists', CNSs' and GPs' viewpoints about the ways in which the role of primary care could be optimised

GPs perceived that CNSs had key roles in provision of follow-up for patients in general practice and in the community.

GPs and oncologists described the potential of GP cancer specialists/nurses in general practice.

GPs described Cancer Care Reviews as a tool to facilitate discussions with their patients, whilst providing individualised care.

GPs and oncologists perceived that research evidence was central in terms of informing best practice.

6.3 Follow-up cancer care in the context of the literature

This study described four domains of survivorship care from the perspectives of oncologists, CNSs and GPs. In the following section the same four domains of survivorship care are used to form a comparison of this study with the literature.

6.3.1 Patients' needs in the context of the literature

The findings in this study suggest that cancer patients face significant health care issues, these challenges are reflected in the literature. Many studies highlight that physical symptoms are likely to emerge soon after treatments or in the following years, a perception confirmed by many (Burton et al. 2007; Kuchinski et al. 2009; Azim et al. 2011; Davis et al. 2014). Other research informs that for most cancer types, patients report significantly more

comorbidities and poorer physical health compared with patients without cancer (Smith et al. 2008).

Unwell patients with cancer frequently present to primary care and acute care settings with issues in relation to established or undiagnosed cancer; complications of cancer treatments or problems relating to comorbidities. Some patients, however, have less than optimal care (Foster and Fenlon 2011; Royal College of Physicians 2012; Sherman et al. 2012; Pauwels et al. 2013).

Chronic disease management is an important issue for survivors, many of whom will have one or more comorbid conditions (Khan 2010). For any type of cancer, different comorbid conditions will have particular health effects. The degree of the comorbidity will influence how that comorbidity impacts on the cancer patient. The impact of comorbidity can occur at any time during the cancer journey and can vary across cancers and treatments including age, sex, ethnicity and social class (Geraci et al. 2005). Poor social networks, for example, can impede a patient's capability to fulfil their social roles, which in turn could interfere with their adherence to treatments. These issues can bring about changes in the functioning of the body's systems and organs, which could have adverse health outcomes (Adler 2008).

Much of the literature on long-term treatment related effects suggests that the focus of care is on treating the cancer, rather than its long-term effects (Hewitt et al. 2006; Rowland and Belizzi 2008; Rowland 2008; Macmillan 2009). Further research is needed to inform recommendations for this issue (McCabe et al. 2013).

The literature informs that psychological distress is common amongst patients affected by cancer and can occur at any time during survivorship care (Gao et al. 2010). After diagnosis, patients' concerns focus on their treatments and prognosis for survival. Once treatments begin these concerns shift toward potential risks of invasive procedures and the effects of treatments. After the acute phase, patients often have worries about a cancer recurrence. With the passage of time, however, fear of recurrence is often replaced by concerns about new primary cancers resulting from treatments (Deimling et al. 2006).

Chambers et al. (2012) claim that cancer patients' psychological needs remain largely unmet. Barriers to accessing psychological support are encountered at provider and patient levels: lack of professional expertise; inadequate clinical time; fragmentation and coordination of care; lack of patients' knowledge around mental health services and patients poor health and social circumstances (Adler et al. 2008; Pincus and Patel 2009).

Financial worries are a significant concern for cancer patients. Macmillan (2012) informs that 91% of households suffer a loss of income or increased costs because of cancer. The difficulty in maintaining employment during treatments is reflected in other survivorship work (Edwards et al. 2004; Adler et al. 2008; Armes et al. 2009; Absolom et al. 2011; Chambers et al. 2012).

Macmillan (2012) reports that there is significant under-claiming of financial benefits by individuals who are entitled to them. Barriers to obtaining benefits include lack of knowledge regarding eligibility and difficulties in knowing how to apply.

NICE Clinical Guidelines (2012) suggests that it is important to acknowledge the issue of patient individuality in the context of health as individuals can experience this in different ways, largely due to their own encounters, hopes and expectations. In terms of cancer care, there is an increasing emphasis on the individual nature of cancer patients' needs, which is likely to span a broad spectrum of medical and psychosocial areas (Feuerstein and Ganz 2011).

In breast cancer, for example, women can use individual coping strategies when addressing the psychological challenges of the disease. Coping strategies might include: step-by-step; pushing away; business as usual; enjoying life; dealing with emotions; preparing for the worst and positive emotions (Lauver et al. 2007; Manuel et al. 2007). Patients value professionals who understand and acknowledge their individuality and the unique way that individuals experience illness and its impact on their life (NICE Quality Statements 2012).

Other research has shown that patients' preference for information is often associated with how active they wished to be concerning their care, especially in relation to information, diagnosis and cure (Hack et al. 1994; Degner et al. 1997). In chapter two, it was reported that the NCSI informed of a shift toward

personalised care planning that takes into account individuals' needs. This study adds to the growing body of evidence, which suggests the importance of ensuring that patients' information needs are not a 'one size fits all' approach.

6.3.2 Professional roles in the context of the literature

The results from this research have shown that oncologists and CNSs described their roles around acute aspects of care, rather than monitoring for long-term or late effects. The previous and current literature searches are predominantly concerned with specialists' roles around treatments and treatment related side effects including identifying psychosocial issues and risk reduction measures.

According to Shankland et al. (2012) and Popescu et al. (2013) oncologists are leaders of the cancer care process. After treatments their role involves: attendance at MDTs; management of short-term side effects; participation in research and provision of education.

Absolom et al. (2011) suggests that oncologists, whilst acknowledging the need to detect emotional distress in cancer patients, usually refer care to CNSs or to other services.

The literature acknowledges the need for individual assessment and risk stratification for cancer patients, to be tailored to the individual (Davies et al. 2010). Efforts to focus on risk reduction measures are consistent with the NCSI initiative (NCSI 2013d). The NCSI, for example, informs that patients deemed at low risk of recurrence and late effects would be supported to manage aspects of their care. Patients considered at medium risk would have planned coordinated care and those at high risk would receive complex support from specialist care (Watson et al. 2012).

The literature demonstrates that CNSs' roles in relation to survivorship care are fraught with confusion largely because of their varied titles and specialisms (Gardener et al. 2007; Duffield et al. 2009; Faith et al. 2010). Nevertheless, CNSs are considered to be a key contact and coordinator of care within specialist care. This involves: organising referrals; symptom management; patient education; psychosocial support; dissemination and provision of information

(Rieger and Yarbrow 2003; Leary et al. 2008; NCAT 2010; Grant et al. 2010; Vidall et al. 2011; Griffiths et al. 2013; Rustoen et al. 2013). In this study, CNSs were integral to care in specialist care as well as acting as an intermediary between specialist and primary care.

Recently, Sharpe et al. (2014) compared a multicentre RCT effectiveness trial (depression treatment delivered by cancer nurses and psychiatrists) with usual care (provided by primary care physicians). The authors found that 1:1 care delivered systematically by cancer nurses and psychiatrists reduced patients' depression, anxiety, pain and fatigue. Additionally, patients had better functioning health and QoL.

It is acknowledged, that CNSs' roles must extend from the boundaries of current service delivery to include a wider outreach of care (YCN 2013). In some cases, CNSs support GPs in their practice by preventing unnecessary admissions to specialist care (Breast Cancer Care 2008). Foster et al's (2005) contribution around asthma suggests that CNSs educate primary care clinicians to help them make clinical recommendations about individual patients. This trial showed that this particular CNS intervention reduced unscheduled asthma visits to specialist care.

The PROSPECTIV, pilot trial aims to evaluate a nurse-led intervention delivered in primary care for men with prostate cancer. The focus of this study is to identify if this type of intervention can improve men's quality of life (Watson et al. 2014).

Chomik et al. (2010) identify several survivorship interventions in primary care. These include: an oncology nurse coordinating care; mentorship where family doctors attend specialist care for education and training; web based approaches supporting GPs' learning; graduate courses on follow-up, which provide formal education and bring attention to survivorship care.

Several self-management programmes have been introduced with some focusing on cancer survivors. For example, the Macmillan "Living with Cancer" programme delivered by an oncology nurse rehabilitates patients by supporting them to adjust to their illness. Patients are encouraged to engage in physical activity and healthy

nutrition. Additionally, patients receive support for their emotional and financial needs (Davies 2009).

GPs are involved in all phases of the cancer pathway, from first presentation to end of life care (Campbell et al. 2002). GPs' roles are characterised by their frequent encounters with patients covering a wide-range of issues. GPs, therefore, are likely to have in depth knowledge about the care of their patients (Bergholdt et al. 2012). Whilst the previous literature search and the findings from this study highlight GPs' roles this way, care for the cancer patient in primary care is often ad hoc and led by the patients themselves. This study adds weight to what it is known about the in depth nature of GPs roles in survivorship. Key roles include: coordination of cancer care; first port of call for treatment related symptoms; surveillance for specific cancers and patient education. This research also provides insight regarding GPs' roles around psychological support. In particular, helping people cope and make sense of their illness.

6.3.3 Communication practices in the context of the literature

Recently, healthcare organisations have begun to address professional relationships and their boundaries in relation to communication practices (Currie and Suhomlinova 2006). It is suggested that professional boundaries can be reinforced by power and conflict between healthcare individuals (Harrison and McDonald 2008). Sutcliff et al's (2004) work on communication failures in medical settings informs that communication can be distorted or withheld in situations where there may be power tensions between communicators, particularly if an individual feels uncertain or does not want to upset the other or feels that the other person is not open to communication.

McDonald et al's (2012) contribution informs that collaboration across organisational settings remains challenging. Power dynamics may affect the strategic choices made by each health professional about whether or not to collaborate, with whom and to what level. This interpretation of power dynamics influencing communication across settings resonates with findings described here. The aspects of feeling uncertain and decisions about whether or

not to collaborate were alluded to in this study. For example, GPs' feelings of inefficiency in terms of follow-up care and decisions about whether or not to communicate may be influenced by: oncologists' ownership issues; patients' preference for care; complex information from oncologists; the expectation that oncologists were responsible for the exchange of information after treatments and the lack of on going education and support.

Oncologists and GPs considered that links and discussions could be established if time permitted regular face-to-face contact. Developing professional relationships is an important aspect of communication, although regular cohesive communication across settings requires effort from all those concerned (Wood 1993; Kvamme et al. 2001; Leese et al. 2006).

It is important for professionals to understand and be aware of other professionals' communication needs regarding their patients' care (Kvamme et al. 2001). A number of studies cite a lack of quality correspondence as an inhibitor to GPs providing optimal cancer care (Wood et al. 1993; Farquhar et al. 2005). Most notable are oncologists differing perspectives about the relevance and timeliness of information to GPs. Babington et al's (2003) contribution suggests that oncologists sometimes include lengthy descriptions perceived to be relevant to the GP, without addressing the GPs questions. In Berta et al's (2009) work, it was found that GPs might dismiss information provided by specialists - perhaps considered important for future follow-up care and only focus on answers relevant to their specific questions. The findings in this study suggest that there were significant issues with regard to the detail and timeliness of letters between oncologists and GPs.

The focus on the literature search and the present findings indicate that oncologists and GPs generally use letters and the telephone to communicate across the interface. Information from oncologists to GPs often refers to a patient's health status, whilst GPs request advice and information from oncologists about their patient's treatment related symptoms (Berendsen et al. 2009; Rowlands et al. 2012). The literature also informs that the clinical exchange of information may have priority over social information, perhaps highlighting information gaps (Rowlands et al. 2012).

According to Chan et al. (2014) the discharge summary is a key clinical document, which provides information to primary care about the patient's inpatient stay, for example, their diagnosis, complications and follow-up. The literature indicates that discharge summaries are often secondary care focussed and can vary with respect to their specific detail (Carey and Hall 1999; Myers et al. 2006; O'Leary et al. 2009). Recently, however, discharge summaries appear more holistic in nature and seem to take into account patients' needs (Rowlands et al. 2012). The findings in this study demonstrated that discharge summaries improved communication practices and facilitated patient care if the nature and details of letters are specific to patients and their GPs. It is important to acknowledge, however, that this area has moved on and discharge summaries are now discussed in the context of survivorship care.

Whilst the telephone method is well established, its use in health care varies and it has only been partially successful (Car and Sheikh 2004). In this study, it was shown that telephone access was difficult if professionals were unavailable at the time of the call.

Farquhar et al. (2005) asserts that telephone access could be improved if oncologists and GPs telephoned at designated time points, for example, at diagnosis and prior to patients' discharge. The findings in this study also point towards the use of the telephone for accessing and receiving professionals' responses. In this regard the telephone may be a useful tool to facilitate communication. However, these findings may be out dated.

Email use in healthcare is not routine (Tay 2013) because of concerns about confidentiality (Moyer 2002; Katzen 2005). Often email use occurs between health care professionals and patients, rather than between health professionals themselves (Atherton et al. 2012). The findings in this study suggest that respondents were concerned with security around email use.

Opportunities for the use of email as a medium for business and social communication are becoming evident (Weaver et al. 2012). Pappas et al's (2012) contribution suggests that web-messaging infrastructure can address issues around email security if emails are encrypted and securely stored. However, some healthcare institutions do not have the means or processes in place for this facility. The findings in this study suggest that health professionals were keen to overcome the issue of email security as a way to improve information exchange across the interface.

Electronic communication now includes the use of telemedicine. George et al's (2014) work may reflect the potential of telemedicine technology in terms of facilitating professional communication and patient care. This study describes professionals using teleconferencing and videoconferencing for patients in remote communities. Other studies also suggest that advancements in telemedicine techniques now allow women access to mammography screening including transmission of their mammography x-ray if patients or doctors are far away (Sussman 2006). The findings in this research point to telemedicine as the force behind changes to communication practices including survivorship care.

6.3.4 Optimisation of primary care in the context of the literature

The literature indicates that nurse-led support in general practice particularly around other chronic conditions is a well established model. Practice nurses play a significant role in the care of individuals with diabetes, asthma and ischaemic heart disease. Often their role involves information and support for patient self-management (Macmillan 2013). Cancer is now considered a chronic illness, but the trend has been slow to develop appropriate models of care (Cooper et al. 2010). The findings in this study support the value of appropriately skilled specialist nurses with community and oncology experience in general practice. Macmillan (2013c) found that practice nurses who participate in oncology training are more confident in conducting Cancer Care Reviews.

Nurses' roles were also extended to include community support. Chapter two described that nurse-led home visits, for example, reduced patients' needs and increased their satisfaction with care. Macmillan (2011) informs that in the

future CNSs' roles will evolve from the confines of specialist care to support patients in the community. This study suggests the potential of enhancing the skills of community nurses to incorporate some of the roles carried out by hospital CNS.

GPs have an important contribution to make in survivorship. They already manage both the physical and psychosocial aspects of cancer care including comorbid conditions (Watson et al. 2011b).

Some GPs act as cancer specialists to improve communication and to facilitate links between oncologists and GPs (Leese et al. 2006). The concept of GP cancer specialists is being examined in the Franco British clinical trial, which involves breast, colorectal and prostate cancer patients. This study aims to compare follow-up between a trained GP and a specialist physician. The GP will be responsible for follow-up care with referral to the physician should the need arise. Outcomes of interest include patient satisfaction, QoL, iatrogenic effects and perceptions of professionals (Senn et al. 2007). Whilst this study shows promise in terms of transitioning care from specialist to primary care, further evaluation is needed (Gray et al. 2013).

Sisler and McCormack (2009) inform that it may be beneficial for family practitioners to regularly attend the cancer system for professional development. This strategy is seen to facilitate education and training, therefore, support family practitioners in their care. Furthermore, working relationships and communication is improved between these groups. Less than optimal follow-up can be traced back to inadequate education and training (Virgo et al. 2013).

In the previous literature search and the present findings GPs described Cancer Care Reviews as a tool to provide supportive care for patients. Adams et al. (2011) informs that more work needs to be done to upgrade Cancer Care Reviews in order to facilitate best practice. QoF indicators for cancer, for example, should be similar to other enduring conditions. Patients should play a key role in their Cancer Care Review. Care should follow a holistic approach and be underpinned by professional education and ICT development (NCSI 2013b).

McCabe et al. (2013) informs that more research is needed to increase the evidence base required to deliver optimal cancer care. Professionals in this study described the importance of evidence in terms of informing best practice.

6.4 Strength and limitations of the research

This study set out to explore the balance of cancer care follow-up as perceived by oncologists, CNSs and GPs. A merit of this study is that it encapsulates the experiences of key professionals who are involved in post treatment cancer care, reflecting many years of experience. By purposely sampling specialists with expertise in different cancer types and GPs from a number of different areas, the student was able to explore their perceptions around patients' experiences. To the best of our knowledge, this is the largest interview study of these groups of professionals. Often research exploring the opinions of health professionals particularly in the area of survivorship, have only addressed the perceptions of one or the other. The implication of this strength is that the student sought to integrate these different perspectives in the analysis.

There are weaknesses, however, that limit the strength of this evidence. This research commenced in 2007 just prior to the fast-paced developments in the discipline of survivorship care. Consequently, some of the data is now out dated. Furthermore, there are no patient insights or experiences in this study, which would have complemented professionals' perceptions.

A further limitation is that the study is more specialties based than primary care focussed. On reflection, it would have been helpful to include the perspectives of practice nurses and community nurses. At the time this study was being designed, practice nurses' roles were concentrated on asthma and diabetes care and nurses were less likely to see cancer patients. However, there is no reason why the skills nurses have in looking after patients with other chronic illness could not be transferable to cancer patients.

Focus groups, which involve both primary care professionals and specialists, may have provided an opportunity to seek to challenge their entrenched positions, which seem to have emerged from the analysis.

6.5 Reflections on the research process

It is suggested that matching interviewer and participant characteristics in terms of cultural background, gender and power may improve data collection (Van Krieken et al. 2000). Doctors and nurses, for example, often share similar knowledge around medical issues (Ritchie and Lewis 2008). Therefore, the student - as a past nurse, felt that this commonality might contribute to a meaningful interview.

Historically male doctors have had considerable power over female nurses, which appear to have influenced nurses' autonomous decision-making (Van Krieken et al. 2000). In this context, the student had characterised the doctor-nurse relationship as patriarchal, which impacted on the student's capacity to successfully interview male clinicians in detail. Ritchie and Lewis (2008) confirm that power imbalances during an interview can inhibit an open conversation. To overcome this issue, the student's used field notes in conjunction with the Gibbs Reflective Model (Gibbs 1988), which improved the quality of future interviews.

There has been much discussion and debate around the role of the researcher in relation to the feminist perspective and interviewing (Oakley 1981; Finch 1984; Ramazanoglu 1992). One focus of this approach assumes that equal interaction is more likely to occur when women interview women. Reciprocity is gained by mutual understanding because of shared gender and cultural issues (Ritchie and Lewis 2008). Similarly, other literature suggests that equal power exists when men interview men also relating to cultural aspects and similar understandings because of masculinities (Schwalbe and Wolkomir 2001; Connell 2005). In contrast, however, analyses of females interviewing males are relatively rare (Lee 1997).

Some respondents may have viewed the student as a health professional working in an academic environment as having an authoritative role, perhaps influencing their responses in the interviews. To overcome this potential issue, the student was respectful and aimed to establish rapport with each professional. Coar and Sim (2006) suggest that for some professionals, taking part in an interview may give rise to feelings of being under scrutiny or the feeling that the interview is a factual assessment.

Finally, it is acknowledged that the findings from this research were the perceptions of oncologists, CNSs and GPs and therefore, may only be transferable to other settings, rather than being representative. The intent of this research was to allow other professionals in survivorship care to make connections between components of this study and their particular experiences.

It is important to reflect on the student's past experience of cancer care follow-up in relation to this research. As a nurse - in the 1980s, the student had the opportunity to provide care for Indigenous Australians (IAs) living in remote communities. Care at that time involved support for lifestyle related illnesses, rather than for cancer. Nevertheless, there were instances of melanoma, prostate and cervical cancers.

Follow-up cancer care was virtually non-existent; rather the focus was on cancer control, for example, cancer prevention strategies and screening measures. IAs were at risk because of their socioeconomic disadvantage. Furthermore, IAs had strong cultural beliefs (customs and social organisations), which impacted on their compliance and uptake of cancer services. As a result of this, IAs with cancer had poorer health outcomes than other Australians.

This nursing experience allowed the student to reflect on the similarities between IAs and head and neck cancer patients in this study. Often these groups originate from disadvantaged backgrounds with poor help seeking behaviours. Models of cancer care that are culturally friendly and those that remove financial constraints to engage these particular individuals are warranted.

6.6 Implications for practice

It is recognised that increasing numbers of cancer survivors means an enhanced role for GPs. GPs are already seeing cancer patients and managing aspects of their immediate and long-term care. However, the care of survivors in primary care is often opportunistic and led by the patients themselves (Rose and Watson 2009; Watson et al. 2011). In this study, specialists acknowledged the need for GPs to receive guidance about the management of survivorship care.

Survivorship Care Plans and electronic treatments summaries have now been developed. These documents ensure appropriate care coordination between specialists and GPs. Survivorship Care Plans and treatment summaries improve communication between professionals and provide a roadmap for individualised supportive care (Hewitt et al. 2006; NCSI 2013a). It may be helpful to investigate different aspects of the discharge letter/treatment record summary in terms of specific cancer groups to assess the impact of these elements on outcomes of interest (Viswanathan et al. 2014).

Emerging evidence involving breast cancer and Survivorship Care Plans describe the benefit of collaborative working in specialist care. In Rosales et al's (2014) contribution, Survivorship Care Plans are reviewed in a joint visit with an oncology nurse and a social worker including the patient. The nurse focuses on surveillance for recurrence, long term and late effects including comorbid conditions, whilst the social worker addresses the psychosocial aspects of survivorship. Evaluation of this model of care showed that an interdisciplinary approach facilitated care and improved patient satisfaction including healthy behaviours. This model has now been extended to include patients with colorectal, anal and lung cancers. Implications of this study may lend itself to include joint appointments between specialist and primary care.

CNSs acting as intermediaries across settings are likely to bring new opportunities for survivorship care, in particular, supporting the transfer of patient care to primary care. CNSs' roles could extend to include supportive self-management. Additionally, there may be scope for CNSs to provide education, training and clinical supervision to health professionals in the community and primary sectors. Whilst these findings showed the benefits of CNS led care in terms of primary care practice, they also highlight the potential role of practice nurses in primary care.

The findings in this research informed that managing patients' needs were difficult because of the individuality and diversity of cancer. However, managing patients' needs may not be as difficult if the focus is on individualised care. Risk based care, for example, takes into account the individuality of the patient and their cancer and is now the new standard for quality survivorship care

(McCabe et al. 2013). The risk stratification model means that clinicians and patients can make decisions about the most suitable type of follow-up care based on the patient's cancer type, treatment related symptoms, comorbid conditions and supportive care needs (NCSI 2014). However, improving the quality of follow-up care will require commitment by primary care professionals in terms of education and clinical practice (Watson et al. 2011b).

6.7 Implications for research and policy

Historically, follow-up cancer care has been the remit of clinicians in specialist care. It is recognised that this type of follow-up draws on scarce oncology resources without any clear evidence of patient benefit (Shulman et al. 2009). Researchers are key in terms of providing evidence for policy makers and health departments. One such example is the formation of the Government backed NCSI in the UK, which is developing new models of care and interventions to improve cancer care (Corner and Wagland 2013). Based on oncologists', CNSs' and GPs' perspectives about survivorship care, the following areas seemed worthy of further research:

How can professional relationships between oncologists and GPs be encouraged?
What types of interventions or strategies might this involve?

What are oncologists', CNS' and GPs' roles in survivorship care? How can these roles complement each other to provide continuity of care?

What types of interventions could CNSs or practice nurses or community nurses provide to support patients with less intensive needs to manage aspects of their care?

What kind of GP educational or training strategies might facilitate the use of survivorship care plans in primary care?

6.7.1 A conceptual model of follow-up care

The following section describes a proposed example of a model of care for breast cancer patients at low risk of recurrence - two to five years post treatment. This is a nurse led strategy to be delivered in primary care. At the point of discharge, CNSs could act as a contact and information resource for practice nurses in primary care. This model is based on analysis of CNSs' roles in specialist care.

Aspects of practice nurses' survivorship roles might include: key contact; working alongside GPs; acting as a link between GPs, patients and the community; conducting nurse-led clinics and supported self management. Practice nurses' roles and components of the proposed model are described in Table seven below. It is important to acknowledge, however, that successful strategies are dependent on tailoring interventions to the unique characteristics of patients, cancer types and treatment regimes (Viswanathan et al. 2014).

Table seven: Proposed practice nurse management of breast cancer patients in primary care (Two-five years post treatment)

CNSs supportive role to practice nurses in primary care
<ul style="list-style-type: none"> • Discharge information to practice nurses • Contact for practice nurses for re-referral to oncologists' care
Proposed practice nurses' roles in general practice (Based on CNS data)
<ul style="list-style-type: none"> • Key contact for GPs, community nurses and patients • Work alongside GPs • Act as a link between GPs, patients, voluntary sector and community nurses • Nurse-led clinics for provision of physical and psychosocial care • Supported self-management
Proposed components of follow-up (Based on CNS data)
<ul style="list-style-type: none"> • <i>Key contact</i> Practice nurse - contact for problems, advice and back-up • <i>Work alongside GPs</i> Practice nurse - appointments and mammograms - refer back to specialist care • <i>Link between GPs, patients, voluntary sector and community nurses</i> Inform and advise oncologists and GPs about patients' progress - sign posting • <i>Provision of nurse-led clinics for physical and psychosocial care</i> Establish rapport, on going support, telephone counselling for patient and families, sign posting for financial support • <i>Supported self-management</i> Support and monitor patients at home - (management strategies for long-term effects and psychosocial issues including education about late effects)

7. Conclusions

7.1 Introduction

The final chapter presents the conclusions that can be drawn from this study within the context of the research objectives. The main conclusions are presented below for each objective.

7.2 Main conclusions

This research demonstrated the challenge and complexity of cancer survivorship. The perceptions of oncologists, CNSs and GPs suggested that patients suffered throughout the cancer trajectory as a result of their treatments. Whilst the evidence showed that physical needs appeared to be met, psychosocial and long-term needs including late effects appeared unmet as part of routine care.

Oncologists were considered to be leaders of the cancer process. Their roles were clearly described within the framework of acute oncological care. CNSs were critical to survivorship care both within and out with specialist care. CNSs' roles involved oncology support and getting alongside patients. Their role also extended to include acting as an intermediary across settings and supported self-management. Oncologists, CNSs and GPs have similar expectations regarding each other's roles.

Increasing numbers of cancer survivors and unsustainable cancer care may inevitably mean an enhanced role for primary care. Indeed GPs were already involved in caring for cancer patients' treatment related physical and psychosocial needs including their comorbidities.

However, significant barriers exist with regard to communication practices across the interface. Professional relationships were seen to impede communication because of insufficient contact and difficulties in gaining access to each other. A lack of understanding around professionals' communication needs was reflected in the timeliness and detail of letters. Other barriers related to scarce resources and confidentiality in terms of email use.

Oncologists, CNSs and GPs considered ways in which the role of primary care might be optimised. Professionals emphasised the importance of improving partnerships across the interface. Oncologists extended an invitation to GPs to attend specialist care on a regular basis. This was seen as a strategy to facilitate social connections and improve GP knowledge around survivorship care. The possibility of GP cancer specialists in primary care was also considered. Cancer Care Reviews were seen as helpful in terms of allowing GPs to engage with their patients, whilst providing individualised cancer care. A key aspect to optimal primary cancer care was the need for quality, timely letters from oncologists. Primary care may also benefit from developments in ICT and further research.

**Appendix1:
and Strength of
Evidence**

Risk of Bias/Grading	Interpretation	Legend: reported = • Half reported or not reported = °
Low risk of bias = • - °	Unlikely to seriously alter the results	
Moderate risk of bias = °°	Raises some doubt about the results	
High risk of bias = °°° or more	Seriously weakens confidence in the results	

Quality

Lohr, K. (2003) Rating the strength of scientific evidence relevance for quality improvement programs. *International Journal for Quality in Health Care*, 16 (1). Cochrane Collaboration (2006) *Cochrane handbook for systematic reviews of interventions: handbook 2006*. [Internet] Available from: <http://www.cochrane.org/training/Cochrane-handbook> [Accessed 1 January].

Systematic reviews/ lit reviews/evidence reviews	Search question	Search strategy	Inclusion	Outcomes	Interventions	Data extract.	Qual. Assess.	Synth. Meta-analysis	Results	Discussion	Grade
Rojas et al. 2012	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Ronohan et al. 2005	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Figueredo et al. 2003	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Jeffroy et al. 2008	•	•	•	•	•	•	•	•	•	•	Low risk of bias
McIntosh et al. 2009	•	•	•	n/a	n/a	•	•	•	•	n/a	Low risk of bias
NCCC 2011	•	•	•	•	○	•	○	○ not MA	○	○	High risk of bias
Taggart et al. 2012	•	•	•	○	•	•	•	○ not MA	•	•	Mod risk of bias
Galway et al. 2012	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Dovino and Westlake 1995	•	○	•	•	•	•	•	•	•	•	Low risk of bias
Schmidt-Hansen et al. 2012	•	•	•	•	•	○	•	○ not MA	•	•	Low risk of bias
Ram et al. 2004	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Laurant et al. 2009	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Keuthe et al. 2013	•	•	•	•	•	•	•	•	•	•	Low risk of bias
Lancaster 2011	•	○	○	•	•	○	○	○ not MA	○	•	High risk of bias
Koutsopoulou et al. 2009 -	•	•	○	•	•	•	•	○ not MA	○	•	High risk of bias
Caird et al. 2010	•	•	•	○	•	•	•	○ not MA	•	•	Low risk of bias
Lewis et al. 2009	•	•	•	•	n/a	•	•	○ not MA	•	•	Low risk of bias
McCorkle et al. 2011	•	•	•	○	•	•	•	○ not MA	•	○	High risk of bias

Appendix 1: Quality and Strength of Evidence

Risk of Bias/Grading	Interpretation	Legend: reported = • Half reported or not reported = ◦
Low risk of bias = • - ◦	Unlikely to seriously alter the results	
Moderate risk of bias = ◦◦	Raises some doubt about the results	
High risk of bias = ◦◦◦ or more	Seriously weakens confidence in the results	

Lohr, K. (2003) Rating the strength of scientific evidence relevance for quality improvement programs. International Journal for Quality in Health Care, 16 (1). Cochrane Collaboration (2006) Cochrane handbook for systematic reviews of interventions: handbook 2006. [Internet] Available from: <http://www.cochrane.org/training/Cochrane-handbook> [Accessed 1 January].

RCTs	Study pop.	Target pop.	Rand.	Blinding	Intervention	Outcomes	Statistical Analysis	Results	Discussion	Grade
Grunfeld et al. 1996	•	•	•	◦	•	•	•	•	•	Low risk of bias
Grunfeld et al. 2006	•	•	•	◦	•	•	•	•	•	Low risk of bias
Beaver et al. 2012	•	•	•	Analyst	•	•	•	•	•	Low risk of bias
Young et al. 2013	•	•	•	◦	•	•	•	•	•	Low risk of bias
Strand et al. 2011	•	•	•	◦	•	•	•	•	•	Low risk of bias
Helegson et al. 2000	•	•	•	◦	•	•	•	•	•	Low risk of bias
Faithfull et al. 2001	•	•	•	◦	•	•	•	•	•	Low risk of bias
Giesler et al. 2005	•	•	•	◦	•	•	•	•	•	Low risk of bias
Verschuur et al. 2009	•	•	•	◦	•	•	•	•	•	Low risk of bias
Grunfeld et al. 2011	•	•	•	◦	•	•	•	•	•	Low risk of bias
Kousgaard et al. 2003	•	•	•	◦	•	•	•	•	•	Mod risk of bias
Rutherford and Burge 2001	•	•	•	◦	•	•	•	•	•	Mod risk of bias

**Appendix 1:
and Strength of
Evidence**

Risk of Bias/Grading	Interpretation	Legend: reported = • Half reported or not reported = °
Low risk of bias = • - °	Unlikely to seriously alter the results	
Moderate risk of bias = °°	Raises some doubt about the results	
High risk of bias = °°° or more	Seriously weakens confidence in the results	

Quality

Anderson, C. (2010) Presenting and evaluating qualitative research. AM J Pharm Educ, 74 (8), pp.141.

Observ. studies	Quest.	Theory	Ethic	Method	Partic.	Recruit.	Inclus./ Exclus.	Consent/a non	Sample	Audio	Analy.	Results	Discus.	Conclus.	Grade
Chlebowski et al. 1992	•	°	°	°	°	°	°	°	•	-	•	•	•	°	High risk
Warren et al. 2013	•	°	•	°	°	°	•	°	•	-	•	•	•	°	High risk
Sussman et al. 2006	•	•	°	•	•	°	•	°	•	-	•	•	•	•	High risk
Adams et al. 2011	•	°	•	•	•	°	•	°	•	-	•	•	•	•	High risk

Appendix 2: Approach to literature searching

Outcome of the literature search from Embase and Medline combined, CINAHL and Cochrane databases Fiona Smith 23/6/2013

AIM: What is the evidence concerning best follow-up practices for cancer care for people expected to survive cancer?

Search term	Database	Medline combined with Embase	CINHAL	Cochrane Database
#1 Cancer		1641024	58972	35173
#2 Surviv\$		77870	9958	3570
#3 Cancer AND Survivor\$		24116	3528	814
#4 Follow-up		1130578	54449	101287
#5 Cancer AND Surviv\$ AND Follow-up		7210	537	99
#6 Family Practice		29409	5870	8073
#7 General Practice		48419	3945	15653
#8 Primary Health Care		59846	12258	23591
#9 Family Practice OR General Practice OR Primary Health Care		121794	18488	34743
#10 Cancer AND Surv\$ AND Follow-up AND Family Practice OR General Practice OR Primary Health Care		77 (De-duplicate = 54)	11	88

Outcome of the literature search from Embase and Medline combined, CINAHL and Cochrane databases 28/10/13

AIM: What does the evidence say about the role of professionals in achieving best follow-up practices in patients following cancer treatment?

Search	Database	Medline combined with Embase	CINHAL	Cochrane Database
#1 Cancer		1813049	8768	47176
#2 Surviv\$		93260	216	4024
#3 Cancer And Surviv\$		29949	57	1018
#4 Follow-up		1253662	80826	111748
#5 Cancer AND Surviv\$ AND Follow-up		8763	5	419
#6 General Practitioners		30689	6586	5930
#7 Physicians		282205	83057	23450
#8 Hospitals		221196	96906	145732
#9 Clinics		87798	16166	29179
#10 Initiated		122565	10862	9470
#11 General Practitioners OR Physicians OR Hospitals OR Clinics OR Initiated		690286	200380	183534
# 12 Cancer AND Surviv\$ AND Follow-up AND General Practitioners OR Physician OR Hospitals OR Clinics OR Initiated		739 (De-duplicate = 630)	1	204

Appendix 3: Characteristics of included studies – systematic reviews

Authors Systematic reviews	Population	Intervention	Patient satisfaction	Psychological functioning	Health related Quality of life
Rojas et al. 2012 (SR-RCTs) Italy Cochrane	Women with breast cancer	<i>(Gvivo et al. 1994; Rosselli Del Turco et al. 1999)</i> Clinical care v intensive tests <i>(Grunfeld et al. 1996)</i> Clinical care v GP <i>(Guilliford et al. 1997)</i> Clinical care with GP - phone	Not reported Patient satisfaction (> GPs) GP consults. (No difference)	Not reported HADS-depression (no difference) Not reported	Overall survival, overall disease (No difference) Time to detection (No difference) Not reported
Renehan et al. 2005 (SR RCTs) UK	Patients with colorectal cancer	<i>(Makela et al. 1995)</i> Intensive V. usual care <i>(Ohlsson et al. 1995)</i> Intensive v. no follow-up <i>(Kjeldsen et al. 1997)</i> Intensive v. conventional <i>(Pietra et al. 1998)</i> Intensive v. usual <i>(Schoemaker et al. 1998)</i> Intensive v. usual	Not reported Not reported Not reported Not reported	Not reported Not reported Not reported Not reported	Intensive - recurrence detected early, not survival Intensive - recurrence detected early, not survival Intensive - recurrence diagnosed early, not survival Intensive - recurrence detected early, improved survival Intensive - detection of recurrence improved survival
Figuredo et al. 2003 (SR-RCTs) Canada	Patients with colorectal cancer	<i>(Secco et al. 2002)</i> Minimal v intensive - tests	Not reported	Not reported	Intensive - improved survival.
Jeffrey et al. 2008 (SR-RCTs) Cochrane UK	Patients with colorectal cancer	<i>(Rodriguez et al. 2006)</i> Fewer tests v more tests <i>(Wattchow et al. (2006).</i> Primary v secondary care	Not reported Patient satisfaction (No difference)	Not reported Anxiety, depression, (No difference)	Intensive surveillance- time to detection earlier- improved survival QoL (No difference)
McIntosh et al. 2009 (SR of guidelines) UK	Patients with prostate cancer	Assessment of international guidelines	n/a	n/a	The results showed considerable diversity of recommendations on the provision of prostate management.

Appendix 3: Characteristics of included studies – systematic reviews

Authors Systematic reviews	Population	Intervention	Patient satisfaction	Psychological functioning	Health related quality of life
NCCC 2011 Evidence review UK International	Patients with lung cancer	(<i>Nakamura et al. 2010</i>) Thoracic surg. V. chest physician.	Not reported.	Not reported.	Thoracic surgeon follow-up > risk of death
		(<i>Virgo et al. 1995</i>) Intensive v. non-intensive.	Not reported.	Not reported.	Time to detection, survival (no difference)
		(<i>Younes et al. 1999</i>) Strict v. symptom follow-up.	Not reported.	Not reported	Symptom follow-up and survival (no difference).
Taggart et al. (SR-RCTs) UK Internat.	Patients with breast cancer	(<i>Koinberg et al. 2004</i>) Nurse-led follow-up on demand v. physician.	SaaC -(no difference)	HADS- (No difference)	Time to detection, death- (No difference).
		(<i>Koinberg et al. 2009</i>) Nurse-led follow-up v. physician.	Satisfaction with care (No difference).	Anxiety depression (No difference).	Time to detection, death, access to medical centre (No difference).
		(<i>Brown et al. 2002</i>) Standard care v. patient initiated- nurse on demand.	Not reported.	Psychological morbidity (No difference).	QoL (No difference).
		(<i>Sheppherd et al. 2007</i>) Nurse-led follow-up on demand v. usual care.	Not reported.	Psychological morbidity (No difference).	QoL (No difference).
Galway et al. 2012 (SR-RCTs) Cochrane UK	Patients with breast cancer	(<i>Kimman 2010</i>) Nurse-led telephone v. usual care.	Not reported.	Psychological functioning (No difference).	HRQoL (No difference).
		(<i>Allard 2006</i>) Nurse-led telephone AFSMI sessions v. usual care.	Not reported.	Nurse-led (Significant mood difference).	Nurse-led (enhance physical function-small effects)
		(<i>Dow Menses et al. 2007</i>) Nurse-led telephone BCEI v. usual Care.	Not reported.	Not reported.	Nurse-led- (Small difference in QoL).
Devine and Westlake 1995 (Meta-analyses) USA	Patients with prostate cancer	(<i>Sandren et al. 2007</i>) Nurse-led telephone therapy for breast cancer patients v. usual care.	Nurse-led (Improved knowledge).	Nurse-led (less stress).	Not reported.
		(<i>Benor et al. 1998</i>), (<i>Clotfelter et al. 1999</i>), (<i>Zimmerman et al. 1999</i>) Nurse-led psycho educational interventions v. usual care.	Not reported.	Anxiety - positive effect on depression.	Nausea and pain reduction including increased knowledge.
Schmidt-Hansen et al. 2012 (SR x 1 RCT)	Patients with lung cancer	(<i>Moore et al. 2002</i>) Nurse-led telephone v. GP follow-up.	Nurse-led > satisfaction, GP visits (No	Not reported	Nurse-led (< severe dyspnoea, peripheral neuropathy), survival (No difference)

Appendix 3: Characteristics of included studies – systematic reviews

Authors Systematic reviews	Population	Intervention	Patient satisfaction	Psychological function.	Health related quality of life
Ram et al. 2004 (SR RCTs) UK	Patients with COPD	(Davies et al. 2000) Nurse-led home care v. usual care.	Rate of readmissions (No difference).	Not reported.	Mortality (No difference).
		(Swarska et al. 2000) Nurse-led supported discharge v. hospital admissions.	Rate of readmission (No difference).	Not reported.	Mortality (No difference).
		(Cotton et al. 2000) Nurse-led early discharge v. usual care.	Rate of readmissions (No difference.)	Not reported.	Mortality (No difference).
		(Hernandez et al. 2003) Nurse-led home care v. usual care.	Rate of readmissions (No difference)	Not reported.	Mortality (No difference).
Laurant et al (SR RCTs) UK	Patients with undifferentiated chronic disease	(Mundinger et al. 2000) Nurse-led v. doctor care in primary care Nurse-led care.	Satisfaction, hospital admissions (No difference).	Not reported.	Health status, objective measures, (No difference).
		(McIntosh et al. 1997) Nurse-led management v. doctor care.	Not reported.	Not reported.	Objective measures (No difference).
		(Moher et al. 2001) Nurse-led management v. doctor care.	Not reported.	Not reported.	Objective measures (No difference).
Keuthe et al. 2013 (SR RCTs) Netherlands	Patients with asthma	(Pilotto et al. 2004) Nurse-led care in asthma clinic v. GPs (Not in asthma clinic).	Nurse-led care (Fewer days absence from work)	Not reported.	QoL-St George Respiratory Questionnaire (SGRQ) (No difference) QoL (no difference). Objective tests- Lung function (No difference).
		(Van Son et al. 2004) Primary care nurse practitioner v. GP.	Patient satisfaction (Unclear) Nurse-led care (Improved knowledge of disease)	Not reported.	Lung function (No difference).

Appendix 3: Characteristics of included studies – systematic reviews

Authors Systematic reviews	Population	Intervention	Patient satisfaction	Psychological functioning	Health related quality of life
Authors Systematic Reviews	Population	Intervention	Quitting	Self-help support	
Lancaster 2011 (SR RCTs) Register of controlled trials from the Cochrane Library	Patients in the primary care, community or specialist setting	<p>(Stead <i>et al.</i> 2008) Brief advice v. no advice Intensive advice v. no advice.</p> <p>(Lancaster <i>et al.</i> 2005) Self-help v. no intervention Tailored characteristics to the individual v. no intervention. Individual counselling v. minimal intervention.</p>	<p>Brief advice (Significant increase in the rate of quitting). Intensive advice higher rate of quitting than brief advice.</p> <p>Tailored characteristics higher rate of quitting than no intervention. Individual counselling higher rate of quitting than minimal intervention.</p>	Not reported.	Self-help materials-low cost option but their effectiveness is low (Just reached statistical significance).
Authors Review	Population	Intervention	Nurses as information providers		
Koutsopoulou <i>et al.</i> 2010 (Review) Greece	Patients with cancer	Nurses' contribution to information delivery (Effectiveness of nurses as information providers; patients' perspectives and types of information).	Nurses were considered are key source of information during and at the end of treatment. However more research is needed around the specific contents of information delivered by nurses.		
Authors Systematic reviews	Population	Intervention	Patient satisfaction	Psychological functioning	Health related quality of life
Caird <i>et al.</i> 2010 (SR of SR) UK	<p>Patients with breast cancer</p> <p>Patients with lung cancer</p>	<p>(Eicher <i>et al.</i> 2006) Nurse-led interventions.</p> <p>(Sola <i>et al.</i> 2004) Nurse-led non invasive interventions.</p>	<p>Not reported.</p> <p>Not reported.</p>	<p>Nurse-led care (improved anxiety, depression and coping).</p> <p>Nurse-led care (improved psychological functioning).</p>	<p>Nurse-led care (Unclear social functioning), physiological outcomes (No difference).</p> <p>Nurse-led care (reduced breathlessness), (No improvements in physical recovery or pain control).</p>

Appendix 3: Characteristics of included studies – systematic reviews

Authors Systematic reviews	Population	Intervention	Patient satisfaction	Psychological functioning	Health related quality of life
Lewis et al. 2009 (SR RCTs) UK	Patients with cancer from various sites	(Nielsen et al. 2003) Share care intervention - transfer of knowledge from the oncologist to the GP (discharge summary according to guidelines), improved communication between parties (named contact details) with active patient involvement v. usual care (no procedure of informing GPs of newly diagnosed patients, discharge summary (not following guidelines).	Patient satisfaction relating to GP contact (No difference).	Not reported.	Younger patients felt that there was more cooperation between professionals. Shared care intervention (increased GP knowledge and contacts) QoL (no difference).
		(Johansson et al. 2001) Individual support (intensified primary health care- nutritional and psychological support). Individual supports complemented by information from specialist clinics and education for GPs and home care nurses v. control.	Not reported.	Psychological distress (No difference).	Reduced number of admissions and days spent in hospitals - older patients. For older patients utilisation of specialist care may be reduced by intensified primary health care.
McCorkle et al. 2009 (SR RCTs UK)	Patients with breast cancer	(Stanton et al. 2005) Video tape and health counselling including educational booklet v. control.	Not reported.	Less cancer related distress.	Improvements in energy and fatigue.
		(Cimprich et al. 2005) Taking CHARGE intervention Interventions X4 Individual and group counselling sessions.	Not reported.	High utility in dealing with concerns.	Not reported.

Appendix 3: Characteristics of included studies – RCTs

Authors RCTs	Population	Intervention	Patient satisfaction	Psychological functioning	Health related quality of life
Grunfeld et al. 1996 UK (RCT)	Women with breast cancer	Hospital follow-up v GP.	Not reported.	HADS-anxiety (no difference).	Time to recurrence, QoL (No difference).
Grunfeld et al. 2006 (RCT) Canada	Women with breast cancer	Usual follow-up v FP.	Not reported.	Not reported.	Recurrence related SCEs, HRQoL (No difference).
Beaver et al. 2012 (RCT) UK	Patients with colorectal cancer	Nurse-led telephone v. usual care.	Nurse-led > patient satisfaction, mentioning of concerns. Contacts between appointments (No difference). Nurse-led (Longer appointment times).	State -Trait Anxiety Inventory (STAI) (No difference).	Local recurrence (No difference). Bio measures, colonoscopies ordered (No difference). Time to detection (No difference). General Health Questionnaire (GHQ) (No difference). Resource usage (No difference).
Young et al. 2013 (RCT) Australian	Patients with colorectal cancer	CONNECT - Nurse-led telephone v. usual care.	Unmet supportive care needs (No difference). Emergency department presentations (No differences). Hospital readmissions (No difference). Care coordination (No differences).	Distress (No difference).	HRQoL (No difference).
Strand et al. 2011 (RCT) Sweden	Patients with colorectal cancer	Nurse-led v. surgeon.	Satisfaction (No difference). Nurse-led (Higher use of resources).	Confidence (No difference).	Medical safety (No difference).
Helegson et al. 2000 RCT Scand.	Patients with prostate cancer	Nurse-led on demand follow-up v. urologist.	Patient satisfaction (No difference) Nurse -led care-resource utilisation (No difference). Access to services (No differences).	HADS-depression scale (No difference).	Medical safety (No difference) Reporting symptoms (No difference), Time to detection (No difference).
Faithful et al. 2001 (RCT UK)	Patients with prostate cancer	Nurse-led v. usual care.	Nurse-led care > satisfaction. Nurse-led care< service costs.	Not reported	Assessment of symptoms scores (No difference).
Giesler et al. 2005 (RCT) USA	Patients with prostate cancer	Nurse-led v. usual care.	Nurse-led care> satisfaction.	Nurse-led care (less cancer worries).	Nurse-led (improved sexual outcomes) Nurse-led (urinary dysfunction - dependant on baseline depression scores).
Verschuur et al. 2009 (RCT)	Patients with oesophageal cancer	Nurse-led v. surgeon.	Nurse-led (small differences satisfaction).	Nurse-led (small differences in depression).	Nurse-led (small differences in mobility, usual activity and pain relief).
Grunfeld et al. (RCT) 2011 Canada	Patients with breast cancer	Comprehensive summary care plan v. control (standard discharge)	Patient satisfaction.	Cancer related distress (No differences).	Continuity of care (No difference) Health status (No difference).

Appendix 3: Characteristics of included studies – RCTs

Authors RCTs	Population	Intervention	Patient satisfaction	Psychological functioning	Health related quality of life
Kousgaard et al. 2003 (RCT) Denmark	Patients with cancer and their GPs.	Structured oncology information pack sent to GPs v. assessment of traditional information provided by the department.	Not reported	Not reported	Structured oncology information pack (Improved GP knowledge. Facilitated GPs to support and counsel their patients - increased GP satisfaction).
Rutherford and Burge 2001 (RCT) Australia	Patients with gynaecological cancer and their GPs.	Visits and telephone calls by GPs to specialist care including a discharge summary (at the point of discharge were measured personal invites.	Patient satisfaction (No difference)		Personal invites increased GP contact GPs valued hospital contact and meeting their patients' needs.

Appendix 3: Characteristics of included studies – observational

Authors Observational	Aim of the research	Methods	Results	Conclusion	Practice implications
Sussman et al. 2006 (Longitudinal cohort design)	Oncology nursing and impact on needs.	Longitudinal cohort design with assessments at various time points. Participants were identified at the time of referral to the Interlink programme.	A reduction in the need for patient care. There was also a reduction in psychological and information needs, which were seen at 4 and at 8 weeks.	For patients who received the community-based nursing programme, there were improvements in their physical and psychosocial outcomes.	This study provides evidence regarding the potential of other nurse-led community based-programmes.
Chlebowski et al. 1992 (Needs assessment survey)	Physicians' perceptions in relation to cancer prevention and control.	1,500 oncologists were sent a self-reported 67 item questionnaire.	70% of oncologists viewed themselves as a resource for cancer prevention and control.	-	Oncologists may represent a potential resource for implementing cancer prevention and control.
Warren et al. 2013 (Online survey Descriptive)	Thoracic oncology providers' perceptions of tobacco use and cessation in cancer patients.	An online survey of oncologists' perceptions and barriers to tobacco assessment and cessation in cancer patients.	90% of physicians believe smoking affects health outcomes. Smoking cessation strategies should be a standard part of clinical care. Physicians feel ill equipped to support patients to stop smoking. Barriers include patient resistance and lack of physician training.	Physicians who care for lung cancer patients recognise the importance of tobacco cessation as a necessary part of clinical care, yet many still do not provide assistance to their patients as part of cancer care.	There is a need to improve cessation support for physicians and patients.
Adams et al. 2011 (Qualitative research)	Implementation of CCR Patients experiences Professionals opinions.	Interviews with patients and focus groups with professionals.	CCRs conducted opportunistically. Patients believed diagnosis and general support as important - not always addressed. Appointment times might facilitate raising concerns. GPs emphasised individual care.	Primary care has an important role to play in cancer care. CCR in their current format are not helpful.	Patients could attend an appointment at the end of treatment, which may help aid transition from secondary care and improve satisfaction with follow-up in primary care.

Appendix 4: Expression of interest form



Date:
Hospital address:

Dear

Re- The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

I obtained your contact details from the xxxx of xxx xxx and I am mailing you in your capacity as the xxx lead of xxx xxx.

I am currently undertaking my PhD at the University of Glasgow and wish to talk to specialists and CNS about their perspectives regarding cancer care follow-up. Specifically, this would involve an interview around current practice, professional roles and potential models of cancer care.

I have attached an information sheet regarding the study. Should you wish any further information, I can be contacted at 01413308387 or Fiona.smith.2@research.gla.ac.uk

Kind Regards

Fiona Smith

Thank you very much for completing this form

Version 1: 02/06/08

Appendix 5a: Covering letter to oncologists



Date

Dear Dr.

The on-going care of patients with cancer: what is the appropriate balance of cancer care between oncologists and primary care?

I am writing to you to ask for your help with my PhD project. I would like to interview some oncologists, clinical nurse specialists and GPs about their views concerning current arrangements for cancer care after diagnosis and treatment. In particular, I am interested in the arrangements for care between specialist and primary care.

This will involve your participation in an audiotaped interview to discuss your views and experiences concerning models of cancer care following diagnosis. Your experiences will be drawn on to discuss the ways in which physical and psychosocial needs of the cancer patient can best be met, including your views about communication practices between professionals. Additionally, oncologists will be asked how the role of primary care could be optimised, including your views on enhancing communication practices.

We have ethical approval for this research. The analysis of the data will be entirely anonymous. Copies of the topic guide will be available if desired. I enclose an information sheet, form for reply and a pre-paid envelope. I would be grateful if you would complete this and return it to me. I will then be in contact with you to arrange an interview at a time convenient to you. If you would like to discuss this with me, please contact me on 0141 3308387 or email me on f.smith.2@research.gla.ac.uk

With thanks for your help

Yours Sincerely

FIONA SMITH

Version 1: 02/06/08

Appendix 5b: Covering letter to clinical nurse specialists



Date

Dear Nurse Specialist

The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

I am writing to you to ask for your help with my PhD project. I would like to interview some oncologists, clinical nurse specialists and GPs about their views concerning current arrangements for cancer care after diagnosis and treatment. In particular, I am interested in the arrangements for care between specialist and primary care.

This will involve your participation in an audiotaped interview to discuss your views and experiences concerning models of cancer care following diagnosis. Your experiences will be drawn on to discuss the ways in which physical and psychosocial needs of the cancer patient can best be met, including your views about communication practices between professionals. Additionally, nurse specialists will be asked how the role of primary care could be optimised, including your views on enhancing communication practices.

We have ethical approval for this research. The analysis of the data will be entirely anonymous. Copies of the interview schedule will be available if desired. I enclose an information sheet, form for reply and a pre-paid envelope. I would be grateful if you would complete this and return it to me. I will then be in contact with you to arrange an interview at a time convenient to you. If you would like to discuss this with me, please contact me on 0141 3308387 or email me on f.smith.2@research.gla.ac.uk

With thanks for your help

Yours Sincerely

FIONA SMITH
02/06/08

Version 1:

Appendix 5c: Covering letter to GPs



Date

Dear Dr.

The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

I am writing to you to ask for your help with this PhD project. I would like to interview some oncologists, clinical nurse specialists and GPs about their views concerning current arrangements for cancer care after diagnosis and treatment. In particular, I am interested in the arrangements for care between specialist and primary care.

This will involve your participation in an audiotaped interview to discuss your views and experiences concerning models of cancer care following diagnosis. The interviews are likely to last 1 hour and your time will be reimbursed at £96 per hour according to NHS Scotland guidelines. Your experiences will be drawn on to discuss the ways in which physical and psychosocial needs of the cancer patient can best be met, including your views about communication practices between professionals. Additionally, general practitioners will be asked how the role of primary care could be optimised, including your views on enhancing communication practices.

We have ethical approval for this research. The analysis of the data will be entirely anonymous. Copies of the topic guide will be available if desired. I enclose an information sheet, form for reply and a pre-paid envelope. I would be grateful if you would complete this and return it to me. I will then be in contact with you to arrange an interview at a time convenient to you. If you would like to discuss this with me, please contact me on 0141 330 8387 or email me on f.smith.2@research.gla.ac.uk

With thanks for your help

Yours Sincerely

FIONA SMITH
02/06/08

Version 1:

Appendix 6a: Information sheet to oncologists



Study Title: The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

We would like to invite you to help us with a research study identifying the process of communication and cancer care between oncologists, clinical nurse specialists and primary care professionals.

Why is the study being done?

There are considerable differences in the way that patients with cancer are followed up and cared for after their treatment. Evidence suggests that there are variations in follow-up care from hospital to primary care. Differences may occur between cancer groups because of different discharge arrangements or because general practitioners receive differing types of information. We would like to obtain oncologists' views on the optimum way in which services could be organised. In order to understand what happens in greater detail, we are asking oncologists employed at hospitals across Scotland to assist us. We hope to conduct fifteen to twenty interviews with oncologists and a similar number each with clinical nurse specialists and GPs.

Why have you chosen me?

You have been identified because you are an oncologist and are employed within a cancer centre in Scotland.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you consent to an interview, you are still free to withdraw your consent at any time and without giving a reason.

Version 1: 02/06/0/08

Information sheet to oncologists

What will I have to do if I take part?

We would like to interview you to discuss your views on how patients with cancer can best be managed and followed up after diagnosis. The interview will take approximately 1 hour and will be at a time and place that suits you. If you would like to take part, please return the reply form back in the pre-paid envelope provided.

What will happen to the information collected about me?

The information collected during the study will be written up in a report as part of a PhD research project. We may also prepare it for publication in academic journals. You will be able to request copies of these reports.

Who is funding this research?

This project is being funded by the Chief Scientist Office at the Scottish Executive Health Department, St Andrew's House Edinburgh.

Who has reviewed the study?

Ethics approval has been given by the NHS NREC Ethics Committee on the 03/09/2008

Who are the research team?

Fiona Smith will carry out the research and will write this up as part of her PhD thesis for which she is studying at the Faculty of Medicine, University of Glasgow. She is being supervised by Dr. U. Macleod and Professor J. Cassidy. Further information can be obtained from:

Dr. U. Macleod
Senior Lecturer,
University of Glasgow,
0141 330 8330
u.macleod@clinmed.gla.ac.uk

Fiona Smith
PhD Student
University of Glasgow
0141 330 8387
f.smith.2@research.gla.ac.uk

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

Version 1: 02/06/08

Appendix 6b: Information sheet to CNSs



Study Title: The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

We would like to invite you to help us with a research study identifying the process of communication and cancer care between oncologists, clinical nurse specialists and primary care professionals.

Why is the study being done?

There are considerable differences in the way that patients with cancer are followed up and cared for after their treatment. Evidence suggests that there are variations in follow-up care from the hospital to primary care. Differences may occur between cancer groups because of different discharge arrangements or because general practitioners receive differing types of information. We would like to obtain clinical nurse specialists' views on the optimum way in which services could be organised. In order to understand what happens in greater detail, we are asking clinical nurse specialists employed at hospitals across Scotland to assist us. We hope to conduct fifteen to twenty interviews with clinical nurse specialists and a similar number each with oncologists and GPs.

Why have you chosen me?

You have been identified because you are a clinical nurse specialist and are employed within a cancer centre in Scotland.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you consent to an interview, you are still free to withdraw your consent at any time and without giving a reason.

Version 2: 02/06/08

Information sheet to Clinical Nurse Specialists

What will I have to do if I take part?

We would like to interview you to discuss your views on how patients with cancer can best be managed and followed up after diagnosis. The interview will take approximately 1 hour and will be at a time and place that suits you. If you would like to take part, please return the reply form back in the pre-paid envelope provided.

What will happen to the information collected about me?

The information collected during the study will be written up in a report as part of a PhD research project. We may also prepare it for publication in academic journals. You will be able to request copies of these reports.

Who is funding this research?

This project is being funded by the Chief Scientist Office at the Scottish Executive Health Department, St Andrew's House Edinburgh.

Who has reviewed the study?

Ethics approval has been given by the NHS NREC Ethics Committee on the 03/09/2008

Who are the research team?

Fiona Smith will carry out the research and will write this up as part of her PhD thesis for which she is studying at the Faculty of Medicine, University of Glasgow. She is being supervised by Dr. U. Macleod and Professor J. Cassidy. Further information can be obtained from:

Dr. U. Macleod
Senior Lecturer,
University of Glasgow,
0141 330 8330
u.macleod@clinmed.gla.ac.uk

Fiona Smith
PhD Student
University of Glasgow
0141 330 8387
f.smith.2@research.gla.ac.uk

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

Version 2: 02/06/08

Appendix 6c: Information sheet to GPs



Study Title: The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

We would like to invite you to help us with a research study identifying the process of communication and cancer care between oncologists, nurse specialists and primary care professionals.

Why is the study being done?

There are considerable differences in the way that patients with cancer are followed up and cared for after their treatment. Evidence suggests that there are variations in follow-up care from the hospital to primary care. Differences may occur between cancer groups because of different discharge arrangements or because general practitioners receive differing types of information. We would like to obtain GPs views on the optimum way in which services could be organised. In order to understand what happens in greater detail, we are asking GPs working in areas of differing demography to assist us. We hope to conduct fifteen to twenty interviews with clinical nurse specialists and a similar number each with oncologists and GPs.

Why have you chosen me?

You have been identified because you are a GP and work in differing areas of demography.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you consent to an interview, you are still free to withdraw your consent at any time and without giving a reason.

Information sheet to GPs

What will I have to do if I take part?

We would like to interview you to discuss your views on how patients with cancer can best be managed and followed up after diagnosis. The interview will take approximately 1 hour and will be at a time and place that suits you. If you would like to take part, please return the reply form back in the pre-paid envelope provided.

What will happen to the information collected about me?

The information collected during the study will be written up in a report as part of a PhD research project. We may also prepare it for publication in academic journals. You will be able to request copies of these reports.

Who is funding this research?

This project is being funded by the Chief Scientist Office at the Scottish Executive Health Department, St Andrew's House Edinburgh.

Who has reviewed the study?

Ethics approval has been given by the NHS NREC Ethics Committee on the 03/09/2008

Who are the research team?

Fiona Smith will carry out the research and will write this up as part of her PhD thesis for which she is studying at the Faculty of Medicine, University of Glasgow. She is being supervised by Dr. U. Macleod and Professor J. Cassidy. Further information can be obtained from:

Dr. U. Macleod
Senior Lecturer,
University of Glasgow,
0141 330 8330
u.macleod@clinmed.gla.ac.uk

Fiona Smith
PhD Student
University of Glasgow
0141 330 8387
f.smith.2@research.gla.ac.uk

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

Appendix 7: Form for reply



Study Title:

The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

Researcher:

Fiona Smith
General Practice and Primary Care
University of Glasgow
1 Horselethill Road
Glasgow G12 9LX
Tel: 0141 3308387
Email: f.smith.2@research.gla.ac.uk

I am happy to be contacted to take part in this research.

I do not want to take part in this research

Contact details:

Name:

Telephone:

Email:

With thanks

Fiona Smith

Appendix 8a: Topic guide for oncologists

TOPIC GUIDE FOR INTERVIEWS WITH ONCOLOGISTS



Study title: The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

Thank you for agreeing to be interviewed. This study focuses on communication and cancer care between oncologists, CNSs and GPs. I would like to ask you about arrangements for cancer care after diagnosis. Can you tell me a bit about how you came to specialise in oncology.

Current practice regarding follow up

What is the usual practice currently regarding the follow-up of cancer patients? What happens after patients have been diagnosed with cancer? Do they continue to be seen at the hospital? Do you have a lot to do with these patients?

How has that changed over the last number of years?

What do you think is the role of oncologists in follow-up?

What do you think is the role of clinical nurse specialists in follow-up?

What do you think is the role of GPs and other primary care professionals in follow-up?

The needs of cancer patients after diagnosis and treatment

What are your views concerning the main physical and psychosocial needs of cancer patients following diagnosis?

In your view what would be an effective post-diagnosis care plan for cancer patients in relation to:

Treatment exposures - pain, fatigue (prevention, early detection, intervention) Co-morbid health conditions (heart disease, secondary cancers, lung disease, diabetes etc.)

Psychological support (anxiety, depression)

Economic well-being

Where should this quality care plan be delivered?

How do you access psychological support for your patients with cancer who need it? What do you think patients want from oncologists, CNSs, GPs? What is the role of the voluntary sector? What are your views as to the role of specialist and primary care in respect to the follow-up care plan of patients with cancer? Do you think patients' needs are being met and if no why

Communication between specialist and primary care

What is the communication you receive about cancer patients like? Is it good enough? What are the issues?

What do you feel are the issues in communicating with primary care colleagues including information communicated and frequency of communication?

What do you believe would enhance the communication practices between specialist and primary care?

What type of information should be communicated?

Describe your views as to the perception of barriers that impede implementation of good practice (communication) between specialist and primary care?

Future models of care

Do you think current models of cancer care will change in the future? How?

Do you think the balance of care for cancer patients between primary and specialist care should change? How?

How do you think the role of primary care could be optimised?

Appendix 8b: Topic guide for clinical nurse specialists

TOPIC GUIDE FOR INTERVIEWS WITH CLINICAL NURSE SPECIALISTS



University
of Glasgow

Study title: The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

The interview will be directed to some extent by the health professional, but it is anticipated that the following topics will be covered.

Current practice regarding follow up

What is the usual practice currently regarding the follow-up of cancer patients?

How has that changed over the last number of years?

What do you think is the role of Clinical Nurse specialists in follow-up?

What do you think is the role of Oncologists in follow-up?

What do you think is the role of GPs and other primary care professionals in follow-up?

The needs of cancer patients after diagnosis and treatment

What are your views concerning the main physical and psychosocial needs of cancer patients following diagnosis?

In your view what would be an effective post-diagnosis care plan for cancer patients in relation to:

Treatment exposures - pain, fatigue (prevention, early detection, intervention)

Co-morbid health conditions (heart disease, secondary cancers, lung disease, diabetes etc)

Psychological support (anxiety, depression) Economic well being

Where should this quality care plan be delivered?

How do you access psychological support for your patients with cancer who need it? What do you think patients want from oncologists, CNSs, GP?

What is the role of the voluntary sector?

What are your views as to the role of the Clinical Nurse Specialist and primary care in respect to the follow-up care plan of patients with cancer?

Communication between specialist and primary care

Are there policies that exist with respect to communication between the Clinical Nurse Specialist and primary care?

What are the current communication practices between the Clinical Nurse Specialist and primary care?

What do you feel are the issues in communicating with primary care colleagues including information communicated and frequency of communication?

What do you believe would enhance the communication practices between the Clinical Nurse Specialist and primary care?

What type of information should be communicated?

Describe your views as to the perception of barriers that impede implementation of good practice (communication) between the Clinical Nurse Specialist and primary care?

Future models of care

Do you think current models of cancer care will change in the future? How?

Do you think the balance of care for cancer patients between primary and specialist care should change? How?

How do you think the role of primary care could be optimised?

Appendix 8c: Topic guide for GPs

TOPIC GUIDE FOR INTERVIEWS WITH GENERAL PRACTITIONERS



University
of Glasgow

Study title: The on-going care of patients with cancer: what is the appropriate balance of cancer care between the General Practitioner and specialist care?

The interview will be directed to some extent by the health professional, but it is anticipated that the following topics will be covered.

Current practice regarding follow up

What is the usual practice currently regarding the follow-up of cancer patients?

How has that changed over the last number of years?

What do you think is the role of General Practitioners in follow-up?

What do you think is the role of GPs and other specialist professionals in follow-up?

The needs of cancer patients after diagnosis and treatment

What are your views concerning the main physical and psychosocial needs of cancer patients following diagnosis?

In your view what would be an effective post-diagnosis care plan for cancer patients in relation to:

Treatment exposures - pain, fatigue (prevention, early detection, intervention)

Co-morbid health conditions (heart disease, secondary cancers, lung disease, diabetes etc)

Psychological support (anxiety, depression)

Economic well being

Where should this quality care plan be delivered?

How do you access psychological support for your patients with cancer who need it? What do you think patients want from oncologists, CNSs, GPs?

What is the role of the voluntary sector?

What are your views as to the role of the General Practitioner in primary care with respect to the follow-up care plan of patients with cancer?

Communication between specialist and primary care

Are there policies that exist with respect to communication between the General Practitioner and specialist care?

What are the current communication practices between General Practitioners and specialist care?

What do you feel are the issues in communicating with specialist care colleagues including information communicated and frequency of communication?

What do you believe would enhance the communication practices between General Practitioners and specialist care?

What type of information should be communicated?

Describe your views as to the perception of barriers that impede implementation of good practice (communication) between General Practitioners and specialist care?

Future models of care

Do you think current models of cancer care will change in the future? How?

Do you think the balance of care for cancer patients between General Practitioners and specialist care should change? How?

How do you think the role of primary care could be optimised?

Appendix 9a: Consent form for oncologists

Centre Number:



University
of Glasgow

Study Number:

Subject Identification Number:

Oncologist Consent Form

Title of Project:

The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

Name of Researcher: Fiona Smith

1. I confirm that I have read and understand the information sheet dated 02/06/08 (Version 1) for the above study. I have had the opportunity to ask questions and I have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason, without my legal rights being affected.

3. I consent to my interview being audio taped.

4. I agree/ do not agree (delete as appropriate) to take part in the above study.

Name of Respondent

Date

Signature

Name of Person taking consent
(If different from researcher)

Date

Signature

Researcher

Date

Signature

Version 1: 02/06/08

Appendix 9b: Consent form for CNSs



Centre Number:
Study Number:
Subject Identification Number:

Clinical Nurse Specialist Consent Form

Title of Project:

The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

Name of Researcher: Fiona Smith

1. I confirm that I have read and understand the information sheet dated 02/06/08 (Version 1) for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason, without my legal rights being affected.

3. I consent to my interview being audio taped.

4. I agree/do not agree (delete as appropriate) to take part in the study

Name of Respondent

Date

Signature

Name of Person taking consent
(If different from researcher)

Date

Signature

Researcher

Date

Signature

Appendix 9c: Consent form for GPs



Centre Number:
Study Number:
Subject Identification Number:

General Practitioner Consent Form

Title of Project:

The on-going care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

Name of Researcher: Fiona Smith

1. I confirm that I have read and understand the information sheet dated 25/7/08 (Version 1) for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving reason, without my legal rights being affected.

3. I consent to my interview being audio taped.

4. I agree/do not agree (delete as appropriate) to take part in the above study.

Name of Respondent

Date

Signature

Name of Person taking consent
(If different from researcher)

Date

Signature

Researcher

Date

Signature

Appendix 10: The One Sheet of Paper method

MDTs/weekly - CNS09
 Consultations/letter to GP - CNS05
 Phone calls to GP/bad news/medications - SPEC10
 Phone calls from specialist/opinions - GP01
 Email from GPs -Telephone calls - care solutions - SPEC14
 Specialist use of Standardised form from computer - CNS07
 Letters from GPs about treatments/ further investigations - SPEC13,
 Letters from GPs about back pain - SPEC03
 Emergency referrals -SCI Gateway -GP06
 Faxes from GPs about patient symptoms - SPEC08

Poor professional relationships with GP - CNS14, CNS11, GP01
 Specialist and GP communication skills - SPEC08
 Lack of time to communicate - SPEC10
 Tension between doctors and nurses - CNS08
 Tension between the hospital and primary care - CNS13
 Lack of co-operation - SPEC08
 Lack of contact -GP01
 Lack of routine communication - SPEC2
 Specialists unaware of patients' appointments with GP - SPEC03
 Expectations about responsibilities - communication - GP06
 Lack of acknowledgment of GP letters - GP07
 Lack of acknowledgement of specialist letters - CNS06
 No communication between referral and referral back - GP06
 GPs out of the communication loop - GP01
 GPs concerns about specialist workload - receiving ++ letters - GP03
 GP communication depends on individual - CNS15, SPEC04
 Access - patients having more than one GP - CNS08, CNS04
 Access- gatekeeping role of receptionist - SPEC07, CNS09
 Access- Specialists unable to contact GPs - out on calls - SPEC10, CNS08, CNS15
 Access -GPs unable to contact specialists - GP02

Lack of understanding around professionals' needs - SPEC03, SPEC16, CNS01,
 SPEC10, SPEC15, GP02, GP03
 Research in relation to GPs' needs - CNS12
 Detail of letters - different between clinics/consultants - CNS12, CNS05
 Detail of letters- too complex for GPs - GP03
 Detail of letters - patchy - SPEC06
 Detail of letters - variable- SPEC04
 Detail of letters - too bulky - CNS04
 Detail of letters - inadequate - SPEC15
 Delay - timeliness of letters to GP - SPEC01, CNS02, CNS09, CNS10, CNS11,
 CNS12, SPEC04, SPEC05, SPEC12, GP09, GP03
 Delay -timeliness of letters to GP - GP unaware of patient progress CNS13, GP01
 Delay - secretarial speed - GP01, SPEC02, SPEC03, GP02

Appendix 10: The One Sheet of Paper method

Delay- dependant on unit/consultant - GP09
 Delay - two-week turn around not effective - SPEC01
 ICT-secure email - SPEC01, CNS10, SPEC04
 ICT - Excelicare - GP inclusion SPEC04
 ICT - Different patient management systems - GP05, GP06
 GPs not embracing email - SEC14
 GPs use of pagers v. email - SPEC08

Professional relationships - building - CNS11, CNS01, GP07
 Professional relationships -regular contact- face- to-face contact - GP03,
 SPEC10, SPEC11, SPEC10, GP02
 Professional relationships - acknowledge need for communication - SPEC01
 Structured discharge letters - meeting needs - GP02, SPEC01
 Structured discharge letters -Specific headings appropriate text - GP07, GP08
 Structured discharge letters - staging, treatments, prognosis, treatments,
 adverse reactions follow-up - GP02, GP07, CNS07
 Structured discharge letter - medications GP08, GP09
 Structured discharge letter - management plans GP04
 Structured discharge letter - what the patient understands GP02, GP06
 Structured discharge letter - named contact for GP - CNS07, SPEC01
 Structured discharge letter - standardised tick boxes - SPEC16
 ICT development - CNS02, CNS08, GP05, GP06, CNS01, CNS05, SPEC10, SPEC11
 ICT Email increased use - CNS14, CNS09, CNS05, CNS11, CNS07, SPEC08, SPEC10,
 SPEC15
 ICT Use Blackberries - CNS04
 ICT Telephone strategy - designated numbers/time points - SPEC01, CNS07, GP03
 ICT Telemedicine/virtual clinics - GP05

CNS support - informing and updating GPs - CNS10
 CNS support - dedicated point of contact - CNS01
 CNS support - telephone - SPEC11
 CNS support - acting as an intermediary- GP02

Appendix 10: The One Sheet of Paper method

Broader themes identified in the extracts from oncologists, CNSs and GPs

Current communication practices- mode and type of information

Letters from specialist to primary care

Consultations/letter to GP- CNS05
Standardised form from computer - CNS07
Report MDTs/weekly CNS09

ICT from specialist care to primary care

Phone calls to GP/bad news/medications - SPEC10
Phone calls from specialist care/opinions GP01
Emergency referrals -SCI Gateway -GP06

Letters from primary care to specialist care

Letters from GPs about treatments/ further investigations - SPEC13
Letters from GPs about back pain - SPEC03

ICT from primary care to specialist care

Email from GPs -Telephone calls - care solutions - SPEC14
Faxes from GPs about patient symptoms - SPEC08

Barriers impeding optimal communication

Professional relationships - challenges

Poor professional relationships with GP - CNS14, CNS11, GP01
Specialist and GP communication skills - SPEC08
Lack of time to communicate - SPEC10
Tension between doctors and nurses - CNS08
Tension between the hospital and primary care - CNS13
Lack of co-operation - SPEC08
Lack of contact -GP01
Lack of routine communication - SPEC2
Specialists unaware of patients' appointments with GP - SPEC03
Expectations about responsibilities - communication - GP06
Lack of acknowledgment of GP letters - GP07
Lack of acknowledgement of specialist letters - CNS06
No communication between referral and referral back - GP06
GPs out of the communication loop - GP01
GPs concerns about specialist workload - receiving ++ letters - GP03
GP communication depends on individual - CNS15, SPEC04

Appendix 10: The One Sheet of Paper method

Access issues between professionals

Access - patients having more than one GP - CNS08, CNS04

Access- gatekeeping role of receptionist - SPEC07, CNS09

Access- Specialists unable to contact GPs - out on calls - SPEC10, CNS08, CNS15

Access -GPs unable to contact specialists - GP02

Lack of understanding around needs

Lack of understanding around professionals' needs - SPEC03, SPEC16, CNS01, SPEC10, SPEC15, GP02, GP03

Research in relation to GPs' needs - CNS12

Detail of letters

Detail of letters - different between clinics/consultants - CNS12, CNS05

Detail of letters- too complex for GPs - GP03

Detail of letters - patchy - SPEC06

Detail of letters - variable- SPEC04

Detail of letters - too bulky - CNS04

Detail of letters - inadequate - SPEC15

Delay of letters

Delay - timeliness of letters to GP - SPEC01, CNS02, CNS09, CNS10, CNS11, CNS12, SPEC04, SPEC05, SPEC12, GP09, GP03

Delay -timeliness of letters to GP - GP unaware of patient progress CNS13, GP01

Delay - secretarial speed - GP01, SPEC02, SPEC03, GP02

Delay- dependant on unit/consultant - GP09

Delay - two-week turn around not effective - SPEC01

ICT challenges

ICT -secure email - SPEC01, CNS10, SPEC04

ICT - Excelicare - GP inclusion SPEC04

ICT - Different patient management systems - GP05, GP06

GPs not embracing email - SEC14

GPs use of pagers v. email - SPEC08

Appendix 10: The One Sheet of Paper method

Enhance communication practices

Professional relationships

Professional relationships - building - CNS11, CNS01, GP07
 Professional relationships -regular contact- face- to-face contact - GP03,
 SPEC10, SPEC11, SPEC10, GP02
 Professional relationships - acknowledge need for communication - SPEC01

Suggested improvements to the structured discharge letter

Structured discharge letters - meeting needs - GP02, SPEC01
 Structured discharge letters -Specific headings appropriate text - GP07, GP08
 Structured discharge letters - staging, treatments, prognosis, treatments,
 adverse reactions follow-up - GP02, GP07, CNS07
 Structured discharge letter - medications GP08, GP09
 Structured discharge letter - management plans GP04
 Structured discharge letter - what the patient understands GP02, GP06
 Structured discharge letter - named contact for GP - CNS07, SPEC01
 Structured discharge letter - standardised tick boxes - SPEC16

ICT development

ICT development - CNS02, CNS08, GP05, GP06, CNS01, CNS05, SPEC10, SPEC11
 ICT Email increased use - CNS14, CNS09, CNS05, CNS11, CNS07, SPEC08, SPEC10,
 SPEC15
 ICT Use Blackberries - CNS04
 ICT Telephone strategy - designated numbers/time points - SPEC01, CNS07, GP03
 ICT Telemedicine/virtual clinics - GP05

CNSs acting as an intermediary

CNS support - informing and updating GPs - CNS10
 CNS support - dedicated point of contact - CNS01
 CNS support - telephone - SPEC11
 CNS support - acting as an intermediary- GP02

Appendix 11: NHS MREC approval Glasgow

Acute Services Division

NHS

Greater Glasgow
and Clyde

West Glasgow Ethics Committee 1

Western infirmary
Dumbarton Road
Glasgow
G11 6NT

Telephone: 0141 211 620
Facsimile: 0141 211 1920

03 September 2008

Ms Fiona Marcuson
General Practice and Primary Care
University of Glasgow
1 Horselethill Road
Glasgow G12 9LX

Dear Ms Marcuson

Full title of study: The ongoing care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?
REC reference number: 08/S0703/97

The Research Ethics Committee reviewed their requested amendments to the above application and approved these.

Ethical opinion

Members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

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40389

Appendix 11: NHS MREC approval Glasgow

08/S0703/97

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Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Application	5.6	02 June 2008
Investigator CV		01 January 2007
Protocol	1	02 June 2008
Protocol	2	25 July 2008
Covering Letter		11 August 2008
Summary/Synopsis	1	02 June 2008
Compensation Arrangements		09 May 2008
Interview Schedules/Topic Guides	1	02 June 2008
Questionnaire: non-validated	1	02 June 2008
Letter of invitation to participant	1	02 June 2008
GP/Consultant Information Sheets	1	02 June 2008
GP/Consultant Information Sheets	2	25 July 2008
Participant Information Sheet	1	02 June 2008
Participant Consent Form	1	02 June 2008
Response to Request for Further Information		11 August 2008
Letter from Prof J Cassidy		11 August 2008
covering letter		02 June 2008
Letter from funder - Scottish Exec		30 May 2008
letter from sponsor NHS GG & Clyde		09 May 2008

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Progress and safety reports

Appendix 11: NHS MREC approval Glasgow

08/S0703/97

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- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

08/S0703/97	Please quote this number on all correspondence
-------------	--

With the Committee's best wishes for the success of this project

Yours sincerely



Andrea H Torrie
Ethics Manager – West Glasgow RECs

Email: andrea.torrie@ggc.scot.nhs.uk

Copy to: *Mr Brian Rae R & D Tennent Inst*

Appendix 12: NHS RD approval Glasgow

North Glasgow University Hospitals
NHS Trust



Central R & D Office, 1st Floor, The Tennent Institute, 38 Church Street, Western
Infirmary, Glasgow, G11 6NT

8th September 2008

Ms Fiona Marcuson
Research Student
General Practice and Primary Care
University of Glasgow
1 Horselethill Road
Glasgow
G12 9LX

Dear Ms Marcuson

Greater Glasgow Health Board, Research Access Letter

The ongoing care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care? (WN08ON280)

On behalf of Greater Glasgow Health Board I am writing to provide you with a **Research Access Letter (RAL)** to enable you to work on this project.

- This letter enables you to undertake research duties and you shall not be deemed an employee of the NHS Greater Glasgow and Clyde.
- You are required to comply with GCP, Research Governance Guidelines, Health and Safety Act, the Data Protection Act and all Policies and Procedures implemented by NHS Greater Glasgow and Clyde.
- In the course of your duties you will have access to confidential information. This information will not be used by you for your own benefit or disclosed to a third party without the consent of the Division.
- This RAL does not come associated with payment for any costs incurred including (but not limited to) travelling expenses, library expenses and hospitality expenses.
- NHS Greater Glasgow and Clyde accepts no responsibility for damage to or loss of personal property, with exception of small valuables handed to their officials for safe custody. You are therefore strongly recommended to take out an insurance policy to cover your personal property.

Appendix 13: NHS approval Lothian

University Hospitals Division

Queen's Medical Research Institute
47 Little France Crescent, Edinburgh, EH16 4TJ



HAC/JB/approval/ssa-exempt

04 December 2008

Ms Fiona Marcuson
Research Student
General Practice & Primary Care
University of Glasgow
1 Horslethill Road
Glasgow
G12 9LX

RESEARCH & DEVELOPMENT
Room E1.12
Tel: 0131 242 3330
Fax: 0131 242 3343
Email: R&DOffice@luht.scot.nhs.uk

Director: Professor Heather A Cubie

Dear Ms Marcuson

MREC No: 08/S0703/97
NRS Ref: NRS08/ON06
R&D ID No: 2008/W/ON/24
Title of Research: The ongoing care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

The above project has undergone an assessment of risk to NHS Lothian and review of resource and financial implications.

I note that the West Glasgow Research Ethics Service approved this study on 02 July 2008 and considered that it is SSA Exempt.

I am satisfied that all the necessary arrangements have been set in place and that all Departments contributing to the project have been informed.

I note that this is a multi centre study sponsored by **NHS Greater Glasgow & Clyde**.

On behalf of the Chief Executive and Medical Director, I am happy to grant management approval from NHS Lothian to allow the project to commence. You should be aware that management approval from NHS Lothian does not commit NHS Lothian staff to taking part.

Yours sincerely

Professor Heather A Cubie
R&D Director

Copies: Eilidh Carmichael, NRS Head Office, Glasgow Royal Infirmary

Appendix 14: NHS Approval Highland

Prof David J Godden, MD, FRCP(Edin), FRCP(Glasg)
 Research Director
 NHS Highland Research Office
 Unit 18
 The Green House
 Beechwood Business Park
 Inverness, IV2 3BL

Tel: 01463 667320
 Fax: 01463 667310
 E-mail: david.godden@hahl.scot.nhs.uk



10 October 2008

NHS Highland R&D ID: 496
 NRS ID : NRS08/ON06

Ms Fiona Marcusson
 Research Student
 General Practice and Primary Care
 University of Glasgow
 1 Horselethill Road
 Glasgow
 G12 9LX

Dear Ms Marcusson,

Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: **'The Ongoing Care of Patients with Cancer : What is the Appropriate Balance of cancer Care Between Specialist and Primary Care?'**. I acknowledge that:

- The project is sponsored by NHS Greater Glasgow and Clyde.
- The project is funded by the Chief Scientist Office
- Research Ethics approval for the project has been obtained from the West Glasgow Research Ethics Committee 1, (Reference Number: 08/S0703/97).
- The project is Site-Specific Assessment exempt.

The following conditions apply:

- The responsibility for monitoring and auditing this project lies with NHS Greater Glasgow and Clyde.

Working with you to make Highland the healthy place to be

Headquarters:
 NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

Chairman: Mr Garry Couits
 Chief Executive: Dr Roger Gibbins BA MRA PhD
Highland NHS Board is the common name of Highland Health Board



Appendix 15: NHS approval Grampian

Research and Development Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB



Date 08/10/08
Ethics 08/S0703/97
R&D Ref: 2008GP009

Ms Fiona Marcuson
General Practice and Primary Care
University of Glasgow
1 Horselethill Road
Glasgow
G12 9LX

Enquiries to	Fiona White
Extension	54656
Direct Line	01224 554656
Email	fiona.white3@nhs.net

Dear Ms Marcuson,

Project title: The ongoing care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project has R & D Management Approval to proceed locally.

Please note that if there are any other researchers taking part in the project that are not named on the original Ethics application, please advise the Ethics Committee in writing and copy the letter to us so that we may amend our records and assess any additional costs.

Wishing you every success with your research

Yours sincerely

F. White

Fiona White
Data Co-ordinator

Appendix 16: NHS approval Tayside



EC/LH

26 September 2008

Ms Fiona Marcuson
 Research Student
 General Practice and Primary Care
 University of Glasgow
 1 Horselethill Road
 GLASGOW
 G12 9LX

Dear Ms Marcuson,

NHS TAYSIDE MANAGEMENT/GOVERNANCE APPROVAL

NRS Ref: NRS08/ON06

R&D Project ID: 2008ON17

Title: The ongoing care of patients with cancer: what is the appropriate balance of cancer care between specialist and primary care?

LREC Ref: N/A LREC Approval Date: N/A

Main REC Ref: 08/S0703/97 Main REC Approval Date: 03/09/08

Funder: Chief Scientist Office

Sponsor: NHS Greater Glasgow and Clyde

NHS Support Costs: £537

The above project has been registered on the NHS Tayside R&D database, as required by the Research Governance Framework. Full ethics approval has been obtained and there are £537 of local NHS Support Costs associated with this research project.

NHS Tayside has no objection to the project proceeding, provided all necessary approvals are in place and all amendments to the protocol, personnel involved and funding be notified to the R&D Office and all appropriate personnel.

It is important to note that all research must be carried out in compliance with the Research Governance Framework for Health & Community Care, GCP and the new EU Clinical Trials Directive (for clinical trials involving investigational medicinal products).

Kind Regards

Elizabeth Coote
 Non-Commercial
 R&D Manager

c.c. Dr Mary Fraser (National Co-ordinator, NRS)



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