

Patients' experiences and perceptions of an outpatient
systemic anti-cancer therapy service – Implementing a
new pre-assessment care pathway for lung cancer
patients

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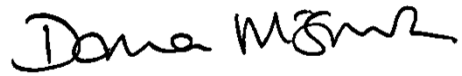
Submitted in Fulfilment of the Requirements of the

Degree of Doctor of Philosophy

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Declaration

I declare the work in this thesis is my own, except where otherwise stated.

A handwritten signature in black ink that reads "Donna McGowan". The signature is written in a cursive style with a large initial 'D' and 'M'.

Donna McGowan
July 2021

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Abstract

The demand for outpatient systemic anti-cancer therapy (SACT) services has increased by 15% in the period 2011–2018. An ageing population, improving cancer survival rates and the ongoing introduction of new and more complex SACT have contributed to the increased demand. Treatment capacity and achieving cancer waiting time targets have also affected the demand for outpatient services. It had become apparent that, in a large regional cancer centre, the current care pathway was no longer person-centred or fit for purpose for lung cancer patients receiving SACT, as they required a greater amount of clinical time in the treatment area than scheduled and involvement from the medical team. A pre-assessment care pathway was identified as a possible alternative and would also provide a person-centred approach.

Lung cancer has remained the most common cancer in Scotland with approximately 5,331 new cases in 2018, 85% of these cases occur in the over-65 years age group and survival rates remain poor. These patients are vulnerable, often present at an advanced stage of their disease and experience distressing symptoms. Many patients have pre-existing long-term medical conditions that often affect their general health, which may determine their fitness and tolerance for treatment.

A comprehensive review of the literature identified a number of key benefits to a pre-assessment care pathway, such as improved patient experience; improved self-management of disease and treatment-related symptoms, and improved efficiency of resource and capacity. The aim of my study was to explore the patients' experiences and perceptions of an outpatient SACT service and whether implementing a new pre-assessment care pathway enables person-centred care for a group of lung cancer patients. Using qualitative methodology, semi-structured interviews facilitated an in-depth inquiry with 32 lung cancer patients undergoing SACT. Thematic analysis using Braun and Clark's framework facilitated analysis of the data to help construct initial codes into themes and then into three overarching themes: *consequence of lung cancer*

diagnosis, care delivery: SACT pre-assessment and phone assessment, and symptoms of lung cancer and side effects from SACT.

The findings have provided insight into the benefits of a SACT pre-assessment care pathway. These have indicated that this provided person-centred and tailored assessment for lung cancer patients, which enabled participants to feel better informed about their decision-making. Findings further indicated being better informed improved compliance with the treatment and management of side effects, positively impacting on the quality of life for these patients. This study provides healthcare professionals with new knowledge of the SACT assessment process which would improve clinical practice and care provision for these patients. From the findings, there is potential for other patient groups undergoing SACT, including gynaecological, breast or colon cancer, to benefit from a pre-assessment care pathway.

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I would like to express my deepest appreciation to the participants who contributed to this work and gave their valuable time during such difficult circumstances. Without their time and co-operation this research project would not have been possible.

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I would like to thank my husband for his endless patience and supply of good food! My grown children, my parents (especially my dad for his endless proof reading) and my close family members, who have endured this process with me. They provided ongoing support and encouragement to keep me going and achieve my ambition. Thank you, you know you are all very special to me!

And finally, I dedicate this work to my wonderful, brave sister, Pauline Jolly, who throughout my research journey fought her own cancer battle and who we sadly lost in November 2018. *Pauline, I kept my promise!*

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Chapter 1: Introduction and overview of the thesis

1.1 Introduction

The early 1990s saw the delivery of Systemic Anti-Cancer Therapy (SACT) shift from the inpatient to the outpatient setting. In recent years, concerns have grown regarding the ever-expanding volume of patients diagnosed with various cancers requiring outpatient services. In addition, these patients continue to require new and more complex SACT treatments, further increasing the demands on outpatient SACT services. This has greatly affected treatment capacity and cancer/SACT waiting time targets (South East Scotland Cancer Network (SCAN), 2017; Information Services Division (ISD), 2018a).

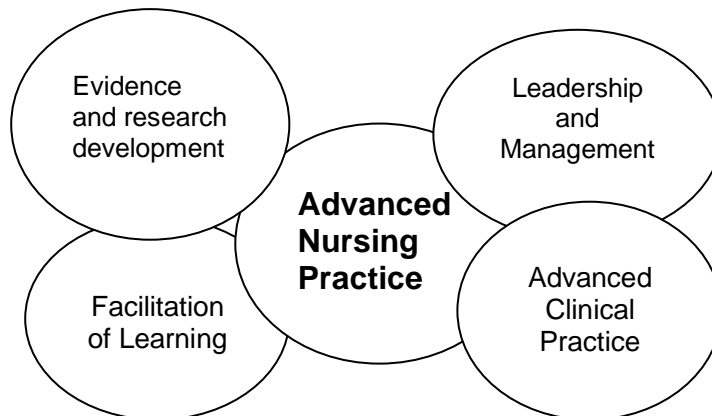
This chapter presents the background to the study with an overview of my clinical background to provide context and details of my personal interest in this concern. An overview of outpatient SACT delivery within a large regional cancer centre is set out to provide the rationale for the development of the study within the setting of the implementation of a new pre-assessment care pathway for a group of lung cancer patients. The relevant policy context is then discussed to illustrate the development of my research aim and questions, and the chapter is then concluded with an overview of the thesis.

1.2 Clinical experience and background

I have worked in a large regional cancer centre as a senior SACT nurse for more than 10 years, contributing significantly to the development of the education of SACT management and its safe administration. In 2008, I was appointed into a new and developing role as Nurse Clinician in the outpatient SACT service. This role involved working alongside medical colleagues within the outpatient setting: managing patients through their treatment; prescribing SACT and appropriate supportive medicines; assessing associated side effects; and adjusting treatment doses in line with local protocols.

My clinical role has continued to develop alongside the Advanced Nurse Practitioner (ANP) role. This has required the completion of further education

and training within the 'four overarching' themes within ANP (Figure 1), which have since been highlighted within the two brief papers relating to 'Advanced Nursing Practice Roles' (Scottish Government, 2010a; Scottish Government, 2017).



Source: Scottish Government (2010a)

Figure 1. Overarching themes of ANP

On my successful completion of the ANP programme, the opportunity to undertake a clinical doctorate programme offered in partnership between the University of Stirling and Macmillan arose. This presented an exciting opportunity for me to continue my academic education as an ANP and senior nurse within oncology whilst enabling me, through research, to have a creditable impact on the quality, efficiencies and effectiveness of patient care within my own clinical area. Having worked in SACT over many years, I was aware of the increased activity within outpatient services and possible contributing factors. These factors, in combination, had created capacity issues within an outpatient SACT service. The ability to deliver treatments in a timely manner and to the standards expected had become a challenge (SCAN, 2017; Information Services Division (ISD), 2019).

In addition, it was apparent that lung cancer patients required increased treatment time and their treatment was frequently delayed/deferred, causing their current care pathway to be no longer person-centred or fit for purpose. The clinical doctorate programme provided the opportunity for me to undertake a

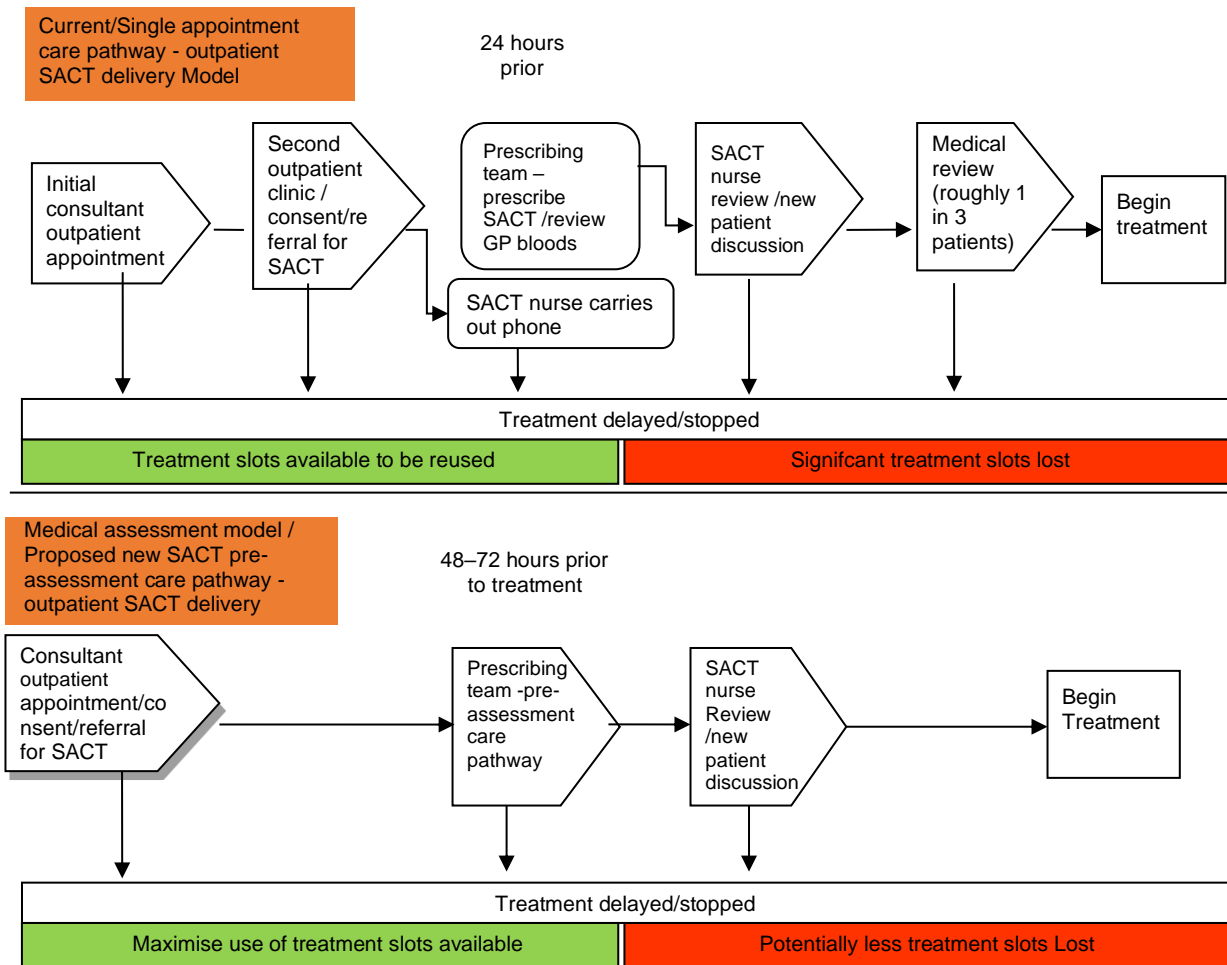
research project, with the aim of implementing a new pre-assessment care pathway as a possible alternative. This could enhance the patient experience of outpatient SACT services and provide a person-centred care approach.

The aim of my research was to explore the patients' experiences and perceptions of attending an outpatient SACT service within a large regional cancer centre and whether introducing a new pre-assessment care pathway enables person-centred care for a group of lung cancer patients.

1.3 Background to the research study

1.3.1 SACT delivery in the outpatient setting

Traditionally, the care pathway for outpatient SACT delivery uses either a single appointment care pathway (one-stop system) or a face-to-face pre-assessment care pathway (two-stop system), which is planned 1–2 days before treatment is due. Most outpatient SACT services within the UK use a pre-assessment care pathway, also known as a medical assessment model (two-stop system), for patients with lung cancer, prior to each cycle of SACT. Both pathways are illustrated in Figure 2 below (Dobish, 2003; Summerhayes, 2003; Cook and Towler, 2009; Noonan-Shearer and Peacock, 2010; Lennan et al., 2012; Griffin, 2014).



(Acknowledgement: Dr M MacKean, Consultant Medical Oncologist, 2017)

Figure 2. Pathways of outpatient SACT delivery

Since 2005, lung cancer patients within the regional outpatient SACT service have been treated using a single appointment care pathway. This begins with blood sampling of patients at their General Practitioner (GP) and a specialist SACT nurse then telephones patients the day before each treatment. These bloods are then reviewed and a non-medical prescriber or medical prescriber, who may not have assessed and/or met the patient, prescribes the SACT. The SACT is then prepared, and its administration is arranged for the same day within the outpatient SACT unit. Within the single appointment pathway, the specialist SACT nurse carries out an assessment of patients' current physical health, disease status and recent blood results, along with the SACT administration.

SACT encompasses cytotoxic chemotherapy, antibodies, small molecule inhibitors, immunotherapies and experimental cancer therapies (Panchal, 2017). These treatments are associated with expected and less frequently serious side effects that have to be managed carefully. The schedule and dosing of SACT is adjusted frequently according to standardised protocols, taking into account any side effects, blood results and the individual's physical condition. Patients undergoing SACT require a thorough clinical assessment before each treatment, as these possible side effects may affect patients physically, emotionally and socially, thus contributing to their symptomatic distress (Lind, 2015).

My clinical concerns increased in relation to lung cancer patients who I felt were vulnerable receiving SACT within the current or single appointment care pathway, in particular, those patients who presented at an advanced stage in the disease process and were experiencing distressing symptoms, both from their disease and the treatment. It became evident, within the regional outpatient SACT service, that patients with lung cancer occupied a significant amount of clinical time or *chair time*, beyond what was scheduled for them to receive their treatment (*chair time is defined as the amount of time a patient occupies the chair within the outpatient SACT service*). This was often due to an unscheduled medical review and/or necessary intervention or investigation. This resulted in delayed or deferred SACT, thus affecting the efficiency of the SACT

service and had a negative influence on patients' expectation and treatment. Improved monitoring through a thorough face-to-face pre-assessment could potentially improve the care pathway for this patient group.

Table 1 shows the results of a small retrospective audit of lung cancer patients, who had received their SACT within the regional outpatient service between December 2013 and March 2014, using the current/single appointment care pathway delivery model. The most striking feature from the audit showed that more than half of this patient group experienced a deterioration in their performance status during their SACT. Calculating a cancer patient's performance status attempts to objectively reflect their general well-being and ability to fulfil their activities of daily living, in order to determine their fitness and tolerance of SACT (West, 2015).

Table 1. Audit of lung cancer patients

Lung Cancer patients (LCP) treated in the period December 2013 – March 2014 (in a large regional Scottish cancer centre)	
Total number of LCP commencing SACT	68 patients
Number of LCP experienced a SACT delay or deferral.	28 (41.2%) (38 treatments in total delayed)
Number of LCP required a hospital admission during their SACT (treatment-related)	51 (75%) (91 hospital admissions in total)
Number of LCP had dose adjustment of SACT	23 (33.8%)
Number of LCP completed planned course of SACT	29 (42.6%)
LCP: Performance Status (PS)	7 (10.3%) patients improved their PS 24 (35.3%) patients had no change in PS 37 (54.4%) patients deteriorated in the PS through the SACT
Survival	85% were alive at 3months 67% were alive at 6 months

(Acknowledgment Dr M Szabo, Consultant Medical Oncologist 2014)

The majority of patients within the audit were receiving palliative SACT, which highlighted further the need for a thorough clinical and physical assessment prior to each cycle to ensure that their treatment remained appropriate, and that any side effects were effectively managed. The complex nature of lung cancer patients had become clear, given the number of required SACT-related hospital admissions, delays and/or deferrals. The audit data further supported the view that the current/single appointment care pathway within this regional outpatient SACT service is not patient-centred and no longer fit for purpose to ensure the safe management and administration of SACT for this patient group.

Exploring the literature, and based on the findings from the audit, highlights that the single appointment care pathway used for SACT delivery creates a number of bottlenecks that occur at key points, and the patient assessment process was most frequently highlighted as a cause (Dobish, 2003; Cook and Towler, 2009; Noonan-Shearer and Peacock, 2010; Griffin, 2014). It is suggested that this bottleneck is created when the SACT toxicity assessment, which is completed on the same day as the administration of treatment, requires further investigation or intervention. This creates a delay or deferral of the SACT and results in a wasted treatment time slot or unacceptable waiting time for patients, which has an impact on their overall experience (Dobish, 2003; Cook and Towler, 2009; Roe and Lennan, 2014).

Most outpatient SACT services within the UK use a pre-assessment care pathway for lung cancer patients and, considering the concerns that have been raised through the audit, this justifies a review of the current/single appointment care pathway within the outpatient SACT service of a large regional cancer centre (Dobish, 2003; Summerhayes, 2003; Noonan-Shearer and Peacock, 2010; Griffin, 2014). A SACT pre-assessment care pathway involves a similar pathway to the single appointment care pathway, however, SACT is planned for delivery one or two days following each patient's attendance at the pre-assessment care pathway. The face-to-face pre-assessment enables the necessary investigation or intervention and a decision can be made as to whether the SACT is to be given. This would reduce same day cancellation of SACT, maximise the efficiency of SACT resources and improve patient

experiences during SACT (Cook and Towler, 2009; Lennan et al., 2012; Roe and Lennan, 2014).

Exploration of the patient experiences and perceptions of a new SACT pre-assessment care pathway can therefore help to guide whether patients were continuing to benefit from, and were willing to continue with SACT, and that it was tailored appropriately to any side effects associated with the treatment and improve the quality of patients' experiences. The pre-assessment care pathway can also help to improve flow through the outpatient service and improve patients' readiness for SACT by carrying out the clinical assessment, examination and a review of patients' tolerance to treatment. A pre-assessment care pathway is designed to ensure that the SACT can be ordered in a timely fashion, for example, the day before treatment was due to be administered. It further aims to reduce the numbers of late and same-day cancellations of SACT. Based on an existing pre-assessment care pathway from other UK outpatient SACT services, I developed the following proforma in collaboration with medical colleagues (Figure 3). This proforma was used to detail the investigations required before each cycle of SACT, and these were applied while adopting the pre-assessment care pathway into the existing service so that it could be examined within the SACT setting.

Pre-assessment care pathway for Lung cancer patients									
Name CHI Age	Performance Status (PS)	0	1	2	3	4	Previous Wt.		
	Blood Pressure (BP)						Today's Wt.		
	Heart Rate						Height		
	Temperature						Creatinine		
	Oxygen sats + Respiratory Rate						Previous PS		
Date of assessment						Time started			
Type and stage of cancer									
Aim of treatment	Concurrent XRT / Adjuvant / Palliative								
Planned Chemotherapy regimen						Cycle	Day		
Cancer assessment									
Last CXR/CT scan									
Result and discussion									
QOL patient score	1	2	3	4	5	6	7		
Pain patient score	1	2	3	4	5	6	7		
Symptom checklist (grade) (Worse/Better/Same)									
Breathing	Grade	W	B	S	Cough/Haemoptysis	Grade	W	B	S
Fatigue	Grade	W	B	S	Pain	Grade	W	B	S
Weight loss	Grade	W	B	S	GI upset	Grade	W	B	S
Sleep	Grade	W	B	S	Other	Grade	W	B	S
Toxicity Assessment									
Hospital admission? Cause?	Y/N								
Chemo care Toxicity	Y/N/Not yet started chemo								
Management plan									
Plan for chemo									
Patient 'worthwhile' score	1	2	3	4	5	6	7	Patient consent confirmed	Y/N
FBC/Blood check						Chemo Authorised	Y/N/Further plan		
Sent to pharmacy	Y/N/Further plan					Annotation Chemo care			
Future plan – Next chemo/CT scan/CXR plan:									

Figure 3. Proforma for SACT pre-assessment care pathway

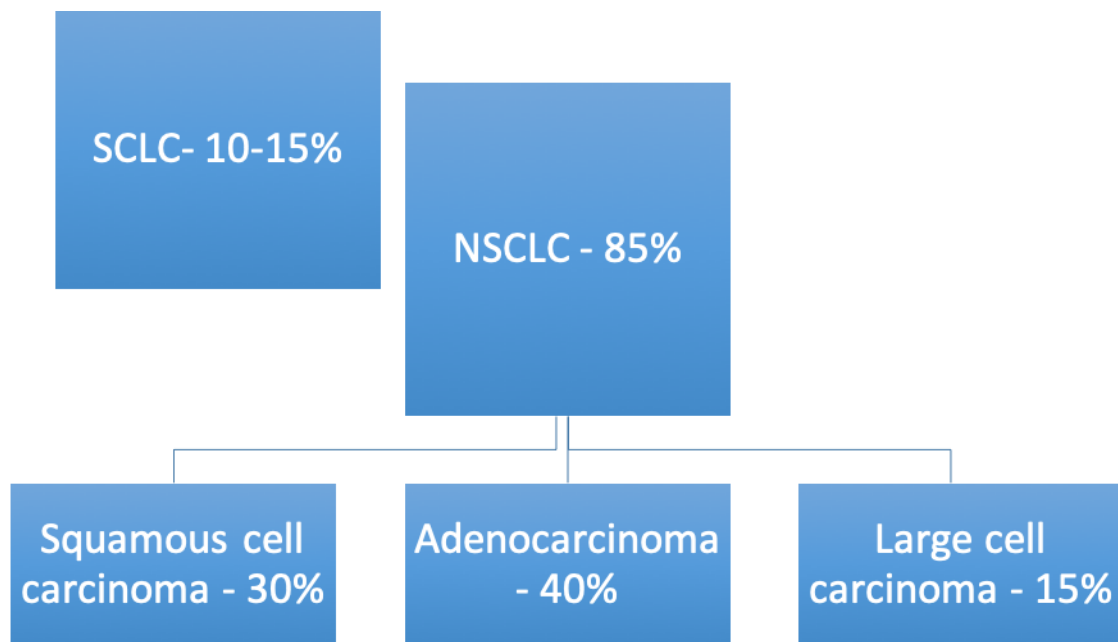
1.3.2 An introduction to lung cancer

Lung cancer is the second-most common cancer in men and women and the leading cause of cancer-related death in Scotland, with approximately 5,331 new cases in 2018. It is estimated that 75% of these cases are diagnosed in the over-65 age group and 47% are at a late stage (ISD, 2019). The incidence of cancers in Scotland has continued to increase over the last 10 years, with 30,000 cases in 2008 and 32,200 cases in 2018. The rise in cancer incidence reflects the ageing population within Scotland. However, the prevalence of associated risk factors such as tobacco smoking, being overweight, poor diet and lack of physical exercise, must also be taken into account (ISD, 2019).

Lung cancer is more common in deprived areas, reflecting the higher prevalence of risk factors such as tobacco smoking. This is the number one risk factor for developing lung cancer and has been linked to 85–90% of all lung cancer cases (De Groot and Munden, 2012; Cancer Research UK, 2013). Age, race, genetics, poor diet, gender, radon exposure, environmental pollution, occupational exposures and pre-existing lung disease are also important contributors (Cancer Research UK, 2013; Carter-Harris et al., 2017; Malhotra et al., 2016). More recently, Elster (2018) highlights that the incidence of lung cancer in non-smokers is also increasing, with the cause thought to be associated with second-hand smoking, passive smoking and gender. In comparison to other common cancers, such as breast, prostate or bowel, which have a 5-year survival rate of 90%, 86% and 59%, respectively, lung cancer has the poorest 5-year survival rate at 9.8%. However, only 16% of patients who are diagnosed with lung cancer are found at an early stage in the disease process where curative therapies can be considered and only 33% of patients will survive one year following diagnosis (ISD, 2018b).

The classification of lung cancer by histological type is crucial for guiding clinical management in distinguishing small cell lung cancer (SCLC) from non-small cell lung cancer (NSCLC). NSCLC is the most common type of lung cancer and accounts for 85% of all cases. There are three main types of NSCLC, including adenocarcinoma, squamous cell carcinoma and large cell carcinoma (Figure 4). Although each of these develop differently, they are grouped together as

treatment approaches are similar. SCLC represents 10–15% of lung cancers, and this is the most aggressive as it spreads rapidly and symptoms develop quickly. SCLC is strongly related to tobacco smoking and is frequently treated with SACT rather than surgery due to the rapid spread of the disease (Panchal, 2017; Samet, 2018).



Source: Adapted from Samet (2018)

Figure 4. Types of lung cancer

Many patients with lung cancer also have pre-existing co-morbidities to cope with, which may affect their general health and determine both their fitness and tolerance for treatment (Islam et al., 2015; Sarfati et al., 2016). The most prevalent physical symptoms in patients with lung cancer include a cough, pain, fatigue and breathlessness. Lung cancer patients have also reported a significantly lower quality of life (QOL) when compared with other cancer patients as a result of these symptoms (Islam et al., 2015; Sarfati et al., 2016; Leduc et al., 2017; Samet, 2018).

Clinical trials from the 1990s demonstrated that SACT for inoperable lung cancer showed a small survival and quality of life benefit (Scottish Intercollegiate Guidelines Network (SIGN), 2014; National Institute for Health

and Care Excellence (NICE), 2019). To assist patients with a good performance status to achieve an optimal progression-free survival benefit and a symptomatic improvement, early initiation of SACT is recommended (SIGN, 2014). Measuring patients' performance status is an attempt to objectively quantify cancer patients' general well-being and their ability to carry on with their activities of daily life. This could determine their fitness and tolerance for treatment and measure quality of life (West, 2015). Achievement of the cancer waiting time targets also need to be considered in such measurements. These include the 62-day waiting time standard from suspicion of cancer to first cancer treatment and the 3-day waiting time standard from decision-to-treat to first cancer treatment for SACT (ISD, 2018a).

1.4 Understanding the relevant policy context

Globally, it is projected that, from 2020, the annual number of new cancer cases will increase by 47% by 2040 (World Health Organisation (WHO), 2020; Bray et al., 2021; European Commission, 2021; Sung et al., 2021). According to the WHO, in 2019 cancer also ranked as the leading cause of death globally (WHO, 2020). Nationally, the rising incidence of cancer is reflected within England, Wales, and Scotland, as the number of new cancer diagnoses has continued to increase, with over half of all diagnoses being one of breast (female), prostate, lung, or colorectal cancers (ISD, 2019; Office for National Statistics (ONS), 2019; Public Health England (PHE), 2019). Cancer therefore concerns us all and, as such, is regarded as a growing global public health concern; thus, the related policies need to be considered.

Cancer's rising prominence globally and nationally reflects the aging and growth of the population. However, due to improved survival through better access to screening programmes, early diagnosis, and the introduction of new and refined treatments, the outcomes and quality of life of cancer patients have improved (NHS England, 2016; WHO, 2020; European Commission, 2021; Bray et al., 2021).

Collecting population-based incidence and mortality data on the current estimates of the cancer burden is necessary to inform and guide global and

national cancer policy and programmes to support healthcare systems in the prevention, early diagnosis and treatment of cancer (American Society of Clinical Oncology (ASCO), 2016; World Health Assembly (WHA), 2017; European Commission, 2021). Chalkidou et al. (2014) suggests that structural organisation with international co-operation that works collaboratively has strengthened global partnerships and created networks to develop cancer policy and programmes that support establishing cancer centres of excellence. These partnerships and networks also help to address the increasing cost of cancer treatments, the increasing resource and demand for specialist cancer services, and ensuring access to safe, efficient, effective, high quality, and evidence-based cancer services.

Within Europe, the European Commission in 2021 presented 'Europe's Beating Cancer Plan' in response to the growing challenges cancer presents. Europe's commitment aimed to tackle the challenge around four key areas: cancer prevention; early detection; prompt diagnosis and treatment; and improving the quality of life of cancer patients and survivors. The policy objectives are supported by ten flagship initiatives with one flagship aimed to provide a high standard of cancer care, maintain treatment capacity, and provide personalised/individualised cancer care and treatment. The focus of this plan is relevant to my research, given its aim is to provide high quality person-centred care and address the increasing resource demand and treatment capacity concerns facing SACT services globally.

In 2016, NHS England commissioned an independent taskforce which set out the 'Achieving World-Class Cancer Outcomes – A Strategy for England.' The strategy outlined a series of initiatives across the patient pathway to improve the outcomes for people affected by cancer and provided a vision for what cancer patients should expect from their health service. At its heart, the vision is that cancer patients should have informed choice, convenient care, access to new cancer treatments and the best effective treatment, with effective management of side effects and the best possible quality of life. Patients should be treated as individuals with compassion, dignity, and respect. The vision of this strategy reflects person-centred care, supporting new models of care within a framework

of national standards. My research therefore responds to this ethos, as it explores the patient experience and perception of a new SACT pre-assessment care pathway for lung cancer patients.

Cancer is regarded as one of the NHS priorities within Scotland and, as it has recently received increased financial investment, I therefore reviewed the related policies (ISD, 2019). In 2008, the Scottish Government introduced 'Better Cancer Care – An action plan', which outlined the way forward for cancer services. This plan focussed on prevention, early detection and better treatment to live with and beyond cancer. The aim was to improve service delivery and overall quality of care to cancer patients. The new Scottish Cancer Taskforce (SCT) has overseen the planned actions by working with the NHS Regional Cancer Networks (Scottish Government, 2008). More recently, the 'Beating Cancer: Ambition and Action' strategy was introduced, outlining a commitment to further improve prevention, detection, diagnosis, treatment and the after care of cancer services across Scotland (Scottish Government, 2016a). With continued input from the SCT, the Scottish Government sought to improve on work commenced in 2008 and recommended quality improvements to ensure the delivery of tailored, supportive and accessible person-centred care, according to individual clinical and informational needs. The strategy aimed to reduce health inequalities by listening to patients and allowing them to share their experiences, which could contribute to the development of efficient sustainable cancer services in the future (Scottish Government, 2016a). The focus of these policies is relevant to patient experiences of outpatient SACT services and the current need to improve service delivery. This would demonstrate that patient experiences influence change and create service delivery that is person-centred and tailored to individual needs.

In 2010, the Quality Strategy provided the blueprint for improving the quality of care that patients and carers receive from the NHS across Scotland (Scottish Government, 2010b). The Quality Strategy was informed by those in Scotland who identified the following as being essential features of the services provided by their healthcare system: *care; compassion; communication; collaboration; clean environment; continuity of care; and clinical excellence*. Three quality

ambitions of safe, person-centred and effective care were developed, and all healthcare policies were aligned to reflect and deliver these ambitions (Scottish Government, 2010b). In 2011, the Scottish Government then set out its strategic vision for achieving sustainable quality healthcare services across Scotland, whilst acknowledging the significant challenges of Scotland's public health record, the changing demography and the economic environment (Scottish Government, 2011).

The 2020 vision provided the strategic narrative and context for taking forward the implementation of the Quality Strategy, and identified the required actions to improve efficiency and achieve financial sustainability of Scotland's healthcare (Scottish Government, 2011). This vision looked for every person to live longer, healthier lives at home, or within a homely setting where healthcare and social care are integrated. There is a focus on prevention and anticipation with supported self-management and day-care services considered 'the norm'. Patients are at the centre of decision-making whilst quality and safety are maintained at the highest standard. The focus of the policy is relevant to lung cancer patients receiving their treatment within an outpatient SACT setting. It takes into account their vulnerability, associated poor prognosis and importance of timely and appropriate SACT that has an impact on their quality of life (Scottish Government, 2011). As previously highlighted in Section 1.2, there is a strong association between lung cancer, timing of appropriate SACT and accurate assessment of associated toxicity to minimise the possible side effects. The assessment process would ensure that SACT remains appropriate with the achievement of optimal outcomes for these patients.

The NHS National Cancer Quality Programme (Healthcare Improvement Scotland, 2013) aimed to develop a culture of continuous improvement in the quality of cancer care services reflecting patients' experiences. The programme developed three Quality Performance Indicators (QPI) underpinned by patients' experiences in order to drive continuous quality improvements in these three key areas. The QPI, selected through public and patient engagement, included communication, information provision and shared decision-making. Focus groups were held throughout Scotland to gather patients' views around the

three QPI, which formed a feedback report. The QPI feedback report demonstrated the significance of sufficient time required by patients to discuss their diagnosis of cancer with an appropriate healthcare professional. They could then discuss their treatment options and digest the information given, which would enable shared decision-making. The report further indicated that patients needed to have adequate time to ask questions, feel listened to and not feel rushed. There were key themes around information provision, which necessitated explanation of each step of the journey, rather than bombarding patients with all the information at the start. It was also required to provide signposting and meaningful information sources to access relevant and appropriate information as and when necessary (Healthcare Improvement Scotland, 2013).

Considering the QPIs and reflecting on the current/single appointment care pathway for SACT delivery, this has been shown to provide inadequate opportunities to facilitate effective communication. Nor does it promote patient involvement through shared decision-making with effective management of SACT side effects and any associated symptoms of lung cancer. Reviewing the QPIs, alongside the introduction of a new face-to-face pre-assessment care pathway, would provide the necessary time for the provision of ongoing relevant information delivered in smaller volumes. This would assist patients' understanding and improve their ability to self-manage during SACT and create confidence in the clinical decisions that are taken.

In 2016, the Scottish Government's Health and Social care delivery plan identified aims which focussed on prevention, early intervention and supported self-management with the provision of high-quality services. Person-centred day-care services would be regarded as 'norm', whatever the setting, by providing high standards of quality care, safety and promoting shared decision-making. Improving scheduled care, reduced cancellations and the introduction of more responsive and efficient secondary care would reduce wastage and the inappropriate use of resources. The plan has indicated that engagement with patients, service users and staff is vital when reviewing the care and service delivery. The care delivery plan supports exploring lung cancer patients' experiences of outpatient SACT service. This could lead to the improvement of

the SACT assessment process with the introduction of a SACT pre-assessment care pathway (Scottish Government, 2016b).

In 2017, Healthcare Improvement Scotland set out its strategy to support better quality health and social care for everyone in Scotland – ‘Making Care Better – Better Quality Health and Social care for everyone in Scotland – A strategy for supporting better care in Scotland 2017-2022’. This strategy builds on the Scottish Government’s National Clinical Strategy and 2020 Vision and the Principles of Quality Strategy. It aims to support the successful integration of health and social care to provide high quality and compassionate services for people in Scotland. It also reflects the importance of ‘experience of care’, ‘the need for a greater understanding about medicine’ and ‘the right care in the right place at the right time’ (Scottish Government, 2016c, pp. 7–13). Progress will be measured against five strategic priorities:

- enable people to make informed decisions about their care and treatment;
- make best use of resources;
- embed quality assurance that gives people confidence in the quality and sustainability of services and supports providers to improve; and
- provide evidence and share knowledge that enables people to get the best out of services they use and to help services improve.

Additionally, in 2017, Cancer Research UK (CRUK) (2017) commissioned a report of cancer services in Scotland and set out the ambitions for the shape of future services – *Where next for cancer in Scotland?* The report examined NHS performance on cancer care and services, including access to effective treatments. The report recommended exploring best practice pathways and new ways of working. This would involve placing an emphasis on making improvements in relation to treatment, treatment delivery and patient experience, thus ensuring safe, effective and person-centred cancer care.

Reflecting on both the strategic priorities of *Making Care Better* and the ambitions of *Where next for cancer in Scotland?*, these policies support exploring patients’ experiences and perceptions to guide whether the introduction of a new SACT pre-assessment care pathway could improve the

quality of their care. Meaningful dialogue and gathering information from real-life settings would help to inform whether a pre-assessment care pathway would maximise resources, provide person-centred care, support shared decision-making, and promote the safe delivery of outpatient SACT.

1.5 Summary

The factors highlighted within this chapter present the significant challenges to an already stretched SACT service within this region and elsewhere. These challenging issues that currently face outpatient SACT services across Scotland include treatment capacity management and achievement of the cancer waiting time targets. There is also evidence that a pre-assessment care pathway is used widely in outpatient SACT services within the UK. Given that many lung cancer patients present with advanced disease, timely and appropriate introduction of SACT can improve associated distressing symptoms of the disease and provide an optimal period before the cancer starts to progress. Thorough assessment of SACT and its associated toxicity is necessary to ensure side effects are managed and well tolerated so that treatment remains appropriate (Dobish, 2003; Summerhayes, 2003; Noonan-Shearer and Peacock, 2010; Griffin, 2014).

Policy documents and strategic frameworks have outlined planned changes and improvements to cancer care including the delivery of lung cancer services, as patient experience is at the heart of these documents. These changes focus on person-centred care that provides tailored support to promote shared decision-making and patients' ability to self-manage. There is acknowledgement that the NHS aims to put patients at the centre of their care and that patients' experiences and feedback are the basis of service planning, delivery and evaluation for cancer services (Scottish Government, 2010b; Scottish Government, 2011; Healthcare Improvement Scotland, 2013; NHS England, 2016; Scottish Government, 2016a, 2016c).

A close review of these policy documents and strategic frameworks supports my research project, designed to explore implementing a new pre-assessment care pathway for a group of patients with lung cancer. Improving the knowledge

and understanding of patients' perceptions and experiences of SACT delivery within outpatient SACT services could determine whether a pre-assessment care pathway enables person-centred care and improves the quality of care delivered.

1.6 Organisation of my thesis

The literature review that follows is formed of two parts: Chapter 2, and Chapter 3. Chapter 2 illustrates the initial process of exploring the research evidence of the patients' experiences of a SACT pre-assessment care pathway. A scoping review of the literature was carried out about research relating to a pre-assessment care pathway within the outpatient SACT service setting. However, there was a lack of research evidence found that related to this clinical setting that would help define the aim of my study. I therefore took the decision to explore the research evidence of an established pre-assessment care pathway within a variety of surgical settings. Chapter 2 presents the construction of a conceptual framework showing the key strengths of a surgical pre-assessment care pathway identified in the review, with patient experience and person-centred care forming the centre of the framework. Chapter 3 illustrates an extended scoping review of the literature to include the patients' experiences of a lung cancer diagnosis, receiving SACT and how using the patients' experiences can help inform healthcare delivery. Part two of the review helped to provide the rationale for selecting the patient group with whom I would trial a pre-assessment care pathway, and to further refine the research aim and define the research questions. Chapter 3 then presents further development of the conceptual framework to illustrate the understanding gained from exploring the experience of a lung cancer diagnosis and receiving SACT.

Chapter 4 presents the research aim and questions. A discussion of the rationale for applying a qualitative methodology with a case study design to answer the research questions is provided. The case of inquiry is identified as a group of lung cancer patients undergoing SACT.

Chapter 5 is a focussed discussion on the research design and method of data collection using semi-structured interviews. A discussion is then presented of

the thematic analysis, which was the method of analysis selected for analysing the data gathered.

Chapter 6 first presents an overview of the participants' information and their sociodemographic characteristics. A discussion of the study findings, with a focus on the initial themes and overarching themes drawn from the data, is then presented.

Finally, in Chapter 7, building on the insights drawn from these findings, a conceptual framework of a SACT pre-assessment care pathway is presented and discussed in relation to the research aim and questions, the themes drawn from part one of the literature review and the overarching themes found through analysis of the findings. The implications and recommendations for future research and clinical practice are then considered.

Chapter 2: Literature Review – Part one

2.1 Introduction

In this chapter, part one of a scoping literature review is presented. The search strategy for reviewing a pre-assessment care pathway within both an outpatient SACT service and a surgical setting is presented. There was a lack of research evidence found relating to assessment pathways within cancer outpatient SACT services, and this initiated a review of the literature exploring a recognised and established operating pre-assessment care pathway currently in use within the surgical setting. This involved reviewing the research evidence of a pre-assessment care pathway within a variety of surgical settings, including orthopaedic, gynaecology, urology, cataract and general surgery, where this care pathway is commonly used. The review is presented in four broad themes: *Improving patient capacity with a pre-assessment care pathway*, *Efficient patient management through patient assessment*, *Improving patients' ability to self-care*, and *Patients' experiences of surgical pre-assessment*. The chapter concludes by illustrating the development of a conceptual framework of a surgical pre-assessment care pathway with a review of patient experiences and the concept of person-centred care which formed the framework's centre.

2.2 Process of reviewing the literature

Conducting a scoping review of the literature aims to generate a research aim, define the research questions, and then help to interpret the findings (Cronin et al., 2008; Onwuegbuzie et al., 2012; Ritchie et al., 2013). Part one of the review involved exploring the research evidence of current assessment operating pathways, including a pre-assessment care pathway for SACT delivery used within outpatient services throughout the United Kingdom (UK). This review examined the evidence of an outpatient SACT service for patients with lung cancer and then cancer patients generally. The literature was reviewed with an aim to better understand a pre-assessment care pathway and to determine whether this could be adapted for use within an outpatient SACT setting for a group of patients with lung cancer.

2.3 Search strategy – review of pre-assessment care pathway in outpatient SACT services

For part one of the literature review, the period of focus reflects the expansion of SACT outpatient services from late 1990 to 2019. A database search of CINAHL, Medline and Ovid found no evidence regarding SACT delivery for lung cancer patients within outpatient services. The search was then broadened to include all cancer patients within SACT outpatient services. Although no primary research studies were found to include the patient experience, the search did reveal a position statement, three audit reports, and one survey report.

Searches were undertaken intermittently between 2016 and 2019, and the publications identified and discussed both a one-stop care pathway and a two-stop care pathway. It appears from the publications that both of these care pathways are currently in use within outpatient SACT services. However, it is the two-stop care pathway or pre-assessment care pathway that appears to be more widely used within cancer outpatient services for SACT delivery within Scotland and the UK (Dobish, 2003; Summerhayes, 2003; Cook and Towler, 2009; Noonan-Shearer and Peacock, 2010; Lennan et al., 2012; Chambers et al., 2013; Griffin, 2014).

The evidence from the position statement, three audit reports and one survey report were not robust enough to support either of the two operating care pathways in use within the outpatient SACT service. These publications were not primary research studies, but were mostly descriptive, anecdotal and aimed at sharing the experience of setting up and organising such services rather than researching the patient experience or the clinical effectiveness of the service. This lack of research evidence supported my rationale and decision to explore and examine the research evidence relating to an established two-stop care pathway or pre-assessment care pathway currently in use within the surgical day-care and inpatient setting. This process aimed to determine whether this recognised and established pre-assessment care pathway could be adapted and utilised within outpatient SACT services for patients with lung cancer. The surgical care pathway within the literature is referred to as a pre-assessment care pathway (also referred to as a pre-admission clinic).

2.4 Search strategy – pre-assessment care pathway within the surgical setting

To retrieve research evidence of a pre-assessment care pathway within the surgical setting, a review of the literature was carried out using the EBSCO host platform. The period of focus reflects the evolution of the pre-assessment care pathway within the surgical setting from 1996 to 2019, and a database search included CINAHL, Medline and Ovid. The search terms included a combination of the terms 'pre-assessment', 'pre-admission', 'clinic', 'patient satisfaction', 'healthcare', 'quality care', and 'surg*'. The searches were undertaken intermittently between January 2016 and May 2019 and were restricted to English language and studies carried out within the UK and Ireland, as their healthcare systems are developed and resourced similarly to those within Scotland. The articles were selected based on the inclusion criteria described in Table 2.

Table 2. Inclusion criteria for literature review within the surgical setting

Inclusion criteria for the search strategy
Adult patients due to undergo elective surgery including; orthopaedics, gynaecology, urology, cataract and general surgery within UK and Ireland
Patients attending an elective surgical pre-assessment clinic, pre-admission and pre-assessment clinics are considered together
Patients' perception, experience and satisfaction. Clinical, healthcare and service outcomes
Research studies within peer-reviewed academic journals

The 75 excluded articles were set outwith the UK and Ireland, did not include patient experience and patient satisfaction, and/or were not research studies. These non-research studies included a significant number of audits and descriptive case reports within known professional nursing publications (Table 3). The selection of articles followed a process of examining the abstract (if available), and then reading each article for relevance.

Table 3. Search Strategy: pre-assessment within the surgical setting

Source	Total Found	Articles excluded	Articles Included
CINHAL	35	29	6
MEDLINE	30	28	2
OVID	20	18	2
Secondary articles			1
Duplicated articles			1
Total	85	75	10

2.5 Literature review of surgical pre-assessment care pathway

The literature selected for both reviews was systematically appraised using the Critical Appraisal Skills Programme (CASP) (2013) tool. The CASP tool is a generic tool for appraising the strengths and limitations of any qualitative research methodology. The tool helps to enable the process of assessing the outcome of research for quality, trustworthiness, relevance and context. Ten research articles were reviewed: five were qualitative studies (Otte, 1996; Lucas, 1998; Malkin, 2000; Gilmartin, 2004; Gilmartin and Wright, 2008); three were quantitative studies that explored both patients' experiences and health care outcomes of a pre-assessment care pathway within the surgical setting (Clark et al., 2000; Fraczyk and Godfrey, 2010; Heaney and Hahessy, 2011). One study used mixed methods (Clinch, 1997); and there was one early literature review (Gilmartin and Wright, 2007) which explored the rapid growth of day surgery and the challenges that this generated for nursing roles. A detailed summary of each article is presented within Appendix 1.

The concept of a pre-assessment care pathway (also referred to as pre-assessment clinic) within the surgical setting is not new. In the early 1990s, such clinics were introduced for those patients due to undergo a surgical procedure, in an attempt to improve the quality and efficiency of both day-care and inpatient resources (Haines and Viellien, 1990; Mulldowny, 1993; Reed et al., 1997; Casey and Ormrod, 2003; Knox et al., 2009; Koris and Hopkins,

2015). In reviewing the literature, I was able to identify key words, and the relationship between these, to then develop four broad themes: *improving patient capacity with a pre-assessment care pathway*; *efficient patient management through patient assessment*; *improving patients' ability to self-care*; and *the patient's experience of surgical pre-assessment*. Each theme will be discussed in relation to the surgical setting and its potential relevance to lung cancer patient within an outpatient SACT service.

2.5.1 Improving patient capacity with a pre-assessment care pathway

Financial drivers for the introduction of surgical pre-assessment clinics were a prominent theme throughout the review. Drivers included maximising resources to reduce waiting time for patients, shortening the admission stay, and reducing the cost of late cancellations, particularly same-day cancellations (Clinch, 1997; Lucas, 1998; Malkin, 2000; Gilmartin and Wright, 2007; Heaney and Hahessy, 2011). There was agreement that a pre-assessment clinic improved the efficiency of both planned surgical admissions and day-care surgery through fewer costly cancellations. Indeed, within the surgical day-care setting, a pre-assessment care pathway enabled the full use of the day-care facilities, reduced the number of late or same-day cancellations, and minimised the potential risk of surgical complications, thus improving discharge planning (Otte, 1996; Malkin, 2000; Gilmartin and Wright, 2007; Fraczyk and Godfrey, 2010). Within the inpatient setting, a surgical pre-assessment care pathway demonstrated fewer late cancellations, fewer complications, shorter admissions and improved efficiency of discharge planning (Otte, 1996; Gilmartin and Wright, 2007; Heaney and Hahessy, 2011).

Heaney and Hahessy (2011) explored patients' satisfaction with a pre-assessment care pathway within an orthopaedic surgical setting. A quantitative exploratory approach was adopted, using a pre-validated self-administered questionnaire with a small convenience sample of 91 adults. The introduction of pre-assessment was a quality initiative aimed at reducing surgical cancellations whilst also enhancing the quality of patient care and experience. The findings demonstrated that 85% of participants overall felt satisfied with their experience of the service, and 98% of the participants felt that sufficient information was

provided. The number of late cancellations of surgical procedures was shown to be reduced, which improved patients' experiences and their overall satisfaction with the service delivery. Findings further indicated areas of patient care that could be improved, such as individualised care and information provision.

Despite the good response rate, it was, however, acknowledged that the small sample size for their selected methodology may have affected the quality of their findings, as this would not be regarded as being statistically sufficient to make a generalisation. Future research recommendations included exploring the importance of individualised care, including person-centred care.

The review found evidence that, whilst a pre-assessment care pathway within the surgical setting improved patient capacity, it also promoted individualised care through its person-centred approach. Using a grounded theory approach, Malkin (2000) explored patients' perceptions of a pre-admission/assessment care pathway. The findings suggested that a pre-assessment clinic helped to relieve patients' anxiety through providing a caring environment and information provision. Furthermore, the findings also suggested that person-centred care had gained increasing significance for its provision of a 'cared for' environment, individualised care and improved efficiency of capacity. It was recognised that 'true' grounded theory was not used due to time restrictions. However, of the small sample, four of the eleven participants interviewed were re-interviewed to confirm the emerging categories generated from the data, and to strengthen the reliability of the findings and theorising.

2.5.2 Efficient patient management through patient assessment

Within this theme, there was consensus in the literature that efficient patient management could be achieved through comprehensive patient assessment and clinical examination, and this was defined as being a key role of a surgical pre-assessment clinic (Clinch, 1997; Lucas, 1998; Green, 2000; Malkin, 2000; Gilmartin, 2004; Heaney and Hahessy, 2011). The review also indicated that the comprehensive assessment and thorough pre-operative health screening identified patients with medical conditions which may have complicated their elective surgery (Otte, 1996; Clinch, 1997; Clark et al., 2000; Malkin, 2000; Fraczyk and Godfrey, 2010; Heaney and Hahessy, 2011). The importance of

the nursing role within a pre-assessment clinic was also highlighted, indicating that the nurses' assessment skills and experience identified those patients with potential risk factors. Their autonomous decision-making enabled the carrying out of appropriate additional investigations prior to their planned surgery (Clinch, 1997; Jones et al., 2000; Malkin, 2000; Gilmartin, 2004).

In an influential early study, Clinch (1997) utilised both ethnographic and survey methods to collate data concerning the level of patient satisfaction with pre-assessment clinics and determine what level of care that nurses delivered in these clinics. Widely cited, these innovative findings provided the grounding for the success of these early clinics and suggested that such nurse-led clinics were highly developed with effective autonomous decision-making and that their assessment skills were important elements of their success.

Two of the studies compared nurse-led pre-assessment with a multi-disciplinary team (MDT) pre-assessment care pathway. These qualitative studies found that the nurse-led pre-assessment was equally as efficient as the MDT pre-assessment care pathway. Gilmartin (2004) conducted semi-structured interviews with a small sample of 30 adult patients awaiting general surgery within a large NHS teaching hospital. Nurses were found to follow local policy and guidelines more accurately and consistently and were able to provide patients with additional individualised information, including health promotion regarding their treatment and follow-up care. Kinley et al. (2001) conducted a large-scale multi-centred randomised controlled trial within four NHS teaching hospitals to determine whether registered nurses were as efficient as the same level of medical staff. Their conclusions were significant and indicated that nurses achieved a similar standard throughout the pre-assessment process for patients prior to elective surgery for general, vascular and breast surgery, including performing clinical examination and in their decision-making skills.

There was evidence from the review that a comprehensive assessment promoted the ongoing physical and psychological well-being of patients. The pre-assessment clinic was successful in improving the quality of patients' experiences emotionally and in meeting their postoperative and discharge

needs. This was achieved through clinical examination along with the provision of individualised information regarding the planned surgical procedure. This helped to relieve patients' anxieties and concerns, which increased their confidence for the recovery process (Clinch, 1997; Clark et al., 2000, Malkin, 2000; Fraczyk and Godfrey, 2010; Heaney and Hahessy, 2011).

A surgical pre-assessment care pathway has shown that it enables efficient patient management through physical patient assessment and the provision of psychological support, whilst undergoing a planned surgical procedure. The evidence from the review lends itself to an enquiry as to whether a pre-assessment care pathway, within a SACT outpatient service, can positively affect the experience and efficiency of patient management through physical and psychological assessment in patients with lung cancer.

Hulbert-Williams et al. (2012) suggest that approximately half of those patients newly diagnosed with cancer suffer distress, significant anxiety and reduced quality of life. Approximately one-third of patients will also suffer ongoing psychological problems, such as clinical anxiety and depression, and will remain dissatisfied with their quality of life. Considering the psychological adjustment associated with a cancer diagnosis and its treatment, the ongoing psychological assessment of patients' wellbeing is therefore as important as the physical assessment. Aumann et al. (2015) highlight that lung cancer is associated with a poor survival rate and that it often develops without notice. It is associated with vague symptoms and most often is not curable once diagnosed. As a result, throughout treatment, patients often experience higher levels of distress which relate to treatment side effects, symptoms from their disease and the psychological impact of their disease being incurable. Given this predicament, there is greater uncertainty for this patient group and the physical and psychological adjustment to lung cancer may create more of a challenge for these patients as they are at higher risk of extreme distress and poorer emotional well being (Carlsen et al., 2005; Gonzalez and Jacobsen, 2012; Hulbert-Williams et al., 2012; Kurita et al., 2013).

Kurita et al. (2013, p. 1398) highlight three variables to assess patients who demonstrate a positive psychological adjustment to their diagnosis:

- few depressive symptoms;
- few symptoms of perceived stress;
- improving emotional well-being.

They further suggest that, whilst patients' psychological adjustment to their diagnosis is unique and variable, it is imperative to recognise those individuals who adjust less well. They may express excessive worrying or demonstrate depressive symptoms and poor emotional wellbeing. It is vital to ensure that there are appropriate ongoing support strategies in place (Kurita et al., 2013). A SACT pre-assessment care pathway may facilitate the ongoing psychological assessment for this patient group and enable support for those who require it.

2.5.3 Improving patients' ability to self-care

Information provision, health promotion and patient education emerged throughout the literature review (Clinch, 1997; Lucas, 1998; Clark et al., 2000; Malkin, 2000; Gilmartin, 2004; Fraczyk and Godfrey, 2010; Heaney and Hahessy, 2011). The potential benefits achieved from a pre-assessment care pathway included increased patient confidence, increased compliance with recovery, and reduced anxiety and stress whilst undergoing surgery (Clinch, 1997; Clark et al., 2000; Malkin, 2000; Heaney and Hahessy, 2011). Clinch (1997) indicated through observational analysis that nurses made effective use of non-verbal communication skills that occurred 'naturally' during patients' consultations. Such non-verbal communication skills included active listening, appropriate eye contact and recognising cues accurately from patients regarding their specific concerns and anxieties. These skills were thought to have had a positive influence on patients' ability to self-care (Clinch, 1997; Lucas, 1998; Clark et al., 2000; Fraczyk and Godfrey, 2010). Malkin (2000) discussed that the majority of participants within their study felt that the information provision improved their understanding of the planned procedure and they felt informed regarding what to expect and what was expected from them. However, within other studies there were small numbers of participants

who described feeling minimal benefit was gained from a pre-assessment care pathway. They described that information provision was an area that needed to be strengthened, as they had been provided with either too much or too little (Otte, 1996; Clinch, 1997; Clark et al., 2000; Gilmartin, 2004; Gilmartin and Wright, 2008).

As discussed in Chapter 1 (Section 1.3), the NHS National Cancer Quality Programme (Healthcare Improvement Scotland, 2013) developed three Quality Performance Indicators (QPIs), one of which included information provision. The QPI feedback report indicated key themes from the following questions:

- what things about healthcare mattered most?
- what made the difference?
- what could be done better?
- what needs to happen to allow good information provision?

Information provision was the most frequently identified issue related to these questions, along with being provided with good information that was delivered effectively. Furthermore, meaningful information, helpful sources and signposting of where and who could help were also prominent themes. The QPI feedback report indicated that individualised assessment, with the relevant information provided in parts, at each stage, was preferential to being bombarded with lots of information at the beginning of the journey and was far more helpful. The feedback report further indicated that delivering information in parts allowed the adequate time required to digest the information provided. It allowed enough time to ask questions, feel listened to and not rushed, thus enabling shared, informed decision-making regarding the treatment options available (Healthcare Improvement Scotland, 2013).

In a study examining the information needs of newly diagnosed lung cancer patients, Gabrijel et al. (2008) conducted a survey to examine their recall of the information delivered. The survey was carried out with 71 patients, 1–3 days following their initial consultation at which the diagnosis was conveyed. The survey examined the ability of these patients to recall information regarding diagnosis, proposed treatment, treatment goals, and whether the patients felt

satisfied with the information provided. The study concluded that newly diagnosed patients with lung cancer were confronted with a huge amount of information under stressful circumstances. Their ability to recall information regarding the intent of their treatment or treatment goal was poor. The results of the study should be considered with caution despite the consistent findings, as the sample size was relatively small, and the research took place in a single centre. However, considering the study conclusions and their implications for clinical practice, it supports the introduction of a clinical intervention that might improve communication with patients at this significant time-point, such as a SACT pre-assessment care pathway.

Mistry et al. (2010) conducted a cross-sectional survey using convenience sampling of 187 participants to explore whether, and in what way, information needs might differ for patients at various stages of their cancer journey. They hypothesised that information needs related to treatment and a cancer diagnosis would be highest among those who were recently diagnosed. The study findings were consistent with previous research that found patients' information needs changed throughout the cancer journey. However, the findings further indicated that those needs also strongly related to demographic factors such as age, gender, ethnicity, education and treatment intent. Mistry et al. (2010) highlighted that patients' seeking of information was largely ongoing from the point of diagnosis. The authors reported that patients wanted to be well informed, regardless of their stage in the cancer journey, and, therefore, guidance in finding appropriate sources of information would be helpful. The study recommendations suggested that patients should be encouraged to use recognised cancer information centres, as these are effective in helping patients to access relevant and appropriate information. The limitations of the study were acknowledged, in that there was the potential for response bias, given the 50% response rate and that the participants were recruited via convenience sampling. In addition, the convenience sample limits the extent to which the findings can be generalised to all cancer patients (Creswell, 2013).

It is also recognised within the literature that those diagnosed with cancer need essential information regarding their diagnosis and treatment options with the

possible side effects of treatment pointed out to them (Leydon et al., 2000; Jenkins et al., 2001; Chapman et al., 2003). The literature further indicates that cancer patients focus on their information needs and the source of obtaining this information. This is most frequently noted during the initial diagnosis and the treatment phase of the journey (Yardley et al., 2001; Rutten et al., 2005; Aranda et al., 2006; Russell and Ward, 2011). Further evidence suggests that patients seek information that is tailored to help them understand and participate in necessary decision-making about their illness and treatment (Rutten et al., 2005; Roe and Lennan, 2014). Indeed, Husson et al. (2011) suggest that the provision of relevant information promotes self-management strategies that can have a positive impact on important aspects of patients' quality of life, including functional independence, physical well-being and well-managed treatment side effects, such as fatigue.

The literature acknowledges that how much information is required will vary between individuals and that their need for information will change throughout the different stages of their cancer (Fallowfield et al., 1995; Fallowfield and Jenkins, 1999; Leydon et al., 2000; Jenkins et al., 2001; Adams et al., 2009). Rutten et al. (2005) and Mazor et al. (2013) highlight that the challenge is therefore understanding what lung cancer patients need to know, whom they receive their information from, providing the relevant information at the right time, and tailoring this to each individual throughout their care. Examining whether the information provision to a group of lung cancer patients could be improved through attending a new SACT pre-assessment care pathway is therefore justified.

2.5.4 The patient's experience of surgical pre-assessment

Otte (1996) highlighted the importance of patient satisfaction and its relevance to quality assurance within healthcare. Enquiries about patient satisfaction are frequently evaluated through a combination of self-administered questionnaires or semi-structured interviews. Fraczyk and Godfrey (2010) employed a cross-sectional survey with 275 adult patients, using a self-administered questionnaire to explore patients' satisfaction with a pre-assessment care pathway for day surgery within two surgical specialities. Despite a low response rate of 39%, the

findings indicated that the majority of patients felt that anxiety was relieved by attending the pre-assessment care pathway. Findings also suggested that patient satisfaction would have been further improved if the information provision had been individualised. Similarly, Clinch (1997) used a self-administered patient satisfaction questionnaire in the second part of her study, which consisted of questions relating to demographic, administrative, communication and quality issues. A convenience sample of 106 in-patients yielded positive results, with up to 92% of respondents feeling satisfied with a pre-assessment care pathway and indicating that a consistent, safe and effective service was provided. Clinch (1997), however, acknowledged weakness in her data collection methods, in that using convenience sampling with inpatients did achieve a good response rate, however, this method may well have biased the results towards those patients' views and responses.

In a further small-scale study, Malkin (2000) explored patients' perceptions of a nurse-led pre-assessment care pathway within a private surgical hospital. In-depth interviews were conducted with eleven patients due to undergo orthopaedic surgery. It was suggested that patients' social and emotional needs were met by the individualised care and when the information is provided within a caring environment. Participants described how this improved the quality of their experience and they felt better prepared for their surgical procedure. Otte (1996) examined patients' experiences of attending a pre-assessment clinic for day-care surgery using a grounded theory approach. A small, non-random, purposeful sample of eight patients indicated that, despite a preference for day surgery, there was dissatisfaction with the pre-assessment care pathway. Complaints included long pre-operative waiting times, poor discharge planning and inadequate informational support. Otte (1996) argued that saturation of the data was achieved despite the small sample.

The findings from these studies highlight patients' satisfaction with the surgical pre-assessment process (Clinch, 1997; Malkin, 2000; Gilmartin and Wright, 2008; Fraczyk and Godfrey, 2010; Heaney and Hahessy, 2011). The positive impact of information provision and emotional support justifies further enquiry of

a pre-assessment care pathway into other clinical areas, such as an outpatient SACT service.

In the literature, patient satisfaction is defined as patients' experiences of aspects of healthcare provision affected by the degree of quality and/or clinical effectiveness (Batbaatar et al., 2015; Berkowitz, 2016). Indeed, Sitzia and Wood (1998) described three functions that fulfil patient satisfaction:

- description of patients' experiences;
- identification of the strengths and weaknesses of service provision;
- evaluation of the care provided.

In contrast, Coulter et al. (2009) suggest that patient experience data provides detail regarding experience rather than evaluation or rating of the care provided. Jackson et al. (2001) further suggest that aspects of patient experience measure patient satisfaction, by either a healthcare intervention or an interaction with a healthcare professional. At the same time, exploring aspects of patient experience can help to measure quality, clinical effectiveness and patient safety.

There is a body of literature, which indicates that patient satisfaction is strongly associated with the quality of communication skills. This includes its clear delivery with the use of familiar words, the degree to which the patient is heard and kept informed, and also that the patient is provided with adequate psychological support (Beckett et al., 2009; Naidu, 2009; Wagner and Bear, 2009; Gadalean et al., 2011). Naidu (2009) conducted a systematic review of international literature to understand and measure factors affecting patient satisfaction and healthcare quality. The review indicates that the effective use of communication skills can help to alleviate the uncertainty that is associated with a life-changing or life-limiting diagnosis and its related treatments. It can also increase patients' awareness of what to expect from treatment and improve their compliance with the care regime and prescribed medicines. This literature supports the aims of a SACT pre-assessment care pathway. Through communication, within the assessment process, it can ensure that SACT will be individually tailored according to its tolerance and side effects. The assessment

process can help to ensure that there will be ongoing benefit, informed consent, understanding and compliance with SACT.

2.5.5 Summary

The evidence from the review of patients' experiences of a surgical pre-assessment care pathway supports an enquiry as to whether a pre-assessment care pathway, within a SACT outpatient service, can provide an equally positive effect on patients' experiences. The quantitative study, whilst acknowledging its small sample size, identified overall patient satisfaction with an orthopaedic pre-assessment care pathway, including factors such as quality of care and improved information provision (Heaney and Hahessy, 2011). The mixed-method and qualitative studies exploring patients' experiences and perceptions of pre-assessment clinics yielded similar themes, which were reflected results from earlier research studies. These themes included improved patient capacity and efficiency, improved information provision, the provision of health promotion and improved patient education. Despite time constraints limiting a number of these studies and affecting recruitment, sample size and data collection, there was sufficient relevant evidence to suggest that a pre-assessment care pathway within the surgical setting delivered person-centred care and created a positive impact on patients' experiences and perceptions.

2.6 Pre-assessment care pathway within the surgical setting – a conceptual framework

From the findings of the literature review of a pre-assessment care pathway within the surgical setting, I constructed a conceptual framework using the four key themes that were identified (Figure 5). This process helped to map an overall picture that visualised how these themes related to one another. This conceptual framework illustrates *improved patient capacity* as the outer-most component of the framework, moving inward with *efficient patient management* and *improved ability to self-care*. Achieving each of these components then leads to *improved patient experience*. Forming the centre of the framework is improved patient experience, which aligns each component with the principles of person-centred care through the provision of personalised care, patient satisfaction and shared decision-making.

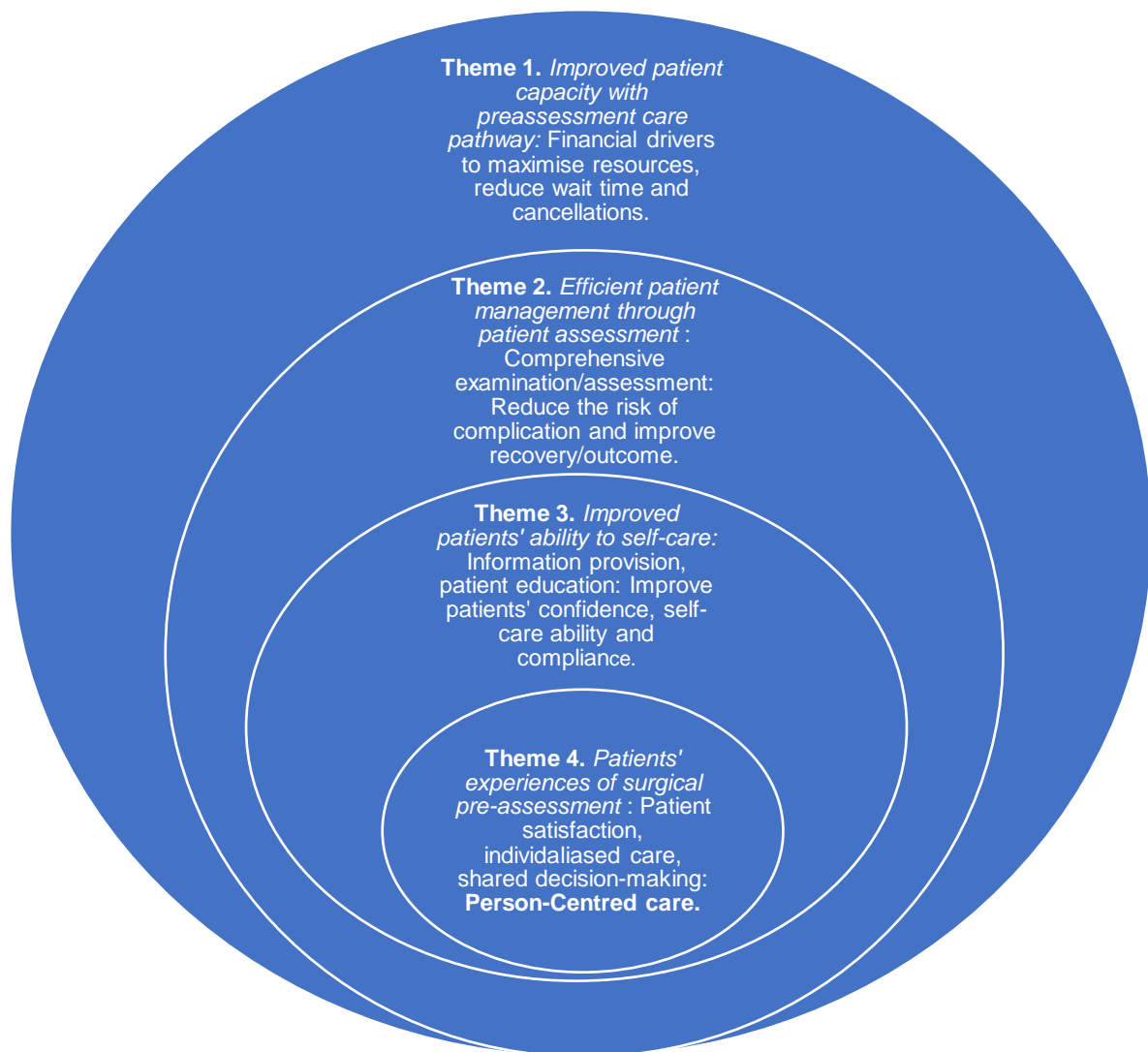


Figure 5. A Conceptual Framework of a surgical pre-assessment care pathway

2.7 Patient experience and person-centred care

The concept of person-centred care has become established within healthcare delivery and embedded within relevant policy documents and strategic frameworks (Scottish Government, 2010b; Healthcare Improvement Scotland, 2013; Scottish Government 2016a, 2016b; The Health Foundation, 2016). Recent evidence into person-centred care has attempted to clarify its meaning, explore its implications within clinical practice, and determine the challenges when implementing this approach. Santana et al. (2018) suggest that this care approach provides a holistic approach, incorporating multiple dimensions within the whole well-being, increased patient satisfaction with care, and reduced anxiety associated with diagnosis and treatment. Existing evidence is consistent

in suggesting that being person-centred requires an effective therapeutic relationship between healthcare professionals, the patient, and their close family with mutual trust built on the understanding and sharing of knowledge (McCormack and McCance, 2006, 2010; The Health Foundation, 2016; Santana et al., 2018).

The literature reveals the existence of a number of definitions and frameworks for person-centred care and, as such, there are a range of approaches available for measuring person-centred care. Most take a holistic view or measure specific subcomponents, such as shared decision-making or communication (McCormack and McCance, 2006, 2010; The Health Foundation, 2016; Santana et al., 2018). Within Scotland and the UK, the need for person-centred health care is widely accepted; the Health Foundation (2016, p. 6) developed this care approach collaboratively in partnership to support patients to develop knowledge, skills and confidence to make informed decisions about their health and to facilitate co-ordinated, tailored management of their care and treatment. Rather than attempt to define person-centred care, a framework was developed that comprised four inter-related principles (Figure 6):

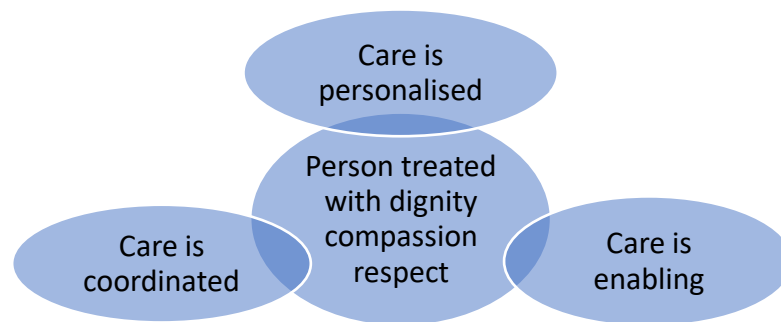


Figure 6. Framework of four inter-related principles of person-centred care – The Health Foundation (2016)

The Health Foundation (2016) suggest that applying a combination of these inter-related principles can improve any aspect of healthcare intervention. Enabling care requires partnership; working together to identify and understand what is important to each patient, make informed decisions regarding care and treatment, and achieve personal goals.

McCormack and McCance (2010, p. 13) describe person-centred care as:

practice established through the formation and fostering of therapeutic relationships between all care providers, patients and others significant to them in their lives. Underpinned by values of respect, individual right to self-determination, mutual respect and understanding.

It is suggested that person-centred care has been driven by evidence that care can be more effective when it is tailored to specific patients' needs (McCormack et al., 2010). It has been argued that person-centred care achieves an improved experience for patients and higher levels of patient satisfaction (McCormack and McCance, 2006, 2010; Pelzang, 2010; Kitson et al. 2013; Santana et al., 2018).

McCormack and McCance (2006) developed 'The Person-centred Nursing Framework' (Figure 7– adapted summary) from early research which focussed on person-centred care with older people (McCormack, 2003) and the experience of caring in nursing (McCance, 2003). The framework was developed to be flexible, to enable nurses to explore person-centred care; provide a lens to implement this care approach to identify any barriers; recognise the key principles; and evaluate developments of person-centred care in practice (McCormack et al., 2010; McCance et al., 2011).

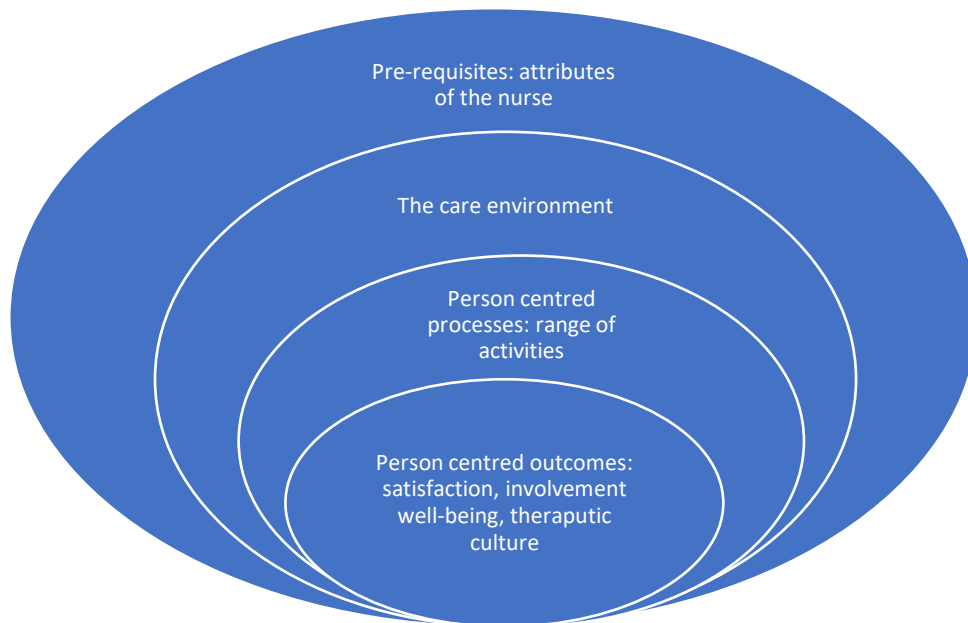


Figure 7. Adapted Summary – The person-centred nursing framework – McCormack and McCance (2006)

The framework comprises four constructs and, in order to reach the centre or the outcomes, the prerequisites which focus on the attributes of the nurse, such as; professional competence, developed interpersonal skills, and commitment should be considered. The care environment, which focuses on the context in which care is delivered, should then be considered. Person-centred processes focus on delivering care through working with patients' beliefs and values within holistic care that enables shared decision-making and expected outcomes, which are the results of providing perceived effective person-centred care (McCance et al., 2011).

The evidence presents differing opinions on what exactly constitutes person-centred care, and its influence on patient satisfaction has not been firmly established. However, applying the expected outcomes of person-centred care from both the work of The Health Foundation (2016) and McCance et al. (2011) to a SACT pre-assessment care pathway could help to deliver individualised quality care and positively enhance the experience of those patients with lung cancer undergoing SACT. It may also ensure that valued NHS resources are directed to meet the needs and preferences of those who require them, as opposed to those of the convenience of the care providers, and ensure best

value for money (Wolf et al., 2008; Epstein and Street, 2011; Pelletier and Stichler, 2014; The Health Foundation, 2016). There is evidence to support the view that a person-centred care intervention may lower overall healthcare costs whilst improving efficiency of healthcare delivery through early management to reduce the severity of the illness or treatment complication, thus reducing the risk of prolonged emergency hospital admissions (Epstein and Street, 2011; Pelletier and Stichler, 2014; Santana et al., 2018).

The cost-effectiveness of person-centred care has been questioned, including whether this care approach can improve service efficiency and patient capacity (The Health Foundation, 2011; The Health Foundation, 2012; Kitson et al., 2013; Collins, 2014; The Health Foundation, 2016; Santana et al., 2018). There are suggestions that the NHS is challenged by the effective implementation of person-centred care whilst its budgets are under increasing pressure. Some suggest that a person-centred approach is 'nice to have' rather than essential (Collins, 2014; The Health Foundation, 2016). Santana et al. (2018), however, argue that there are indeed financial drivers to support the implementation of person-centred care within the NHS. They suggest that this care approach can help to reduce the burden on vital healthcare resources and also reduce how often these valued resources are used. The evidence weighed in the review supports an enquiry into whether a pre-assessment care pathway within a SACT outpatient service can have a positive impact on capacity issues and whether this care approach can facilitate the delivery of person-centred care for patients with lung cancer.

2.8 Summary

The review undertaken of surgical pre-assessment care pathways has demonstrated sufficient evidence to support its potential benefits to the quality of patient care. I have also established my concern for a group of lung cancer patients undergoing SACT with the current care pathway and their need for ongoing clinical assessment/examination to ensure there is continued benefit from SACT, and that it is tailored appropriately to address any treatment side effects. Exploring the experience of this patient group attending a new SACT

pre-assessment care pathway may also help determine whether such a pathway improves the quality of care and whether a person-centred care approach is achieved. Furthermore, such an enquiry will help to determine whether a pre-assessment care pathway can improve SACT readiness; reduce late and same-day SACT cancellations; and whether it should be implemented into clinical practice.

In the next chapter, part two of the literature review is presented, which provides the rationale for selecting a group of lung cancer patients and determining how the patient experience can help to inform healthcare delivery.

Chapter 3: Literature Review – Part two

3.1 Introduction

In this chapter, part two of the review is presented. The search strategy for exploring patients' experiences of a lung cancer diagnosis, including those undergoing SACT, is set out. The research evidence relating to the patient experience of people who have been diagnosed with lung cancer, receiving SACT, and using the patient experience to inform health care and service delivery, is presented to support the aim of my research study and refine the research questions.

3.2 Search strategy – patient experience of a lung cancer diagnosis and receiving SACT

In the search to retrieve evidence of the patient experience of a lung cancer diagnosis, undergoing SACT, and using the patient experience to inform service delivery, a review of the relevant literature was carried out using the EBSCO host platform. The period of focus reflects the shift of SACT delivery for lung cancer patients into the outpatient setting, which occurred from 2000 to 2019, and a database search included Medline, CINAHL and Ovid. The search terms included combinations of 'lung cancer', 'diagnosis', 'patients', 'experiences', 'chemotherapy', 'treatment', 'side effects', 'symptoms', 'healthcare', and 'service delivery'. The search was undertaken in December 2020 and repeated in February 2021 and was restricted to English language and studies carried out within the UK, Ireland, Eastern Europe, USA and Australia, as their healthcare systems are developed and resourced similar to those within the UK. The articles selected were based on the inclusion criteria displayed within Table 4.

Table 4. Inclusion criteria for literature review: patient experience of lung cancer diagnosis and receiving SACT

Inclusion criteria for the search strategy
Adult patients with a lung cancer diagnosis within the UK, Ireland, Eastern Europe, USA and Australia.
Patients diagnosed with lung cancer
Patient experience of lung cancer diagnosis and receiving SACT (chemotherapy)
Patient experience used to inform healthcare and service delivery
Research studies within peer-reviewed academic journals

The 920 articles excluded were out with the UK, Ireland, Eastern Europe and Australia, did not relate to patient experience, did not relate to lung cancer, and were not research studies. These non-research studies included a significant number of audit reports and descriptive case reports within known professional nursing publications (Table 5). The selection followed a process of examining the abstract (if available), and then reading each article for relevance.

Table 5. Search Strategy: patient experience of lung cancer diagnosis and receiving SACT

Source	Total Found	Articles Excluded	Articles Included
CINAHL	524	512	12
Medline	298	288	10
OVID	124	120	4
Total	946	920	26

The CASP tool was utilised to help the process of assessing the outcome of each article for its quality, trustworthiness, relevance and context. Twenty-six articles were reviewed, nine were qualitative studies that explored the patients' experiences of a lung cancer diagnosis and explored how patient experience might inform healthcare delivery (Yardley et al., 2001; Krishnasamy et al., 2007; McCarthy and Dowling, 2009; Dale and Johnston, 2011; Tsianakas et al., 2012; Ellis et al., 2013; Maguire et al., 2014; Boiko et al., 2014; Dong et al., 2016). Four studies that were quantitative in design explored the lived experience of people diagnosed with lung cancer and receiving SACT (Akin et al., 2010; Buchanan et al., 2010; Wintner et al., 2013; Karczmarek-Borowska, 2014).

Three literature reviews (Gilbert et al., 2011; Ryan et al., 2014; Mooney et al., 2017) and four systematic reviews examined the evidence on patient experience and lung cancer, including the symptoms and healthcare service delivery (Harrison et al., 2009; Doyle et al., 2013; Maguire et al., 2013; Gleeson et al., 2016).

There was one evaluation report (LaVela and Gallan, 2014), which explored the measurement of patient experience, and one executive summary from the Healthcare Quality Strategy for Scotland, which has developed quality ambitions to be reflected within healthcare policies. These include timely, safe, person-centred and effective care (Scottish Government, 2010b). In the two remaining articles, a feasibility study examined the impact of fatigue for cancer patients (Ream et al., 2005), and one project report (Robert and Cornwell, 2011) examined the challenges of using the patient experience to inform healthcare delivery. Finally, two policy documents outlined action plans to improve the quality of cancer care using shared patient experience (Scottish Government, 2008; Coulter et al., 2009).

3.3 Patient experience of a lung cancer diagnosis

Lung cancer is associated with a high burden of physical and psychological distress, and this is reflected in the literature (Yardley et al., 2001; Buchanan et al., 2010; Dale and Johnston, 2011; Ellis et al., 2013; Kotronoulas et al., 2018). Alongside the symptoms of lung cancer and the progression of the disease, there is a high prevalence of SACT-related side effects, including fatigue, nausea, vomiting, constipation, mucositis, and reduced appetite, often associated with changes to taste. In the literature, a person-centred care approach is described as contributing to the management of the associated physical and psychological distress with lung cancer whilst promoting quality of life, to ensure that SACT remains appropriate (Sarna, 1998; Bahl et al., 2006; Bezjak et al., 2008; Akin et al., 2010; Karczmarek-Borowska et al., 2014).

In an early qualitative study, Yardley et al. (2001) used a phenomenological approach to consider patients' interpretations, perceptions and perspectives of receiving a lung cancer diagnosis. Data saturation was achieved in semi-

structured interviews completed with thirteen participants. Despite the small sample, five key areas were categorised from the data:

- *Communication*, or how information is communicated and how language is used.
- *Family/community issues*, in that not all participants choose to tell their family members of their diagnosis, they want privacy, and do not want to cause worry or feel as though they are being a burden.
- *Reaction to diagnosis*, which varied between shock, relief, and reassignment.
- *Views on treatment and prognosis*, which included that information delivery at the time of diagnosis made a difference and, for some participants, their acceptance of the illness, how much information was retained and, in particular, the aim of treatment discussed and re-discussed at a later date.
- *Suggested improvement*, which included the provision of co-ordinated care with limited time between stages of treatment, and consistency of care to build confidence in health care professionals.

In conclusion, Yardley et al. (2001) highlighted a need to develop lung cancer services from the point of diagnosis that provide quality care and tailored management of symptoms and treatments.

More recently, in a small qualitative study, Dale and Johnston (2011, p. 287) explored the concerns of patients diagnosed with inoperable lung cancer. An in-depth semi-structured interview was carried out with a purposive sample of six patient participants. Three themes were categorised from the data collated, including:

- *Steadfastly living life*; the link with normality, good symptom control, promoting self-management and confidence.
- *Family support and separation from family*; protecting the family from burden and worry and the fear of being separated from the family.

- *Trust in professionals*; the need for information and how this is delivered, feeling cared for and listened to.

The findings identified that the nurse–patient relationship is one of partnership that enables the patients’ voice, supporting them to express their concerns. The nurse–patient relationship was thought to be crucial to enable a person-centred perspective and the delivery of individualised/person-centred care.

Considering the findings from both studies (Yardley et al., 2001; Dale and Johnston, 2011), they have suggested that person-centred care from the point of diagnosis and throughout treatment could improve the quality of care delivered and therefore would benefit this patient group. Exploring lung cancer patients’ experiences and perceptions of a pre-assessment care pathway could provide a better understanding of the potential benefits, determine whether it delivers person-centred care and whether it should be introduced routinely into clinical practice for this patient group undergoing SACT.

There is reported distress associated with a diagnosis of lung cancer, and several studies have explored patients’ experiences to gain an understanding about the symptoms that contribute to their physical and psychological distress. Buchanan et al. (2010) conducted a prospective observational evaluation of 170 lung cancer patients attending an outpatient clinic. The aim of the study was to evaluate lung cancer patients’ anxiety, physical symptoms, performance status and their perception of anxiety within their support network (measuring performance status is an attempt to objectively quantify cancer patients’ general well-being and their ability to carry on with their activities of daily life – West, 2015). Data were collated utilising the validated adapted Palliative Outcome Scale questionnaire, which quantified the participants’ physical and psychosocial needs in terms of impact on life and perception of worry within their support network. Buchanan et al. (2010) observed the prevalence of anxiety within lung cancer patients. They observed that, as symptoms increased, often in association with the progression of the cancer, physical function declined, and anxiety further increased. Furthermore, as a patient’s own anxiety increased, they perceived increased anxiety within their social

network. Recommendations included ongoing assessment to ensure early recognition of anxiety and to facilitate support and intervention.

More recently, Maguire et al. (2014) used interpretative phenomenological analysis to explore the lived experience of people following a diagnosis with advanced lung cancer. The study aimed to better understand the symptoms of lung cancer that contribute to the high burden of physical and psychological distress. A small purposeful sample of ten patients with advanced lung cancer took part in two consecutive in-depth interviews with the aim of better understanding the experience of multiple concurrent symptoms of lung cancer (also referred to as symptom clusters). These participants were found to experience concurrent symptoms, including fatigue, cough, pain, and breathlessness, and described a reduction in their physical and social functioning associated with these concurrent symptoms, in particular, breathlessness and cough.

Maguire et al. (2013) conducted a systematic review to determine the supportive needs of people living with lung cancer. Reporting on 53 studies retrieved from a pre-specified selection criterion, the trends and gaps in the assessment of these supportive needs were explored. Complex supportive needs were evident and classified into nine domains. These included: their *physical needs*, described as a major concern and often causing considerable distress, their *daily living needs*, dominated by treatment and investigations; and their *psychological/emotional needs*, which were found to be highly prevalent, for example, feeling anxious, worried, sad and a loss of control (Graves et al., 2007; Ellis et al., 2013). *Spiritual needs* were identified, given the uncertainty that this patient group faced and the fear of the unknown; the *informational needs*, which were prominent and often included distress related to lack of information, or the provision of too much information to comprehend and interpret, especially around managing their illness and the side effects of treatment to enable optimal self-care ability (Krishnasamy et al., 2007; Buchanan et al., 2010). Having a trusting and available *patient–clinician relationship* was important to discuss aspects of the illness and treatment and also offered consistency. Other domains included *practical needs, social and*

family-related needs, and *cognitive needs* (Berterö et al., 2008; Dale and Johnston, 2011). The challenge of comprehensively supporting these care needs is recognised, and there is the need for ongoing research to determine validated needs assessment tools that might add to the existing knowledge (Broberger et al., 2007; Maguire et al., 2013).

Considering these nine domains, developing a person-centred intervention that will assess, examine and manage these concurrent symptoms is therefore recommended.

Introducing a new SACT pre-assessment care pathway for this patient group could enable the ongoing assessment, clinical examination and management of both disease-related symptoms and SACT-associated side effects. Exploring the patient experience of this care pathway may also help to determine whether this enables a person-centred care intervention.

3.3.1 Patients' experiences of receiving SACT for lung cancer

I have considered the patient experience of a lung cancer diagnosis and the associated symptoms of the illness. Exploring the patient experience of receiving SACT may help further substantiate the need for person-centred monitoring through clinical examination and assessment throughout SACT for this patient group.

Fatigue has been described as the most debilitating side effect of SACT, with up to 75% of patients' indicating that it has a negative impact on their quality of life. Fatigue is often associated with nausea and loss of appetite, with up to 54% of patients developing significant weight loss as a result (Bahl et al., 2006; Molassiotis et al., 2008; Butt et al., 2008; Akin et al., 2010; Polanski et al., 2016). If the aims of SACT are to be realised in those who are diagnosed with an advanced/inoperable lung cancer, such as, improved survival, improved symptom management, and thereby improved quality of life, it is suggested that ongoing assessment and clinical examination with effective management of SACT side effects is essential (Socinski et al., 2003; Bahl, 2006; Bezjak et al., 2008; Butt et al., 2008; Akin et al., 2010).

In an early prospective trial, Bahl et al. (2006) examined the development of SACT-related side effects in patients with a locally advanced lung cancer receiving on average three cycles of a standard combination. Forty participants completed three SACT cycles and were available for the final evaluation. Over twenty-three months, data were collated from clinical examinations and assessments using the Common Toxicity Criteria (CTC v2) (National Cancer Institute, 1999). The findings concluded that treatment-related side effects limited quality of life for this patient group and, when associated side effects were not managed, they interrupted the proposed treatment regimen, thus potentially reducing the success of treatment. The recommendations included robust ongoing monitoring with person-centred assessment throughout SACT. The promotion of self-care ability along with compliance with treatment guidance was also highlighted in order to achieve an optimal treatment outcome.

A small interpretive phenomenological study (McCarthy and Dowling, 2009) explored the patient experience of lung cancer whilst receiving SACT. Six participants were interviewed; the interview was unstructured, using open-ended questions. Four themes were identified from the data: *Maintaining my life*; *The enemy within*; *Staying on the train*, and *I'm still me*. Despite the small sample size, these findings make a relevant contribution to the literature and, as it was indicated, these patients were willing to endure treatment side effects as no treatment was not an alternative. Therefore, the need to manage disease-related symptoms and the side effects of SACT was highlighted, as was the need for a care intervention that will enable optimal benefit from treatment whilst optimising quality of life.

Akin et al. (2010) conducted a quantitative study exploring symptom distress associated with lung cancer, the side effects of SACT, and the impact on various dimensions of quality of life. A purposive sample consisted of 154 lung cancer patients undergoing SACT. Data were gathered using a patient questionnaire about personal characteristics, disease process and SACT. These data were supplemented by information from medical case notes. Responses were evaluated using the Memorial Symptom Assessment Scale

and Quality of Life Index – Cancer version (Chang et al., 2000). The findings indicated that the disruption in quality of life for lung cancer patients was multifactorial, and related to the disease process, its treatments and varied socio-demographic characteristics. Akin et al. (2010) identified the need for continued regular evaluation of symptoms and quality of life assessment, which are known to identify predictors of distress and enable appropriate referral. Regular evaluation could also ensure the efficiency and effectiveness of SACT so that the optimal benefits are received.

More recently, Karczmarek-Borowska et al. (2014) explored the influence of SACT on lung cancer patients' health status, the occurrence of adverse events, and how this affected daily life. Sixty-two lung cancer patients completed the standard MOS SF-20 (Medical Outcome Study Short Form 20) (Carver et al., 1999) evaluating their functioning across six domains (mental, physical, health perception, pain, role and social). A self-administered questionnaire (prepared by the authors) also assessed various aspects of quality of life, including symptoms and distress experienced during SACT. The findings indicated that SACT decreased quality of life for these patients, especially in those over 65 years of age, while those under the age of 65 years struggled to cope with the psychological impact of the disease. Exploring the experiences of a group of lung cancer patients who attended an outpatient SACT service would therefore allow their voice to be heard whilst contributing new knowledge and understanding of SACT delivery and determine whether a pre-assessment care pathway offers a person-centred care approach to evaluate and manage associated side effects.

More recently, multiple courses of SACT have become available treatment options. Bezzak et al. (2008) assessed the quality of life of lung cancer patients during treatment. Their findings indicated an association between multiple lines of SACT and reduced level of quality of life. The deterioration in quality of life affected individuals' performance status and ability to undertake daily living activities. Wintner et al. (2013) also explored lung cancer patients' quality of life across multiple lines of SACT with the aim of gaining knowledge and understanding of patients' experiences. A purposive sample of one-hundred-

and-eighty-seven patients, irrespective of the SACT regime or previous treatment, completed a self-administered quality of life questionnaire. The findings suggested that aspects of quality of life remained unchanged during an early course/first course of SACT. However, these aspects of quality of life deteriorated significantly between and with increased courses of SACT in relation to disease progression and treatments.

It is evident from the review that those patients undergoing SACT for lung cancer require close monitoring and ongoing assessment throughout treatment to ensure it remains appropriate and that any change to quality of life is recognised early enough to enable informed decision-making regarding ongoing SACT management. Patient experience is of growing interest and relevance to inform healthcare and to measure quality and clinical effectiveness. A discussion of the relevant literature related to patient experience is now discussed.

3.4 Patient experience: informing health care and service delivery

The patient experience and perspective is increasingly recognised as an important indication of what brings value to healthcare, what provides satisfaction, and what provides a means of evaluating the quality of healthcare that might inform and improve service delivery (Black and Jenkinson, 2009; Robert and Cornwell, 2011; Lavela and Gallan, 2014; Ryan et al., 2014; Mooney et al., 2017). Healthcare organisations are therefore required to consider the feedback gathered through patient experience and translate this into clinical practice and service delivery as part of their quality and performance reporting (Black and Jenkinson, 2009; Boiko et al., 2014; Doyle et al., 2013).

Gleeson et al. (2016) conducted a systematic review exploring how patient experience is collated and utilised to inform service delivery and quality improvement within healthcare. Thirty-two journal articles were initially examined, and eleven qualitative and quantitative articles were then included within the review. Patient experience data were most commonly gathered through patient surveys, with patients describing this as a way for their voice to

be heard (Boiko et al., 2014). Patient surveys were found to be successful when influencing small organisational changes; however, when clinician behaviour was required to change as part of quality improvement, this was often more challenging and less likely to be influenced through the findings of patient surveys. It was further indicated that, regardless of the method used, informing clinical practice and service delivery is challenging, with limited time and resources being included as influencing factors, along with difficulty translating feedback into action. In addition, the feedback is often insufficient to stimulate any significant change (Coulter et al., 2009; Boiko et al., 2014; Coulter et al., 2014).

The patient complaint procedure was thought to be more influential when informing clinical practice and clinician behaviour, as it was thought that using the patients' perspective encouraged a shift toward person-centred care (Davies and Cleary, 2005). It was concluded that using patient experience provides positive value and the recommendations suggested that formal processes and training within quality improvement planning that developed an understanding what might drive change or inform clinical practice is necessary to utilise the data collated effectively and measure the impact of changes that are made. It was further highlighted that, when person-centred care was a key concept of healthcare policy, higher levels of positive patient experiences were associated with higher levels of patient safety and clinical effectiveness (Doyle et al., 2013; Boiko et al., 2014; Ryan et al., 2014).

In a systematic review, Doyle et al. (2013) explored the evidence on the links between patient experience, clinical safety, and effectiveness. An analysis of fifty-five studies suggest that patient experience is increasingly recognised as a pillar of measuring quality within healthcare and found a positive association between patient experience, patient safety and clinical effectiveness within a wide range of clinical settings. There was evidence to suggest that patients look for a therapeutic relationship with their clinician, one which is two-way empathic, effective and includes clear communication, respect for their beliefs and concerns, and the provision of information tailored to meet their needs. Patients described these elements of care provision as being essential to feel informed

and to be able to disclose sensitive information. Furthermore, patients described the need to be involved in the decision-making process and being able to take ownership of their illness and treatment.

My research utilises the patient experience and perception of an outpatient SACT service and a new pre-assessment care pathway for patients with lung cancer. A review of the literature of using patient experience to inform health care providers may further encourage a shift toward introducing a person-centred care intervention.

3.5 Summary

Part two of the review has provided relevant insight into patients' experiences of a lung cancer diagnosis, and the associated distress and anxieties that result from the symptoms of the disease process and the side effects from SACT. The review has highlighted the need for ongoing assessment and delivery of individualised healthcare services from the point of diagnosis for this patient group. The evidence suggests that regular evaluation and monitoring can ensure the effective management of SACT side effects and that it remains appropriate. Furthermore, early recognition of associated distress/anxiety can facilitate the appropriate and timely psychological support and intervention.

I appraised the conceptual framework I constructed in Chapter 2 (Figure 5) by undertaking a review of a pre-assessment care pathway within a variety of surgical settings. Figure 8 illustrates the conceptual framework with the four key strengths from a surgical pre-assessment care pathway with *improved patient capacity* as the outer-most component of the framework, moving inward with *efficient patient management* and *improved ability to self-care*. Achieving each component of the framework leads to *improved patient experience*. Forming the centre is improved patient experience, which aligns each of these components with the principles of person-centred care through patient satisfaction, individualised care and shared decision-making. The addition of the findings from part two of the review that examined the patient experience of lung cancer and receiving SACT are highlighted in red.

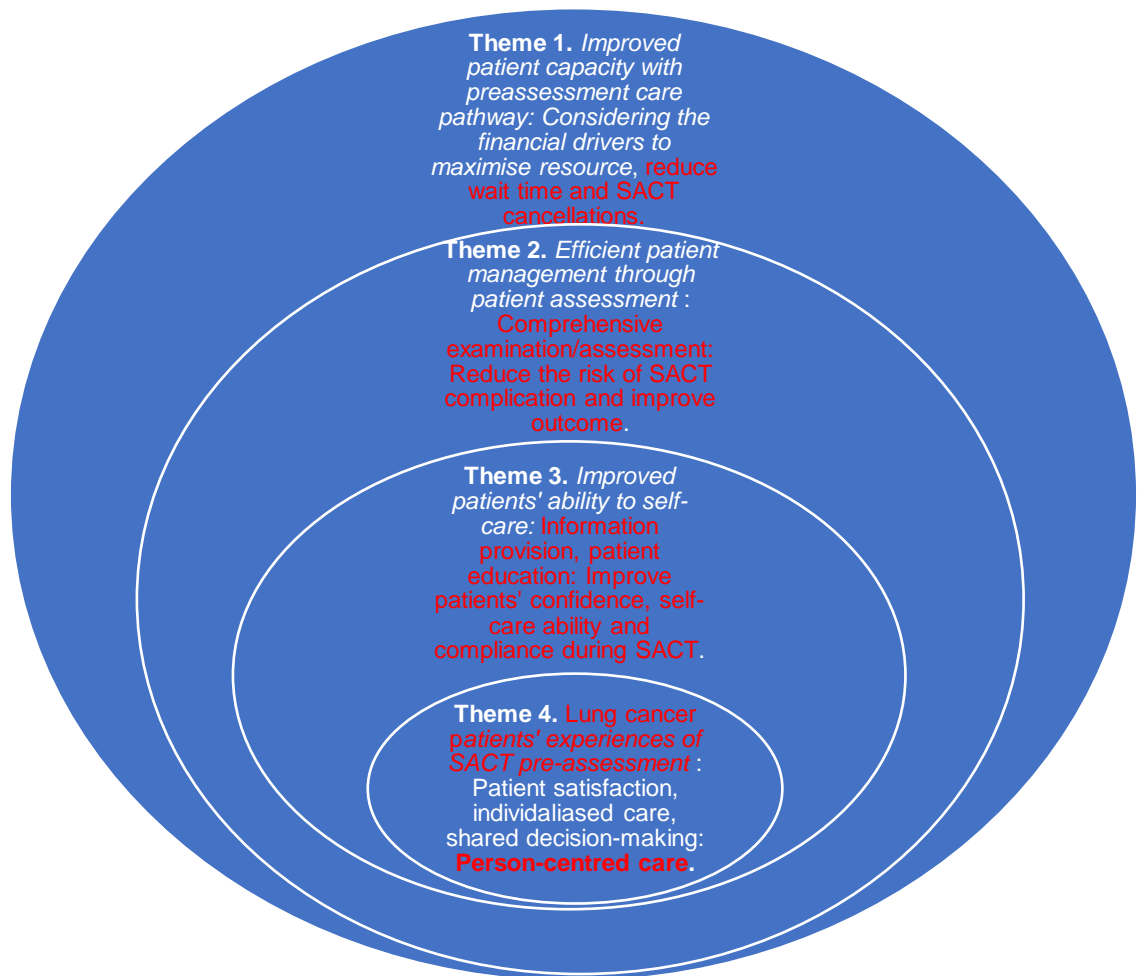


Figure 8. Conceptual Framework for a SACT pre-assessment care pathway for lung cancer patients

Conducting parts one and two of the literature review has helped to define the research aim and refine my research questions.

Having presented and discussed a comprehensive review and its findings, the rationale for the research methodology and approach will be discussed in the next chapter.

Chapter 4: Rationale for Methodology

4.1 Introduction

Informed by the literature review, the research aim and questions are presented in this chapter. The rationale for utilising a qualitative methodology with a case study design to answer the research questions is discussed. The methodology has been selected to facilitate an in-depth inquiry and allow an exploration into the real-life setting of patients' experiences and perceptions whilst attending the outpatient SACT service (Merriam, 2009). The case of inquiry is a group of lung cancer patients undergoing SACT.

4.2 Research aim

The aim of my research was to explore the lung cancer patients' experiences and perceptions of outpatient SACT services and determine whether a pre-assessment care pathway enables a person-centred care approach.

4.3 Research questions

1. How do lung cancer patients describe their experiences and perceptions when attending an outpatient SACT service?
2. How do lung cancer patients describe their experiences and perceptions having attended a new SACT pre-assessment care pathway?
3. Does a SACT pre-assessment care pathway reflect the constructed conceptual framework and enable person-centred care for patients with lung cancer?

4.4 Rationale for adopting a qualitative methodology

Quantitative research attempts to explain phenomena according to collated numerical data which consist of measurable variables that are analysed utilising statistics to test or explain a theory (Yilmaz, 2013; McCusker and Gunaydin, 2015; Patten and Newhart, 2017). This approach was not considered appropriate for my research study as there was little known about my subject of

interest and there was no hypothesis to test. My research aims and questions dictated the qualitative methodology chosen, as this supported the discovery of new information in real-world terms. I wanted to explore and understand lung cancer patients' experiences and perceptions of attending an outpatient SACT service and following the introduction of a new SACT pre-assessment care pathway.

I felt confident that using qualitative methodology would enable me to collate the meaningful and rich data that would provide the information that I required to answer the research questions. Indeed, Srivastava and Thomson (2009) suggest that qualitative data provide in-depth, purposeful and rich descriptions of behaviours, attitudes, thoughts and beliefs from people who have experienced, or are experiencing, the phenomenon of interest. I was influenced by the value and usefulness of verbatim quotations within qualitative data, as the literature suggests that these can help to interpret the study findings, support presented arguments, and illuminate the participants' experiences whilst capturing their emotions (Russell and Gregory, 2003; Pope and Mays, 2006; Houghton et al., 2013; Cleary et al., 2014).

My research methodology was further guided by Creswell (2009), who suggests that qualitative research seeks to establish the in-depth meaning of a phenomenon through the exploration of those who have personal knowledge of that experience within their natural setting. Furthermore, there is evidence which indicates that a specific strength of qualitative research is its ability to obtain complex textual descriptions of individual values, opinions and experiences of a particular population (Patton, 2002; Pope and Mays, 2006; Corbin and Strauss, 2008; Creswell, 2009; Yilmaz, 2013).

Qualitative methodology also provides the flexibility to explore participants' responses, particularly with the use of open-ended questions. This approach enables the participants to respond in their own words, rather than replying with a simple yes or no answer.

4.5 Qualitative approaches

When selecting the appropriate qualitative methodology to use within my research, I performed a critical review of the relevant literature to explore traditional methodologies while considering the overall aim and research questions of my study. Phenomenology and Grounded Theory (GT) are both traditionally used in nursing research as they are helpful when exploring the social setting and the experiences of those within that setting (Corbin and Strauss, 2008; Flick, 2009; Creswell, 2013). GT is particularly helpful when there is little known regarding the area of inquiry – any theoretical preconceptions should be avoided, and the theory developed is grounded within the data generated (Wuest, 2012; Creswell, 2013). However, despite aiming to explore the patients' experiences and perceptions within a real-life context of a group of lung cancer patients attending an outpatient SACT service and a new pre-assessment care pathway, in order to develop an in-depth understanding, I eliminated GT as a suitable methodology as I had already gained some theoretical insight by undertaking a scoping review of the literature of a pre-assessment care pathway within the surgical setting.

Phenomenology is a humanistic study of phenomena that aims to explore feelings, responses and the individually lived experiences of the study participants. The researcher, through immersion within the study data, then interprets this (Balls, 2009; Creswell, 2013; Munhall, 2012). I did not intend to study patients' experiences of lung cancer itself; rather, I aimed to explore lung cancer patients' experiences of an outpatient SACT service, and I therefore eliminated this as a suitable methodology.

Ethnography is the systematic collection of data that a researcher gathers in an attempt to tell the story of people's daily lives, whilst also describing the cultural setting in which they live (Creswell, 2013). Ethnographic research enables different cultures to be described and compared, with data collection often occurring over an extended time period in the field with the aim of adding to our understanding of the impact of culture on human behaviour and health (Wolf, 2012; Creswell, 2013). However, my study aimed to explore the experiences of

lung cancer patients and did not seek to understand their cultural setting or their held values and beliefs.

In relation to my own research, and having critiqued and explored the differing types of qualitative methodology, I recognised that each approach has its limitations. I therefore took a practical approach and chose one that would best answer my research questions, whilst allowing exploration in a natural real-life context from the perspective of those involved. The case study design offered a flexibility that was not readily available with the other potential qualitative approaches. I was able to define my case of inquiry as a group of lung cancer patients undergoing SACT around which there are defined boundaries. Defining the boundaries of my case is a fundamental step in case study design and would also enable a rich holistic description of the study participants' stories through describing their own views and experiences of their reality. This would allow new knowledge to develop that is reflective of their reality and render an evaluation of a relevant clinical intervention, such as introducing a new SACT pre-assessment care pathway (Stake, 2005; Merriam, 2009; Simons, 2009; Yin, 2014; Harrison et al., 2017).

4.6 A case study design

Case study design has grown in reputation and has established itself within health and social science research as a means with which to effectively investigate and understand complex issues within their natural settings (Stake, 2005; Brown, 2008; Anthony and Jack, 2009; Merriam, 2009; Crowe et al., 2011; Creswell, 2013; Yin, 2014). The term 'case study' is referred to as a methodology, a method, an approach, research design, research strategy, and a form of enquiry, and the varied use of terminology is often found to be confusing (Anthony and Jack, 2009; Merriam, 2009; Simons, 2009; Creswell, 2013; Cronin, 2014; Yin, 2014; Harrison et al., 2017). Mills (2014) helps to provide some clarity and distinguishes methods as the strategy and tools used within a study that gather data, whilst methodology does not provide a solution but instead provides the rationale for the research approach and outlines how the study has been undertaken. I found clarity in Mills' (2014) description of

case study research, which suggests that the method places a focus on specific situations that provide rich, vivid descriptions of single or multiple cases.

I made the decision to examine the work of three prominent researchers, namely, Stake (2005), Merriam (2009), and Yin (2014), who have contributed to the development of case study research design over the last decade. These researchers offer differing philosophical perspectives, which has resulted in the pragmatic and flexible research approach that has proven to be useful across various disciplines (Boblin et al., 2013; Yazan, 2015; Harrison et al., 2017). These differing philosophical perspectives often present a challenge to defining and understanding case study design. An exploration of these differing philosophical perspectives that helped informed my eventual decision will now be presented.

4.6.1 Philosophical Perspectives – Case Study Design

Yazan (2015) suggests that exploring the philosophical perspectives of different case study approaches is essential to building a basis for how to approach a research study. This process was helpful in allowing me to develop a better understanding of how to apply these principles in practice and to justify my initial decision to approach my research using a qualitative, single case study design.

Case study has been described as having a practical versatility with regard to the philosophical positioning of the various approaches to conducting research. Ontology refers to the study of being and of our understanding of what constitutes reality (Creswell, 2013). At the extreme thresholds of how we understand reality, there are two ontological positions to consider: first, a realist positioning assumes that reality exists independently of our perception, irrespective of our beliefs, and that that reality can be apprehended objectively to build knowledge based on facts or laws. Conversely, a relativist ontology denies the possibility of the existence of one objective scientific truth, and assumes that realities are multiple and socially constructed, and that knowledge-building is holistic in nature, as viewed, for example, from the perspectives of the participants involved in a research study, searching for an

understanding of the whole over time (Creswell, 2013; Yilmaz, 2013). One's own ontological positioning may be situated at any point between these two extremes, and, ultimately, will influence one's choice of research methodology.

Epistemology is the study of the nature of knowledge – its origin, the conditions in which it manifests, and its justification – and, as such, one's epistemological positioning will also guide the choice of research methodology (Crotty, 2003; Yilmaz, 2013). A wide variety of different epistemologies have emerged, however, here I shall discuss those that are most relevant to the work of three prominent researchers who inform case study research design, namely Stake (2005), Merriam (2009), and Yin (2014). Objectivism is the view that knowledge, understandings, and values are objectified in the people being studied and that there exists an objective truth 'out there' waiting to be discovered (Crotty, 2003). In contrast, within a constructivist epistemology, it is assumed that knowledge is co-created in the subjective constructions of understanding rather than being 'discovered'. The construction of meanings and understandings are therefore dependent on individuals' interactions with the world (Pring, 2004). Finally, within the epistemology of subjectivism, the researcher assumes that knowledge is something that is interpreted by individuals. Knowledge is not generated from the interaction between individuals, but is instead imposed on the object by the subject. Subjects do construct meaning, however, not from the object, but from their unconsciousness, feelings, and beliefs (Crotty, 2003).

Table 6 illustrates the philosophical perspectives that were most relevant in guiding my study. Yin's (2014) positioning leans towards positivism, embracing the ideals of objectivity and the generalisability of results, while Stake (2005) maintains a constructivist/interpretivist approach, promoting learning through experience and reflection. Merriam's (2009) positioning leans towards a constructivist inquiry, offering a pragmatic approach that is informed by the rigour of Yin (2014) and enriched by the creative interpretation of Stake (2005). Brown (2008) places these influential researchers along a quantitative — qualitative continuum, where Yin (2014) is placed at one end, and Stake (2005) is situated on the other. Merriam (2009), as a pragmatic constructivist, draws on elements of both and rests somewhere between the two, near the centre.

Table 6. Philosophical perspectives – Case study design

YIN (2014)	←→	MERRIAM (2009)	←→	STAKE (2005)
<p>REALIST</p> <p>POSITIVIST</p> <p>OBJECTIVITY: minimises interaction with research subjects</p>		<p>PRAGMATIC</p> <p>CONSTRUCTIVIST: reality constructed from lived experience, meanings and understandings are developed through interactions with those around us</p> <p>As a researcher, share their reality with research participants to co- construct an understanding of their world/their reality.</p>		<p>RELATIVIST: views reality as multiple.</p> <p>CONSTRUCTIVIST/ INTERPRETIVIST</p> <p>SUBJECTIVITY: partners with research subjects: experiencing the activity of the case as it occurs in its context.</p>
<p>CONTINUUM</p> <p>QUANTITATIVE ←→ QUALITATIVE</p> <p>(Brown, 2008)</p>				

Considering my own ontological and epistemological positioning in relation to my study, I was not aligned with either Yin’s (2014) positivist perspective or Stake’s (2005) constructivist and interpretivist orientation. I took care to determine which research paradigm would address my research aim and answer the research questions. I identified that using Merriam’s (2009) pragmatic constructivist approach to case study design would be more appropriate for allowing the exploration of the participants’ experiences and perceptions whilst attending an outpatient SACT service and a new pre-assessment care pathway and facilitate an in-depth enquiry. As a researcher, I

situated my study within a constructivist paradigm, as I adopt the understanding that each participant constructs their own reality, and, in engaging in the research process, we are able to co-construct their reality to enable a better understanding of their world and to generate new knowledge.

4.6.2 Merriam's (2009) – Pragmatic constructivist – Case study design

Merriam (2009) suggests that the most defining characteristic of case study research is to establish the case or unit within which there are boundaries. The single case of inquiry in my research is a group of lung cancer patients undergoing SACT and attending a new SACT pre-assessment care pathway. I aimed to explore and explain their real-life setting, enabling a rich description and account of their experiences. I also considered its inductive, flexible, step-by-step approach, accompanied by clear informative guidance, to be a valuable way in which to enable a dependable and appropriate research design (Table 7).

Table 7. Operationalisation of Merriam's (2009) case study design

Case – a person, a program, a group – around which there are defined boundaries
Defining characteristics – yields rich, thick description of the phenomenon under study
Steps of research design – conduct literature review, construct theoretical framework, identify research problem, mould research questions, and select purposeful sample
Research skills – flexible and effective interview skills
Data analysis – recognises processes such as descriptive, thematic analysis – contributes to the quality of a study by promoting a descriptive organised detailed chain of evidence.

Source: Yazan (2015)

In keeping with Merriam's (2009) approach to case study, a theoretical framework was constructed from the literature to support an enquiry of lung cancer patients' experiences and perceptions of an out-patient SACT service, including introducing a new pre-assessment care pathway. This process involved examining the literature of an established pre-assessment care pathway within the surgical setting, enabling the construction of a conceptual framework (Otte, 1996; Clinch, 1997; Lucas, 1998; Malkin, 2000; Gilmartin and Wright, 2007; Fraczyk and Godfrey, 2010; Heaney and Hahessy, 2011). This was followed by examining the literature and reporting the patient experience of a lung cancer diagnosis and undergoing SACT to guide the inquiry and help refine my research aim and questions (Akin et al., 2010; Buchanan et al., 2010; Dale and Johnston, 2011; Maguire et al., 2013) and determine how using the patient experience might help to inform service delivery, given the introduction of a new pre-assessment care pathway into an outpatient SACT service (McCarthy and Dowling, 2009; Robert and Cornwell, 2011; Lavela and Gallan, 2014; Ryan et al., 2014; Mooney et al., 2017).

Considering the quality of my study, Merriam (2009) indicates the importance of careful planning and the maintenance of a rigorous chain of evidence. This frames the research process to demonstrate that the approach taken is credible and transparent. It is further suggested within the framework that the researcher requires basic skills to help create trustworthiness in the data. These skills include asking the right questions, interpreting the answers, practising good listening skills, and the ability to be adaptive and flexible and remain unbiased by preconceived ideas from the literature (Merriam, 2009).

I acknowledged and appreciated Merriam's (2009) perspective that the interaction between study participants and the researcher is seen as being essential in order to generate the rich, in-depth data required to gain an understanding of the participants' experiences. I was confident that this case study design would enable this connection between the researcher and the study participants (Stake, 2005; Merriam, 2009; Creswell, 2013; Yazan, 2015).

Multiple sources and methods of data collection and analysis can be used within a case study design (Stake, 2005; Brown, 2008; Anthony and Jack, 2009; Merriam, 2009; Creswell, 2013). However, I considered a number of factors and made the decision to collect my data using semi-structured interviews. This method of data collection is interactive and would enable two-way communication, providing the opportunity to explore or clarify answers. Further factors included an awareness of the time required to conduct a multi-method case study and the time required to analyse the volume of data that might be generated. I also considered the possible implications on the case of inquiry for my research study and how this might impact on the participants, given their diagnosis of lung cancer, some of whom might be affected by comorbid medical conditions and be at risk of treatment-related toxicity (Langer et al., 2021). As a novice researcher, I was reassured by my choice, as Harrison et al. (2017) indicate that novice researchers should utilise a simple design when conducting case study research for the first time. They further suggest that using this case study design would also provide the pragmatic, flexible framework to carry out the in-depth analysis of the data. This enables an understanding of the study findings to be presented from the perspective of the participants.

Having discussed the rationale for selecting a qualitative methodology and exploring the key principles of a case study design, the application of this methodology and design is the focus of the discussion presented in Chapter 5.

Chapter 5: Research Design and Method

5.1 Introduction

This chapter discusses patient, public and peer review of the research project; the ethical approval process; sampling; and the process of recruiting participants to the study. In keeping with a defining feature of case study design, the data collection method, gathered through semi-structured interviews, is described, and, finally, the process for completing the analysis of the data gathered is then presented.

5.2 Patient and public review

Stewart et al. (2011) suggest that patients have a unique and subjective viewpoint, based on their first-hand experience regarding where quality of care could and should be improved. Indeed, partnership with patients and the public in service development is considered to be person-centred and enhances any proposed change to service delivery (NHS Education for Scotland (NES), 2011). Patient and public involvement (PPI) improves the relevance and quality of research (Scottish Government, 2014). Research carried out with patients rather than about them allows patients to actively contribute to the research design and its relevance and acceptability. This encourages patients to participate, thus improving the quality of the research (Hoddinott et al., 2018).

My research focussed on introducing a person-centred care intervention for a group of lung cancer patients undergoing systemic anti-cancer therapy (SACT), and it was therefore appropriate and relevant to seek patient involvement. My research project was initially shared and discussed with a patient advisor who I had known for some time through my own clinical practice. She had attended the SACT day unit for a number of years whilst receiving treatment for breast cancer. She had a long background within healthcare and pharmaceutical research and had shown an interest in my idea and the project as it evolved. She was aware that the research project would only be offered to patients with a diagnosis of lung cancer and therefore would not benefit her. However, she was keen to use her own experience and took an active role in reviewing and

constructively criticising the relevant study documents, including the Patient Information Sheet (PIS) and the consent form. I found this involvement particularly helpful, as this process helped to ensure consistency and clarity of the information given to potential participants.

5.3 Peer review

My research idea was initially presented to the Lung Cancer Team in the regional centre. The team includes medical consultants, a specialist registrar and nurse specialists. This took the form of presenting my research ideas in an informal open discussion with the aim of developing a research proposal. As a result, the profile of my research idea was raised and, following my presentation to the Quality Improvement Team (QIT), the introduction of a SACT pre-assessment care pathway was accelerated and given priority (Appendix 2). It was agreed that I would take forward my proposed research project and develop a proposal to explore patients' experiences and perceptions of attending an outpatient SACT service with the implementation of a pre-assessment care pathway for a group of lung cancer patients. To distinguish the difference between service/practice improvement and my proposed research project, I examined the relevant literature to help provide guidance and clarity that differentiated between research and other data collection activities (Brain et al., 2011; National Research Ethics Service, 2013; Tywcross and Shorten, 2014). Table 8 illustrates a series of questions I took time to work through.

Table 8. Questions that distinguished my research project from service improvement

Question	Yes	No
1. Do I want to explore the effect of a new treatment or technique on patients/carers? Do I want to test a hypothesis? Do I want to introduce and evaluate a new practice with limited evidence that has completed assessment of risks and benefits?		No
2. Do I want to conduct this project to generate new knowledge and extend the body of knowledge by means of a systemically defensible process of enquiry?	Yes - I have conducted a comprehensive scoping review of the literature and found a lack of research evidence regarding the patient experience of SACT delivery in the outpatient setting.	
3. Do I want to introduce/implement new practice based on evidence of implementation and evaluation in other NHS settings?	Yes - I have introduced a new SACT pre-assessment care pathway for patients with lung cancer, this new practice is based on the evidence gathered exploring the patient experience.	
4. Do I want to investigate/explore the experiences, perceptions (physical/functional, psychological or social), of staff, patients or carers where current evidence or knowledge is lacking?	Yes - I have applied case study methodology to my research project to generate an original contribution of new knowledge about a new SACT pre assessment care pathway.	
5. Do I want to follow a systematic approach and gain approval through NHS research and development/committee and comply with research governance requirements?	Yes - I followed a systematic approach about my area of inquiry to gain approval through NHS research and development to comply with research governance.	
6. Do I want the new knowledge generated to have the potential to be generalisable or transferable?	Yes – I have generated new knowledge and this new knowledge is transferable to other relevant clinical day care services.	

(Brain et al., 2011; Tywcross and Shorten, 2014)

Furthermore, the QIT had previously explored the potential health outcomes and efficiency of an outpatient SACT service. This was done by gathering quantitative data following the implementation of the pre-assessment care pathway, including patients' chair time (treatment time), saved treatment slots, patients' admission rate, saved pharmacy time and any reduced drug wastage (these data remain unavailable on enquiry; however, they were reported internally at Health Board level).

5.4 Ethics approval

In February 2016, I was therefore invited to prepare a revised draft IRAS application to reflect my qualitative study. This aimed to explore lung cancer patients' experiences and perceptions of an outpatient SACT day-care service and determine whether a pre-assessment care pathway enables a person-centred care approach.

The Ethics Committee at the University of Stirling provisionally approved the study proposal, conditional on changes to the IRAS application and the Patient Information Sheet (Appendix 3). Following submission of these changes, the Ethics Committee subsequently granted approval of the research study, and sponsorship was formally approved with the University of Stirling on 5th April, 2016 (Appendix 4).

Following approval by the Faculty of Health Studies and Sport Studies Research Ethics Committee, I had a short timescale to commence phase one of the SACT pre-assessment care pathway. The IRAS application and supporting documents were submitted initially for a proportionate review through the Central Booking Office (CBO), and I found the submission process unclear and complicated. On reflection, the frustration felt in obtaining all the authorised signatures that were necessary to submit the application was stressful.

Through discussion with key individuals, it was agreed by the scientific officer that the research study would not require NHS ethics review under the terms of the governance arrangements for Research Ethics Committee. This was based on the view that the research study was part of service development and quality improvement (Appendix 5). In order to recruit potential participants into the research study, the final hurdle to register the research study locally with NHS Clinical Governance was completed on 13th April, 2016.

5.5 Case study: sampling process

The study population comprised individuals with a diagnosis of lung cancer, currently receiving SACT in a regional outpatient SACT service which covers a population of 1.4 million over four NHS health boards. Sampling strategies

commonly associated with qualitative research included convenience, purposeful, and theoretical sampling (Pope and Mays, 2006; Ritchie et al., 2013; Yin, 2014). In keeping with a case study design, Merriam (2009) highlights that a purposeful sample should be selected based on the research aim and questions, as this is most useful for capturing rich data, enabling an understanding of an organisation’s activity or the phenomenon of interest. Although there was a convenient nature to my sampling strategy, in that I took the sample from a population that was available, a purposeful sample was deemed to be the most appropriate for this study. The focus of my study was an in-depth exploration of real-life events for patients with lung cancer and therefore only the subjects eligible were selected. Guest et al. (2006) suggest that a purposeful sample may consist of different varieties, but is selected according to a pre-determined criterion, relevant to the research subject. The eligibility criteria for this study were a group of individuals diagnosed with lung cancer and referred to receive SACT within outpatient services, as illustrated in Table 9.

Table 9. Eligibility criteria for study

Inclusion criteria	Exclusion criteria
Patients aged 18 years and over	Patients aged under 18 years
Patients with the mental capacity to provide informed consent	Patients with mental incapacity and unable to provide informed consent Patients with neurological impairment
Fluency in the English language	Patients unable to speak English
Patients diagnosed with a lung cancer and receiving SACT within the SACT day unit (Second phase – patients local to the regional cancer centre with new diagnosis of lung cancer and referred for SACT)	Patients diagnosed with a mental illness, for example, bipolar disorder, schizophrenia, and Alzheimer’s disease

Patients scheduled to start SACT in the day-care unit	Patients who require to be clinically reviewed by the chief investigator's caseload and sphere of responsibility
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Qualitative studies from the literature review that explored patients' experiences within the surgical pre-assessment setting used purposeful sample sizes ranging from twelve to thirty participants. These studies focussed on identifying themes and coherent patterns until data saturation was reached (Malkin, 2000; Gilmartin, 2004; Gilmartin and Wright, 2008). Following discussion with both academic supervisors, and considering the literature reviewed, the sample size aimed for was identified as being between thirty to forty interviews in an attempt to achieve data saturation.

Data saturation is key to good qualitative research, yet Fusch and Ness (2015) suggest that there is little guidance provided in the literature regarding what sample size might reach data saturation. Creswell (2013) suggests anything between five to twenty-five interviews might be sufficient, whilst Morse (2000) indicates that up to six interviews may be enough. Data saturation is determined when there is no new information collated, therefore no new themes and new codes are generated (Fusch and Ness, 2015).

5.6 Recruitment process

The single case of inquiry was a group of lung cancer patients undergoing SACT, and thirty-two participants were recruited and divided into three groups. The three groups were formed to identify: those participants who had attended phase one or phase two of the new pre-assessment care pathway; those who received their SACT with the current assessment care pathway; and those who had declined to attend the new pre-assessment care pathway. The first phase of the SACT pre-assessment care pathway ran from April to May 2016 and had to be interrupted after four weeks due to an unexpected limitation in the available staff resources.

In order maintain full engagement with the Lung Cancer Team (LCT) and gather support to continue the SACT pre-assessment care pathway, I prepared and presented a brief summary of the preliminary findings from the first phase of the

SACT pre-assessment care pathway to the LCT. This summary included feedback from participants' semi-structured interviews, which indicated that the pre-assessment care pathway was perceived as a positive experience (Appendix 6). In November 2016, it was agreed, in collaboration with the LCT, to run a second phase of the SACT pre-assessment care pathway until I was able to achieve data saturation.

As a health board employee, I have access to 'TrakCare', which is the local secure healthcare information system for detailed patient-held medical records. From this system I identified potential participants who met the sample criteria through their Community Health Index (CHI) numbers. This was displayed on the SACT outpatient clinic list, which is held on the TrakCare information system. Whilst attending for their first cycle of SACT, I approached those potential participants and provided verbal information about my research. Those who agreed to consider participating and attend a SACT pre-assessment care pathway were provided with a Participant Information Sheet (PIS) (Appendix 7).

The PIS was developed using guidance from the Health Research Authority (HRA) on-line resource, as previously discussed (Section 5.2), and reviewed by a patient advisor. Whilst attending for their second cycle of SACT, I arranged to meet with each potential participant, as the time period between cycles (3–4 weeks) allowed the opportunity for them to study the information provided and consider any questions regarding my research. The interview was planned around cycle 3 or 4 of the SACT within the treatment area, or at a preferred location chosen by each participant. This time-point in the course of each participant's SACT was selected, as the symptoms of lung cancer, such as fatigue, pain and breathlessness, may have been eased by the treatment and thus enable them to participate (Aumann et al., 2015; Leduc et al., 2017). Participants were reassured at each meeting that they could withdraw from the study at any time, and that this would not affect their care in any way. I offered my contact details by phone or email to answer any further questions and planned to take informed consent on the day of each interview.

5.6.1 Participants in group one

The first phase formed group one, with seventeen participants who attended the SACT pre-assessment care pathway. In order to gather the data that would best answer my research questions, I approached seventeen potential participants with a PIS, but I was only able to complete nine interviews. Details of the participants who attended the first phase of this care pathway over the four-week period are illustrated in Table 10. One participant was considered to be unsuitable due to their deteriorating health, and nine interviews were completed (Appendix 9).

Table 10. Recruitment for phase one: SACT pre-assessment care pathway (PAC)

Week 1	11 patients were invited to attend the SACT PAC by the LCT	5 patients declined the PAC	6 patients agreed to participate and attend the PAC
Week 2	14 patients were invited to attend the SACT PAC by the LCT	8 patients declined the PAC	6 patients agreed to participate and attend the PAC
Week 3	10 patients were invited to attend the SACT PAC by the LCT	7 patients declined the PAC	3 patients agreed to participate and attend the PAC
Week 4	6 patients were invited to attend the SACT PAC by the LCT	4 patients declined the PAC	2 patients agreed to participate and attend the PAC
Total	17 patients participated and attended the first pilot of the SACT PAC		

5.6.2 Participants in group two

Group two participants had received SACT with the current assessment care pathway and/or declined the SACT pre-assessment care pathway. The current assessment care pathway involves blood sampling of patients at their General Practitioner (GP) followed by a telephone assessment the day before SACT by a specialist nurse. The bloods are reviewed and SACT is prescribed by a non-medical prescriber or medical prescriber, who may not have assessed and/or met the patient. During the first phase, forty-one patients were invited to a voluntary SACT pre-assessment care pathway, with only seventeen patients agreeing to attend. The reasons that participants declined the pre-assessment care pathway are illustrated in Table 11.

Table 11. Reasons for refusal of SACT pre-assessment care pathway (phase one)

Travelling distance	7
Extra visits required to the hospital	3
Too unwell	3
GP was nearby/more convenient	2
Not known	2

(D McGowan, 2016 and Acknowledgement Dr M Sakala, Associate specialist in Oncology).

I identified twenty-two patients through their CHI numbers, taken from the SACT outpatient clinic list, and seventeen potential participants were given a PIS. Of those seventeen, five participants were unable to proceed with the planned interview due to their deteriorating health. I completed twelve interviews (Appendix 9).

5.6.3 Participants in group three

The first phase of the SACT pre-assessment care pathway had been unexpectedly interrupted after four weeks due to limited staff resources. Reviewing the data and the emerging themes from the interviews carried out during the first phase provided sufficient evidence to support a second phase of the SACT pre-assessment care pathway. When planning the second phase of the SACT pre-assessment care pathway, the patient refusal rate from phase one was considered and a further inclusion criterion was added to address the travelling distance and enable the pre-assessment to be incorporated into routine clinical practice for the lung cancer patient group. The inclusion criteria comprised patients local to the regional SACT day-care unit who had received a new diagnosis of lung cancer and been referred to receive SACT. Participants were asked to attend the SACT pre-assessment care pathway prior to cycle one and cycle two of their SACT.

The second phase formed group three, and twenty-two potential participants were approached and provided with a PIS, but eleven were unable to proceed due to health reasons or declined to participate in the study. I completed a further eleven semi-structured interviews with those who attended the SACT pre-assessment care pathway over a four-month period (Appendix 10). Enabling the second phase was felt to be essential in order to achieve the sample size identified in the IRAS application and to reach data saturation.

5.7 Data collection

As previously discussed (Section 5.6), each interview was planned at the participant's convenience whilst attending and receiving their SACT. Informed consent was obtained on the day of each interview, to ensure that the participants, who had been given both verbal and written information beforehand, were given the opportunity to review this and ask any questions (Appendix 11).

Semi-structured interviews are the most common of all qualitative research methods as they provide an effective and flexible opportunity to explore the meaning of complex social or organisational phenomena (Qu and Dumay,

2011). In within-case study design, Harrison et al. (2017) suggest that interviews are a useful form of qualitative data collection. Kvale and Brinkman (2009) describe a semi-structured interview as an interview with prepared questions guided by identified broad themes. These questions are delivered in a consistent and systematic manner to help direct the conversation towards topics and issues of interest. Probes are introduced which encourage more detailed responses from those being interviewed. Merriam (2009) offers useful techniques for the novice researcher attempting to conduct an effective interview. These include asking succinct questions, probing skills, questions to avoid, and an appropriate way to open and close the interview.

As a novice researcher, and having had no prior experience of interviewing participants within a research setting, I was conscious that careful planning and thought were necessary to undertake these interviews effectively and gather the data that I required. Indeed, Merriam (2009) advocates that careful planning and preparation of good interview techniques can help to provide the rich data that is required. I was also confident that my years of experience within oncology nursing and existing good communication skills would prove to be of value as transferable skills. Fusch and Ness (2015) discuss the concept of a personal lens through which the research data are collated and then analysed; my personal lens was that of an experienced oncology nurse. I prepared an interview guide for the participants, and an academic supervisor and senior nursing colleagues who had previous experience of conducting research reviewed this. Some minor changes to the wording of the questions were required to the interview guide for groups two and three in order to ensure that I was able to gather the data I required (Appendix 12). I also studied my interview techniques and reflected on the experience of conducting my first interview in order to identify any areas of strength and weakness (Appendix 13).

Polit and Beck (2011) indicate that rapport can be established through transparency and honesty during the research process and that good rapport can be key to achieving meaningful data. Applying Merriam's (2009) interview techniques, I attempted to establish a rapport with each participant through each meeting whilst introducing and discussing the research study. Therefore,

at the start of conducting the interview, each participant recognised what my role as a researcher was. In my role as chief investigator for the research study I was not involved in the delivery of care to the participants. I was conscious that the participants had confidence in me, as they were aware of my clinical background and my current role as a doctoral research student. I was also aware that the clothing a healthcare researcher might wear during an interview might create a power imbalance between the researcher and participant (Parahoo, 2006). I took the decision to wear smart/casual clothes and removed my NHS name badge in order to distinguish my role as a research student and maximise participant comfort during interviews.

As I was seeking information on aspects of care participants received and their opinions on service delivery, it was essential to adopt a non-biased and non-judgmental approach. Adams (2010) suggests that listening skills and attempting to explore participants' feelings rather than challenge their response can help to enable such an approach. Furthermore, careful planning and preparation of the interview topic guide was required in order to avoid any blurring of roles during the interview. When planning the interview guide, I was also aware of the importance of asking pertinent questions to maintain the flow of conversation and to allow each participant the time to digest the questions and relate their opinions and experiences. This included the effective use of introductory questions to focus the interview quickly:

'Tell me about your recent visit to the SACT pre-assessment care pathway.'

'What are your thoughts about the SACT day unit and the care you have had?'

I found this approach to be effective, with each interviewee fully focussed on the subject of interest. A primary technique used in semi-structured interviews is the effective use of probing questions to help develop the conversation:

'Tell me a little bit more about how ... was able to reassure you.'

Reflecting on my first interview I felt my probing skills were in need of more practice, in terms of being able to pick up on verbal cues and having the confidence to probe further to expand answers. I found this particularly difficult with male participants, as I became aware of their direct response to my open questions and, initially, I found it difficult to probe these responses and encourage the participant to expand on their response. Affleck et al. (2012) indicate that the male research participant often has difficulty with emotional expression, especially when emotions relate to illness, as these may evoke feelings of fear, sadness, guilt and loneliness.

As my interview technique developed, I became more confident in probing participants' initial responses to ask why and how. I found this effective in encouraging participants to respond and express as many of their own views and opinions as possible. Adams (2010) indicates the benefits of placing an emphasis on active listening rather than on the traditional two-way communication method. I was aware as a researcher to remain focussed on my questions and then listen, allowing the participant to talk and share their experiences. Acknowledging the effective use of active listening and learning to know when and how to explore a point further and pick up on participants' non-verbal cues, I also incorporated other interview techniques, such as asking follow-up questions. This encouraged the participants to expand on their responses by using semi-verbal sounds such as 'aha' and 'mm'. With practice, I became more confident in probing and was able to elicit more meaningful responses. I made efforts to rephrase statements to clarify responses and structured the questions to help focus the interview, moving it from one subject to the next. I also became more aware of the importance of allowing silent pauses and became more comfortable in allowing these to happen. I became aware that a silent pause might help participants reflect on their response and encourage a meaningful answer to the question. Adams (2010) highlights that a silent pause enables participants to take time to consider their response, especially if the question is personal or probing.

5.8 Researcher–participant considerations

Given that this patient group have a life-limiting condition, are possibly in an advanced stage of their illness, and are experiencing physical symptoms from the disease, it was acknowledged that participation in the interview may be tiring and could exacerbate their existing physical symptoms. Each interview was therefore planned to take place after delivery of cycle 3 of SACT. This time-point in the course of each participant's SACT was selected as the presenting symptoms of lung cancer, such as fatigue, pain and breathlessness, may have been eased by the treatment (Aumann et al., 2015; Leduc et al., 2017).

All the interviews took place within the SACT day-care unit, which was the most convenient for each participant as the interviews were arranged around their existing hospital visits. The interviews were carried out in a side room, allocated to ensure sufficient privacy and a quiet environment. Participants were assured of confidentiality and anonymity concerning the information provided during the interview. They were reassured that the interview would be interrupted to allow for necessary pauses or comfort breaks, and would be stopped should they so wish.

It was also acknowledged that the interview could cause some emotional upset or embarrassment through discussing difficult issues relating to their cancer diagnosis, SACT treatment and the quality of care/service delivery. The participants were reassured that, if there was any emotional distress caused by the interview process, the interview would be stopped and rescheduled, or they could withdraw from the study with no reflection on their care. Contact would also be made with the relevant clinical nurse specialist (CNS) for ongoing support.

The interview time estimated within the IRAS application was originally 60–90 minutes. However, it became apparent whilst undertaking the interviews during the first phase that longer than 60 minutes proved to be too tiring for some participants, as it was difficult for them to maintain their concentration. On this basis, the interview time for the following group of participants (group two) was shortened to between 45–60 minutes. This was felt to be a more acceptable

time for the participants to undertake each interview and, as I had developed confidence with my interviewing skills, I was able to gather the necessary data within this allocated time. The interview times for participants within group three were further adjusted as I became more comfortable with my interview technique and ability to focus on the subject matter, and the length of these interviews lasted between 24 and 47 minutes. In my role as a nurse researcher I was also aware of my duty of care and responsibility regarding confidentiality concerning the participants' health information and that I would be required by the *The Code: Professional standards of practice and behaviour for nurses, midwives and nursing associates* (Nursing and Midwifery Council (NMC), 2015) to act upon this.

5.9 Data storage and security

All personal data in the form of demographic details, digital recordings and research-related materials, including hard copies of non-identifiable data, were kept in a locked drawer within a filing cabinet in NHS premises. This is in accordance with the NHS Code of Confidentiality (Department of Health, 2003) and General Data Protection Regulations (Department for Digital, Culture, Media & Sport, 2018). All study participants were anonymised and allocated a code at the start of the study. Interview transcripts were also anonymised, and hand-written notes and data analysis were digitalised and kept on an NHS computer on a password-protected user account, with pre-existing security checks, for the duration of the study. Following completion of the study, the University of Stirling will securely store all data relating to the study for a period of 10 years.

5.10 Data analysis

The decision to conclude the interviews was determined on the basis that the new data being gathered no longer provided additional insight into the research questions. Participant interviews were carried out from April 2016 to May 2017. In keeping with the case study design, the method of analysis selected for my study was the flexible and pragmatic approach of thematic analysis (Merriam, 2009; Harrison et al., 2017). As a novice researcher, I found this method simple

to use, following an adapted version of the six-step framework suggested by Braun and Clarke (2006) (Table 12). Merriam (2009) suggests that thematic analysis can contribute to the quality of a study by promoting a descriptive, organised detailed chain of evidence. I briefly examined Framework Analysis (Srivastava and Thomson, 2009) as a possible alternative approach to analysing the data. However, upon reviewing the technical terms used in the Framework Method, I found that this did not fit with the practical, pragmatic approach that Merriam (2009) discussed, as the terms were complex and more difficult to understand. Indeed, Gale et al. (2013) highlight that this method often requires an element of training to use effectively and is therefore often favoured by more experienced qualitative researchers.

Table 12. Braun and Clarke’s six-step framework for conducting thematic analysis

Step	Description of the process
1. Become familiar with the data:	Actively engage with the data by transcribing the data, reading and re-reading the data – immersed in the data, writing down any initial ideas.
2. Generate initial codes:	Code interesting features of the data systematically, collating data relevant to each code to create initial themes.
3. Search for themes:	Collate the codes and potential initial themes, looking for relationship between these. Organise into overarching theme relevant or meaningful to the research question.
4. Review themes:	Review, modify and develop preliminary themes identified in step 3 (phase 1). Generate a thematic ‘map’ of the analysis (phase 2).
5. Define themes:	Ongoing analysis to identify the essence of what each theme is about. Generating clear definitions and names for each theme.

6. Write up:

End point of research is some kind of report, journal article or dissertation.

Source: Braun and Clarke, 2006

Applying Braun and Clark's (2006) six-step framework of thematic analysis provided the clarity and rigour that Nowell et al. (2017) suggest is important. This provides transparency of the process in order to increase the strength of the findings and ensures that the readers are able to understand how conclusions are reached.

Step one – Become familiar with the data: Each interview was digitally recorded and I transcribed each verbatim, excluding any confidential information. Braun and Clarke (2006) indicate that the participants' voices should be heard by using 'vivid' extract examples from the interviews that relate directly to the themes identified and address the research questions. This supported my use of verbatim quotations, which gave participants their voice within the findings. Using these also contributed to the credibility and transparency of the analysis process, through showing my thought process when coding the data and how these were associated with a particular theme. In addition, some hand-written notes were taken during each interview to complement the recordings (Appendix 14). Each transcript was then reviewed and re-reviewed for accuracy and transcribing. Reviewing each interview proved to be time-consuming, taking approximately 10 hours. In order to validate the transcripts for quality and trustworthiness, five participants were approached and two agreed to review their own transcripts for accuracy and consistency (Mero-Jaffe, 2011).

The decision to transcribe each recording independently was considered important in order to familiarise myself with the data, increase my theoretical sensitivity of the data, gain an in-depth understanding of participants' experiences, and initiate the analysis process. An example of this process is provided as an appendix (Appendix 15). Ritchie et al. (2013) suggest that theoretical sensitivity is concerned with helping the researcher to achieve a certain depth of understanding by means of interacting with the data. 'Immersion in the data' is often described as being fundamental in order to

achieve theoretical sensitivity (Ritchie et al., 2013). As a novice researcher, one of the most challenging aspects I have found in the research process is having the confidence to make decisions regarding ideas which emerge from the data, and to determine what was of more or less importance. However, I developed theoretical sensitivity in the data as the analysis process progressed and my familiarity with the data deepened. My personal lens, with a professional clinical background as an oncology nurse, was again a great assistance in my decision-making.

Continuing with Braun and Clarke's (2006) six-step approach, I chose a combination of a software package and a manual method to facilitate analysis of the data gathered from participants' interviews. A qualitative data analysis computer program, NVivo 11 (QSR International Pty Ltd., 2017), designed to facilitate organisation and analysis of the transcribed interviews was used initially. NVivo 11 offers the benefit of increased transparency and enables the exploration and examination of recurring words and themes (Bazeley and Jackson, 2013; QSR International Pty Ltd., 2017). As I had no prior experience of using this software package, I undertook an on-line self-learning programme to become familiar with the basics. I found the software package to be time-consuming and difficult to use, and felt that I was spending valuable time learning to use the package rather than continuing with the analysing process. I also became aware that the software would only do what I was able to ask it to do, and therefore decided to include a manual approach of analysing the data.

Step two – Generate initial codes: This step involved importing the source material and storing participants' transcripts in order to explore any patterns and look for emerging themes and words that might enable a greater understanding of their context. The transcripts from the three groups were initially examined using word frequency queries and text searches to explore the frequently occurring words within the data. Visualisation of these findings was created by generating 'word clouds' and a 'text search tree', which I found helpful when looking for recurring themes (QSR International Pty Ltd., 2017). Figure 9 demonstrates a 'word cloud' created from the transcripts from participants in

group 1. Figure 10 demonstrates a 'text search tree' from recurring words within the 'word cloud', which illuminates the richness of the data.

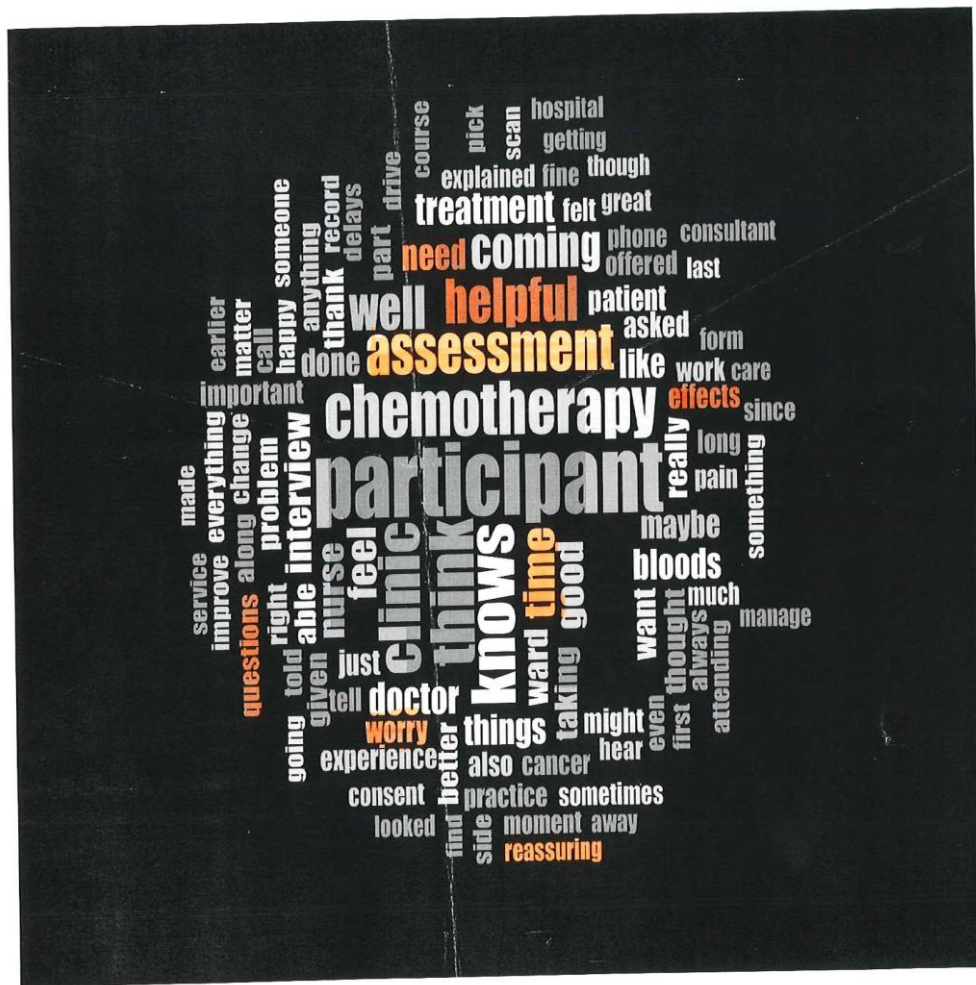


Figure 9. Word cloud – word frequency

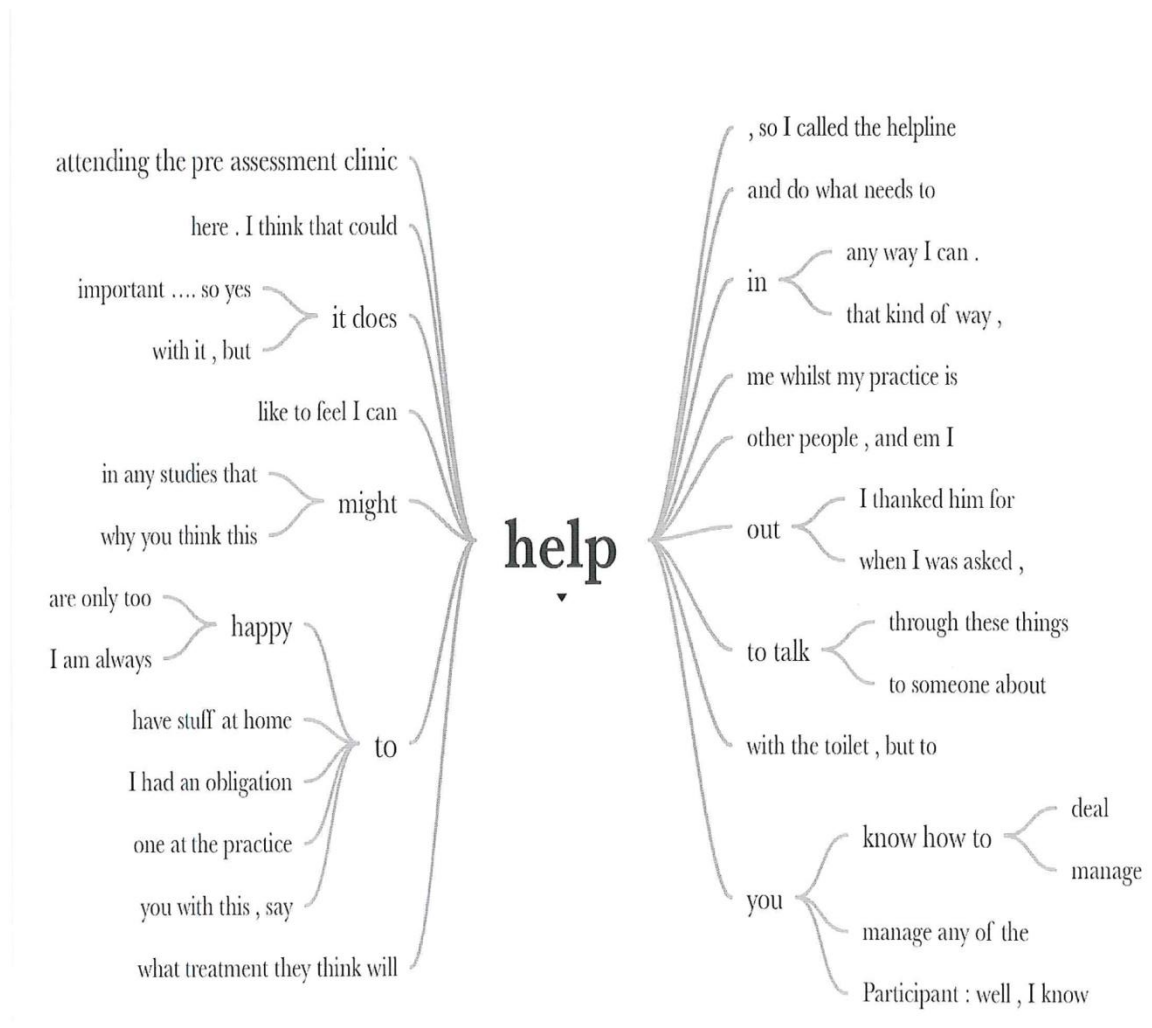


Figure 10. Text search tree

5.10.1 Manual method of data analysis

I used the NVivo 11 software package with good effect by importing, sorting and organising the data within-case analysis. I had reached a useful starting point for moving onto a manual method of analysing the data. Applying Braun and Clarke's (2006) six-step analytic process, I began this process, repeating step one by re-reading and examining the transcript of each interview in order to re-familiarise myself with the data, whilst also noting themes of interest. In step two of the process, I considered the 'word clouds' and 'text search trees' obtained from the participant interview data and that were developed using the NVivo 11 package. I found using different coloured pens and coloured post-it notes to highlight any initial codes of interest. Repeating these two steps of the analysis process allowed the data to be sub-divided as I manually cut and pasted the

initial codes identified and, through categorising and interpretation, refined these codes into initial themes.

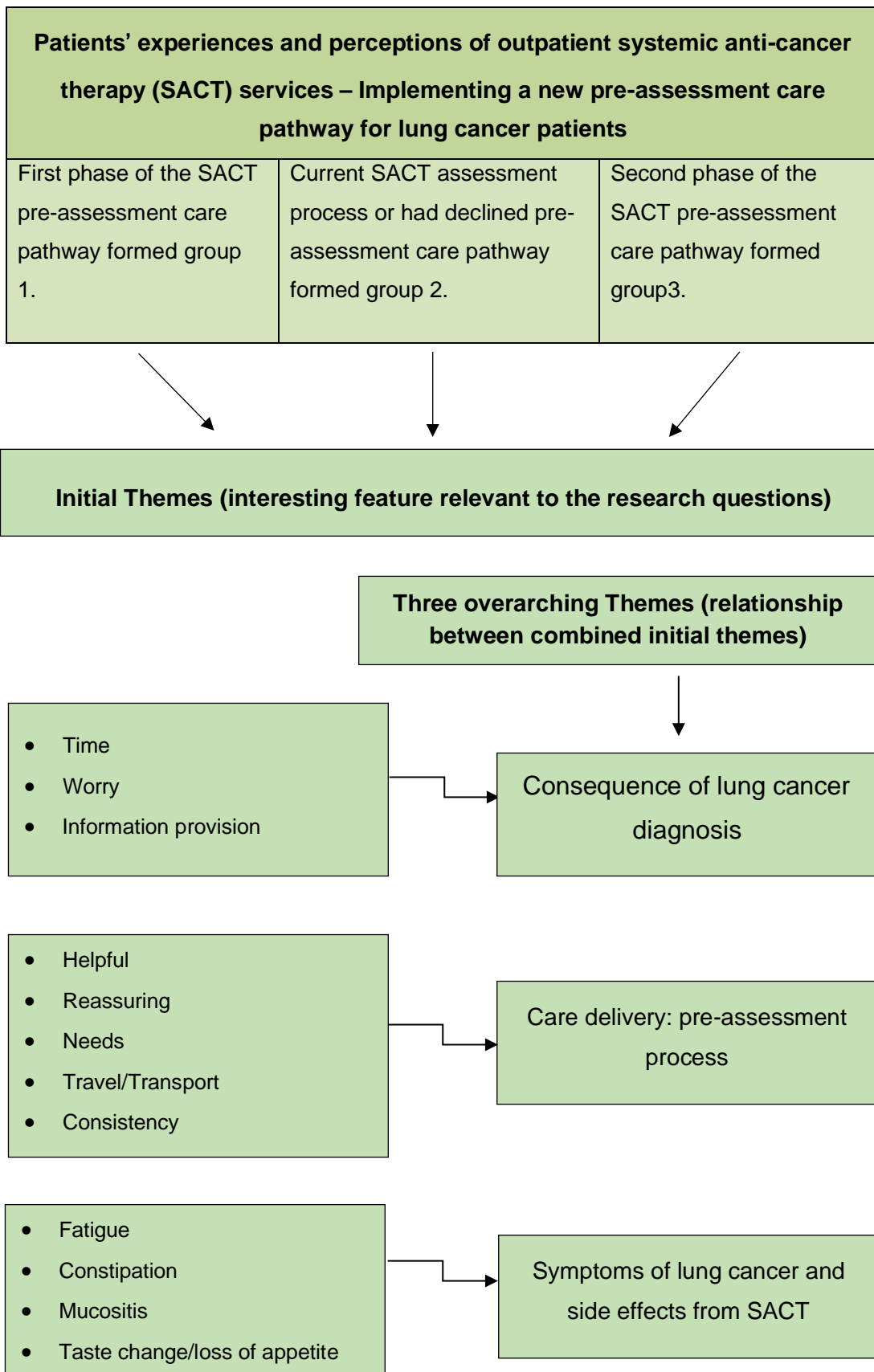
Step three – searching for themes: Applying step three of Braun and Clarke's (2006) six-step framework and Merriam's (2009) pragmatic approach, I was able to make sense of the initial codes identified and relate these to the research questions and relevant literature. I developed a number of initial themes, as illustrated in thematic map one (Table 13). Thematic map one illustrates the initial codes that were generated by performing an within-case analysis, which I then collated into initial themes.

Table 13. Thematic map 1: codes and initial themes

<p>Initial theme: 'Time'</p> <p>Codes:</p> <ul style="list-style-type: none"> • SACT can give more time (quality) • Time at the start makes a difference • Symptoms improve with SACT • What time is left? <p>"I know the reality of my situation, time left is important. I want the time to be good and don't want to risk feeling bad. On the other side I could get more time and feel ok"</p>	<p>Initial theme: 'Travel/Transport'</p> <p>Codes:</p> <ul style="list-style-type: none"> • A struggle to come along/across town • Half day to travel in and out • The cost/extra visit • Telephone worked for me • Wasn't viewed as an 'extra visit' but part of my treatment plan
<p>Initial theme: 'Worry'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Couldn't sleep for worry • Worried cancer might spread <p>"Worry constantly...is it the cancer or is it the treatment?"</p>	<p>Initial theme: 'Consistency'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Lack consistency primary care • PAC allows consistency to care • Prefer access to experts <p>"Coming here I see the same doctors that I know, I dont get my own GP, it's a locum. I really want consistency"</p>
<p>Initial theme: 'Information provision'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Information overload 'chunked' • Not able to understand it all • Relevant information • More informed than attending my GP 	<p>Initial theme: 'Fatigue'</p> <p>Codes:</p> <ul style="list-style-type: none"> • So tired, couldn't cope, no energy • Tiredness was the worst (impacts daily life) • Unable to interpret symptoms from cancer or treatment. <p>"The worst and like nothing experienced before"</p>
<p>Initial theme: 'Help/Helpful'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Face-to-face was helpful • Decision-making • Relieve stress/practical help 	<p>Initial theme: 'Constipation'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Terrible constipation • Distress, treatment deferral • Needed hospital admission
<p>Initial theme: 'Reassuring'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Checked over, was reassuring • Face-to-face had personal touch • Restore confidence with expert opinion. • Being able to cope <p>"When I told them how I felt they said that's ok, its normal, reassuring to have a face-to-face-meeting"</p>	<p>Initial theme: 'Mucositis'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Sore mouth, couldn't eat • Hospital admission <p>"Face-to-face assessment was better, I felt the side effects were better managed"</p>
<p>Initial theme: 'Needed/Needs'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Questions answered/pre-assessment care pathway meet needs • Meet individual care needs 	<p>Initial theme: 'Taste change/loss of appetite'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Couldn't taste my food • Weight loss

Steps four and five – review and define themes: I achieved these steps through further review and interpretation, collating the initial themes that emerged from analysis of the data generated within the case, and formed three overarching themes. These were formed according to their relevance and relationship between these themes, as presented in thematic map two. Thematic map two summarises these remaining steps within the case analysis (Table 14).

Table 14. Thematic map 2: overarching themes and summary of analysis process



Step six – write up: Applying the last step of Braun and Clarke's (2006) six-step framework, I began the final analysis within the themes extracting vivid examples from the data that related to the research aim and questions, themes and literature. This step also involved constructing an interpretative story in a concise, coherent and logical manner, interwoven with relevant literature to relay the results of the analysis and demonstrate the merit and validity of the analysis and findings.

To summarise, in Chapter 5, I have presented the application of the qualitative methodology utilising a semi-structured interview, and the key principles of case study design. An adapted version of Braun and Clarke's (2006) six-step analytic approach was well chosen to provide clarity to the analytic process. The findings of my study are now presented in Chapter 6.

Chapter 6 – The Research Findings

6.1 Introduction

In this chapter, the research findings are presented in relation to each overarching theme that was formed through ongoing review and interpretation of the initial themes as previously illustrated in Table 12 (Section 5.10.1). An overview of the participants' information in relation to the three groups is presented.

The three overarching themes are: *Consequence of lung cancer diagnosis*; *Care delivery: pre-assessment process*; and *Symptoms of lung cancer and SACT side effects*. The findings relevant to the research aim and reflecting the initial themes are described and explained within each related overarching theme. Verbatim quotations are used to illustrate the findings and represent similarities and differences in participants' varied experiences, perceptions and views.

6.2 Participant information

The following tables (15–17) provide participant information in relation to their gender, age, diagnosis, marital status, education level and occupation. I collated this data once agreement to participate in my research was obtained from each participant.

Fifteen women and seventeen men were recruited, and participants' average age was 66 years with just over half diagnosed with a stage IV lung cancer at presentation. This is representative of the data provided by ISD (2019), as discussed in Chapter 1 (Section 1.3.2). Half of the participants were undergoing concurrent SACT and radiotherapy (SACT administered on the same day as radiotherapy), and half were receiving SACT alone. Seventeen participants were married, eight were widowed, and seven were either single or divorced. Two-thirds of participants were retired, three were in employment, and the remainder were on sick leave or unemployed as a result of their cancer.

Table 15. Group 1 participants: patient information

Group 1 – Participants who attended the first phase of a SACT pre-assessment care pathway						
	Gender	Age	Diagnosis	Marital status	Education	Occupation
01	woman	62	SCLC: stage IV	Married	University	Retired (teacher)
02	man	71	NSCLC: stage IV	Widowed	Secondary	Retired (building)
03	man	68	NSCLC: stage III	Married	University	Retired (GP)
04	woman	66	NSCLC: stage IV	Married	Secondary	Retired (industry)
06	man	71	NSCLC: stage IV	Married	University	Retired (bank)
07	man	74	NSCLC: stage III	Married	Secondary	Own business
08	woman	61	NSCLC: stage IV	Married	Secondary	Unemployed
09	man	78	SCLC: stage III	Married	Secondary	Retired (bank)
11	man	53	NSCLC: stage IV	Married	Secondary	Employed (chem. eng.)

Table 16. Group 2 participants: patient information

Group 2 – Participants who underwent the current SACT assessment process or declined a pre-assessment care pathway						
	Gender	Age	Diagnosis	Marital status	Education	Occupation
01	woman	65	NSCLC: stage III	Single	Secondary	Retired (office)
02	woman	60	SCLC: stage IV	Single	Secondary	Retired (office)
03	man	32	SCLC: stage IV	Single	Secondary	Unemployed
04	woman	69	SCLC: stage IV	Widowed	Secondary	Retired (cleaner)
05	woman	62	SCLC: stage IV	Widowed	Secondary	Unemployed
06	woman	74	SCLC: stage III	Widowed	Secondary	Retired (office)
07	man	54	NSCLC: stage III	Single	Secondary	Retired (medical)
08	man	76	NSCLC: stage III	Widowed	Secondary	Retired (council)
09	woman	61	NSCLC: stage IV	Married	Secondary	Retired (office)
10	woman	78	NSCLC: stage III	Widowed	University	Retired (teacher)
11	man	48	NSCLC: stage III	Married	Secondary	Working (own bus)
12	woman	74	SCLC: stage III	Widowed	Secondary	Retired (office)

Table 17. Group 3 participants : patient information

Group 3 – Participants who attended the second phase of a SACT pre-assessment care pathway, were local to the regional cancer centre and received a new diagnosis of lung cancer						
	Gender	Age	Diagnosis	Marital status	Education	Occupation
01	man	80	NSCLC: stage III	Widowed	Secondary	Retired (building)
02	man	60	NSCLC: stage III	Married	Secondary	Sick (building)
03	man	62	NSCLC: stage IV	Married	Secondary	Retired (medical)
04	man	80	NSCLC: stage IV	Married	Secondary	Retired (office)
05	woman	63	NSCLC: stage II	Single	Secondary	Healthcare (sick leave)
06	man	53	NSCLC: stage IV	Single	Secondary	Retired (medical)
07	woman	79	SCLC: stage IV	Married	Secondary	Retired (shop)
08	man	78	NSCLC: stage III	Married	Secondary	Retired (fitness)
09	woman	78	NSCLC: stage IV	Married	Secondary	Retired (office)
10	woman	52	NSCLC: stage III	Divorced	University	Nurse (sick leave)
11	man	59	SCLC: stage IV	Married	Secondary	Building (sick)

6.3 Overarching theme – Consequence of a lung cancer diagnosis

6.3.1 Initial theme – Time

The context of what time meant within the case appears to be complex. Its meaning seemed to differ for each participant, and this probably related to individual circumstances and the stage of their illness. Many participants within the case described time as being essential to provide the support required through their initial diagnosis and management of the symptoms associated with cancer. Time was also essential to assist the support provided throughout their treatment and its associated side effects.

At the start of the interview, each participant was asked broadly about their experience of either attending a pre-assessment care pathway or their reasons for refusal and their opinion regarding the phone assessment. I wanted to focus the interview on their experience of the assessment process, whilst allowing any initial opinion that would help to guide the interview. When I probed further by asking about the importance of the assessment process during their treatment, a number of participants described the significance of receiving support through discussion and explanation of treatments. They appreciated the opportunity to ask questions and felt that the value of the time spent with experts in lung cancer and its treatments was important. Participants were also provided with the option to bring along their partner or family friend, allowing them time to ask questions and have their concerns addressed. The value of time is illustrated in the quotations that follow:

Group1 01: I had a horrible time with cisplatin, I needed the reassurance at that time and contact with people that know all about this.

Group3 02: Well, it's all unknown isn't it, the fear of not knowing is massive so having that time at the start makes all the difference. It calmed me. The practical help from the people that know all about this was what I liked. I was told what to expect, that is so important.

Group3 04: I was a freaked by all this ... some good advice given. It was important for my wife; she could come along too. It was helpful to

her to have the time with people that know all about this and the treatment. We needed time from the experts here.

For many of the participants within the case study there was a clear focus on the hope that SACT might prolong their survival time. During the interview, each participant was asked about their expectation of SACT and how they felt the treatment had helped their cancer. It was often in response to this question that participants talked about their limited life expectancy. Given the sensitivity of this subject, I was guided by each participant as to whether this was a topic that they felt comfortable discussing. On listening to those participants who offered to discuss this subject, I became aware of how overwhelming and difficult this conversation was for each one of them. There were silent pauses in the conversation, an adjustment to their body language, and a saddened change in their facial expression. The quotations shown below illustrate their responses:

Group1 11: Oh yes, without a doubt it has helped me, I know I wouldn't be here without it, it's buying me extra time ... I know I am lucky as I said before it has worked really well for me and the cancer has been controlled for a long time now, but I am grateful for that.

Group2 02: I would do it again ... in a minute ... of course I would, I know I need it to help the cancer, there is no other option is there? If it gets me more time and I feel ok, I'll take it. For me, it is more time, you know that don't you ... they can't cure me.

Group2 04: Oh yes, of course it has, I know it can't be cured, it's about more time and quality time ... I understand that and that's why I get so worked up being here so much too. I know you all know what you're talking about here, I hate being such a moan but sometimes that's just the way I feel.

Of those participants who talked about their life expectancy, more than half of them described that the quality of their survival time was as equally meaningful as the length of their survival time.

Group1 09: I know I am one of the lucky ones as the chemo has worked, and everything is stable, yes it has been hard at times, but with the cancer stable and I feel well just now, I have good quality, which is as important as more time for me. It has been worth it.

A number of participants from the case also indicated that they regarded treatment to be effective if it maintained or improved their well-being as well as their survival, as illustrated in the quotations below:

Group1 02: Oh yes, I've been lucky really, yes it has helped me. I'm able to get out and about, I'm not in any pain just now I know the outcome, of course I do, but for now I feel good and it's all about extra time and quality time, isn't it?

Group3 06: My partner came along, we had planned with short notice to get married, so we both wanted it to be the right thing to do. We both wanted to look at the pros and cons of having treatment. It was a tough decision, I know the reality of my situation, but the time left is important. I want this time to be good and didn't want to risk feeling rotten, then the other side I could get more time and feel ok.

6.3.2 Initial theme – Worry

Those diagnosed with a lung cancer have been known to experience a significant amount of worry regarding their illness. The impact of this worry should be recognised, as this may have a negative influence on health, social behaviour and the overall well-being of these individuals. This may result in physical problems and interfere with daily activities of life (Balasooriya-Smeekens et al., 2015; Murphy et al., 2018).

There was evidence from the data that participants described similar worries, for example, the cancer progressing despite treatment. They described fear/anxiety that the treatment might affect their quality of life, ability to function socially, and also how the emotional impact might affect their close family and friends.

Group2 10: It's very hard; I do think it's very hard. It's very tiring, exhausting, you are in complete shock too that all this is happening to you, having no energy worried me. I do know that I wouldn't have changed my mind though; I would still do it and take the chemo, I could do all this and it still might come back.

A number of participants within the case who described attending a pre-assessment care pathway helped to alleviate some of their worries. This offered the opportunity to discuss these worries with healthcare staff who they regarded as experts, as illustrated in the following quotations:

Group1 08: I was worried about pain I had, I couldn't sleep, I worried all the time as this pain was there when they found the cancer. They brought my scan forward and I was able to know sooner that everything was ok and this bit here has actually reduced in size, I still worry about the pain, but the scan was reassuring and even speaking to the doctor was helpful.

Group3 01: I have been taken aback by how tired I feel. It's frustrating to suddenly feel unwell and have no energy and then you worry it's the cancer making me feel like this, so it is helpful to have these worries put aside when I come here and they tell me it's all normal to feel this way on treatment.

6.3.3 Initial theme – Information provision

During each interview, participants were asked how informed they felt at the beginning of their SACT. It was apparent from the data that, at certain points in the participants' cancer journey, more than half within the case felt they were given too much information to process, about either their cancer diagnosis or their planned treatment. Those participants who had attended a SACT pre-assessment care pathway indicated that this provided an opportunity for them to discuss some of the information that they felt was necessary. The data suggested that this created a better understanding regarding their treatment and the possible side effects. Evidence from the data further suggests that the face-to-face consultation pre-assessment care pathway enables the discussion

of pertinent information. These discussions included improving participants' knowledge of SACT side effects, their self-care ability to manage their side effects, and, importantly, an ability to recognise when to seek medical advice.

Group1 09: I have trouble hearing so the face-to-face is helpful, we went through how I had been in the past few weeks and all the symptoms that I had, that was helpful, think there was a problem with my bloods so that was sorted too. My kidneys weren't doing so good; she said that might be why I had felt tired, too ...

Group3 05: It gave me an idea what was going to happen. There was plenty of time for my questions. Face-to-face is better when there is lots to ask, I think I would have found that hard to do over the phone. To physically see the place also helped I think too. It wasn't so scary coming in the next day I remember thinking.

Group3 10: For me the meeting provided clarity ... being able to understand all this and have some control of my life.

The provision of tailored information appears to be more relevant when starting treatment, as participants are still coming to terms with their diagnosis and facing an uncertain future. A number of participants within the case suggested that grouping or staging the information that is provided at intervals in their cancer journey was helpful and that a SACT pre-assessment care pathway helped them to do this. One participant described that attending the pre-assessment care pathway improved their understanding of the treatment and what to expect, as the following quotation illustrates:

Group3 02: It was information overload. I couldn't take it all in, too much really. That's why it was good my wife came along too. We were able to put things into chunks, that way I could deal with it and understand it. Like now I know how I will feel tomorrow and the rest of the week. I know what to expect. The first time oh no ... fear of the unknown wasn't it?

The pre-assessment care pathway also enabled those participants who didn't want to read written material or were maybe afraid to read the wrong material, to have the time to talk through their concerns and worries in relation to their illness or treatment. This is illustrated in the quotation that follows:

Group3 05: To be honest I think a little too much information. I could have read forever, I was nervous what to read too, so I only read what I was given here and to be honest once I had been to the pre-assessment thing I haven't read much because I have been given the time to ask the questions and go through the things that worried me.

Having presented the findings from the overarching theme, *Consequence of a lung cancer diagnosis*, in relation to lung cancer patients' experiences and perceptions whilst receiving SACT, the findings from the overarching theme *Care delivery-pre-assessment process* will now be presented.

6.4 Overarching theme – Care delivery – pre-assessment process

6.4.1 SACT pre-assessment care pathway

The primary purpose of a SACT pre-assessment care pathway is to provide a face-to-face assessment with patients to examine their ongoing suitability for receiving SACT. One focus of the assessment is to ascertain that there is ongoing informed consent to treatment. One participant described the face-to-face discussion to be of value, which helped with their decision-making about whether to have treatment, as the next quotation illustrates:

Group3 06: Very much for me it was, it helped me to make the decision about chemotherapy. I was very much in two minds. I was sure I didn't want to feel any worse because of the chemotherapy. So, yes, it did help me to talk through the concerns I had about the chemotherapy ... So it was almost like an individual plan. I suppose that shows the importance of a face-to-face chat and discussion.

A further focus of a SACT pre-assessment care pathway is to ensure that there is ongoing benefit from the SACT and that the side effects associated with the

treatment are appropriately managed and tolerated. This information is obtained by taking an accurate history and carrying out a physical examination and assessment. An evaluation of the participants' physiological well-being and their performance status (physical ability to manage their day-to-day tasks) is also taken into account (Harrold, 2007; Scullin et al., 2017). This information allows for necessary adjustments to SACT and the supportive medicines, including delaying the SACT to allow recovery from any side effects, as illustrated in the next quotation:

Group3 07: Well, I was terribly sick after the first cycle; I couldn't eat and couldn't keep anything down after the chemotherapy ... I lost a lot of weight. That did worry me, and I think everyone else was worried, the next chemotherapy coming along to the pre-assessment was important for me, yes, some adjustments were made to see if they could help the sickness.

A specific phrase used by one participant created a clear descriptive image of his care experience whilst attending a pre-assessment care pathway:

Iron fist within a velvet glove.

This is suggestive of strict, firm, inflexible care, cloaked with an outward supportive, kind and gentle care approach.

There was evidence of the practical help that a pre-assessment care pathway provides, for example, undertaking the necessary investigations in order to receive SACT safely and in good time.

Group1 07: Yes I think so, she told me what was happening with the treatment, checked me over, my heart and all and reassured me that she was happy with me, things I've got to know about the treatment, my nurse at the practice knows nothing of this, takes my blood and I'm out the door.

Group1 03: Well for me it's the bloods, the questions and it will take less time if I would have it done in one place and there are also the

questions that arise I could have answered so yes, I think that's all very positive and there are advantages over the existing system, yes.

My analysis of the data demonstrated that those participants who had received a new diagnosis of lung cancer had received no previous SACT. They had a limited understanding of what to expect from treatment and, therefore, their first visit to the pre-assessment care pathway was of particular value. It was important to provide necessary information regarding their treatment and self-care advice, as illustrated in the following quotation:

Group3 01: Oh yes, definitely. Even the second time helped me as I said. I think the first time is more helpful as there was more questions and it certainly made things easier for me, but it certainly has real value at such a horrible time.

The SACT pre-assessment care pathway also provided an opportunity for participants' partners or a family member to attend and listen to the information provided, ask questions, and discuss their concerns. Some of the participants expressed a difficulty in relaying information back to their family members. Therefore, having a family member present appeared to be helpful in processing relevant key information and gaining a better overall understanding of the information delivered.

Group3 02: Very helpful yes, so helpful, it was a scary time for me. That's what is needed, gets you to the next stage. Lots of questions at the start, these were answered. I had plenty time I wasn't rushed. My wife came along too; this helped a lot as it's hard to remember everything. I was unsure about stuff and that wasn't a nice feeling.

Group3 04: I brought my wife, that helped her, so that helps me. There are always questions and things on your mind ... I could not recall any of the discussion with my doctor ... she is able to take things in.

For participants who had no prior SACT, the travelling distance or extra hospital visit did not appear to be an issue. However, it was highlighted that travelling

from outside the local area might prove to be more challenging for some participants, as the next quotations illustrate:

Group2 04: Another visit was just too much for me ... I live out the town ... I'm not able or prepared to travel in twice in a week.

Group3 04: I think I would be happy to come along here each time. I live near the hospital, so it suits me. I know I am lucky, as others have to travel miles to get here. I might not feel so happy to come here if I had long distance to travel. But for me I would prefer to come here.

The quotation that follows created a perception of the quality of care that a participant felt was provided during his treatment. There is a suggestion that, from a distance, he felt he was being continually observed, and that his care was individually tailored to his needs through this observation.

Group3 04: Having the time is important ... I also thought it was great monitoring. I feel like I am being watched from afar ... I mean that, I have even been phoned at home to follow some things up and I sometimes wonder how you remember all the things that need to be remembered and I am only one patient.

This is indicative that a SACT pre-assessment care pathway can contribute to the provision of a person-centred care approach. The participant indicated that his care and treatment was individualised through the provision of the support and care that was needed. This enabled him to manage his treatment and feel supported.

In addition, a further participant from the case created a vivid visual descriptive image of his perception and experience following his cancer diagnosis and starting upon his SACT journey. Initially the quotation creates an image of the existence of a world with people living with cancer:

Group2 11: It's another world in here. I never thought this stuff really happened ... I have passed this place a thousand times and never gave it a second thought what went on in here ...

Although this world is known to exist no one really thinks that this will be their world. He describes feeling oblivious to cancer and its treatment, however, there is the realisation that this is now his world. This illustrates the participant's psychological adjustment to his cancer diagnosis as, initially, denial and fear of the cancer are expressed:

Group2 11: The first time I did think I can't do this ... this isn't happening to me.

He then provides insight into the positive impact and support attending the SACT pre-assessment care pathway provided. There is then an indication of a gradual coming to terms with the diagnosis and the impact of treatment, and finding some level of acceptance – the adjustment:

Group2 11: But now it's not so difficult, it's a safe place, I feel cared for.

6.4.2 SACT phone assessment

The most frequent alternative to a face-to-face meeting is a phone assessment. As discussed in Section 1.3.1, a phone assessment carried out the day before treatment forms part of the current assessment care pathway. The primary benefit of a phone assessment is that it enables an evaluation of possible side effects induced by SACT in a timely manner, and provides ongoing reassurance and relevant information to patients. This is achieved through effective communication by experienced nurses with knowledge of SACT and management of the side effects.

Group2 02: The phone is a good way to keep in touch with the nurse here and I felt able to ask questions that I wanted to ask.

Group2 11: The telephone assessment thing works well, my doctor is near so you can see the convenience, the nurse went through the questions, I could ask things if I needed to, for me that was a great service.

Should the phone assessment identify any of the associated side effects which require further evaluation, prompt intervention may avoid the need for a possibly prolonged hospital admission, as the next quotation suggests:

Group2 10: When I didn't feel great, I've had problems with constipation twice now, I was able to tell her that over the phone ... I came here and saw a doctor or a nurse I think, I was allowed home a few hours later ... the assessment bit before the chemotherapy works well over the telephone.

My analysis of the data has indicated that most of those participants assessed by phone felt it to be thorough, with meaningful discussion and exchange of relevant information. For some, the phone assessment allowed their daily life, family life or work commitments to carry on, as demonstrated in the following quotations:

Group1 11: Well, I didn't feel it was any more helpful to me as I normally go along to my GP practice for the blood and then wait to receive the telephone call from the nurse from here and she takes me through the assessment questions. The questions at the pre-assessment thing here were just the same as the telephone.

Group2 01: The telephone assessment has always been thorough, I do get the chance to ask questions, I have missed them occasionally if I have been out, but I never have trouble getting through to the nurse ... maybe a timed call might be helpful, 'Iceland' even offer a timed call so maybe the NHS can try to.

Group2 11: For me no, it would be the time that would take, it's an hour just to travel here from home, and because I know for me the telephone assessment thing works well ... The telephone assessment, it lets me get on with my life, I continued to work, I have my own business.

However, the data also highlighted that the telephone SACT assessment did not always meet participants' needs in terms of its completeness of the assessment and the convenience for participants, as illustrated next:

Group3 06: I would not have managed the decision over the phone, if someone had asked me over the phone I think I would have said no and cancelled the treatment.

Group2 05: Sometimes did chat to the nurse but often forgot to say things or felt it was rushed, would prefer face-to-face and didn't know when nurse would call. Nurses were nice; maybe better if I knew when the nurse would call.

Group2 07: Sometimes it's good, it depends who is phoning. But I am given the opportunity to ask any questions that I have, and they will tell me if the bloods are ok. I know a lot of the nurses here now, so I think that does make the difference.

The participants who declined to attend the first phase of the SACT pre-assessment care pathway stated that their decision was influenced by the travelling distance to and from the hospital and the time necessary for an extra hospital visit to attend a pre-assessment care pathway. Furthermore, some of the participants who required hospital transport to attend for SACT highlighted that their journey home was often difficult and took longer, as there were other patients to drop off.

Group2 04: I need transport each time, no one to bring me in that can drive. Transport once each week, that makes my day longer and is harder ... I don't get home sometimes until late, and when you don't feel great ... well, I just have to go to bed.

My analysis of the data indicated that there were essential skills required to carry out an accurate SACT assessment, either face-to-face or by phone. These skills were identified as including effective listening, communication skills and the ability to acknowledge patients' perspectives, concerns and worries.

6.4.3 Care delivery – SACT assessment process – initial themes

There were a number of initial themes identified within the case from the SACT assessment process, including a pre-assessment care pathway and the phone

assessment. These themes, described below, are descriptive features of the assessment process defined as being meaningful by the participants.

6.4.3.1 Helpful

There was evidence that many of the participants within the case who attended a SACT pre-assessment care pathway found it helpful. Attending a SACT pre-assessment care pathway was described as facilitating an early rapport with relevant healthcare staff. This enabled the provision of both informative and practical discussions regarding their planned treatment, as the following quotation indicates:

Group3 06: Yes, very much for me it was, it helped me to make the decision about chemotherapy. I was very much in two minds ... I was sure I didn't want to feel any worse because of the chemotherapy. So, yes, it did help me to talk through the concerns I had about the chemotherapy and what the side-effects might be.

Furthermore, there was evidence that a pre-assessment care pathway was also helpful, as this provided an opportunity for participants to see the clinical environment and how treatment was administered. When reflected upon it was described how this relieved some stress whilst attending for the first cycle of SACT. The following quotation illustrates this:

Group3 02: Very helpful yes, so helpful. It was a scary time for me. But seeing the place and others sitting having their treatment, helped. Everything else that's going on and then having to get your head around all of this. It is practical help isn't it?

6.4.3.2 Consistency

The Scottish Government (2010a) and National Institute for Health and Care Excellence (NICE) (2012) recommend that relevant information should be effectively delivered and shared with patients and their families in order to achieve consistency of care. Healthcare staff should be knowledgeable and competent within their speciality and demonstrate effective use of the named

nurse concept and the co-ordination of care between primary and secondary care. The following quotation demonstrates the value that consistency of care provided one participant:

Group3 05: I need to have consistency, my GP wasn't able to provide this, I would see someone different each time and go through the same story. That was no good for me. The care here offers me consistency ... same doctor and nurses that know me and the treatments.

The need for consistency was a theme identified within the data as it suggested that the pre-assessment process contributed to achieving consistency of care for the participants undergoing SACT, within the outpatient setting. This is illustrated in the following quotation:

Group2 01: My GP started the pain relief, it is always a stressful thing to get an appointment that suits, I find there is a lack of consistency as I'm not sure who my own GP is ... I feel you all know me, know what's going on with my treatment and know what my medications are. You all know straight away what to do and how to do it, it happens quickly without any fuss.

6.4.3.3 Reassuring

The data indicated that reassuring the participants took place through effective communication, along with the provision of information that was tailored to meet each individual's need, as shown in the next quotation:

Group3 01: I suppose no one can prepare you ... when you tell one of the nurses or the doctors how you feel they are reassuring and explain saying we expect that and that's normal. So that's what is helpful, the reassurance.

Furthermore, there was evidence from the data that reassurance was facilitated through the pre-assessment care pathway, as this provided an opportunity for discussion and explanation of SACT. This helped to lessen the associated

anxiety and fear that the participants described regarding their treatment, as the subsequent quotations suggest:

Group3 09: I was feeling so nervous at the thought of the treatment. I didn't know what to expect I had this terrible picture in my head. I needed the reassurance, so I really liked the face-to-face meeting. It has a personal touch for me.

Group1 06: Yes, it is helpful. It's reassuring to me. It's easier too when they know about the chemotherapy. They ask the right questions. If I need to ask anything too, they can answer these.

6.4.3.4 Needs

There was evidence from the data to support the benefits of tailored information, effectively delivered. Those participants within the case who attended the new pre-assessment care pathway indicated that their care needs were met. They described how this improved their ability to cope during treatment and helped to reduce their associated anxiety and low mood. It also improved communication with their family members and increased their involvement in the decision-making process, allowing a greater understanding of their treatment choices.

The SACT pre-assessment care pathway was thought to be more helpful than the phone assessment in meeting the information needs of the participants through the face-to-face discussion. As described in the subsequent quotations, the pre-assessment care pathway provided support and reinforced essential information regarding treatment. This met the needs of the participants as this enabled them to acquire a better understanding of their treatment and how to manage their side effects.

Group3 10: I needed the support that speaking to someone here gave me. I found it so tough ... I know I needed to have SACT to help the cancer, but I needed the support as much.

Group3 08: The pre-assessment session did help me sort out some of the stuff I needed to know about. So maybe that's when you need to be told all about the treatment. I know everyone is different, but I needed to move in stages and take each thing one at a time.

Having presented the findings from the overarching theme, *Care delivery- pre-assessment process*, in relation to lung cancer patients' experiences and perceptions whilst receiving SACT, the findings from the overarching theme, *Symptoms of lung cancer and side effects of SACT*, will now be presented.

6.5 Overarching theme – Symptoms of lung cancer and side effects of SACT

Given that current SACT does not offer a curative option for the many patients who are diagnosed with stage IV lung cancer, treatment is often aimed at relieving symptoms caused by the cancer and improving patients' survival period (Scottish Intercollegiate Guidelines Network (SIGN) 137, 2014; Masters et al., 2015). The subsequent quotations illustrate the symptom improvements that participants benefitted from in receiving SACT:

Group3 06: I have felt well ... don't know if I have gained any more time ... but my breathing is better and my pain ... I have no regrets trying the treatment.

Group1 08: I just remember feeling so rotten ... I hadn't felt well for so long ... terrible pain ... with treatment it was so much better ... any pain panics me now, though ... but it's well controlled, thankfully.

Quality of life and managing both the symptoms of lung cancer and any side effects caused by the SACT are therefore important. Participants indicated that a SACT pre-assessment care pathway enabled helpful discussion and explanation regarding these side effects and enabled the provision of advice on how to effectively manage them. The phone assessment, as well as being convenient, was also helpful in providing participants with the opportunity to discuss their concerns and provided advice in managing the side effects from SACT. Within the case, participants reported that the most frequently

experienced side effects from the SACT were fatigue, constipation, mucositis and taste changes. The findings from each of these side effects will now be presented.

6.5.1 Fatigue

Participants reported fatigue as the most challenging side effect caused by the SACT. It was described as being distressing and debilitating and that it created considerable difficulty in maintaining normal daily activities with a good quality of life. The following quotations illustrate the impact that fatigue had on a number of the participants during their SACT:

Group2 06: Well my energy just goes completely, I feel totally shattered, I manage to shower and have breakfast then after that I am totally exhausted again, I really can't do anything else for myself. It helps to talk about this and be told it's ok to feel this way with the treatment.

Group3 06: Tiredness was the worst, I sleep a lot and I mean a lot. But I am tired anyway, so I am not sure if the chemotherapy actually made that worse or if that was going to happen anyway because of the cancer.

The ongoing assessment during SACT provided participants with support. However, the pre-assessment care pathway offered an additional opportunity to discuss face-to-face possible coping strategies, especially related to fatigue, as participants described their anxiety with not knowing if this related to their cancer or the treatment.

Group3 01: I have been taken aback by how tired I feel. It's frustrating to suddenly feel unwell and have no energy and then you worry it's the cancer making me feel like this, so it is helpful to have these worries put aside when I come here or across the road and they tell me it's all normal to feel this way on treatment.

6.5.2 Constipation

A number of participants within the case reported constipation as a side effect that caused them distress and created a negative impact on their quality of life.

If left untreated it contributed to increasingly unpleasant symptoms, such as abdominal pain, nausea, vomiting and anorexia. Participants described this as serious enough for them to contact the cancer treatment helpline for advice and further management, and, with one participant from the case, the SACT was interrupted. The following quotations illustrate the benefits of ongoing assessment which enable appropriate intervention to promote the ability to effectively self-manage this side effect of SACT.

Group2 10: I got constipated and that's not nice, that's been difficult too. I have missed one chemotherapy because of that, I didn't know that would happen. I saw the doctor here that day, and she said I couldn't get the chemotherapy. That was disappointing.

Group1 09: The first time was constipation ... I phoned in as I had not went in five days ... no movement, I had left it, but I was feeling so full up that I had to phone they advised me what to do I just thought I need to know I was doing it right.

6.5.3 Oral mucositis

Oral mucositis can affect up to 40% of patients receiving SACT (Jaroneski, 2006; Harris et al., 2008). This was reflected in my findings as oral mucositis and altered oral function caused by localised pain was reported by approximately half of the participants within the case at some point during their SACT. This affected participants' ability to swallow and caused significant distress and impacted on their quality of life. A smaller number of participants described that the experience of oral pain and associated distress was significant enough for their oral function to be affected:

Group1 09: Knocked me for six a bit, I was very tired, and sometimes felt light-headed, I was slower at home, too. I had the sore mouth too, so wasn't able to eat great.

With one participant, the mucositis was so severe that her dietary intake was significantly reduced and she required a hospital admission which delayed her treatment, as the next quotation illustrates:

Group2 04: Well, it hit me didn't it, I couldn't eat, my mouth was terrible I felt terrible ... That's why I am running a month late with the chemotherapy. I couldn't have it because I felt so bad ... until I could eat better, I lost a fair bit of weight and, as you can see, I don't have a lot to lose. I was washed out totally.

6.5.4 Taste alteration and loss of appetite

There was evidence from the data that taste changes were associated with both the lung cancer and its treatments. The participants described reduced pleasure from their food and ability to enjoy social functioning. The taste changes contributed to some participants' unintentional weight loss and, ultimately, this had a negative impact on their quality of life.

Within the case, participants under-reported taste changes and reported more loss of appetite. Those who experienced these effects from their SACT described changes to their taste as being so miserable it reduced their enjoyment of food, ultimately affecting their mood and quality of life:

Group2 11: My taste is rotten and some days I am grumpy and irritated. I can't really taste some food great, but I make the effort to keep up my calories and intake, I think my weight is up, which I am pleased about.

There were increased numbers of participants who reported that their loss of appetite was a contributing factor to their weight loss. This was recognised as a major source of worry for these participants diagnosed with lung cancer.

Group3 05: Annoyingly I have lost my appetite and have terrible taste, nothing tastes nice. I also had some nausea together this has caused me to lose weight, quite a bit and that worries me.

In summary, the assessment process in SACT administration and its management is integral to providing high-quality person-centred care, which lung cancer patients expect. There was evidence within the data to suggest that the context of time following a diagnosis of lung cancer is complex and significant. This relates to individual circumstances and these circumstances

must be considered in order to provide a person-centred approach. Analysis of the data has identified that there are potential advantages in terms of patients' experiences, to both a phone assessment and a face-to-face pre-assessment care pathway, before and during their SACT. However, to enable individualised person-centred care, the SACT assessment process requires to be individualised in order to meet patients' needs. The data indicates that this might be achieved by either combining a face-to-face pre-assessment with a phone assessment or utilising the pre-assessment care pathway model.

In Chapter 7, a summary of the research findings is presented, answering the research questions. The research aim and questions are related to the four themes generated from part one of the literature review, these are presented, and consideration is given to current and relevant research evidence. A summary of the findings is presented, reflecting the three overarching themes. The quality, strengths and limitations of the research design and process are discussed and, finally, the implications for clinical practice, policy and education are considered, with recommendations for further research identified.

Chapter 7: Discussion, Implications for Clinical Practice and Future Research

7.1 Introduction

This chapter begins with Figure 11, which provides a summary of the findings, to build on the conceptual framework presented in Chapters 2 and 3. In section 7.2, Figure 11 illustrates the research aim and the connection between the research questions (RQ), the themes developed from part one of the literature review (LR), and the overarching (OA) themes generated in within the case analysis.

A synthesis of the research findings is then presented, addressing each of the research questions. The findings are then discussed, and consideration is given as to how the LR themes contribute to current and other relevant research evidence, relating these to the research aim and research questions.

A summary of the key findings is then presented, relating these to the generated OA themes, before the quality, strengths and limitations of the research design and process are discussed. Finally, the implications for clinical practice and policy are described, and recommendations for future research are identified.

As part of my thesis submission, I also prepared a draft article for publication in the *British Journal of Nursing*, which further summarises the key findings of this thesis and presents a discussion of the synthesis presented here, highlighting the unique and original contribution that this research makes to the knowledge. I have chosen this journal, given that it is peer-reviewed, widely accessed, and covers all aspects of nursing research, training, education and practice. The draft manuscript is presented in Appendix 16.

7.2 Summary – research findings and new knowledge

A summary of the research findings is presented in Figure 11 below. In addition, using arrows to illustrate, it provides a visual representation of the interplay between the study aim, the research questions, the various themes identified in

the LR, and how these link to the OA themes presented in my analysis, which contribute new knowledge.

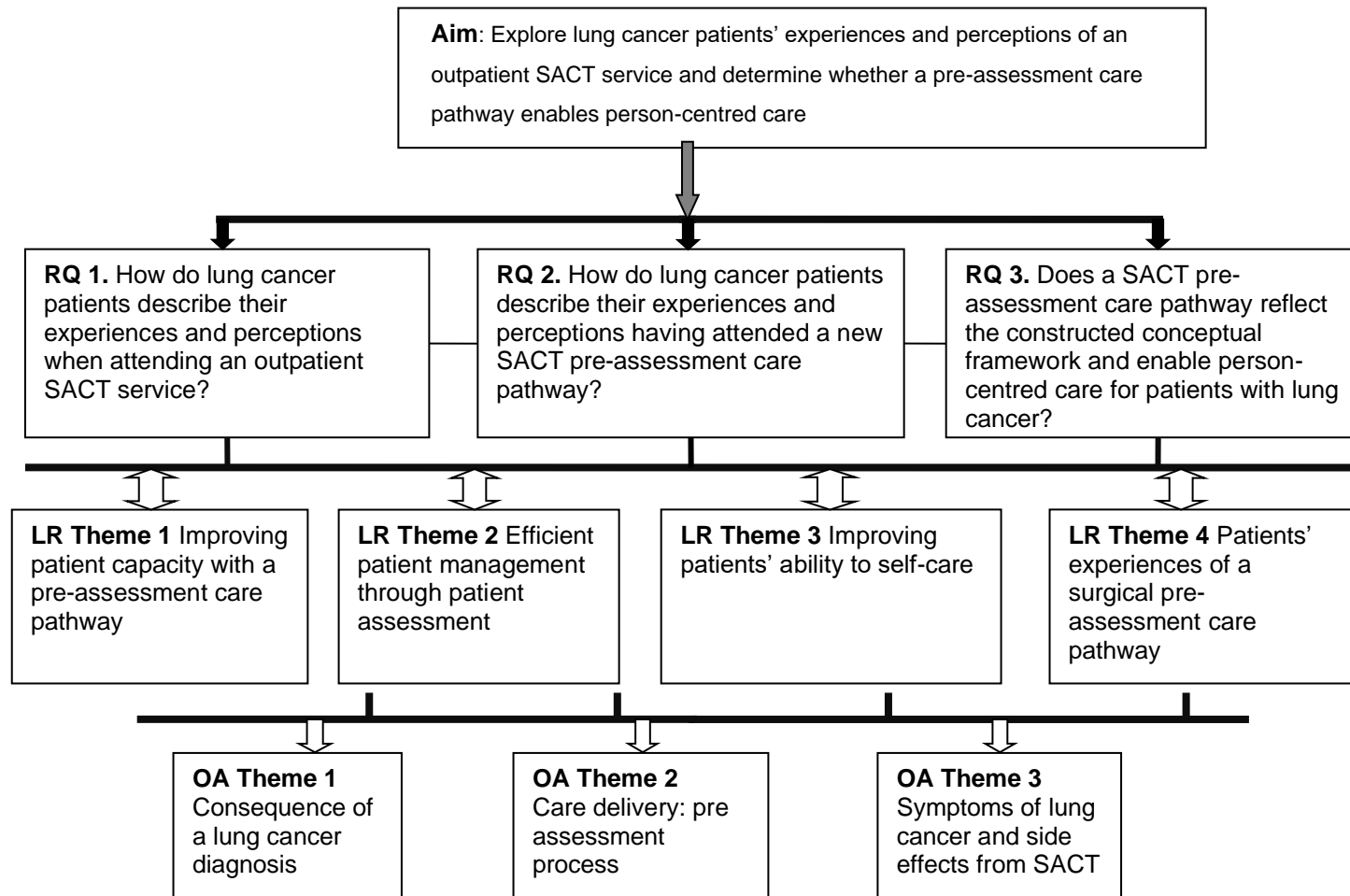


Figure 11. Developed Conceptual Framework: connecting – research questions with themes emergent from surgical pre-assessment care pathway to the overarching themes generated in the within-case analysis

My research used a single case study design to explore lung cancer patients' experiences and perceptions of an outpatient SACT service. This exploration included whether a pre-assessment care pathway provided a person-centred care approach during SACT.

Revisiting my research questions, I explored the experiences and perceptions of lung cancer patients attending an outpatient SACT service, and those having attended a new SACT pre-assessment care pathway. I sought to identify whether a pre-assessment care pathway reflects the themes of the constructed conceptual framework from Chapter 2. Finally, I explored whether this care pathway enabled person-centred care for these lung cancer patients undergoing SACT.

A summary of the research findings and new knowledge is presented and these are related to the research questions:

RQ 1. How do lung cancer patients describe their experiences and perceptions when attending an outpatient SACT service?

RQ 2. How do lung cancer patients describe their experiences and perceptions having attended a new SACT pre-assessment care pathway?

RQ 3. Does a SACT pre-assessment care pathway reflect the constructed conceptual framework and enable person-centred care for patients with lung cancer?

7.2.1 RQ 1. How do lung cancer patients describe their experiences and perceptions when attending an outpatient SACT service?

The evidence from the data demonstrated that the SACT assessment process carried out by phone or attending the pre-assessment care pathway provided the opportunity and time that participants within the case required to discuss their planned SACT. It also gave them the opportunity to raise concerns about their cancer and any other associated symptoms related to their illness. This therefore suggests that the assessment process significantly influenced the participants' experiences and perceptions of an outpatient SACT service.

As previously highlighted (Section 1.3.2), the early initiation of SACT aimed to improve both the quality and quantity of time for those diagnosed with lung cancer (Scottish Intercollegiate Guidelines Network (SIGN), 2014; Masters et al., 2015; Polanski et al., 2016; NICE, 2019). The significance of the SACT assessment process is further emphasised as this process endeavoured to minimise any side effects induced by SACT and maintain a good quality of life for these patients.

Furthermore, there was evidence from the data that the time participants spent with the healthcare professional during the SACT assessment process generated a positive experience and fostered therapeutic relationships. The assessment process included an ongoing clinical examination and assessment to ensure that SACT remained an appropriate treatment. Also, the process ensured that ongoing consent was obtained and that the patients would benefit from SACT and that any treatment induced side effects were minimal and being safely managed.

The assessment process carried out by telephone 24 hours before the SACT administration created both positive and negative experiences for a number of the participants within the case. The assessment process provided the time that was necessary to discuss the relevant aspects regarding their SACT and any symptoms that related to their lung cancer. The telephone assessment was found to be convenient, as it avoided an additional visit to hospital and allowed some of the participants to carry on with their normal lives. The telephone assessment was carried out by an experienced SACT nurse who was able to identify both acceptable SACT-induced toxicity and any other toxicity that required prompt intervention. The telephone assessment also provided the opportunity to reinforce SACT-related information and education. However, there was some evidence that indicated that the telephone assessment did not always meet participants' needs. This could occur if the assessment phone call was missed because patients were not provided with a time to expect the phone call, or where the call felt rushed and the assessment process was incomplete. This often caused a delay in the delivery of the SACT for participants as the assessment had to be repeated and carried out on the day of the SACT.

Overall, the new SACT pre-assessment care pathway created a positive experience. The pathway enabled participants to spend quality time with a senior SACT Advanced Nurse Practitioner (ANP) or Oncology Registrar for a face-to-face, one-to-one discussion. During this discussion, the side effects associated with SACT, and any concerning symptoms related to their disease, were identified and assessed. The pre-assessment also enabled an appropriate clinical examination with some of the participants being given assurance of an early indication to treatment response (chest x-ray). Furthermore, there was confirmation of ongoing consent for SACT, and participants described appreciation that their partner or family member could attend and have any of their concerns addressed.

Consideration of the relevant global and UK policy documents and strategic frameworks, as discussed in Section 1.4, outlined proposed changes for ongoing improvement to patient care. These aimed to promote a continuous approach of review and monitoring to ensure that the valued NHS resources remained effective, efficient, person-centred and underpinned by patients' experiences (Scottish Government, 2010b; Healthcare Improvement Scotland, 2013, 2017; World Health Assembly, 2017; NHS Health Scotland, 2018; Public Health England, 2019; European Commission, 2021). Time is recognised as a valued NHS resource and, similarly, my findings indicate that the concept of time became increasingly significant to participants during SACT. Most of the participants within the case pursued quality of time over quantity. They valued time with family and friends and time with healthcare professionals whom they regarded as experts in managing their lung cancer. A review of the SACT assessment process utilising the patient's experience has ensured that any change to service provision is person-centred and meets their needs, whilst ensuring that valued NHS resources remain effective and efficient.

Having presented a summary of the findings related to how lung cancer patients describe their experiences and perceptions of attending an outpatient SACT service, their experiences of attending a new pre-assessment care pathway will now be presented.

7.2.2 RQ 2. How do lung cancer patients describe their experiences and perceptions having attended a new SACT pre-assessment care pathway?

My analysis of the data provided evidence that replacing the phone assessment with a new SACT pre-assessment care pathway created a positive experience for participants within the case. The analysis also highlighted that the provision and delivery of relevant information through the pre-assessment care pathway was a key factor that positively influenced patients' experiences regarding this service.

Information provision began at the initial consultation with the Oncology Consultant, where the diagnosis of lung cancer was delivered. The treatment options were offered, and patients' prognoses were discussed, if this was something that the patient so desired. There were a number of participants who were informed that their cancer was advanced and not curable and that the aim of SACT was to treat the symptoms caused by the cancer, slow down its growth, improve their quality of life, and, hopefully, prolong their survival. It was evident from the case data analysis that participants described feeling unable to concentrate on what was discussed during their initial consultation, having received the news of their diagnoses. They felt able to retain only a small amount of the information that was given or were unable to recall any details of the information given. These findings are consistent with the literature, as it is recognised that an individual's ability to interpret and absorb information becomes compromised when they are faced with the distressing news of a life-threatening or life-limiting illness.

In the literature, and from my findings, it is highlighted that the most frequent discrepancy is that observed between the information delivered to the patient and the message that the patient actually receives from the information (Jenkins et al., 2001; Yardley et al., 2001; Jefford and Tattersall, 2002; Chapman et al., 2003; Hagerty et al., 2004; Rutten et al., 2005; Gabrijel et al., 2008; Innes and Payne, 2009; Russell and Ward, 2011; Bumb et al., 2017).

The pre-assessment was scheduled to take place before cycle one of SACT and again before cycle two. The SACT pre-assessment care pathway involved a one-to-one consultation with a clinical assessment and examination carried

out by a Senior SACT ANP or an Oncology Registrar. Participants were also given the opportunity to have someone accompany them during the pre-assessment meetings to assist with their concerns and queries. This helped to reduce their anxiety and generated feelings of safety and security.

The pre-assessment before cycle one enabled the unique opportunity for the participant's first one-to-one discussion with a healthcare professional, following on from their meeting with the Oncology Consultant. Having had some time to begin the process of coming to terms with the diagnosis, it was evident that there was the need for information and clarification of the information that had been delivered by the Consultant. The first pre-assessment before cycle one therefore facilitated both a clinical examination and an assessment of the information that the patient had processed and understood from their initial consultation. This process enhanced the patient experience, as any gap in the information provided and/or misunderstandings were explained, as well as provided the opportunity for their questions to be addressed.

I found that the provision and delivery of information during the pre-assessment meetings were more easily digested and understood by the participants. Relevant information included the potential SACT side effects and how these can be managed. The data analysis further demonstrated that the appropriate timing of information provision delivery encouraged and promoted self-management during SACT with a greater awareness of SACT side effects, and participants described feeling more confident with their ability to self-manage and with their decision-making ability relating to when to seek medical advice. This helped to create realistic expectations of treatment and foster better control of any symptoms related to their disease. This finding reflects the literature that recognises patients' information needs throughout their illness trajectory, understanding the depth and manner of how this is delivered, can have an impact on their well-being and ability to participate in the treatment decisions and create feelings of empowerment along with facilitating improved compliance with treatment (Jenkins et al., 2001; Jefford and Tattersall, 2002; Rutten et al., 2005; Innes and Payne, 2009; Russell and Ward, 2011).

Having presented a summary of the findings related to lung cancer patients' experiences and perceptions of attending a new SACT pre-assessment care pathway, a summary is now presented as to whether this care pathway reflects the constructed conceptual framework and enable person-centred care for lung cancer patients.

7.2.3 RQ 3. Does a SACT pre-assessment care pathway reflect the constructed conceptual framework and enable person-centred care for patients with lung cancer?

My findings indicate that there was benefit from a SACT pre-assessment care pathway, as the analysis of the case data suggests that this enables person-centred and tailored assessment for these lung cancer patients receiving SACT. Considering the conceptual framework from Chapter 2 (Section 2.6, p. 35), a pre-assessment care pathway was found to enable the timely and safe delivery of SACT, and capacity within the outpatient service was optimised as SACT was authorised and prepared by the pharmacy the day before treatment was due. SACT that was planned and coordinated through pre-assessment created a positive patient experience with a small number of treatment slots released and reallocated when SACT was not able to proceed.

There was evidence from the analysis of the case data that a pre-assessment care pathway demonstrated the significance and weight of a clinical examination and assessment to show ongoing SACT benefit and to ensure that there was no deterioration in clinical condition and/or psychological well-being. The pre-assessment care pathway also provided the opportunity for support, assessment of adjustment/well-being, and signposting for those who required additional psychological support.

The participants reported that individualised care provided by skilled healthcare professionals helped them feel better informed and more confident within their own decision-making. Within the case, participants described feeling supported with shared decision-making about treatment and the provision of appropriate information about their illness enabled a better understanding of SACT side effects and the ability to manage them. Compliance with supportive treatments such as anti-sickness and laxatives was also shown to be improved. The

participants described how, through collaboration and a meaningful interpersonal relationship with healthcare professionals, this person-centred care approach created a positive impact on their quality of life.

The following metaphor created an image of a participant's experience of the pre-assessment prior to cycle two of SACT:

Group3 11: I have been looked after with an iron fist within a velvet glove.

The image revealed through this quotation was that the pre-assessment care pathway created a strict, firm and inflexible approach to the care delivery during SACT, but that the care delivery was cloaked with an outward approach of kindness and gentleness. The use of this metaphor created a powerful tool that provided a greater understanding of the perception of the care received and the emotions that were associated with the care experience. The participant described an underlying firm approach by the nursing staff, but also described feeling cared for, with compassion and understanding of his current situation.

There is literature to suggest that providing a focus on reassurance aims to reduce patients' concerns, fears and worries regarding their illness/treatment (Donovan and Blake, 2000; Linton et al., 2008). The participant experienced sudden restrictions with his ability to carry on with his full and busy social life during SACT. When these restrictions were ignored, it created potentially life-threatening consequences. The face-to-face meeting enabled a one-to-one discussion, highlighting the significance of understanding and complying with SACT guidance. It became further evident from within the case analysis of this participant's interview that his cancer diagnosis had created feelings of loss, and, in this particular situation, the loss was of his normal life and social status. I found that the one-to-one discussion further enabled the provision of ongoing reassurance and support to make the necessary short-term changes to his lifestyle during SACT. Improving his understanding and ability to recognise the need to comply with treatment guidance helped to minimise the risk of further serious toxicity, improved his overall quality of life, and ensured that he achieved an optimal outcome to treatment.

The evidence drawn from the case data analysis demonstrates that the SACT pre-assessment care pathway enables person-centred care to reflect elements of both the Health Foundation's (2016, p. 6) framework and *The Person-Centred Nursing Framework* developed by McCormack and McCance (2006), as discussed in Section 2.7. The elements of person-centred care focus on patients playing a central role in their care, and that the care provided is supportive and respectful of individual values, preferences and choices.

I have provided an overview of the key research findings and evidence that a SACT pre-assessment care pathway provided person-centred care. The findings will now be discussed in relation to other relevant theories and research evidence. This is presented using the four broad LR themes which constructed the conceptual framework in Chapters 2 and 3: *improving patient capacity with pre-assessment care pathway*; *efficient patient management through patient assessment*; *patient experience of SACT pre-assessment care pathway*; and *improving patients' ability to self-care*. Each LR theme is discussed, in order to meet the research aim, by answering each of the research questions and explaining the importance of the study findings of an outpatient SACT service and implementing a new pre-assessment care pathway.

7.3 Literature review theme: Improving patient capacity with a SACT pre-assessment care pathway

It was highlighted in Chapter 2 (Section 2.5.1) that financial drivers were a prominent theme for the introduction of a surgical pre-assessment care pathway. Similar drivers were apparent that set in motion a review to explore a group of lung cancer patients' experiences of an outpatient SACT service. These drivers included maximising the resources within outpatient services to reduce cancer and SACT waiting time targets. This would help to reduce same-day, late cancellation rates and reduce the number of related admissions, through improved patient knowledge and the management of side effects. Considering relevant global and UK policy and given the increasing pressure upon UK-wide NHS resources and financial targets, it must be certain that healthcare provision is focussed on promoting patient safety, patient satisfaction and positive care outcomes (Naidu, 2009; Gadalean et al., 2011; Lees, 2011;

Farley et al., 2014; NHS England, 2016; World Health Assembly, 2017; European Commission, 2021).

There is consistency within the literature regarding a surgical pre-assessment care pathway that contributes new knowledge about a SACT pre-assessment care pathway. A key study finding from my research shows that appropriate pre-assessment is fundamental for the timely, safe delivery and management of common SACT side effects. Santana et al. (2018) highlighted that patient-centred care is an essential foundation for quality healthcare services and can help to ensure patient safety. Notably, my findings have indicated that the pre-assessment care pathway promoted a person-centred approach that enabled the safe delivery and helped to improve the management of potential complications associated with SACT.

My findings have also confirmed the positive effect of a pre-assessment care pathway on the issues that relate to increasing patient capacity within outpatient services. Decision-making regarding future healthcare services requires a review of the entire cost of a care pathway of patients' journeys to ensure that vital NHS resources maximise value at the lowest cost, whilst achieving high-quality patient care with the best possible outcomes (Santana et al., 2018). There was evidence from the data that a SACT pre-assessment care pathway enabled the resources of the outpatient service to be optimised. The pre-assessment care pathway enabled SACT to be authorised and prepared by the pharmacy the day before treatment was due. It also allowed a small number of treatment slots to be released and re-allocated if a participant was unable to proceed with SACT due to low blood counts or the side effects of treatment. This contributed to a reduction of late and same-day cancellations whilst promoting patient safety and satisfaction.

Gyllensten et al. (2017) conducted a small randomised study that compared the costs of a person-centred care intervention, similar to a pre-assessment care pathway, against standard medical care within an oncology setting. The intention was to improve the self-management of patients' symptoms and maximise satisfaction in their care experience. The person-centred care

intervention focussed on the development of self-care resources and the strengthening of patients' self-confidence, through a structured approach of partnership and shared decision-making. The key findings of their study demonstrated that the person-centred approach benefitted this group, as the intervention improved patients' self-care abilities whilst healthcare costs were not increased. Pelletier and Stichler (2014) also reported a financial benefit by implementing person-centred care, whilst giving patients the opportunity to self-manage their treatment, which led to fewer outpatient visits and less associated hospitalisation.

Given that I did not have access to the data gathered by the Quality Improvement Team (QIT), which had looked at chair time usage (treatment time), saved treatment slots, patients' admission rate, saved pharmacy time and any reduced drug wastage in relation to a pre-assessment care pathway, I was unable to provide any evidence from their data of any cost savings. However, my findings are consistent with those of Gyllensten et al. (2017), in that the SACT pre-assessment was shown to facilitate a person-centred approach. There was further evidence from within the case that the one-to-one discussion with a healthcare expert was beneficial, as this improved participants' understanding of SACT side effects, how to manage them, and when to seek medical advice. They felt better informed, which helped with their decision-making and increased their confidence and ability to self-manage their care and treatments. These feelings created a positive influence on participants' experiences of care provided through this pathway.

Santana et al. (2018) highlight that person-centred care improved patients' experiences and outcomes from a healthcare intervention, whilst enabling their ability to self-manage by learning more about their illness and treatment. They suggest that person-centred care encouraged patients to actively participate in their care and use their own self-care resources, such as relationships, physical activities, emotions and spiritual beliefs to improve their outcomes and have a positive effect on their quality of health and life. My findings add new knowledge to the literature, as the participants discussed their preference and need for practical help and individualised information, which led to a better

understanding of their illness and treatment. This allowed them an optimum quality of life throughout their SACT journey.

Epstein and Street (2011) suggest that person-centred care helps engage patients as active participants in their own care, with outcomes defined in terms of what is meaningful and of value to the individual. My findings reflect the literature, as the pre-assessment care pathway has shown that participants felt better engaged with their plan of treatment and it ensured that there was ongoing informed consent. Participants within the case also felt that their care and treatment delivery was better co-ordinated and was focussed on the elements of personalised care and support, which was paramount to them.

7.4 Literature review theme: Efficient patient management through patient assessment

My findings from part one of the literature review highlighted that efficient patient management could be achieved through accurate patient assessment and clinical examination, as this was a key role of the surgical pre-assessment care pathway. Similar key findings from my research support the view that an accurate patient assessment and appropriate clinical examination during SACT improved the efficiency of patient management within a SACT outpatient service. From the participants' perspectives, they described feeling reassured by the clinical examination, as this helped to reduce their worries and fears regarding their cancer. Participants within the case frequently expressed their fear of the cancer progressing, despite receiving SACT. One participant described her ongoing distress regarding her symptoms associated with the cancer during her treatment and how this had a negative impact on her quality of life. There was evidence within the case that the pre-assessment and clinical examination provided the opportunity to assess participants' symptoms and provide reassurance that the SACT was helping and controlling their cancer. These findings make an important new contribution to the literature regarding SACT pre-assessment and the role of clinical examination. This care pathway was able to demonstrate the ongoing benefits of SACT on participants with no deterioration in their performance status or physical ability to manage their day-to-day tasks, such as dressing, eating or bathing.

I found new knowledge that the SACT pre-assessment care pathway provided a key one-to-one opportunity for both an initial and an ongoing physical and psychological assessment with an experienced healthcare professional. It was through clinical assessment and use of communication and listening skills that the SACT pre-assessment care pathway helped participants to manage their associated uncertainty regarding a diagnosis of lung cancer. This discussion assured participants that the expected physical symptoms of lung cancer occurring alongside the side effects from SACT were not an indication of their cancer progressing. This also provided an important opportunity to identify those who were struggling to adjust to their diagnosis and support them in managing their psychological distress. This opportunity was achieved through appropriate referral or signposting to additional psychological support, for example, their nurse specialist or cancer support group. Psychological adjustment to a cancer diagnosis might be positively influenced by an improved awareness of the expected signs and symptoms (Stanton et al., 2005). This suggests that ongoing assessment and support, and consistent patient-clinician communication, can foster coping skills that will help to manage associated distress and deal with uncertainty. Roe and Lennan (2014) highlight that assessing the psychological impact of a lung cancer diagnosis and its treatment is essential, given the uncertainty associated with treatment outcomes. Whilst my findings are in keeping with existing literature, they also make an important contribution of new knowledge to the literature, as the SACT pre-assessment care pathway has shown to have a positive impact on the efficiency of patient management, both physically and psychologically.

The participants within the case frequently described their concern of how or when the cancer might recur or progress and that this created significant uncertainty and worry regarding their future. Notably, they were clear on how desperate they felt on receiving their diagnosis of lung cancer and described feelings of shock, disbelief and an overwhelming fear. New knowledge was discovered regarding the importance of time to participants. My findings suggest that the context of time was complex for this patient group. Participants within the case described time in terms of survival; time with healthcare experts to talk and listen, and its quantity and quality, and family time. Bennett and White

(2013) discussed improving the care and quality of life for patients with lung cancer and described time only briefly: in terms of relating quality time with improved quality of life.

I found that the SACT pre-assessment care pathway promoted the underpinning principles of person-centred care and the ongoing assessment of both participants' physical and psychological wellbeing along with assessment of their adjustment to a cancer diagnosis. New knowledge was realised, as participants gave examples of how this care pathway helped them to cope with their diagnosis, provided support to help reduce anxiety, and enabled informed, shared decision-making. Within the case, one participant described that having the one-to-one meeting was instrumental in helping to manage her low mood and symptoms of depression during SACT. My findings indicate that, with ongoing expert support offered by healthcare professionals, the provision of tailored information and knowledge of treatment options available can assist with the process of psychological adjustment. My findings are consistent with the literature that indicates that the majority of patients do adjust to their cancer diagnosis, with ongoing input from healthcare professionals and relevant information about the illness and available treatments. However, the literature does report a subset of patients who remain at a higher risk of distress and life disruption. These include patients diagnosed with an incurable life-limiting illness, such as lung cancer (Stanton et al., 2005; Kurita et al., 2013; Roe and Lennan, 2014). Considering my findings and the literature, which suggests that patients with lung cancer are at greater risk of psychological distress and life disruption, together this supports the provision of a pre-assessment care pathway for this patient group.

7.5 Literature review theme: Patients' experiences of SACT pre-assessment care pathway

Considering relevant global and UK policy context, namely NHS England's strategy for 'Achieving World-Class Cancer Outcomes' and the growing body of research to support the argument that patient experience, alongside patient satisfaction, are fundamental predictors when attempting to measure quality within healthcare service and delivery (Wagner and Bear, 2009; Doyle et al.,

2013; Manary et al., 2013; NHS England, 2016). Within Chapter 2 (Section 2.5.4), the importance of both the patient experience and patient satisfaction to healthcare outcomes and examining quality assurance within the surgical setting was highlighted.

The majority of participants within the case described an overall greater satisfaction with the care and service that a SACT pre-assessment care pathway provided. The concept of patient satisfaction remains increasingly relevant when influencing healthcare outcomes which compare different health systems. It is necessary to evaluate quality of care and encourage regular monitoring of healthcare quality in order to maintain high levels of patient care (Naidu, 2009; Batbaatar et al., 2015; Berkowitz, 2016). Indeed, Lees (2011) suggests that exploring patients' experiences is a valuable measure for evaluating the quality of healthcare services and identifying which aspects of a service might need to be improved.

Research evidence indicates that there are predicted factors which are thought to influence the extent of patient satisfaction (Batbaatar et al., 2015; Berkowitz, 2016). These include: communication, empathy, caring, reliability and responsiveness, and, to a lesser extent, service availability. Consistency, confidence and efficiency have also been discussed within the literature (Jackson et al., 2001; Naidu, 2009; Wagner and Bear, 2009; Gadalean et al., 2011; Atallah et al., 2013; Farley et al., 2014; Mulugeta et al., 2019).

My findings also present new knowledge of the factors predicting patient satisfaction. I have identified factors predicting patient satisfaction attending a SACT pre-assessment care pathway, as illustrated in Table 18. King et al. (2008) report that consistency of care has been shown to support the quality of patient care through the establishment of trusting, empathetic and reliable relationships with healthcare staff. The Scottish Government (2010b) indicate that consistency of care provides patients with stability when it is needed most, which, in turn, can improve the outcome for many patients.

Table 18. Predicted factors of patient satisfaction

Predicted factors of patient satisfaction attending a SACT pre-assessment care pathway
Communication – ‘treatment was explained so I was able to understand what to expect’; ‘My partner/family member could attend ... the pre-assessment helped me make my decision about SACT’
Empathy – ‘Treated with compassion’
Caring – ‘I felt cared for – my treatment was tailored’
Reliability – ‘The SACT was clearly explained and ready when I went in for my treatment’
Responsiveness – ‘There was plenty time for my questions’
Consistency – ‘It’s consistency that is important to me’
Efficiency – ‘Feel everything has been so well organised for me, under control, everyone knows what they are doing’

Jackson et al. (2001) have highlighted the complexity of utilising patient satisfaction to measure quality of patient care, as it was reported that there are also recognised predicted factors of dissatisfaction. These factors include mood, anxiety, psychological distress, and unmet patient expectations, such as failure of symptoms to improve or an acceptable level of functional status. Patient expectation can influence both patient experience and satisfaction (Hamilton et al., 2013), but these predicted factors do not necessarily measure or reflect the quality of care, the service provided, or clinical effectiveness (Jackson et al., 2001; Naidu, 2009; Wagner and Bear, 2009; Gadalean et al., 2011; Batbaatar et al., 2015; Berkowitz, 2016). However, it remains unclear within the literature whether patients’ experiences, level of satisfaction with their care, or the feeling that service provided did not meet their expectation is an indication of poor quality of care.

My findings also present new knowledge relating to the factors that predict dissatisfaction. I found a number of predicted factors which had a negative

influence on patient satisfaction, such as heightened anxiety, psychological distress and unmet expectations, examples of which are illustrated in Table 19.

Table 19. Predicted factors of patient dissatisfaction

Predicted factors of patient dissatisfaction
Anxiety receiving bad news – ‘I have never had any positive news ... coming here’
Poor symptom control/psychological distress – ‘I’m never sure who to speak to ... the pain is still there, not as bad but still there’
Communication delivery – ‘information overload’ ‘didn’t know what to read, there’s too much’
Not enough nurses – ‘had to wait to my turn ... sometimes there were no chairs’
The ward environment – ‘too noisy’, ‘too small’

However, I found no evidence within my findings that suggested that the participants felt dissatisfied with the quality of care received and/or the clinical effectiveness provided by the SACT pre-assessment care pathway.

There is consistency with my findings and those within the literature to indicate the complexity of utilising patient satisfaction to measure clinical effectiveness and quality of healthcare. Using patient satisfaction requires awareness and careful consideration of its limitations and an understanding of the relevance of timing, patients’ previous experiences, and the relevant personal characteristics, such as attitude (Jackson et al., 2001; Turris, 2005; Batbaatar et al., 2015).

7.6 Literature review theme: Improving patients’ ability to self-care

It was highlighted in part one of the literature review that information provision, health promotion and patient education were prominent themes when positively influencing patients’ ability to self-care. The further potential benefits achieved

from a surgical pre-assessment care pathway included increased patient confidence and compliance with recovery, and reduced anxiety and stress whilst undergoing surgery (Clinch, 1997; Malkin, 2000; Heaney and Hahessy, 2011).

In exploring lung cancer patients' experiences and perceptions of the SACT pre-assessment process, the significance of information provision became apparent from my findings. This applied to both the SACT pre-assessment care pathway and the SACT phone assessment. It became clear that the participants within the case wanted and needed information to help them understand more about their cancer, and, in particular, they described that information provision was their greatest need when starting treatment. Participants' perceptions were that the provision of information enabled them to make informed decisions and feel able to cope with their treatment and the possible SACT side effects. However, some participants acknowledged that, given the volume of information that was available to them, it often felt overwhelming, as some of the information was both inappropriate and irrelevant. Notably, some participants within the case reported that knowing where to access accurate information was also a concern. Indeed, one participant provided an example of how they felt that their information needs changed from the point of receiving their diagnosis to then starting treatment. Initially, it was whether their cancer could be treated and information regarding the treatment, then the need for information to enable an understanding of the side effects and learning how to manage them. My findings add new knowledge to the literature regarding a SACT pre-assessment care pathway and enabling information provision to be staged. My findings also mirror those of Mistry et al. (2010), who concluded that patients' information needs changed throughout the cancer journey and that the majority of patients wanted to be well informed and signposted to appropriate information resources.

Furthermore, Halkett et al. (2010) conducted a qualitative study to examine the information and support needs along the disease trajectory of patients diagnosed with a brain malignancy. Their findings concluded the need for individualised information and identified critical time-points within patients'

cancer journeys. These included the initial consultation whilst awaiting diagnosis, pre-treatment, starting treatment and approaching completion of treatment. The implications for healthcare professionals and clinical practice suggest the need for regular assessment of patients' information needs and an awareness that these needs change throughout their journey.

In a prospective longitudinal study, Matsuyama et al. (2013) examined and measured the information needs of newly diagnosed cancer patients over a nine-month period using an information needs questionnaire at three time-points: baseline, or at the start of treatment; mid-way; and then on completion of treatment. Their findings suggest that information needs were highest at diagnosis, as new patients wanted and needed extensive information relating to their diagnosis, treatment and prognosis. Their findings support my findings, as it is recognised that patient information needs change throughout the course of treatment and that patients would benefit from tailored information.

Considering Matsuyama et al.'s (2013) findings and their implications for clinical practice, my findings regarding the SACT pre-assessment care pathway before cycle one confirm and contribute new knowledge to this literature. My findings indicate that participants' information needs were significant at the start of their SACT and that these needs changed through the course of SACT. There was evidence that the pre-assessment care pathway enabled tailored information to be given, creating a positive impact on the participants' abilities to self-manage. The care pathway helped to alleviate participants' concerns, reduced their anxiety and helped in their decision-making. My findings further highlight that having the opportunity to visualise the treatment area is helpful and contributed to the participants' understanding of how the SACT is delivered, thus reducing their stress and anxiety. Several participants benefitted from seeing the treatment area beforehand, with one participant describing this as a source of practical support.

Participants within the case spoke of their difficulty in recalling the information given during their initial consultation with the consultant. They described feeling overwhelmed at receiving their diagnosis, and unable to focus on the discussion

and process the information. Similarly, Gabrijel et al. (2008) discussed information provision at the point of diagnosis and also concluded that patients' abilities to recall this information was poor. My findings add to existing evidence by demonstrating that the SACT pre-assessment process enabled an evaluation of what information had been retained and understood by the participants and what further information was required or wanted. The participants' views of their first attendance at the SACT pre-assessment care pathway proved to be noteworthy. They described how being given support with their decision-making regarding their treatment gave them a better understanding of the treatment and the possible side effects. They had confidence in the information provided, as this was delivered by a healthcare professional with specialist knowledge of lung cancer and SACT. One participant within the case described initially feeling indecisive about having treatment and how having the opportunity to revisit the relevant and appropriate information assisted in making an informed decision to proceed with treatment.

A meta-analysis study conducted by Haskard-Zolnieriek and DiMatteo (2009) examined the relationship between doctors' communication skills and patient compliance. Their meta-analysis involved a systematic review of the relevant research evidence, which allowed an evaluation of the overall effects of training for doctors' communication skills and patient compliance. This study concluded that good communication skills within healthcare were highly correlated with improved patient adherence, and that there was a higher risk of non-adherence among patients when a doctor demonstrated poor communication skills. My findings support the argument that interactive communication is essential and can improve patient adherence. The participants within the case reported feeling 'in a better place' to understand the information that was given to them, as it had been some time since they had received their diagnosis. Indeed, a number of these participants were actively seeking information about the treatment and its possible side effects.

Participants found that the SACT pre-assessment care pathway enabled the information to be tailored to meet their needs. It also helped participants understand their treatment in terms of the importance of compliance, and the

possible side effects and the management of these. The participants described that having a family member or friend in attendance further improved their ability to process the information and ask the relevant questions. These findings have both contributed to and added new knowledge to the existing literature regarding a SACT pre-assessment care pathway, as this enabled the SACT ANP or Oncology Registrar to gauge the most appropriate way to deliver information. The care pathway enabled an awareness of how much information each participant required to optimise their well-being, promoted coping strategies and improved their ability to self-care. Furthermore, a better understanding of SACT and its more prevalent side effects, such as fatigue and taste changes, which often go unreported and under-recognised, was achieved. This enabled participants to actively manage these and know when they should seek medical advice.

Socinski et al. (2003) discuss the benefits of ongoing assessment to reinforce necessary information in managing treatment side effects. They suggest that the assessment process promotes independence and compliance and the ability to self-care, thus helping to reduce anxiety and improve overall quality of life. I have added new evidence that a SACT pre-assessment care pathway promoted self-care ability and improved compliance with managing SACT side effects. My findings also concur with what has been discussed in the literature regarding communication skills and improved patient compliance (Halkett et al., 2010; Mistry et al., 2010; Matsuyama et al., 2013; Healthcare Improvement Scotland, 2013; NHS England, 2016). Farley et al. (2014) reported a positive association between communication skills, patient satisfaction and improved patient compliance with treatment and care guidelines, findings which align with my own, presented in this thesis.

Having discussed the theme of *improving patients' abilities to self-care* in relation to the SACT pre-assessment care pathway, a summary of the key findings reflecting the generated overarching themes is now discussed.

7.7 Summary of key findings: generated overarching themes

The three overarching themes are: *Consequence of lung cancer diagnosis*; *Care delivery, pre-assessment process*; and *Symptoms of lung cancer and SACT side effects*. The key findings are presented within each overarching theme.

7.7.1 Consequence of lung cancer diagnosis

New evidence about understanding the consequence of a lung cancer diagnosis was generated within my findings; the participants reported that associated distress, uncertainty and worry created a focus on time in terms of survival, quality and family time and time with relevant healthcare professionals. The role of the pre-assessment care pathway provided participants with a timely opportunity for support and the assessment of adjustment/well-being, and enabled signposting for those who required additional psychological support.

7.7.2 Care delivery – pre-assessment process

New knowledge emerged that a pre-assessment care pathway promoted person-centred care whilst enabling the timely and safe delivery of SACT through a one-to-one discussion and the delivery of tailored information. The participants reported a better understanding of their illness, feeling better informed about SACT and the associated side effects, how to manage them, and when to seek medical advice, which, in turn, improved compliance and self-management. I found new evidence that a pre-assessment care pathway optimised capacity, as SACT was authorised and prepared by the pharmacy the day before treatment was due. A small number of treatment slots were released and reallocated when SACT was not able to proceed.

Having used the patient experience to evaluate satisfaction, assess quality of healthcare services, and guide service improvement, new knowledge has been generated about both the predicted factors of patient satisfaction and patient dissatisfaction when attending a SACT pre-assessment care pathway.

7.7.3 Symptoms of lung cancer and SACT side effects

New knowledge was also found indicating that a pre-assessment care pathway improved the management of symptoms related to lung cancer and SACT side effects. New evidence has been added to the literature reporting that patients' information needs change throughout their cancer journey, specifically when starting treatment. A pre-assessment care pathway was found to provide person-centred care and tailored information to help maintain quality of life and manage SACT side effects. The significance of a clinical examination and assessment was shown to enable an ongoing SACT benefit with no deterioration in performance status (physical ability to manage daily tasks) and/or psychological well-being. The participants reported that the clinical examination and assessment also provided reassurance that the SACT was controlling their cancer.

Having presented a summary of the key findings, the quality – strengths and limitations – of the research design and process will now be discussed.

7.8 Quality – strengths and limitations of the research design and process

As a novice researcher, I initially felt that identifying an appropriate qualitative methodology that would answer the research aim and questions was challenging. In researching case study design, I found the terminology confusing, and this is also a feature highlighted within the literature (Anthony and Jack, 2009; Merriam, 2009; Creswell, 2013; Harrison et al., 2017). With perseverance and re-reading, I grew eventually confident by using Merriam's (2009) pragmatic constructive approach to case study design, as this provided a flexible, step-by-step approach to explore the real-life setting of lung cancer patients undergoing SACT.

My analysis of the case data presented a further challenge. However, as I applied Braun and Clarke's (2006) six-step framework, I became more familiar and immersed within the data. I developed confidence interpreting and reducing the data to collate the initial themes and then form three overarching themes. Figure 12 demonstrates case analysis utilising Merriam's (2009) case study methodology and Braun and Clarke's (2006) six-step framework for thematic

analysis. Despite the challenges I encountered, I remain assured that Merriam's (2009) approach to case study design was appropriate and I would feel confident using case study as appropriate with future research.

Braun and Clarke's (2006) six-step analytic framework	Step 1 Become familiar with the data	Step 2 Generate initial codes	Step 3 Search for themes	Step 4 Review themes	Step 5 Define themes	Step 6 Write up
Case study methodology, Merriam (2009)	Within-case analysis					Construction of experiences and perceptions

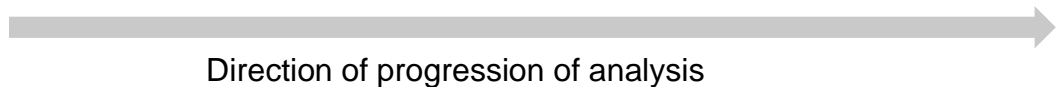


Figure 12. Case analysis using case study methodology (Merriam, 2009) with a six-step thematic analysis framework (Braun and Clarke, 2006)

Qualitative methods are widely used in health research; however, the process of assessing quality remains unclear, as there are no agreed methods to evaluate this approach (Smith and Firth, 2011). The literature suggests that assessing the quality of qualitative research is essential if the findings and any substantive theory are to be credible and incorporated into clinical practice (Mays and Pope, 2000; Noble and Smith, 2015). Qualitative research can be assessed according to two broad criteria: relevance, and reliability (Mays and Pope, 2000). By applying these criteria to my research and assessing its relevance, I have previously discussed the significant capacity and demand pressures that currently face cancer services, in particular those within outpatient SACT services. These pressures have highlighted the need to examine the current assessment care pathway for patients undergoing SACT, as this was no longer felt to be person-centred or fit for purpose. Additionally, a

review of the literature highlighted a lack of patient experience research within outpatient cancer services.

Relevant global and UK policies have recommended that a focus on patients' experiences and perceptions could prove to be a valuable asset to promote collaborative change to clinical practice, which would benefit and improve the quality of patient care (The Scottish Government, 2010b; NHS England, 2016; World Health Assembly, 2017; European Commission, 2021). My study aimed to inform regional and national clinical practice through using the patient experiences and perceptions of a one-stop SACT assessment process and then following the implementation of a new pre-assessment care pathway, however considering relevant global and UK policy, my findings can inform SACT delivery within the outpatient setting.

To assess the strength of the research design and processes, several strategies were adopted to ensure that the findings accurately reflected the data. The recruitment process proved challenging, given the progressive nature of lung cancer and the deteriorating health of a number of participants. To complicate matters, the first phase of the SACT pre-assessment care pathway was interrupted after four weeks, due to unexpected staff sickness. I had initially estimated that the recruitment of study participants would take 4–6 months, however, the process went on for approximately 12 months. Despite this, I achieved data saturation within each participant group, as discussed in Chapter 5 (Section 5.5).

As previously discussed within Chapter 5 (Sections 5.6 and 5.8), the timing of participants' interviews was planned at their convenience, and this proved to be central to ensuring the interview process caused minimal upset and inconvenience to each participant. This process prolonged the time required to complete all participants' interviews and it took a year to undertake the data collection, with the transcribing of the data taking a further four months.

The anonymised interview transcripts were sent to my research supervisors to ensure transparency of the analytic process. Transparency and guidance within

this process was further supported through one-to-one discussions with my research supervisors regarding the data and hand-written notes taken during each interview. To further increase the robustness of the analysis and, as discussed in Chapter 5 (Section 5.10), I invited five participants to comment on their interview transcripts to check for accuracy and resonance of their experience, and two agreed to review their own transcripts. This is known as respondent validation, which is a useful technique for exploring the credibility of the study findings (Mays and Pope, 2000).

I have summarised the quality of my research, highlighting the strengths and limitations of the research design and processes. My choice of case study methodology for this research provided the practical and flexible approach necessary to gather the detailed information from this patient group. The implications for clinical practice, education and policy will now be presented.

7.9 Implications for clinical practice, education and policy

By exploring lung cancer patients' experiences and perceptions of an outpatient SACT service and implementing a pre-assessment care pathway, a person-centred care approach has been demonstrated. Participants reported a positive experience which influenced their ability to self-care through improved information provision and a better understanding of the common SACT side-effects. They reported feeling overwhelmed by their diagnosis and valued a one-to-one discussion to help with their decision-making, ensure informed consent, and help with treatment compliance, and also the psychological support it provided. The participants' views have informed clinical practice regionally in that a pre-assessment care pathway has improved the timely, safe and efficient delivery of SACT for this patient group, describing consistency of their care and limited delays when attending for their treatment. This efficiency helped to optimise capacity with improved SACT delivery within the outpatient service. My findings are transferable and have wider implications for SACT delivery within the outpatient setting both nationally and internationally that a pre-assessment care pathway can have a positive impact on the patient experience through improved safety, efficiency and capacity.

Considering that there was no research evidence found in part one of the literature review regarding a SACT pre-assessment care pathway, and that the pre-assessment process has shown to be key throughout SACT delivery, my findings will influence clinical practice. Regionally, a SACT pre-assessment care pathway has since been implemented for lung cancer patients and is being considered for other cancer patient groups, including those who have been diagnosed with an advanced cancer when the associated distressing symptoms need careful assessment and monitoring. In wider global settings, and throughout the UK, a pre-assessment care pathway is relevant to SACT delivery within the out-patient setting and my findings are transferable to other clinical settings, including day-care services within urology, haematology and renal dialysis, particularly when there is a focus on communication skills, staged information provision and ongoing psychological support.

My findings provide healthcare providers with insights into lung cancer patients' experiences and perceptions of a new person-centred pre-assessment care pathway that will directly inform regional, national and international cancer services and policy, reflecting the LR themes developed from part one of the review and which formed the conceptual framework, as shown in Chapters 2 and 3. My findings are transferable and inform a range of clinical care settings, both nationally and globally, including oncology, haematology, rheumatology and renal dialysis.

Education and training provision of healthcare professionals is essential to be able to deliver this level of service, including: advanced communication skills, prescribing, clinical examination and history-taking skills, and the management of SACT side effects. Healthcare management, both national and international, will need to consider how this will be resourced to enable and ensure that there are adequate skilled personnel, as nurse education and training programmes may take up to three years to complete in order to deliver this level of care. It is worth considering that, from an economic point of view, the improved efficiency and optimised capacity indicated by a pre-assessment care pathway could mitigate some of the education and training costs.

Wider global and UK cancer policies focus on prevention, early diagnosis, treatment, and supported self-care management to improve cancer patients' outcomes and quality of life (ASCO, 2016; World Health Assembly, 2017; European Commission, 2021). The vision of NHS England's (2016) strategy – 'Achieving World-Class Cancer Outcomes' set out a series of initiatives reflecting the principles of person-centred care and supporting new models of care to enable the best possible quality of life. In 2010, the Quality Strategy identified care, compassion, communication, collaboration, clean environment, continuity of care and clinical excellence as essential elements of their healthcare system. Three quality ambitions of safe person-centred and effective care were developed, and healthcare policies are aligned to reflect and deliver these ambitions (Scottish Government, 2010b). In 2011, the 2020 vision provided the strategic narrative and context with which to implement the Quality Strategy and the necessary actions to improve efficiency and achieve financial sustainability of Scotland's healthcare service (Scottish Government, 2011). The 2020 vision looked for every person to live longer, live healthier lives at home or within a homely setting, where healthcare and social care are integrated. My findings therefore support the wider global, UK and Scottish cancer policy context through implementing a new SACT pre-assessment care pathway which has been found to promote person-centred care.

Having considered the implications of my findings for clinical practice, education and policy, the recommendations for future research are now presented.

7.10 Recommendations for future research

My findings have shown that the assessment process is central to the safe delivery of SACT and that a pre-assessment care pathway delivers person-centred care. I have reflected the experiences of lung cancer patients only, and further research in relation to other cancer groups, such as people affected by breast, gynaecological and colon cancer, should be explored to determine whether my findings can be replicated within these patient groups. Future research should be performed with these different cancer patient groups to explore whether criteria can be identified for whom a pre-assessment care

pathway is indicated. For example, stage of cancer, symptoms related to the cancer and pre-existing co-morbidities, which might increase the risk of SACT complications. Conducting such research might help to inform the wider global and national cancer policy for SACT delivery as there are increasing demands on resource and capacity within the outpatient setting alongside increasing annual numbers of new cancer cases and the availability of new and more improved cancer treatments (Chalkidou et al., 2014; ASCO, 2016, World Health Assembly, 2017; ISD, 2019; Public Health England, 2019; WHO, 2020; European Commission, 2021).

As a result of the findings of my research, an interim 48-hour telephone assessment was initially introduced regionally (previously 24-hour) for all cancer types, with the subsequent implementation of a pre-assessment care pathway for patients with lung cancer, which is now in place. The option of being prescribed with the pre-assessment care pathway is for those lung cancer patients who have been identified from the telephone assessment as having concerns of SACT side effects or cancer-related symptoms. There is the need for further research to gather quantitative data to help determine whether pre-assessing SACT patients can reduce treatment cancellations and minimise drug wastage. Further qualitative research to determine the criteria for when a SACT pre-assessment is required, and which patient groups might benefit most. Such further research may well influence the wider global and UK policies and strategies that can support patients to make informed treatment decisions, provide access to new and improved cancer treatment, and enable safe and efficient delivery of SACT with management of associated side effects.

7.11 Conclusion

In conclusion, the driver for this study was to explore the experiences and perceptions of lung cancer patients who attended an outpatient SACT services and determine whether a pre-assessment care pathway could provide person-centred care. I have provided a clear rationale for the study and the methodology used. My study has generated new knowledge about the SACT assessment process, leading to a change in clinical practice within a large

regional cancer centre, informed through the patients' experiences. Reflecting the work of McCormack and McCance (2006) and The Health Foundation (2016), new knowledge of a person-centred care approach has enabled participants to feel better supported and informed, enabling the safe and efficient delivery of SACT. New knowledge has informed clinical practice for SACT delivery in relation to communication, information provision and psychological support within a large regional cancer centre, with the potential to improve the quality of care for other cancer patients undergoing SACT within the wider global and UK cancer centres.

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Appendices

Appendix 1: Literature review of surgical pre-assessment care pathway

Author and Year	Title	Setting
Otte, DI. 1996	Patients' perspectives and experiences of day case surgery	Large University teaching hospital within UK
Type of study	Sample	Aim
Grounded Theory Ethical approval	8 adult patients (ENT) Recruitment: volunteers via post	Examine patients' experiences and views of day case surgery to improve health professionals' knowledge and understanding in order to improve future services
Method	Data analysis	Findings
Semi structured interviews within patient's home. Each lasted 35-45 minutes. Patients requested to reflect: Experience of PAC Discuss feelings Observations Expectations decision-making ability Quality The interviews were altered to focus on issues to further illuminate emerging themes. Interviews were recorded.	Constant comparative analysis: open coded: transcribed into meaningful themes and coherent patterns until saturation achieved.	Analysis of the data a Core construct emerged: Increasing level of satisfaction: From this: Four theoretical constructs emerged: importance of planning fear of the unknown improving the service the value of day case surgery Overall, patients dissatisfied with the service: long waiting time and inadequate information and educational support and poor discharge planning.

Author and Year	Title	Setting
Clinch, CA. 1997	Nurses achieve quality with pre-assessment clinics	Teaching hospital within UK: 4 pre assessment clinics within different specialties.
Type of study	Sample	Aim
<p>Appropriate approach: Part one: Qualitative: Ethnography</p> <p>Part two: Mixed Method approach:</p> <p>Ethical Approval</p>	<p>Part one: 12 nurses. Part two: 106 patients (convenient sample)</p>	<p>Clear aim: To identify the level of patient satisfaction with pre-assessment clinics and also what care nurses deliver in these clinics</p>
Method	Data analysis	Findings
<p>Part one: Observation of nursing activities.</p> <p>Part two: Semi structured questionnaire using both open and closed questions.</p>	<p>Part one: One researcher: carried out 29 observations of nursing activities: notes taken and then transcribed on to spreadsheet. Analysed using adapted model from Holisti.</p> <p>Part two: pilot study of 8 patients using patient satisfaction questionnaire.</p>	<p>Clear findings: Part one: Observations: six categories: Administration Communication Physical assessment Actions Teaching, education and information provision. Psychological assessment Part two: Patient satisfaction questionnaire: 4 sections: Administration Communication Quality Demographic details. Nonverbal communication observed listening skills, eye contact, picking up cues regarding anxiety and stress levels.</p>

Author and Year	Title	Setting
Lucas, B. 1998	Orthopaedic patients' experiences and perceptions of pre-admission assessment clinics	Two teaching hospitals within London. A - medical run with OT support B - Multidisciplinary
Type of study	Sample	Aim
Qualitative study Ethics approval	A convenient sample of 16 adult patients due to undergo orthopaedic surgery between 2 hospital sites. (8 in each site)	Accurately represent the experience and patients perspective of attending an Orthopaedic PAC
Method	Data analysis	Findings
Non-participant observation of patients attending PAC and the OT home visit. Semi structured Interviews within the patients home and whilst in hospital.	Field notes taken during the observations of PAC and home visit. Patient interviews tape recorded and transcribed. Coded into common phrases and themes. Pilot was conducted in both sites with 2 patients from each site.	Patient Experience of PAC visit and experience of PAC combined with an OT home visit. Patient information needs: importance of communication. what to expect from attending a PAC Nursing role: key to the success of PAC: being able to adapt to individual patient needs.

Author and Year	Title	Setting
Malkin, K.F. 2000	Patients' perceptions of a pre-admission clinic	Nurse led PAC within an Orthopaedic Hospital in the UK
Type of study	Sample	Aim
<p>Appropriate approach: Grounded theory: acknowledges with time limits: true grounded theory was not used.</p> <p>Ethics approval not applied for: permission granted by ward charge nurse and patients consultant.</p>	Suitable sample: 11 Adult patients in total	<p>Clear aim: Explore the patients' perceptions of a pre admission clinic in an orthopaedic hospital.</p> <p>Clear research question</p>
Method	Data analysis	Findings
<p>Initially 4 unstructured interviews. These were carried out within the clinic area, lasted 20 minutes: aim: allowing 4 participants to tell their story.</p> <p>Themes that evolved formed basis for further 7 semi-structured interviews which enabled on going generation of data.</p> <p>4 patients re-interviewed to verify patient experience.</p>	Using a constant comparative analysis and coding enabled themes to generate, these were further analysed for similarities enabling categories to form.	<p>Clear findings: Four categories generated:</p> <ol style="list-style-type: none"> 1. Dimensions of the clinic experience: <ul style="list-style-type: none"> • Individualized care • Being care for • Efficient functioning • Receiving comprehensive information • Medical assessment 2. Impact of the PAC 3. Identification of personal coping styles 4. Past negative experiences.

Author and Year	Title	Setting
Gilmartin, J. 2004	Day Surgery: Patients' perceptions of a nurse-led preadmission clinic (PAC)	Large teaching hospital within the UK – Nurse led PAC
Type of study	Sample	Aim
<p>Appropriate approach:</p> <p>Qualitative: Hermeneutic phenomenological</p> <p>Ethics approval</p>	<p>Good sample size for study type: 30 Adult patients: 17 F, 13 M.</p> <p>4: general surgery</p> <p>14: gynae surgery</p> <p>12: urology surgery</p>	<p>Clear aim: To Elicit patients' perceptions of the pre assessment preparation they received prior to day surgery</p>
Method	Data analysis	Findings
<p>Face-to-face interview carried out within patients home 7-10 days post attending the PAC.</p> <p>Interviews involved set questions informed through relevant literature exploring interrelated themes:</p> <ul style="list-style-type: none"> ▪ Experience ▪ Forms of assessment ▪ Information provision ▪ Psychological preparation ▪ Health education <p>Each interview lasted one hour these were recorded and then transcribed.</p>	<p>Using procedures by Colaizzi (1978) and Van Manen (1990) raw data was read and transcribed. Themes were identified and reviewed through familiarizing, coding and naming of categories the four themes evolved.</p>	<p>Clear findings: PAC functions effectively: Providing comprehensive information reducing patients anxiety, allows the opportunity to ask questions and provide health education.</p> <p>Four themes present the participants experience of the pre assessment stage:</p> <ul style="list-style-type: none"> ▪ Efficient functioning ▪ Assessment of patient ▪ Information giving ▪ Problem cancellation <p>Improvement could be strengthened: information provision and psychological support.</p> <p>Study limitations acknowledged: sample size of the patient groups within each of the specialties – unable to generalise findings. One hospital sight within one region.</p>

Author	Title	Setting
Gilmartin, J. Wright, K. 2007	The nurse's role in day surgery: a literature review	Literature review: RCN library database, British Nursing Index, CINAHL and Medline
Type of study	Sample	Aim
Literature review	152 research studies with 20 meeting the search criteria.	Report the evidence on day surgery, demonstrating its usefulness for innovative nurses
Method	Data analysis	Findings
Terms included day surgery, financial/economic benefits, patient experience /satisfaction: English language 1990-2005 with an adult focus	Relevance of included papers: using critical appraisal criteria: eight themes emerged: Economic benefits Best practice in day surgery Information giving and anxiety related effect Improved communication Effect of music on pre-operative anxiety Pain management Wound infection Nausea/vomiting	Presented using eight emerged themes:

Author and Year	Title	Setting
Gilmartin, J. Wright, K. 2008	Day surgery: patients' felt abandoned during the preoperative wait	Large teaching hospital, North of England. Consisted of gynaecology, urology and general surgery patients attending a pre assessment clinic
Type of study	Sample	Aim
Qualitative study Hermeneutic phenomenological Local ethical approval gained.	Purposeful sampling: 20 adult participants.	Clear Aim: to describe and interpret patients' experiences of contemporary day surgery.
Method	Data analysis	Findings
Data was collected by unstructured interview: conducted within participants homes.	Thematic analysis generated four broad themes.	Presented using four main themes relating to aspects of the patients' experience of day surgery the emerged from the data: <ul style="list-style-type: none"> • The feeling of empowerment during preparation • The apprehensions encountered • The feeling of abandonment in the preoperative waiting area • The dynamics of recovery Study limitations acknowledged: 1. Small sample size 2. One study site only.

Author and Year	Title	Setting
Fraczyk, L. Godfrey, H. 2010	Perceived levels of satisfaction with the pre-operative assessment service experienced by patients undergoing general anesthesia in a day surgery setting	General surgical setting and urology setting within general Hospital in the UK
Type of study	Sample	Aim
Cross-sectional Survey. Quasi-qualitative. Ethical approval.	275 Adult patients: calculated by power analysis with statistician help. (703 questionnaires distributed)	Clear Aim: To explore patient satisfaction with pre operative assessment for day surgery: between two specialties.
Method	Data analysis	Findings
Pilot of 6 patients using the self-administered questionnaire. Questionnaire using both open and closed questions: self-administered.	Statistical analysis of quantitative data. Mann-Whitney U-test for ordinal data and a chi-square test for nominal data. Thematic analysis of Quasi-qualitative data generated three broad themes.	Low response rate of 39.1%: Quantitative data revealed general satisfaction with PAC. Quasi-qualitative data suggested several areas of lower satisfaction with PAC: provision of information, individual anxiety, 96% of these respondents expressed satisfaction with PAC. 86% felt PAC helped prepare for the procedure. Satisfaction that PAC helped to relieve anxiety. Insufficient health promotion. Three broad themes: <ul style="list-style-type: none"> • Exchange of preoperative information • Supportive attitude • Anxiety and fearfulness Study limitations acknowledged: 1. Recruitment to the study was an issue. 2. One study site only.

Author and Year	Title	Setting
Heaney, F. Hahessy, S. 2011	Patients satisfaction with an orthopaedic pre-operative assessment clinic	One site only: University hospital in west of Ireland
Type of study	Sample	Aim
Quantitative exploratory design. Ethical approval	Convenient sample of 91 Adult patients. Small convenient sample: not ideal with quantitative design.	Explore the factors that influence patient satisfaction with an orthopaedic PAC.
Method	Data analysis	Findings
Self-administered modified version of the Leeds satisfaction questionnaire. (Previously validated). Researcher did provide help if required/requested Pilot study of 10 patients used adapted version of the questionnaire: further adaptations were made to improve usability.	Statistical analysis using SPSS version 15 for windows.	Response rate of 88%: Patient satisfaction: overall 85% (15% dissatisfaction: relates to long waiting times –also reflects earlier studies). Information provision: sufficient: 98%, language complicated: 93%, valuable written: 98%. Empathy: overall satisfaction: 81%. Quality competence: 100%!! Attitude: enough time spent: 95%

Appendix 2: Presentation to lung team and Quality Improvement Team

Introducing a Pre Assessment clinic into Out-patient SACT Services

Donna McGowan
Nurse Clinician - Chemotherapy

Background to research proposal

- Increased demand out-patient SACT services
 - Improving survival rates
 - Aging population
 - On going introduction of new and more complex SACT
 - Treatment capacity issues
 - Cancer waiting time targets

Why Lung cancer?

- Remains one of the common cancers in Scotland
- 85% of those diagnosed are over 65 years
 - Many have pre existing associated co-morbidities i.e. COPD, PVD, heart disease
- Often diagnosed in Advanced stage of disease
 - Distressing symptoms caused by the cancer
- Poor survival rates

Why lung cancer patients?

- This Patient Group
 - Occupy significant chair time
 - Require frequent medical reviews
 - Frequent delays and deferrals with SACT
 - Impacting already pressured service

Could a pre assessment clinic improve the service for this patient group whilst also improve the efficiency of out-patient SACT services?

Opportunity – Clinical Doctorate with University of Stirling

- Support from Lung team Consultants
- Support from Colleagues - Associate Specialist
- Support from Nursing Management
- Latterly -Support through Quality Improvement Project

Aim of SACT Pre Assessment clinic

- **Primary Aim**
 - To improve the quality of patient experience by improving patient flow through outpatient SACT day care services
- **Secondary Aims**
 - To check the patient is benefiting from SACT (symptoms and CXR/Scan results)
 - To check the patient is coping with SACT (toxicities, weight and blood check)
 - To check the patient is happy to continue SACT (ongoing consent)
 - To tailor SACT as appropriate (dose adjustments and supportive care, reduce admissions)
 - To order SACT in a timely fashion for the following day (s)
 - To assess patient satisfaction and barriers to the SACT pre assessment clinic
 - To optimize SACT chair time

SACT pre assessment clinic -
What can be achieved?

- Reduce cancellations on the same day of treatment as it will allow the identification of patients who are not fit for treatment and patients who are not responding to treatment.
- Reduce chair time by ensuring appropriate SACT prescription(dose reductions etc) are made in advance and ensuring that Pharmacy have timely receipt of the SACT prescription

SACT pre assessment clinic - con'd

- Improve the scheduling process: SACT prescriptions will be available to pharmacy the day before treatment, minimising the delay in SACT being available therefore improving chair time.
- Develop a process to ensure that 'free' chair time is reallocated within 24 hours to improve chair time efficiency within SACT outpatient .

The role of the Quality
Improvement Team

- Gather quantitative data /evidence
 - How much chair time could be saved with a pre assessment clinic?
 - If SACT was delayed/deferred, could a pre assessment clinic allow the treatment slot to be re allocated?
 - Could a pre assessment clinic have any impact on the number of admissions for lung patients?
 - Could it save pharmacy time in preparing SACT?
 - **Importantly** - could money be saved through avoiding wastage of SACT?

The Patient's voice is the loudest!

- **Lung cancer patient's experiences and perceptions of SACT out-patient services:**
 - Propose and develop a qualitative research study to undertake Clinical doctorate with University of Stirling

Introducing the Pilot SACT pre assessment clinic:

- Aim to start April/May 2016
- This will be **offered** to all patients with a lung cancer diagnoses that are currently receiving SACT within the SACT out-patient day care unit.

Pilot – April/May 2016

- Offered to all patients with a lung cancer diagnoses that were currently receiving SACT within the out-patient day care unit
- The pilot was interrupted after 4 weeks: this was due to a lack of staff resources
 - data for the period of 4 weeks is shown as below:
 - Week 1: 11 patients offered: 5 declined (6 attended the pre assessment clinic)
 - Week 2: 15 patients offered: 6 declined and 1 patient became unwell. (8 attended the clinic)
 - Week 3: 9 patients offered: 5 declined and 1 patient unwell. (3 patients attended the clinic)
 - Week 4: 6 patients offered: 2 declined and 1 patient too unwell to attend, (3 attended the clinic)
 - Total of 20 patients attended the pilot SACT pre assessment clinic.

Pilot - What did this tell us? - Findings from Quality Improvement Team

- Summary of quantitative findings from pre assessment April pilot
 - Patients attending pre assessment for lung cancer chemotherapy over one month compared to those not attending showed
 - A reduction in hospital admissions post chemotherapy (27.8% vs 40.7%)
 - A reduction in hospital days per patient post chemotherapy (1.5 vs 3.1 days)
 - A reduction in pharmacy verification delays, median reduction of 88 minutes
 - A reduction in wasted chemo care slots (0 vs 5)
 - An improvement in reallocated chemo care slots (4 vs 0)
 - A reduction in wasted drugs (£19.15 vs £64.78)
 - A reduction in wasted aseptic pharmacy time (29.5 vs 114.5 minutes)
 - An improvement in patient satisfaction with the service and patient symptom control

The patients experiences and perceptions of SACT pre assessment clinic

- Patient interviews - conducted one off semi structured interview with 9 participants - some of the patients thoughts and comments:
- Offers consistency; get things sorted (occur in the community; this was brought up frequently; unable to see same GP or regular GP)
 - Face to face discussion; chance to sit and ask questions; go through any concerns
 - Staff that know about the illness and treatments; reassuring
 - Knowledge of what's happening with treatment; i.e. if bloods low or problem with blood
 - Time to get everything done; blood, weight and a nap
 - Felt looked after; more informative than GP; felt in more control
 - Knowledge of the treatment and how to manage the side effects
 - Not viewed as an extra visit; if felt part a necessary part of the treatment
 - Very positive with top team; advantages; everything done in one place with people that know about the illness and treatment and how these are managed.
 - Got to know the staff here and develop confidence to them
 - Staff know what questions to ask and what to look for; that is good to know
 - Felt happy coming here; felt safer; less rushed and time to go through my concerns
 - Continuity is better coming here
 - Felt more able to ask questions and have confidence that they know the answer; developed relationship with staff here and don't have to go through my story time after time

What next? - Need a second Pilot - November 2016

- Second Pilot SACT PAC - Newly diagnosed patients with a lung cancer:
 - Initial plan to recruit 30 new Lothian patients diagnosed with a lung cancer - proved advantageous and therefore continued
 - Newly diagnosed patients will be informed that they will be reviewed in a pilot SACT pre-assessment clinic before the first treatment to ensure that nothing has changed with their condition, that they remained fit for the planned treatment and that all the necessary tests prior to treatment had been carried out.
 - It was planned that they will attend the pre assessment clinic prior to their second cycle of SACT to review how treatment was tolerated and ensure remains appropriate.
 - Conduct further participant interviews : with aim to facilitate on going in-depth inquiry into patient experience and perception.

Appendix 3: Ethics Committee: Version 1: March 2016



PH/SN

17 March 2016

Ms D McGowan
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Dear Donna

**Lung Cancer Patients' Experiences and Perceptions of Outpatient Chemotherapy Services – A Qualitative Case Study Approach
SREC 15/16 – Paper No.55 – Version 1**

Thank you for your recent re-submission to SREC which was considered at the Committee meeting on 16 March 2016.

I am pleased to inform you that the Committee has provisionally approved your application, but this approval is conditional on the following changes. These changes should be marked as track on the relevant documents and sent to the email address above for approval by Chair's Action:

1. The language used within the Patient Information Sheets (PIS) and the Lay Summary requires to be simplified. We would recommend that all researchers follow HRA guidance and use the Flesch Reading Ease Formula or the 'The Fog Index' to ensure that information is in plain English. Equity for all levels of education and for those where English is not the first language, is an important consideration. <http://www.readabilityformulas.com/flesch-reading-ease-readability-formula.php>
<http://gunning-fog-index.com/fog.cgi>
2. Please ensure that interview timescales are consistent throughout your documentation i.e. 60mins or 60-90mins.

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The University of Stirling is recognised as a Scottish Charity with number SC 011159

3. PIS: There is inconsistency regarding when consent will be gathered, and an 'opt-out' option should be included to prevent patients being approached by the nurse at cycle 2 if they do not wish to participate.
 4. PIS: Given the vulnerable group involved, please emphasise that participants can stop the interviews at any time.
 5. PIS: "*What is the purpose the study?*" please amend to "*What is the purpose of the study?*"
 6. PIS: Include the contact details of an independent i.e. Professor Jayne Donaldson, and those of relevant helplines.
 7. PIS: "Benefits", there are no direct benefits to participation in this study, other than the opportunity to discuss the clients situation with a professional. This should be highlighted.
 8. PIS: Please remove underlining as this feels overly persuasive.
 9. Patient Consent Form, statement 4, please replace "*consultation*" with "*interview*" for consistency.
 10. 40 interviews within 3 months – is this a realistic expectation given diagnosis rates, recruitment rates and the time to the 3rd cycle of chemotherapy when the interviews will take place?
 11. IRAS form, A13: The timetable is unrealistic ie Approvals in 1 month.
 12. IRAS form, A17-1: Exclusion criteria need to be specified and clarified. People should not necessarily be excluded for mental illness (eg depression). You could change this exclusion criterion to be severe psychiatric illness.
 13. IRAS form, A21: Participation time in the study requires to be clarified. This means the whole study, not just the interview.
 14. IRAS form, A22: For privacy of participants, interviews should be held in a private area
 15. IRAS form, A23: The CI should not be managing distress (blurring of roles) but should simply refer the participant.
 16. IRAS form, A27.3: Please state that transcripts will be anonymised.
 17. IRAS form, A43: There is no valid justification for personal information to be retained for three years. Is this perhaps a confusion with personal information and hard copy data?
 18. IRAS form, A49-1: The Committee recommend that GPs are notified of clients' participation in the study.
-

19. IRAS form, A64-1: Should be "other" not "academic". Please verify this with Carol Johnstone, Research Development Manager.

20. IRAS form, A76-1: Should be "other" not "academic". Please verify this with Carol Johnstone, Research Development Manager.

We look forward to receiving your revisions.

SREC 15/16 – Paper No.55 – Version 1
Please quote this number on all correspondence

Yours sincerely



DR JOSIE EVANS
(Depute Chair)
School of Health Sciences Research Ethics Committee

Cc Dr K Stoddart & Dr A Taylor, Supervisors

Appendix 4: Ethics Committee: Version 2: April 2016

UNIVERSITY of
STIRLING 

PH/SN

5 April 2016

Ms D McGowan
Research Student/
Nurse Clinician – Chemotherapy
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Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU

Web: <http://www.stir.ac.uk/health-sciences/research/ethics/>

Professor Pat Hoddinott
Chair
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Dear Donna

**Lung Cancer Patients' Experiences and Perceptions of Outpatient Chemotherapy Services – A Qualitative Case Study Approach
SREC 15/16 – Paper No.55 – Version 2**

Thank you for your recent email correspondence including the following amended documentation:

- Participant Information Sheet 1 (current patients) – Version 4
- Participant Information Sheet 2 (new patient group) – Version 4
- Patient Consent Form – Version 4
- Full Dataset – Version 4

I am happy to grant formal approval by Chair's Action, and wish you and your team all the best with the study.

May I remind you of the need to inform SREC prior to making any amendments to this protocol, of any changes to the duration of the project and provide notification of study completion. A site file of all documents related to the research should be maintained throughout the life of the project, and kept up to date at all times. The site file template can be found on the SREC page of the School's website.

<http://www.stir.ac.uk/health-sciences/research/ethics/>

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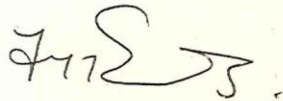
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The University of Stirling is recognised as a Scottish Charity with number SC 011159

Please bear in mind that your study could be audited for adherence to research governance and research ethics protocols.

SREC 15/16 – Paper No.55 – Version 1
Please quote this number on all correspondence

Yours sincerely



DR JOSIE EVANS
(Depute Chair)
School of Health Sciences Research Ethics Committee

Cc *Dr K Stoddart & Dr A Taylor, Supervisors*



**UNIVERSITY OF
STIRLING**

STIRLING FK9 4LA SCOTLAND

Joy Taylor
Research Funding Officer
RESEARCH & ENTERPRISE OFFICE
Tel: 01786 466443
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05 April 2016

To Whom It May Concern

**Research Study: Lung Cancer Patients' Experiences and Perceptions of Outpatient
Chemotherapy Services - A Qualitative Case Study Approach**

I am pleased to confirm that the University of Stirling will undertake the role of sponsor as outlined in the Research Governance Framework for Health and Community Care for the project entitled "Lung Cancer Patients' Experiences and Perceptions of Outpatient Chemotherapy Services - A Qualitative Case Study Approach " Chief Investigator: Donna McGowan, School of Health Sciences, University of Stirling.

Yours sincerely

Joy Taylor
Research Funding Officer



UNIVERSITY OF
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STIRLING FK9 4LA SCOTLAND

Joy Taylor
Research Funding Officer
RESEARCH & ENTERPRISE OFFICE
Tel: Tel:
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05 April 2016

To Whom It May Concern:

Research Study: Lung Cancer Patients' Experiences and Perceptions of Outpatient Chemotherapy Services - A Qualitative Case Study Approach

This study is included in the following cover put in place by Aon Ltd. These policies are renewed annually and the current period of insurance is 1 August 2015 - 31 July 2016.

I confirm that the following cover is in place:

Professional Indemnity policy provides indemnity for legal liability to third parties arising from breach of professional duty, neglect, error or omission in the course of the business of the University of Stirling. The limit of the Professional Indemnity cover is £5,000,000 for any one event/aggregate any one period of insurance.

Combined Liability Insurance: Employers Liability cover is provided for legal liability to employers for death, injury, illness and disease arising out of the business of the University of Stirling. Public/Products Liability is provided for legal liability for accidental loss of or damage to Third Party property or for death, injury, illness or disease arising out of the business of The University of Stirling including liability arising from goods sold or supplied. Indemnity Limit for each is £10,000,000.

Combined Excess Liability Insurance: Employers Liability & Public/Products Liability cover limit is £10,000,000 in excess of £10,000,000 with a total limit of indemnity in respect of Employers Liability and Public Liability of £20,000,000.

I trust that this is sufficient for your requirements. Please do not hesitate to get in touch with me should you have any further queries.

Yours sincerely

Joy Taylor, Research Funding Officer

Appendix 5: South East Scotland Research Ethics Service: 13 April 2016

South East Scotland Research Ethics Service

Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG



Name: Donna L McGowan
Address: 39 Ale Moor Park
Edinburgh
EH7 6US

Date: 13/04/2016
Your Ref:
Our Ref: 16/SS/0088
Enquiries to: Alex Bailey
Direct Line: 0131 465 5679
Email: alex.bailey@nhslothian.scot.nhs.uk

Dear Donna,

Project Title: Lung cancer patients' experiences of outpatient chemotherapy services

You have sought advice from the South East Scotland Research Ethics Service on the above project. This has been considered by the Scientific Officer and you are advised that, based on the submitted documentation (email correspondence and REC form IRAS ID: 192082), it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees (A Harmonised Edition).

The advice is based on the following:

- *The project is a survey seeking the views of NHS patients on service delivery*

If the project is considered to be health-related research you will require a sponsor and ethical approval as outlined in The Research Governance Framework for Health and Community Care. You may wish to contact your employer or professional body to arrange this. You may also require NHS management permission (R&D approval). You should contact the relevant NHS R&D departments to organise this.

For projects that are not research and will be conducted within the NHS you should contact the relevant local clinical governance team who will inform you of the relevant governance procedures required before the project commences.

This letter should not be interpreted as giving a form of ethical approval or any endorsement of the project, but it may be provided to a journal or other body as evidence that NHS ethical approval is not required. However, if you, your sponsor/funder feel that the project requires ethical review by an NHS REC, please write setting out your reasons and we will be pleased to consider further. You should retain a copy of this letter with your project file as evidence that you have sought advice from the South East Scotland Research Ethics Service.

Yours sincerely,

Alex Bailey
Scientific Officer
South East Scotland Research Ethics Service



1 Headquarters
Waverley Gate, 2-4 Waterloo Place
Edinburgh EH1 3EG
Chair: Mr Brian Houston
Chief Executive: Tim Davison
Lothian NHS Board is the common name of Lothian Health Board

Appendix 6: First phase: SACT pre-assessment care pathway: themes of interest

SACT Pre assessment care pathway
Offers consistency: get things sorted (locum GP in the community: this was brought up frequently: unable to see same GP or regular GP) - Continuity is better coming here
Face-to-face discussion: chance to sit and ask questions go through any concerns
Staff that know about the illness and treatments: reassuring
Knowledge of what's happening with treatment: i.e. if bloods low or problem with blood
Time to get everything done: blood, weight and x ray
Felt looked after: more informative than GP: felt in more control
Not viewed as an extra visit if felt part a necessary part of the treatment
Very positive with too many advantages: everything done in one place with people that know about the illness and treatment and how these are managed.
Get to know the staff here and develop confidence in them
Staff know what questions to ask and what to look for: that is good to know
Feel happier coming here: feels safer: less rushed and time to go through my concerns
Feel more able to ask questions and have confidence that they know the answer: developed relationship with staff here and don't have to go through my story time after time.

SACT management
Tiredness difficult to cope with but can accept that if chemotherapy works
Would do it again: more time, 'I need my chemotherapy'
Allowed me to continue my life: I can still work: my cancer is under good control: I feel very well.
Tiredness is the worst: I work around this though: controlling the disease
Pain has gotten better: my breathing too; I feel lucky that the chemotherapy is working
Feel lucky that the chemotherapy has helped my cancer: more time with my family
Felt so unwell before, I actually feel better than I have felt in a long time
Knowing what to expect is the scary thing: first time was tough but then knowing its help control the cancer: would take it as long as it works

Staffing
Named nurse would be helpful
Professional and helpful, friendly
Nurses know what they are doing here
Too busy sometimes I feel sorry for them
Nurses know their jobs here, Good care: very attentive
Very grateful for all the care the girls show even when they are run off their feet
Genuine concern shown

SACT telephone assessment: themes of interest drawn from patient interviews

SACT Telephone assessment
Telephone assessment worked well. Timed assessment might be helpful
During radiotherapy had weekly face-to-face discussion with nurse: found that very informative and helpful: could see the value in similar approach to SACT
Not enough time if see my GP: I had to have my questions at the ready to make sure I didn't go too much over the time
Admit didn't understand the point of the pre assessment: wasn't explained and now having had chemotherapy I feel different and might feel different if offered
I declined the pre assessment as I didn't think it was necessary, I did feel bad as everyone here is so good and I have been so well looked after.
I admit I just said the right thing to the nurse on the phone: I wanted my chemotherapy
Phone assessment was very good: enough time to ask questions, but I suppose it's never as good as a sit down with someone and going through it face-to-face.
Missed telephone call: helpful to know when might phone: Iceland can give a time slot, maybe the NHS can
I would be happy to phone in myself and give my assessment to the nurse rather than waiting for the phone call as it can hold my whole day up
I missed the pre assessment thing, but I did see the nurse over there during the radiotherapy and I did prefer the sit down with her so I do think that a sit down with a nurse or a doctor here would be a good thing. I didn't mind the telephone thing but it's not the same

SACT management
Coped really well I think: good support from here
Still managing to work: important for me: it keeps things normal
My pain is so much better: the treatment has shrunk the cancer. I am so pleased.
Do it again in a minute, I have no option: it's all about more time isn't it.
It's so emotional at the start: very scary: I was in shock the first month
It's been tough, it knocked me for six at the start but I still want it, my cancer can't be cured but it will give me more time
I really wanted the treatment in St John's: I wouldn't have any of this bother if I could have it in the hospital near me
Here for hours getting different things done, didn't even get my chemo that day
Time is limited so need to make most of it: worthwhile if can get more time
Tiredness the most frustrating thing ; no energy: but I know it's helping so I accept that
This is my second time and I have coped well: it helped last time and I hope it will again. I would take anything to help
Lots of delays low bloods, need to see the doctor here and few times didn't get the chemotherapy
Small chance the cancer will stay away, so I will do everything that is asked of me
I was lucky they cut the cancer out, so I felt I had to take the chemotherapy so if it does come back then I know that I done everything to stop it.
Feel brilliant: felt so unwell before the treatment: I feel great: I have worked and I am back at the gym

Staffing
Supportive, caring, and attentive, Fantastic staff, Nurses are great, very patient here
Not enough staff here, So busy, too busy; Place is just too small eh!
No proper rooms when I had to see a doctor: he had to stand and talk to me
They do an amazing job in here: just have to wait your turn though sometimes they are just too busy ; The constant beeping does my head in

Cancer treatment helpline (CTH)/Travel
Drove in each day for radiotherapy: if felt necessary as part of the treatment
Need Patient transport: so an extra visit is a lot for me: tiring too: especially at the start of the treatment
GP is round the corner: feels odd that I would come all the way here if could go to the GP
Refused the extra clinic: my neighbour brings me in, I can't ask them to bring me in an extra day.
Hospital transport takes you all over the place doesn't it: that's no good
Lives out of town and need transport: declined pre assessment: too much
Face-to-face is better than phone call which felt to be rushed but feeling unwell extra visit is a lot
Doesn't get on that great with GP but just around the corner so it is easier
Its two buses in for me so the extra visit would be a lot
I missed the pre assessment thing: travel not a problem for me: happily come here and deal with people that know me and know what I am getting
Prefer using the CTH; they are great: sort out everything in good time and know what they are doing
Another world in here that I didn't know existed
Feel brilliant: felt so unwell before the treatment: I feel great: I am at work and I am back at the gym
like the phone assessment: prefer that actually would not want to come here anymore than needed
Phone assessment is good: lets me get on with my life: I can speak to the nurse I know them all, I tell them any issues and I know things will be addressed the day I come. I think it works well. But saying that I have coped well and not really needed to see a doctor.

Appendix 7: Patient Information Sheet



Participant Information Sheet

Study title: Lung cancer patients' experiences and perceptions of outpatient chemotherapy services

Invitation: I am inviting you to take part in a research study. This research is part of a clinical doctorate programme with the University of Stirling. My current role within NHS Lothian is Nurse Clinician in Chemotherapy.

It is up to you to decide whether to take part in this research study. It is important that you understand why the research is being done and what it will involve for you. Please take time to read the following information sheet and ask any questions if anything is not clear, or if you would like more information. This information sheet is yours to keep whatever you decide.

If you agree to participate you can change your mind at any time and withdraw from the study without giving a reason. The standard of care you will receive will not change.

What is the purpose of the study? An ongoing quality improvement project reviewing an outpatient chemotherapy service found that lung cancer patients require considerable treatment time and care within the chemotherapy unit and the current care pathway no longer meets the needs of this patient group.

There is suggestion that in other areas of healthcare (an example is surgery) the addition of a pre-assessment care pathway can provide quality patient centered care.

I would like to invite you to participate in this study which aims to explore your experiences and perceptions of how we currently work within the outpatient chemotherapy unit.

Why have I been chosen? You have been chosen to take part in this study as you have been referred for a course of chemotherapy.

What happens next? I will arrange to meet you at your first cycle of chemotherapy here at the hospital. If you are considering taking part in the study, I will provide you with an information sheet. If you agree to take part, I will arrange to meet you at your second cycle of chemotherapy, and answer any questions you may have.

If you do not wish to participate please mark in the box and return this form when you attend for your second cycle of chemotherapy.

If you do not wish to take part the standard of care you will receive will not change.

What will happen if I take part? I will ask you to sign a consent form and you will be given a copy of this to keep. You will be invited to take part in an interview after your third cycle of chemotherapy. The interview will last approximately 60-90 minutes. The interview will be arranged at a time that suits you and at a place where you feel most comfortable, whether at your home or within the hospital. The interview can be interrupted to allow for pauses or comfort breaks as necessary or can be stopped at any time should you wish. I would like to audio record the interview so that I have an accurate record instead of relying on taking notes.

The aims of the interview in particular are to:

- (1) Hear about your experiences and perceptions of attending for your chemotherapy.
- (2) Learn from your views as to how we can improve the overall service within chemotherapy day-care services that may help other patients.

The interview will be audio recorded and transcribed within 4-6 weeks from the interview and then destroyed. All your personal details will be removed from the transcript and will be kept safely and held in confidence.

Will my taking part be kept confidential Information which is collected about you, or that you provide during this study, will be kept strictly confidential. Your personal details will be removed so that you will only be identified by a code number. The researcher and her supervisory team will be the only people to have access to your details.

All information will be held securely for a period of 10 years, as required by the University of Stirling policy. However, any audio-recorded information from you will be destroyed once the study is complete.

What are the possible disadvantages of taking part? There is a time commitment of approximately 60-90 minutes. Understandably, some patients may find it difficult to talk about parts of their cancer treatment. It is important that you know if there is anything which makes you feel uncomfortable; you do not need to take part and the interview can be stopped. The researcher is available to discuss any anxieties you may have.

What are the possible benefits of taking part? There are no direct benefits to you taking part in this study however the information gathered will be used to help advise improvement in the care of patients with lung cancer receiving chemotherapy within the outpatient chemotherapy unit.

Who is reviewing the study? The study proposal has been reviewed and approved by the School of Health Sciences Research and Development Ethics Committee within the University of Stirling. The study has also been reviewed and approved by the South East Scotland Research Ethics Service (SESRES) and by NHS Lothian Research & Development.

What will happen to the results of the study? Once the results of the study have been analysed I will write a report, which will be shared locally through a presentation at a conference. I will also prepare the results to be published within a peer-reviewed journal. A summary of the results of the study will be provided to participants if they would like a copy. Please let me know.

Thank you for taking the time to read this information.

If you would like to find out more about the study; please feel free to contact –

Donna McGowan
Research Student: University of Stirling
(Nurse Clinician – Chemotherapy)
Ward 1, Edinburgh Cancer Centre
Western General Hospital
Crewe Road South
Edinburgh
EH4 2XU
Donna.mcgowan@luht.scot.nhs.uk
Tel: 0131 537 1185

Or, if you wish to speak to an independent advisor about the study or if you have any complaints, please contact:

Professor Jayne Donaldson
Head of School of Health Sciences and Sport
RG Bomot Building
University of Stirling
FK9 4LA
Tel: 01786 466

Patient Information Leaflet

Systemic Anti-cancer Treatment (SACT) Pre-Assessment Clinic

*(SACT will refer to chemotherapy from this point onwards)

Why do I need to attend the chemotherapy pre assessment clinic?

Before each cycle of your chemotherapy, we need to make sure that you are well enough to proceed. Before starting each cycle, you will be assessed by a Doctor or Advanced nurse practitioner.

Our aims of the chemotherapy pre assessment clinic:

- Assess you are fit and well for each cycle of chemotherapy
- Assess all the relevant tests that are required before each chemotherapy
- Discuss your planned chemotherapy and side effects of the chemotherapy that you have concerns about
- Ensure any changes to your treatment plan are outlined and discussed

A treatment plan will have been outlined by your consultant:

- The nature and duration of the chemotherapy
- Written and verbal information about the possible side effects of the chemotherapy
- Discussed and signed the consent form for chemotherapy

What you can expect at your first chemotherapy pre assessment clinic appointment:

During the first pre assessment clinic a number of tests will be carried out:

- Chest X-ray and Blood tests
- Electrocardiogram
- Check your blood pressure, pulse, temperature and oxygen levels
- Measure height and weight to work out your BSA (Body Surface Area)
- List your current medications including any supplements or herbal medicines

During subsequent appointments, the following tests will be carried out:

- Chest X-Ray (as necessary) and blood tests
- Check your blood pressure, pulse, temperature and oxygen levels
- Check your weight
- Discuss any new symptoms or side effects of the chemotherapy that you are concerned about

Appendix 8: Participant Recruitment: Group 1 – First phase of SACT pre-assessment care pathway (April 2016)

	Participants Name	Patient Information Sheet	Interview and Comments	Outcome and Patient code	Interview complete
1	R H (m-74)	yes	Interview: C4 (cis/pem)	Group 1:07	Yes
2	G S (m-71)	yes	Interview: C4 (carbo/etop)	Group 1: 06	Yes
3	B W (f-62)	yes	Interview: C4 (carbo/etop)	Group 1: 01	Yes
4	C B (f-61)	yes	No reason provided	No: withdrawn	no
5	C D (m-84)	yes	Feels is too much for him	No: withdrawn	no
6	A H (m-62)	yes	Withdrawn from study	Group 1: 05: became unwell: unable to interview	no
7	J C (m -71)	yes	Interview: C3 (cis/pem)	Group 1: 02	Yes
8	A R (m-68)	yes	Interview: 4/7/16	Group 1: 03	Yes
9	C M (f-66)	yes	Interview: C2 maintenance	Group 1: 04	Yes
10	T C (m -78)	yes	Interview: C1 maintenance	Group 1: 09	Yes
11	B M (m -61)	No	Admitted: unwell and unfit	No: withdrawn	no
12	J C (m-68)	yes	Progressed on CT scan: withdrawn	No: withdrawn	no
13	L M (f -61)	yes	Interview: C4 (pem)	Group 1: 08	Yes
14	A L (m -74)	yes	became unwell: withdrawn	Group 1: 10:	no
15	MM (m -55)	yes	No reason provided	No: withdrawn	no
16	IM (m -78)	yes	feeling tired and feels it all been too much	No: withdrawn	no
17	J M (m- 53)	posted	Interview: 4/7/16	Group 1: 11	Yes

Appendix 9: Participant Recruitment: Group2 - Current assessment process and those declined first phase of pre-assessment care pathway

	Participant Name	Patient information sheet	Comments	Outcome and Patient code	Interview complete
1	SL (f -65)	Yes	Interview: 17/6/16	Group 2: 01	Yes
2	S M (f -60)	Yes	Interview: 29.6.16	Group 2: 02	Yes
3	MB-J (f -54)	Yes	No: declined	Too much: withdrawn	No
4	EL (f- 67)	Yes	No appropriate	Became unwell: withdrawn	No
5	LH (f-69)	Yes	Interview 30/6/16	Group 2: 04	Yes
6	DB (m-54)	Yes	Interview 27/6/16	Group 2: 07	Yes
7	JD (f-85)	No	Did not attend: unwell	Became unwell: Not approached	No
8	MB (f-74)	Yes	Interview: 21/6/16	Group 2: 12	Yes
9	J S (m -32)	Yes	Interview: 29/7/16	Group 2: 03	Yes
10	SB (m-47)	No	No (chemo deferred)	Unwell: too much: not approached	No
11	MC (f-62)	Yes	Interview: 16/6/16: C4D8	Group 2: 05	Yes
12	JO (f-74)	Yes	Interview 11/7/16	Group 2: 06	Yes
13	JM (m-78)	Yes	No appropriate	Too much for me, don't like that kind of thing: withdrawn	No
14	DC (m-76)	Yes	Interview 03/08/16	Group 2: 08	Yes
15	JS (m-75)	No	Not appropriate	Became unwell: not approached	No
16	W J (m-78)	No	Not appropriate	Became unwell: not approached	No
17	SM (f-60)	Yes	Too Tired, feeling unwell: not appropriate	No: withdrawn	No
18	MY (f-61)	Yes	Interview: 4/8/16	Group 2: 09	Yes
19	RG (m-76)	No	Unwell	Not fit for chemotherapy: not approached	No
20	PM (f -78)	Yes	Interview: 18/8/16	Group 2:10	Yes

21	GH (m-71)	Yes	SACT stopped	Became unwell: withdrawn	
22	RB (m-48)	Yes	Interview: 09/08/16	Group 2:11	Yes

Appendix 10: Participant Recruitment: Group3 - Second phase SACT pre-assessment care pathway (November 2016)

	Participant Name	PIS given	Comments	Outcome and Patient code	Interview complete
1	MB (f-78)	Yes	SACT : C1: 26/10/16, C3: 21/12/16	Became unwell: withdrawn	no
2	AN (m-62)	Yes	SACT : C1: 01/11/16, C3: 13/12/16	Group 3: 03	yes
3	GC (m-60)	Yes	SACT :C1: 01/11/16, C3: 13/12/16	Group 3: 02	yes
4	WT (m-80)	Yes	SACT : C1: 02/11/16, C3: 14/12/16	Group 3:04	yes
5	JM (f-76)	No	SACT : C1: 08/11/16, C3: 03.01.17	Not appropriate: not approached	no
6	RM (m-80)	Yes	SACT :C1: 09/11/16, C3: 21/12/16	Group 3: 01	yes
7	MM (f-63)	Yes	SACT :C1: 10/11/16, C3: 22/12/16	Group 3: 05	yes
8	BL (m-53)	Yes	SACT :C1: 14/11/16, C3: 26/12/16	Group 3: 06	yes
9	CT (f-79)	Yes	SACT : C1: 17/11/16, C3: 29/12/16	Group 3: 07	yes
10	RC (m-78)	Yes	SACT : C1: 22/11/16, C3: 03/01/17	Group 3: 08	yes
11	MM (f-65)	Yes	SACT : C1: 01/12/16, C3: 12/01/17	Patient too unwell: withdrawn	no
12	JK (f-78)	Yes	SACT : C1: 29/11/16, C3: 10/01/17	Group 3:09	yes
13	JJ (m-65)	Yes	SACT : C1: 07/12/16, C3: 18/01/17	Not appropriate: withdrawn	no
14	LH (f-58)	yes	SACT : C1: 02/01/17, C3: 14/02/17	Refused too much: withdrawn	no
15	AA (f-78)	No	SACT : C1: 10/01/17	Became unwell: not appropriate	no
16	K F (f-52)	yes	SACT : C1: 18/01/17, C3:01/03/17	Group 3: 10	yes
17	CH (f-65)	No	SACT : C1: 25/01/17	Became unwell: not appropriate	no
18	CS (m-61)	Yes	SACT :C1: 30/01/17	Refused: too much: withdrawn	no
19	AW (m-76)	Yes	SACT : C1: 03/02/17	Refused: withdrawn	no
20	DH (m-54)	No	SACT : C1: 01/02/17	Became unwell: not appropriate	no
21	HS (f-78)	no	SACT : C1: 06/03/17	Became unwell: not appropriate	no
22	GF (m-65)	yes	SACT : C1: 14/03/17	Became unwell: withdrawn	no

23	MF (f-81)	yes	SACT : C1: 29/03/17 C2: 19/04/17	Refused: changed mind: withdrawn	no
24	JM (m-59)	yes	SACT : C1: 07/03/17, C3: 08/05/17	Group 3: 11	yes
25	MF (f-61)	no	SACT : C1: 08/03/17, C2: 29/03/17	Became unwell: not appropriate	no
26	CM (m-74)	yes	SACT : C1: 06.03.17, C2: 03/04/17	Became unwell: withdrawn	no
27	S J (m-68)	no	SACT cancelled: unfit for treatment	Not appropriate: not approached	no
28	DL (m-78)	yes	SACT : C1: 21/03/17 C2: 11.04/17	Refused: withdrawn	no
29	JG (m-58)	no	SACT : C2: 05.04.17	Became unwell: not appropriate	no
30	AM (m-65)	yes	SACT : C1: 28/03/17 C2: 18/04/17	Refused : withdrawn	no

Appendix 11: Consent form



Patient Consent Form

Lung cancer patients' experiences and perceptions of outpatient chemotherapy services - A qualitative case study approach.

		Please initial box
1.	I confirm that I have read and understand the patient information sheet for the above study and have had the opportunity to ask questions.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.	
3.	I agree to take part in the above study.	
4.	I understand and agree to participate in an interview.	
5.	I would like to audio record the interview to have an accurate record instead of relying on taking notes.	

Name of participant

Date

Signature

Name of researcher

Date

Signature

Version 4. 24/03/2016 (ref: SREC 15/16 – Paper No. 50 – version 1)

Appendix 12: Interview guide: group1–3

Group 1: Interview topic guide – SACT Pre Assessment care pathway: (April 2016)

Experience/perception of the chemotherapy outpatient unit will be explored through the following:

1. Introductions: thank you for agreeing to participate in this study. As I have explained this is a study with the University of Stirling. As a department we have been looking at how the service is delivered within the outpatient chemotherapy unit.
As you have recently attended the new pre assessment chemotherapy clinic I would like to hear about your experiences and views of the clinic.
2. Care needs addressed/met. Medical assessment:
 - a. What has been important to them (about the medical assessment)? Why was this important?
 - b. What was good/bad for them or could be better?
 - c. Symptom control of disease and treatment related side effects. Has chemotherapy helped? Has chemotherapy been worthwhile? What was expectation?
 - d. Did you see a nurse or a doctor? Does that matter?
3. Information provision/needs (try to take them back to the consultation):
 - a. Tell me about the consultation:
 - i. How informed did this make you feel?
 - ii. Did this matter to them?
 - iii. Were their concerns addressed?
 - iv. If offered the service again would they want this service?
 - v. Were side effects from the chemotherapy worse/better than you thought?
4. Travel time and distance travelled: how this impacts their life:
 - a. Who brought you?
 - b. Parking?
5. Detail length of wait to start chemotherapy:
 - a. How this influenced the chemotherapy?
6. Detail delays during your chemotherapy, length of the delay and reasons for the delay.

10/04/2016 version 2

Group 2: Interview topic guide: SACT Telephone assessment (current practice)

Experience/perception of the chemotherapy outpatient unit will be explored through the following:

1. Introductions: thank you for agreeing to participate in this study. As I have explained this is a study with the University of Stirling. As a department we have been looking at how the service is delivered within the outpatient chemotherapy unit.
I would like to hear about your experiences and views of when you received your chemotherapy within the outpatient chemotherapy unit.
2. Were your care needs addressed/met?
 - a. Telephone assessment: views and thoughts?
 - b. What has been important to them? Why was this important?
 - c. What was good: what was bad? And what could be better?
 - d. GP visit for bloods?
 - e. What was good what was bad? or what could be better?
 - f. Symptom control of disease and treatment related side effects.
 - i. Has chemotherapy helped?
 - ii. Has chemotherapy been worthwhile?
 - iii. What was expectation?
3. Information provision/needs:
 - a. How informed do you feel about chemotherapy?
 - b. Is this important? More information? less information?
 - c. Were their concerns addressed when attended ward 1?
 - d. Were side effects from the chemotherapy worse/better than you thought?
4. Travel time and distance travelled: how this impacts their life:
 - a. Who brought you to ward 1?
 - b. Parking?
5. Detail length of wait to start chemotherapy:
 - a. Anxious to start?
 - b. When did they get appointment?
 - c. How long they had to wait?
6. Detail any delays during your chemotherapy, length of the delay and reasons for the delay.

9/06/2016 version 1

Group 3: Interview topic guide: Follow-up SACT Pre Assessment care pathway (Oct 2016):

Experience/perception of the chemotherapy outpatient unit will be explored through the following:

1. Introductions:

- Thank you for agreeing to participate in this study.
- Explain this is a study with the University of Stirling.
- Explain as a department we are looking at a pre assessment service for patients undergoing SACT for lung cancer.

Having attended the pilot chemotherapy pre assessment clinic I would like to hear about your experiences and views of the service.

2. Pre assessment: care needs addressed/met:

- What was important to you from the pre assessment?
 - Why was this important?
- Can you tell me what you think was good and bad about the service and what you think could this have been better?
- Thinking about helping to control the symptom of your lung cancer and the treatment related side effects:
 - Do you think the chemotherapy has helped you?
 - Do you think the chemotherapy been worthwhile for you?
 - What was your expectation from the treatment?
- Did you see a nurse or a doctor at the pre assessment clinic?
 - Does that matter if it is a nurse or doctor

3. Information provision/needs:

- Tell me about the consultation:
 - How informed did this make you feel about the treatment?
 - How important is it to feel informed?
 - Were your concerns addressed?
 - If offered the pre assessment service, would you want this type of service as standard?
 - Tell me about any side effects you have experienced from the chemotherapy and how these have been managed for you?

4. Travel time and distance travelled:

- Who brought you in each visit?
- Did you experience any car parking issues/transport issues?

5. Did you experience any delays during your chemotherapy?

- Detail any length/reason of the delay in chemotherapy.

Appendix 13: Reflective piece –post first interview

I was somewhat surprised to feeling more nervous than I thought I would have considering that communicating with patients is something that I do every day and something I feel confident in my ability to I do well.

I was however aware that the participant was also feeling nervous about taking part in the interview, as he had said on a number of occasions that he had never been asked to do anything like this before. Aware that he was feeling nervous helped to settle my nerves, as I certainly didn't want to cause the participant any unnecessary stress during the interview. I had reserved a small consulting room within the SACT treatment area and it provided sufficient privacy and comfort to carry out the interview. I found it was useful to have prepared the introduction and a topic guide for the interview however I was aware this was a guide and I planned to evaluate how helpful it would prove. It was possibly a bit more wordy than it needed to be but I did feel it would help to 'set the scene' and useful to start the discussion.

I thought it was important to reinforce that I wanted to collect his views and experience from the first phase of the SACT pre assessment care pathway. These were valuable to me and were the main purpose for conducting the interview.

Throughout the interview, he was very willing to answer my questions but I felt it was initially difficult to open up the conversation and widen his replies. Some of his answers were quite closed and further probing was needed. I felt it would have been easy to take the lead in the discussion and prompt his replies but instead I persisted and continued to try and probe further for more detail about his experiences.

Despite this, as the interview progressed, his answers remained short which although they answered my questions they continued to lack depth. I also felt that it was apparent that he was grateful for his care and the treatment he was receiving and he appeared anxious to provide positive feedback. He described one experience of an incident when his SACT had been delayed on the day of

treatment. This was apparently due to a preparation error and he was anxious to ensure that no one got blamed for this, but at the time he had found it stressful. He has continued to work full time within his own business, so found it very frustrating to spend four hours within the treatment area instead of two hours. He described the importance of SACT as he felt that his treatment was going well. He had experienced few side effects since his first treatment when he was admitted to the hospital with an infection and low blood counts and clinically he now felt very well.

I felt that I rushed the interview despite trying to consciously slow it down. I think this was due to his closed responses and answering the questions very directly. When I switched the digital recording off as he asked, I felt he then spoke more freely, so possibly the fact he was being recorded intimidated him more than I realised.

Summary/points to take forward: I felt that my probing skills needed more practice and I lacked confidence picking up cues and probing further.

Appendix 14: Example of hand-written notes from interview

24/5/16 PAC 08 - Quality Time / Quantity
 - Aware life limiting

Interview topic guide:

Experience/perception of the chemotherapy outpatient unit will be explored through the following:

- Doesn't cope well with diagnosis.
- everything is done ^{questions} answered
- Know what's happening

1. Introductions: thank you for agreeing to participate in this study. As I have explained this is a study with the University of Stirling. As a department we have been looking at how the service is delivered within the out patient chemotherapy unit.

feel happier

As you have recently attended the new pre assessment chemotherapy clinic I would like to hear about your experiences and views of the clinic.

nurse knows nothing at CTP practice.

worried+++

Care needs addressed/met. Medical assessment:

someone to talk too

a. What has been important to them (about the medical assessment)? Why was this important?

reassurance : anxious - always

- Calms my nervous very anxious

b. What was good/bad for them or could be better?

- Always would want to come here :- anxious but inbetween can carry on when time

c. Symptom control of disease and treatment related side effects. Has chemotherapy helped? What was expectation?

- Yes very much : informative

GP isn't able to

d. Did you see a nurse or a doctor? Does that matter?

expert!!

asks questions - no answer.

3. Information provision/needs (try to take them back to the consultation):

a. Tell me about the consultation:

i. How informed did this make you feel?

overwhelmed

Very anxious

ii. Did this matter to them?

Time!!

Reassured

iii. Were their concerns addressed?

- Consistent / knows staff here now.

iv. If offered the service again would they want this service?

would want this service Never feel same all the time. GP

v. Were side effects from the chemotherapy worse/better than you thought?

Can cope - wants treatment.

4. Travel time and distance travelled: how this impacts their life:

a. Who brought you? husband / daughter - no problem.

b. Parking?

- no concerns.

10/05/2016 version 2

Really hope they speak this I was spelt wrong the GP yesterday
 Normies started about everything. depressed?
 nurse or doctor as long as in home d.
 clinic or ward?
 - clinic
 - need space + no noise.
 bleep bleep does my head in
 - why chains so close

⊗ Nurses so busy its not their fault I actually feel for them.

-
5. Detail length of wait to start chemotherapy:
a. How this influenced the chemotherapy? - No.

6. Detail delays during your chemotherapy, length of the delay and reasons for the delay.

Yes: bloods too low: repeat usually done in
the ward
- Wrong Chemo. - ↑ time on the ward
- discussed! - ↑ delays treatment!

Environment - noisy / over crowded
machines.
nurses work incredibly hard.
more staff.

I know I can bring my appointment
forward but I know how busy she
is so I don't like to. - Experts!
Reassuring!

Appendix 15: Transcribed interview

Thank you for agreeing to participate in this interview. As I explained earlier that this is a research study I am doing with the University of Stirling as part of doctorate programme, so as such there is a consent form to sign if that's ok with you. You'll see the consent form highlights that I would like to record the interview to ensure I pick up everything that's said and I can listen and not have to take too many notes. Is that ok with you?

Participant: yes, that's fine. *(shown and consent form signed)*

Me: *ok, so, I have asked you to participate in this interview as you have attended the unit over the last couple of months for your chemotherapy. So, tell me what are your thoughts about the the unit, the care you have had and the service provided?*

Participant: absolutely excellent, yes, to be honest with you its been excellent, it's a shame that there are few things broken around the ward like I've seen a bedpan keeping the window open and there are bits of the electrical panel hanging off the wall, that's a shame because these things are not important and wouldn't take much to fix I suppose but I noticed them straight away.

Me: *that's interesting that you notice the environment straight way though, did that have any effect on you and how you felt about coming here for your treatment?*

Participant: well, I suppose maybe, its first impressions isn't it but in terms of the staff and the treatment, well, they have both been fantastic, every single staff member has been so supportive, caring and attentive, so I am grateful for that and that is what's important.

Me: *ok, so thinking about aspects of your care in the unit, what about any waiting times you might have experienced: waiting for treatment, waiting for a nurse or a doctor, waiting at reception?*

Participant: no, I haven't had any problems there at all. I have needed to be seen both by a nurse and a doctor when I had problems with my hearing but that was maybe only 10-15 minutes I waited, and there are lots of people here so I really can't complain about that.

Me: *ok we also want to look at the assessment bit, you have received a telephone assessment by a chemotherapy nurse before each chemotherapy, is that right?*

Participant: yes that's right, I have, I think it's been fairly thorough and certainly I have always been given the opportunity to ask a question. When I had a telephone assessment when I called the treatment helpline that felt more like a tick box exercise, the telephone assessments before the chemotherapy sessions have been different they were more like an enquiry into how I am feeling and a conversation.

Me: *and are you given ample or enough opportunity to ask any questions or concerns that you have?*

Participant: yes, absolutely.

Me: *and are you aware of when the nurse might call you?*

Participant: no, I can see how that might be a problem for some people but that's not been a problem for me, I think once I wasn't able to take the call but I called back and I did get through with no problem. I do understand that giving a time might be difficult from this end given the number of calls to be made but I can also see how that might help patients, for me though it really hasn't been an issue.....maybe a timed call might be helpful, 'Iceland' even offer a timed call so maybe the NHS can try to"

Me: *ok, that's useful thank you, so when you do come in the next day then are you given the opportunity to go through this assessment that's been done and any of the concerns that you have had?*

Participant: yes, I am, I have always gone through with the nurse and chatted through things before the treatment starts, but twice I have had to get my bloods re checked, so that has always been what worried me the most. I have had problems with my hearing too, but I know that's an effect from the chemotherapy and I manage that well anyway.

Me: *ok so I'm not sure if you are aware of the pilot pre assessment clinic that was set up here in the ward, which looked at maybe replacing the visit to the GP/practice nurse and the telephone assessment with a face-to-face assessment and other investigations that were needed also done here? has that been explained to you?*

Participant: well, I've not really needed to see my GP, maybe only once since my diagnosis, the practice nurse is who I see for the blood test and any repeat prescriptions for my pain relief I pick up that up from the chemist.

Me: *so, is it the GP that monitors your pain control at the moment?*

Participant: Well I monitor it, but I think I would likely ask here if I thought I needed it reviewed, purely because I don't see the same GP, its mostly locums and there is always a problem getting an appointment at my practice anyway.

Me: *so, even if you highlight that you need a review related to your cancer treatment you still have problems getting an appointment with a doctor?*

Participant: yes, I do, even though my GP started the pain relief, it is always a stressful thing to get an appointment that suits, and I find there is a lack of consistency. I'm not actually sure who my own GP is now

Me: *and is consistency an important aspect of the care you receive?*

Participant: yes, of course it is you know me, know what's going on with my treatment and know what my medications are. It's different here because you all know straight away what to do and how to do it.it happens quickly without any fuss.

Me: *ok, so thinking about a chemotherapy pre assessment clinic option here within the unit? Is that something of interest? You would have a face-to-face assessment; bloods would be done here also.*

Participant: well, I think I had just missed that as I started my treatment at the end of April, but I do actually think I have had the opportunity to have a face-to-face discussion when I have been getting my radiotherapy alongside the chemotherapy. The day before the chemotherapy session, it's the radiotherapy nurses that have been doing my bloods the last 2 chemotherapy sessions and certainly I have had the opportunity to sit with Roseann and go through questions I have had, and I have to say I have found that very useful and helpful. Especially as I started having trouble with my hearing the face-to-face discussion was very helpful and reassuring.

And of course she knows a lot about the chemotherapy, so was able to reassure me about a lot of things, so I suppose I did have the best of both worlds.

Me: *can you tell me a little bit more about how Roseann was able to reassure you then?*

Participant: well, I did build up a connection there and she knew if I wasn't feeling great, once even by looking at me she said I looked tired and I was. I didn't feel great; I was then seen by one of the doctors and checked over, that was so reassuring. Even if there is communication between radiotherapy and here Roseann would do all that. If I needed repeat bloods, things like that. Now my radiotherapy finishes next week, but I've still more chemotherapy to have so it will be interesting how I manage as I won't have that chance anymore

Me: *does that worry you?*

Participant: no, not really because I know everyone here now and over the road so I think if I wasn't sure I would phone here for the reassurance or even the helpline.

But I do say I do absolutely think the face-to-face discussion is great, very helpful, even simple things to check is this ok, is that ok, you just want to make sure the treatment goes as well as it can and there are no hic ups. Even someone to say well try this, try that. Yes I really really appreciated that.

Me: *so, do you think the face-to-face assessment should replace the telephone assessment completely?*

Participant: well, I'm not sure really, did you say the assessment thing here might be optional? I do think with the telephone assessment there is less time given for any discussion and I'm not one for long telephone chats anyway

Me: *it could be yes? Would that be acceptable? Useful?*

Participant: well, when I go to the GP, I have to have question 1, question 2, question 3 and keep to time, I have actually been congratulated for keeping the GP to time and I suppose the telephone assessment can be a little like that. I'm not sure you can cover a face-to-face assessment with a telephone assessment. They are different aren't they? Like I said before Roseann could often look at me and knew if I was feeling poorly. So maybe optional if I'm not feeling great or I have concerns, maybe?

Me: *ok, I do understand what you are saying there: visually a nurse may be able to see if a patient isn't looking well which might be missed on a telephone assessment.*

Participant: Yeh, I think so, I don't think you can hear that over the phone and sometimes you don't want to admit you're feeling rubbish in case it affects the treatment and they say you can't have it. If I felt good though, I would be happy with the telephone assessment, so maybe I did have the best of both worlds.

Me: *ok, that is really helpful.*

(Break in interview: infusion bag change and comfort break)

Me: *ok, are you feeling ok to continue with the interview?*

Participant: yes, I am thank you.

Me: *so thinking about side effects from the chemotherapy, how have you managed with those you have experienced?*

Participant: well, I think I have been really lucky really, I've not really had too much, after the first cycle, I did feel rubbish but I think I just didn't know what to expect, but then after that I felt I have coped better. Yes, I have had problems with some hearing loss, but I know that's an effect from the chemotherapy. The tiredness too, that's sometimes a struggle, but I just do what I can, I try to carry on with what work I can manage.

Me: *and were you able to discuss these effects with Roseann (from radiotherapy) that helped you deal with them better?*

Participant: yes, I did and yes, it did help a lot. I also have some indigestion actually, and she managed to sort medication for that too.

Me: *so do you think the chemotherapy has made you feel better or worse?*

Participant: I have felt worse; I think oh yes I do feel worse. But I appreciate that I am having a combination of both radiotherapy and chemotherapy and I think that has made me more tired and I do feel it's getting worse steadily but I want to do all I can to try to beat this so I will take what is the best chance of that.

Me: *ok, now you mentioned that you are continuing to work at the moment?*

Participant: yes, I am I'm not managing a full day, I go for radiotherapy in the morning and maybe get to work for say 10am, I maybe work to about 3pm, sometimes its earlier, it just depends. I hit a mental wall almost and can't function anymore so I head home and usually fall asleep after my evening meal in the chair, sitting upright I add, for a couple of hours, I go into a deep sleep. But I have no problem getting off to sleep at night either, I am lucky there. But I wake early may 3 or 4; I maybe have a cup of tea/coffee and go back for an hour before getting up for the day.

Me: *and are you able to work Monday through to Friday?*

Participant: yes, it is, for me its normality, I would go mental sat at home all day and day time TV isn't great and I want to keep doing what I can. If I stop I'm afraid I will just completely stop, I do read, but again there's only so much reading I can do. It's keeping my mind active, that's how I cope

Me: *ok travelling in and out for both treatments, has that been difficult for you?*

Participant: no, not at all, I drive in; I have always been able to get parked.

Me: *Have you experienced any delays with your chemotherapy – on the day of treatment?*

Participant: no delays on the day really, I have had to have my bloods checked a couple of times and last week I was sent home as my bloods weren't good, that was disappointing, but I know that's common and so didn't worry once I was home.

Me: *Is there anything you would want to add about the ward?*

Participant: the beeping from the machines does my head in, it goes through my head, I think it's the changes to my hearing that has done it, but I sometimes do struggle with the noise level in the ward. I understand it's the machines and the need for it, but it is noisy. I know the nurses struggle with the noise too. One other thing I will mention which occurred the first time I came here for treatment, now for me it wasn't the end of the world, but in another scenario, this could have been very tricky.

I was asked to leave my specimen in the loo and given a label to put on the container. A woman who I know and that I didn't know was here as she was in another treatment bay went into the loo behind me and saw my name on the label. This lady didn't know that I had cancer, now as I said for me this wasn't the end of the world, it was complicated, a mutual friend of our mothers didn't know I had cancer and therefore I had to make sure they were told before hearing anything from someone else. In another scenario, that wouldn't have been ok, so I'm wondering if the labels are the best option here? Should names be taken off and a code used instead.

Me: *that's interesting and something I agree should be addressed within the unit. Is this something you would want taken forward on your behalf?*

Participant: well, the other person involved is a nurse, she I think has already spoken to someone about this, we grew up together. I haven't said anything to anyone, I'm alright about it now, but I do think it's something that could cause upset in another given scenario.

Me: *well, I think if you don't mind I will make sure that the charge nurse of the ward is informed about this so something else can be put in place. Does that seem ok with you?*

Participant: yes, I think that would be ok and I do think it's right, yes but I don't want to cause any upset to anyone and cause trouble, I am ok with it now but certainly it does need sorting doesn't it, yes that would be ok, thank you. I thanked her for taking part in the interview.

Total time: 52 minutes

Appendix 16: Draft article for publication in the *British Journal of Nursing*

Patients' experiences and perceptions of outpatient systemic anti-cancer treatment services – Implementing a new pre-assessment care pathway

Abstract

Background The demand for outpatient SACT services has increased by around 15% in the period 2011-2019. This has greatly affected treatment capacity and cancer/SACT waiting time targets for a variety of cancers. It became apparent within a large regional outpatient SACT centre the current care pathway for lung cancer patients was no longer person-centred or fit for purpose. Given this patient group face considerable challenges associated with their diagnosis, poor survival rate and disease/treatment-related side effects implementing a new pre-assessment care pathway had been identified as a possible alternative.

Objective Using qualitative methodology, semi-structured interviews with lung cancer patients were conducted to explore their experiences, perceptions and opinions of an outpatient SACT service following the implementation of a pre-assessment care pathway. The interviews were digitally recorded, transcribed and evaluated using a thematic analysis framework, combining a manual method and the computer software package NVivo.

Setting and Participants Thirty-two participants with lung cancer undergoing SACT in an outpatient setting were interviewed.

Results Through evaluation of the data, findings are presented within three overarching themes that were constructed from initial codes and initial themes. The overarching themes included: *consequence of lung cancer, the care delivery – a SACT pre-assessment care pathway and phone assessment and symptoms of lung cancer and side effects of SACT.*

Discussion and Conclusion Participants reported insight into the benefits of a SACT pre-assessment care pathway indicating this provided person-centred through tailored information and assessment. New knowledge of a SACT pre-

assessment care pathway reflects four broad themes that evolved from part one of the literature review, these themes include; improved patient capacity, efficient patient management through assessment, improved ability to self-care and improved patient experience. There was a connection between the SACT pre-assessment care pathway and participants feeling better informed about their decision-making. This showed improved compliance with treatment and improved management of side effects positively impacting on the quality of life for these patients.

Key words Lung cancer, systemic anti-cancer therapy, pre-assessment care pathway, person-centred, patients' experiences

Introduction

Traditionally the care pathway for systemic anti-cancer treatment (SACT) delivery uses either a single appointment pathway (one-stop system), or a pre-assessment care pathway (two-stop system) (Dobish, 2003; Summerhayes, 2003; Cook and Towler, 2009; Noonan-Shearer and Peacock, 2010; Lennan et al., 2012; Griffin, 2014). Since 2005, lung cancer patients within the regional outpatient SACT service have been treated using a single appointment SACT pathway. It had become apparent that the current care pathway was no longer person-centred or fit for purpose for lung cancer patients receiving SACT. They occupied a greater amount of chair time beyond what was scheduled for them and frequently required involvement from the medical team.

Alongside this, the demand for outpatient SACT services have increased by 15% in the period 2011-2019. An ageing population, improving cancer survival rates and the ongoing introduction of new and more complex SACT have contributed to the increased demand. Treatment capacity and achieving cancer waiting time targets have also affected the demand for outpatient services. A pre-assessment care pathway has been identified as a possible alternative and would aim to provide a person-centred care pathway.

Lung cancer is the second most common cancer in men and women and the leading cause of cancer-related deaths in Scotland, with approximately 5,331

new cases in 2017. It is estimated that 75% of these cases occur in the over 65 years age group and 47% are at a late stage (Information Services Division (ISD), 2019). Lung cancer is more common in deprived areas reflecting the generally higher prevalence of risk factors such as tobacco smoking. This is the number one risk factor for developing lung cancer and has been linked to 90% of all lung cancer cases. Age, race, genetics, poor diet, gender, radon exposure, environmental pollution, occupational exposures and pre-existing lung disease are also important contributors. (De Groot and Munden, 2012; Carter-Harris et al., 2015; Malhotra et al., 2016).

In relation to other cancers, lung cancer has a poor 5-year survival rate of 9.8%. This is thought to reflect that only 16% of patients who are diagnosed with lung cancer, found at an early stage in the disease process, were potentially curative and only 33% will survive one year following diagnosis (ISD, 2019). Many patients with lung cancer have pre-existing co-morbidities to cope with, which may affect their general health and determine both their fitness and tolerance for treatment (Islam et al., 2015; Sarfati et al., 2016). The most prevalent physical symptoms in patients with lung cancer include pain, fatigue and breathlessness. Lung cancer patients have also reported a significantly lower quality of life (QOL) compared with patients who have other cancers (Islam et al., 2015; Sarfati et al., 2016; Samet, 2018).

In keeping with a person-centred approach, this study aimed to explore a group of lung cancer patients' experiences and perceptions of current practice within outpatient SACT service, following the implementation of a pre-assessment care pathway. The aim of the research study is to explore lung cancer patients' experiences and perceptions of outpatient SACT service and determine whether a pre-assessment care pathway provided a person-centred care approach. The research questions included:

1. How do lung cancer patients describe their experiences and perceptions of attending an outpatient SACT service?
2. How do lung cancer patients describe their experiences and perceptions having attended a new pre-assessment care pathway for SACT?

3. Does a SACT pre-assessment care pathway reflect the constructed conceptual framework and provide perceived effective person-centred care for patients with lung cancer?

Literature review

A comprehensive review of the literature was conducted in two parts; part one included reviewing the literature of a pre-assessment care pathway within both an outpatient SACT service and within the surgical setting. Part two of the literature review reports on patients' experiences of a lung cancer diagnosis and receiving SACT. This process aimed to support my research aim and define the research questions.

Part one of the review found a lack of evidence to support either of the two currently operating pathways in use within outpatient SACT services. The research evidence from an established two-stop pathway or pre-assessment care pathway used within the surgical day-care and inpatient setting was explored. This was to determine whether it could be applied within an outpatient SACT service for a group of patients with lung cancer. The concept of a pre-assessment care pathway within the surgical setting is not new. In the early 1990s such clinics were introduced for these patients due to undergo a surgical procedure in an attempt to improve efficiency of both day-care and inpatient resources (Haines and Viellien, 1990; Mulldowny, 1993; Reed et al., 1997; Casey and Ormrod, 2003; Knox et al., 2009; Koris and Hopkins, 2015). Four broad themes were generated from the literature review: they included *'improving patient capacity with a pre-assessment care pathway'*, *'efficient patient management through patient assessment'*, *'the patients' experience of surgical pre-assessment'* and *'improving patients' abilities to self-care.'*

This enabled the construction of a conceptual framework (Figure1) to illustrate the four key strengths of a pre-assessment care pathway within a variety of surgical settings with patient experience and the principles of person-centred care forming the centre of the framework.

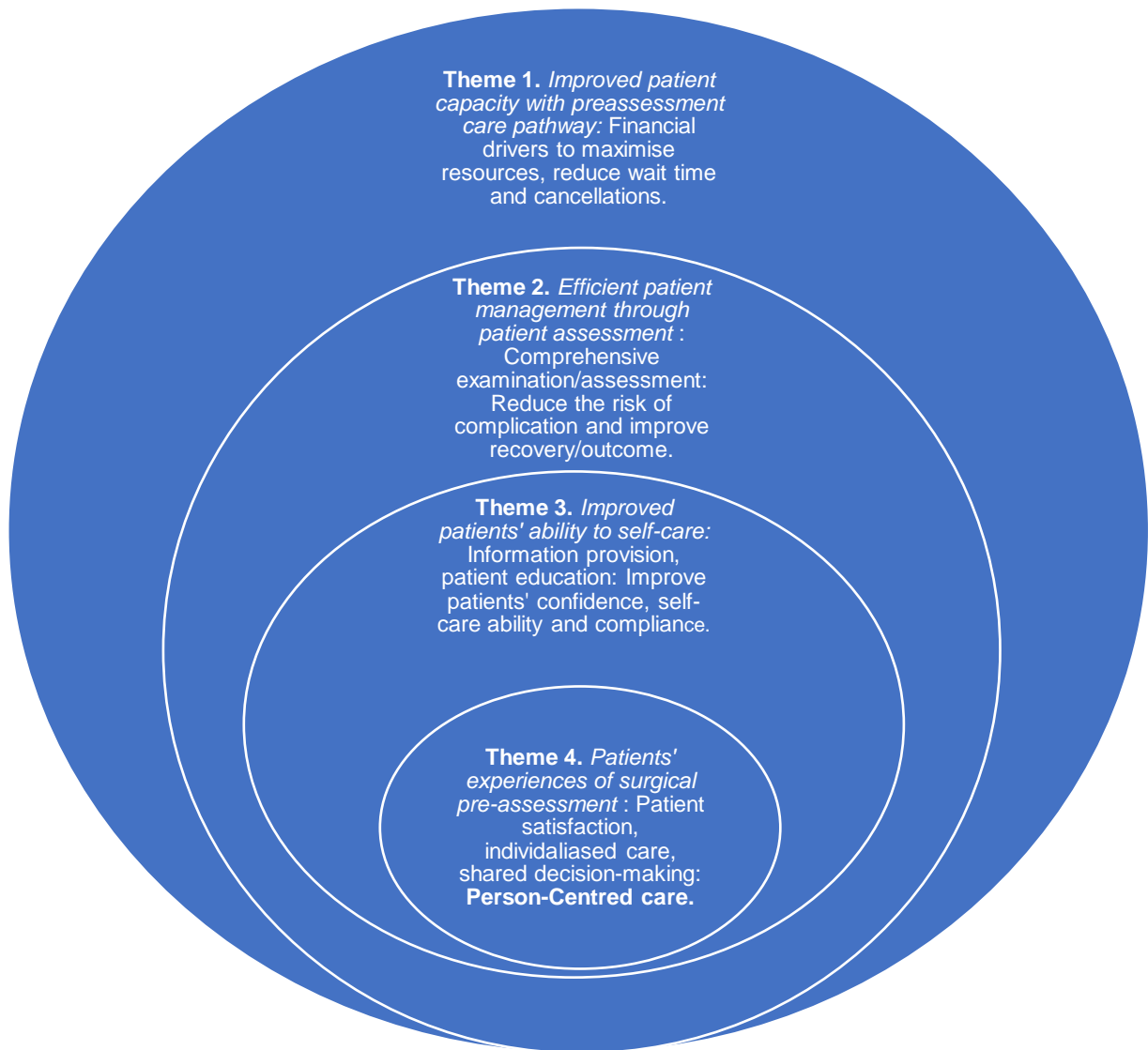


Figure 1. Conceptual Framework of a surgical pre-assessment care pathway

Part two of the review provided the understanding of patients' experiences' of a lung cancer diagnosis, the associated distress caused by both symptoms of the disease and side effects from SACT. The review also included how the patient experience can inform healthcare delivery to further support the aim of this research and further refine the research questions.

Methods

Qualitative methodology was dictated by the research aim and questions. This supported the discovery of new information in real-world terms. The research methodology was also guided by Creswell (2009), suggesting that qualitative

research seeks to establish the in-depth meaning of a phenomenon through the exploration of those who have personal knowledge of that experience within their natural setting. Using case study design offered a flexibility that was not readily available with the other qualitative approaches. A case study design enabled the study participants to tell their story through describing their own views and experience of their reality. This allowed new knowledge to develop and an evaluation of a relevant clinical intervention data to provide the information required. Case study design allowed the research questions to be answered and the usefulness of verbatim quotations within qualitative data to be evaluated. It assisted in the interpretation of the findings, support presented arguments and illuminate the participants' experiences whilst capturing their emotion (Stake, 2005; Merriam, 2009; Simons, 2009; Yin, 2014).

Sample

The study population were all individuals with a diagnosis of lung cancer, currently receiving SACT in the regional outpatient SACT service. Eligibility was determined using the criteria in Table1.

Table 1. Eligibility criteria

Inclusion criteria	Exclusion criteria
Patients aged 18 years and over	Patients aged under 18 years
Patients with the mental capacity to provide informed consent	Patients with mental incapacity and unable to provide informed consent Patients with neurological impairment
Fluency of the English language	Patients unable to speak English
Patients diagnosed with lung cancer and receiving SACT within the SACT day unit	Patients diagnosed with a mental illness., for example, bipolar disorder, schizophrenia and alzheimer's disease.

(Second phase: patients local to regional cancer centre with new diagnosis of lung cancer and referred for SACT)	
Patients scheduled to start SACT in the day-care unit	Patients that require to be clinically reviewed by the chief investigators' caseload and sphere of responsibility.

Potential participants for the study were identified through their community health index held on an information system. Whilst attending for their first cycle of SACT I approached those potential participants and provided verbal information about my research. Those who agreed to participate and attend a SACT pre-assessment care pathway were provided with a Participant Information Sheet. The participants were divided into three groups in order to identify those who had attended a pre-assessment care pathway and those who attended current clinical practice or had declined a pre-assessment care pathway.

Data collection

Thirty-two semi-structured interviews were carried out as these allowed the most beneficial and flexible opportunity to explore the textual descriptions about the participants' values, opinions and experiences. All the interviews were performed within NHS facilities and at the participants' convenience whilst attending and receiving SACT. Informed consent was obtained on the day of the interview, to ensure participants had been given both verbal and written information beforehand and the opportunity to ask any questions. A discussion guide was developed consisting of open-ended questions to encourage discussion. This allowed the freedom to express as many views as possible and also a small number of closed questions were added to clarify points during the discussion. Digitally recorded Interviews lasting 24 to 47 minutes were held, with transcribed verbatim removing personal information to maintain anonymity.

The decision to conclude the interviews was determined on the basis that no new information emerged and saturation had been achieved.

Ethical approval for the study was obtained from the Faculty of Health Studies and Sport Studies Research Ethics Committee. The IRAS application and supporting documents were submitted. Through discussion with key individuals it was agreed by the scientific officer that the research study did not require NHS ethics review, under the terms of the governance arrangements for Research Ethics Committee. This was based on the view that the research study was part of service development and quality improvement.

Data Analysis

In keeping with case study design the method of analysis selected was the flexible and pragmatic approach of thematic analysis. An adapted version of the six-step framework suggested by Braun and Clarke (2006) was utilised (Table 2).

Table 2. – Braun and Clarke's six-step framework for conducting thematic analysis

Step	Description of the process
1. Become familiar with the data:	Actively engage with the data by transcribing the data, reading and re-reading the data – immersed in the data, writing down any initial ideas.
2. Generate initial codes:	Code interesting features of the data systematically, collating data relevant to each code to create initial themes.
3. Search for themes:	Collate the codes and potential initial themes, looking for relationships between these. Organise into overarching themes relevant or meaningful to the research question.

4. Review themes:	Review, modify and develop preliminary themes identified in step 3 (phase 1). Generate a thematic 'map' of the analysis (phase 2).
5. Define themes:	Ongoing analysis to identify the essence of what each theme is about. Generating clear definitions and names for each theme.
6. Write up:	End point of research is some kind of report, journal article or dissertation.

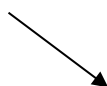
Braun and Clarke's (2006) six-step approach was used in combination with the software package NVivo and a manual method to facilitate analysis of the data gathered from the participants' interviews. This combination enabled exploration of any patterns and emerging themes and words that might enable a greater understanding of their context. The transcripts were initially examined using word frequency queries and text searches to explore the frequently occurring words within the data. Visualisation of these findings were created by generating 'word clouds' and 'text search trees' which were helpful when looking for recurring themes. Braun and Clarke's (2006) six-step framework was applied when manually analysing the data, this allowed the data to be subdivided into the initial codes and then refined into initial themes. Through further review and interpretation, the initial codes and themes were collated as shown in thematic map 1 (Table 3). Then according to their relevance and relationship between these themes, three overarching themes were formed as illustrated in thematic map 2 (Table 4).

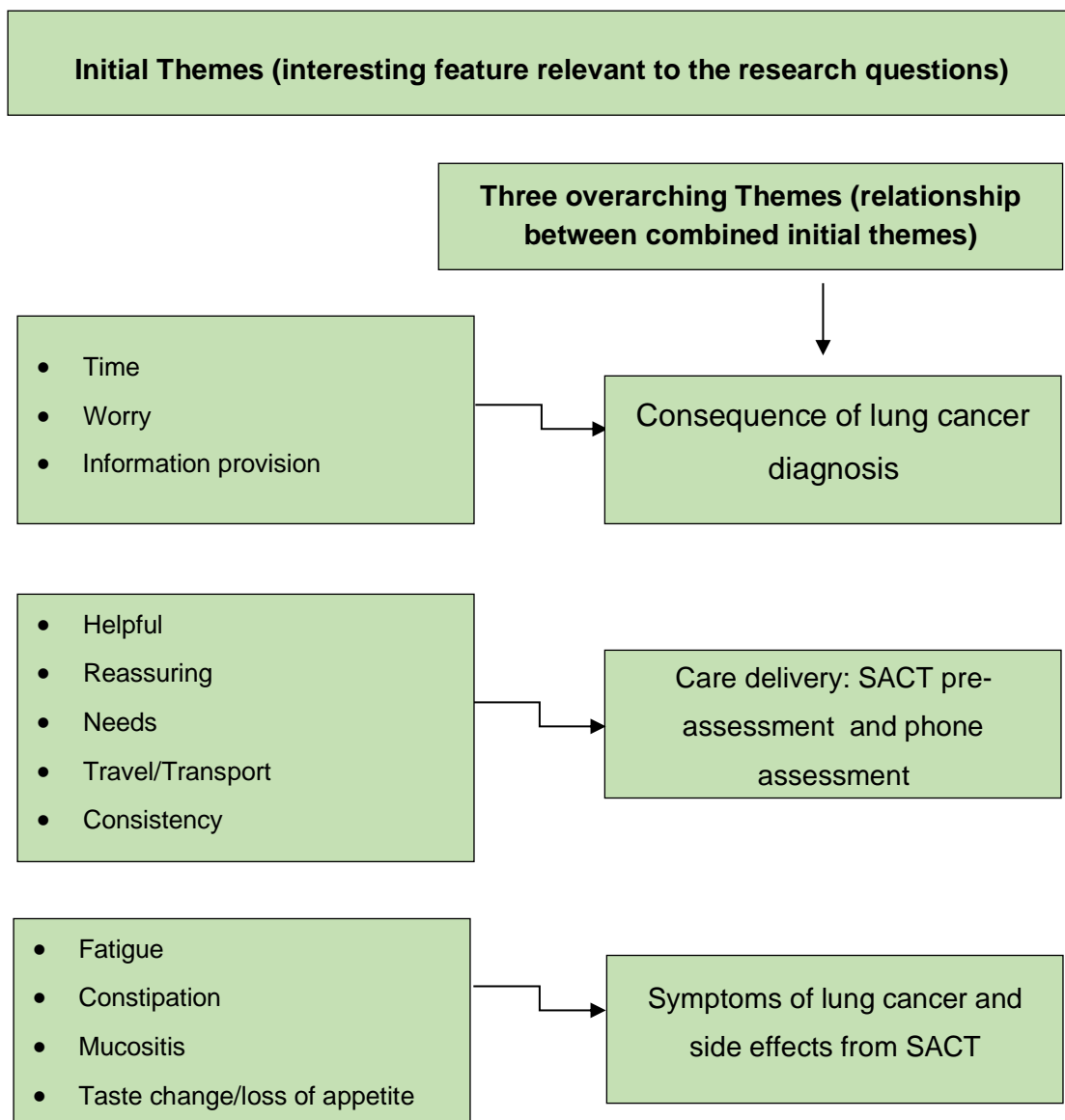
Table 3. Thematic map 1: codes and initial themes

<p>Initial theme: 'Time'</p> <p>Codes:</p> <ul style="list-style-type: none"> • SACT can give more time (quality) • Time at the start makes a difference • Symptoms improve with SACT • What time is left? <p>"I know the reality of my situation, time left is important. I want the time to be good and don't want to risk feeling bad. On the other side I could get more time and feel ok"</p>	<p>Initial theme: 'Travel/Transport'</p> <p>Codes:</p> <ul style="list-style-type: none"> • A struggle to come along/across town • Half day to travel in and out • The cost/extra visit • Telephone worked for me • Wasn't viewed as an 'extra visit' but part of my treatment plan
<p>Initial theme: 'Worry'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Couldn't sleep for worry • Worried cancer might spread <p>"Worry constantly.....is it the cancer or is it the treatment?"</p>	<p>Initial theme: 'Consistency'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Lack consistency primary care • PAC allows consistency to care • Prefer access to experts <p>"Coming here I see the same doctors that I know, I dont get my own GP, it's a locum. I really want consistency"</p>
<p>Initial theme: 'Information provision'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Information overload 'chunked' • Not able to understand it all • Relevant information • More informed than attending my GP 	<p>Initial theme: 'Fatigue'</p> <p>Codes:</p> <ul style="list-style-type: none"> • So tired, couldn't cope, no energy • Tiredness was the worst (impacts daily life) • Unable to interpret symptoms from cancer or treatment. <p>"The worst and like nothing experienced before"</p>
<p>Initial theme: 'Help/Helpful'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Face-to-face was helpful • Decision-making • Relieve stress/practical help 	<p>Initial theme: 'Constipation'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Terrible constipation • Distress, treatment deferral • Needed hospital admission
<p>Initial theme: 'Reassuring'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Checked over, was reassuring • Face-to-face had personal touch • Restore confidence with expert opinion. • Being able to cope <p>"When I told them how I felt they said that's ok, its normal, reassuring to have a face-to-face meeting"</p>	<p>Initial theme: 'Mucositis'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Sore mouth, couldn't eat • Hospital admission <p>"Face-to-face assessment was better, I felt the side effects were better managed"</p>
<p>Initial theme: 'Needed/Needs'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Questions answered/pre-assessment care pathway meet needs • Meet individual care needs 	<p>Initial theme: 'Taste change/loss of appetite'</p> <p>Codes:</p> <ul style="list-style-type: none"> • Couldn't taste my food • Weight loss

Table 4. Thematic map 2: overarching themes and summary of analysis process

Patients' experiences and perceptions of outpatient systemic anti-cancer therapy (SACT) services – Implementing a new pre-assessment care pathway for lung cancer patients		
First phase of the SACT pre-assessment care pathway formed group 1.	Current SACT assessment process or had declined pre-assessment care pathway formed group 2.	Second phase of the SACT pre-assessment care pathway formed group3.





Findings - Overarching theme - Consequence of a lung cancer diagnosis

Initial theme – Time

The context of what time meant to participants within the case appeared complex. Its meaning seemed to differ for each participant and this is probably related to individual circumstances and stage of illness. Many participants described time was essential to provide the support they required through their initial diagnosis and management of the symptoms associated with cancer.

Time was also essential to assist the support throughout their treatment and its associated side effects.

The interviews focussed on participants' experiences of the assessment process. They were asked broadly about their experience of either attending a pre-assessment care pathway or their reasons for refusal and their opinion about the telephone assessment. A number of participants described the significance of support through discussion and explanation of treatment. They appreciated the opportunity to ask questions and the value and importance of time spent with people regarded as experts in lung cancer and its treatment:

“Well it’s all unknown, the fear of not knowing is massive so having that time at the start makes all the difference. It calmed me. The practical help from the people that know all about this was what I liked. I was told what to expect.”

For many of the participants within the case there was a clear focus on the hope that SACT might prolong their survival time. During the interview each participant was asked about their expectation of SACT and how they felt the treatment had helped their cancer. It was often in response to this question that participants talked about their limited life expectancy:

“I would do it again... in a minute... of course I would, I know I need it to help the cancer, there is no other option is there? If it gets me more time and I feel ok, I’ll take it. For me, it is more time, you know that don’t you...?”

Of those participants who talked about their life expectancy, more than half of them described that the quality of their survival time was as equally meaningful as the length of their survival time.

“I know I am one of the lucky ones as the chemo has worked, and everything is stable, yes it has been hard, but with the cancer stable and I feel well just now, I have good quality, which is as important as more than time for me”

Initial theme – Worry

Those diagnosed with a cancer have been known to experience a significant amount of worry regarding their cancer. The impact of this worry should be recognised as this may have a negative influence on health behaviour and the overall well-being of these individuals. This may result in physical problems and interfere with daily life (Balasooriya-Smeekens et al., 2015; Murphy et al., 2018). There were similar worries that participants described: such as the cancer progressing despite treatment; that the treatment might affect their quality of life and also the emotional impact on their close family and friends.

“I do think it’s very hard. It’s very tiring, exhausting, you are in complete shock too that all this is happening to you, having no energy worried me. But there is no guarantee is there... that’s the worrying thing, I could do all this and it still might come back.”

A number of participants described that attending a pre-assessment care pathway helped to alleviate some of their worries as there was the opportunity to discuss these worries with healthcare staff who they regarded as experts:

“I was worried about pain I had, I couldn’t sleep, I worried all the time as this pain was there when they found the cancer, I still worry about the pain, right enough, but the scan was reassuring and even speaking to the doctor was helpful.”

Initial theme – Information provision

During each interview participants were asked how informed they felt at the beginning of their SACT. It became apparent from the data that at certain points of participants’ cancer journeys more than half of them felt they were given too much information to process either about their cancer diagnosis or their planned treatment. Those participants who had attended a SACT pre-assessment care pathway indicated that it provided an opportunity to discuss some of the information that they felt was important. This created a better understanding about their treatment and the possible side effects. Furthermore, evidence from the data suggested that the face-to-face consultation or pre-assessment care

pathway enabled the discussion of relevant patient information which improved participants' knowledge of SACT side effects, their self-care ability to manage their side effects and importantly an ability to recognise when to seek medical advice.

“I liked the face-to-face chat, I got lots of information, it's a lot to take in, sometimes there is too much but I feel I was given enough so that I could understand what I needed to understand.”

The provision of tailored information appeared to be more relevant when starting treatment, when participants are still coming to terms with their diagnosis and an uncertain future. A number of participants within the case suggested that grouping the information that was provided at intervals in their cancer journey would be helpful and that a SACT pre-assessment care pathway helped them to do this. One participant described that attending the pre-assessment care pathway enabled a better understanding of their treatment and what to expect:

“It was information overload. I couldn't take it all in, too much really. We were able to put things into chunks, that way I could deal with it and understand it. Like now I know how I will feel tomorrow and the rest of the week. I know what to expect. The first time oh no ... fear of the unknown.”

The pre-assessment care pathway also enabled those participants who didn't want to read written material or were maybe afraid to read the wrong material were given the time to discuss their concerns and worries in relation to their illness or treatment.

Overarching Theme – Care delivery – Pre assessment Process

SACT Pre assessment Care Pathway

The primary purpose of a SACT pre-assessment care pathway is an assessment face-to-face with patients to determine their ongoing suitability to receive SACT. A focus of the assessment was to ascertain that there is ongoing

informed consent to treatment. There was evidence of improved decision-making about whether to proceed with treatment.

A further focus of a SACT pre-assessment care pathway is to ensure there is ongoing benefit from the SACT and that the side effects associated with the treatment are appropriately managed and tolerated. Through an accurate history, a physical assessment and an evaluation of patients' physiological well-being including the performance status or physical ability to manage their day-to-day tasks was also taken into account. This information allowed for necessary adjustments to treatment and supportive medicines, including delaying the SACT and allowing recovery of side effects:

“Well, I was terribly sick after the first cycle; I couldn't eat and couldn't keep anything down after the chemotherapy... I lost a lot of weight, the next chemotherapy coming along to the pre-assessment was important for me, yes, some adjustments were made to see if they could help the sickness.”

There was evidence of the practical help a pre-assessment care pathway provided, for example undertaking the necessary investigations in order to receive SACT safely.

“Yes I think so, she told me what was happening with the treatment, checked me over, my heart and all and reassured me that she was happy with me.”

It was evident from the data that those participants who had received a new diagnosis of lung cancer, had received no previous SACT and had a limited understanding of what to expect from treatment. Their first visit to the pre-assessment care pathway was of particular value as this enabled the provision of information regarding their treatment and self-care advice:

“Oh yes definitely. Even the second time helped me, I think the first time is more helpful as there was more questions and it certainly made things easier for me, but it certainly has real value at such a horrible time.”

The SACT pre-assessment care pathway also provided an opportunity for participants' partners or a family member to attend and listen to the information provided, ask questions and talk through their concerns. Some of the participants expressed a difficulty in relaying information back to their family. Having a family member present appeared to be helpful in processing relevant key information and gaining a better overall understanding of the information delivered.

Participants who had no prior SACT, the travelling distance or extra hospital visit did not appear to be an issue. However, it was highlighted that travelling from outside the local area might prove more challenging for some:

“I think I would be happy to come along here each time. I live near the hospital, so it suits me. I know I am lucky as others have to travel miles to get here. I might not feel so happy to come here if I had long distance to travel.”

There was evidence from the data that a SACT pre-assessment care pathway contributed to the provision of a person-centred approach. The participant suggested that his care and treatment was individualised, through providing the support he needed and sharing of relevant information. This enabled him to manage and make informed decisions about his treatment.

SACT telephone assessment

The most frequent alternative to a face-to-face meeting is a phone assessment. The primary benefit of a phone assessment enabled an assessment of possible side effects induced by SACT in a timely manner. This was achieved through active listening and interactive communication by experienced nurses with knowledge of SACT and management of the side effects. Should the assessment process identify any of the associated side effects which required further evaluation, prompt intervention aimed to avoid the need for a possibly prolonged hospital admission:

“The phone is a good way to keep in touch with the nurse here and I felt able to ask questions that I wanted to ask.”

Analysis of the data has indicated that most of those participants assessed by phone felt it to be thorough, with meaningful discussion and exchange of relevant information. For some the phone assessment allowed their daily life to carry on; for example family life, work commitments:

“For me no, it would be the time that would take, it’s an hour just to travel here from home, and because I know for me the telephone assessment thing works well... The telephone assessment, it lets me get on with my life, I continued to work, I have my own business”

However, the data also highlighted that the telephone SACT assessment did not always meet participants’ needs, in terms of its completeness of the assessment and the convenience for participants:

“Sometimes did chat to the nurse but often forgot to say things or felt it was rushed, would prefer face-to-face and didn’t know when nurse would call. Nurses were nice; maybe better if I knew when the nurse would call”

The participants who declined to attend the first phase of the SACT pre-assessment care pathway stated that their decisions were influenced by the travelling distance to and from hospital and the time necessary for an extra hospital visit that attending a pre-assessment care pathway would have required. Some of the participants who required hospital transport to attend for SACT highlighted that their journey home was often difficult and took longer, as there were other patients to drop off.

“I need transport, no one to bring me in that can drive. Transport once each week, that makes my day longer and is harder... I don’t get home sometimes until late, and when you don’t feel great...well I just have to go to bed.”

Care delivery – SACT assessment process - Initial themes

There were a number of initial themes identified by participants from their assessment process. These themes are descriptive features of the assessment process defined as meaningful by the participants.

Helpful - There was evidence many of the participants who attended a SACT pre-assessment care pathway found it helpful. Attending a SACT pre-assessment care pathway was described as facilitating an early rapport with relevant healthcare staff. This enabled the provision of both informative and practical discussions about their planned treatment:

“Yes, very much for me it was, it helped me to make the decision about chemotherapy. I was very much in two minds...”

Furthermore, a pre-assessment care pathway provided an opportunity for participants to see the clinical environment and how treatment was administered. When reflected upon it was felt this relieved some stress whilst attending for the first cycle of SACT:

“Very helpful yes, so helpful. It was a scary time for me.. seeing the place and others sitting having their treatment, helped.”

Consistency - Scottish Government (2010) and NICE (2012) recommend that relevant and evidence based information should be delivered and shared with patients and their families in order to achieve consistency of care. Consistency of care helps to establish trusting, empathetic and reliable relationships with healthcare staff and it provides patients with stability when it is needed most. Consistency of care was a theme highlighted within the data which suggested that the assessment process contributed to achieving consistency of care for patients undergoing SACT, within the outpatient setting:

“My GP started the pain relief, it is always a stressful thing to get an appointment that suits, and I find there is a lack of consistency. I’m not actually sure who my own GP is... you know me, know what’s going on with my treatment and know what my medications are.”

Reassuring - The data suggested that reassuring patients took place through communication, along with the provision of information that was tailored to meet each individual's need:

“I suppose no one can prepare you.... when you tell one of the nurses or the doctors how you feel they are reassuring and explain saying we expect that and that's normal. So that's what is helpful, the reassurance.”

There was evidence from the data that reassurance was facilitated through a pre-assessment care pathway, as this provided an opportunity for discussion and explanation about SACT. This helped to lessen associated anxiety and fear for the participants regarding treatment:

“I was feeling so nervous at the thought of the treatment. I didn't know what to expect I had this terrible picture in my head. I needed the reassurance so I really liked the face-to-face meeting. It has a personal touch for me.”

There was further evidence from the data to demonstrate the value of the telephone assessment:

“sometimes it's good, it depends who is phoning. But I am given the opportunity to ask any questions that I have and they will tell me if the bloods are ok. I know a lot of the nurses here now so I think that makes the difference.”

Needs - There was evidence to support the potential benefits to patients when tailored information was delivered. It improved their ability to cope during diagnosis and treatment thus reducing associated anxiety and low mood. It improved communication with their family members and increased their involvement in the decision-making, allowing a greater understanding of their treatment choices. The SACT pre-assessment care pathway was thought to be more helpful than the telephone assessment in meeting the information needs of the participants through the face-to-face discussion. As described in the following quotation the pre-assessment care pathway provided support and

reinforced essential information about treatment. This enabled a better understanding of their treatment and how to manage the side effects.

“My wife could come along too. It was helpful to her and to have the time with people that know all about this and the treatment we needed time from the experts here.”

Overarching themes - Symptoms of lung cancer and side effects of SACT

Quality of life, relieving the symptoms caused by lung cancer and managing the side effects caused by the SACT are often the aim of SACT. Participants reported that the most frequently experienced side effects from the SACT were fatigue, constipation, mucositis and taste changes. Participants indicated that a SACT pre-assessment care pathway enabled discussion and explanation regarding these side effects and enabled advice on how to manage them. The telephone assessment, whilst thought to be convenient, was also helpful in providing participants with the opportunity to discuss their concerns and provided advice in managing side effects from SACT.

Fatigue - Participants reported fatigue as the most challenging side effect caused by SACT. Literature supports this, suggesting that fatigue is one of the most prevalent symptoms patients with cancer experience. It is often described as distressing and debilitating and creates considerable difficulty in maintaining normal daily activities and good quality of life:

“Tiredness was the worst, I sleep a lot and I mean a lot. But I am tired anyway, so I am not sure if the chemotherapy actually made that worse or if that was going to happen anyway because of the cancer.”

Constipation - A number of participants reported constipation as a side effect that caused them distress. It was described as serious enough for them to seek advice and further management, and in one case the SACT was interrupted. The following quotation illustrates the benefit of ongoing assessment, which enabled appropriate intervention to promote the ability to self-manage this side effect:

“I got constipated and that’s not nice, that’s been difficult too. I have missed one chemotherapy because of that, I didn’t know that would happen. I saw the doctor here that day, and she said I couldn’t get the chemotherapy. That was disappointing.”

Oral mucositis - Oral mucositis was reported by approximately half of the participants at some point during their SACT. A smaller number of participants described the experience of oral pain and associated distress was significant enough that their oral function was affected. This reduced dietary intake as one participant required hospital admission delaying treatment:

“Well, it hit me didn’t it, I couldn’t eat, my mouth was terrible I felt terrible... That’s why I am running a month late with the chemotherapy. I couldn’t have it because I felt so bad... I lost a fair bit of weight and as you can see I don’t have a lot to lose.”

Taste alteration and loss of appetite - The participants less frequently reported taste changes and loss of appetite. Those who experienced this effect from their SACT described changes to their taste as miserable and reduced their enjoyment of food, ultimately affecting their mood and quality of life:

“My taste is rotten and some days I am grumpy and irritated. I can’t really taste some food great, but I make the effort to keep up my calories and intake, I think my weight is up, which I am pleased about.”

There were a small number of participants who reported that the changes to their taste was a contributing factor to their weight loss, which is a major source of worry for patients diagnosed with a cancer.

“Annoyingly I have lost my appetite and have terrible taste, nothing tastes nice. I also had some nausea together this has caused me to lose weight, quite a bit and that worries me.”

Discussion

The conceptual framework illustrates four broad themes that evolved from the literature review of a surgical pre-assessment care pathway: *‘improving patient*

capacity with a pre-assessment care pathway', 'efficient patient management through patient assessment', 'patients' experiences of a SACT pre-assessment' and 'improving patients' abilities to self-care'.

Literature review theme - Improving patient capacity with a pre-assessment care pathway: Financial drivers were a prominent theme for the introduction of a surgical pre-assessment care pathway. Similar drivers were apparent that set in motion a review to explore lung cancer patients' experiences of an outpatient SACT service. These drivers included maximising the resources within outpatient services to reduce cancer and SACT waiting time targets. This would help to reduce same-day and late cancellation rate and reduce the number of SACT-related admissions, through improved patient knowledge and management of side effects.

Having explored lung cancer patients' experiences of an outpatient SACT service, an important finding has shown that the assessment process is crucial for the timely, safe delivery and management of SACT side effects. Most significantly, the findings have indicated that the pre-assessment care pathway promoted a person-centred approach that contributed to the safe delivery and improved management of the potential complications that are associated with SACT. The literature reveals the existence of a number of definitions and useful frameworks for person-centred care. Most taking the holistic view to include a collaborative approach with shared decision-making and individualised care (McCormack and McCance, 2010; Health Foundation, 2016).

Considering a pre-assessment care pathway and the differing opinions on what constitutes person-centred care, the literature would suggest that applying the expected outcomes of person-centred care can improve any aspect of healthcare including the issues that relate to increasing patient capacity. The resources of the outpatient SACT service were maximised efficiently as the care pathway enabled the SACT to be prepared in pharmacy the day before the treatment was due. This process also contributed to a reduction of late and same-day SACT cancellations. The care approach also showed that participants felt better engaged with their plan of treatment and it ensured there

was ongoing informed consent. Participants also felt that their care and treatment delivery was better co-ordinated and focussed on the elements of care and support which were personalised and mattered most to them.

The findings whilst consistent with the literature have also provided a contribution of new information about a SACT pre-assessment care pathway. The pre-assessment facilitated an individual one-to-one discussion with a healthcare expert. Participants felt that this care pathway improved their understanding of the side effects and how to self-manage these. They expressed feeling better informed which helped with their decision-making and increased their confidence and ability to self-manage their care and treatments. These feelings created a positive influence on participants' experiences of the care that was provided.

Literature review theme - Efficient patient management through patient assessment: It was highlighted that efficiency of patient management could be achieved through accurate patient assessment and clinical examination and this was a key role of the surgical pre-assessment care pathway. Similar key findings from this research support the opinion that an accurate patient assessment and appropriate clinical examination during SACT improved the efficiency of patient management within a SACT outpatient service. Participants' perspectives described feeling reassured by the clinical examination as this helped to reduce their worries and fears regarding their cancer. Participants expressed their fear of the cancer progressing and it was often through the assessment or clinical examination they felt reassured that the SACT was working and the cancer was under control.

These findings have contributed to the literature as Scullin et al. (2016) suggest that clinical examination, assessment and skilled-shared decision-making can help to ensure there is ongoing SACT benefit with no deterioration in patients' performances, status or physical ability to manage their day-to-day tasks. Furthermore, the findings demonstrated that the SACT pre-assessment care pathway promoted the ongoing assessment of both participants' physical and psychological wellbeing along with their adjustment to a cancer diagnosis.

Participants provided examples of how the pre-assessment care pathway supported their ability to cope with their diagnosis, reduce their anxiety and help with their decision-making. Participants' views were clear on how overwhelming they felt receiving a diagnosis of lung cancer. They described feelings of shock, disbelief and an overwhelming fear. The findings further suggested that with ongoing expert support, the provision of tailored information and knowledge that treatment options are available assist with the process of adjustment.

It was further evident from the findings that the SACT pre-assessment care pathway provided a key one-to-one opportunity for both an initial and ongoing physical and psychological assessment with an experienced healthcare professional. This provided the opportunity to identify those participants who were struggling to adjust to their diagnosis and/or manage their psychological distress. This allowed for appropriate referral or signposting for additional support. Through thorough patient assessment and use of communication and listening skills, the SACT pre-assessment care pathway helped participants to manage their uncertainty. They were helped by discussion and reinforcement of what physical symptoms to expect with the side effects from SACT and that these were not an indication of disease progression. For some of the participants the assessment process enabled reassurance of treatment response through their clinical examination. These findings have made a contribution to the literature as the SACT pre-assessment care pathway was shown to positively impact on the efficiency of patient management, both physically and psychologically.

Literature review theme - Patients' experience of SACT pre-assessment care pathway: There is a growing body of research to support the argument that patient experience, alongside patient satisfaction are fundamental predictors when attempting to measure quality within healthcare service and delivery (Wagner and Bear 2009; Doyle et al., 2013; Manary et al., 2013). The importance of both the patient experience and patient satisfaction to healthcare outcomes and examining quality assurance within the surgical setting has been highlighted. Examining patients' experiences of an outpatient SACT service, the majority of participants described an overall greater satisfaction with the care and service that a SACT pre- assessment care pathway provided.

Research evidence indicates that there are predicted factors which are thought to influence the extent of patient satisfaction. These include: communication, caring, empathy, reliability, responsiveness and to a lesser extent service availability. Continuity, confidence and efficiency have also been discussed within the literature (Jackson et al., 2001; Naidu, 2009; Wagner and Bear, 2009; Gadalean et al., 2011; Batbaater et al., 2015; Berkowitz, 2016; Mulugeta et al., 2019). My findings present new knowledge of the factors predicting patient satisfaction. I have identified factors predicting patient satisfaction attending a SACT pre-assessment care pathway, as illustrated in Table 5.

Table 5. Predicted factors of patient satisfaction

Predicted factors of patient satisfaction from SACT pre-assessment care pathway
Communication - 'treatment was explained so I was able to understand what to expect' 'My partner/family member could attend... the pre-assessment helped me make my decision about SACT'
Empathy - 'Treated with compassion'
Caring - 'I felt cared for – my treatment was tailored'
Reliability - 'The SACT was clearly explained and ready when I went in for my treatment'
Responsiveness - 'There was plenty time for my questions'
Consistency – 'It's consistency that is important to me'
Efficiency – 'Feel everything has been so well organised for me, under control, everyone knows what they are doing'

Jackson et al. (2001) have highlighted the complexity of utilising patient satisfaction to measure quality of patient care, as it was reported that there are

also recognised predicted factors of dissatisfaction. These factors include mood, anxiety, psychological distress and unmet patient expectations, such as failure of symptoms to improve or an acceptable level of functional status. Furthermore, Hamilton et al. (2013) indicate that patient expectation can influence both the patient experience and satisfaction. These predicted factors do not necessarily measure or reflect the quality of care, service provided or clinical effectiveness (Jackson et al., 2001; Naidu, 2009; Wagner and Bear, 2009; Gadalean et al., 2011; Batbaater et al., 2015; Berkowitz, 2016). However, it remains unclear within the literature whether patients' experiences, level of satisfaction with their care or the feeling that service provided did not meet their expectation is an indication of poor quality of care.

My findings also present new knowledge relating to the factors that predict dissatisfaction. I found a number of predicted factors which had a negative influence on patient satisfaction, such as heightened anxiety, psychological distress and unmet expectations; examples are illustrated in Table 6.

Table 6. Predicted factors of patient dissatisfaction

Predicted factors of patient dissatisfaction
Receiving bad news - 'I have never had any positive news...coming here'
Poor symptom control - 'I'm never sure who to speak to... the pain is still there, not as bad but still there'
Communication delivery – 'information overload' 'didn't know what to read, there's too much'
Not enough nurses – 'had to wait to my turn...sometimes there were no chairs'
The ward environment - 'too noisy', 'too small'

There is consistency with my findings and those within the literature to indicate the complexity of utilising patient satisfaction to measure clinical effectiveness and quality of healthcare. Using patient satisfaction requires awareness and careful consideration of its limitation and an understanding of the relevance of timing, patients' previous experiences and relevant personal characteristics such as attitude (Jackson et al., 2001; Turris, 2005; Batbaater et al., 2015).

Literature review theme - Improving patients' ability to self-care: It was highlighted that information provision, health promotion and patient education were prominent themes when positively influencing patients' abilities to self-care. The further potential benefits achieved from a surgical pre-assessment care pathway increased both patient confidence and compliance with recovery, and reduced anxiety and stress whilst undergoing surgery (Clinch, 1997; Malkin, 2000; Heaney and Hahessy, 2011).

Exploring patients' experiences and perceptions of the SACT pre-assessment process the significance of information provision became apparent. This applied to both the SACT pre-assessment care pathway and the SACT phone assessment. It became clear that participants wanted and needed information to help them understand more about their cancer. Participants' perceptions were that information provision enabled them to make informed decisions and feel able to cope with their treatment and the possible side effects. However, some participants acknowledged that given the volume of information that was available to them it felt overwhelming as some of the information was both inappropriate and irrelevant. Some participants reported that knowing where to go and what to read was often a concern.

Findings regarding the SACT pre-assessment care pathway before cycle one further confirm and contribute to literature by suggesting that participants' information needs are significant at the start of SACT and change later. There was evidence that the pre-assessment care pathway enabled tailored information and had a positive impact on participants' abilities to self-manage. Furthermore, the care pathway helped to alleviate their concerns, reduced their anxiety and helped with decision-making. The findings also suggest that they gained a better understanding of the treatment and possible side effects and were boosted with the knowledge that the information relating to SACT was provided by an appropriate healthcare expert.

Conclusion

In conclusion, the driver for this study was to explore the experiences and perceptions of lung cancer patients who attended an outpatient SACT services

and determine whether a pre-assessment care pathway could provide person-centred care. I have provided a clear rationale for the study and the methodology used. My study has generated new knowledge about the SACT assessment process, leading to a change in clinical practice within a large regional cancer centre, informed through the patients' experiences. Reflecting the work of McCormack and McCance (2006) and The Health Foundation (2016), new knowledge of a person-centred care approach has enabled participants to feel better supported and informed, enabling the safe and efficient delivery of SACT. New knowledge has informed clinical practice for SACT delivery in relation to communication, information provision and psychological support, with the potential to improve the quality of care for other cancer patients undergoing SACT within other regional cancer centres throughout the UK.