

**An exploration of oncology specialist nurses' roles  
in nurse-led chemotherapy clinics**

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Doctor of Philosophy  
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## **Abstract**

### **The University of Manchester.**

Abstract of thesis submitted by Carole Denise Farrell for the degree of Doctor of Philosophy and entitled:

#### **An exploration of oncology specialist nurses' roles in nurse-led chemotherapy clinics.**

The purpose of this study was to investigate nurses' roles within nurse-led chemotherapy clinics. There has been a rapid expansion and development of nursing roles and responsibilities in oncology, but little understanding of how roles are enacted and their impact on patient experiences and outcomes. This was a two stage approach comprising a survey of UK oncology specialist nurses followed by an ethnographic study of nurses' roles in nurse led chemotherapy clinics. Ethics approval was obtained prior to each study; research and development approval was obtained from each hospital site prior to Study 2. Study 1 used a questionnaire survey to explore the scope of nurses' roles. A purposive sample of oncology specialist nurses perceived to be undertaking nurse-led clinics was obtained using snowball methods. Data analysis included descriptive and inferential statistics. Study 2 used ethnographic methods to explore nurses' roles in nurse-led chemotherapy clinics, which included clinical observations, interviews with nurse participants and studying documentation (protocols) for nurse-led chemotherapy clinics. Findings were coded and thematic analysis undertaken.

In study 1, 103 completed questionnaires were received with a response rate of 64%, however analysis identified 79 (76.7%) nurses undertaking nurse-led clinics, therefore statistical analysis was limited to this sample of 79 nurses. An additional 12 (11.7%) nurses wanted to undertake nurse-led clinics, therefore findings from this group were analysed separately. There was little congruence between nurses' titles and clinical roles, with significant differences in practice between different groups of nurses, in relation to history-taking ( $p=.036$ ), assessing response to treatment ( $p=.033$ ). Although there was no difference in the number of nurses undertaking clinical examinations ( $p=.065$ ), there were differences in the nature of examinations undertaken, including respiratory ( $p=.002$ ). There were also significant differences between groups of nurses in relation to nurse prescribing ( $p<.0001$ ).

Study 2 included observations (61 consultations by 13 nurses) and interviews ( $n=11$ ). There was variability in patient numbers within nurse-led clinics, identifying implications for service delivery and sustainability. Disparities in nurses' roles and responsibilities revealed four different levels of nurse-led chemotherapy clinics, from chemotherapy administration to totally nurse-led clinics. The identification of four levels of nurse-led chemotherapy is a new finding, and suggests a framework for nurse-led chemotherapy clinics that could

link with nurse competencies and training. Five main themes were identified in study 2; a central theme of autonomy linked with themes of knowledge, skills, power and beliefs. A key finding was the reduced emphasis on compassionate care with greater medical (clinical) responsibilities within nurses' roles, and poor communication skills by some nurses.

Despite a great diversity in oncology specialist nurses' roles, the lack of clarity in roles and responsibilities is creating confusion. Similarly the rapid increase in nurse-led chemotherapy clinics has been ad hoc with no formal evaluations. Although nurses in study 2 perceived they were providing holistic care there was no evidence of this in observations, and nurses appear to use a medical model care based on doctor-nurse substitution, which may have led to reduced emphasis on nursing skills and compassionate care.

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## **Chapter One**

## **Introduction**

## **1.1 Introduction**

This is a two stage study exploring oncology nurses' roles within nurse-led clinics using survey and ethnographic methods. It focuses on nurses' autonomy, communication with patients and health professionals, nurses' clinical practice and operational aspects of nurse-led chemotherapy clinics. Given the government drive to increase nurse-led chemotherapy services and the current paucity of research, this study seems timely and will provide important information for clinicians and policymakers regarding nurse-led chemotherapy clinics and nurses' roles. This chapter sets the context for this study by outlining current definitions for nursing, including specialist and advanced nursing practice, discussing different models of nursing and nurse-led clinics, and considering the policy context in relation to service demands. The chapter starts by exploring definitions of nursing.

## **1.2 Defining nursing**

### ***1.2.1 Concepts and definitions of nursing***

In order to focus on nurses' roles it seems crucial to consider current operational definitions for nursing, specialist and advanced practice, and nurse-led clinics, which will add clarity to discussions throughout this thesis. This seems particularly important given the confusion created by the plethora of nurses' titles and clinical roles. The International Council of Nurses (ICN) states that the title of "nurse" should be protected by law and applied to and used only by those legally authorised to represent themselves as nurses and to practice nursing (ICN, 2013b). However in the UK there is no legal definition of nursing, although a legislative definition for 'registered nursing care' is in place to distinguish between other types of care, such as social care (RCN, 2003). Whilst the RCN (2003) suggests it is difficult to provide a single definition for nursing since the profession is constantly evolving to meet new needs and incorporate new knowledge, international consensus of the core concepts of nursing would be beneficial.

Nevertheless, although most countries have a legal definition of the title 'nurse' and some have a legal definition of 'nursing', the definitions and scope of

practice vary from country to country. However the following broad definition of nursing is provided by the ICN:

*“Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. (ICN, 2013a)*

Nursing care usually refers to the tasks and activities of the nurse, and often reflects everything a nurse does for a patient (Dal Pezzo, 2009). Although there are many attributes of nursing care, there appears to be three main categories:

- The tasks or procedures
- The nature of nursing care (for example skilled, compassionate, holistic)
- The functions of nursing care (for example, listening, assessing, monitoring). (DalPezzo, 2009).

These categories reflect different aspects of nurses' roles and are important factors to consider when exploring what nurses do within clinical practice.

### **1.2.2 Scope of clinical practice**

The scope of nursing practice is defined as *“the range of responsibilities which fall to individual nurses....related to their personal experience and skill”* (UKCC, 1992 cited in RCN, 2003 p9). This is based on the premise that the limits of nursing practice should be determined by the knowledge and skills required for safe, competent performance. However, nursing is often defined by what nurses do, which is expressed in terms of their roles, functions, or tasks (RCN, 2003). However, the inadequacy of this approach is highlighted by changes to nurses' roles over time, including changes to professional boundaries where nurses take on medical tasks and responsibilities.

Nursing expertise can be linked to a framework of role extension. This expansion and development within a continuum (Daly and Carnwell, 2003), is similar to Benner's framework using five levels from novice to expert (Benner, 1984). However, determining the position of individual nurses on the continuum may be problematic, and the phrases of role extension, expansion and development may be semantics rather than distinct compartments of clinical practice (Callaghan, 2007). In order to understand this further it seems

important to consider the concepts, definitions and clinical aspects of specialist and advanced practice.

### **1.3 Specialist and advanced nursing practice**

Advanced nursing practice is defined as a level of practice rather than a person's role or job title (RCN, 2010, 2012), which reflects the Nursing and Midwifery Council (NMC) definition of advanced nurse practitioners:

*“Highly experienced and educated members of the care team who are able to diagnose and treat [patients’] healthcare needs or refer [patients] to an appropriate specialist if needed,”* (NMC, 2005).

However, the RCN highlights that a number of nurses are using the title of nurse practitioner and advanced nurse practitioner without undertaking an appropriate level of education or training (RCN, 2008). The Nursing and Midwifery Council (NMC) (2007) describes this as *“a major concern... the existence of a plethora of job titles that do not help the public to understand the level of care that they can expect”* (NMC, 2007). A position statement from the Department of Health (2010) also recognises that ‘advanced level practice’ has been applied inconsistently to a number of different roles, which has often created confusion about the scope and competence required at this level of practice (DH, 2010).

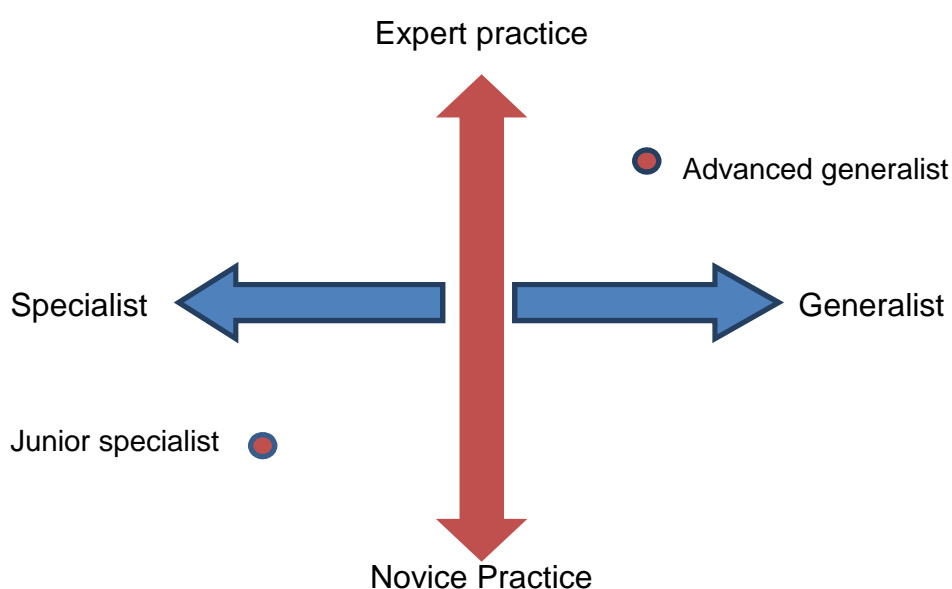
Mills and Pritchard (2004) suggest that advanced nursing practice focuses on how and what nurses do, rather than their qualifications, and therefore places greater emphasis on competencies within clinical practice. Distinguishing between advanced practice and nurse consultant levels, the National Leadership and Innovation Agency for Healthcare (NLIAH, 2011a) suggest that consultants have higher levels of strategic thinking, knowledge and skills, integrating research into clinical practice, and working strategically across a range of models of service delivery (NLIAH, 2011a). In a systematic review of advanced practice roles in the UK, USA and Australia, the roles of the nurse consultant, clinical nurse specialist, and clinical nurse consultant were found to be similar, however variation appeared to come from organizational or individual choices, rather than individual countries (Jokiniemi et al, 2012). Role domains were advanced clinical practice, practice development, education, research,

consultation, and administration (Jokiniemi et al, 2012). In other studies, advanced clinical practice appeared to be the central domain (Vaughan et al, 2005; Jinks & Chalder, 2007; Redwood et al, 2007) accounting for 23–50% of the advanced practice nurse's total working time (Charters et al, 2005; Darmody, 2005; Jinks & Chalder, 2007). However, a reduction in the expert clinical practice of nurse consultants was noticed over time, with a shift towards more strategic engagement within acute care trusts (Dawson and Coombs, 2008)

Although research is considered important for advanced practice roles, involvement in research was generally low (Jokiniemi et al, 2012), and lack of time was the main factor cited for this (Dawson & McEwen, 2005). Organisational challenges, including lack of managerial support, were found to aggravate the implementation of advanced practice roles (Jokiniemi et al, 2012), exacerbated by vague definitions and role ambiguity (Abbott, 2007; Charters et al, 2005; Redwood et al, 2007; O'Connor & Chapman, 2008).

There has also been considerable debate regarding specialist practice, and its position in relation to the development of advanced practice. However, there is increasing acceptance that specialist should be considered one pole on the continuum of specialist and generalist, rather than on the development continuum from novice to expert, which is illustrated in figure 1.1 (National Leadership and Innovation Agency for Healthcare (NLIAH), 2011a).

**Figure 1.1: Relationship between specialist and advanced practice**



In contrast it is argued that advanced practice is a stage on the continuum from novice to expert, characterised by high levels of clinical skills, competence and autonomous decision-making (NLIAH, 2011a). Therefore, within a specialist area there will be nurses working at different levels of practice from junior to advanced. Specialist nurses are specialists within one specific area of practice, which may include caring for people with long-term conditions and diseases such as cancer, diabetes, Parkinson's disease, chronic heart failure, and dementia (RCN, 2010). In oncology the title Clinical Nurse Specialist (CNS) is generally used to describe a skilled practitioner with expert knowledge working at an advanced level in a specialist area (Knowles, 2007). However, the presumption that specialist nurses are all working at an advanced level seems erroneous and misleading. It seems more appropriate to consider two separate continuums, as indicated in figure 1.1. Using this model, the continuum of novice to expert reflects nurses' level of clinical practice and competencies; in contrast the generalist to specialist continuum is descriptive, indicating the nature of nurses' area of practice.

This overview crosses all domains of nursing, placing emphasis on the level of nurses' practice and developments towards advanced clinical practice, rather than descriptors such as nurses' titles or areas of clinical practice. Therefore this interpretation will be used throughout this thesis. In addition, the following operational definitions are given to add clarity to further discussions of nurses' titles, roles and nurse-led clinics (table 1.1)

**Table 1.1     Operational definitions**

<b>Nursing title</b>	<b>Operational definition</b>
Specialist nurse (clinical nurse specialist)	Nurses who specialise within a specific condition or treatment pathway (RCN, 2013)
Advanced nursing practice	A level of practice beyond initial registration (RCN, 2013)
Advanced nurse practitioner	Nurses with advanced level skills and knowledge, working in a specialist or a generalist area within primary, secondary or tertiary care (RCN, 2013).
Oncology clinic	An outpatient clinic for patients with cancer
Chemotherapy clinic	An outpatient clinic for patients undergoing chemotherapy
Nurse-led clinic	An outpatient clinic that is run or managed by registered nurses (Hatchett, 2008)
Nurse-led chemotherapy clinic	An outpatient clinic for patients undergoing chemotherapy that is run or managed by registered nurses

Whilst some operational definitions are clearly defined in the literature, the remainder are outlined by the author where definitions are elusive.

#### **1.4     Clinical nursing roles and nursing models**

The original nursing role incorporated a biomedical model of care, which was prescribed by a physician and focused on physical aspects of care and the treatment of disease (McCrae, 2011). The historical development of nursing and dependence on doctors over the years has led to nurses adopting a subordinate role to doctors, often regarded as a doctor's handmaiden (McCrae, 2011), and in some cases this seems to hold true today, based on anecdotal comments from some nurses in the UK. Aggleton and Chalmers (2000) suggest that this will continue unless nurses value the unique contribution that they make to healthcare. This is an important point in relation to understanding nurses' roles and changes to nurses' clinical practice, and will be considered further throughout this thesis.

Although the medical model seemed straightforward and relevant to clinical care, concerns were raised regarding its suitability for nursing, which strengthened the rationale for a distinct nursing model (Pearson, 1996). Nursing

models were developed in the 1980s and 1990s in an attempt to define a theoretical framework for nursing, and to guide practice and education (Murphy et al, 2010). A nursing model is defined as a collection of interrelated concepts or components that can be taken apart and understood. However since the components of nursing are complex and difficult to define several models were created, each offering a different way of thinking to guide nursing practice (Murphy et al, 2010). For example, some of the nursing models focused on the response of patients' 'systems' to environmental stressors (Neuman, (1984); activities of daily living (Roper, Logan and Tierney, (1980); self care (Orem, 1991); and psychological interactions (Peplau, 1988).

Nursing models have been criticised for their frequent use of jargon and complex concepts, which led to problems in understanding their application to practice (Hodgson, 1992; Kenny, 1993). In addition, some of the models developed in the USA appeared inappropriate for health systems in the UK (Murphy et al, 2010), or appeared to have narrow perspectives that failed to capture the meaning of nursing (Hardy, 1982). Despite seeking to articulate the nature of nursing as a discipline, the models seemed idealistic and increased the gap between theory and practice (Hardy, 1982). Models also lacked research underpinning the relationship between the concepts and impact on patient care (Fraser, 1996; Dickoff and James, 1968), and the application of nursing theories (Draper, 1990).

Some of the theoretical models also failed to resonate with clinical practice, since they appeared to focus more on documentation rather than clinical nursing care. In addition, the availability of different theoretical models created conflict in determining the most appropriate model for nurses' within clinical practice, and this lack of consensus may have led to their demise. This contrasted with medicine, where one medical model focused on diagnosis, treatment and curing physical disease. More recently the introduction of care pathways in the UK changed the direction towards multidisciplinary approaches to care, which emphasised quality in service provision (Currie and Harvey, 2000). However rising healthcare demands and shortages of medical and nursing staff have led to new models of clinical care delivery and new operational models of nursing care (Dubois et al, 2012). A major factor driving changes to nurses' roles in the UK was the European Working Time Directive,



which was introduced in 1993 and considerably reduced the working hours of junior doctors (Goddard et al, 2010; Pickersgill, 2001).

#### **1.4.1 *Alternative clinical models***

In 1970s, the concept of the nursing process was introduced in the UK, which was a four stage model incorporating assessment, planning, implementation, and evaluation (MacFarlane and Castledine, 1982). More recently nursing models of care during follow-up after cancer treatment focus on encouraging patient self-management. A systematic review of cancer follow up suggests the potential benefits of coordinated transition planning, and recommends further research to evaluate the efficacy of models of care (Howell et al, 2012). This has implications for multidisciplinary and also nurse-led care planning, or modelling. However the current lack of theoretical underpinning to clinical models of care needs to be addressed in order to bridge the gap between theory and practice.

Alternative nursing models have developed from researching clinical aspects of patient care. Corner (1995) developed an integrative approach to breathlessness, considering the synergistic effect of emotional and physical experiences. This led to the development of a “*parallel model of care*”, which sits alongside the traditional bio-medical model (Krishnasamy et al, 2001). The parallel model is characterised by a requirement to work with the mind and body, and development of a therapeutic relationship with the patient based on partnership and mutual inquiry, which contrasts with the passivity of patients in the bio-medical model (Krishnasamy et al, 2001). The combination of a theoretical and pragmatic approach to nurses’ clinical practice encouraged the translation of this model into clinical practice, with direct benefits for patients.

A wide variety of models are described within the literature, encompassing a range of meaning from organisational models of service delivery and processes (Dubois et al, 2012), to specific service models of specialist areas such as chronic disease management for epilepsy (Fitzsimmons et al, 2012), or cardiac rehabilitation (Clark et al, 2013). Models also describe aspects of care or consultations, for example integrated care for chronic wounds (Rosenbaum, 2012). Therefore the disparate concepts and interpretation of models within the NHS has created great variability in their application, which appears to have

diluted the impact on nurses' clinical practice and recognition of changes to nurses' roles.

The lack of theoretical and empirical evidence for changes in organisational models of care has created disparities in clinical service delivery and inconsistent classifications of how nursing care is organised at a unit level (Dubois et al, 2012; Aiken and Patrician, 2000; Jennings, 2008). However a conceptual model is considered central to developing service delivery systems by facilitating the identification of systems, processes and major components, and enabling the analysis of resources and processes in relation to outcomes (McLaughlin and Jordan, 2004).

Nurses are involved in all aspects of healthcare delivery across different settings, therefore the way that nursing resources are organised is critical to the organization's performance; in addition healthcare managers are being challenged to find operational models that maximise available nursing resources (Dubois et al, 2012). Hospitals have had to restructure the way clinical services are delivered in order to meet increasing demand, which has led to a growth in nurse-led models of care. The development of the advanced nurse practitioner has created a hybrid role, bridging the gap between nursing and medicine. However, the emphasis on clinical tasks, such as clinical procedures, clinical examination and diagnosis appears to have driven a wedge in the identity of nursing with the greater focus on medical tasks than nursing care. The following section outlines the types of legislation in relation to clinical and advanced nursing practice.

## **1.5 Legislation and accountability for nurses' roles**

There are different types of legislation applicable to nurses' roles and responsibilities, including the criminal justice system and the scope or boundaries of professional practice. Certain legislation must be in place before nurses can undertake certain activities that have traditionally been doctors' responsibilities. This section outlines the different types of law relevant to nursing to understand the implications for clinical practice.

### **1.5.1 Types of law relevant to nursing**

Statute laws are enacted by the Crown in Parliament and give a broad framework to the rules; if ANPs take on a task previously performed by a doctor they must perform it to the same standard as a doctor (Duke, 2012).

Civil law refers to actions between individuals and the state.

Tort law enables a patient to bring an action against an ANP for negligence. In a civil case four areas will be assessed:

- To determine whether there has been a failure in the duty of care
- The standard of care
- A causal link between the duty of care and the harm suffered
- If harm was a reasonably foreseeable consequence of the breach of duty

Professional law is governed by the NMC, and the code for professional conduct, which focuses on the main ethical principles of autonomy, beneficence, non-maleficence and justice (NMC, 2008). The NMC Code of Conduct (2010 p2) states that:

*“As a professional, you are personally accountable for actions and omissions in your practice, and must always be able to justify your decisions. You must always act lawfully, whether those laws relate to your professional practice or personal life”.*

In addition to professional accountability with the NMC, nurses have a contractual accountability to their employer and are accountable in law for their actions (NMC, 2013).

Public law governs the DH and NHS, and all employees. If a nurse has broken public law, criminal proceedings would follow in addition to actions by the NMC and the nurse's employer.

Employment law ensures ANPs are accountable to their employer, and have a duty to act with reasonable skill and care, obey reasonable orders, maintain confidentiality and not compete with the employers business. In vicarious liability the employer is held

accountable for the 'wrongful acts' of an employee whilst in the course of employment, and is liable to pay damages.

The RCN (2012) claims that advanced nurse practitioners carry the same risk of claims of negligence as other nurses, given the educational underpinning to their role. The principle of vicarious liability determines that it is the employer who is sued, rather than an individual nurse, unless the nurse is self-employed (RCN, 2012). However, individual nurses at any level must ensure that they work within their own area of competence and knowledge.

Legislation has also taken place to enable nurses to prescribe medicines independently. The key points are outlined in the next section.

### ***1.5.2 Independent nurse prescribing***

Many nurses within the UK are independent non-medical prescribers, with similar prescribing responsibilities as doctors once their prescribing registration is registered with the NMC. Medicines management and prescribing in the UK are governed by a complex framework, comprised of legislation, policy and standards (DH, 2006; Courtney et al, 2007).

In order to prescribe medicinal products nurses and midwives must have their prescriber qualification recorded on the NMC register. There are two types of nurse prescriber:

1. Community nurse prescriber
2. Independent and supplementary nurse and midwife prescriber

The Home Office is the government department responsible for licensing and regulation of controlled drugs under misuse of drugs regulations in England, Scotland and Wales (DH, 2006). Changes to Misuse of Drugs Regulations (DH, 2012c) mean that nurse independent prescribers are able to prescribe any controlled drug listed in schedules 2-5 for any medical condition within their competence, (DH, 2012c).

The National Prescribing Centre became part of the National Institute for Health and Clinical Excellence (NICE) in the UK in April 2011, and steps were taken to provide a single common framework that is relevant to doctors, dentists and non-medical prescribers (DH, 2012c).

## **1.6 Nurse-led clinics**

### **1.6.1 Overview of nurse-led clinics**

Nurse-led clinics in the UK evolved from primary care, where practice nurses set up clinics for patients with chronic diseases such as diabetes (Clark et al, 2011), asthma (Clack, 2009), and hypertension (Clark et al, 2011; Woodward et al, 2011; Chummun, 2009). The later expansion within GP practices included nurse practitioners / advanced nurse practitioners and other health professionals, where nurses substituted for doctors and appeared to adopt a medical model of care. More recently in primary care there have also been an increasing number of district nurse clinics (Griffith and Tegnah, 2013), and nurse-led clinics focusing on screening and risk assessments (Koelewijn-van Loon et al, 2009; Gulzar et al, 2007), which crosses the boundaries of work undertaken in secondary care.

Nationally nurse-led clinics are being undertaken for a wide variety of diseases and patient groups across secondary and tertiary care. This includes a pan-London nurse-led tuberculosis service (Belling et al, 2012), nurse-led genetics clinics (O'Shea, 2012), and a ward-based nurse-led clinic to manage post-operative problems after thoracic surgery (Williams et al, 2012). Nurse-led clinics in secondary care seem to focus around chronic diseases such as coronary heart disease (Schadewaldt and Schultz 2011; Murchie et al, 2005; Raftery et al, 2005), rheumatology (Ndosi et al, 2011), diabetes (Mason et al, 2005; Youngman, 2004), and epilepsy (Hadjikoutis and Smith, 2005). However, nurse-led clinics are also built around patient pathways in order to reduce waiting times for patients (Lane and Minns, 2010; Shakeel et al, 2008). The nature of nurse-led clinics in hospitals are diverse, and include nurse-led paediatric clinics to manage sensitive issues such as continence (Rogers, 2008), sexually transmitted disease / HIV (Challenor et al, 2006), and sleep apnoea (Tomlinson and Gibson, 2006); whilst other nurse-led clinics focus on one specialist areas such as dermatology (Duce and Gouldstone, 2006; Moore et al, 2006).

Internationally there is variability in the number and nature of nurse-led clinics, which include continence, wound care (Shiu et al, 2012), diabetes (Edwall et al, 2008), rheumatology (Bala et al, 2012), hypertension (Kengne et al, 2009), and

HIV/AIDS (Labhardt et al, 2009). However, the legislation in each country is variable and may restrict the expansion of nurses' roles and nurse-led clinics.

### **1.6.2 Nurse-led clinics in oncology**

Within oncology there has been a rapid increase in the number and range of nurse-led clinics in the UK over the past ten years, which reflect developmental opportunities within cancer policies (NAO, 2001; DH, 2007, 2008, 2009; NCAG, 2009), and changes in professional regulations and legislation, such as nurse prescribing (DH, 2006; Stenner and Courtenay 2008a, 2008b; Courtenay et al, 2007). In addition the reduction in junior doctors' hours has placed increased demands on redesigning the NHS workforce (Ferguson and Kearney, 2000), and created opportunities for more nurse-led clinics within several areas of oncology. Associated with this is a need to ensure that cancer services provide value for money and cost effectiveness (DH, 2007), which has paved the way for an increasing number of nurse-led clinics.

The majority of nurse-led clinics in oncology appear to be for routine follow-up after completion of adjuvant therapy; however current reductions in routine medical follow-up may influence this trend, leading to considerations of alternative methods of follow-up (Beaver et al, 2007). The reduction in doctors' hours has also identified gaps in service provision in relation to clinical / surgical assessments and procedures, therefore nurses have expanded their roles to undertake pre-operative assessments and minor surgical procedures, such as taking biopsies, nipple tattooing, and central line insertion. However, whilst nurse-led clinics appear safe and acceptable to patients, there is little evidence of nurses' roles within nurse-led clinics / services and aspects of their clinical practice. Therefore a literature review is required to increase understanding of the range of nurse-led clinics in oncology, nurses' roles and their impact. The greatest gap appears to be in relation to nurse-led chemotherapy clinics, which is worrying given the government recommendations for more nurse-led chemotherapy clinics (DH, 2007; NCAG, 2009).

### **1.6.3 Nurse-led chemotherapy clinics**

Endorsement of nurse-led chemotherapy by the National Chemotherapy Advisory Group (NCAG 2009) is an important landmark for oncology nursing,

although this represents significant challenges for nurses themselves to deliver quality and safety improvements. Approximately 4,000 staff in 200 hospitals in the UK are involved in administering chemotherapy, which is a major responsibility within the NHS (Lennan and McPhelim, 2012). However, a lack of consistency in systems to categorize and commission chemotherapy delivery has created variability in the organisation of chemotherapy services (Lennan and McPhelim, 2012).

Recent developments in nurse-led chemotherapy services have arisen ad hoc and have been poorly evaluated; therefore it is difficult to appreciate their clinical impact and effectiveness. Furthermore the term 'nurse-led' is open to interpretation with great disparities in scope of clinical practice, autonomy and responsibilities, which is creating confusion. Whilst some nurses appear to have fully autonomous nurse-led chemotherapy services, other nurses may not be able to prescribe independently, therefore may rely more on medical staff. This warrants further exploration and seems crucial before further developments take place.

Currently there are an increasing number of patients who require ambulatory treatment and care, with fewer in-patient admissions for treatments such as chemotherapy (Lennan et al, 2012, Wiseman et al, 2005). This places a greater burden on outpatient departments, which are struggling to cope with increasing capacity. Given the increased development of nurse-led clinics over the past decade it seems important to look at the rationale for, and developments to, nurse-led clinics in oncology. In the UK there is variability in the delivery of chemotherapy services. Whilst the administration of chemotherapy is usually undertaken by nurses (Wiseman et al, 2005), the clinical management of patients undergoing chemotherapy is mainly undertaken by doctors. However, some of this responsibility is now devolving to senior nurses who may prescribe chemotherapy and supportive medication, assess toxicities of treatment and other aspects of clinical management through 'nurse-led' clinics (Lennan et al, 2012).

The Cancer Reform Strategy (DH, 2007) recognises the potential variability in current chemotherapy services and recommends the development of a "strategic framework" for chemotherapy service delivery. Given the current

developments in cancer nursing, it seems important that nurse-led chemotherapy services are taken into account within national strategic planning and commissioning processes. This seems to have particular merit given the emphasis placed on continuity of care by specialist nurses and the importance of access to psychosocial and financial support for patients. However, the absence of a comprehensive evaluation of chemotherapy services makes it impossible to accurately assess the impact of nurse-led chemotherapy, which suggests that further research is required. In order to increase understanding of the context of chemotherapy within oncology, the following section provides a brief overview of chemotherapy treatment, common side-effects and implications of service delivery.

### **1.7 Systemic anti-cancer treatment (chemotherapy)**

Chemotherapy has traditionally been one of the main treatments in oncology alongside surgery and radiotherapy. Patients will have a course of chemotherapy; each treatment is referred to as a cycle and several cycles make up a course of treatment, or regimen (NCEPOD, 2008). The number of cycles for each chemotherapy regimen is determined by evidence from clinical trials, and there are numerous chemotherapy drugs and different schedules / regimens for each cancer group. Chemotherapy may be given alone or in combination, and with curative or palliative intent. In potentially curative treatment maximum tolerated doses are used to achieve greater efficacy, however this carries a greater risk of morbidity and mortality from treatment (NCEPOD, 2008). In contrast, palliative chemotherapy aims to relieve or delay the onset of symptoms, therefore drug doses are often reduced to minimise treatment-related toxicities (NCEPOD, 2008).

The side-effects of chemotherapy vary according to each regimen; however they can also vary in severity, with individual differences for each patient (NCEPOD, 2008). Potential side-effects include hair loss, nausea and vomiting, mouth ulceration, diarrhoea, and bone marrow suppression. An international grading system by The National Cancer Institute (NCI) in the United States has provided a standard grading scale to assess toxicities (NCI 2009), which provides consistency amongst health professionals in recording chemotherapy-



related toxicities, and can facilitate decisions to defer, stop or dose reduce chemotherapy.

In addition, systemic treatments now include a variety of intravenous biological agents, or targeted therapies, which have implications for chemotherapy nurses and clinical services (Vickers et al, 2012). A study by the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) in 2008 reviewed the care of patients who died within 30 days of receiving systemic anti-cancer therapy (SACT). The report highlighted safety issues, including 43% (220/514) of patients who had grade 3 or 4 treatment related toxicity, and 36% (97/267) of cases where toxicities had not been recorded (NCEPOD, 2008). Alongside this, a report by The National Chemotherapy Advisory Group (2009) highlighted issues within chemotherapy services, making 20 recommendations to improve quality and safety. Some of the recommendations included prescribing chemotherapy where chemotherapy regimens require approval by cancer networks and prescribers must follow clear guidelines (DH, 2009, 2003). NCEPOD (2008) also recommends that junior medical staff should not be authorised to initiate SACT, although there are no clear recommendations for nurses.

## **1.8 Policy context and service demands**

Cancer remains the biggest cause of premature death in adults under 75 years old, although there has been a recent reduction in cancer mortality (DH 2007). To address this, the government introduced a National Cancer Plan (DH 2000a) that aimed to improve the efficiency and effectiveness of cancer services, and a Cancer Reform Strategy (DH 2007) which emphasised the importance of high quality services reflecting patients' needs. However, the increasing incidence of cancer, and an ageing population, has huge implications for the NHS to meet government targets and ensure high quality cancer services that are tailored to meet patients' needs (Cox et al, 2006).

Government policies have been instrumental in changing the directions of the NHS and influencing service delivery through mandatory directives. However, whilst the focus on targets, such as two week waiting times for patients with suspected cancer, resulted in earlier diagnosis for some patients (Cox et al, 2006), there were some negative consequences. Firstly, this immediately

placed the rising demands on existing clinical services and stretched clinical resources, since many hospitals were already working at full capacity. Secondly, clinicians were under pressure from hospital managers to meet targets, which focused on patient numbers and throughput rather than individuals. Thirdly, the drive to meet targets moved attention away from patients' experiences and the quality of service provision (DH, 2007).

The turnaround came in 2008 with the government's realisation that patients should be put first, by greater choice and emphasis on quality of care (DH, 2008) with subsequent recommendations to measure health outcomes rather than process targets (DH, 2010a). This also reflects the definition of quality set out by Lord Darzi in that high quality care comprises effectiveness, patient experience and safety (DH 2008), and this has been enshrined into the recent Health and Social Care Act 2012 (DH 2012a). To achieve this aim the Darzi review (DH 2008) set out to ensure that the NHS has a professional workforce that can meet demand, offer quality assurance for patients and their families, and meet demands set by health service commissioners.

The current NHS Outcomes Framework 2013/14 focuses on measuring health outcomes (DH 2012b), aiming to act as a catalyst to drive quality throughout the NHS within five domains (DH, 2012b):

1. Preventing people from dying prematurely
2. Enhancing quality of life
3. Helping people recover from ill health
4. Ensuring that people have a positive experience of care
5. Treating and caring for people in a safe environment and protecting them from avoidable harm (DH, 2012b).

The five domains also resonate with the philosophy of cancer nursing.

### ***1.8.1 Policy influences on oncology nursing practice***

Several cancer policy documents have included key recommendations for clinical staff, leading to pivotal developments in cancer nurses' roles (DH 1999a, 1999b, 2000a, 2007, 2008). 'Making a Difference' outlined a need for nurses to work in different ways by extending nurses' skills and clinical roles (DH 1999b).

This was echoed in 'The National Cancer Plan' (DH 2000a), which proposed re-designing cancer services to make the best use of health professionals' skills. Emphasis was also placed on a need to introduce new service models for cancer (DH, 2007), and the potential benefits of nurse-led clinics and services (DH, 2008). However, whilst the policies open new directions for cancer services and provide resounding support for nurse-led clinics, they fail to provide any recommendations or strategies to develop and evaluate clinical and nurses' roles and nurse-led services. This is a crucial omission in ensuring the quality and effectiveness of nurses' roles and nurse-led clinics.

Alongside these government policies, professional policies were also introduced, which reviewed service provision and 'skill-mix' within cancer nursing (DH 2006; 2000b); aiming to clarify clinical leadership as well as individual roles and responsibilities (Bolton & Laycock, 2006). However, the Chief Nurse of England also emphasised the importance of nursing values, stating that *"patients want to feel safe, cared for, respected and involved"*, recognising the value of nurses who "can combine technical skills with a deep understanding and ability to care", which highlights the value base, or essence, of nursing. (DH, 2006 p4)

The Royal College of Nursing (RCN) (2007) proposed a need to redefine nurses' roles and careers, promoting unambiguous job titles with streamlined role definitions. In addition the RCN began developing professional nursing career pathways with four levels of practice, ensuring links with future demands for nursing care (RCN, 2007). However in reality the ad hoc development of new cancer nursing roles has created confusion and there is little evidence of evaluation. Unless new nursing roles are carefully evaluated it seems difficult to appreciate their impact and effectiveness on patients and cancer service delivery, which may lead hospital managers to question their value.

### **1.8.2 Ensuring 'value for money' and quality of care**

One of the most fundamental aspects within the Cancer Reform Strategy is the need to ensure quality of care within service provision (DH, 2007). However there is also a strong emphasis on providing *"value for money"* within cancer service delivery, and this may become the local driver for nurse-led services within NHS hospital trusts. Therefore it seems important that issues of quality

are not lost within this process. In considering the satisfaction of patients, the Cancer Reform Strategy pledges to reduce “*spending on services that do not make a difference to patients*” in order to “*invest more in services which do*” (DH, 2007). Therefore, in terms of evaluating nurse-led services, it seems crucial to identify potential differences from patient’s perspectives between nurse-led and medical management. This seems particularly important given that a further pledge from this policy document is to focus cancer spending on cost-effective interventions that make a difference to patients (DH, 2007). This is important given the current disparity between nurses’ and doctors’ pay, since the substitution of doctors by specialist nurses may be utilised as a cost-cutting exercise. However, the need to develop clinical nurse specialist roles and introduce advance nurse practitioners and independent prescribers should primarily be in order to improve patients’ experiences; included in this is the need for “successful” nurse-led follow-up (DH, 2007).

## **1.9 Summary**

The rapid growth in nurse-led models of care and clinical cancer management certainly reflect service development opportunities within cancer policy documents (NAO, 2001). Indeed, reducing waiting times for patients has been one of the main drivers in the introduction of nurse practitioners and nurse-led clinics in order to meet local and national targets. However, it also seems important to focus on how cancer nurses have developed their practice; consider what training, support and infrastructure are provided for role developments; and explore how service developments may have affected patients and service delivery. If nurse-led services are set up as a substitute for medical management, it seems crucial to evaluate their effectiveness and acceptability to patients, therefore evidence of this will be explored within the literature review

Cancer policies have clearly set out a comprehensive strategy for improving cancer services in the UK. This aims to eradicate the ‘*post code lottery*’ and ensure patients have equality of access to high quality cancer services and increasing choice (DH 2000a, 2007, 2008). However, government targets for new referrals and first treatment have placed a huge burden on service providers to see new patients and deliver cancer treatments within tight

deadlines. Given the current financial pressures within the NHS, and the increasing costs of cancer treatments, this has tremendous implications for service delivery and clinical management.

The reduction in junior doctors' hours forced the NHS to look at redesigning the workforce to meet the clinical needs of patients and provide appropriate clinical management to address the reduction in medical staff (Ferguson and Kearney, 2000). At the same time the nursing profession made plans to allow nurses to extend their roles and take on some of the tasks that were previously within the doctors' domain. Changes to nursing regulations have revolutionised the scope of professional nursing practice, increased nurses' autonomy and led to a higher level of advanced nursing practice, with many nurses running clinics and services independent of medical staff.

The advent of non-medical prescribing has made a fundamental improvement in increasing nurses' autonomy to provide a more comprehensive and holistic package of care for patients (Stenner and Courtenay 2008a, 2008b; Courtenay et al, 2007). A significant number of nurses are now prescribing independently for patients, which has paved the way for more nurse-led clinics with the potential for greater continuity and increased choice for patients, as well as meeting government and hospital targets (Stenner and Courtenay, 2008b; Farrell and Lennan, 2013). Considering the disparities between medical and nursing salaries, this move also seems favourable to hospital trusts in their bid to provide cost-effective services.

However, despite the advances in nursing practice and improvements in nursing legislation to support it, there is a current lack of clarity regarding competencies for advanced practice and no clear role definition for advanced nurse practitioners. This is exacerbated given the plethora of nursing titles and lack of clear definition and regulation for the use of new titles, such as nurse practitioner and advanced nurse practitioner, which may cause confusion for patients, the public and other healthcare professionals. From this it seems important to explore more fully the concept of advanced nursing practice and new roles within it.

Similarly, although there has been a rapid growth in nurse-led clinics there seems to be a gap in the legislation surrounding them, with a lack of clarity in

definition, training and competencies. Although some work has been undertaken on evaluating advanced nursing practice and nurse-led clinics, this seems limited, particularly within oncology. It seems that more work is needed to explore the concept of nurse-led clinics and consider the scope of nurse-led clinics within oncology. Although the driver for nurse-led clinics may be cost-effectiveness, it seems important to consider the impact on patients and existing services.

Although there is some evidence of what nurse-led clinics are operating across all domains of practice, there is a lack of evidence regarding the nature of nurse-led clinics in oncology. Therefore a literature review will increase understanding of the nature and scope of nurse-led clinics for patients with cancer. This should help to clarify the scope of advanced nursing practice and provide important information on the impact of nurse-led developments within oncology, and will be presented in the next chapter.

## **Chapter Two**

## **Literature review**

## 2.1 Introduction

This literature review aims to examine studies conducted on nurse-led clinics in oncology to answer the following question:

*What is the role of the nurse in nurse-led oncology clinics?*

Consideration was given to the different types of review that may be chosen, and the main choices are briefly outlined. A systematic review or meta-analysis would be appropriate if there is enough homogeneity and primarily quantitative evidence. However heterogeneity, with a combination of quantitative and qualitative evidence, would render a systematic review inappropriate (Dixon-Woods et al, 2005). Systematic reviews tend to rely on evidence from randomised clinical trials (RCTs) due to the reduced risk of bias (Ajetunmobi, 2002). However, for practitioners and policy-makers, the traditional forms of systematic review can be limited due to the inability to utilise all forms of evidence (Dixon-Woods et al, 2005), therefore a systematic review would limit the amount of evidence that could be included.

Although there is increasing recognition of the contribution of qualitative research within reviews, alongside quantitative research studies, there appears to be a lack of consensus regarding this (Campbell et al, 2011), and arguments continue regarding the feasibility of synthesising qualitative and quantitative evidence from multiple research studies (Pope and Mays, 2006). A realist review aims to understand what works for who and in what circumstances (Petticrew et al, 2013). This takes a more pragmatic approach to the review by including both qualitative and quantitative evidence, therefore is appropriate for complex policy interventions (Pawson et al, 2005).

When evaluating complex interventions, there is little guidance on how to review and synthesise evidence (Petticrew et al, 2013). Synthesis can be done quantitatively using formal statistical techniques such as meta-analysis, or through a narrative approach (Sterne et al, 2011). As well as drawing results together, synthesis should consider the strength of evidence, explore whether any observed effects are consistent across studies, and investigate possible reasons for any inconsistencies, which enables reliable conclusions to be drawn



(Sterne et al, 2011). A clear review question is also essential, irrespective of the precise approach used to undertake the review (Mays et al, 2005).

A narrative review aims to summarise, explain and interpret evidence, with the flexibility to incorporate different types of evidence, although it does not generate new theories (Mays et al, 2005). There are also slight distinctions between a narrative review and a narrative synthesis; whilst a narrative review provides a summary of the findings, a narrative synthesis may incorporate thematic analysis, conceptual mapping or tabular summaries, which enables greater synthesis of the findings (Mays et al, 2005).

Petticrew et al (2013) propose that the choice of review should be driven by the research questions. To review nurses' roles in nurse-led oncology clinics, a wide range of studies is likely, incorporating both quantitative and qualitative methods. Either a realist review or narrative review could be appropriate types of review to answer the research questions. However, a narrative review was chosen since the ability to integrate both quantitative and qualitative evidence through narrative synthesis could enhance the interpretation of complex processes (Dixon-Woods et al, 2005). In addition the systematic presentation of the data within a narrative summary can facilitate the identification of themes by exploring the similarities and differences between studies (Petticrew et al, 2013).

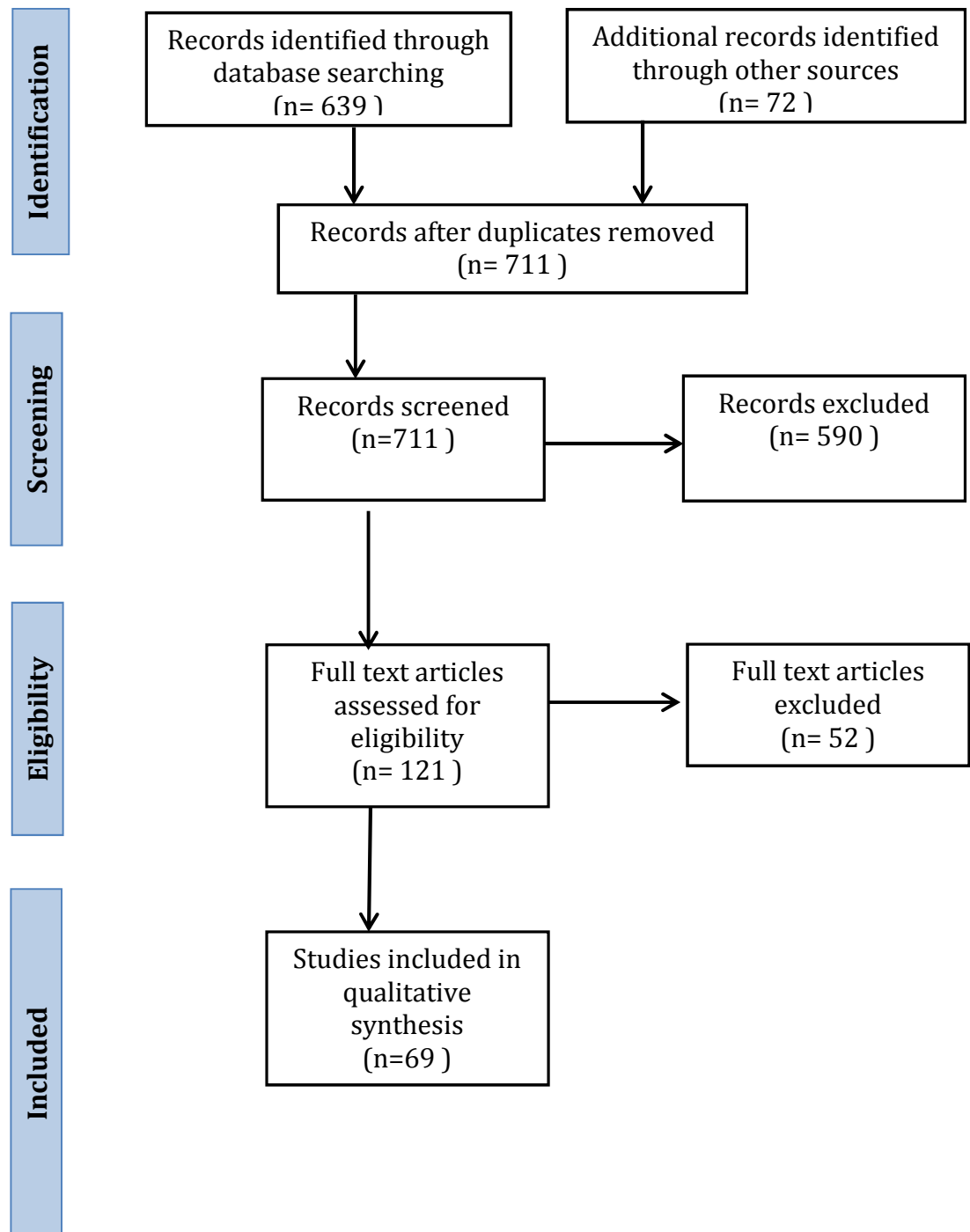
## **2.2 Search strategy**

The literature search was conducted in 2006 to define the research questions and inform the research studies prior to study 1, and again in November 2012 to ensure the literature review was up to date following completion of study 2. For clarity this thesis will focus on the most recent literature search and review, although takes into account findings from the first review.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (Moher et al, 2009) was followed to determine the content required, and systematic process for this review. Figure 2.1 illustrates the flow of information through the review, mapping out the number of records identified at each stage.

**Figure 2.1 PRISMA flow diagram for search results**

This highlights results from the different stages in the search strategy in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al, 2009).



It is important to conduct a robust search for evidence (Popay et al, 1998), giving consideration to different approaches (Dixon-Woods et al, 2005; Mays et al, 2005; Boaz et al, 2006) and the use of resources (Crumley et al, 2005), including searching for grey literature (Cook et al, 2001). Chronology of the literature reviewed is displayed in the search results to illustrate developments over time. Searching for qualitative evidence is considered more difficult than quantitative (Dixon-Woods et al, 2005), therefore consideration should be given to different search strategies that may facilitate this process (Shaw et al, 2004). A systematic approach to searching for evidence was undertaken in this review using the principles of a systematic review.

The main part of the search strategy incorporated an electronic search of the five main databases related to healthcare. Secondly a hand search was undertaken of key journals for oncology nursing to identify any additional relevant studies. Journals hand searched included Cancer Nursing Practice, European Journal of Oncology Nursing, British Journal of Nursing and Journal of Advanced Nursing, from January 2000-November 2012. Finally, the references of included papers were also searched.

### **2.2.1 Databases accessed**

- MEDLINE: produced by US National Library of Medicine (1946-November 2012)
- EMBASE: Reed-Elsevier Excerpta Medica Database (1980-November 2012)
- CINAHL: Cumulative Index to Nursing and Allied Health Literature] (1937-November 2012)
- PsycINFO: Psychology database (1806-November 2012)
- Cochrane: Cochrane central register of controlled trials (November 2012)  
Cochrane database of systematic reviews (2005-2012)  
Database of abstracts of reviews and effects (4<sup>th</sup> quarter 2012)

No time limits were used when searching the electronic databases in order to make the review as comprehensive as possible, and date ranges of each search are governed by the range of each database, as shown above. The search was limited to English, since resources were not available to undertake translations.

### **2.2.2 Search terms**

Search terms were identified through the thesaurus, Medical Subject Headings (MeSH), and keywords, and linked to the operational definitions identified in chapter 1 (table 2.1). This ensured that the operational definitions were closely linked to the research questions, and also matched the MeSH headings. In addition, the search was expanded or combined as necessary for each database using truncations and wild cards, such as \$ and \*, together with Boolean operators of AND/OR.

The research question explores nurses' roles in nurse-led clinics in oncology / chemotherapy, which includes a wide variety of nurses' roles and titles such as specialist nurse, advanced nurse practitioner and oncology nurse. Searching MeSH provided specific search terms for nurses' titles / roles that were broader for specialist nurses and also included nursing care, process and services, therefore operational definitions were used to ensure consistency and clarity of meaning. Similarly MeSH and search terms were matched to oncology / chemotherapy clinics, and also nurse-led clinics (see table 2.1).

**Table 2.1 MeSH and operational definitions**

Title	Operational definition	MeSH headings and search terms
Specialist nurse (clinical nurse specialist)	Nurses who specialise within a specific condition or treatment pathway	<ul style="list-style-type: none"> <li>• Nurse (nurses, nursing personnel, personnel, nursing)</li> <li>• Nurse clinician (clinical nurse specialist, clinical nurse specialists, nurse specialist, clinical; nurse specialists, specialist, clinical nurse, specialists, clinical nurses)</li> <li>• Nursing care</li> <li>• Nursing diagnosis</li> <li>• Nursing process</li> <li>• Nursing services</li> </ul>
Advanced nursing practice	A level of practice beyond initial registration	
Advanced nurse practitioner	Nurses with advanced level skills and knowledge, working in a specialist or a generalist area within primary, secondary or tertiary care.	
Oncology nurse	Nurses who work with cancer patients	<ul style="list-style-type: none"> <li>• Oncology nursing (cancer nursing, nursing, oncologic, oncologic nursing, oncological nursing)</li> </ul>
Oncology clinic	An outpatient clinic for patients with cancer	<ul style="list-style-type: none"> <li>• Cancer</li> <li>• Neoplasm</li> <li>• Ambulatory care (clinic visits; health services, outpatient; outpatient care; outpatient health services; services, outpatient health; urgent care)</li> <li>• Ambulatory care facilities (clinic activities; clinic, free standing; outpatient clinic(s))</li> </ul>
Chemotherapy clinic	An outpatient clinic for patients undergoing chemotherapy	<ul style="list-style-type: none"> <li>• Antineoplastic agents</li> <li>• Cancer chemotherapy agents</li> <li>• Cancer chemotherapy drugs</li> <li>• Drug therapy (chemotherapy)</li> <li>• Nurses practice patterns (nurse-led clinics)</li> </ul>
Nurse-led clinic	An outpatient clinic that is run or managed by registered nurses	
Nurse-led chemotherapy clinic	An outpatient clinic for patients undergoing chemotherapy that is run or managed by registered nurses	

## 2.3 Search strategy

There were three sections to the search strategy, which is outlined in table 2.2. Results from each section were then combined. An excerpt from the actual search using Medline is given in appendix 1.

**Table 2.2 Combining search terms**

<b>Nursing practice</b>	<b>Nurse-led clinics</b>	<b>Oncology</b>
Specialist nurse OR Advanced nursing practice OR Advanced nurse practitioner OR Oncology nurse	Nurse-led clinic OR Nurse-led chemotherapy clinic OR ambulatory care	Cancer OR Neoplasm OR Oncology OR Chemotherapy OR Oncology clinics
Nursing practice AND Nurse-led clinics AND Oncology		

The search strategy was applied to each database in turn, using the following inclusion and exclusion criteria (table 2.3).

**Table 2.3 Inclusion criteria for search strategy**

The inclusion criteria were kept as broad as possible to capture the range of nurse-led clinics within this specialty. All research designs were included, in addition to non-research studies that addressed the research questions.

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Design</b>	Any design included	None
<b>Participants</b>	Oncology nurses Palliative care nurses	Nurses in other specialities General nurses Nurses in primary care
<b>Interventions</b>	Oncology nurse-led clinics or services in outpatient settings	Non-oncology nurse-led clinics Inpatient settings Procedures
<b>Outcomes</b>	Any patient outcomes. Any professional nursing outcomes / service development	None

**Table 2.4 Search results from each database**

This shows the number of hits per database within each section of the search strategy. The results shown take account of the following limitations: humans and English language, with publications up to November 2012.

Database	Advanced nursing practice	Nurse-led clinics	Oncology & Chemotherapy	All Combined
Ovid Medline	86493	1829	437088	231
CINAHL	10953	140	94209	5
Embase	696209	2649	5102085	335
Cochrane	1479	392	37133	36
PsycINFO	236345	318	155054	32
<b>TOTALS</b>	<b>1031479</b>	<b>5328</b>	<b>9080218</b>	<b>639</b>

This revealed a total of 639 potential papers for abstract review. Following application of the inclusion and exclusion criteria (table 2.3) 121 abstracts appeared relevant to the research questions and considered suitable for further review of the whole paper. A further 52 paper were rejected at this stage since they did not meet the inclusion criteria, resulting in 69 papers for inclusion in this literature review. Table 2.5 shows additional relevant abstracts from each journal that was hand-searched. The results from all stages in this search strategy are also illustrated in the PRISMA diagram (figure 2.1).

**Table 2.5 Results of key journal hand searching**

This table shows the number of additional abstracts from hand-searching key journals. A summary of the results is shown in figure 2.1.

Journal	Relevant abstracts
Cancer Nursing Practice	54
European Journal of Oncology Nursing	9
British Journal of Nursing	9
Journal of Advanced Nursing	0
<b>Totals</b>	<b>72</b>

## 2.4 Systematic synthesis

Systematic synthesis brings together different types of evidence to clarify the findings (Gough, 2004), which includes making judgements about the quality

and relevance of the evidence (Gough, 2007). Thematic synthesis was developed to address broader questions regarding intervention need, appropriateness and acceptance, in addition to effectiveness; initial descriptive themes are further interpreted to include analytical themes and synthesis (Barnett-Page and Thomas, 2009). In addition, thematic synthesis also considers potential variability in the participants and context (Barnett-Page and Thomas, 2009). In contrast, narrative synthesis and framework synthesis go beyond the primary studies to transform the data, by describing and summarising the data in a detailed way to translate the studies into one another (Barnett-Page and Thomas, 2009). However narrative synthesis is a more subjective process than meta-analysis; therefore, the approach used should be rigorous and transparent to reduce the potential for bias (Popay et al, 2006;.Rodgers et al, 2009).

## **2.5 Critical appraisal**

Critical appraisal is important to determine the quality of studies (Khan et al, 2001). The NHS Centre for Reviews and Dissemination (2001) acknowledges the difficulties in achieving consensus regarding the criteria for quality standards. Some authors argue that weak studies should be included (Campbell et al, 2003; Estabrooks et al, 1994), whilst others argue against exclusion due to quality (Jensen et al, 1996; Sandelowski et al, 1997). In a traditional systematic review the inclusion of only empirical research within narrow criteria may create limitations in the findings. In contrast, the inclusion of papers where researchers have extensive knowledge in an area, including informed comment and opinion papers would add breadth to an iterative review (Hawker et al, 2002). West et al (2002) argue that systems used to rate the quality of both RCTs and observational studies may be difficult to use, therefore may measure study quality less precisely.

To address this, Hawker et al (2002) propose a framework to assess the quality of evidence from research studies using different methodological approaches, whereby three stages are used to critically appraise studies:

- Stage 1: Assessment of relevance. Articles are rejected or accepted for full review based on the abstract and inclusion / exclusion criteria.



- Stage 2: Data extraction. A full review of the paper is undertaken and relevant data extracted to answer the research question.
- Stage 3: Scoring for methodological rigor. A framework is used to assess and score the quality of both qualitative and quantitative studies, using the following nine domains:
  1. Abstract and title
  2. Introduction and aims
  3. Method and data
  4. Sampling
  5. Data analysis
  6. Ethics and bias
  7. Findings / results
  8. Transferability / generalizability
  9. Implications and usefulness.

Scores in each domain range from 1 (very poor) to 4 (good), therefore the total score for each study ranges from 9 to 36 (Hawker et al, 2002). The full quality criteria for the 9 domains are given in appendix 2.

Where there is little research on a topic area, it becomes important to gather information about any good quality, credible work and undertake critical appraisal to determine whether to include it in a literature review (ENB, 2000). However, it also seems important to consider non-research clinical papers where evidence from research studies is sparse, since the volume of evidence may be an important factor within a review. For this reason non-research, including clinical audits, were included in this review. However, critical appraisal of clinical audits should assess the clinical importance of the area to be assessed and identify a measurable aspect, determine appropriate standards, and measure clinical practice against these standards (Ajetunmobi, 2002 p167). When considering the inclusion of low quality studies in a review, Higgins et al (2006) suggests that sensitivity analysis may be useful. Within this, studies are assessed according to their impact on the conclusions, thus low quality studies may be included if they do not change the conclusions provided by other studies (Gough, 2007).

Bodies of evidence should be summarised in terms of four characteristics:

- The (technical) quality of the studies constituting the body of evidence;
- The size of the body of evidence;

- The context in which the evidence is set;
- The consistency of the findings produced by studies constituting the body of evidence (DFID, 2013).

Assessment of the overall strength of a body of evidence is directly linked to the quality, size, consistency and context of the evidence (Harbour and Miller, 2001). Therefore these factors were all taken into account within this review to determine the weight of evidence in addition to the quality of evidence. Weight of evidence is a concept in several areas that relates to the consideration of evidence to inform decision-making (Gough, 2007). Gough (2007) proposes that quality appraisal should be considered more broadly than generic criteria; emphasising the importance of 'question specific quality' and relevance criteria when determining the 'weight of evidence'.

A hierarchy of evidence places more emphasis on systematic reviews and RCTS (Petticrew & Roberts 2003). However, there are different examples of hierarchies, and the status accorded to certain research methods (Nutley et al, 2012). Although matrices of evidence may be helpful, Nutley et al (2012) suggests that there will be conflicting views regarding the merits of different forms of evidence for policy or practice questions.

Within this literature review there was a large body of literature based on clinical experience. Given that there was little research on this topic, all relevant literature was included in this review and critically appraised by assessing accuracy, credibility and quality. If only research papers had been included, this would have excluded a wealth of innovations in clinical practice and discussion papers.

## **2.6 Structure of the review**

The search strategy revealed a wide variety of research approaches across 40 studies, including one systematic review, three literature reviews and ten randomised controlled trials (RCTs). Most studies were from the UK, five from Sweden, one from Denmark, the Netherlands and Korea. In addition, 29 patient satisfaction surveys / audits were included; the majority were from the UK, two from Sweden and one from New Zealand. The publication of study 1 from this research was deliberately excluded (Farrell et al, 2011b). Tables 2.6, 2.7 and 2.8 provide a summary of studies included in this literature review.

**Table 2.6** *Literature reviews on nurse-led clinics in oncology*

Author	Study design	Aims	Findings	Quality appraisal
Corner,J (2003) UK	Literature review of nurse-led clinics in cancer (9 relevant articles)	To review the evidence for nurse-led clinics in cancer	The use of nurses is effective and safe. Nurse-led care is acceptable to patients. Satisfaction with nurse-led care is high, and seems greater than doctor-led care. Nurse-led models do not seem more costly than doctor-led.	27 / 36
Cox and Wilson (2003)	Literature review and meta-analysis of 150 papers (37 relevant articles)	To evaluate the impact of nurse-led follow up in cancer care	Nurse-led follow up is acceptable, appropriate and effective. Nurse-led follow up meets patients' needs for information and psychological support. The telephone is a suitable means of providing this service	27 / 36
Lewis et al (2009) Lewis and Hendry (2009)	Systematic review of nurse-led versus doctor-led follow up for patients with cancer	To evaluate the effectiveness and cost-effectiveness of nurse-led follow up for patients with cancer	From 4 RCTs: no difference in survival, recurrence or psychological morbidity. Patients with lung cancer more satisfied with telephone follow up, and more patients able to die at home; patients with breast cancer found patient initiated follow up more convenient, but conventional follow up more reassuring.	34 / 36
Cusack and Taylor (2010)	Literature review of telephone follow up in colorectal cancer (11 relevant articles)	To examine the potential of telephone follow up for patients with colorectal cancer.	Telephone follow up by an experienced nurse specialist is cost-effective and accepted by the majority of patients. Aspects of care: symptom management, reassurance possible over the phone.	28 / 36

**Table 2.7** *Research studies on nurse-led clinics in oncology*

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Kelly et al (1999) UK	Questionnaire survey	To assess telephone follow up post chemotherapy	31 patients with ovarian cancer	Nurse-led telephone follow up assessment post chemotherapy	Nurse-led telephone follow up helped patients manage their symptoms post chemotherapy, assess treatment toxicities and promote self-care	Abstract only

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Moore et al (1999) UK	Observational study and case notes audit	To assess the medical model of follow up care; feasibility of nurse-led follow up	44 patients with lung cancer	Feasibility of nurse-led clinics for patients with lung cancer	Conventional follow up lacked coordination, continuity and good assessment of patients' symptom control and psycho-social needs. Nurse-led follow up seems safe, effective and acceptable to patients	28 / 36
Campbell et al (1999) UK	Non-randomised study. Mixed methods	To develop a patient focused model of care; To evaluate the effectiveness of a nurse-led service during radiotherapy.	Patients attending a radiotherapy clinic 141 (nurse-led), 71 (doctor-led)	Nurse-led versus doctor-led radiotherapy clinic	Increased interventions and interactions in nurse-led clinics. Nursing consultations longer but resulted in shorter waiting times. Greater referrals for support and prescriptions, less investigations. Patients liked the openness of the clinic and found it easier to talk to the nurses. Overall the nurse-led service was considered to be more holistic.	17 / 36
Helgesen et al (2000) Sweden	RCT	To evaluate medical safety, satisfaction and resource utilization	400 patients with prostate cancer on follow up.	Nurse-led telephone on demand follow up versus standard doctor-led care	No difference in psychological distress. No difference in accessibility, treatment prescribed, or investigations requested. 37% reduction in cost of nurse-led	Abstract only
Pennery and Mallet (2000) UK	Cross-sectional descriptive interview survey	To ascertain patients' perceptions of follow up after treatment for breast cancer	24 patients with breast cancer	Feasibility of nurse-led follow up	In conventional follow up 75% felt rushed, 79% not comfortable raising emotional concerns, 46% had unmet information needs. 92% considered continuity unacceptable. 54% felt follow up with specialist nurse would be more supportive	28 / 36
Faithfull et al (2001) UK	RCT	To evaluate the effectiveness of nurse-led follow-up versus conventional care	115 men undergoing pelvic radiotherapy for prostate cancer.	Nurse-led care with open access clinics and telephone follow-up versus standard doctor-led care	Greater satisfaction with nurse-led care ( $p<0.002$ ), including greater information and greater continuity of care. Costs 31% lower with nurse-led care. No difference in Quality of Life (QoL) or symptoms.	31 / 36

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Koinberg et al (2002)  Sweden	Qualitative descriptive study	To describe patients' satisfaction with specialist nurse check-up visits	19 patients with breast cancer on follow up	Follow up undertaken by specialist nurse but initiated by patients	Strong satisfaction with nurses' knowledge and professional skills. Identified patients' needs for accessibility and flexible solutions to follow up. Need for information. Need for trust, security and reassurance. Need for confirmation and support. Need for self-care.	30 / 36
Brown et al (2002)  UK	RCT	To compare 2 types of follow up <u>Outcomes:</u> QoL, psychological morbidity and satisfaction	61 patients on routine follow up for stage 1 breast cancer.	Standard follow up versus patient initiated follow up	No difference in QoL and psychological morbidity. Patients having standard follow up reported advantages to be reassurance of check-ups; advantage of patient initiated follow up was convenience	29 / 36
Corner et al (2002)  Moore et al (2002)  UK	RCT	To assess the effectiveness of nurse-led follow up in the management of patients with lung cancer	203 patients with lung cancer on follow-up.	Open access to nurse-led clinic or telephone follow up for lung cancer patients versus standard medical follow up	High acceptability (75%) and satisfaction with nurse-led. At 3 months patients on nurse-led care had less dyspnoea ( $p=0.03$ ), and improved emotional functioning at 12 months ( $p=0.03$ ). Patients on nurse-led had fewer medical consultations at 3 months, fewer x-rays ( $p=0.04$ ), and were more likely to die at home ( $p=0.04$ ) than hospital or hospice. No difference in costs	30 / 36
Allinson (2004)  UK	Non-randomised study	To evaluate the effectiveness and acceptability of a nurse-led family history clinic for patients with breast cancer	Patients with a family history of breast cancer 44 (nurse-led) 15 (doctor-led control group)	Nurse-led family history clinic for patients at risk of developing breast cancer	High patient satisfaction (100%) Patients felt less rushed during nurse-led consultations. All patients in nurse-led felt they had sufficient time to discuss their concerns and risks. In doctor-led clinic 61% had not been given time to discuss concerns and only 39% understood their risks better.	17 / 36

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Baildam et al (2004) UK	RCT	To compare follow up by specialist breast care nurses with doctors	525 women with breast cancer undergoing routine follow up.	Nurse-led versus doctor-led follow up for patients with breast cancer	No difference in detection of cancer recurrence. No significant difference in psychological distress, although nurses failed to recognise this in 47% and doctors in 92%. Greater satisfaction with nurse-led consultations ( $p<0.01$ ) but significantly more time spent with the nurse ( $p<0.01$ ). No financial advantage of nurse-led	Abstract only
Booker et al (2004) UK	Pilot questionnaire survey	To explore the acceptability of nurse-led telephone follow up and patients' satisfaction	36 men on follow up after radiotherapy for prostate cancer	Nurse-led telephone follow up after radiotherapy for prostate cancer	High level of satisfaction, advantages reported more convenient and time-saving. Only one patient was unhappy with telephone follow up and found it to be poorer than traditional follow up	22 / 36
Fitzsimmons et al (2005) UK	Qualitative study with semi-structured interviews	To explore patients' perceptions of doctor-led chemotherapy and acceptability of nurse-led chemotherapy	26 patients with breast, colorectal, lung and gynaecological cancers, and 22 health professionals.	Feasibility of a nurse-led chemotherapy service	Mixed opinions from patients on acceptability of nurse-led chemotherapy. Nurse-led role viewed as different but complementary to that of medical staff, rather than doctor-nurse substitution. Patients considered benefits to be service and economic; health professionals reported additional patient-based benefits.	30 / 36
Koinberg et al (2004) Sweden	RCT	To compare nurse-led follow up on demand with doctor follow up. <u>Outcomes:</u> Well-being, satisfaction, access to medical care, safety	264 women with breast cancer on follow-up.	Nurse-led telephone follow up on demand versus standard doctor-led follow up	High patient satisfaction and access to clinic and nurse specialist (93-100%). No difference in satisfaction. No difference in safety of practice. No difference in anxiety and depression. No difference in recurrence.	31 / 36

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Egan and Dowling (2005)  UK	Cross-sectional survey	To determine patient satisfaction of a nurse-led oncology day ward	72 patients attending nurse-led oncology day ward	Nurse-led oncology day ward	89% satisfaction with staff. 65% see same person each time. 80% fully informed; 23% had no explanation about disease or treatment, 12% unsure if had any information. 91% satisfaction with skills / attitude of nurses but 12/72 (17%) reported no confidence. 13% felt unable to access staff and 15% unsure	18 / 36
Faithfull and Hunt (2005)  UK	Pilot study qualitative study	To explore the therapeutic value of a nurse-led service	5 patients undergoing radiotherapy	Nurse-led service for men undergoing radiotherapy	Seven professional values integral to nurse-led care: Therapeutic support, working with uncertainty, timeliness, enhanced professional autonomy, role flexibility, organizational openness (communicativeness), continuity and trust in care	26 / 36
Sharp and Tishelman (2005)  Sweden	Qualitative descriptive study	To explore patients and nurses experiences of a smoking cessation programme for head and neck cancer	13 patients with head and neck cancer undergoing radiotherapy and interested in smoking cessation	Nurse-led smoking cessation clinic for patients with head and neck cancer due to start radiotherapy	The importance of a therapeutic patient-nurse relationship on the smoking cessation process suggest benefits for this nurse-led intervention	25 / 36
Beaver, K et al (2006)  UK	Non-randomised trial	To examine the feasibility of a nurse-led telephone intervention to meet information needs	135 patients on breast cancer follow up	Nurse-led telephone intervention for information needs and standard care versus standard medical care	More information needs met in the intervention group and fewer physical problems at time 2 Greater anxiety in the control group at time 2 (p=0.05)	30 / 36

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Cox et al (2006) UK	Questionnaire survey and interviews with patients and clinical staff	To assess the feasibility of nurse-led follow up	54 patients with lung cancer on follow up post treatment	Feasibility of nurse-led follow-up for patients with lung cancer	Patients' perceptions preferred medical-led than nurse-led follow up ( $p < 0.001$ ), and nurse-led than GP led follow up ( $p = 0.012$ ) Telephone follow up was the least preferred option. Hospital staff and GPs considered nurse-led follow up to be acceptable. Continuity of care and patient choice were important considerations.	27 / 36
Knowles et al (2007) UK	Pilot study	To improve pathway and follow up care after surgery in colorectal cancer; To assess the feasibility of nurse follow up	60 patients on colorectal cancer follow up	Nurse-led follow up for patients with colorectal cancer.	Nurse-led follow up is safe, efficient and acceptable to patients. Significant improvements in QoL, physical functioning, role functioning, social functioning, fatigue, pain, sleep disturbance, appetite loss, diarrhoea. High patient and clinician satisfaction. Potential annual savings of £28,000 with nurse-led follow up.	29 / 36
Moore et al (2006) UK	Mixed methods: case notes review, nurse interviews	To describe the rationale for and nature of nurse-led follow up care. To identify key nursing interventions and insights into specialist nurses' experiences	Case note review of 51 patients with lung cancer on follow up; 4 nurse interviews; analysis of 8 team meetings	Nurse-led clinic and telephone follow up for patients with lung cancer	Case note review ( $n = 51$ ): average contact with patients was telephone review 3 times a month, increasing frequency if unwell or at crisis points. Nurse-led follow up lasted 1-27 months (mean 10 months). 84% had contact with palliative care team. Areas of care: psychological, social, financial support, disease monitoring, coordination of care, providing information, liaison with other professionals. Themes from nurse interviews: training, becoming credible, emotional burden and making a difference	28 / 36



Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Cox et al (2008) UK	Pilot study	To evaluate the effect of a nurse-led telephone intervention	52 women with ovarian cancer on follow up.	Nurse-led telephone follow up for women with ovarian cancer	Opportunity for psycho-social support. 42% discussed anxiety or depression, 33% fear of cancer recurrence, 51% work or finance, 41% sexual intimacy and 8% spiritual. . 73% preferred nurse-led telephone follow up. Main advantages: relationship and discussion with nurse, convenience	28 / 36
Wells et al (2008) UK	Non randomised historical control study	To evaluate a nurse-led clinic for patients undergoing radiotherapy to the head and neck	43 patients receiving radiotherapy for head and neck cancer	Nurse-led (n=23) versus doctor-led (n=20) on treatment reviews during radiotherapy for head and neck cancer	Patients valued relationship with nurse specialist; had longer and more frequent consultations, with increased referrals to the multidisciplinary team. No difference in QoL. 83% of nurse consultations did not need consultant involvement. Information to GPs greater in nurse-led.	29 / 36
Beaver et al (2009) UK	RCT	To compare traditional hospital follow up with telephone follow up in breast cancer	374 patients after breast cancer treatment	Nurse-led telephone follow up (structured) versus standard medical follow up for breast cancer	Higher satisfaction in nurse-led telephone group. No difference in anxiety or information needs. No difference in investigations. No difference in time to recurrence detection	31 / 36
Sheppard et al (2009) UK	RCT	To evaluate effectiveness of point of need care versus standard follow up	214 patients with breast cancer to compare methods of follow up.	Nurse-led point of need access versus routine 6 monthly clinical review	No difference in psychological morbidity or QoL. No difference in recurrence. Patient choice important. Point of need access by trained specialist nurses can provide a fast responsive management system when patients need it.	32 / 36
Seiback Peterson (2009) Denmark	Prospective Questionnaire survey	To develop and evaluate a rehabilitation programme on self-assessed health and coping	20 patients with localised gynaecological cancer following surgery.	Nurse-led multidisciplinary rehabilitation programme following surgery versus standard care	The nurse-led rehabilitation programme significantly improved patients' coping, pain, vitality and physical functioning at 12 months compared to 3 months. No improvements were found in the control group at 12 months.	24 / 36

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Beaver et al (2010a)  UK	Qualitative study	To explore patients and nurses' views of nurse-led telephone follow up	28 patients with breast cancer on telephone follow up; 4 breast care nurses	Nurse-led telephone follow up after breast cancer surgery	5 themes from patient interviews: convenience, continuity, normalizing, structure and putting a face to a voice. 4 themes from nurse interviews: patient benefits, developing skills, meeting needs and patient choice.	30 / 36
Beaver et al (2010b)  UK	Exploratory qualitative study with interviews	To explore patients' perceptions of follow up care	27 patients with colorectal cancer on follow up	Nurse-led follow up for patients with colorectal cancer compared with routine doctor-led care	Patients who had nurse-led care received useful information that helped them to cope. Routine hospital appointments may not address patients' psycho-social and information needs.	30 / 36
Kimman et al (2010) Netherlands	RCT with 2x2 factorial design	To compare patient satisfaction for nurse-led telephone follow up and standard doctor-led follow up	299 patients with breast cancer on follow up: Doctor-led (n=149) and 150 on nurse-led telephone follow up	Nurse-led telephone follow up, educational group programme versus standard outpatient care	High patient satisfaction. Increased satisfaction with access to care for nurse-led ( $p=0.015$ ), although may not be clinically relevant.	27 / 36
Krishnasamy et al (2011)	Prospective survey	To assess patients' preferences for follow up	31 patients post treatment for lung cancer	Feasibility and acceptability of nurse-led follow up after treatment for lung cancer	78% of patients supported the concept of nurse-led follow up within a model of shared care. Care coordination and continuity of care were important for over 80% of patients	22 / 36
Lee, H et al (2011)  Korea	Quasi-experimental study with pre-test/post-test design	To evaluate the effect of nurse-led CBT on fatigue and QoL	71 patients with breast cancer undergoing radiotherapy.	Nurse-led cognitive-behavioural therapy for 6 weeks during radiotherapy for breast cancer versus standard care	Patients in the experimental group had less fatigue and greater QoL after the 6 week intervention than the control group.	28 / 36

Author	Study design	Aims	Participants	Intervention	Main findings	Quality appraisal
Strand et al (2011)  Sweden	RCT	To compare patient satisfaction, resource utilization and medical safety, comparing doctor and nurse-led follow up	110 patients with colorectal cancer on follow-up post-surgery	Nurse-led follow-up after colorectal cancer versus standard doctor-led care	High patient satisfaction (NS) Longer nurse consultations (24 vs 15 minutes $p=0.001$ ) and more blood samples taken (29% vs 7% $p=0.002$ ). Surgical assistance needed in 13/182 nurse consultations. Costs for nurse consultations were lower but costs for investigations were higher.	27 / 36
Hutchison et al (2011)  UK	Prospective survey	To identify type of cancer nurse-led clinics Establish scope of clinics and factors that affect development and success	88 cancer nurse-led clinics in one region of Scotland	Nurse-led cancer clinics	51%(n=45) of nurse-led clinics were for treatment; 31%(n=27) follow up; 24% (n=21) symptom management; 14% (n=12) diagnostic. Additional purpose of 26%(n=23) clinics: psychological support, genetic screening, pre-assessment or tasks such as PICC line insertion. 20% (n=18) no admin support. 38% (n=33) no absence cover. Nurse competency assessed in 70% (n=62). 48% (n=42) clinics running for > 5 years, but 55% (n=48) not audited. Perceived benefits: continuity of care (n=26), reduced waiting times	21 / 36

**Table 2.8 Audits and satisfaction surveys on nurse-led clinics in oncology**

Author	Study design	Cancer group	Type of Nurse-led clinic	Main findings
James et al (1994) UK	Audit of consultation times and effectiveness of care	Patients receiving radiotherapy for central nervous system tumours	Nurse-led on treatment reviews during radiotherapy for central nervous system tumours versus standard doctor-led care. Then nurse-led telephone clinic following radiotherapy	Nurse-led care equally effective and resulted in estimated 30% saving in medical time. Telephone clinic alternative to conventional follow up and less costly.
Earnshaw and Stephenson (1997) UK	Prospective audit	382 patients with breast cancer on follow up	Nurse-led follow up for patients with breast cancer	Increased time for nurse consultations and continuity of care to allow greater discussion of patients' problems Popular with patients. Well supervised. No significant lesion missed
Garvican et al. (1998) UK	Patient satisfaction survey. Audit of FNA investigations to compare performance of doctors and nurse specialists	119 patients with breast cancer	Nurse-led breast cancer diagnostic clinic	High satisfaction with clinical care (100%). Only 5 patients expected to see a nurse but being seen by a nurse was acceptable to patients and GPs. Clinical expertise compared favourably with other clinicians in that nurses produced a lower proportion of inadequate samples
Sardell et al (2000) UK	Patient satisfaction survey	45 patients with glioma on follow up	Nurse-led telephone follow-up clinic for patients with glioma. Patients self-selected conventional or nurse-led telephone follow up.	High level of patient satisfaction Symptoms easily monitored over the phone
Booker et al (2004) UK	Patient satisfaction survey	36 patients with prostate cancer on follow up after radiotherapy	Nurse-led telephone follow up clinic for patients with prostate cancer after radiotherapy	High level of patient satisfaction and acceptability. Saving time and convenience were the 2 main themes, and flexible working practices within the MDT
Coughlan (2005) UK	Audit of referrals to nurse-led family history clinic for colorectal cancer	98 patients at risk of developing colorectal cancer	Nurse-led family history clinic for colorectal cancer	38/98 did not attend; 42/98 eligible for screening, 18 reassured no screening required, 25/85 referred for genetic assessment

Author	Study design	Cancer group	Type of Nurse-led clinic	Main findings
Groves,E (2005)  UK	Audit of patient calls to a chemotherapy triage telephone service	178 patient calls during chemotherapy	Nurse-led chemotherapy triage telephone service	118/178 calls between 0900-1700; n=32 1701-0000; n=10 0000-0859. 37% of calls dealt with by HCAs. Most common enquiries pyrexia (n=33), nausea (n=17), vomiting (n=21), sore mouth (n=16). 23 patients needed admission. Recommendations: continuity for telephone triage, evening and weekend support, education and training
James and Eastwood (2005)  UK	Patient satisfaction audit	79 patients with prostate cancer on follow up	Nurse-led follow up for patients with prostate cancer	High satisfaction with nurse-led. 97% have confidence and trust in the CNS but 6% would prefer to see a doctor for follow up. Advantages to nurse-led include continuity, time, knowledge and sensitivity
Mills,S (2005)  UK	Audit of waiting times in a diagnostic clinic for endometrial cancer	Endometrial cancer Diagnostic clinic	Nurse-led diagnostic clinic for post-menopausal bleeding	Nurse-led clinic had increased the number of patients meeting the 31 day diagnostic target from 25% (pre nurse-led clinic) to 82% (post nurse-led)
Fletcher and Hornsby (2007) UK	Patient satisfaction survey	57 patients receiving radiotherapy for breast cancer	Nurse or radiographer reviews during radiotherapy, determined by patients' completion of a concerns checklist	Radiographers saw patients with concerns about radiotherapy and symptoms (n=39). Nurses saw patients with more complex needs/concerns (n=18). High levels of patient satisfaction
James and Eastwood (2007) UK	Patient satisfaction survey	157 patients attending follow up for prostate cancer	Nurse-led evening clinic for patients with prostate cancer on routine follow up	90% wanted increased availability of evening clinics. Advantages: less busy, parking easier. Disadvantages: public transport, pharmacy not open
MacLeod et al (2007) UK	Patient satisfaction survey	52 patients on capecitabine for colorectal cancer	Nurse/pharmacist-led capecitabine colorectal cancer clinic	85-100% satisfaction with nurse-led clinics
Shaïda et al (2007) UK	Patient satisfaction survey	696 patients with prostate cancer on follow up	Nurse-led telephone follow up for patients with prostate cancer versus standard outpatient care	No difference in patient satisfaction between face-to-face or telephone consultations. Telephone consultations and waiting times shorter than standard outpatient appointments

Author	Study design	Cancer group	Type of Nurse-led clinic	Main findings
Warren,M (2007)  UK	Patient satisfaction survey	20 patients attending nurse-led clinic for histology results	Nurse-led clinic for surgical histology results prior to medical appointment	High patient satisfaction (100%) Patients were not asked whether they would have preferred to see a doctor.
Williamson et al (2007)  UK	Patient satisfaction audit	40 patients with lung cancer attending a nurse-led follow up clinic	Nurse-led follow up for lung cancer	High patient satisfaction. 12 (30%) reported the ability to discuss some issues because they were seen by a nurse. For future appointments 12(30%) wanted nurse only; 12(30%) wanted doctor only and 16(40%) wanted shared care with alternating appointments
James and McPhail (2008)  UK	Patient satisfaction audit	33 patients attending a nurse-led prostate biopsy clinic	Nurse-led prostate biopsy clinic	High patient satisfaction. Supportive of the nurse-led concept and would not like to see a doctor. However 10% said they would have preferred to be seen initially by a consultant urologist
Wilkinson and Sloan (2009)  UK	Retrospective patient satisfaction audit	121 patients who received nurse-led follow up after surgery for colorectal cancer	Nurse-led follow up after surgery for colorectal cancer	95% patient satisfaction. 90% reported reduced anxiety, 80% continuity, 86% personalised care, 88% sensitive approach to examinations, 91% able to discuss concerns. Patients recommended follow up call post diagnosis and 48 hours after discharge
Hewlett and Howland (2009) UK	Patient satisfaction survey	25 patients with head and neck cancer	Nurse / dietician led follow up for patients with head and neck cancer	High levels of patient satisfaction. Useful to see the nurse and dietician at the same time.
Anderson (2010)  UK	Patient satisfaction survey	43 patients with prostate cancer on nurse-led follow up	Nurse-led Prostatic Specific Antigen (PSA) telephone follow-up clinic	High patient satisfaction (99%)

Author	Study design	Cancer group	Type of Nurse-led clinic	Main findings
Jeyarajah et al (2010)  UK	Prospective audit	193 patients attending nurse-led follow-up clinics after colorectal surgery	Nurse-led protocol-based clinic for patients on follow-up post colorectal cancer resection	Decreased costs for nurse-led follow up compared with doctor-led estimates within a previous meta-analysis. Results given for mortality and local recurrence rates within nurse-led but no direct comparator for doctor-led. (However this appeared to be a retrospective audit)
Collins (2010)  UK	Patient satisfaction survey	38 patients with lymphoma in a nurse-led bone marrow biopsy clinic	Nurse-led bone marrow biopsy clinic for patients with lymphoma	High patient satisfaction. Patient choice of four options of pain relief. Appropriate quality of samples for interpretative results. Benefit of information and support when procedure performed by a CNS.
Palmer and Thain (2010)  UK	Patient satisfaction survey	18 patients with lung cancer who attended a nurse-led diagnosis clinic	Nurse-led diagnostic results clinic for patients with lung cancer	High patient satisfaction 12(67%) understood everything and 6(33%) most aspects of their diagnosis. 16(89%) thought their diagnosis had been explained sensitively. Consultants were supportive and GPs responded positively.
Bau-Berglund and Bergenmar (2011) Sweden	Patient satisfaction survey	503 patients on nurse-led telephone follow up for prostate cancer	Nurse-led telephone follow up after radiotherapy for PSA results	High patient satisfaction with telephone clinic for PSA results (86%) and information needs (86%). 3% thought it was bad to get results by phone; 8% information needs partly met and 2% not met. 6% searched for further information after the telephone clinic
Farrell et al (2011a)  UK	Patient satisfaction survey	225 patients with breast cancer attending nurse-led Herceptin clinics	Nurse-led clinics and clinical management of breast cancer patients on Herceptin	High levels of patient satisfaction Improved continuity of care, cardiac monitoring / safety, and completion of treatment during nurse-led Herceptin
McFarlane et al (2011)  New Zealand	Audit	950 patients with colorectal cancer on nurse-led follow-up	Nurse-led follow-up clinic for 5 years after colorectal surgery	Structured medical assessment Focus on numbers seen, number of recurrence / death. No mention of symptom management, psychological or social issues.No nursing assessment

Author	Study design	Cancer group	Type of Nurse-led clinic	Main findings
Wallberg et al (2011)  Sweden	Patient satisfaction survey	392 patients attending nurse-led follow up clinics in 2009; 142 patients in 2007	Nurse-led follow up after cancer treatment	High levels of patient satisfaction. Increase of 10% in continuity from 2007- 2009 but continuity and information remain areas for improvement.
Guest et al (2012)  UK	Patient satisfaction survey	12 Patients with gynaecological cancer attending a pre-operative assessment clinic Focus group (n=5)	Nurse-led pre-operative assessment clinic for gynaecological cancer	All patients (n=12) considered their needs addressed. 6 (50%) found the Holistic Needs Assessment useful. Focus group found the nurse-led clinic reassuring, provided platform to discuss concerns and could meet CNS pre surgery.
Turner and Wells (2012)  UK	Patient satisfaction survey	29 patients with prostate cancer on nurse-led telephone follow up	Nurse-led telephone follow up for patients with prostate cancer	High patient satisfaction (90%). 23/29 (79%) preferred telephone follow up but 6(21%) wanted face-to-face hospital appointments
Winter et al (2012)  UK	Patient satisfaction survey	35 patients attending a gastrointestinal clinical trials nurse-led clinic	Nurse-led gastrointestinal clinical trials clinic	High patient satisfaction (95%) All patients felt anxious. 4/35 patients would have preferred to see a doctor. 3/35 wanted more information on how to take medication.



## **2.7 Review results**

This review includes a narrative synthesis of empirical studies using thematic analysis (Mays et al, 2005), focusing on nurses' roles and nurse-led oncology clinics. This was an iterative process. The themes were devised from reading and re-reading evidence from all studies included in the review and presented in the tables, comparing and contrasting findings from each study, and then synthesising the findings to answer the research question on nurses' roles within oncology nurse-led clinics. From this five themes were identified:

1. Rationale for developing nurse-led clinics
2. Mode of delivery of nurse-led clinics
3. The content of nurse-led clinics
4. Exploring patient outcomes
5. Appraisal of nurse-led clinics

Each theme is discussed in turn; however outcomes from individual studies are discussed collectively within theme 4. Theme 1 starts with the rationale for setting up nurse-led clinics to consider what drivers are involved.

## **2.8 Theme 1: Rationale for developing nurse-led clinics**

Thirty one papers from the literature review provided information on the rationale for developing nurse-led clinics. Studies include: Five randomised controlled trials (RCT) (Moore et al, 2002; Beaver et al, 2009; Sheppard et al, 2009; Kimman et al, 2010; Strand et al, 2011); two non-randomised studies (Allinson, 2004; Wells et al, 2008); nine qualitative studies (Beaver et al, 2010a, 2010b; Cox et al, 2006, 2008; Faithfull and Hunt, 2005; Fitzsimmons et al, 2005; Knowles et al, 2006; Moore et al, 1999, 2006); two cross-sectional surveys (Krishnasamy et al, 2011; Pennery and Mallett, 2000). In addition there were nine patient satisfaction surveys (Anderson, 2010; Fletcher and Hornsby, 2007; Guest et al, 2012; Macleod et al, 2007; Sardell et al, 2000; Booker et al, 2004, Turner and Wells, 2012; Warren, 2007; Winter et al, 2011); and three audits (James et al, 1994; Jeyarajah et al, 2010; McFarlane et al, 2011).

### **2.8.1 The feasibility of nurse-led clinics**

Four studies consider the feasibility of developing nurse-led clinics for routine follow up in breast (Pennery and Mallet, 2000) and lung cancer, (Moore et al, 1999; Cox et al, 2006; Krishnasamy et al., 2011) although there are differences

in the aims and research methods. The quality of the cross-sectional surveys were good, providing some information on the feasibility of nurse-led follow-up (Krishnasamy et al, 2011) and exploring patients' perceptions (Pennery and Mallett, 2000). However more detail was obtained from qualitative studies to improve understanding of current issues in medical follow-up prior to developing nurse-led models of care (Moore et al, 1999; Cox et al, 2006).

In contrast, Fitzsimmons et al (2005) explore the feasibility of a nurse-led chemotherapy service in a very good qualitative study to ascertain perceptions of patients and hospital staff. All studies place emphasis on the importance of ascertaining patients' perceptions regarding existing medical management and the potential for nurse-led care. Involving patients at this initial stage prior to developing nurse-led services seems crucial, not only to elicit patients' opinions, but also to explore issues within existing clinical care. This helps to provide a framework for patient-centred nurse-led services, and in some cases leads to an alternative model of care (Moore et al, 1999).

A literature review on the development of nurse-led clinics in cancer care concludes that nurse-led clinics are primarily developed to meet patients' perceived unmet needs, improve quality of the service, or to solve patients' problems (Loftus and Weston, 2001). However the review is badly structured and the quality poor; only three studies are included (Campbell et al, 1999; Garvican et al, 1998; Corner et al, 1995) and minimal information presented.

Although some nurse-led clinics may be developed to improve services and address patients' unmet needs, the findings from a qualitative study suggest that the main driver is often service redesign and clinical need rather than patients' experiences (Faithfull and Hunt, 2005). This resonates with policy influencing clinical changes, beginning in the 1980s with the reduction in junior doctors' hours (Ferguson and Kearney, 2000; DH 1999, 2000c) and a need to meet clinical targets (Mills, 2005).

The drivers for initiating and developing nurse-led clinics can be divided into two main categories: service needs and patient needs. The motivating factors seem important since they appear to influence how nurse-led clinics are set up, how they operate, and also nurses' roles and responsibilities within the clinics.

### **2.8.2 Service needs**

Studies show that increasing clinical demands are the main driver for nurse-led clinics (Allinson, 2004). This is also supported by evidence from clinical audits, which adds weight to the research evidence. There are indications that clinics are exceeding capacity, medical staff feel overburdened (Anderson, 2010; Turner and Wells, 2012), with an increasing number of patients within the medical clinics (James et al, 1994; Allinson, 2004; Booker et al, 2004; Anderson, 2010).

Strand et al (2011) highlight that patient waiting times are increasing, which is supported by additional evidence from clinical audits (Anderson, 2010; Turner and Wells, 2012). This is exacerbated by government targets which place increased pressure on clinical services, for example a need to see patients within two weeks of referral for suspected cancer (Cox et al, 2006). A randomised trial compared nurse-led and doctor-led follow-up to understand operational aspects of care and factors that may influence patient satisfaction, which revealed that nurse-led consultations were significantly longer and more blood tests undertaken, which influenced service costs (Strand et al, 2011).

To address clinical demands nurses, working in partnership with doctors, may select a group of patients that can be seen independently within a nurse-led clinic, thus easing the pressure (and numbers) within the medical clinic. However, focusing on patient numbers and medical workloads seems to give priority to a medical model of care focusing on doctor-nurse substitution, rather than patient-focused care using nursing values. Some studies report that nurses work to a protocol, often designed by medical staff, which requires nurses to follow a structured list when reviewing patients in outpatient clinics (Loftus and Weston, 2001; Knowles et al, 2006; Strand et al, 2011). There is additional clinical evidence in outpatients (Macleod et al, 2007; Jeyarajah et al, 2010; McFarlane et al, 2011; Turner and Wells, 2012), and by telephone (Moore et al, 1999; Booker et al, 2004; Anderson, 2010), and radiotherapy (James et al, 1994).

Other studies identify an assessment proforma designed by nurses, which incorporates nursing assessments in addition to medical assessments and

includes a greater focus on psychological issues (Moore et al, 2006; Wells et al, 2008). This suggests potential additional benefits for patients by amending the standard medical model of care.

### **2.8.3 Patient needs**

Other studies recognise problems with medical-led clinics and explore patients' perspectives prior to setting up nurse-led clinics. Cox et al (2006) highlighted that nurse-led clinics aim to provide holistic patient care, which is supported by additional clinical evidence (Fletcher and Hornsby, 2007; Guest et al, 2012), however in the main this seems lip service. The satisfaction survey by Guest et al (2012) included only 12 patients attending a pre-assessment clinic, and one focus group of five patients. Insufficient information was provided on the focus group to assess its quality; it was not clear how holistic needs assessments were conducted, and only six out of 12 patients found it useful. Although Fletcher and Hornsby (2007) used a larger sample size (n=57) for their satisfaction survey, there were no clear indications that holistic needs assessments had been undertaken. In contrast, Moore et al (2002) conducted a RCT to explore differences between nurse-led and standard medical follow-up for lung cancer, clearly identifying the importance of nurses in undertaking comprehensive holistic patient assessments to understand key aspects of patients' experience that were not evident in standard medical follow-up. Similarly, Cox et al (2008) demonstrated how complex and sensitive information and concerns can be explored using holistic assessments that include psychological, social, sexual, and spiritual assessments.

Issues affecting patients accessing doctor-led clinics include lack of coordination (Moore et al, 1999; Krishnasamy et al, 2011) and lack of continuity (Moore et al, 1999; Pennery and Mallet, 2000; Krishnasamy et al, 2011), which adversely affected patients' experience of medical care. Patients also reported problems with inadequate symptom control and psychosocial care (Moore et al, 1999; Pennery and Mallet, 2000), and unmet information needs with medical management (Pennery and Mallet, 2000; Beaver et al, 2009, 2010a, 2010b).

The quality of randomised and qualitative studies was good, with an appropriate number of patients for the research design, however the majority of surveys had a low number of participants, which was inappropriate (Anderson, 2010;

Fletcher and Hornsby, 2007; Guest et al, 2012; Macleod et al, 2007; Sardell et al, 2000; Turner and Wells, 2012; Warren, 2007; Winter et al, 2011; James et al, 1994; Jeyarajah et al, 2010).

#### **2.8.4 Acceptability of nurse-led clinics**

Some studies focus on the feasibility and future acceptability of nurse-led clinics, rather than nurses' roles (Krishnasamy et al, 2011; Cox et al, 2006; Fitzsimmons et al, 2005; Pennery and Mallet, 2000; Moore et al, 1999). All the studies identify that the concept of nurse-led clinics is acceptable to patients on follow-up after lung cancer (Moore et al, 1999; Cox et al, 2006; Krishnasamy et al, 2011), breast cancer (Pennery and Mallett, 2000), however patients opinions were mixed regarding nurse-led chemotherapy (Fitzsimmons et al, 2005).

It also seems that patients' responses may reflect their lack of understanding of nurses' roles, particularly given the changes to nurses' roles and nurse-led developments over time. A lack of understanding regarding expanding nurses' roles may also explain the mixed opinions of patients in relation to the feasibility of nurse-led chemotherapy clinics (Fitzsimmons et al, 2005), and patients' preferences for doctor-led rather than nurse-led follow up (Cox et al, 2006). Both studies appear well constructed with high quality appraisal scores. However, whilst their aims to incorporate patients' perceptions are important their findings may be biased by patients' limited understanding of nurse-led developments. Whilst patients may automatically have some degree of confidence in doctors' competence, this could be influenced by the quality of consultations and interactions with individuals. In contrast changes to traditional nurses' roles may create uncertainty for patients who are not familiar with the scope of their role and competencies, and this could create challenges for nurses who have to build patients' trust and confidence in their abilities.

#### **2.8.5 Training**

Few studies and clinical audits report what training nurses complete in order to undertake their extended role within the nurse-led clinic. In the UK training includes clinical examination skills (Sheppard et al, 2009; Winter et al, 2011), shadowing or observing doctors (Moore et al, 1999; Sardell et al, 2000; Sheppard et al, 2009), and non-medical prescribing (Winter et al, 2011). Warren

(2007) reports that nurses undertook three months supervised training with the lead cancer nurse and theoretical training on breaking bad news, however no details are given on the content of training and assessment of competencies. Training for non-UK nurses is only mentioned in two studies: a half-day session on telephone communication skills (Kimman et al, 2010) and six months training by a consultant surgeon on clinical examination and sigmoidoscopy (Strand et al, 2011).

An audit of consultation times and effectiveness of care for patients receiving cranial radiotherapy focused mainly on doctors' workloads and how patient numbers reduced by the introduction of nurse-led clinics (James et al, 1994). This seems a missed opportunity and a sad reflection of nursing where the main focus is time and a patient numbers, rather than patients' experiences. There is no discussion about training nurses had undertaken prior to setting up nurse-led clinics, and how their roles had changed. This highlights the difficulties in assessing nurses' roles, competencies and the quality of nurse-led clinics when no evidence of this is provided. James et al (1994) place emphasis on a medical model of care where nurses work to a protocol, which includes using a structured list to review patients during radiotherapy and telephone follow-up; therefore it is difficult to assess the content of nurses' consultations and potential benefits for patients.

Theme 2 explores the literature in relation to the mode of delivery of nurse-led clinics to understand the different ways nurse-led clinics can be undertaken.

## **2.9 Theme 2: Mode of delivery of nurse-led clinics**

A total of 17 papers and four reviews provide information on the mode of delivery of nurse-led clinics. This section of the review looks at the delivery of nurse-led clinics, including the different methods of nurse-led clinics and timing of appointments. Whilst some nurse-led clinics consist of doctor-nurse substitution and continue a medical model of care, others develop alternative models of follow up such as nurse-led telephone follow up.

### **2.9.1 Nurse-led face-to-face clinics**

In eleven studies, nurses within the nurse-led clinics see patients face-to-face, including eight studies comparing nurse-led and doctor-led care (Lee et al, 2011; Strand et al, 2011; Beaver et al, 2010b; Seibeck and Peterson, 2009; Wells et al, 2008; Baildam et al, 2004; Allinson, 2004; Faithfull et al, 2001; Campbell et al, 1999). The remaining studies aim to evaluate the effectiveness of nurse-led clinics by exploring the therapeutic value of a nurse-led radiotherapy clinic (Faithfull and Hunt, 2005), the feasibility of nurse-led follow-up for patients with colorectal cancer, including an economic evaluation (Knowles et al, 2007), and patient satisfaction with a nurse-led oncology day ward (Eagan and Dowling, 2005). In addition, Hutchison et al (2011) review 88 nurse-led clinics in Scotland, identifying a wide range in the nature of nurse-led clinics and perceived benefits for patients included continuity of care and reduction in waiting times. However, no information was provided about the mode of delivery within each clinic. 48% of the nurse-led clinics had been running for over five years, although 55% had not been evaluated. In addition systems were in place to assess nurses' competency, which had been undertaken for 70% of nurses in nurse-led clinics (Hutchison et al, 2011).

Four studies are conducted in radiotherapy departments, three of which compare clinical reviews by a doctor during radiotherapy with clinical reviews by a nurse (Wells et al, 2008; Faithfull et al, 2001; Campbell et al, 1999). Nurses describe their difficulties setting up their clinics within radiotherapy, including obtaining clinic space and recognition for their roles since less priority is given to nurse-led clinics (Faithfull et al, 2001).

For some nurses it is clear that they want to improve patients' experiences during radiotherapy through symptom management, provision of information and psychosocial support (Wells et al, 2008; Faithfull et al, 2001). Both studies highlighted the importance of increased accessibility by adopting an open access policy where patients can contact them in addition to regular clinic appointments during radiotherapy. Wells et al (2008) identified that patients had longer and more frequent consultations in the nurse-led clinic in comparison with medical clinics, which provided additional benefits for patients. Faithfull et al (2001) created a different model of care within nurse-led radiotherapy clinics,

which provided continuity after completion of treatment through telephone monitoring.

Two studies are also included since they meet the inclusion criteria; however provide a programme of care in addition to standard medical appointments. A course of cognitive behavioural therapy (CBT) during radiotherapy includes weekly appointments for six weeks and aims to address psychological issues related to breast cancer (Lee et al, 2011); a rehabilitation programme for gynaecological cancers aims to improve quality of life and physical functioning (Seibeck and Peterson, 2009). Both studies draw comparisons with doctor-led care and quality appraisal scores are high, indicating that the studies are well constructed and evaluated.

### **2.9.2 Timing of appointments**

Few comments are made about the duration of consultations with patients; however some studies identify that nurse consultations appear longer than doctors (Strand et al, 2011; Wells et al, 2008; Allinson et al, 2004; Baildam et al, 2004; Campbell et al, 1999). When timings of consultations are given it seems that nurse-led clinics are deliberately set up to give patients at least twice as much time as medical clinics (see table 2.9).

**Table 2.9 Clinic appointment times**

Telephone clinics
  Face-to-face clinics
  Both clinic types

Doctor-led (Time in minutes)	Nurse-led (Time in minutes)	Reference
10	30	Beaver et al, 2009
10-15	30	Coughlan, 2005
	10 (mean)	Sardell et al 2000
10	20	Faithfull et al, 2001
	20-30	Faithfull and Hunt, 2005
10	15-20	Kimman et al, 2010
15	15-30	McFarlane et al, 2011
20	45	Palmer and Thain, 2010
15	30	Warren, 2007
4 (mean)	16 (mean)	Wells et al, 2008
	30	Winter et al, 2011

There are also differences in patients' perceptions regarding the duration of follow-up in that some prefer more, and others fewer, appointments than



planned (Pennery and Mallet, 2000). Indeed, Beaver and Luker (2005) question the value of routine follow-up following adjuvant breast cancer treatment and suggest using alternative approaches that may address the diversity of patients' needs. However, controversy exists regarding the need for routine follow up, including the frequency and nature of appointments (Cox and Wilson, 2003, Pennery and Mallet, 2000) and the importance of clarifying patients' expectations regarding follow-up (Beaver and Luker, 2005). Clarification of patients' perceptions and expectations seem important when reconfiguring and developing services, yet does not appear to have much prominence in the literature presented here.

There are also reports that patients value the relationship with nurse specialist, and nurse-led consultations are more frequent than doctor-led management (Wells et al, 2008). This may provide additional benefits to traditional medical follow up, and is illustrated in a nurse-led family history clinic where patients report feeling less rushed, with sufficient time to discuss their concerns, which contrasts with patients' perceptions of medical clinics (Allinson, 2004).

The next section focuses on literature for nurse-led telephone clinics.

### ***2.9.3 Nurse-led telephone clinics***

Two literature reviews of 11 and 37 studies respectively (Cusack and Taylor, 2010; Cox and Wilson, 2003) report that telephone consultations are an appropriate means of providing nurse-led follow-up. In particular telephone follow up for patients with colorectal cancer is considered to be cost-effective and accepted by the majority of patients (Cusack and Taylor, 2010); aspects of care include symptom management and also highlight the potential to provide reassurance over the phone. However, many of the studies identified by Cox and Wilson are non-oncology nurse-led clinics, which decrease its relevance for this review.

In addition to the literature reviews, a further 17 studies focus on nurse-led telephone clinics. This highlights how services are changing to meet increasing demands in the medical clinics, and also how nurses are being used to address this. The majority of nurse-led telephone clinics are used to replace routine follow-up after early treatment, which was previously undertaken in outpatient

clinics by doctors. An indication of the interest in telephone clinics is illustrated by the number of studies using this method for a range of cancer groups including prostate cancer (Booker et al, 2004; Helgessen et al, 1999), ovarian cancer (Cox et al, 2008), lung cancer (Lewis et al, 2009; Moore et al, 2006; Corner et al, 2002; Moore et al, 2002), and breast cancer (Kimman et al, 2011, 2010; Beaver et al, 2010a, 2009, 2006; Sheppard et al, 2009; Koinberg et al 2004, 2002; Brown et al, 2002).

However, for some studies it is not known whether the impetus for switching to nurse-led telephone clinics came primarily from medical staff, nurses, patients or hospital managers. Similarly it is not known how much influence nurses have regarding the timing and content of nurse-led clinics. This seems an important factor in determining nurses' roles within the clinic and their degree of autonomy. There is strong evidence of greater patient-centred care when nurses take over whole episodes of care and introduce nursing interventions such as breathing retraining, addressing psychosocial issues, (Corner et al, 2002; Moore et al, 2002) and focus on patients' information needs (Beaver et al, 2006, 2009, 2010a).

For the majority of patients, nurse-led telephone follow-up is described as acceptable, safe and convenient (Moore et al, 1999; Corner, 2003; Cox and Wilson, 2003). Aspects of safety are discussed further in the section on patient outcomes (theme 4). This includes measurable factors such as the detection of cancer recurrence, results of fine needle aspiration (FNA), and psychological distress. From this literature review it appears that older studies focus more on safety aspects and making comparisons with doctor-led care, whereas more recent studies focus more on patient satisfaction and acceptability.

All nurse-led clinics appear to score highly on patient satisfaction surveys, and although some patients seem to prefer the reassurance of traditional clinic follow-up, this appears to be a small minority (Lewis et al, 2009). A difference in patients' expectations may create some natural resistance in the early stages of developing nurse-led clinics and changing from traditional clinics, particularly if patients are uncertain about nurses' roles (Fitzsimmons et al, 2005). However over a period of time the concept of nurse-led clinics may become more

acceptable to patients as the normal method of follow-up. Nevertheless it appears that patients do not have much, if any, choice in the method of follow up outside of research studies.

Nurses also adopt different methods of undertaking telephone follow up. After testing the feasibility of telephone follow up to address patients' information needs, Beaver et al (2006) conducted a randomised trial to compare standard doctor-led follow up with nurse-led telephone follow up using an intervention to address information needs (Beaver et al, 2009). This approach creates a very structured nurse-led consultation, which differs to the unstructured approach of other nurse-led telephone clinics (Kimman et al, 2010; Cox et al, 2008; Booker et al, 2004). In these clinics the main focus is information and symptom management, although this will be discussed in more detail in the following section. However, one study focusses specifically on patients' symptoms following chemotherapy (Kelly et al, 1999), illustrating the versatility this approach may offer.

A number of studies place more responsibility on patients themselves during routine follow-up by using a nurse-led telephone service on demand for patients with prostate cancer (Helgessen et al, 1999), or patient-initiated follow-up after breast cancer (Sheppard et al, 2009; Koinberg et al, 2004, 2002; Brown et al, 2002). Although on demand services are considered safe, acceptable and convenient, some patients seem to prefer the reassurance of a clinical examination in addition to mammography, therefore patient choice seems an important consideration (Sheppard et al, 2009). In contrast, studies involving patients with lung cancer adopt a different approach to telephone follow up which relates directly to patients' symptoms, developing a nurse-led intervention to improve patients' dyspnoea and quality of life (Corner et al, 2002; Moore et al, 2002). Here the emphasis is on patient-centred care driven by nursing values, which is reflected in the findings. In addition to regular telephone monitoring, the authors introduce an open access nurse-led clinic and increase liaison with services such as palliative care, which enables more patients to die at home.

In summary there is strong evidence that nurse-led clinics are acceptable to patients, irrespective of the mode of delivery, however patient choice is

important. Although telephone follow-up is safe, effective and acceptable to the majority of patients, some will prefer attending clinics where they can have a face-to-face discussion. The potential benefits of involving patients in nurse-led service developments is clear (Fitzsimmons et al, 2005), however this study also demonstrates patients' lack of understanding regarding expansion to nurses' traditional roles, and illustrates how this may influence their acceptance of nurse-led clinics. What is not clear from the literature is how nurses' interact with patients in nurse-led clinics to provide a greater understanding of nurses' roles, particularly in nurse-led chemotherapy clinics.

Theme 3 considers the content of nurse-led clinics and evidence from the literature, in order to understand the nature of nurse-led clinics and nurses' roles.

## **2.10 Theme 3: The content of nurse-led clinics**

22 papers and one review provide information about the content of nurse-led clinics. Information on the content of nurse-led clinics is important to understanding nurses' roles within the clinic. However, although some studies discuss certain aspects of the clinic, there is a lack of descriptive detail regarding nurses' roles, for example how they perceive their role, what they actually do in the clinic, and how they communicate with patients and their family.

The largest category of studies on nurse-led clinics is follow-up. However, in contrast to this a survey of 88 nurse-led clinics in Scotland identified that 51% of clinics were during treatment and only 31% for follow up (Hutchinson et al, 2011). Considering that this is a recent study it may reflect the current decline in routine follow-up, yet is also indicative of the lack of nursing research on radiotherapy and chemotherapy clinics.

### **2.10.1 *Follow-up***

In the majority of follow-up studies there is limited information on the content of nurse-led clinics, and a lack of information on nurses' roles within the clinic. In follow-up clinics where nurses have replaced the doctor, the nurses' role appears to follow a medical model of care: checking for possible recurrence,

checking for signs and symptoms and undertaking a clinical examination (Baildam et al, 2004; Strand et al, 2011). Similarly, swapping a medical clinic for nurse-led telephone clinic may also be conducted in a structured way to elicit signs or symptoms of possible recurrence (Brown et al, 2002; Koinberg et al, 2002, 2004; Knowles et al, 2007; Sheppard et al, 2009; Kimman et al, 2011) or side-effects of treatment (Booker et al, 2004).

In contrast, some of the nurse-led follow-up clinics set out to provide something different, or additional to, the medical clinics. After identifying problems within the medical clinic for patients with lung cancer, the nurse-led clinic was set up to focus on the patient as a whole, trying to improve complex symptoms and coordinate care (Corner et al, 2002; Moore et al, 2002; Moore et al, 2006). This new model of nurse-led care provided significant benefits for patients, including increased satisfaction, improved symptom management, reduced dyspnoea, improved emotional functioning, less medical appointments, and patients were more likely to die at home than hospital or hospice (Corner et al, 2002; Moore et al, 2002). Moore et al (2006) demonstrated greater contact with palliative care teams, improved psychosocial and financial support, and improved coordination of care from nurse-led clinics.

Several studies focus on patients' information needs, devising a structured information needs intervention that can be administered over the telephone by specialist nurses (Beaver et al, 2006, 2009, 2010a, 2010b). A large trial shows no differences for information and anxiety in nurse-led versus doctor-led breast cancer follow-up (Beaver et al, 2009), and nurse-led follow up in colorectal cancer appears to meet patients' information needs and helps them to cope (Beaver et al, 2010b).

Although some studies indicate that nurse-led clinics successfully address patients' psychological distress (Baildam et al, 2004; Cox et al, 2008), or provide psychological support (Hutchison et al, 2011), there are no details about how nurses assess anxiety, depression, and patients' concerns. Despite frequent suggestions in the literature that nurse-led clinics can offer advantages to patients by undertaking holistic care, or by offering psychological support, there is little evidence of this taking place. There are no details of nurses' consultations with patients within nurse-led clinics, and minimal descriptions of

nurses' roles, which creates speculation regarding the nature and content of consultations and nurse-patient interactions.

### **2.10.2      *Symptom management***

The assessment and management of patients' symptoms can be undertaken at any point during active treatment with chemotherapy or radiotherapy, and also following completion of treatment during subsequent follow-up. Although symptom management may be undertaken in an outpatient clinic, telephone consultations are often used. A literature review of 11 studies focuses on telephone follow-up after surgery for colorectal cancer where symptom management is successfully undertaken and provides reassurance for patients (Cusack and Taylor, 2010). In these studies telephone follow-up is undertaken by specialist nurses who are familiar with the common symptoms and able to discuss strategies over the phone to improve patients' symptoms, for example nutrition and diet to alleviate bowel problems.

For patients with lung cancer, symptom management appears complex and nurse-led clinics adopt an alternative approach (Corner et al, 2002; Moore et al, 2002). The authors identify that dyspnoea is a complex symptom, incorporating psychological, physical and physiological elements, which requires an alternative approach to standard medical reviews or doctor-nurse substitution. Patients are taught different breathing and relaxation techniques, psychosocial and financial concerns are addressed, the disease monitored, symptoms managed, and care coordinated through the nurse-led clinics and liaison with palliative care services. A combination of face-to-face clinics and telephone clinics are used, with a patient-centred approach tailored to each individual (Corner et al, 2002; Moore et al, 2002).

The assessment and management of symptoms is also undertaken during chemotherapy to assess treatment toxicities and manage patients' symptoms by telephone (Kelly et al, 1999). This proactive approach is acceptable and considered beneficial in promoting self-care (Kelly et al, 1999). However only the abstract was available therefore no further details are known. A satisfaction study of patients attending a chemotherapy oncology day ward is disappointing since the author makes some claims regarding the nature of nurses' roles yet provides no evidence for this (Egan and Dowling, 2005). The authors suggest

that nurses' roles include comprehensive assessment, symptom management, psychosocial care and information provision, however provide no further details and no evidence within this study (Egan and Dowling, 2005).

Although studies in this review discuss the importance of symptom management, there is little information to show how this is undertaken, which fails to provide comprehensive information regarding nurses' roles and their interactions with patients.

### **2.10.3      *Treatment management***

Symptom management is also a considerable part of nurse-led clinics in radiotherapy, although there may be variability in the clinic's remit. The role of the nurse also seems to vary in each of the studies reviewed, often depending on how much autonomy nurses have within their clinic. Greater autonomy is evident where nurses take on more responsibility for patients' treatment (Faithfull et al, 2001; Faithfull and Hunt, 2005; Wells et al, 2008), or conduct a specific nurse-led programme over several weeks (Lee et al, 2011; Seibeck and Peterson, 2009).

One of the main advantages of nurses managing patients' treatment is the continuity of care, which enables them to build a relationship with patients (Faithfull and Hunt, 2005; Wells et al, 2008; Earnshaw and Stephenson, 1997; Egan and Dowling, 2005; Faithfull et al, 2001). During radiotherapy patients are reviewed weekly to determine how they are tolerating the treatment and assess side-effects. However, the introduction of nurse-led clinics allows nurses to be more flexible with appointments, which increases interventions (Campbell et al, 1999), allows the addition of telephone monitoring (Faithfull et al, 2001; Faithfull and Hunt, 2005) and facilitates longer and more frequent consultations (Wells et al, 2008). However, although greater continuity of care was evident in nurse-led clinics, there was no difference in patients' quality of life (Faithfull et al, 2001). Similarly, patients appeared to value their relationship with the nurse in nurse-led radiotherapy clinics; however quality of life was unchanged. Whilst some studies show high levels of patient satisfaction and acceptability from nurse-led clinics, there are no comparisons with traditional medical clinics (Egan and Dowling, 2005). Faithfull and Hunt (2005) eloquently describe therapeutic values integral to nurse-led care, however exploring whether this affected

patient outcomes was outside the scope of this pilot study. The potential impact of nurse-led clinics on patient outcomes will be discussed further in the next section.

Providing more time for patients enables them to receive more information within nurse-led clinics (Faithfull et al, 2001) and facilitate greater communication of information to GPs (Wells et al, 2008). Although there appear to be no significant differences in psychological well-being or quality of life within nurse-led radiotherapy clinics, patients seem to value their relationship with the nurse (Wells et al, 2008), and there is evidence of therapeutic support (Faithfull and Hunt, 2005).

The value of time for patients is also evident in other studies, including a nurse-led family history clinic (Allinson, 2004). Although this is doctor-nurse substitution where the nurse seems to maintain a medical model of care, the way that nurses conduct their consultations seems different; patients report feeling less rushed and appear to understand their risks better than in the medical clinics (Allinson, 2004).

Whilst there is some information on nurses' roles and autonomy within nurse-led radiotherapy clinics, information on nurses' interactions and communication with patients is limited. This is due to the design of studies and how the findings are reported. Although Faithfull and Hunt (2005) go some way to addressing this when identifying professional values integral to nurse-led care, there are still gaps in the fine details of nurse-led interactions which would provide a greater understanding of nurses' roles within nurse-led clinics.

In addition there is a lack of research on nurse-led chemotherapy clinics, which is in contrast to their rapid developments over the past ten years. As a result there is no current evidence on operational aspects, nurses' roles and responsibilities and impact on patients in relation to nurse-led chemotherapy clinics.

Theme 4 focuses on literature exploring patient outcomes within nurse-led clinics to understand the potential impact on patients from nurse-led care.



## **2.11 Theme 4: Exploring patient outcomes**

Wong et al (2006) suggest an important link between the processes of care within nurse-led clinics and the outcomes that nurses can achieve. Clinical outcomes may be defined as a change in the patient's health status between two points in time, including both psychological and physical components (Hill 1999). Selecting 'nurse sensitive' indicators seems key to choosing appropriate outcome measures (Wong et al, 2006) with some consensus regarding three main areas of clinical outcomes (Hill, 1999, Urden 2001):

- Clinical outcomes, for example morbidity
- Functional outcomes, for example activities of daily living
- Cost and utilization, for example frequency of treatment / clinics

However, suggestions for a fourth indicator vary between:

- Satisfaction outcomes (Hill, 1999)
- Psychosocial outcomes, such as coping (Urden 2001).

From this it seems that choosing the most appropriate clinical outcomes is crucial to assessing the effectiveness of nurse-led clinics and determining the potential value and possible differences between medical management. The first three indicators appear to be more traditional clinical outcome measures to compare medical (clinical) effectiveness and cost effectiveness of nurse-led versus medical services. However, the addition of a fourth indicator (satisfaction or psychosocial outcomes) may be the most important factor to show possible differences of quality or added value of nurse-led and medical clinics.

With this in mind it seems sensible to use the above categories to explore patient outcomes within this review. However issues of satisfaction will be addressed separately in the next section of this review. A summary of these sub themes is given in table 2.13.

### **2.11.1 Clinical Outcomes**

A systematic review of four RCTs of nurse-led follow-up clinics shows no difference in survival, or the detection of cancer recurrence between nurse-led and doctor-led follow-up (Lewis et al, 2009), however a greater duration of long-term follow-up is important to assess how this may change over time.

These are important clinical outcomes to demonstrate the safety and effectiveness of clinics where nurses replace doctors in managing patients' follow-up care. A number of studies identify safe clinical practice within nurse-led follow up for patients with breast cancer (Baildam et al, 2004; Koinberg et al, 2004; Beaver et al, 2009; Sheppard et al, 2009) and colorectal cancer (Knowles et al, 2006). Nurse-led clinics may also increase the number of patients meeting clinical targets, for example the 31 day diagnostic target for endometrial cancer increased from 25% to 82% following the introduction of a nurse-led clinic (Mills, 2005).

Two studies show an increase in the number of interventions, prescriptions and greater referrals for support (Campbell et al, 1999), and more blood tests undertaken in nurse-led clinics compared with doctor-led clinics (Strand et al, 2011); however there is no evidence of this from other studies in this review (Helgessen et al, 1999, 2000; Corner et al, 2002; Beaver et al, 2009).

Whilst some studies report outcomes related to the identification and management of patients' symptoms, synthesising the findings is difficult due to the way findings were reported. Two studies show no difference in patients' symptoms in comparison to medical clinics (Faithfull et al, 2001; Brown et al, 2002), and a literature review concludes that nurse-led colorectal telephone clinics are a safe way to undertake symptom management (Cusack and Taylor, 2010), however details of how this is undertaken are not provided, therefore it is open to interpretation.

In addition, four studies report an improvement in patients' physical symptoms with nurse-led clinics in comparison with medical clinics; with a reduction in the number of physical problems (Beaver et al, 2006) and improvements in dyspnoea after three months (Corner et al, 2002). The high quality of the studies strengthens the credibility of the findings. There was also evidence of improvements in patients' physical symptoms over time within nurse-led clinics, including improvements in fatigue (Knowles et al, 2007; Lee et al, 2011), and also pain (Seiback and Peterson, 2009). However, the sample size was poor (n=20) for a survey comparing nurse-led rehabilitation to a control group, therefore this lacked sufficient power to demonstrate a measurable difference in patients' pain (Seibeck and Peterson, 2009). Other reports of improvements in

physical symptoms include sleep disturbance, loss of appetite and diarrhoea (Knowles et al, 2007). However, the sample size in this study is quite small.

### **2.11.2      *Functional outcomes***

Several studies comparing doctor-led and nurse-led care report no differences in patients' quality of life (Faithfull et al, 2001; Brown et al, 2002; Wells et al, 2008; Sheppard et al, 2009; Kimman et al, 2011). Whilst Lee et al (2011) report some improvement in quality of life and patients' fatigue, specific details are lacking, which raises questions regarding the quality of the findings. However, two studies demonstrate improvements in physical functioning in nurse-led colorectal cancer follow-up compared with doctor-led (Knowles et al, 2006) and from a nurse-led post-operative rehabilitation programme (Seiback and Peterson, 2009), although samples sizes are small. Patients with colorectal cancer also show improvements in social functioning within nurse-led follow-up (Knowles et al, 2007). However, given the lack of a control group it is difficult to know how much patients' quality of life would naturally improve over time. In contrast, patients who were not randomised to a nurse-led rehabilitation programme show no improvements in their quality of life at 12 months (Seiback and Peterson, 2009), which demonstrates effectiveness of the nurse-led intervention. Similarly, a randomised trial of patients with lung cancer demonstrates favourable results for nurse-led follow-up with less dyspnoea at 3 months in comparison to doctor-led follow-up (Moore et al, 2002; Corner et al, 2002).

### **2.11.3      *Cost and utilization***

There is little evidence in the literature regarding costs of nurse-led services, although there seems to be a general assumption that nurse-led care should be more cost-effective than doctor-led care due to differences in salaries. However, evidence from randomised controlled trials shows no difference in the cost of doctor-led and nurse-led follow-up care (Corner et al, 2002; Baidam et al, 2004; Strand et al, 2011). This appears to be influenced by the length of consultations, since nurse consultations are often longer than doctors (Campbell et al, 1999; Baidam et al, 2004; Wells et al, 2008). In addition it is important to take the cost of nurses' salaries into account, particularly for senior nurses whose salary may be similar to that of junior doctors.

Other factors influencing costs appeared to be the number of interventions and investigations. For example, Strand et al (2011) found that although costs are lower for nurse consultations, more investigations are ordered which increases costs. In contrast to this, Knowles et al (2007) reports a potential saving of £28,000 per annum with nurse-led follow-up for colorectal cancer. However these are not actual costs; and it is also difficult to know whether the cost predictions included investigation costs in addition to salaries.

Changing the method of delivery of nurse-led clinics seems to be the greatest factor in influencing costs. Nurse-led telephone consultations for follow-up appear cost-effective (Cusack and Taylor, 2010), identifying a 37% reduction in costs compared with face-to-face clinics (Helgessen et al, 2000). The cost of nurse-led radiotherapy clinics also seem cost-effective, reducing costs of 31% from nurse-led versus doctor-led care (Faithfull et al, 2001).

In addition to financial considerations for nurse-led clinics, studies also report advantages in reducing the number of patients attending medical clinics. Although James et al (1994) identify that nurse-led clinics resulted in a reduction of 30% medical time, in reality this seems difficult to quantify and insufficient details are provided regarding how this estimation is calculated.

#### **2.11.4      *Psychosocial outcomes***

Beaver et al (2010b) argue that traditional doctor-led follow-up may not meet patients' psychological needs, whilst nurse-led follow-up improves patients' information needs and helps them to cope. However, it seems that information may be a key factor linked to patient anxiety / psychological distress since patients receiving a nurse-led information needs intervention show less anxiety than patients on standard follow-up and report more information needs met (Beaver et al, 2006).

Despite indications in the literature that some nurse-led clinics may improve patients' psychological distress (Cox et al, 2008), several studies show no differences in comparison to doctors (Helgessen et al, 1999, 2000; Brown et al, 2002; Baidam et al, 2004; Koinberg et al, 2004; Lewis et al, 2009; Beaver et al, 2009; Sheppard et al, 2009; Kimman et al, 2011). However, although there may

be no difference in patients' psychological distress, nurses in one study are able to detect this more frequently than doctors (Baildam et al, 2004).

Faithfull and Hunt (2005) propose that nurse-led clinics may have a therapeutic value for patients where continuity, communication and trust in care are pivotal to dealing with uncertainty and the provision of therapeutic support, whilst others report how much patients value their relationship with the nurse (Wells et al, 2008; Cox et al, 2008). Two studies identify some psychological benefits from nurse-led clinics, improving emotional functioning from baseline to 12 months (Corner et al, 2002), and improving patients' ability to cope (Seiback and Peterson, 2009).

Giving patients sufficient time within consultations seems a key factor, since patients may feel less rushed and have enough time to discuss their concerns, which can also improve their understanding (Allinson, 2004). Links between patients' concerns and levels of psychological distress are well recognised (Heaven and Maguire, 1997; Farrell et al, 2011), however this has not been addressed by authors within this review.

Theme 5 explores the literature to understand evaluations on nurse-led clinics, which includes safety, effectiveness, meeting patients' needs, and patient satisfaction.

## **2.12 Theme 5: Appraisal of nurse-led clinics**

34 papers and 4 reviews provided information on the appraisals of nurse-led clinics. Cox and Wilson (2003) emphasise the importance of obtaining patients' views when evaluating nurse-led services so that service provision can be tailored according to patients' needs. The main way that this is undertaken for nurse-led clinics is through clinical audit or patient satisfaction surveys, which will form the main body of evidence within this section. However, there is also evidence from research studies in relation to the acceptability, satisfaction and effectiveness of nurse-led clinics to meet patients' needs.

### **2.12.1 *Safety, acceptability and effectiveness***

When nurse-led clinics are set up one of the main questions to come from research studies is whether the nurse-led clinic is acceptable to patients, in

comparison to doctor-led care. Conclusions from four previous literature reviews covering 51 studies confirm that nurse-led clinics are safe, acceptable and appear effective (Corner, 2003; Cox and Wilson, 2003; Lewis et al, 2009; Cusack and Taylor, 2010). The notion of acceptability is also reflected in all studies included in this review, irrespective of the cancer group, treatment, follow-up, or mode of delivery.

### **2.12.2      *Meeting patients' needs***

A systematic review of four RCTs designed to evaluate the effectiveness and cost-effectiveness of nurse-led follow-up for patients with cancer confirms that nurse-led follow-up clinics meet patients' psychological needs and also needs for information (Lewis et al, 2009). There are suggestions in the literature that nurse-led clinics may be more likely to meet patients' psychosocial needs and information needs than traditional medical clinics (Beaver et al, 2006, 2009, 2010a, 2010b). This may be due to the duration of appointments, since patients report feeling less rushed in nurse-led clinics (Allinson, 2004).

During radiotherapy patients appear to like the openness of the nurse-led clinic and find it easy to talk to the nurse (Campbell et al, 1999). The way that nurse-led clinics are set up may increase accessibility; and the addition of telephone surveillance can facilitate this (Faithfull et al, 2001). This also provides greater continuity for patients, since they often see the same person within nurse-led clinics, which is in sharp contrast to medical clinics. The value of continuity is highlighted in a study of patients attending an oncology day ward, despite only 65% seeing the same person (Egan and Dowling, 2005). However there are also negative reports in that 17% of patients lack confidence in staff and 13% are unable to access nursing staff. Nevertheless continuity of care is often reported as a positive outcome of nurse-led clinics (Earnshaw and Stephenson, 1997).

It is difficult to know how much value patients place on continuity, and how much they value the interpersonal skills of the nurse in meeting their needs. The therapeutic value of nurse-led interactions is identified in two studies of patients undergoing radiotherapy (Faithfull and Hunt, 2005; Sharp & Tishelman, 2005), although this seems a difficult concept to define and warrants further

consideration in relation to meeting patients' needs. Koinberg et al (2002) identifies that patients' needs include trust, security and reassurance in addition to support. This fits with patients' desire for continuity, since regular contact with a nurse should facilitate the development of trust, support and reassurance.

There are also suggestions that patients may have their own personal perceptions of doctors' and nurses' roles, which could influence their preferences. Pennery and Mallett (2000) highlight that 54% of patients with breast cancer report that nurse-led follow-up is more supportive than doctor-led care. However, it is difficult to know how much patients are influenced by their relationship with a specialist nurse.

### **2.12.3      *Satisfaction with nurse-led clinics***

Comparing nurse-led and doctor-led care often results in greater satisfaction for nurse-led clinics (Corner, 2003; Faithfull et al, 2001; Baildam et al, 2004; Beaver et al, 2009), including several evaluations of nurse-led clinics that are rated highly in terms of patient satisfaction (Knowles et al, 2006; Kimman et al, 2010, 2011; Strand et al, 2011).

However, asking patients to choose between follow-up in clinic or by telephone sometimes appears to create dilemmas for patients with breast cancer who may find clinic follow-up reassuring but telephone follow-up more convenient (Lewis et al, 2009; Brown et al, 2002). However patients with lung cancer report telephone follow-up to be the least preferred option (Cox et al, 2006); although this is not found in other studies with different cancer groups (Cox et al, 2008). A large survey of 696 patients on follow-up after prostate cancer shows no difference in satisfaction between face-to-face or telephone consultations, although telephone consultations and waiting times are shorter than standard outpatient appointments (Shaida et al, 2007). Similarly, patients with colorectal cancer find telephone follow-up reassuring (Cusack and Taylor, 2010), and those with lung cancer are more satisfied with telephone follow-up (Moore et al, 2002). In contrast, although 79% are satisfied with a nurse-led telephone clinic for prostate cancer, 21% express a preference for face-to-face clinic appointments (Turner and Wells, 2012), which suggests possible variability between cancer groups as well as individual preferences.

Similarly, there are mixed opinions from patients regarding the concept of nurse-led chemotherapy clinics (Fitzsimmons et al, 2005), however this may reflect a lack of understanding of nurses' roles since patients regarded nurses as different but complementary to doctors.

There is on-going debate regarding the conceptual quality of satisfaction measures, which may limit its use in research studies, although there was no evidence of this within studies included in this review. Nevertheless, it is often difficult to define and measure nursing values to determine the quality of nursing practice, therefore some assessment of patient satisfaction is important. In this review nurse-led clinics are rated highly in patient satisfaction surveys. This includes one study of a nurse-led breast cancer diagnostic clinic where patients report 100% satisfaction even though only 5/119 patients expected to see a nurse (Garvican et al, 1998).

However, it seems important to establish patients' preferences for nurse-led and doctor-led care where possible. Although 97% of patients place trust in the specialist nurse undertaking follow up for prostate cancer, 6% report a preference to see a doctor (James and Eastwood, 2005). Findings are similar in a gastrointestinal clinic where 4/35 patients would prefer to see a doctor (Winter et al, 2012). Few studies appear to ask patients' preferences for doctor-led or nurse-led care, which seems an important consideration when reconfiguring services and developing nurse-led clinics. Warren (2007) recognises this when discussing findings of a survey of a nurse-led surgical histology clinic which reports 100% patient satisfaction, although the author comments that patients are not asked whether they would prefer to see a doctor.

Clinician preference may depend on a number of different factors, including communication and psychosocial needs. This is highlighted in a survey of patients with lung cancer on follow-up where there is high satisfaction with nurse-led follow-up and 30% of patients report the ability to discuss some issues because they are seen by a nurse rather than a doctor (Williamson et al, 2007). However preferences for future appointments appear mixed since 30% prefer nurse only, 30% doctor only and 40% prefer shared care (Williamson et al, 2007).



### **2.13 Summary of the literature review**

The literature review has identified five main themes with several subthemes in relation to nurses' roles within nurse-led chemotherapy clinics. The findings from the themes are summarised in several tables to provide clarity with the findings and the number of relevant papers supporting each finding. Table 2.10 provides a summary of the key findings for nurse-led versus doctor-led clinics and table 2.11 summarises the main findings for nurse-led clinics. This highlights the current evidence for nurses' roles in nurse-led clinics in oncology / chemotherapy, and identifies where there are major gaps in knowledge.

The summaries within this review also indicate the volume and strength of evidence, which is determined by the number of research and non-research studies identified.

**Table 2.10 Summary of studies: Comparison of nurse-led and doctor-led clinics**

<b>Benefits of nurse-led clinics versus doctor-led</b>			
	<b>Nurse-led versus Doctor (11)*</b>	<b>Telephone nurse-led vs doctor (5)</b>	<b>On demand follow up (2)</b>
<b>Psychological</b>	<ul style="list-style-type: none"> <li>Increased emotional functioning (2)</li> <li>Increased time to discuss concerns</li> <li>Easier to talk to the nurse</li> <li>Longer nurse consultations (4)</li> <li>Increased continuity</li> </ul>	<ul style="list-style-type: none"> <li>Reduced anxiety</li> </ul>	
<b>Information</b>	<ul style="list-style-type: none"> <li>Improved information (3)</li> </ul>	<ul style="list-style-type: none"> <li>More information needs met</li> </ul>	
<b>Physical</b>	<ul style="list-style-type: none"> <li>Increased symptom control (2)</li> </ul>	<ul style="list-style-type: none"> <li>Reduced physical problems</li> </ul>	
<b>Satisfaction</b>	<ul style="list-style-type: none"> <li>Increased satisfaction (3)</li> </ul>	<ul style="list-style-type: none"> <li>Increased satisfaction (3)</li> </ul>	
<b>Operational</b>	<ul style="list-style-type: none"> <li>Fewer medical consultations</li> <li>Less investigations (2)</li> <li>Increased referrals (2)</li> <li>Patients more likely to die at home</li> </ul>		More convenient
<b>Cost</b>	<ul style="list-style-type: none"> <li>31% reduction in cost</li> <li>Lower costs in nurse-led but higher cost of investigations</li> </ul>	<ul style="list-style-type: none"> <li>37% reduction in cost</li> </ul>	
<b>No difference between nurse-led and doctor-led</b>			
<b>Psychological</b>	<ul style="list-style-type: none"> <li>Psychological distress</li> <li>Quality of Life</li> </ul>	<ul style="list-style-type: none"> <li>Psychological (3)</li> <li>Quality of life</li> </ul>	<ul style="list-style-type: none"> <li>Psychological distress (2)**</li> <li>Quality of Life</li> </ul>
<b>Information</b>		<ul style="list-style-type: none"> <li>Information needs</li> </ul>	
<b>Physical</b>	<ul style="list-style-type: none"> <li>Detecting recurrence</li> <li>Symptoms</li> </ul>	<ul style="list-style-type: none"> <li>Recurrence detection (2)</li> <li>Treatment prescribed</li> <li>Investigations</li> </ul>	<ul style="list-style-type: none"> <li>Detecting recurrence</li> </ul>
<b>Satisfaction</b>	<ul style="list-style-type: none"> <li>Satisfaction</li> </ul>		<ul style="list-style-type: none"> <li>Satisfaction</li> </ul>
<b>Operational</b>		<ul style="list-style-type: none"> <li>Accessibility</li> </ul>	<ul style="list-style-type: none"> <li>Safety of practice</li> </ul>
<b>Cost</b>	<ul style="list-style-type: none"> <li>Costs (2)</li> </ul>		

\*However, potential issues were an increase in prescriptions and blood samples with nurse-led care.

\*\* However, standard doctor-led care and check-ups was more reassuring than nurse-led.

Although there is some evidence of improvements in physical and psychological well-being in nurse-led clinics, other studies show no differences between nurse-led and standard medical care. Similarly, there are conflicting findings in relation to patients' information needs and the cost of face-to-face clinics.

**Table 2.11 Summary of benefits from research studies of nurse-led clinics (7 studies)**

	Qualitative studies (7)	Surveys (9)
<b>Psychological</b>	<ul style="list-style-type: none"> <li>• Continuity (2)</li> <li>• Reassurance</li> <li>• Trust (2)</li> <li>• Addressing psychosocial needs (2)</li> <li>• Therapeutic support</li> </ul>	<ul style="list-style-type: none"> <li>• Opportunity for psychosocial support</li> <li>• Continuity (2)</li> <li>• Improved quality of life</li> <li>• Improved social functioning</li> </ul>
<b>Physical</b>		<ul style="list-style-type: none"> <li>• Improved physical functioning</li> <li>• Improved symptom management</li> <li>• Promote self-care</li> </ul>
<b>Satisfaction</b>	<ul style="list-style-type: none"> <li>• Satisfaction</li> </ul>	<ul style="list-style-type: none"> <li>• Satisfaction</li> </ul>
<b>Operational</b>	<ul style="list-style-type: none"> <li>• Convenient</li> </ul>	<ul style="list-style-type: none"> <li>• Convenient</li> <li>• Safe</li> <li>• Efficient</li> <li>• Acceptable</li> <li>• Reduction in patient waiting times</li> </ul>
<b>Cost</b>		<ul style="list-style-type: none"> <li>• Potential saving of £28k per year</li> </ul>

In both qualitative research and surveys, nurse-led clinics are shown to improve continuity of care. There is also some evidence of improvements in quality of life, physical functioning, symptoms, and emotional well-being within nurse-led clinics. However, this must be balanced with the evidence from comparison studies.

**Table 2.12 Summary of current evidence: feasibility of nurse-led clinics in oncology**

Key findings	Research studies (n=)	Non-research (n=)	Gaps in evidence
<b>Feasibility of nurse-led clinics</b> <ul style="list-style-type: none"> <li>Feasibility of nurse-led clinics: Follow up</li> <li>Feasibility of nurse-led chemotherapy</li> </ul>	7 4 1	0	Limited evidence on the feasibility of nurse-led chemotherapy clinics
<b>Service needs</b> <ul style="list-style-type: none"> <li>Existing clinics exceed capacity</li> <li>Increased patient waiting times</li> <li>Need to meet government targets</li> </ul>	6 4 3 1	8	Limited evidence on the impact of policy and targets on nurses' roles and nurse-led clinics
<b>Patient needs</b> <ul style="list-style-type: none"> <li>Aim for holistic care</li> <li>Issues in medical clinics: <ul style="list-style-type: none"> <li>Lack of coordination</li> <li>Lack of continuity</li> <li>Poor symptom control</li> <li>Unmet information needs</li> </ul> </li> </ul>	9 5 2 3 2 4	10	Although nurses aimed for holistic care, there is a lack of evidence in the literature.
<b>Operational aspects</b> <ul style="list-style-type: none"> <li>Doctor-nurse substitution</li> <li>Protocol-led practices in nurse-led clinics</li> <li>Protocol-led practices in nurse-led telephone clinics</li> <li>Nurse assessment proforma with psychological focus</li> </ul>	5 5 5 3 3	0	Although there is some evidence of the general way that nurses are working in nurse-led clinics, there is no detailed evidence of how this is being undertaken.
<b>Training for nurse-led clinics</b> <ul style="list-style-type: none"> <li>Clinical examination skills</li> <li>Shadowing doctors</li> <li>Prescribing</li> <li>Telephone communication skills</li> </ul>	4 2 4 1 1	4	Some evidence of skills required for nurse-led clinics. However, limited evidence on the training required for, or undertaken in, nurse-led clinics

**Table 2.13 Summary of current evidence: mode of delivery of nurse-led clinics in oncology**

Key findings	Research studies (n=)	Non-research (n=)	Gaps in evidence
<b>Face-to-face nurse-led clinics</b> <ul style="list-style-type: none"> <li>Comparison of nurse-led versus doctor <ul style="list-style-type: none"> <li>Reduction in patient waiting</li> <li>Improved continuity of care</li> </ul> </li> <li>Radiotherapy nurse-led versus doctor <ul style="list-style-type: none"> <li>Improved symptom management</li> <li>Improved patient information</li> <li>Improved psychological support</li> <li>Improved continuity of care</li> <li>Improved access</li> <li>Telephone monitoring</li> </ul> </li> </ul>	9 8  4	0	No evidence for nurse-led chemotherapy, or comparisons with medical clinics
<b>Timing of appointments</b> <ul style="list-style-type: none"> <li>Nurse consultations longer than doctors</li> <li>Therapeutic value of nurse-patient relationship</li> </ul>	9 9 3	0	Lack of evidence on nurses' roles and responsibilities within nurse-led clinics
<b>Telephone nurse-led clinics</b> <ul style="list-style-type: none"> <li>Cost effective</li> <li>Nurses replacing doctors for follow up</li> <li>Patient-centred care</li> <li>Acceptable and safe <ul style="list-style-type: none"> <li>Addresses information needs</li> <li>Symptom management</li> <li>Symptoms post chemotherapy</li> </ul> </li> <li>Telephone on demand</li> </ul>	20 19 16  5 3 2  3  1 5	1	Lack of evidence on how nurses address patients' symptoms and ensure care provision is safe. Limited evidence on chemotherapy, and managing side-effects.

**Table 2.14 Summary of current evidence: content of nurse-led clinics in oncology**

Current evidence: Content of nurse-led clinics	Research studies (n=)	Non- research (n=)	Gaps in evidence
<b>Follow up</b> <ul style="list-style-type: none"> <li>• Doctor-nurse substitution <ul style="list-style-type: none"> <li>○ Checking for recurrence</li> <li>○ Checking for signs and symptoms</li> <li>○ Clinical examination</li> </ul> </li> </ul>	16	2	Lack of evidence on nurses' roles: what they do in clinic, how they do it, how they perceive their role, and how they communicate with patients
<b>Symptom management</b>	4	0	No evidence how nurses assess and monitor patients' symptoms during treatment
<b>Treatment management</b> <ul style="list-style-type: none"> <li>• Alternative nurse-led approaches <ul style="list-style-type: none"> <li>○ Patient-focused</li> <li>○ Managing complex symptoms</li> <li>○ Coordinating care</li> </ul> </li> <li>• Information needs</li> <li>• Improved psychological support</li> <li>• Continuity of care</li> <li>• Longer consultations</li> <li>• Telephone monitoring</li> <li>• Flexible appointments</li> </ul>	9 3  4 5  5 1 2 2	0   0 0    	No evidence on the operational aspects of chemotherapy management and nurse-led chemotherapy. Limited evidence on alternative models of nurse-led care No evidence detailing nurses' consultations with patients Lack of evidence of how nurses assess patients' anxiety, depressions and concerns No evidence of how nurses communicate with patients in nurse-led clinics Limited evidence of nurses' roles and responsibilities within nurse-led radiotherapy and chemotherapy clinics

**Table 2.15 Summary of current evidence: patient outcomes**

<b>Current evidence: Patient outcomes</b>	<b>Research studies (n=)</b>	<b>Non-research (n=)</b>	<b>Gaps in evidence</b>
<b>Clinical outcomes</b> <ul style="list-style-type: none"> <li>• Safe practice</li> <li>• Increase meeting hospital targets</li> <li>• Improved patients' symptoms</li> </ul>	19 5 1 4	1	There is a lack of evidence regarding the impact of nurse-led clinics on meeting hospital targets
<b>Functional outcomes</b> <ul style="list-style-type: none"> <li>• Improved quality of life</li> <li>• Improved physical functioning</li> </ul>	10 1 2	1	There is conflicting evidence to show whether nurse-led clinics have a positive impact on patients' quality of life and physical outcomes
<b>Cost and utilization</b> <ul style="list-style-type: none"> <li>• Nurse consultations longer</li> <li>• More investigations in some nurse-led</li> <li>• Reduction in costs with nurse-led telephone</li> <li>• Reduced patients in medical clinics</li> </ul>	10 3 2 3 1	1	There is some evidence of the duration of consultations , although limited information regarding nurses' roles and responsibilities within nurse-led clinics, and no evidence for nurse-led chemotherapy clinics
<b>Psychosocial outcomes</b> <ul style="list-style-type: none"> <li>• Improved information needs</li> <li>• Improved psychological distress</li> <li>• Improved emotional functioning / coping</li> <li>• Therapeutic value of nurse-led</li> </ul>	18 2 1 2 1	0	Although some studies suggest that nurse-led clinics reduce patients' psychological distress, this is limited, and restricted to follow up and radiotherapy.

**Table 2.16 Summary of current evidence: Appraisal of nurse-led clinics**

Main findings	Research studies (n=)	Non-research (n=)	Gaps in evidence
<b>Safety, acceptability, efficacy</b>	4	0	Although there is some evidence that nurse-led clinics are safe, acceptable and efficient, further research is needed, and greater comparisons with doctor-led clinics. No studies have considered the safety and efficacy of nurse-led chemotherapy.
<b>Meeting patients' needs</b> <ul style="list-style-type: none"> <li>• More likely to meet psychosocial needs</li> <li>• More likely to meet information needs</li> <li>• Increased accessibility</li> <li>• Increased continuity</li> <li>• Therapeutic value of nurse-led</li> </ul>	12 5 4 1 2 3	1	There is no evidence to show whether nurse-led chemotherapy clinics meet patients' needs
<b>Patient satisfaction</b> <ul style="list-style-type: none"> <li>• Patients' lack of understanding of nurses' roles</li> <li>• Individual patient choice for type of clinic and mode of delivery</li> <li>• Individual patient choice for health professional in clinic</li> </ul>	15 1 3 2	7	There is a lack of evidence on nurses' roles and patients' understanding, within nurse-led chemotherapy clinics. Few studies ask patients' preferences for nurse-led or doctor-led clinics.

Current cancer policies emphasise the need for change and to develop innovative ways of working. In the Cancer Reform Strategy (DH, 2007), the need for flexibility within the NHS to meet patients' needs and introduce greater choices for patients is directly linked with developing nurses' roles and models of nurse-led care.

Despite legislation not keeping pace with clinical developments, there has been a huge drive for nurses to develop their roles, with a significant increase in nurse-led clinics and services. Although financial constraints in the NHS,



together with a reduction in junior medical staff, may influence the development of nurse-led services, there may be a similar drive from nurses themselves. The debate continues around nurse-led clinics regarding whether advanced practice is doctor-nurse substitution or an extension of nurses' existing roles, although the literature review demonstrates acceptability for patients and effective clinical outcomes with nurse-led clinics. Furthermore, several studies report the 'added value' of nurse-led care in providing a more holistic package of care for patients than simply nurse-doctor substitution. Clearly in oncology there has been a rapid increase in the number and nature of nurse-led clinics and services over the past decade, which reflects the changes in government and professional policies, the advances in non-medical prescribing, and influences by nurses and patients themselves. However, despite such advances in nurse-led service provision, this is mainly in relation to follow-up care within oncology.

The variability in chemotherapy provision in the UK presents an increasing challenge in view of limitations in capacity and resources at cancer centres and units, which leads to greater consideration for nurse-led models of care in relation to chemotherapy administration and clinical management of patients in outpatient departments. Although this creates a great potential for nurses to develop their practice and set up nurse-led clinics, it is important to ensure that adequate training, preparation and support for such posts are provided to keep pace with professional and clinical developments.

There is little research on the effectiveness of chemotherapy nurse-led services, and no studies to date have explored the key components of nurse-led chemotherapy, nor incorporated patients' perceptions of nurse-led chemotherapy clinics. The following chapter will discuss the different research approaches that may be used to study nurses' roles within nurse-led clinics, in order to ascertain the most appropriate research design. This aims to fill the gap in current knowledge, which has been identified by the literature review. Given the drive to increase provision of nurse-led chemotherapy management, this seems important and timely.

## **Chapter Three    Research methods**

### **3.1 Introduction**

This chapter considers the different theoretical approaches and research methods that may be used, before determining the most appropriate methods to answer the research question: *“What is the role of the nurse in nurse-led clinics in oncology and chemotherapy?”* The chosen methods will then be discussed in more detail in chapters four and five.

The literature review has identified that there is little information on nurses’ roles within nurse-led clinics in oncology, and minimal information on nurse-led chemotherapy clinics. Therefore an exploratory approach is required to obtain basic information on the role of nurses in nurse-led clinics in oncology, and then a more in-depth approach to understand nurses’ roles and responsibilities within nurse-led clinics. This research will help to identify what nurse-led clinics are being undertaken in the UK, and by whom, and also provide a detailed understanding of what nurses are doing within nurse-led oncology clinics. This approach suggests that two separate studies are required, each focusing on different aspects of nurses’ roles and nurse-led clinics to increase understanding and knowledge of this area.

Research into nurse-led clinics appears complex given the different factors that may be involved and their inter-relationships, therefore this must be taken into account in the research design. In addition it is hoped that the findings from this study may lead to further research, and a possible intervention study involving nurse-led clinics. The following section provides a brief overview of the different approaches that may be used, and outlines the possible advantages and disadvantages of each for this study.

### **3.2 Overview of research methods**

The two basic paradigms in nursing science are empirical and interpretative (Monti & Tingen 1999), and either could be used to study nurses’ roles within nurse-led clinics. Empirical approaches emphasise the importance of objectivity, measurability and generalizability using quantitative methods of data collection and analysis. In contrast, interpretative approaches aim to provide a greater understanding of people’s experiences from their own perspective using qualitative methods of data collection and analysis (Watson et al, 2008).

However, Monti & Tingen (1999) propose that qualitative and quantitative approaches are often complementary and the different perspectives of each can emphasise different dimensions of the same phenomenon.

Although empirical approaches may provide objective evaluations, including an overview of key components within nurses' roles, and a broad understanding of what nurse-led clinics are being undertaken, the information will be quite superficial. Therefore an interpretative approach seems essential to understand what nurses are doing within nurse-led chemotherapy clinics, including how they are interacting with patients and colleagues. The next section considers the different paradigms and theoretical approaches that may be used, and their relevance for this study.

### **3.2.1 Paradigms**

A paradigm is defined as a set of beliefs that guide actions, and contains three elements:

- Ontology: what is the nature of reality (theory or set of ideas)
- Epistemology: what is known about the world; relationship between people/things (set of questions)
- Methodology: how knowledge about the world is gained (methods of data collection and analysis) (Denzin and Lincoln 1998b).

Empirical studies lie within a positivist paradigm structure, which is based on logical and deductive scientific approaches, and are said to provide the 'backdrop' against which other paradigms operate (Denzin and Lincoln, 1998b). In contrast, interpretative studies cross four main paradigms: positivism, post-positivism, constructivism, and critical theory (Denzin and Lincoln, 1998b). In order to understand the relevance of paradigms for these studies and determine the most appropriate research design, it is important to consider the different theoretical approaches.

### **3.2.2 Theoretical approaches**

This section provides a brief summary of different theoretical approaches and outlines the basic differences between paradigms before discussing their relevance and their advantages / disadvantages for this study.

1. Positivist and post-positivist approaches. Guba and Lincoln (1998 p196) propose that these approaches focus on “*efforts to verify (positivism) or falsify (post-positivism) a priori hypotheses.*” The strength such approaches lie in their attempts to confirm whether a hypothesis is correct or not proven. Quantitative methods can provide objective measurements and statistical analysis of large numbers of participants, however important context information may be lost. In contrast qualitative methods are embedded in context but appear less objective with smaller sample sizes..
2. Critical theory. This consists of several alternative paradigms, such as Marxism, feminism, and materialism, and can be divided into three sub strands: poststructuralism, postmodernism and a blending of the two (Guba and Lincoln 1998). It is based on *historic realism* whereby current reality is shaped by past events, including social, political, cultural, economic, ethnic and gender factors.
3. Constructivist and interpretive approaches. The premise of constructivism is that multiple complex mental constructions are derived from social and experiential experiences, which depend on the individual/group holding that construction. Constructivism aims to understand the constructions held by people, considering also that knowledge, meaning and interpretations can change over time (Guba and Lincoln, 1998). Constructivist, or interpretivist, approaches seek to understand the complexities within the *lived world* from the perspective of those within it (Schwandt 1998). However, in order to understand a person’s *world* the researcher must accurately interpret it.

Table 3.1 identifies the differences in basic beliefs between the paradigms, considering their aims, quality criteria and relevance for this study.

**Table 3.1 Basic beliefs of paradigms**

Paradigm	Ontology	Epistemology	Methodology	Aims and nature of knowledge	Quality criteria	Relevance for this study
Positivism	Naïve realism – ‘real’ reality but apprehendable (assumed to exist)	Dualist / objectivist Findings true	Experimental / Manipulative. Verification of hypotheses. Chiefly quantitative methods	Explanation, prediction and control of phenomena. Verified hypotheses established as facts/laws	Rigor, internal and external validity, reliability and objectivity	Does not take account of the context within nurses’ roles and nurse-led chemotherapy clinics
Post-positivism	Critical realism – ‘real’ reality but only imperfectly apprehendable	Modified dualist / objectivist. Critical traditions. Findings probably true	Modified experimental manipulative. Critical multiplism (triangulation). Falsification of hypotheses. May include qualitative methods	Explanation, prediction and control of phenomena. Non-falsified hypotheses that are probably facts or laws	Rigor, internal And external validity, reliability and objectivity	The inclusion of qualitative methods is essential to understand meaning of behaviour in nurses’ roles and nurse-led chemotherapy clinics
Critical theory/ Marxist	Historical realism – shaped by social, political, cultural, ethnic, economic and gender values crystallized over time	Transactional / subjectivist. Value-mediated findings	Dialogic / dialectical	Critique and transformation of social, political, cultural, ethnic, economic, gender structures that constrain mankind. Over time restitution emancipation should occur. Structural / historical insights	Historical situated-ness, erosion of ignorance and misapprehension, action stimulus	This type of paradigm is based on historical approaches. Does not fit with the aims of this study
Constructivist Interpretivist	Relativism – local And specific constructed realities	Transactional / subjectivist. Created findings	Hermeneutic / dialectical	Understanding/ reconstruction of the constructs people hold. Individual reconstructions but aiming for consensus, facilitated by the researcher	Trustworthiness, transferability, confirmability and authenticity	This approach seems the most appropriate to understand the complexities within nurses’ roles and nurse-led chemotherapy clinics

Denzin and Lincoln 1998b p203-10).

Considering the research question and basic beliefs within the different paradigms, post-positivism and constructivist approaches seem the most appropriate. Post-positivists recognise that it is impossible to reach 'one truth' but aim to capture as much reality as possible using multiple methods (Racher and Robinson, 2002). The lack of current evidence regarding nurse-led chemotherapy clinics places greater emphasis on a constructivist, or interpretivist paradigm to guide this research framework.

### **3.2.3 *Empirical approaches***

From table 3.1, a post-positivist paradigm may be appropriate to explore nurses' roles and nurse-led clinics, focusing on what nurse-led clinics are being undertaken, by whom, and general components of nurses' roles. Several empirical approaches could be used to answer the research question, which requires careful consideration to compare the advantages and disadvantages of each. This is summarised in table 3.2.

### **3.2.4 *Interpretative approaches***

Qualitative methods reflect a more inductive approach to research than quantitative methods by exploring experiences and meanings from the perspective of participants and the context of their environment (Greenhalgh et al, 1998). This approach may provide a more in-depth understanding of nurses' roles within the context of nurse-led clinics than empirical approaches. However, the sample size for qualitative approaches would be smaller than for empirical studies, thus limiting the generalisability of the findings and narrowing the range of nurse-led clinics that could be included.

**Table 3.2 Empirical approaches**

Research approach	Design, data collection and analysis	Advantages for this study	Disadvantages for this study
RCT	Comparison of an intervention and control group using measurement tools, quantitative methods and statistical analysis	Robust objective evaluation Would allow comparison of nurse versus medical clinics to identify potential differences and possible impact on patients	Insufficient current information on nurse-led chemotherapy clinics to inform study design. Insufficient information to guide use of measures that are likely to be appropriate
Quasi-experimental	No control or randomisation group, but intervention with pre-test and post-test measurements for one or more groups using quantitative methods and statistical analysis	Robust objective evaluation before and after an intervention (nurse-led clinics)	Nurse-led clinics already set up so pre and post-test design inappropriate. Insufficient information to guide use of measures that are likely to be appropriate
Cohort	Follows a group of people over time and comparisons with a control group. Using measurement tools, quantitative methods and statistical analysis	Robust objective evaluation. Would allow comparison of nurse versus medical clinics. Would identify potential differences and potential impact on patients	Insufficient current information on nurse-led chemotherapy clinics to inform study design. Insufficient information to guide use of measures that are likely to be appropriate
Case studies	Detailed study of a person or group using either quantitative, qualitative or mixed methods for data collection and analysis	Uses multiple techniques for data collection. Case study investigated in depth, which would be useful to understand an identified group of nurses and nurse-led clinics	Insufficient current information on nurse-led chemotherapy clinics to inform study design and provide an appropriate sample
Surveys	Surveys with structured questionnaires or interviews, quantitative methods and statistical analysis	Can reach a large number of respondents easily. Can obtain information on different aspects of nurses' roles and nurse-led clinics Useful to provide an overview of nurses' roles / nurse-led clinics as a foundation.	Information provided lacks depth Structured questions restrict explanations and detail. Data collected is subjective



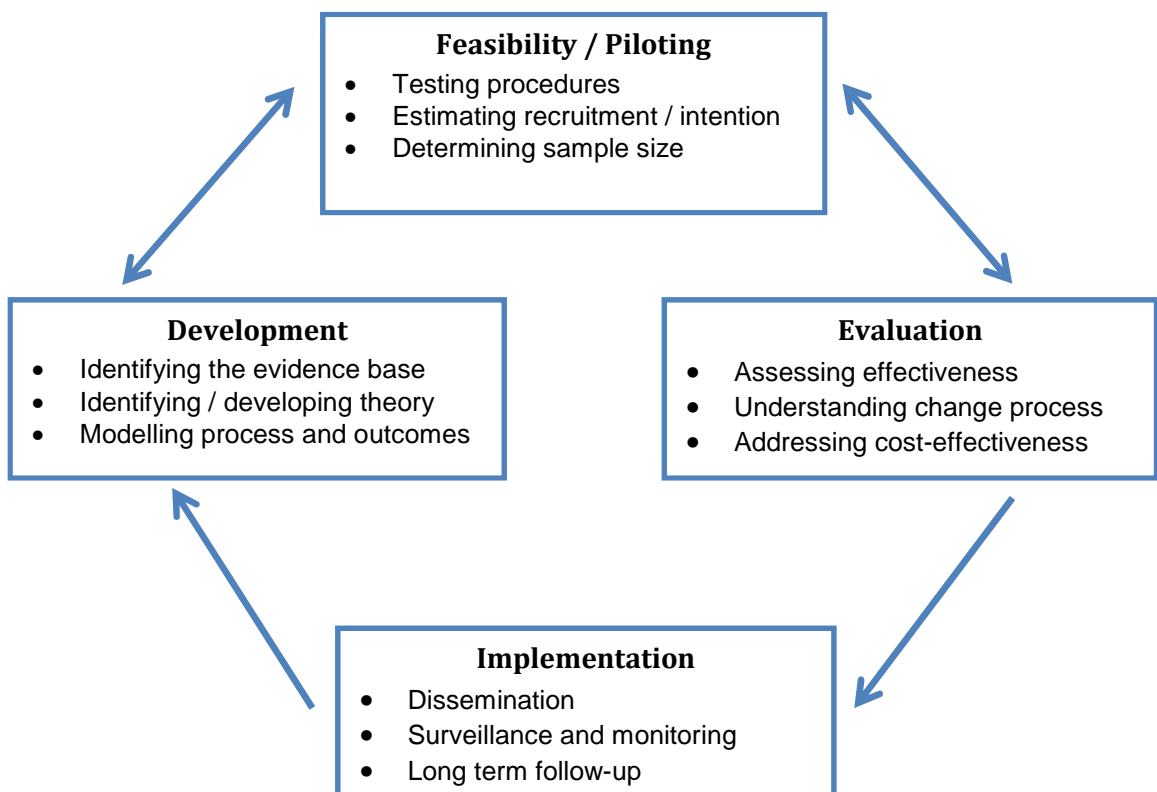
### 3.3 Complexities within nurse-led chemotherapy clinics

Given the exploratory nature of this research, and the potential complexities within nurse-led chemotherapy clinics, the Medical Research Council (MRC) guidance for complex interventions may be appropriate (Campbell et al., 2000b; MRC, 2000, 2008). Following a brief overview of the MRC guidance, the relevance for this research will be discussed.

Within the MRC guidance, complex interventions are described as interventions that contain several interacting components (MRC 2008). Although many research interventions adopt a linear approach, Craig et al (2008) suggest that others may not follow a linear or even cyclical pattern, and that best practice is to develop interventions systematically. This is outlined in figure 3.1.

**Figure 3.1 Key elements of the development and evaluative process**

(MRC, 2008)



### **3.3.1 *Relevance of the MRC guidance for this research***

One of the key recommendations in the MRC guidance is to pay greater attention to early phase piloting and developmental work. This recommends undertaking a series of pilot studies targeting each area of uncertainty before moving onto an exploratory and then a definitive evaluation (Craig et al., 2008). This seems appropriate for the design of this study in order to understand more about nurses' roles in nurse-led clinics before focusing on nurse-led chemotherapy clinics. The findings from each study will address different areas of uncertainty within nurse-led chemotherapy clinics, and may lead to a future intervention study. This will enable greater understanding of the different factors within nurses' roles and nurse-led chemotherapy clinics prior to developing an intervention. However, this research will form the foundation by establishing the key components that underpin the study.

The MRC guidance suggests that an iterative process can integrate both quantitative and qualitative methods (Craig et al, 2008; 2013). Campbell et al (2000) highlight the potential benefits of surveys to define relevant components, and also suggest that descriptive studies may help to determine variations in service delivery by locating potential barriers that could affect professional or patient behaviours (Campbell et al 2000). This approach appears to reflect the uncertainties of nurses' roles in oncology and nurse-led chemotherapy clinics, and supports a developmental stage that incorporates two studies that focus on different aspects of nurse-led clinics.

The MRC guidance (2008) has outlined the advantages for using methods that incorporate quantitative and qualitative aspects, and spending more time in the developmental phase of the research.

### **3.4 *Choice of research design for this study***

Both quantitative and qualitative research designs may be used to study nurses' roles within nurse-led oncology clinics. However, considering the advantages and disadvantages of empirical approaches, the lack of current literature on nurse-led clinics restricts the choice of study design. A lack of clarity with the literature on nurses' roles within nurse-led clinics suggests

that an exploratory study is preferable to identify and understand issues of interest within nurse-led clinics in oncology. This will provide some basic information to facilitate building a more in-depth view of nurse-led clinics, and refining the research questions prior to a further in-depth study. The lack of current evidence in the literature means that there is insufficient evidence to develop a randomised trial or an intervention study, therefore an exploratory study is required to collect preliminary data, and survey methodology appears to be the most appropriate empirical method to gather preliminary data on nurses' roles within nurse-led clinics.

A survey has the advantage of approaching a larger number of nurses in a timely manner, rather than using qualitative approaches to sample a small number of nurses. Undertaking a survey will also provide important contextual information on nurses within nurse-led clinics in oncology, in preparation for a more in-depth study on nurses' roles within one type of nurse-led clinic.

The first study (Study 1, Chapter four) will provide an overview of nurses' roles to determine what nurse-led clinics are being undertaken in the UK within oncology, identify who is running nurse-led oncology and chemotherapy clinics, and also provide a broad understanding of different aspects of nurses' roles. Alongside results from the literature review, the findings from Study 1 will identify gaps in knowledge and understanding of nurse-led oncology clinics. This will enable a more in-depth focus on one aspect of nurse-led clinics to provide greater understanding of nurses' roles, which will result in a second study, based on the findings from Study 1.

The next chapter is divided into three sections to include the aims, research questions, methods, results and discussion of Study 1.

## **Chapter Four     Study 1**

## **Section one:      Methods for Study 1**

### **4.1.1 Aims and objectives**

The overall aim for this research is to understand nurses' roles in nurse-led oncology and chemotherapy clinics. To achieve this, the aims and objectives for Study 1 focus on exploring the different aspects of nurses' roles, and factors within hospital organisations that may influence nurses' roles and nurse-led clinics.

The aims and objectives for study 1 are:

- To explore the scope of practice within nurses' roles and nurse-led clinics in oncology /chemotherapy
- To understand what factors within a hospital organisation may influence nurses' roles and nurse-led oncology / chemotherapy clinics

The aims were broad since the literature review identified a lack of evidence on nurses' roles and nurse-led clinics in oncology. Study 1 aims to address the current gaps to meet the aims and objectives and answer the following research questions:

1. What nurse-led oncology / chemotherapy clinics are being undertaken in the UK?
2. What training have nurses undertaken within nurse-led clinics?
3. What are the key components of nurses' roles in nurse-led oncology / chemotherapy clinics?
4. How does the multidisciplinary team view nurse-led oncology / chemotherapy clinics?
5. What evaluations are nurses undertaking of nurse-led oncology / chemotherapy clinics?

One of the main aims is also to identify the focus of nurse-led clinic for study 2 so that aspects of nurses' roles identified in study 1 may be explored further in study 2. This will also enable research questions for study 2 to be developed.

#### **4.1.2 Introduction**

The study design reflects the current lack of evidence regarding nurses' roles in nurse-led oncology and chemotherapy clinics. The research aimed to focus on nurses who may be undertaking nurse-led oncology and chemotherapy clinics within the UK. Study 1 aims to provide an overview of nurses' roles within nurse-led clinics in oncology.

Study 1 is a survey of nurses who are undertaking nurse-led clinics in oncology within the UK. This chapter is divided into three sections to include the methods, findings and discussion of study 1. This first section focuses on the methods, identifying the aims, objectives and research questions before considering the methodological perspectives in relation to survey design. This will include a discussion of the different types of survey and survey methods that may be used for this study, including survey design, data collection and analysis.

#### **4.1.3 Types of survey design**

There are two main survey designs: descriptive and analytic. Descriptive surveys identify what proportion of the sample has certain characteristics; determining representativeness of the sample can facilitate making inferences about the population as a whole (Oppenheim, 1992). However, descriptive surveys are not designed to provide any explanations or show causal relationships between variables. In contrast, analytic surveys are set up specifically to explore hypotheses or associations between variables, seeking explanations and predictions rather than descriptions and enumerations (Oppenheim, 1992).

The aim of this study is to obtain a descriptive understanding of nurses' roles and nurse-led clinics, rather than seek to explain relationships or between the different variables or predictions. Therefore a descriptive survey seems more appropriate.

#### **4.1.4 Types of survey administration**

There are two main types of survey: questionnaire or interview. However, there are also differences in the way that surveys may be administered. Traditionally surveys were postal or self-administered questionnaires (by a researcher or

other person) (Oppenheim, 1992). However, with developments in technology surveys may also be administered via email or the internet. The potential advantages and disadvantages of each method are shown in table 4.1.

**Table 4.1** *Types of survey administration: advantages and disadvantages*

Survey method	Advantages for this study	Disadvantages for this study
Postal questionnaire	<ul style="list-style-type: none"> <li>• Low cost data collection</li> <li>• Low cost data processing</li> <li>• Avoids interviewer bias</li> <li>• Able to reach respondents at widely dispersed locations</li> </ul>	<ul style="list-style-type: none"> <li>• Lower response rates – bias</li> <li>• No opportunity to correct any misunderstandings</li> <li>• No control over order in which questions are answered</li> <li>• May be incomplete answers</li> </ul>
Email questionnaire	<ul style="list-style-type: none"> <li>• Low cost data collection</li> <li>• Low cost data processing</li> <li>• Avoids interviewer bias</li> <li>• Able to reach respondents at widely dispersed locations</li> <li>• Quick administration and response</li> </ul>	<ul style="list-style-type: none"> <li>• Response rates may be higher than postal</li> <li>• Any misunderstandings may be corrected via email</li> <li>• No control over order in which questions are answered</li> <li>• Any incomplete answers may be corrected via email</li> </ul>
Internet survey	<ul style="list-style-type: none"> <li>• Quick and easy to complete</li> <li>• Quick and easy to analyse</li> <li>• Low cost</li> <li>• Increased accuracy</li> <li>• Flexible</li> </ul>	<ul style="list-style-type: none"> <li>• Not widely available for this survey in 2007</li> <li>• Hospital firewalls may restrict administration and responses</li> </ul>
Interview	<ul style="list-style-type: none"> <li>• Ability to correct any misunderstandings</li> <li>• Can control for completeness</li> <li>• Able to carry out observations</li> </ul>	<ul style="list-style-type: none"> <li>• Expensive to conduct and reach a widely dispersed sample</li> <li>• Time consuming to conduct and process data</li> <li>• Risk of interviewer bias</li> </ul>
Self-administered questionnaire	<ul style="list-style-type: none"> <li>• Explanations by interviewer prior to completion</li> <li>• Personal contact may increase response rate</li> </ul>	<ul style="list-style-type: none"> <li>• Use of a third person to hand deliver questionnaires may introduce bias</li> </ul>

For this study, interviewing individual nurses was not possible since the potential sample was widely dispersed across the UK, and funds were not available to travel to each geographical location. Similarly, although questionnaires administered by a researcher may increase response rates by hand delivering questionnaires to each participant (Oppenheim, 1992), it was too expensive to undertake. Telephone methods of data collection may be useful, and are regarded as ‘low cost’ and faster than face-to-face interviewing (Oppenheim, 1992). However, Hox and de Leeuw (1994) report a greater

decline in response rates for telephone surveys in comparison to paper questionnaires.

Internet surveys can reduce costs in questionnaire development, can be easy to complete and provide faster data collection / analysis (Dillman et al, 2009). However there is evidence that many people may respond more to postal surveys than those conducted over the internet (Couper, 2005; Dillman et al, 2009). In addition, technology was not as advanced in 2007 when this survey was conducted, therefore an internet survey was not considered for this study. Therefore, postal or email questionnaires seemed preferable, given the wide distribution of nurses in the UK and cost advantages

#### **4.1.5 Questionnaire design**

Given the lack of research on nurses' roles within nurse-led oncology / chemotherapy clinics, a previously used survey tool was not available to answer the research questions. Although Wiseman et al (2005) have explored the role of the chemotherapy nurse this was in relation to chemotherapy administration, which did not include nurse-led clinics. Trevatt et al (2008) conducted a survey of clinical nurse specialists in oncology, however this aimed to determine the number of specialist nurses per tumour type in England (Trevatt et al, 2008), which did not meet the aims of this research in understanding nurses' roles. Therefore a questionnaire had to be devised specifically for this study to answer the research questions.

There are several factors which must be taken into consideration when designing a questionnaire, including the layout, choice of questions, piloting and administering the questionnaire (Kelley et al, 2003). The design stage also considers the design of a covering letter, the sample and sampling strategies; data collection and analysis; reliability and validity (Kelley et al, 2003; Burns et al, 2008). The implications of these for Study 1 will be described in turn, including the justification for items included in the questionnaire to address the aims of the study and answer the research questions. This will be followed by a discussion of the methodological procedures undertaken.

Dillman et al (2009) suggests that questionnaire surveys may be used to gather different types of information:



- Attributes. These include personal characteristics, such as age to identify “*what people are*”.

This will aid understanding of nurses’ scope of practice, and will also be used to identify potential participants for study 2.

- Behaviour and events. These include “*what people do*” or “*what has happened in people’s lives*”.

This will aid understanding of training completed, nurse-led clinics undertaken, and identify key components of nurses’ roles.

- Beliefs/knowledge. This entails assessing “*what people think is true*”.

This will help to understand potential factors in the organisation that may influence nurses’ roles and nurse-led clinics, which may identify potential barriers.

- Attitudes/opinions/reasons. This includes assessing “*what people say they want*” or “*how people feel about something*”.

This will help to understand nurses’ perceptions regarding opinions of the multidisciplinary team and management towards nurse-led clinics.

#### **4.1.6 Questionnaire layout and appearance**

##### **4.1.6.1 Introduction**

When designing the survey, a number of methodological principles were addressed to enhance the strength, reliability and appearance of the questionnaire. Following discussion of each principle, their application within this study will be outlined. Moser and Kalton (1971) suggest that questionnaire design is a matter of art rather than science, where the researcher’s main tools are common sense and past experiences. In addition, the design of this questionnaire will also draw on the author’s clinical experience. The appearance of the questionnaire can influence participants’ interest and completion of the questionnaire; in particular relevant and salient opening items may improve motivation to respond (McColl et al, 2001). Careful attention to the design and layout of the questionnaire can also reduce errors in interpreting questions and coding responses. (McColl et al, 2001). The aim of this survey was to produce a questionnaire that was clear, concise and easy to complete,

therefore great attention was paid to the general layout, spacing and ease of completion, in addition to the actual questions and their format.

#### **4.1.6.2      *Length of questionnaire***

The length of a questionnaire is important, since this may influence response rates (McColl et al, 2001). Long questionnaires may cause fatigue and boredom, which may lead to careless responses or response strategies that reduce the burden of answering, particularly with questions at the end of the questionnaire (McColl et al, 2001). Shorter questionnaires have been shown to increase response rates by up to 50% (Edwards et al, 2009). In addition, Brown et al (1989) highlight improved response rates with a larger type-face, although this increases the questionnaire length.

Careful consideration was given to the length of this questionnaire, however including questions about nurses' roles and nurse-led clinics extended the questionnaire to five pages of A4 in portrait style. To reduce the questionnaire length Ariel size 11 was used, with line spacing of 1.5, and spaces removed before and after each paragraph. The appearance was enhanced with consistency in numbering and spacing the questions, and including 'tick boxes' where possible, which has been shown to increase response rates (Edwards et al, 2009). For consecutive questions with yes or no answers, tick boxes were placed in the same location on the page; multiple questions on the same topic with tick boxes were placed in a vertical list with adjacent tick boxes in a vertical line for ease of completion. Some open responses were required; therefore an open horizontal box was placed across the width of the page with a 2cm depth to provide sufficient space and consistency across all questions (appendix 3). There is some evidence that this may enhance response rates (Edwards et al, 2009).

#### **4.1.6.3      *Pagination and print details***

Although constructing booklets of the questionnaires may improve the appearance for postal surveys (McColl et al, 2001), this was not possible for study 1 due to the additional printing costs. However, the main intention was to administer the questionnaire via email to increase accuracy of completion and speed of delivery (Edwards et al, 2009). The questionnaire was emailed as a

double-sided A4 word document with a separate covering letter, unless participants requested a postal anonymous copy.

Dillman et al (2009) recommends that the front cover should contain the title of the survey and its purpose, the identity of the organisation and brief instructions. For study 1, whilst the survey contained the study title, hospital logo and instructions, additional information, including the researcher's contact details and photograph were provided in the covering letter. In addition, the last page of the questionnaire contained a note of thanks to the respondent for completing the questionnaire. Edwards et al (2009) recommends keeping questionnaires and letters short but personal, which may increase response rates by 30-50%..

#### **4.1.6.4      *Question and response category format***

Care was taken in the structure of the questionnaire and question placement to ensure that each question, instructions and response categories were on the same page to improve clarity and reduce response errors (Dillman et al, 2009). However, when designing study 1 this required slight adjustments to the order of some questions and spacing to maintain the overall appearance. Sudman and Bradburn (1982) recommend that increased 'white space' makes the questionnaires appear less cramped, easier to complete, which can increase response rates.

Numbering each question is important to reduce the risk of missing responses and facilitate data processing (Sudman and Bradburn, 1982). For this survey consecutive numbers were used for each question and indented letters for subgroups to improve clarity. There was also consistency in formatting questions and response categories, including the placement of tick boxes to improve the visual appearance and ease of completion.

#### **4.1.6.5      *Instructions***

Sudman and Bradburn (1982) recommend that general instructions about the questionnaire should be placed at the beginning of the questionnaire, whilst specific instructions about individual questions should be as close as possible to the relevant question. This was incorporated into study 1, and particular attention was paid to instructions involving 'skip responses' when questions

were not relevant. These included clear directions to the next question respondents should navigate to.

#### **4.1.6.6 Questionnaire wording and sequencing**

Question wording and sequencing can impact on the nature and quality of responses, particularly if questions may be interpreted as threatening or non-threatening (McColl et al, 2001). However, this did not apply to study 1 since there were no threatening questions.

The following principles of question wording may improve response (Moser and Kalton, 1971; Oppenheim, 1992):

- Using simple language, avoiding acronyms and abbreviations
- Keeping questions short (sentences of < 20 words)
- Ensuring questions are specific and avoiding ambiguity
- Avoiding double-barrelled questions, double negatives and leading questions
- Avoiding loaded words / concepts, presuming or hypothetical questions

In study 1 there were no acronyms or abbreviations; questions did not exceed 20 words, and there were no ambiguous, leading or double-barrelled questions. Care was also taken to avoid presumptions or hypothetical questions.

The sequence of questions within a questionnaire is important and can influence response rates, for example placing sensitive or embarrassing questions early may distort respondents' answers or result in non-response (McColl et al, 2001). However there are suggestions that this effect may be reduced in postal surveys since respondents can read all the questions before answering (Smith et al, 1982).

The different effects on responses are:

- Consistency effect (responses may be influenced by previous questions)
- Saliency effect: (answers to specific questions can influence responses to more general questions) (Bradburn and Mason, 1964, McColl et al, 2001).

- Context effects (grouping questions together by topic may introduce bias, although grouping questions in this way can improve continuity and coherence) (McColl et al, 2001).

Sudman and Bradburn (1982) recommend putting easy, non-threatening questions first and ordering filter questions in a way that will encourage complete responses

In study 1, demographic questions were asked first, and there were no embarrassing or sensitive questions. The order of questions was carefully considered to ensure a logical flow between questions about aspects of nurses' roles, such as training, skills, prescribing, perceptions and the number and nature of nurse-led clinics.

#### **4.1.6.7 Response format**

McColl et al (2001) emphasises the importance of developing questions that are clearly formulated and precise, recommending that researchers should address four factors related to response error: memory, motivation, communication and knowledge. The main types of questions are open or closed, and the advantages and disadvantages are shown in table 4.2. Hybrid questions are described as partially closed questions which includes a list of responses plus an 'other' category to allow additional options (Dillman et al, 2009).

**Table 4.2 Advantages and disadvantages of different types of questions**

<b>Question type</b>	<b>Advantages for this study</b>	<b>Disadvantages for this study</b>
Open questions	<ul style="list-style-type: none"> <li>• Freedom and spontaneity of answers</li> <li>• Opportunity to probe</li> <li>• Enables more detail</li> </ul>	<ul style="list-style-type: none"> <li>• Time-consuming</li> <li>• Coding costly and slow to process, may be unreliable</li> <li>• Demands more effort from respondents</li> </ul>
Closed questions	<ul style="list-style-type: none"> <li>• Requires little time</li> <li>• No extended writing</li> <li>• Low costs</li> <li>• Easy to process data</li> <li>• Make group comparisons easy</li> </ul>	<ul style="list-style-type: none"> <li>• Loss of spontaneous responses</li> <li>• May be subject to bias</li> <li>• May irritate respondents by limiting available responses</li> </ul>

McColl et al (2001) recommend using open questions sparingly in self-completion questionnaires, given the potential disadvantages, In study 1 the majority of questions were closed in order to improve completion rates and

facilitate analysis (Dillman et al, 2009). However several open boxes were included for further comments if required. The use of 'don't know' boxes was avoided, since this could result in less meaningful responses (Poe et al, 1988).

A range of questions was planned around each of the research questions to ensure they were all addressed. The final survey consisted of 24 main questions over five pages of A4, although several were multiple questions (see appendix 4). To improve response rates the majority of questions were closed and dichotomous, and tick boxes provided for ease of completion. Other questions covered a range of answers where respondents were asked to tick 'all that apply', and there were also single answer selections from a multiple choice list. Filter questions were used for non-medical prescribing and nurse-led clinics to ensure the sequence of questions remained relevant for each respondent, and clear instructions were provided to facilitate navigation between these sections. Table 4.3 highlights how each question relates to the research questions.

**Table 4.3     *Matching research questions to the questionnaire***

Research question	Number of questions on the questionnaire survey
1. What nurse-led oncology / chemotherapy clinics are being undertaken in the UK?	1, 16, 17,
2. What training have nurses undertaken within nurse-led clinics?	5, 6, 8,
3. What are the key components of nurses' roles in nurse-led oncology / chemotherapy clinics?	2, 3, 4, 5, 7, 9, 10, 11, 14, 20
4. How does the multidisciplinary team view nurse-led oncology / chemotherapy clinics?	12, 13, 15, 18,
5. What evaluations are nurses undertaking of nurse-led oncology / chemotherapy clinics?	19, 21, 22, 23, 24

#### **4.1.6.8     *Enhancing response rates***

Several factors may influence response rates to questionnaire surveys, which are based on minimising the cost of responding, maximising the rewards of responding and establishing trust (McColl et al, 2001; Dillman et al, 2009); illustrated in table 4.4:

In study 1 the questionnaire was designed to be as clear and concise as possible, was designed to be as simple as possible to complete, with clear instructions and avoidance of sensitive questions. The content of the questionnaire should be of interest to participants since it targeted specialist nurses who were running nurse-led clinics in oncology. The absence of current literature on this topic was highlighted in the covering letter, emphasising the need for this research, which aimed to improve response rates. The covering letter also expressed gratitude for completion of the questionnaire, and this was reiterated in the email responses to participants; there is some evidence that this may enhance response rates (Edwards et al, 2009). The use of headed notepaper from the author's NHS Trust and use of the hospital email address also aimed to increase trust between the participant and researcher. The use of email to a named participant also seemed more personable than an anonymous postal questionnaire, which may increase response rates by a third (Edwards et al, 2009). Although monetary or material incentives may improve response rates (McColl et al, 2001), this seemed unethical for health professionals.

**Table 4.4 Factors influencing response rates for study 1**

<b>Minimising the cost</b>	<b>Maximising the rewards</b>	<b>Establishing trust</b>
<u>Clear and concise questionnaire</u> <ul style="list-style-type: none"> <li>• Question wording</li> <li>• Question sequencing</li> </ul>	<u>Interesting questionnaire</u> <ul style="list-style-type: none"> <li>• Topic choice</li> <li>• Interesting questions</li> </ul>	<u>Benefit for participants</u> <ul style="list-style-type: none"> <li>• State how results will benefit respondents</li> </ul>
<u>Appears simple to complete</u> <ul style="list-style-type: none"> <li>• Questionnaire appearance</li> </ul>	<u>Express positive regard</u> <ul style="list-style-type: none"> <li>• State importance of contribution</li> <li>• Personalised salutation</li> </ul>	<u>Establish researcher's credentials</u> <ul style="list-style-type: none"> <li>• Use headed notepaper</li> <li>• Name researchers</li> </ul>
<u>Reduce effort to complete</u> <ul style="list-style-type: none"> <li>• Simple questions</li> <li>• Clear instructions</li> <li>• Careful handling of sensitive questions</li> </ul>	<u>Express verbal appreciation</u> <ul style="list-style-type: none"> <li>• State thanks on all communication</li> <li>• State thanks on questionnaire</li> <li>• Follow-up thank you letter</li> </ul>	<u>Build on other relationships</u> <ul style="list-style-type: none"> <li>• Endorsement by well-regarded person/organisation</li> </ul>
Avoid subordination of respondent to researcher	<u>Support respondent's values</u> <ul style="list-style-type: none"> <li>• Appeal to personal utility</li> <li>• Appeal to altruism</li> </ul>	
<u>Reduce direct monetary costs</u> <ul style="list-style-type: none"> <li>• Offer pre-paid envelopes</li> </ul>	<u>Incentives</u> <ul style="list-style-type: none"> <li>• Make results available</li> </ul>	

The timing of the survey may be beneficial (Dillman et al, 2009), however, for study 1 there were time restrictions in distributing the questionnaire. Although pre-notification of a survey may have a positive effect on response rates (Edwards et al, 2009; McColl et al, 2001; Groves et al, 1992), the number of contacts and follow-up reminders are considered more important (Dillman et al, 2009; Jones and Lang, 1980; Peterson et al, 1989). In study 1, respondents were contacted two to four times: first with an invitation letter, second with the questionnaire, then up to two follow-up reminders.

#### **4.1.7 Pilot work**

Piloting the questionnaire is important to ensure that it will produce the data required and reduce non-response rates (Oppenheim, 1992). The pilot includes the layout and sequence of questions, how they are worded; what scales are used, and the design of the introduction and instructions (Oppenheim, 1992). Pilot studies can also provide important feedback on the survey design, including each component of the survey and the connections to other components (Dillman et al, 2009).

Oppenheim (1992) recommends selecting participants for pilot studies who are as similar as possible to the main sample. For study 1, a sample of 10 oncology specialist nurses from the author's hospital trust was used to pilot the questionnaires and obtain feedback on the appearance and general design. For the pilot, nurses were informed of the purpose of the study by email, inviting them to take part in the survey and pilot the questionnaire. A copy of the questionnaire was attached, which they were asked to complete and return by email or post. Nurses in the pilot were also asked to comment on the appearance of the questionnaire, ease of completion, understanding of the questions and instructions, and asked whether there were any other issues in relation to the questionnaire. The same procedure as the main survey was followed in the pilot to highlight potential problems in response (Kelley et al, 2003). All 10 nurses responded, and their responses checked for completeness to see whether any questions were systematically missed (Kelley et al, 2003). The pilot for study 1 did not reveal any problems with understanding, appearance, or completion, and this lack of negative feedback meant that no



changes were made to the questionnaire for the main survey. The time for completing the questionnaire ranged from 10-20 minutes.

#### **4.1.8 Sampling and recruitment**

##### **4.1.8.1 *Determining the sampling frame***

Oppenheim (1992) suggests that sampling is often a compromise between theoretical requirements and practical limitations, such as time and resources; whilst a larger probability sample can provide better estimates of the population than a smaller sample, it will be more costly, which may restrict the design. In addition, the number of subgroups requiring comparison within a survey is also an important consideration when determining the sample size, since a greater number of subgroups will need a larger sample size to make comparisons between the groups (Oppenheim, 1992). Dillman et al (2009 p56-57) describe statistical formulae to determine appropriate sample sizes for random probability sampling using different confidence intervals, however proposes that available funding may have a greater influence on determining the sample size for surveys, rather than strict calculations. In addition, the response rate is also important in determining the sample size since the potential difference between responders and non-responders is greater if the response rate is lower (Dillman et al, 2009).

A key issue for any research is to ensure that the sample is representative of the population being studied (Burns et al, 2008), and the accuracy of the sample in representing the population can be more important than the sample size (Oppenheim, 1992).

For study 1, the population was oncology specialist nurses in the UK who undertook nurse-led clinics. However it was difficult to identify potential nurses since there are no regional or national lists of nurses who have an advanced or extended role, and nurses' titles often do not reflect nurses' roles and scope of practice. Similarly there are no regional or national lists of nurse-led clinics in the UK. These issues had an adverse effect on the results of the sampling strategy.

Oppenheim (1992) recognises the difficulties in drawing a 'sampling frame' when the size and demographic characteristics are unknown, and suggests that some ingenuity may be useful to achieve this. To reduce bias the preferred type of sampling is random sampling, which aims to select a random sample from the population and requires lists of the population, together with contact information, to draw from (Burns et al, 2008). In contrast, deliberate sampling is chosen for groups that are difficult to identify, using known characteristics of individuals to guide selection (Burns et al, 2008). In study 1, a lack of knowledge about the population of nurses within nurse-led clinics meant that random probability sampling strategies were not appropriate.

From the non-probability designs, insufficient information about oncology nurse-led clinics in the UK mean that snowball sampling had the highest chance of identifying nurses who were representative of the population. This is also known as respondent driven sampling, which is increasingly used to access hidden populations (McCreesh et al, 2013; Semaan et al, 2009; Ramirez-Valles et al, 2005; Salganik and Heckathorn, 2004). In addition this sampling technique has demonstrated effectiveness in sensitive areas of practice, such as medication errors (Sheu et al, 2009), and difficult to reach populations (Gyarmathy et al, 2014). Snowball techniques aim to identify a small number of appropriate individuals known to the researcher, who are then asked to identify others who may fit the sampling requirements (Oppenheim, 1992; Burns et al, 2008). Although this process is effective (Malekinjad et al, 2008), and there are indications that this may provide a sample that is representative of a hidden population (Voltz and Heckathorn, 2008), others have expressed concerns regarding the ethical implications of using this approach (Scott, 2008).

In study 1, a small number of nurses known to be undertaking nurse-led clinics in oncology were contacted initially, and each was asked to identify other nurses running nurse-led clinics within their organisation, and in the UK.

#### **4.1.8.2      *Inclusion and exclusion criteria***

The selection criteria of nurses was kept as broad as possible in order to obtain the greatest range of nurses' roles within nurse-led clinics, and to ensure that

the sample was representative of the general population of specialist oncology nurses. Table 4.5 outlines the inclusion and exclusion criteria for study 1.

**Table 4.5**     *Inclusion and exclusion criteria*

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Participants</b>	Advanced nurse practitioners Nurse clinicians Nurse consultants Nurse practitioners Lead nurses Research nurses Chemotherapy nurses Clinical nurse specialists Palliative care specialists	Ward sisters Staff nurses
<b>Nurse-led clinics</b>	Any outpatient nurse-led clinics within oncology	Inpatient nurse-led services Non nurse-led clinics Not oncology
<b>Intervention</b>	Willing to complete the questionnaire	Unwilling to complete the questionnaire
<b>Location</b>	Any hospital within the UK	Hospitals outside the UK

#### **4.1.8.3**     *Approaching participants and sampling*

One of the main advantages of this study was the interest of this topic to potential participants, and the invitation letter was carefully worded to reflect that. It was initially emailed to nurses known to the researcher who met the inclusion criteria. Nurses were asked, via email, to identify other nurses working in oncology and running nurse-led clinics. The researcher then made contact by email with an invitation to take part in the study. This strategy maintained a more reliable audit trail of the number of contacts approached and how many responded with completed questionnaires than a completely anonymous postal survey.

To promote wider distribution in the UK, an invitation letter was also emailed to all UK cancer network managers, lead cancer nurses, nurse consultants, and specialist cancer nurse groups. An invitation to participate was also advertised in *Cancer Nursing Practice* and disseminated via the UK Oncology Nursing Society. By using a variety of different approaches, this aimed to increase the representativeness of the sample to the population of UK oncology nurses. The

findings from study 1 (chapter 4 section two) include the number of responses from initial contacts and 'snowball contacts'.

#### **4.1.8.4      *Method of questionnaire administration***

Potential participants were contacted by email to outline the study and invite them to participate in the survey. Following this an invitation letter detailing the aims of the study was emailed (appendix 4), together with a copy of the questionnaire. Participants were given the option of returning the completed questionnaire by email or post, where a stamped-addressed envelope was provided. Participants were asked to identify other nurses involved in nurse-led clinics and to forward their names and email addresses to the researcher. On receipt of this information the researcher contacted the new participant with a formal invitation to take part in the survey, attaching a copy of the questionnaire and covering letter.

#### **4.1.9    Data collection and processing**

Completed questionnaires were either emailed or posted to the researcher who checked them for completeness. Having the respondents' names and email addresses meant that individual respondents could be personally contacted by the researcher if any emailed questionnaires were incomplete, drawing their attention to responses required for specific questions. This was also possible if incomplete questionnaires were posted, provided they contained the participant's name. However it was possible for participants to omit their name or other personal information and return the anonymous questionnaire by post to avoid revealing their identity. This was possible for both questionnaires that were originally emailed or posted. Data collected from questionnaires were mainly quantitative, indicating frequency counts or rates. This structured format enabled objective measurements of concepts and attitudes to provide comparable results across the sample (McColl et al, 2001).

The use of computer software packages are often used to facilitate data entry and analysis (Oppenheim, 1992). For study 1 the Statistical Package for Social Scientists (SPSS) was used for data entry and analysis. Coding techniques included numerical responses to classify categorical data prior to data entry. A code book was created to identify the list of questions, variable name allocated,

and numerical codes provided for each response. Although time consuming to set up, this ensured that labels were created for each variable, with an appropriate description and a consistent numerical coding system, for example 1=yes, 2=no. The code book provided a meaningful list of all variables, and was a useful reference source during data entry. A consecutive series of case numbers were used for each respondent to maintain anonymity and consistency. Having one person to undertake the coding, data entry and analysis facilitated this process and prevented potential problems of inter-coder reliability.

#### **4.1.10 Data entry and analysis**

On receipt of completed questionnaires, data were entered anonymously onto SPSS v13 (v22 in 2013). Data analysis for the survey findings consisted of descriptive and inferential statistics. Non-parametric tests were used since the distribution was not normal (Foster. 2001). The data was mainly nominal, or categorical. For univariate analysis with categorical data the chi squared test was used, unless 2 x 2 tables had an expected frequency of < 5 in more than 20% of cells, where Fisher's exact test was more appropriate. However the Kruskal-Wallis test was used for three or more groups when continuous data was used.

Multivariate analysis is a collection of methods that can be used when several measurements (variables) are made on each individual; variables are measured simultaneously and correlated. However, some authors warn against applying multivariate techniques to data if the measurement scale is not ordinal or ratio, however many multivariate techniques can give reliable results when applied to ordinal data (Rencher, 2002). However, there was little continuous data in this survey; the majority of the data was nominal / categorical. In addition, the majority of multivariate procedures are underpinned by a normal distribution; however the data in this survey does not follow a normal distribution. Therefore, although multivariate analysis was considered during data analysis, it was rejected as inappropriate.

The quantitative findings are summarised using tabular displays, which include a variety of tables and charts. Respondents' open comments and written descriptions were entered into a word processing document (WORD), using

separate sections for each topic. Taking each section in turn, the comments were read and re-read several times before summaries were created of the key points. Respondents' comments were mainly used to provide more detail for certain quantitative responses; therefore these results were amalgamated with the main quantitative findings.

#### **4.1.11 Ethics and disclosure**

Ethical approval for the study was obtained from the local ethics committee prior to initiating study 1, however the NHS committee recommended that ethical approval was not required for this preliminary stage (Reference: 08/H1009/4; January 2008). This was also true for governance arrangements at The University of Manchester and Research and Development (R&D) departments at The Christie. Adherence to the main ethical principles of respect for persons, confidentiality, anonymity, and informed consent was ensured.

##### **4.1.11.1 Confidentiality and anonymity**

Although anonymity and confidentiality may be used synonymously, there are important differences. In anonymity no individual identification details appear on the questionnaire with no links to an individual; however confidentiality conditions use an identification code that researchers can link to an individual (Zeinio, 1980). For study 1 the need for anonymity was outweighed by the requirement to identify potential participants for study 2, therefore linking individuals to their responses was crucial. Confidentiality was also compromised by email contacts and administration of the questionnaire, which established links between individual participants and their completed questionnaires. However, nurse participants were aware of this from the outset and had the option of returning a completely anonymous questionnaire by omitting demographic details and returning the questionnaire by post.

Attempts were made to maintain confidentiality since only one researcher was involved in approaching individuals, and conducting all data collection, data entry and analysis. Completed questionnaires and forms with personal data were kept in a locked drawer in the researcher's office, and records will be destroyed two years after completion of the study. Emails from participants and all electronic data were stored in an encrypted file on a secure hospital server.

A code number was assigned to each participant to ensure anonymity and confidentiality during electronic data entry and analysis. In addition, confidentiality was ensured during publication and presentations of the findings by ensuring there were no links to any personally identifiable information.

#### **4.1.11.2      *Informed consent***

Issues of informed consent were addressed via the information letter. Although written consent is usually requested prior to participation in interviews, this is not usually considered necessary for questionnaire surveys since completion and return of the questionnaire implies tacit consent (Watson et al, 2008). Participants were given at least 24 hours to consider the study before deciding whether to take part; in reality no deadlines were imposed on participants to consider taking part in the study; however an email reminder was sent if respondents had not replied after two weeks. This process was free from coercion, and although participants could withdraw from the study at any time without giving any reason, their involvement in the study was complete after they returned the questionnaire.

#### **4.1.12          *Quality assurance***

The key aim for quantitative surveys is to collect information that is valid, reliable and unbiased (McColl et al, 2001). To assess the quality of the questionnaire for study 1 it was important to ensure reliability (to obtain the same results consistently and repeatedly), validity (whether the questions measure what they are supposed to measure), and unbiased responses (do not over or under-estimate the true value of the responses). This was assessed during piloting.

It is also important to reduce the four types of survey error (Groves, 1989): coverage (adequate coverage of the population), sampling, nonresponse and measurement (ensuring accuracy and precision in respondents' answers) (Dillman et al, 2009). Although steps were taken in this study to try to minimise errors through the sampling strategy, the survey was at greater risk of coverage and sampling errors because a random sample could not be used. In contrast, the risk of nonresponse and measurement errors was low due to the questionnaire design and efforts taken to improve response rates. Bennett et al

(2011) highlight the lack of consensus regarding reporting survey research, however guidelines from the Equator network (Kelley et al, 2003; Burns et al, 2008) were used to structure the methodology and findings of study 1.

A pragmatic approach to quality assurance is also indicated by assessing whether this survey meets recommendations for survey design and implementation (Dillman et al, 2009). Tables 4.6 to 4.9 identify relevant recommendations (Dillman et al, 2009) and show whether each has been achieved. Comments for not achieving recommendations are also provided after each table.

**Table 4.6 General appearance and question format**

(Dillman et al, 2009 p105-6)

Recommendations	Achieved
<u>Choosing words and forming questions</u>	
• Make sure the question applies to the respondent	✓
• Make sure the question is technically accurate	✓
• Ask one question at a time	✓
• Use simple and familiar words	✓
• Use specific and concrete words to specify the concepts clearly	✓
• Use as few words as possible to pose the question	✓
• Use complete sentences with simple sentence structures	✓
• Make sure 'yes' means yes and 'no' means no	✓
• Be sure the question specifies the response task	✓
<u>Visual presentation of survey questions</u>	
• Use darker or larger print for questions than answer choices or spaces	✓
• Use spacing to help create subgrouping within a question	✓
• Visually standardise all answer spaces or response options	✓
• Use visual design properties to emphasize elements that are important to responders	X
• Use design properties with consistency and regularity	✓
• Make sure the words and visual elements that make up the question to send consistent messages	✓
• Integrate special instructions into the questions, where they will be used, rather than including them as free standing entities	✓
• Separate optional or occasionally needed instructions from the questions by font or symbol variation	X
• Organise each question in a way that minimises the need to re-read portions in order to comprehend the response task	✓
• Choose line spacing, font, and text size to ensure legibility of the text	✓



Visual design properties were not used in this survey to emphasise elements that may be important to respondents, since the majority of questions in this survey were considered to be important to nurses. Priority was placed on consistency in the style and placement of instructions, rather than emphasising differences in instructions that were only required occasionally.

**Table 4.7 Question format**

(Dillman et al, 2009 p149-50; p 230-1)

Recommendation	Achieved
<u>Open-ended requests for description and elaboration</u>	
<ul style="list-style-type: none"> <li>• Provide extra motivation to respond</li> <li>• Provide adequate space for respondents to completely answer the questions</li> </ul>	✓ ✓
<u>Guidelines for closed-ended questions</u>	
<ul style="list-style-type: none"> <li>• State both positive and negative sides of the question stem when asking either types of questions</li> <li>• Develop lists of answer categories that include all reasonable possible answers</li> <li>• Develop lists of answer categories that are mutually exclusive</li> <li>• Maintain spacing between answer categories that is consistent with answer length</li> </ul>	✓ ✓ ✓ ✓
<u>Closed end nominal questions</u>	
<ul style="list-style-type: none"> <li>• Ask respondents to rank only a few questions at a time</li> <li>• Avoid bias from unequal comparisons</li> <li>• Randomise response options if there is a concern about order effects</li> <li>• Use forced choice questions rather than check all that apply questions</li> <li>• Consider using different shaped answer spaces to help respondents distinguish between single and multiple answer questions</li> </ul>	✓  X ✓ ✓
<u>Closed end ordinal</u>	
<ul style="list-style-type: none"> <li>• Choose an appropriate scale length</li> <li>• Provide scales that approximate the actual distribution in the population</li> <li>• Consider how verbally labelling and visually displaying all response categories may influence answers</li> <li>• Align response options vertically in one column or horizontally in one row and strive for equal distance between categories</li> </ul>	✓ ✓ ✓ ✓
<u>Ordering the questions</u>	
<ul style="list-style-type: none"> <li>• Group related questions that cover similar topics, and begin with questions likely to be salient to all respondents</li> <li>• Choose the first question carefully</li> <li>• Place sensitive or objectionable questions near the end of the questionnaire</li> <li>• Ask questions about events in the order they occurred</li> <li>• Avoid unintended question order effects</li> </ul>	✓ ✓ ✓ ✓ ✓

Questions were ordered in a logical sequence, and there were no concerns regarding order effects.

**Table 4.8 Visual recommendations**

(Dillman et al, 2009 p231-3)

Recommendation	Achieved
<u>Creating a common visual stimulus</u>	
<ul style="list-style-type: none"> <li>Establish consistency in the visual presentation of questions and use alignment/ vertical spacing to help respondents organise the information on the page</li> </ul>	✓
<ul style="list-style-type: none"> <li>Use colour and contrast to help respondents organise the components of questions and the navigational path through the questionnaire</li> </ul>	X
<ul style="list-style-type: none"> <li>Visually group related information through the use of contrast and exposure</li> </ul>	X
<ul style="list-style-type: none"> <li>Consistently identify the beginning of each question and section</li> </ul>	✓
<ul style="list-style-type: none"> <li>Use visual elements and properties consistently across pages to emphasise or de-emphasise certain types of questions</li> </ul>	X
<ul style="list-style-type: none"> <li>Avoid visual clutter</li> </ul>	✓
<ul style="list-style-type: none"> <li>Minimise the use of matrixes and their complexity</li> </ul>	✓
<u>The mail questionnaire</u>	
<ul style="list-style-type: none"> <li>Determine whether optical imaging and scanning will be used, and assess the potential limitations on design and processing</li> </ul>	✓
<ul style="list-style-type: none"> <li>Construct paper questionnaires in booklet format, and choose dimensions based on printing and mailing considerations</li> </ul>	X
<ul style="list-style-type: none"> <li>Decide question layout and how questions will be arranged on each page</li> </ul>	✓
<ul style="list-style-type: none"> <li>Use symbols, contrast, size, proximity and pagination effectively when designing branching instructions</li> </ul>	✓
<ul style="list-style-type: none"> <li>Create interesting and informative front and back cover pages</li> </ul>	X
<ul style="list-style-type: none"> <li>Avoid placing questions side by side on a page so that respondents are asked to answer two questions at once</li> </ul>	✓
<u>The web questionnaire</u>	
<ul style="list-style-type: none"> <li>Decide whether an electronic alternative to a web survey is more appropriate (eg fillable PDF or embedded email survey)</li> </ul>	✓
<ul style="list-style-type: none"> <li>Evaluate the technological capabilities of the survey population</li> </ul>	✓
<ul style="list-style-type: none"> <li>Take steps to ensure that questions will display similarly across different platform browsers and user settings</li> </ul>	X

Colour and contrast was not used, however this may have been helpful to improve navigation through the questionnaire, however careful and consistent formatting was used to group related questions. Visual elements were not used

to emphasise certain types of questions, since it was perceived that nurses would consider the majority of questions to be important.

Although scanning questionnaires was considered, this would have been difficult to implement for the nature of questions included. The questionnaires could have been constructed in booklet format, however the main intention was to deliver the survey via email attachment, therefore this was not appropriate. Similarly, creating interesting front and back covers was not required.

Although an internet questionnaire was considered, there was limited availability in 2007. In addition, potential problems with hospital servers and firewalls could restrict nurses' ability to access this type of survey. An alternative to this was email attachment, which was considered more personal, direct and faster to deliver than a postal survey. The potential issue of displaying questions across different browser settings was not applicable since this survey was delivered by email attachment.

**Table 4.9     Pretesting and implementation**

(Dillman et al, 2009 p233; 298-9)

Recommendation	Achieved
<u>Pretesting questionnaire</u> <ul style="list-style-type: none"><li>• Obtain feedback on the draft questionnaire from a number of people, each of whom has specialized knowledge of some aspect of the questionnaire quality</li><li>• Conduct cognitive interviews of the complete questionnaire in order to identify wording, question order, visual design, and navigation problems</li><li>• Conduct a small pilot study with a subsample of the population in order to evaluate interconnections among questions, the questionnaire, and the implementation procedures</li></ul>	<div>✓</div> <div>✓</div> <div>✓</div>
<u>Implementation guidelines for web surveys</u> <ul style="list-style-type: none"><li>• Personalize all contacts to respondents where possible</li><li>• Send a token of appreciation with the survey request</li><li>• Use multiple contacts, each with a different look and appeal</li><li>• Carefully time all contacts with the population in mind</li><li>• Consider contacting respondents by another mode</li><li>• Keep email contacts short and to the point</li><li>• Take steps to ensure that emails are not flagged as spam</li><li>• Carefully select the sender name and address and subject line text for email communication</li><li>• Provide clear instructions on how to access the survey</li><li>• Make obvious connections between the opening screen and other implementation features</li><li>• Assign each sample member a unique ID number</li><li>• Know and respect the capabilities and limits of the web server</li><li>• Establish a procedure for dealing with bounced emails</li><li>• Establish procedures for dealing with respondent inquiries</li><li>• Implement a system for monitoring progress and evaluating early completion</li></ul>	<div>✓</div> <div>✓</div> <div>✓</div> <div>✓</div> <div>✓</div> <div></div> <div>✓</div> <div>✓</div> <div>✓</div> <div></div> <div>✓</div> <div>X</div> <div></div> <div>✓</div> <div>✓</div> <div>✓</div> <div>✓</div> <div>✓</div>

Recommendations for implementing web surveys were more relevant for this email attached survey than those for implementing mail surveys which addressed potential issues in mail delivery. However, some issues were not relevant, such as potential issues of connections on the screen.

#### **4.1.13       Summary**

The first part of this chapter has considered the different qualitative and quantitative methodological approaches that could be used for this study. Given

the lack of evidence on nurse-led chemotherapy clinics, an exploratory approach is necessary. Although qualitative designs, including interview methods, could be used to gather information from nurses in oncology regarding their roles, aspects of clinical practice and nurse-led clinics, this would usually result in a small sample size, limiting generalizability of the findings. In addition the geographical distribution of nurses and limited resources for this study would hinder recruitment and data collection. A range of quantitative methods could also be used, however the lack of current evidence on nurses' roles within nurse-led clinics indicates preference for an exploratory descriptive design; therefore a survey was considered the most appropriate for study 1. This section has also outlined the methodological procedures required to implement this study. Sections two of this chapter will present the findings from Study 1.

## **Section two: Results from Study 1**

### **4.2.1 Questionnaire response**

A total of 161 questionnaires were sent directly to nurses who were perceived to be running nurse-led clinics. This resulted in 103 completed questionnaires by 21.04.08, with an overall response rate of 64%. However, analysis showed that only 79 (76.7%) nurses were actually undertaking nurse-led clinics, therefore the statistical analysis was limited to these nurses. In addition, 12 (11.7%) nurses wanted to undertake nurse-led clinics, and the findings from this group will be shown in a separate analysis.

### **4.2.2 Demographics**

#### **4.2.2.1 *Geographical location***

There were similar proportions of participants from the north of England (n=35, 44.3%), and the south 31 (39.2%), with 5 (6.3%) from the midlands, and a small representation from Scotland (n=2, 2.5%), Wales (n=3, 3.8%), Northern Ireland (n=2, 2.5%), and the Channel Isles (n=1, 1.3%), which reflected the distribution of the surveys.

All five advanced nurse practitioners were based in the North. There was a similar distribution of nurse consultants and lead nurses in the North and South of England, but none in Scotland and Northern Ireland within this survey. Clinical nurse specialists were the only group covering all geographical areas.

#### **4.2.2.2      *Nursing titles***

Nurses had 19 different job titles, although many of the specialist nurse titles were similar, therefore were combined into one title of 'clinical nurse specialist'. Nurse clinician and advanced nurse practitioner represent the same role; therefore were combined into 'advanced nurse practitioner'. Similar titles were noted for lead nurses, which were combined into one group. The different titles for chemotherapy nurses were also combined into one group. The only unambiguous title was nurse consultant. This resulted in a total of six main job titles (table 4.10).

**Table 4.10    *Main job titles for nurse participants***

This shows the six main job titles for nurse participants

	<b>n=79</b>	<b>%</b>
Clinical Nurse specialist (CNS)	43	55.1
Nurse Practitioner (NP)	7	9.0
Nurse Clinician (ANP)	5	6.4
Nurse Consultant (NC)	9	11.5
Lead Nurse (LN)	8	10.3
Chemotherapy Nurse	6	7.7

#### **4.2.2.3      *Age and time in post***

Ages ranged from 28 to 61 (median age 44 years) and there was no significant association between age and job title ( $p=.506$  Kruskal-Wallis test). 51 nurses had remained in their job for five years or more, including 17 (21.8%) who had been in the same post for 10 years or more, and there was a significant difference between nurses' job title and time in post ( $p=.018$  Kruskal-Wallis test) (see table 4.11).

**Table 4.11** *Ages of nurse participants and time in post*

	Age (years)		Time in post (years)	
	Median	Range	Median	Range
<b>Clinical nurse specialist</b> (n=43)	46	28-61	7.0	1-26
<b>Nurse practitioner</b> (n=7)	38.5	31-55	7.0	2-12
<b>Advanced nurse practitioner</b> (n=5)	47	40-48	7.0	3-11
<b>Nurse consultant</b> (n=9)	45	35-54	4.0	1-8
<b>Lead nurse</b> (n=8)	45.5	38-53	8.5	2-15
<b>Chemotherapy Nurse</b> (n=6)	40.5	34-48	2.5	1-6

This includes the ages of nurse participants and time in their current post, showing the range and median in years. Median scores were selected since the distribution was not normal.

#### **4.2.2.4**      *Main cancer group*

Although a third of nurses worked within breast cancer (n=29, 36.7%), there was a broad distribution across other cancer groups (see table 4.12).

**Table 4.12** *Cancer groups*

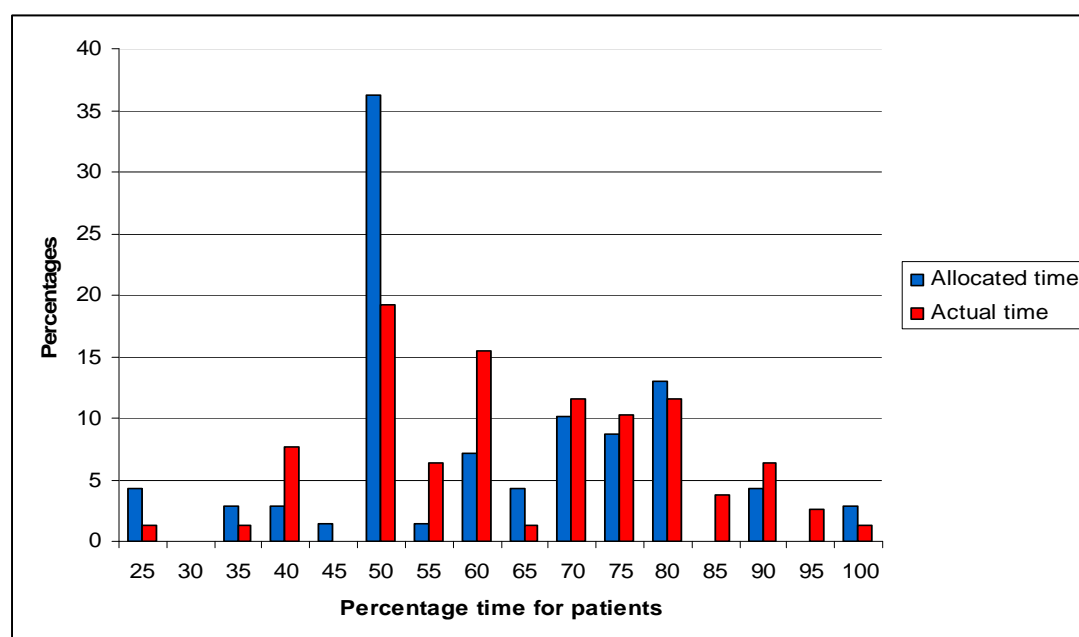
	<b>n=79</b>	<b>%</b>
Breast	29	36.7
All types	13	16.5
Urology	13	16.5
Colorectal	10	12.7
Haematology	4	5.1
Gynaecological	4	5.1
Lung	2	2.5
Upper	1	1.3
Gastrointestinal	1	1.3
Head & Neck	1	1.3
Lymphoma	1	1.3
Breast & colon	1	1.3

This shows some similarities to the distribution of cancer groups in the UK, however colorectal, lung and gynaecological groups appear under-represented. In addition 13 (16.5%) nurses were responsible for multiple types of cancer.

#### 4.2.2.5 Time allocated to patients

Time allocated for patients ranged from 25-100% (median 60%), which matched the range of time that nurses actually spent with patient. However, there were individual discrepancies between the allocated time and time spent with patients; 28 (41.2%) nurses spent more time than allocated and 24 (35.3%) nurses spent less time with patients than allocated. Despite this disparity, 38 nurses (49.4%) perceived that the time for patients was *'just right.'* However, 27 (35.1%) felt they did not have enough time with patients, and 12 (15.6%) thought that too much time was spent with patients. There were also significant differences between the nurse groups in the time allocated for patients ( $\chi^2 = 21.01$ ,  $df=12$ ,  $p=.050$ ), and the actual time spent with patients ( $\chi^2 = 23.21$ ,  $df=12$ ,  $p=.026$ ), (See figure 4.1).

**Figure 4.1** Time for patient contact



#### 4.2.3 Training

##### 4.2.3.1 Training for current role

69 (93.2%) nurses reported that they had received specific training to undertake their current role; however there was great variation in the nature of training. Nurses were not asked specifically about academic qualifications; therefore this may be under-reported. However 21 (35.6%) nurses reported having completed



a Master's degree (see table 4.13). The following legend aims to clarify abbreviations used in table 4.13:

Nurse title	Abbreviation
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

**Table 4.13 Courses undertaken**

Type of course	CNS (n=43)	NP (n=7)	ANP (n=5)	NC (n=9)	LN (n=8)	CN (n=6)
	n=(%)	n=(%)	n=(%)	n=(%)	n=(%)	n=(%)
Masters' degree	10 (23.3)	0	5 (100)	4 (44.4)	2 (25)	0
Bachelors' degree	9 (20.9)	1 (14.3)	0	0	0	1 (16.6)
Communication skills	11 (25.6)	2 (28.6)	2 (40)	2 (22.2)	3 (37.5)	0
Oncology courses	17 (39.5)	1 (14.3)	1 (20)	5 (55.5)	4 (50)	2 (33.3)
Clinical examination	12 (27.9)	3 (42.9)	5 (100)	3 (33.3)	3 37.5)	0
Leadership	1 (2.3)	0	0	2 (22.2)	2 (25)	0

#### **4.2.3.2 Clinical examination training**

Clinical nurse specialists (n=43): 12 clinical nurse specialists had received formal training in clinical examination skills, including Master's level (n=3). However many nurses relied on 'in house training' or 'shadowing' senior doctors to gain appropriate clinical skills.

Nurse practitioners (n=7): Although there was strong evidence of clinical skills training, this was primarily 'in house training' or 'consultant led training'.

Advanced nurse practitioners (n=5): All advanced nurse practitioners received formal training in clinical skills at Master's level

Nurse consultants (n=9): Although one nurse consultant had undertaken clinical skills at Master's level and one at 'degree' level, three gained clinical skills training through 'shadowing' a consultant.

Lead nurses (n=8): Two of the lead nurses had undertaken clinical skills training at Master's level, and three had 'in house training'.

Chemotherapy nurses (n=6). None of the chemotherapy nurses had undertaken any training in clinical examination skills.

#### **4.2.4 Aspects of current role**

##### **4.2.4.1 *Main components of role***

There were key differences in the main aspects of nurses' roles across the groups, and clinical nurse specialists appeared to have the greatest variability.

Clinical nurse specialists: When asked to list the main components of their role approximately half of the clinical nurse specialists included information giving, providing support, clinical, teaching and nurse-led clinics. Additional aspects included psychological support, audit, and research, management, developing services and staff training; advocacy for patients, leadership and consultancy were mentioned once.

Nurse practitioners: The main elements of the nurse practitioners' roles also included providing information and support and running nurse led clinics. In addition they reported more medical tasks, such as ordering and undertaking diagnostic investigations, clinical examination, assessing new and symptomatic patients, assessing fitness for chemotherapy and planning / co-ordinating the multidisciplinary team (MDT) meetings.

Advanced nurse practitioners: The main part of the advanced nurse practitioners' role was around clinical assessment, clinical management and making treatment decisions. In addition they interpreted investigations, liaised with other health professionals, prescribed treatment and ran nurse-led clinics, as well as providing support, advice and counselling for patients. They also saw their role as encompassing a variety of additional aspects, such as staff training, audit, research, teaching, management, presentations, publications and strategic input.

Nurse consultants: In comparison to other nurse groups, the nurse consultants' role had a much greater emphasis on research, education, service development

and audit in addition to clinical leadership and clinical assessment / management. They also included nurse-led clinics, chemotherapy administration and counselling in the main aspects of their role. Two nurse consultants reported that they were also a University lecturer / module leader; one was a Lead Cancer Nurse and one a clinical governance lead. Management, consultancy, staff training and presentations were reported on one occasion.

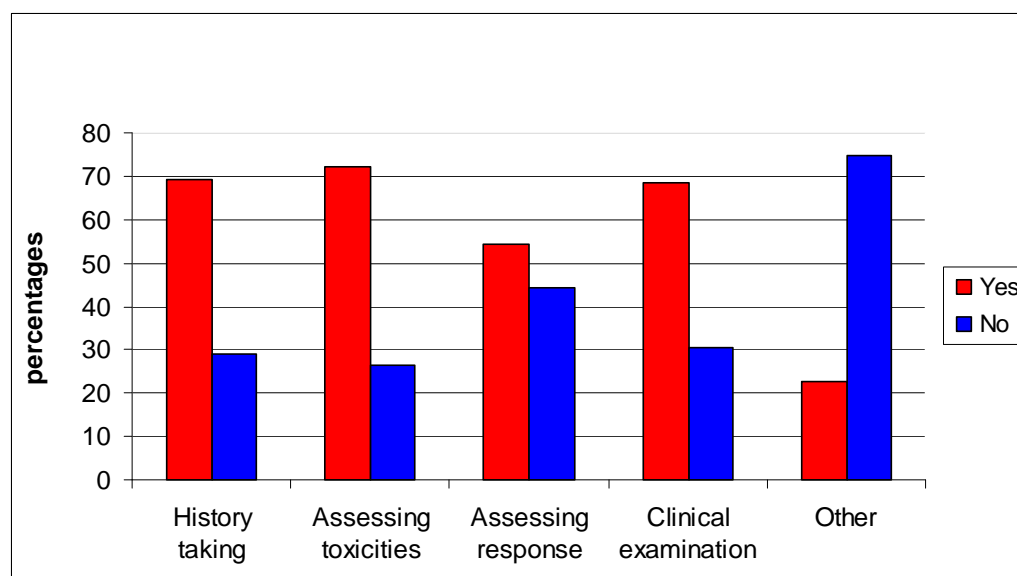
Lead nurses: Some of the lead nurses would have the 'lead' for a clinical nurse specialist service, chemotherapy service or a group of research nurses. In addition they were involved in clinical assessment, management, education and service development. Approximately half of lead nurses included nurse-led follow up, audit, leadership, staff training and the organisation / management of chemotherapy services. Some lead nurses had a patient-focussed role by providing support, giving information, counselling, assessing / managing chemotherapy-related toxicities, administering chemotherapy and complex treatments. Two lead nurses also acted as 'cancer services lead' and one a lead for clinical trials. Research and strategic input were reported once.

Chemotherapy nurses. The chemotherapy nurses' role involved administering chemotherapy, assessing chemotherapy toxicities, developing chemotherapy services, and undertaking nurse-led clinics. Nurses were also involved in education and training regarding chemotherapy and lines for intravenous access.

#### **4.2.4.2      *Clinical assessments***

54 (68.4%) of nurses in the survey reported that they undertook clinical assessments however there were disparities in the nature of assessments across groups of nurses (see figure 4.2).

**Figure 4.2** *Clinical assessments undertaken*



A large proportion of nurses undertook some of the traditional medical responsibilities; 55 (70%) took clinical histories, 57 (72.2%) assessed treatment-related toxicities and 43 (54.4%) assessed treatment response. Other medical assessments included taking biopsies, family history assessments, interpreting blood or radiology investigations, and ordering investigations. However there were disparities in the nature of assessments across the groups. The following legend includes the abbreviations used in table 4.14:

Nurse title	Abbreviation
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

**Table 4.14** *Nurses undertaking clinical assessments*

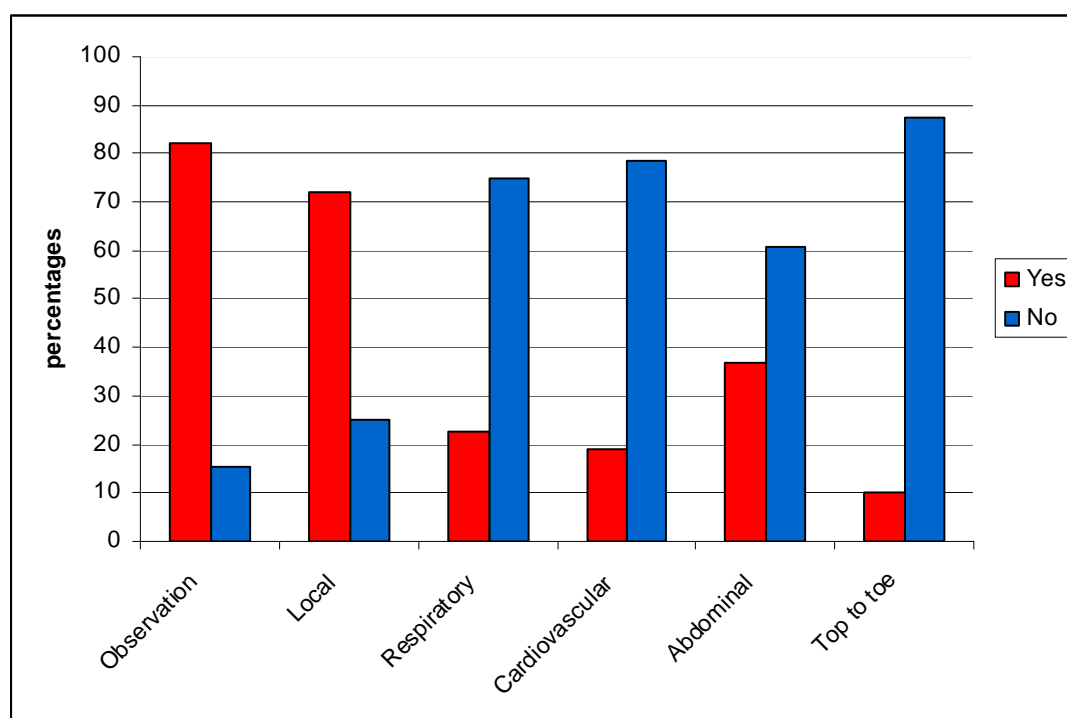
	History taking		Assessing toxicities		Assessing response to treatment		Clinical examination	
	n=	%	n=	%	n=	%	n=	%
<b>CNS</b> (n=43)	26	60.5	24	55.8	22	51.2	26	60.5
<b>NP</b> (n=7)	7	100	6	85.7	3	42.9	7	100
<b>ANP</b> (n=5)	5	100	5	100	5	100	5	100
<b>NC</b> (n=9)	9	100	8	88.9	7	77.8	7	77.8
<b>LN</b> (n=8)	5	62.5	8	100	6	75	6	75
<b>CN</b> (n=6)	3	50	5	83.3	6	100	2	33.3

Across the groups there were statistically significant differences relation to history taking ( $\chi^2=11.93$ , df = 5, p=.036); assessing toxicities ( $\chi^2=11.752$ , df= 5, p=.038), and assessing the response to treatment ( $\chi^2=12.14$ , df=5, p=.033). However there was no significant difference for nurses undertaking clinical examinations ( $\chi^2=10.38$ , df=5, p=.065).

#### 4.2.4.3 *Clinical examinations conducted*

Although 62 nurses (78.5%) reported that they were undertaking clinical examinations within their role the extent of nurses' clinical skills was variable; and only 48 (60.8%) had received formal training in clinical examination skills. Also, seven nurses only observed patients and did not examine them. Excluding these seven nurses from the analysis resulted in 55 (69.6%) nurses who undertook clinical examination of patients, yet only 46 (58.2%) had received formal training in clinical examination skills (see Figure 4.3)

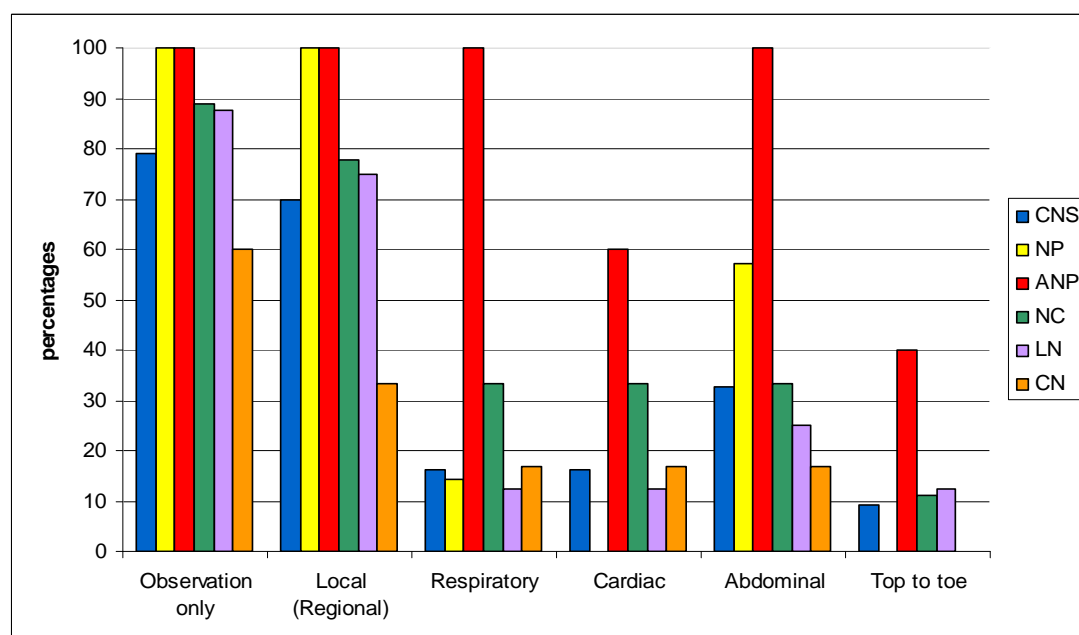
**Figure 4.2** *Nature of clinical assessments*



There were also significant differences in the nature of clinical examinations between the groups of nurses for respiratory ( $\chi^2=19.194$ , df=5, p= .002) and abdominal examination ( $\chi^2= 11.031$ , df = 5, p=.051). However there was no difference between the nurse groups for local ( $\chi^2=8.561$ , df=5, p=.128),

cardiovascular ( $\chi^2=9.021$ ,  $df=5$ ,  $p< .108$ ) and top-to toe examinations ( $\chi^2 = 6.158$ ,  $df=5$ ,  $p=.291$ ). Advanced nurse practitioners undertook the most extensive range of clinical examinations, whilst there was variability across the other groups. Although nurse practitioners all undertook local clinical examinations, they did not perform any cardiovascular or top to toe examinations, and only one did respiratory examinations (figure 4.4).

**Figure 4.3 Range of clinical examinations across the groups of nurses**



#### 4.2.4.4 Other medical assessments undertaken

There was a wide variety of medical assessments reported within the 'other' category, which included surgical pre assessments, wound checks and disease specific procedures. However nurses also reported some medical investigations within this category. Those conducted by clinical nurse specialists' included practical skills, such as blood tests, seroma assessments, but also more advanced medical investigations, for example colposcopy and biopsies. In addition, some conducted family history screening / assessment and formulated clinical management plans. In comparison, nurse practitioners were mainly involved in booking scans, ordering pathology, seroma drainage and wound assessments.

Advanced nurse practitioners did not seem to be as task orientated as the clinical nurse specialists and nurse practitioners. Their role focused on assessment,

screening and diagnosis, assessment of possible relapse and referral to other specialities. Nurses were also involved with detecting possible relapse and monitoring late effects of treatment. Nurse consultants reported undertaking 'out of hours' telephone advice, family history screening / assessment and biopsies. Some nurses undertook more specific aspects of clinical management, such as lymphoedema, counselling and pain management. Lead nurses appeared to have similar responsibilities to advanced practitioners in detecting disease progression, requesting and reviewing bloods and imaging, and making referrals to colleagues as necessary. Chemotherapy nurses did not report undertaking any additional medical assessments.

#### **4.2.4.5 Similarities within the hospital Trust**

Of the nurses surveyed, 59 (74.7%) reported others within the Trust who had a similar role. The number of other similar nurses ranged from 1 to 54, median 2.0, and much of this was in relation to other clinical nurse specialists'. The majority of nurses were accountable to a senior nurse manager (n=55; 69.6%), although a wide variety of different managers was reported, which is shown in table 4.15.

**Table 4.15 Accountability**

The following table shows managerial accountability for nurses

	<b>n=79</b>	<b>%</b>
Senior nurse manager	55	69.6
Director of Nursing	11	13.9
Non-nurse manager	6	7.6
Nurse Consultant	2	2.5
Cancer services manager	1	1.3
Deputy Director of Nursing	1	1.3
Head of nursing (surgical)	1	1.3
Charity trustees	1	1.3

In addition, 13 (16.5%) nurses were also accountable to a medical consultant.

#### **4.2.4.6 Perceived value of nurses' roles**

The majority of nurses perceived their role was highly valued (n=44, 55.7%) or moderately valued (n=21, 26.6%) within the multidisciplinary team (MDT). However 11 (13.9%) felt their role was occasionally valued and one nurse felt

that their role was not valued at all. The following comments illustrate nurses' perceptions of the value of their role.

### **Positive views**

Some nurses gave positive opinions on the value of their role by the MDT, which indicated good working relationships within their team and included reports of mutual respect, highly valued and appreciated, with support for practice and promotion of autonomy:

*"MDT are appreciative of CNS role - much of our extended roles has reduced clinician workload..." [CNS]*

This is reflected in other groups of nurses:

*"Within the MDT / care team. The role is valued for its leadership, service development, strategic direction, consultancy role" [NC]*

*"Particularly with regard to nurse-led services. Huge support from consultants and other nurses who work with me in the clinics" [LN]*

*"I am very much appreciated by my medical colleagues - who understand the pressures of the clinical aspect of the role and level of practice necessary" [ANP]*

...although there is an element of sarcasm to the positive comments:

*"...Especially when medical cover needed" [ANP]*

### **Negative views**

In contrast some clinical nurse specialists suggest that perceptions of their role have changed over time and they now do not feel valued or feel they have to 'prove' themselves:

*"I think it was highly valued at first but now I fear it's invisible" [CNS]*

*"I am repeatedly told I am an expensive nurse who needs to prove my worth" [CNS]*

### **Mixed views**

Many nurses reported mixed perceptions within their Trust regarding the value of their role, which suggest feelings of frustration and disillusionment from the nurses themselves:

*"Some MDT members highly value, others less so. CNS role does not feel to be valued by wider organisation" [CNS]*



*"I believe many people lack an understanding of the role and what it entails. Surprisingly the medical staff are the ones who recognise how much we do rather more than nursing colleagues" [CNS]*

There may also be issues in succession planning and career development:

*"I struggle to get financial value and feel the pressure of the glass ceiling in terms of career development" [NC]*

One clinical nurse specialist illustrates the potential problems that can arise with a change in role:

*"My current role of CNS is reasonably valued but the change in role to ANP is not. There is no understanding of the role or its place..." [CNS]*

Whilst none of the advanced nurse practitioners reported outright negative comments to perceived value of their role, some had mixed views:

*"Although I think my consultant colleagues value my work, my training does not appear to be as high a priority as that of SpRs etc" [ANP]*

The following comment reflects the frustrations of developing roles and services:

*"I am valued by the MDT and outside organisations. I do not feel that I am valued by the Trust (nursing / exec level) due to the barriers that are incurred in developing services and by a general lack of understanding of a clinical research role and the complexity of it" [LN]*

This suggests differences in expectations and perceptions between clinical staff and managers.

#### **4.2.4.7 Perceived autonomy of nurses' roles**

48 nurses (60.8%) reported that they had a significant level of autonomy, whilst 12 (15.2%) reported their role was fully autonomous. However 16 (20.3%) had only 'some' autonomy and 2 (2.5%) relied on indirect supervision. There were mixed views on perceived level of autonomy about nurses' current role, with no comments by nurse practitioners and lead nurses. The following comment illustrates some of the difficulties of developing existing roles, and conflict that can arise within organisations:

*"...We want our role to change from CNS to practitioner... [and] incorporate some elements of the practitioner role without eroding the core value of the CNS. Unfortunately organisations appear to be valuing the practitioner role at the expense of the CNS." [CNS]*

The following comment by a nurse consultant raises an interesting point in relation to how much independence nurses should have within nurse-led clinics:

*“I don't believe nurse consultants should work fully independently. We still need doctors for some decisions and diagnostics” [NC]*

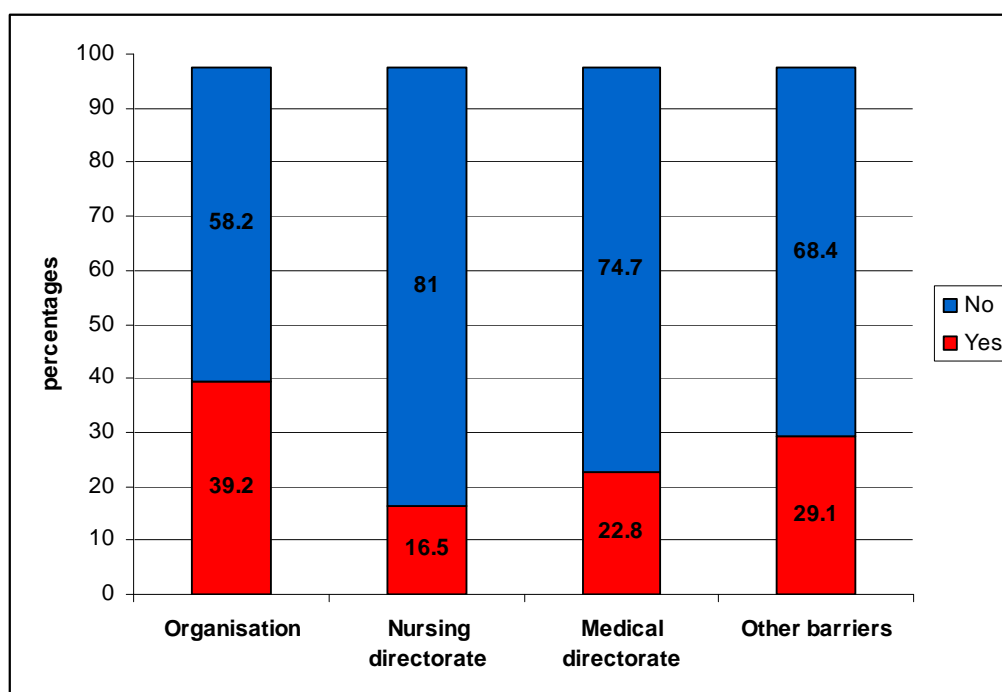
#### 4.2.5 Barriers

Two groups of potential barriers were explored within the survey, as they were perceived to be important for oncology nurses in developing clinics and services. Nurses were asked to identify whether any barriers limited their practice and later asked if they perceived any barriers to setting up more nurse-led clinics.

##### 4.2.5.1 Perceived barriers limiting practice

56 (70.9%) nurses indicated that some barriers limited their practice. Three possible categories for barriers were outlined in the questionnaire: the organisation (n=31, 39.2%), the nursing directorate (n=13, 16.5%) and the medical directorate (n=18, 22.8%), plus an open category titled ‘other barriers’ (n=23, 29.1%) (see figure 4.5).

**Figure 4.5 Barriers limiting nursing practice**



#### **4.2.5.2 Other barriers**

Nurses reported a range of different barriers that limited their practice. These have been grouped to increase clarity:

Time and training were the main additional barriers to nurses' roles across all the groups that affected clinical practice. Time factors were in relation to patient care, the general workload and time to expand the service. Training issues included inability to prescribe independently. However, sometimes barriers were multifactorial, often reported to be due to a combination of lack of time, capacity issues and environmental problems, such as clinic room space.

Lack of support and understanding from managers and medical staff was reported to adversely affect nurses' clinical practice and/or potential service development:

*"Difficulties getting some urologists to accept nurses giving a cancer diagnosis to patients" [CNS]*

The following quote highlights the need for good communication between managers and clinical staff:

*"Lack of information from management of crucial structural changes which will impact significantly on role or quality of service for patients" [ANP]*

Infrastructure and environment appeared to be significant barriers to clinical practice, particularly regarding secretarial and clerical support for many nurses. One of the main difficulties for nurses in setting up or running their own clinics seemed to be a lack of designated clinic rooms, which limited nurse-led services in some cases, whilst prohibiting other nurses from initiating clinics or services. Although in some cases there was simply no physical space for new nurse-led clinics, other nurses perceived that doctors were often given priority over nurses in the competition for clinic rooms.

*"Working environment counter-productive - limits what we can offer to patients as no dedicated rooms." [NC]*

*"I have completed the nurse endoscopy course but have been unable to complete the competency training as we only have one room and immense pressure to fit in all the endoscopies. [CNS]*

A lack of resources was highlighted by many nurses, which was often driven by financial pressures. Although some of the issues with resources were related to the clinical environment, other issues were in relation to nursing staff and secretarial / clerical support:

*“Our service could develop significantly if the team was larger. Increased cost would be more than offset by the increased productivity. Addition of admin support would also allow us to develop the nursing service and release us from non-nursing duties” [CNS]*

*“...study leave and support policy makes it very difficult to take modules eg prescribing course. Developing new services eg nurse-led clinics takes a long time to implement. Can be very demotivating” [LN]*

Obstruction from medical staff was frequently perceived to hinder clinical work and further development. In some case this was perceived to be due to a lack of understanding for new nursing roles, or changes to existing roles. However, some nurses reported that medical colleagues gave priority to junior doctors and medical students in relation to training and seeing, for example, new patients. In addition there were reports of resistance by some medical consultants to nurses developing their roles, which seems a more difficult obstacle to overcome:

*“Due to this being a new role there are barriers at different levels with all disciplines although overall acceptance of the role has been good. I only work alongside the consultants that are accepting of ANP roles” [ANP]*

*“One surgeon obstructive at times to developing staff / practice and very inconsistent in decision making generally so there are difficulties in agreeing vision for service at times” [NC]*

Barriers from managers also influenced clinical practice and service development, which was mainly due to financial implications:

*“Current director of nursing does not wish to employ more nurse consultants as feels they are too expensive (she inherited me!)” [NC]*

*“Nationally there is a need to make savings. The role of the CNS is not understood by all, especially some managers” [CNS]*

## 4.2.6 Nurse led clinics

### 4.2.6.1 Number of nurse led clinics

The number of nurse-led clinics per nurse ranged from 1-7; some nurse-led clinics occurred every day whilst others were only once a month. The number of nurse-led clinics per nurse ranged from 1-30 per month (median 9.0), however, there were no significant differences between nurse groups ( $p=.305$  Kruskal-Wallis test). In addition some nurses undertook telephone or 'virtual clinics', ranging from 0-5 per nurse. Some nurses held telephone clinics once a week, whilst others only held them once a month. The range of telephone clinics per nurse was 0-21 per month (median 4.0), with no difference between the number of telephone clinics across the nurse groups ( $p=.380$  Kruskal-Wallis test). Patients attending face-to-face nurse-led clinics ranged from 4-25 (median 8.0); patients attending telephone clinics ranged from 4-25 (median 10.0).

The time allocated for each appointment ranged from 5-60 minutes (median 20 minutes), however there was no difference in appointment times for nurse-led clinics across the nurse groups ( $p=.126$  Kruskal-Wallis test). The number of patients for each nurse group is shown in table 4.16. The following legend aims to clarify abbreviations used in table 4.16:

Nurse title	Abbreviation
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

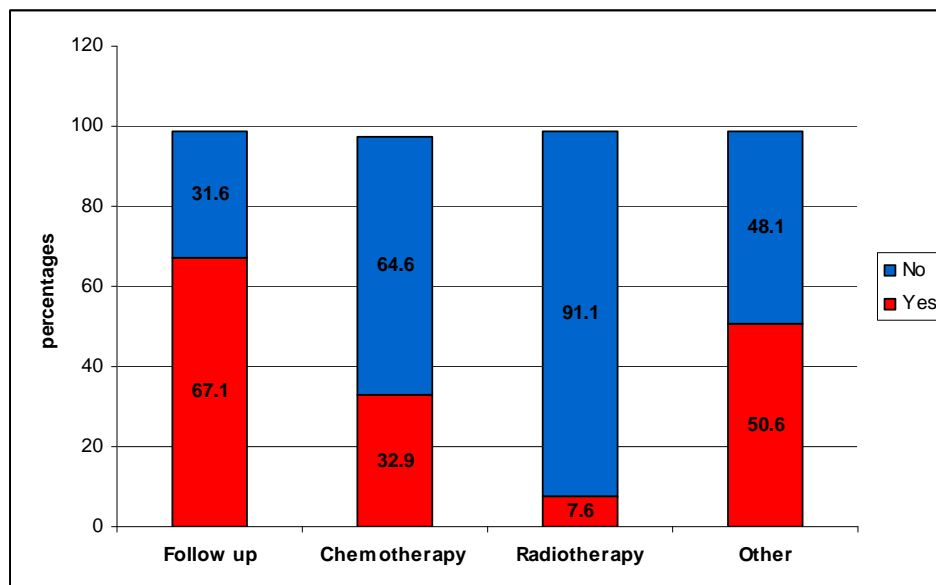
**Table 4.16 Number of nurse led clinics across nurse groups**

	Face-to-face clinics (month)		Patient numbers		Telephone clinics (month)		Patient numbers	
	median	range	median	range	median	range	median	range
<b>CNS</b>	10.0	1-30	8.0	4-16	9.0	4-17	16	10-25
<b>NP</b>	13	4-21	10	7-25	4.0	4	8	8
<b>ANP</b>	6	4-9	10	8-14	0			
<b>NC</b>	13	4-17	7	5-15	12.5	4-21	7	4-10
<b>LN</b>	4	4-13	10	6-20	0			
<b>CN</b>	13	4-17	7	5-15	12.5	4-21	7	4-10

#### 4.2.6.2 Nature of nurse led clinics

There were differences in the nature of nurse-led clinics undertaken by nurses, and the findings were grouped into three main categories of follow up, chemotherapy and radiotherapy clinics, and one open category for other nurse-led clinics. (figure 4.6).

**Figure 4.6 The nature of nurse-led clinics**



This shows that the majority of nurse-led clinics are in relation to routine follow up by 67.1% of nurses. Almost a third (32.9%) of nurses ran nurse-led chemotherapy clinics, but only a small number (7.5%) had nurse-led radiotherapy clinics. Additional nurse-led clinics included family history, pre-assessment and certain procedures such as seroma aspiration, wound checks, prosthesis fitting, colposcopy and colonoscopy, which were often within a specific cancer group.

The following legend aims to clarify abbreviations used in table 4.17:

Nurse title	Abbreviation
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

**Table 4.17 Nature of nurse led clinics**

	Follow-up		Chemotherapy		Radiotherapy		Other clinics	
	n=	%	n=	%	n=	%	n=	%
<b>CNS</b>	32	74.4	7	16.3	1	2.3	23	53.5
<b>NP</b>	6	85.7	2	28.6	2	28.6	4	57.1
<b>ANP</b>	2	40	3	60	2	40	3	60
<b>NC</b>	6	66.7	3	33.3	0	0	8	88.9
<b>LN</b>	6	75	4	50	0	0	1	12.5
<b>CN</b>	0	0	6	100	0	0	1	16.7

Comparing the groups of nurses, there were significant differences in those undertaking follow-up clinics ( $\chi^2 = 16.906$  df=5,  $p=.005$ ), chemotherapy ( $\chi^2=20.665$ , df=10,  $p=.024$ ), and radiotherapy clinics ( $\chi^2=17.632$ , df=5,  $p=.0003$ ).

#### **4.2.6.3 Other nurse led clinics undertaken**

There is a great diversity in the nature of nurse led clinics within this group of oncology nurses. Clinical nurse specialists have the greatest range of nurse led clinics, covering information, counselling, giving results and undertaking clinical reviews, pre assessment and certain practical procedures. In addition some clinical nurse specialists have specific clinics, such as family history, stoma care and erectile dysfunction.

The nurse led clinics run by nurse practitioners seem mainly concerned with clinical reviews, such as pre assessment and symptomatic clinics, although some nurse practitioners run specific nurse led clinics for example family history. Advanced nurse practitioners have very specific nurse led clinics, such as chemotherapy and radiotherapy, whilst nurse consultants seem to run more nurse led clinics, including daily 'drop in', symptomatic and family history. In addition some nurse consultants have specific clinics, such as palliative care.

#### **4.2.6.4 Nurses' comments on nurse-led clinics**

Although many nurses run nurse led clinics independent from medical staff, some prefer to have clinics alongside them:

*“Runs parallel to consultant's clinic - set up as makes more sense for nurse to assess patient first and liaise with surgical staff” [CNS]*

Some nurses have a large commitment to nurse led clinics within their workload, running daily nurse-led clinics, and several nurses report that they are planning further nurse-led clinics, including pre-assessment, PICC line insertion, giving histology results, new patient clinics:

*“... I would like to be involved in more nurse led clinics with a nurse clinician as a lead” [LN]*

However, some nurses do not feel there would be a benefit to setting up nurse led clinics

*“Currently we are striving for multidisciplinary care and trying to establish MDT clinics. There may be a role for a nurse-led service within this clinic but I am reluctant to see patients in isolation” [ANP]*

*“Work autonomously within existing consultant-led clinic format. See this very much as 'nurse managed' as opposed to 'nurse-led' [ANP]*

*“I would like to test it out to assess the need. I am not convinced these are required / valuable in a very rural county for very sick palliative care patients - maybe a good idea alongside oncology clinics” [NC]*

It also seemed that other nurses were reluctant to set up further nurse-led clinics for a variety of reasons, including time, resources and nurses' perceptions regarding their usefulness.

#### **4.2.6.5 Nurse-led clinics: independence of nurse-led clinics**

62 (78.5%) nurses reported that they could run their nurse-led clinics independently of doctors, and there was no difference between the nurse groups ( $\chi^2=5.248$  df 10  $p=.874$ ). However 26 (32.9%) patients attending nurse-led clinics also attended medical clinics.

Doctors alone prescribed for patients attending all nurse led clinics run by nurse practitioners, and most of those run by clinical nurse specialists. Doctors alone prescribed within 46 (58.2%) of nurse-led clinics, and a combination of doctors and nurses in 12 additional nurse-led clinics (15.2%). Between the nurse groups differences in prescribing were statistically significant ( $\chi^2=23.859$  df 10  $p=.008$ )

49 (62%) of nurses had 'cover' for their nurse-led clinic from another nurse ( $n=33$ , 41.8%), a doctor ( $n=12$ , 15.2%, or a pharmacist ( $n=3$ , 3.8%), although



there was no difference between the nurse groups ( $\chi^2=18.063$  df 15  $p=.259$ ).

Table 4.18 summarises aspects of nurses, independence in nurse-led clinics.

The following legend aims to clarify abbreviations used in table 4.18:

Nurse title	Abbreviation
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

**Table 4.18 Autonomy within nurse led clinics**

	Independent		Also see doctors		Nurse prescribes		Doctor only prescribes		Cover available	
	n=	%	n=	%	n=	%	n=	%	n=	%
<b>CNS</b>	33	76.7	19	44.2	5	11.6	30	69.8	25	58.1
<b>NP</b>	5	71.4	1	14.3	0	0	6	85.7	5	71.4
<b>ANP</b>	4	80	2	40	2	40	0	0	4	80
<b>NC</b>	8	88.9	6	66.7	3	33.3	3	33.3	4	44.4
<b>LN</b>	6	75	1	12.5	3	37.5	3	37.5	6	75
<b>CN</b>	5	83.3	2	33.3	1	16.7	3	50	5	83.3

From this it appears that the majority of nurse led clinics were functioning independently. Although there was no significant difference between groups of nurses in patients attending medical clinics, there was a trend showing an increased number of patients attending clinics run by clinical nurse specialists and nurse consultants had to also attend medical clinics ( $\chi^2=17.431$  df 10  $p=.065$ ). Some nurses reported a preference to run nurse-led clinics parallel to medical clinics, which provided nurses with the security of medical colleagues close by if needed:

*“Consultants are running their own non-urgent clinic and are available to review patients whom we are worried about or to prescribe different hormonal treatments” [CNS]*

Some patients will also need to attend medical / oncology clinics in addition to nurse-led clinics; therefore medical colleagues retain significant responsibility for patient management in many cases.

*“I prefer to do clinics with consultant / reg [registrar] present as unable to do flexi sigis if these are needed. Occasionally patients need to attend oncology clinics as well” [NP]*

*“Patients seen in medical clinics routinely if alternating with oncologist or symptoms / signs requiring medical assessment” [NC]*

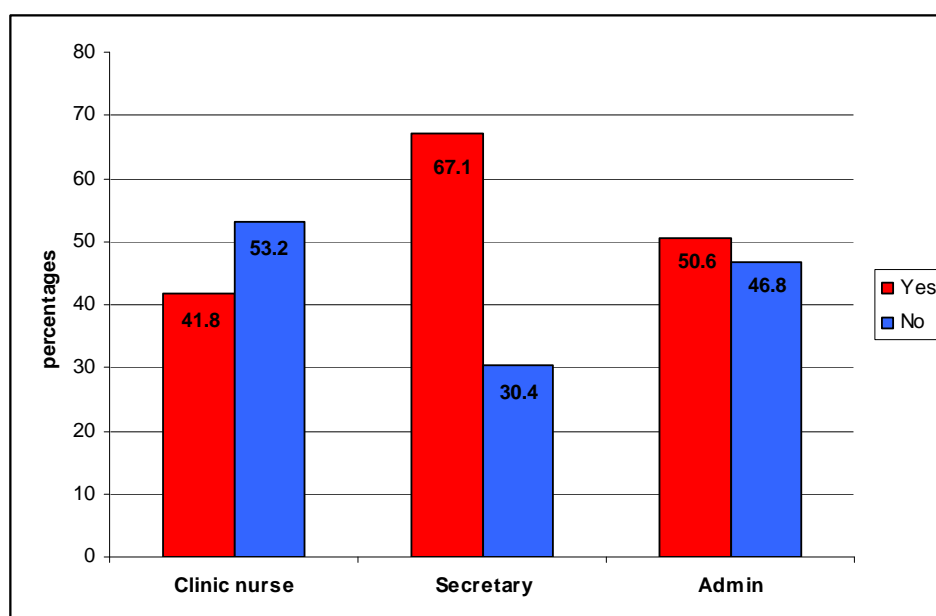
*“...can't see chemo pts independently as can't prescribe” [NP]*

This illustrates that some aspects of clinical practice may be limited if nurses cannot prescribe, which may be a concern in nurse-led chemotherapy clinics.

#### **4.2.6.6 Support for nurse led clinics**

Additional support was generally poor for nurse-led clinics, in terms of clinic nurse, secretarial and administration support, as shown in figure 4.7:

**Figure 4.7 Support available for nurse-led clinics**



Although secretarial support is often provided for nurse consultant and some lead nurse posts, support for other groups of nurses may be limited:

*“In danger of losing this support when our secretary retires...posts frozen when someone leaves” [CNS]*

*“clinic nurse depends on [which] clinic day I do; secretarial support depends on goodwill” [ANP]*

*“Have 20 hours per week secretary, have asked for more hours for years but asked to work more efficiently as no more money available” [CNS]*

There were often difficulties in obtaining adequate cover for nurse led clinics. In some cases the cover was ad hoc and unpredictable, with doctors taken from another clinic or cover from another nurse, but non-prescriber. One nurse also

reported that there was no face-to-face cover available, but virtual cover in the form of telephone contact.

#### **4.2.6.7      *Support for nurse led clinics: differences between groups***

The support for nurse led clinics seems generally poor for some groups, such as chemotherapy nurses where 1 (16.7%) had secretarial support, and 3 (50%) had administrative support. 18 (41.9%) of clinical nurse specialists receive administrative support. This contrasts with nurse consultants in that 66.7% secretarial support and admin support. Similarly secretarial and admin support for nurse practitioners and advanced nurse practitioners are reasonable at 57-60%, whilst higher for lead nurses (63-88%).

There is also variability regarding clinic nurse support for nurse-led clinics. Only 13 (30.2%) of clinical nurse specialists, 37.5% of lead nurses and 40% of advanced nurse practitioners have help from a clinic nurse. This contrasts with 71.4% of nurse practitioners and 66.7% of nurse consultants.

#### **4.2.6.8      *Rating support for nurse-led clinics***

There were clear differences in how individuals rated the support they had from colleagues in relation to their nurse led clinics. Many were positive and show how nurse led clinics can complement medical management to benefit patients:

*“Patients have appointment with surgeon same day. Nurse and surgeon discuss their perspectives from each other’s assessment and info giving of each patient” [CNS]*

The benefits of appropriate levels of clerical support are clearly demonstrated in the following comment, which also highlights local disparities in support services provision:

*“We have our own department assistant who prepares the notes, helps in clinic and follows up results. The medical secretaries type up letters and medical records pull the notes for the clinic so we are in a very fortunate position compared to our sister hospital who have to do it all for themselves” [CNS]*

However it was often the case that difficulties in running nurse-led clinics arose from a lack of clerical and secretarial support, or ad hoc provision that results in

delays Again, comparisons were made with the support available for medical staff:

*“Often have to wait 2-3 weeks for typing and letters to be done” [ANP]*

The following comments illustrate other difficulties nurses often face when setting up and running nurse led clinics:

*“No room allocated. Notes not always available. Receptionists therefore get confused” [CNS]*

*“Difficult at times of unplanned leave ie illness...always the nurse led that suffers” [CNS]*

*“nurse led clinic service has expanded but not the resources to support it” [LN]*

Whilst the above are mainly practical difficulties that can be overcome by creating additional resources to the infrastructure, some of the obstacles may be more difficult to overcome if the problem is a lack of managerial or financial support:

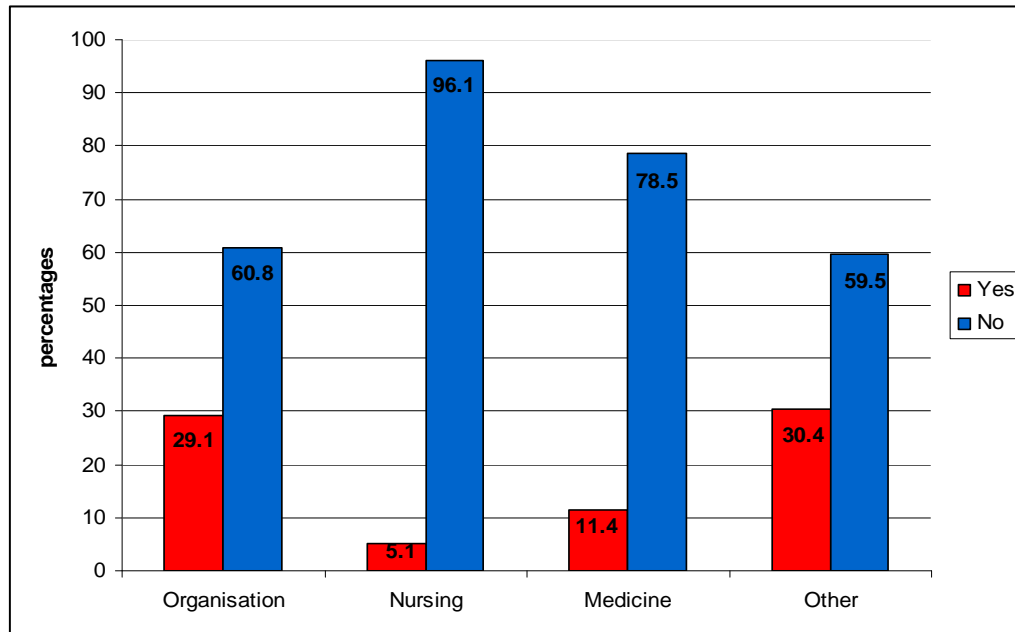
*“There is scope for funding nurse-led clinics but these are not seen as something that nurses should be doing” [CNS]*

In questioning nurses about how they perceived the level of support for nurse-led clinics, 35 (44.3%) nurses reported the level of support to be ‘just right’ but 42 (53.2%) felt that it was ‘not enough’. Despite this 51 (64.6%) nurses wanted to have more nurse-led clinics.

#### **4.2.6.9      *Barriers to nurse-led clinics***

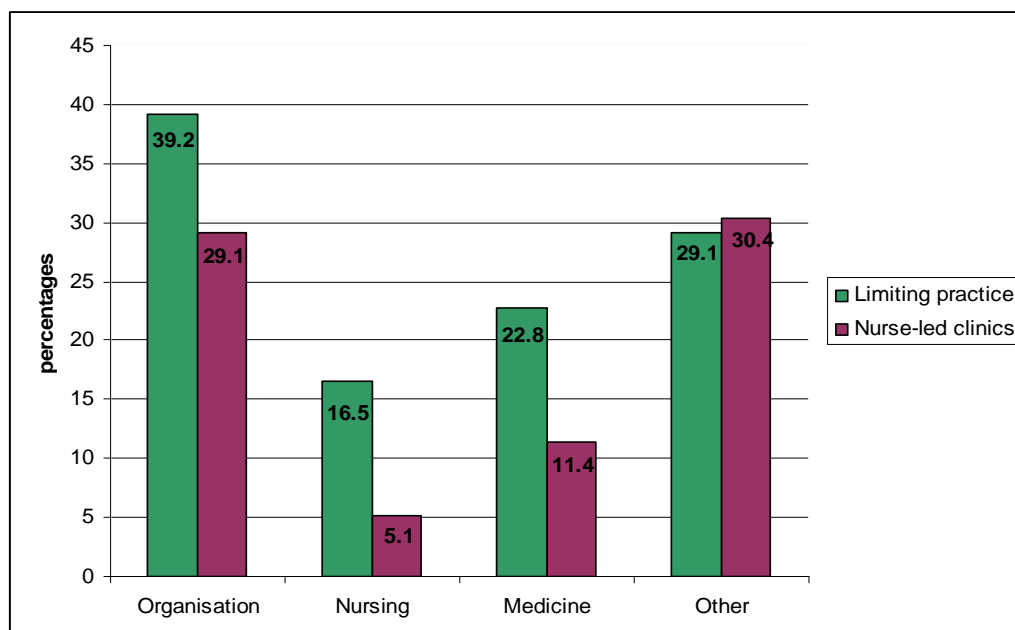
49 (62%) nurses reported there were some barriers to setting up more nurse-led clinics. Categories used for the nature of barriers related to the organisation, the nursing directorate and medical directorate, as well as an open category for any other barriers, and this is shown in figure 4.8.

**Figure 4.8 Barriers to nurse-led clinics**



The majority of barriers were perceived to be due to the organisation (29.1%) and 'other' (30.4%), in which time was the most reported factor, although there were also many reports of issues relating to clinic space and practicalities. The same categories were used in questions about barriers relating to nursing practice and also barriers to nurse-led clinics, therefore it was possible to compare the impact barriers can have on both areas of advanced practice. This is shown in the figure 4.9:

**Figure 4.9 Comparison of clinical barriers**



Apart from the category of 'other' barriers, there were more barriers to limiting nursing practice from the organisation, nursing and medical directorates, than there were barriers to nurse-led clinics. However this was not statistically significant.

#### **4.2.6.10 Barriers to setting up more nurse-led clinics**

When considering whether to set up more nurse led clinics, nurses reported potential barriers. These often arose from nurses themselves and mainly related to lack of time within their current role:

*"I do not want to spend more time on follow up when there is no back fill for other BCN tasks & I would not want a purely clinic-based role" [CNS]*

Training issues were also a problem linked with time factors as a barrier for nurse led clinics:

*"Until I have completed my training I do not have all the skills I need. Also time is short as I have 2 days at University" [CNS]*

However the influence of managers and medical colleagues on nurse led clinics cannot be overlooked, since they are possibly the two greatest barriers (or supporters) for nurse led clinics:

*"Management not keen due to limited resources and space" [CNS]*

*"Sometimes I think nurse-led clinics are undertaken without the appropriate level of support or knowledge because of managerial pressures" [NClin]*

Several nurses also report that medical colleagues can be reluctant to delegate or share some of the traditional medical responsibilities to nurses:

*"The consultants want to keep their patients, do not like the idea of delegating their work" [LN]*

*"Some resistance from medical colleagues as it is such a big change in how they manage the care for those patients, but there are some extremely proactive and supportive medical colleagues" [LN]*

*"Would like to set up histology giving nurse led clinic. In process of planning how best to "sell" this to docs as have reason to think they will not want to give up this part of their role" [CNS]*

In the current budget-constrained NHS most nursing developments will depend on financial resources, which are increasingly difficult to secure and may hinder nurse-led services:

*“There appears to be resistance to nurse led clinics with regard to the input administration are able to put in. There are also funding issues associated with the cost of these. Obtaining funding for admin support in nurse led clinics is difficult” [LN]*

*“There is a lack of clarity within the organisation about tariff & payment for nurse led clinics. Whilst tariff may be available PCTs are anxious that nurse led clinics are part of SLA before they will pay for the service” [CNS]*

Locally, one of the biggest difficulties is in relation to capacity and providing the infrastructure for new clinics / clinical services. This is particularly hard for nurse led clinics, since medical clinics are often given priority over clinic rooms and resources:

*“No clinic room available. Already no resources to support clinic” [CNS]*

*“Don't need more clinic space as running everyday but need more capacity within clinics in terms of staffing and space as demand for more chemo patients to be seen in this clinic (consultant requests) is out weighing present capacity...” [LN]*

#### **4.2.6.11 Benefits of nurse-led clinics**

When asking nurses their perceptions about possible benefits to nurse-led clinics, 96 (99%) nurses thought that they improved services, were of benefit to patients (n=93, 95.9%) and benefit to staff (n=64, 66%). Only one nurse felt that nurse led clinics were of no benefit, however qualified the comment by stating that she was new in post. Comments from nurses in relation to other potential benefits of nurse-led clinics show the potential impact in a number of ways:

...benefits in relation to hospital / government targets:

*“Assist in cancer targets; continuity of care” [CNS]*

*“Benefit organisation ie targets, reputation” [NC]*

...benefits in improving medical management:

*“Free doctors up for theatre, emergencies” [NP]*

*“Free clinic slots for more patients within my shared clinics; patients who are poorly and new” [ANP]*

*“Benefits the Trust. More effective way to deliver the chemotherapy service” [LN]*

...benefits in improving patient care:

*“I feel the best benefit is to the patients who are seen by a nurse who assesses them holistically, but it is really difficult to quantify” [ANP]*

*“Address different issues to medics; combination of skills achieves best outcomes for patients” [NC]*

*“greater continuity” [NC]*

...benefits for nurses themselves:

*“Good learning opportunities” [CNS]*

*“Team working” [LN]*

However the possible drawbacks must also be considered:

*“There can be drawbacks as well eg if nurse-led clinics erode other components of care” [CNS]*

#### **4.2.7 Non-medical prescribing**

Almost a third of nurses were able to prescribe independently, and did so frequently, with a further 5 (6.3%) undergoing training. There were significant differences across the groups of nurses in relation to nurse prescribing ( $\chi^2 = 26.033$ ,  $df = 5$ ,  $p < .0001$ ), since none of the nurse practitioners and only 8 (16.3%) of the clinical nurse specialists and two (33.3%) chemotherapy nurses were independent prescribers. In comparison, all five of the advanced nurse practitioners, six (66.7%) nurse consultants and five (62.5%) lead nurses were prescribing independently, with one nurse consultant currently undertaking the course. (see table 4.19).

The following legend aims to clarify abbreviations used in table 4.19:

<b>Nurse title</b>	<b>Abbreviation</b>
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN



**Table 4.19 Non-medical prescribing**

	Prescribing			
	Completed		Training	
	n=	%	n=	%
<b>CNS</b> (n=43)	8	16.3	4	9.3
<b>NP</b> (n=7)	0	0	0	0
<b>ANP</b> (n=5)	5	100	0	0
<b>NC</b> (n=9)	6	66.7	1	11.1
<b>LN</b> (n=8)	5	62.5	0	0
<b>CN</b> (n=6)	2	33.3	0	0

#### 4.2.7.1 Independence with prescribing

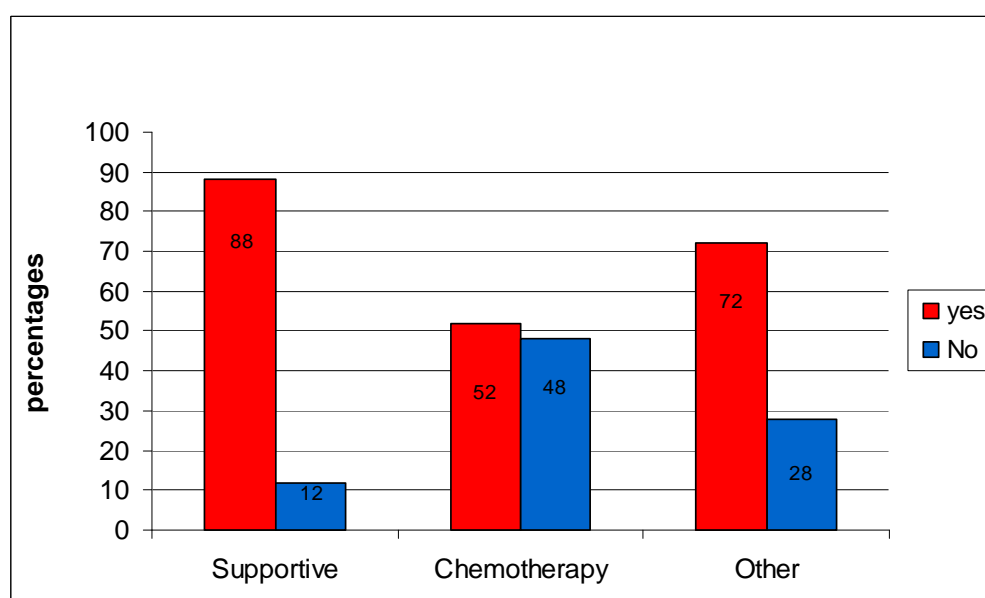
Many nurses run nurse led clinics but are unable to prescribe independently, therefore may run their clinics alongside medical colleagues so that prescriptions can be signed. Other nurses would obtain prescriptions for patients by writing to General Practitioners (GPs):

*"I don't prescribe. I write an " advisory letter" to GPs asking for changes of medication as per protocols ie Tam / Letrozole" [CNS]*

#### 4.2.7.2 Nature of non-medical prescribing

The following graph shows prescribing practices for nurse prescribers only, indicating the percentage of nurses who prescribed chemotherapy (n=13, 52%), supportive medication (n=22, 88%) and other medication (n=18, 72%).

**Figure 4.10 Medicines prescribed by nurses**



#### 4.2.7.3 *Nurse prescribing: differences between groups*

There was a significant difference between the nurse groups in the number of non-medical prescribers who prescribed chemotherapy ( $\chi^2=11.416$  df 4  $p=.022$ ). Although the majority of nurses were prescribing supportive (general) medication independently, few specialist nurses and nurse consultants were prescribing chemotherapy, in contrast to all advanced nurse practitioners and chemotherapy nurses (see table 4.20).

The following legend aims to clarify abbreviations used in table 4.20:

Nurse title	Abbreviation
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

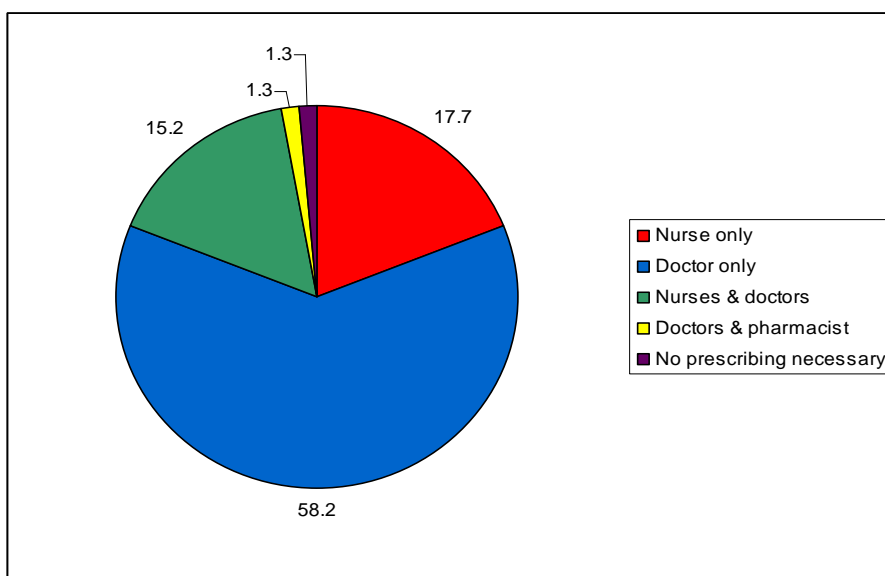
**Table 4.20** *Nature of nurse prescribing*

	Supportive		Chemotherapy		Other	
	n=	%	n=	%	n=	%
<b>CNS</b> (n=8)	6	75.0	1	12.5	4	50.0
<b>ANP</b> (n=5)	5	100.0	5	100.0	4	80.0
<b>NC</b> (n=6)	5	83.3	2	33.3	4	66.6
<b>LN</b> (n=5)	5	100.0	3	60.0	5	100.0
<b>CN</b> (n=2)	2	100.0	2	100.0	1	50.0

#### 4.2.7.4 *Implications for autonomy with non-medical prescribing*

Although a significant number of nurses independently prescribe medicines, an inability to prescribe within nurse-led clinics could limit the autonomy of nurses. In this survey doctors alone prescribed in 46 (58.2%) nurse-led clinics. Fourteen (17.7%) nurses were able to prescribe within their own nurse-led clinic, a further 12 (15.2%) prescribed in combination with doctors, and one nurse reported that no prescribing was necessary in her nurse-led clinic. This is shown figure 4.11:

**Figure 4.11 Nurse prescribing within nurse-led clinics**

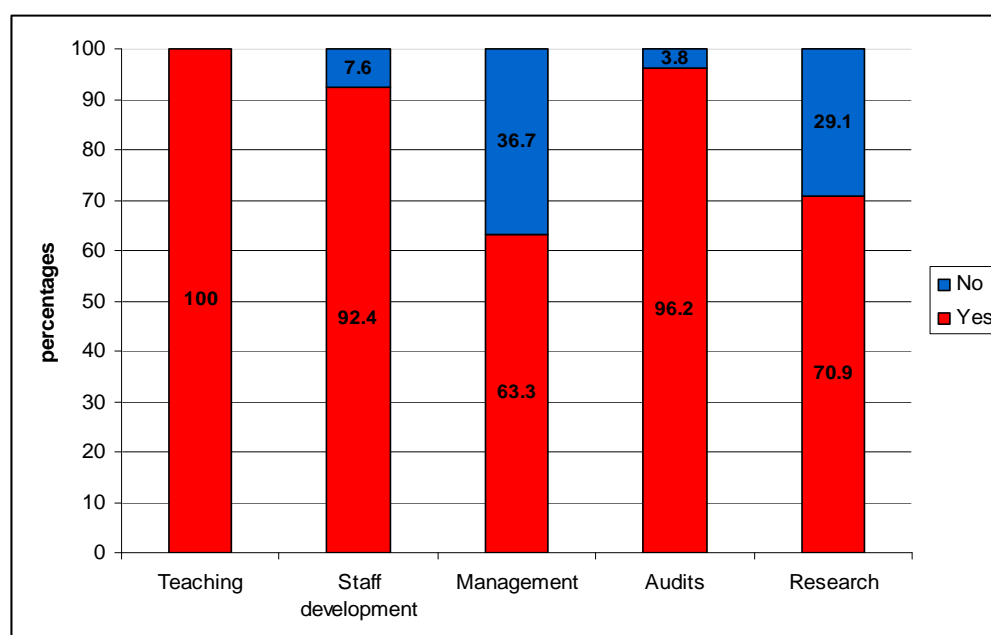


#### 4.2.8 Additional responsibilities within role

##### 4.2.8.1 Range of additional responsibilities

A large proportion of nurses reported additional responsibilities within their role with regard to teaching (n=79, 100%), staff development (n=73, 92.4%), managerial (n=50, 63.3%), research (n=56, 70.9%), audit (n=76, 96.2%) and developing guidelines or protocols (n=73, 92.4%). The range of these is shown in figure 4.12:

**Figure 4.12 Additional responsibilities of role**

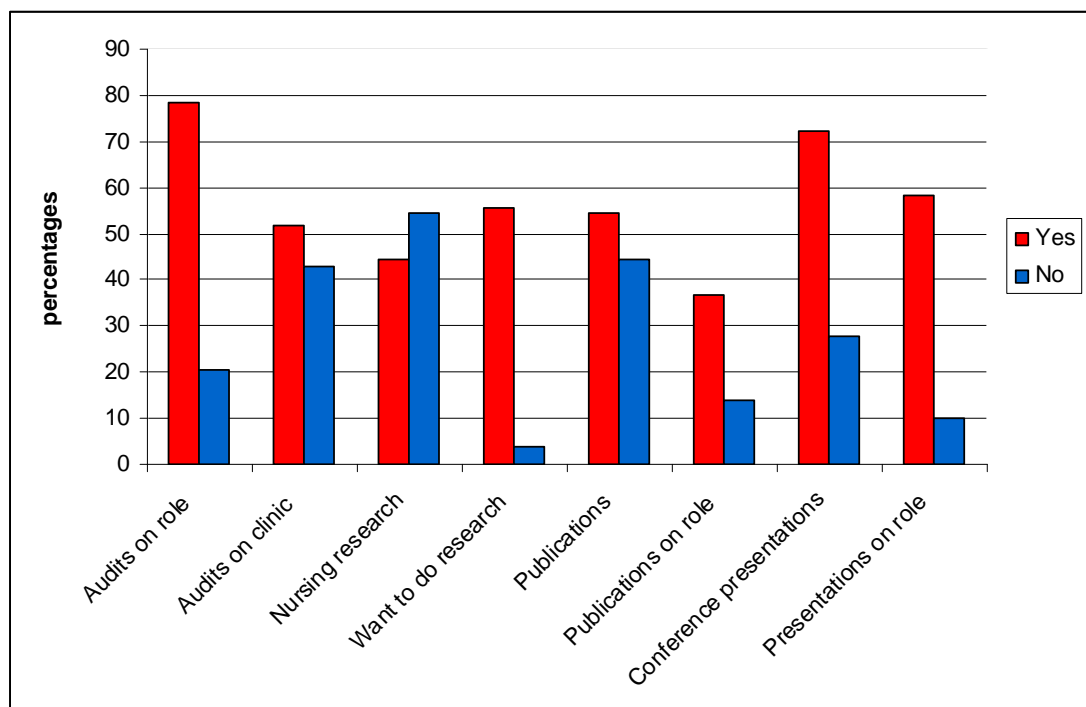


#### 4.2.8.2 *Developmental aspects undertaken*

Although many nurses reported that they had responsibilities for the above aspects of their role, not all of them had achieved this in practice. For example, 96% of nurses reported that they had additional responsibilities for audit, but only 62, (78.5%) had actually undertaken an audit on their role, and 41 (51.9%) had audited their nurse-led clinic. Similarly 71% reported they had responsibilities for research, however only 35 (44.3%) had actually undertaken any nursing research, although 44 (55.7%) wished to do so.

43 (54.4%) nurses had a written publication, with one in progress, and 29 (67.4%) of these were in relation to their current role. Similarly, 57 (72.2%) nurses had presented at conferences and 46 (80.7%) of the presentations were in relation to their role. This is illustrated in figure 4.13:

**Figure 4.13** *Other aspects of nurses' roles*



#### 4.2.8.3 *Additional aspects of role: differences between groups*

Involvement in teaching, staff development, audits and writing guidelines is high across all groups of nurses, however managerial and research is variable. Advanced nurse practitioners have little managerial responsibilities (n=1, 20%), in contrast to all lead nurses. Involvement in research ranged from one of the nurse practitioners to all of the nurse consultants (see tables 4.21 and 4.22).

The following legend aims to clarify abbreviations used in tables 4.21 and 4.22:

<b>Nurse title</b>	<b>Abbreviation</b>
Clinical Nurse Specialist	CNS
Nurse Practitioner	NP
Advanced Nurse Practitioner	ANP
Nurse Consultant	NC
Lead Nurse	LN
Chemotherapy Nurse	CN

**Table 4.21** *Additional responsibilities across the groups*

	<b>Teaching</b> n (%)	<b>Staff</b> n (%)	<b>Manager</b> n (%)	<b>Audits</b> n (%)	<b>Research</b> n (%)	<b>Guidelines</b> n (%)
<b>CNS</b> (n=43)	43 (100.0)	39 (90.7)	27 (62.8)	41 (95.3)	27 (62.8)	40 (93.0)
<b>NP</b> (n=7)	7 (100.0)	6 (85.7)	5 (71.4)	6 (85.7)	6 (85.7)	6 (85.7)
<b>ANP</b> (n=5)	5 (100.0)	4 (80.0)	1 (20.0)	5 (100.0)	4 (80.0)	5 (100.0)
<b>NC</b> (n=9)	9 (100.0)	9 (100.0)	4 (44.4)	9 (100.0)	9 (100.0)	9 (100.0)
<b>LN</b> (n=8)	8 (100.0)	8 (100.0)	8 (100.0)	13(100.0)	8 (100.0)	7 (87.5)
<b>CN</b> (n=6)	6 (100.0)	6 (100.0)	4 (66.7)	6 (100.0)	3 (50.0)	5 (83.3)

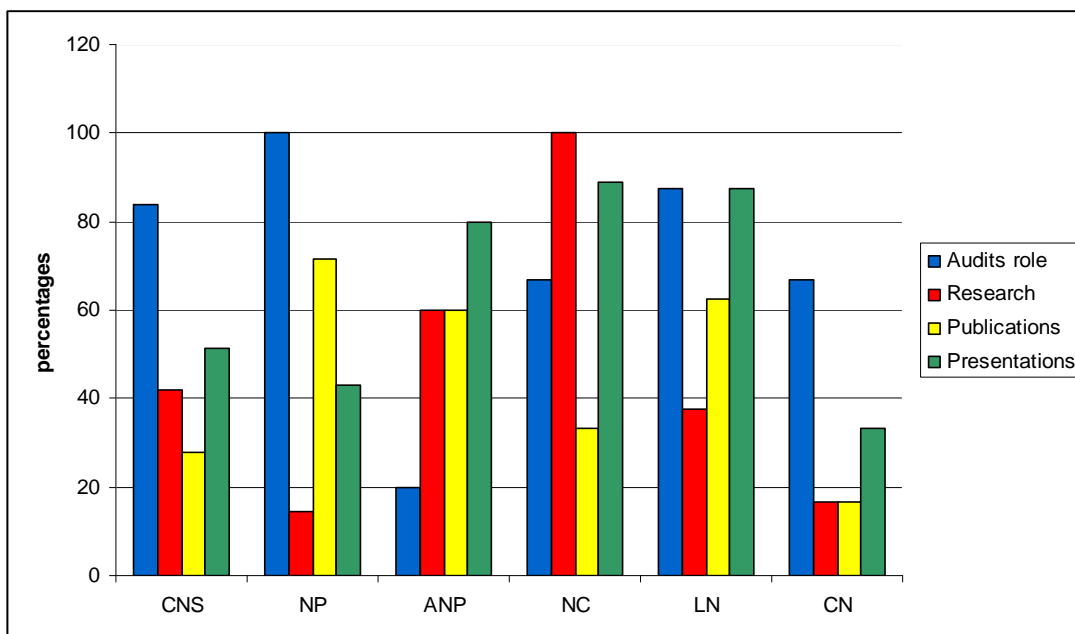
**Table 4.22** *Additional aspects of nurses' roles*

	<b>Audits of role</b> n= (%)	<b>Audits of clinic</b> n= (%)	<b>Undertaken research</b> n= (%)	<b>Publications on role</b> n= (%)	<b>Presentations on role</b> n= (%)
<b>CNS</b> (n=43)	36 (83.7)	24 (55.8)	18 (41.9)	12 (70.5)	22 (51.2)
<b>NP</b> (n=7)	7(100.0)	3 (42.9)	1 (14.3)	5(71.4)	3 (42.9)
<b>ANP</b> (n=5)	1 (20.0)	2 (40.0)	3 (60.0)	3 (60.0)	4 (80.0)
<b>N C</b> (n=9)	6 (66.7)	4 (44.4)	9 (100.0)	3 (33.3)	8 (88.9)
<b>LN</b> (n=13)	7 (87.5)	5 (38.5)	3 (37.5)	5 (62.5)	7 (87.5)
<b>CN</b> (n=6)	4 (66.7)	2 (33.3)	1 (16.7)	1 (16.7)	2 (33.3)

It is clear from the two tables above that nurse consultants conduct more nursing research than nurses in other groups. Nurse practitioners seem to struggle with aspects such as nursing research (n=1, 14.3%), despite 86% stating that their role included responsibilities for research. Nevertheless, many

nurses expressed a desire to undertake nursing research. It may be that some nurses struggle with certain aspects due to their heavy clinical commitments and time constraints.

**Figure 4.14 Aspects of role development**



In terms of responsibilities attached to their role, there were no significant differences between the groups in terms of teaching responsibilities, staff development ( $p=.613$ ), managerial responsibilities ( $p=.069$ ), audits ( $p=.660$ ), research ( $p=.132$ ) and developing guidelines ( $p=.766$ ).

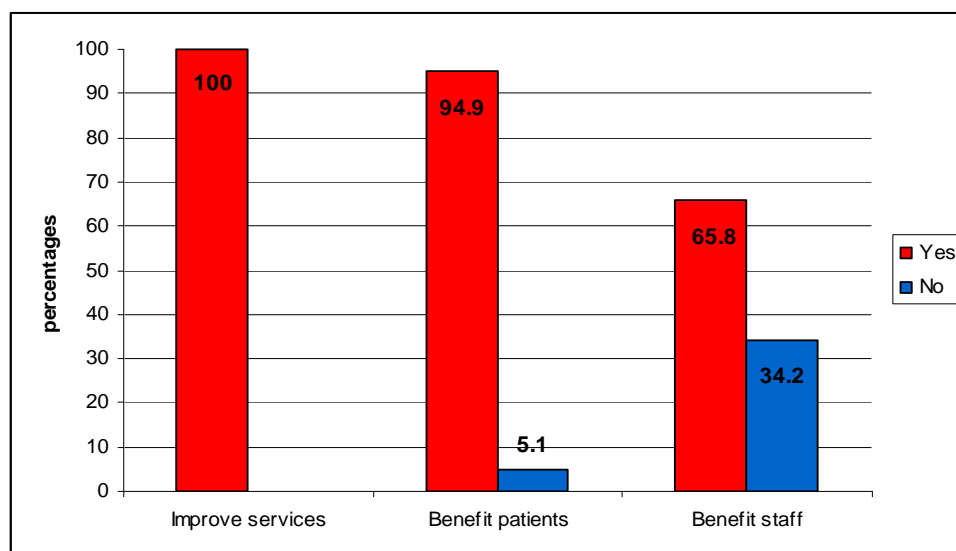
However, more specific aspects undertaken in relation to nurses' roles showed some differences between nurse groups. Whilst there was no difference in audits undertaken in relation to nurses' roles ( $p=.114$ ), there was a significant difference between the nurse groups in audits undertaken on their nurse-led clinics ( $\chi^2=16.175$  df 5  $p=.006$ ). There were also differences in the groups of nurses who had undertaken nursing research ( $\chi^2=16.294$  df 5  $p=.006$ ), had publications ( $\chi^2=17.935$  df 5  $p=.003$ ), and presented at a conference ( $\chi^2=12.051$  df 5  $p=.034$ ).

#### **4.2.8.4 Perceived benefits of nurse-led clinics**

Nurses were asked their perceptions regarding potential benefits of nurse-led clinics on three areas: to improve services, to benefit patients, and to benefit staff. Whilst all nurses perceived the clinics would improve clinical services,

34% considered that they would not benefit staff, and 5.1% that they would not benefit patients (see figure 4.15).

**Figure 4.15 Perceived benefits of nurse-led clinics (n=79)**



The following section contains data from the 12 nurses in the original sample (n=103) who wanted to set up nurse-led clinics.

#### **4.2.9 Nurses who wanted to set up nurse-led clinics (n=12)**

This section provides an overview of nurses who wanted to set up nurse-led clinics (n=12). .

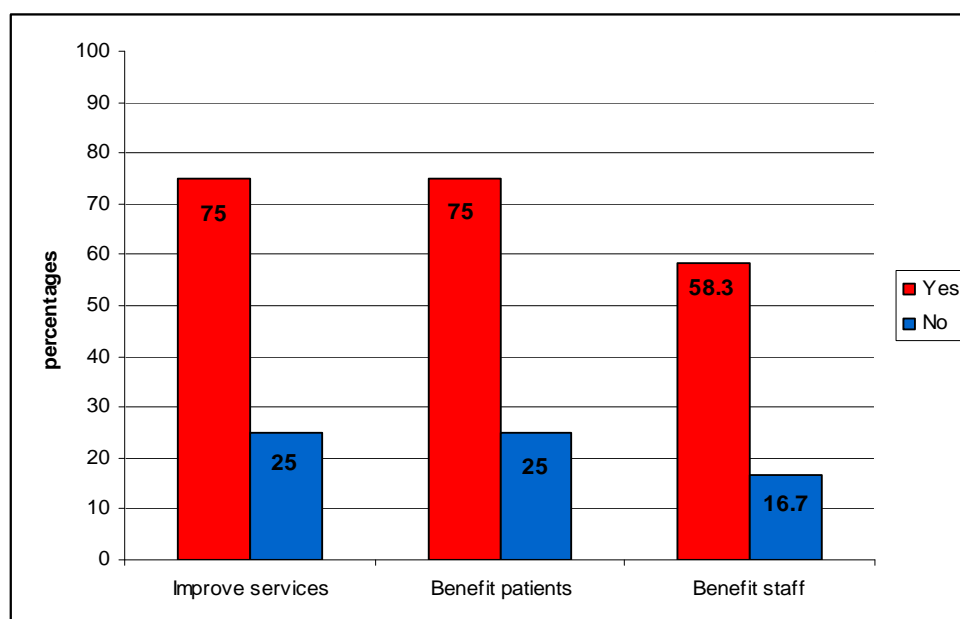
##### **4.2.9.1 Demographics**

Ages ranged from 32-50 (median 42 years), and nurses had spent 1-9 years in their current post (median 3 years). Five (41.7%) nurses were clinical nurse specialists, one (8.3%) nurse practitioner, two (16.7%) nurse consultants, two lead nurses and two chemotherapy nurses. The majority of nurses (n=6, 50%) were responsible for all types of cancer, whilst three (25%) saw patients with breast cancer, two (16.7%) lung cancer, and one (8.3%) colorectal cancer.

##### **4.2.9.2 Perceived benefits of nurse-led clinics**

Although the nurses wanted to set up nurse-led clinics, some nurses perceived less potential benefits to nurse-led clinics than nurses who were already undertaking nurse-led clinics (see figure 4.16).

**Figure 4.16 Perceived benefits of nurse-led clinics (n=12)**



#### **4.2.9.3 Time for patient care**

The time allocated for patients ranged from 25-75% (median 50%), which was less than time actually spent with patients (median 60%, range 25-95%). Whilst six (50%) considered the amount of time spent with patients was just right, three (25%) considered it was not enough, and a further three thought the time with patients was too much.

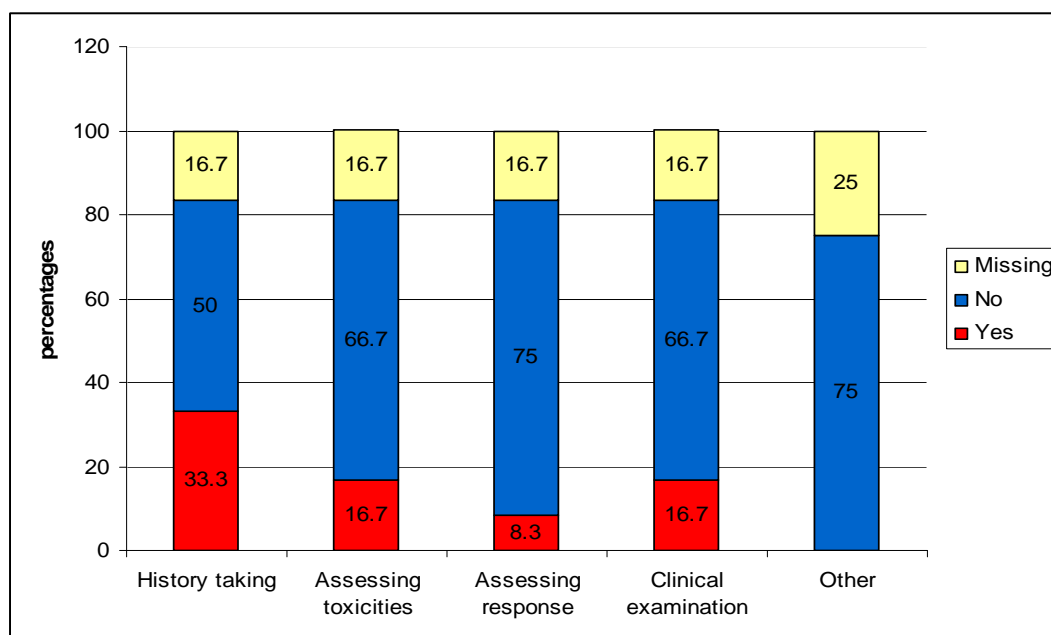
#### **4.2.9.4 Training and clinical skills**

Eight (66.7%) nurses reported that they had received specific training for their current role, and five (41.7%) had undertaken a Master's degree. However, only one nurse was an independent nurse prescriber. This clinical nurse specialist prescribed often; however did not prescribe chemotherapy.

Although four (33.3%) nurses had received formal training in clinical examination skills, only two (16.7%) undertook clinical examination. However, a greater proportion of nurses (n=6, 50%) reported that they undertook medical assessments (see figure 4.17)

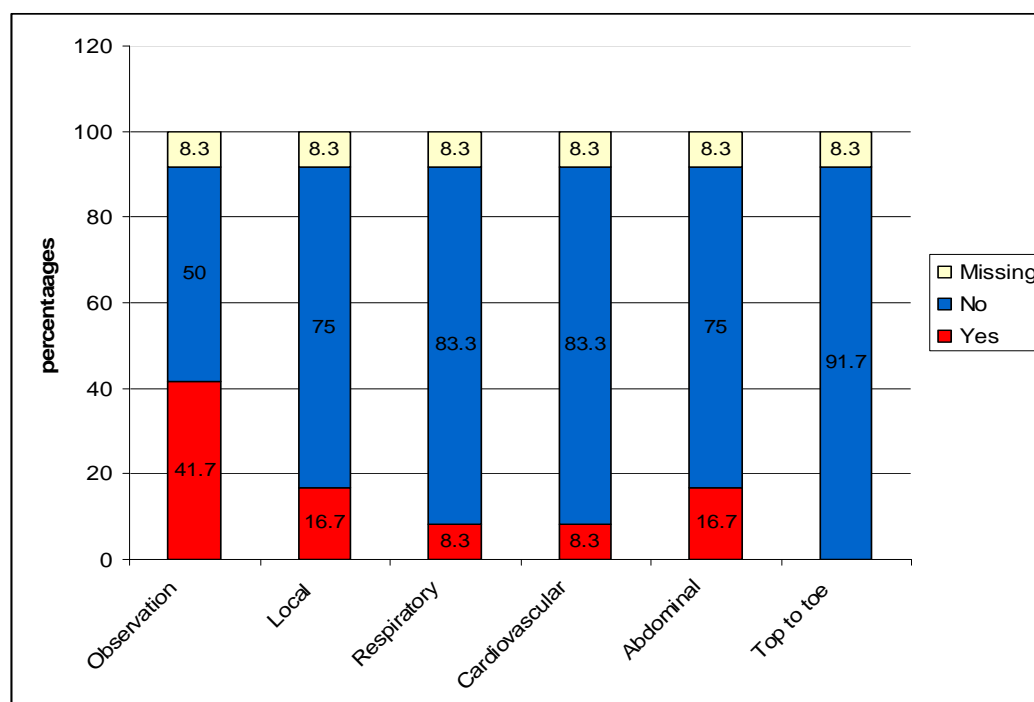


**Figure 4.17 Clinical skills**



In addition, four (33.3%) nurses reported that they undertook clinical examination skills as part of their role, however there were differences in the nature of examinations undertaken (see figure 4.18).

**Figure 4.18 Nature of clinical examination skills**



#### **4.2.9.5 Perceptions of role value and barriers**

Five (41.7) nurse perceived their role was highly valued by the multidisciplinary team, and a further six (50%) moderately valued. Only one nurse perceived the role to be occasionally valued by the MDT.

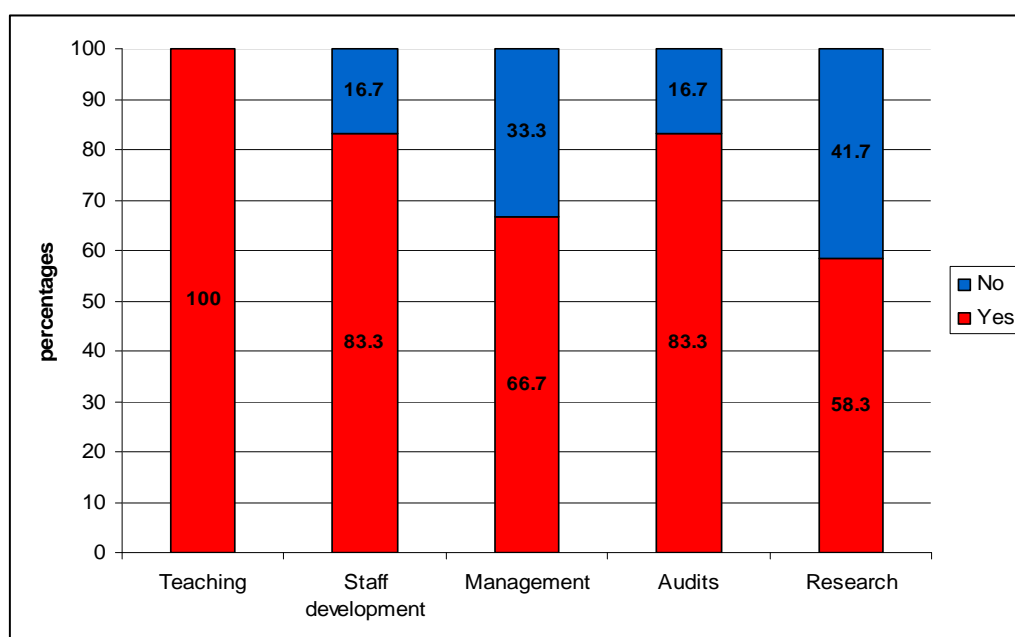
Four (33.3%) perceived their role to be fully autonomous, and a further two (16.7%) had significant autonomy. In contrast five (41.7) had some autonomy and one nurse had indirect supervision.

Nine (75%) nurses perceived that barriers limited their practice. Nurses did not consider any barriers from the nursing directorate, however five (41.7) came from the organisation, two (16.7%) from the medical directorate, and two (16.7%) from other sources, which included environmental and national factors. In addition, nurses also reported constraints in time and resources, which adversely affected their clinical practice.

#### **4.2.9.6 Additional responsibilities**

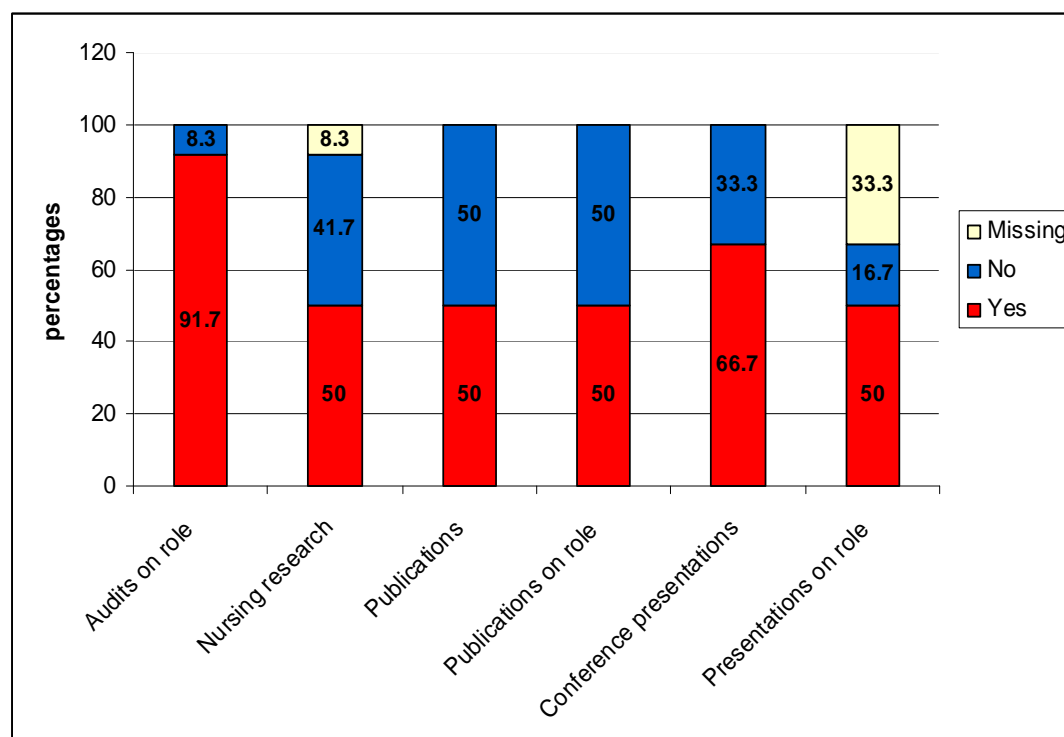
The twelve nurses who wanted to set up nurse-led clinics also had additional responsibilities within their role, similar to those who were already undertaking nurse-led clinics (see figure 4.19).

**Figure 4.2.19 Additional responsibilities**



Eleven nurses (91.7%) reported that they had undertaken audits on their current role; however this figure is actually higher than in the previous question, which suggests some misunderstanding. The seven nurses (58.3%) who reported involvement in research confirmed that they had undertaken nursing research. A summary of nurses' additional activities is shown in figure 4.20.

**Figure 4.20 Additional activities**



#### 4.2.10 Summary of results

Although 103 completed questionnaires were received, with an overall response rate of 64%, only 79 nurses were undertaking nurse-led clinics therefore the analysis was conducted on this group alone. There was a broad distribution of nurses across the UK, although small numbers in Scotland, Wales, Ireland and the Channel Isles. The majority of nurses were clinical nurse specialists (n=43, 54.4%), whilst the other main groups were nurse practitioners (n=7, 8.9%), advanced nurse practitioners (n=5, 6.3%), nurse consultants (n=9, 11.4%), lead nurses (n=8, 10.1%), and chemotherapy nurses (n=6, 7.6%). The main cancer group represented was breast cancer although there was a broad distribution across other cancer types.

The majority of nurses had received specific training to undertake their current role; however there was great variability in the nature of training and academic

education. In relation to the main aspects of nurses' roles, there were also differences across the groups of nurses. Clinical nurse specialists had the greatest variability within their role, although a large proportion of the role related to giving information and providing support. In addition, many clinical nurse specialists undertook certain practical tasks, procedures, and ran nurse-led clinics, however few could prescribe independently. There was some similarity with nurse practitioners in the scope of their role, although none of the nurse practitioners could prescribe. In contrast, the advanced nurse practitioner role centred mainly on clinical assessment, clinical management and making treatment decisions, and all were nurse prescribers; whereas the nurse consultant role had a much greater emphasis on research, education, service development and audit in addition to clinical leadership. It appeared that lead nurses had the greatest diversity of role, since some would have the 'lead' for a number of different services; in addition the lead nurse role could also include a combination of clinical, research, managerial and strategic elements. The chemotherapy nurses were responsible for chemotherapy administration, reviewing patients and running nurse-led clinics, although few nurses could prescribe independently and there was little emphasis on clinical examination skills.

From the whole group, almost a third of nurses were able to prescribe independently and did so frequently, although only 17% of nurse prescribers were prescribing chemotherapy. 46 (58.2%) nurses reported that doctors alone prescribed in the nurse-led clinics, which raises questions regarding operational practices and nurses' level of autonomy.

Although 93% of nurses in the survey reported that they undertook medical assessments there was a great disparity in the nature of assessments across the whole group, and statistically significant differences between the groups of nurses in relation to the nature of medical assessments undertaken. Similarly there was a great disparity in the range of clinical examination skills between the groups, although most nurses could undertake local examination. In addition, many nurses undertook additional medical assessments, investigations and practical procedures, such as endoscopies, biopsies, requesting and interpreting clinical investigations and screening.

Considering that the majority of nurses had extended their roles and taken on many of the traditional medical procedures and responsibilities, many nurses expressed mixed views about how valuable their role was perceived by the MDT. Although there were several reports of medical colleagues and managers that clearly appreciated nurses extending their role to meet targets and improve service delivery, some nurses expressed feelings of frustration and disillusionment at the lack of support and infrastructure to new / extended roles. In addition, some nurses also showed the financial pressure organisations have placed on them, by suggesting the nurse's role / service was too "expensive" and that nurses now have to "prove (their) worth". In several of the nurses' comments they emphasised the lack of understanding from members of the organisation, nursing colleagues and the medical directorate towards their role, particularly if the nurse had developed her role whilst remaining in the same post.

In terms of additional barriers that can limit clinical practice and/or develop nurse-led clinics, time and capacity were the greatest factors. However lack of resources and obstructions by medical staff and managers also featured highly. Financial implications featured strongly in this and appeared to add to nurses' frustrations.

67% of the nurse-led clinics were for routine follow up, and 33% were nurse-led chemotherapy clinics, although these tended to be run by advanced nurse practitioners and nurse practitioners. Many nurses ran nurse-led clinics independently from medical staff but some preferred to run nurse-led clinics alongside their medical colleagues for easy access to advice if needed. This was also an important consideration for nurses who were unable to prescribe, and also for nurses who did not have the practical support needed for nurse-led clinics, such as rooms, clinic nurses and clerical assistance. Again, several nurses expressed their frustration in relation to limited support, particularly in comparison with medical staff/clinics. This was often a barrier to setting up more nurse-led clinics or developing services.

Despite such difficulties, the majority of nurses perceived nurse-led clinics to have many benefits, such as improving hospital targets, improving medical management, improving patient care and continuity, and also benefits for

nurses themselves in terms of team working and good learning opportunities. However comments by one nurse warn that “*nurse-led clinics* [must not] *erode other components of care.*” This is an important statement with implications for nursing practice, which will be discussed further in the next section.

The final section of study 1 discusses the findings in relation to evidence from the literature review and additional literature outside the review.

## **Section three: Discussion of Study 1**

### **4.3.1 Introduction**

This chapter includes a discussion of the key issues within specialist nurses’ roles in oncology and nurse-led clinics, although emphasis is placed on nurse-led chemotherapy clinics. Throughout this chapter there is a discussion of relevant professional and national cancer policies, outlining the implications for clinical roles and specialist / advanced nursing practice in oncology.

### **4.3.2 Specialist nurses’ roles and advanced nursing practice**

Study 1 identifies a distinct lack of clarity between nurses’ titles and their roles and responsibilities. This reflects findings in the literature where developments in nurses’ roles have been ad hoc (Folland, 2000), with variability across the UK, in Europe and also worldwide differences (Bryant-Lukosius et al, 2004). Henderson (2006) explains that nurses’ training and professional role varies within and between countries, although nurses may have the same title. To address this, the International Council of Nurses set out the following definition for advanced nursing practice:

*"A registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice. A Master's degree is recommended for entry level."* (ICN, 2013)

Nevertheless, the lack of regulation in the UK regarding nurses’ titles, role development, competencies and responsibilities causes considerable confusion (Gardner et al, 2007). The Department of Health report that confusion about the scope of nurses’ roles and competence results from ‘advanced practice’ being

inconsistently applied to nurses' roles (DH, 2010c). However, the NMC (2012) has outlined that advanced nursing practice is an umbrella term to describe a number of specialist roles, which include specialist nurses and advanced nurse practitioners.

In study 1, elements of nurses' roles became clear from replies to questions within the survey, including free text response, although nurses' scope of clinical practice was not evident from their professional titles. The greatest confusion appears to be around nurse practitioner and advanced nurse practitioner roles, and the lack of protection for these nursing titles are associated with a lack of clearly defined competencies and responsibilities (NMC, 2005) despite government recommendations that the Nursing and Midwifery Council (NMC) should regulate advanced nursing practice (DH, 2010). Torn and McNichol (1998) discuss how the nurse practitioner title is misused, since many nurses are using the title without having formal qualifications to do so. A greater clarity for advanced nursing practice would help to safeguard nurses and generate greater confidence in their roles and professional practice, which would also provide greater understanding for patients and the general public.

However, the situation in the UK contrasts with the US where legislation and regulatory mechanisms provide protected titles for clinical nurse specialists and nurse practitioners (Bryant-Lukosius et al, 2004). Pulcini et al (2010) identified that 23 out of 32 countries reviewed had formal recognition of nurse practitioner and advanced nurse practitioner roles, and half of them required practitioners to undertake continued practice development in order to maintain or renew their licence. In addition, the authors report that support for advanced nursing roles came from domestic nursing organisations (92%), individual nurses (70%) and government (68%); whilst opposition to introducing advanced nursing roles came primarily from doctors (83%) and doctor organisations (67%) (Pulcini et al, 2010). This highlights tensions between medicine and nursing in relation to the expansion of nurses' roles.

In the survey from study 1, the majority of oncology specialist nurses had taken on many of the traditional medical responsibilities, such as clinical examination and clinical consultations. However there were significant differences in the

nature of nurses' clinical practice, including clinical examination skills and nurse prescribing. Disparities were greatest within clinical nurse specialist roles, where many specialist nurses had developed their role to take on additional clinical responsibilities and nurse-led clinics. Thorpe (1997) reports that some nurse practitioners have been employed specifically to undertake medical tasks, such as admitting and clerking patients, which may restrict a nursing focus of care. An ethnographic study of advanced nurse practitioners on hospital wards identified that other nurses perceived their roles to be more closely allied with medicine than nursing, although they were viewed as more approachable than doctors and had a positive impact on nursing practice (Williamson et al, 2012).

However, it is difficult to know from the survey how nurses' roles had changed, for example whether nurses had taken on 'medical responsibilities' in addition to their other commitments, or whether they had to reduce some of the 'supportive' elements of their role to do so. Mills and Pritchard (2004) highlight the difficulties of specialist nurses in maintaining their competency and continuing professional development. This is an important issue that has implications not only for patient care and clinical services, but also for the future of nursing practice, and will be discussed further in study 2.

The survey findings reflect current literature and government policies. Henderson (2006) argues that traditional roles for doctors, nurses and others are in question, which reinforces the uncertainty for nurses' roles and advanced practice. A position statement by the Department of Health describes levels of practice for nurses working at an advanced level (DH, 2010c), benchmarking 28 elements of advanced practice within the following four themes:

- Clinical/direct care practice
- Leadership and collaborative practice
- Improving quality and developing practice
- Developing self and others (DH, 2010c).

The themes identified in the position statement mirror the main areas of practice reported in the survey, however in the survey nurses' time is weighted towards clinical aspects of care.



Evidence from the literature supports the survey results in relation to the challenges of advanced nurse practitioner roles; some nurses reported that they did not feel part of the medical or nursing team and faced antagonism from colleagues (Williamson et al, 2012). This is similar to study 1 where nurses reported the rapid development of their roles and pressure from increasing clinical demands. As a result the necessary resources and infrastructure failed to keep pace, and this often left nurses feeling unsupported and frustrated. This is supported by evidence in the literature, which showed that insufficient administrative support and competing time demands within clinical practice were barriers to participation in research, education and leadership activities (McFadden and Miller, 1994; Irvine et al, 2000; Sidani et al, 2000).

This illustrates the difficult situation for senior oncology nurses in trying to meet clinical commitments as well as other responsibilities of their role, which may create dilemmas regarding role development. There is some evidence within the survey that resources and infrastructure may be provided for new roles at the outset; however this does not appear to be the case for nurses who expand their current role over time. This has implications for nurses within the current financial climate where resources for nurses and nurse-led clinics may have a low priority in comparison to medical staff.

#### **4.3.3 Multi-disciplinary team functioning**

This survey illustrated that nurses' face increasing pressures in terms of their workload and clinical commitments, although there was a large range in the time nurses perceived they spent with patients, from 25 to 100% of their time. There were similar disparities between the time allocated within nurses' job plans, and the time nurses actually spent with patients. Half the participants felt either too much or too little time was spent with patients, which has implications for nurses and their managers when developing services. Furthermore, if nurses feel overburdened by clinical demands this may leave insufficient time to undertake other aspects of their role, such as research, education, and audit. Emphasis on clinical work is illustrated in the findings of study 1 and also reflected in the literature. Role overload is said to occur where there are competing, excessive and unexpected role demands; in addition a lack of

administrative and practical support may have an adverse effect on developing research and new nursing knowledge (Bryant-Lukosius et al, 2004).

Furthermore, a survey of 758 members of the Royal College of Nursing (RCN) in 2005 found that nurses in advanced roles spent approximately 60% of their time in clinical activities, 17% on education, 14% on management activity and 4% on research (Ball, 2005). Although the RCN survey was not specific to oncology nurses, the findings reflect those of study 1 in relation to key areas of activities and responsibilities between groups of nurses, such as clinical nurse specialists, nurse practitioners and advanced nurse practitioners (Ball, 2005).

In study 1, although many nurses reported that their role was valued by the multidisciplinary team, other nurses' perceptions appeared to change over time. Some nurse reported that they no longer felt valued and that colleagues failed to understand their role. Evidence from the literature shows a similar lack of understanding in relation to clinical nurse specialists (Mills and Pritchard, 2004), nurse consultants' roles (Kennedy et al, 2011), nurse practitioners (Torn and McNichol, 1998), and advanced nurse practitioners (Williamson et al, 2012). Whilst there is some definition for the role of nurse consultants in the UK, the role is less clearly defined in Australia, where the role reflects that of a clinical nurse specialist in the UK; there is also a lack of recognition for nurse consultant roles in the USA (Kennedy et al, 2011), therefore comparison of international roles may not be appropriate. However, two systematic reviews of nurse consultant roles showed little impact of their roles in the UK (Kennedy et al, 2011; Humphries et al, 2005). There was no evaluation of the 'added value' and cost-effectiveness of nurse consultants (Humphries et al, 2005), and none of the included studies considered the cost-effectiveness of nurse consultants (Kennedy et al, 2011).

The survey in study 1 suggested tensions between nurses and medical staff, which reflected evidence in the literature. Advanced nurse practitioners reported that they did not feel part of the medical or nursing team and also faced antagonism from colleagues (Williamson et al, 2012). This may lead to frustration and disillusionment, if nurses perceive their role is devalued, which may adversely affect communication and the dynamics within a multidisciplinary team. In one study British and Australian nurses were dissatisfied with their

professional status and perceived that the general public understood and accepted the medical profession more than nurses (Adamson and Kenny, 1995).

The idea of role conflict within the survey reveals greater complexities. Nurses perceived that a range of barriers restricted their practice, including time, training, support, infrastructure and lack of resources. However, there was variability regarding the perceived barriers; some nurses perceived this came from medical staff who failed to recognise their role and obstructed developments in nurse-led services. In contrast, other nurses reported that managerial barriers came from financial implications of role development and nurse-led clinics. This highlights the uncertainties and vulnerabilities within nurses' roles and nurse-led clinics, whereby several factors could destabilise their position and the sustainability of nurse-led clinics. Changes in attitudes over time suggest that developments to nurses' roles may become taken for granted by medical staff, leading to a decrease in appreciation and perceived value of nurses.

Historically there has been conflict between medicine and nurses, which may influence current issues. In an ethnographic study where nurses recounted their experiences of nursing in the 1920s and 1930s, nurses spoke of how their relationship with hospital doctors influenced their progress and gave them '*special status*' over other nurses (Keddy et al, 1986). This involved respect and obedience in carrying out the doctors' orders, which was perceived as good nursing care (Kalish and Kalish, 1977), and relied on nurses being subservient to doctors and not challenging their decisions. The patterns of interactions between nurses and doctors are described as the 'doctor-nurse game' where nurses learn covert strategies of decision-making in the way they offer advice to doctors (Keddy et al, 1986; Stein, 1967). However there are suggestions that this power game may result in poor communication and conflict due to the lack of openness in communication (Keddy et al, 1986; Sweet and Norman, 1995).

In addition, when staff are involved in conflict at work this has been shown to have a negative effect on their performance and effectiveness (Jehn, 1997). In addition, long term exposure to a hostile work environment is recognised as a major source of stress resulting in adverse effects on a person's health

(Hockley, 2002). In contrast, a positive work environment has been shown to influence patient satisfaction and outcomes (Kangas et al, 1999). Kilman and Thomas (1997) identify five ways of managing conflict in the workplace: competing, avoiding, accommodating, compromising and collaborating. An Australian study revealed problems with intra-professional relationships between nurses, which were mainly managed by avoidance strategies, and many nurses developed resilience to the workplace conflict (Duddle and Boughton, 2007).

There are certainly tensions between government policy, clinical demands and nurses' roles where nurses seem to be pulled in different directions, which highlights their flexibility but also exacerbates their vulnerability. For example, the Cancer Reform Strategy (2007) recommends greater flexibility within the NHS and innovative ways of working to benefit patients, which opens an important pathway for nurse-led clinics and new models of clinical practice. However, despite this recognition, cost-cutting exercises have reduced some specialist nursing posts (Sullivan and Elliot, 2007; Kelly and Trevatt, 2006), which creates vulnerability amongst specialist nurses (Kelly and Trevatt, 2006). This is also seen within the findings from study 1, where nurses reported future uncertainties regarding their roles. Despite placing clinical nurse specialists at the forefront of modernising healthcare, playing a crucial role in improving the quality of cancer care and being an essential part of the MDT, Sullivan and Elliott (2007) warn of the danger that the role of the CNS may be seen as a luxury.

#### **4.3.4 Training and extending nurses' roles**

The findings of study 1 showed considerable variability in training and academic qualifications between the groups of nurses; however university qualifications may be under reported due to the question wording in the survey. Whilst some hospitals in the UK may place mandatory educational requirements for advanced practice roles, including clinical nurse specialist, nurse practitioner and nurse consultant (Hopwood, 2006), this is not a national requirement in the UK. The findings from study 1 are supported by evidence in the literature, identifying disparate levels of training and lack of clarity in nurses' roles (Torn and McNichol, 1998; Lloyd-Jones, 2005; Williamson et al, 2012).

In study 1, clinical skills training for clinical nurse specialists and nurse practitioners were primarily 'in house' and ad hoc, with no formal structure; similar disparities in clinical skills training were evident for nurse consultants, lead nurses and chemotherapy nurses. However, the mandatory requirement for advanced nurse practitioners / nurse clinicians in the UK to undertake clinical skills training within an MSc in advanced nursing practice provides some standardisation and regulation of roles, although the titles remain unprotected. Evidence in the literature supports the findings that advanced nurse practitioners receive clinical training at masters' level (Williamson et al, 2012), whilst training disparities created a lack of role recognition for nurse practitioners (Torn and McNichol, 1998). Where clinical examination skills' training is not undertaken as part of a university accredited course, there is a lack of standardisation in training and assessments of competency. This is an important issue for nurses since nurses' skills may not be recognised outside their own organisation, which may cause problems when moving to a different hospital trust. Extending nurses' roles in this way also has implications for patients and colleagues, since it creates a lack of clarity and understanding regarding the nurse's role and scope of clinical practice. These issues highlight that greater transparency is needed for advanced nursing practice, including a competency framework for role development, and on-going training and appraisals of clinical practice.

The survey also illustrated great disparities in the frequency and nature of clinical examinations undertaken by nurses. 55 (70%) nurses undertook clinical examinations within their practice, although only 46 (58%) had received formal training in clinical examination skills. However there was no scope in the survey to explore this further in order to understand this disparity. Therefore it is not clear what range of skills was necessary for each nurse's role and nurse-led clinic, and why some nurses failed to use their clinical examination skills after training. However, this is an important issue, given the time required for training, and the implications for clinical practice and service delivery. There is some evidence in the literature regarding maintaining clinical competency after nurses' initial clinical skills' training; Mills and Pritchard (2004) highlight the difficulties that can arise when nurses in extended roles may not be carrying out enough procedures to maintain their skills. Furthermore the authors identify

issues of maintaining competencies and meeting demands for professional development (Mills and Pritchard, 2004).

Whilst one could speculate that monitoring on-going training is unnecessary since this is not a requirement of medical staff, it does raise concerns if nurses are not using their skills after training, or using them infrequently. This contrasts with intravenous skills' training, where there is a more rigorous and clearly defined competency framework for training and on-going assessments. The introduction of *The NHS Knowledge and Skills Framework* (DH, 2004) can provide a framework for continuing development (Mills and Pritchard, 2004). However, the vast amount of detail within each domain of the framework, the necessity for cross-referencing across the domains, and areas of repetition, makes this process unwieldy.

However further exploration of these complex issues are beyond the scope of this survey, which suggests that a more in-depth study is required to provide deeper understanding of nurses' roles, including implications for clinical practice within nurse-led clinics.

#### **4.3.5 Developing nurse-led clinics**

The development of nurse-led clinics within oncology has helped to streamline service delivery by meeting targets for new patients and starting anti-cancer therapy (Mills, 2005; Cox et al, 2006), as well as reducing waiting times for outpatient visits during treatment and follow up (Anderson, 2010; Wells et al, 2008; Strand et al, 2011; Gulzar et al, 2007; Booker et al, 2004). There has been a rapid increase in nurse-led follow up clinics, which is reflected in the findings from this survey where 67% of nurses were undertaking nurse-led follow-up, in comparison to 33% of nurse-led chemotherapy clinics, and 7.5% nurse-led radiotherapy clinics. However, there was considerable variability within nurse-led initiatives in relation to the nature of clinics / services, nurses' clinical skills and aspects of autonomy. The findings also revealed a wide variation in the number of patients per clinic and duration of consultations. This variability is important since it identifies implications for clinical services and staff resources given the current economic climate and changes to NHS commissioning. It also raises questions about sustainability, particularly where

patient numbers are consistently small, and further research into this seems warranted.

One explanation for the increased prevalence of nurse-led follow-up clinics may be because the clinical management of patients on routine follow-up is more straightforward than patients who receive chemotherapy or radiotherapy treatment. Patients on follow-up require less input from medical staff and prescribing is infrequent, which increases nurses' independence. In contrast, patients receiving chemotherapy or radiotherapy are more likely to have medical problems during treatment that are beyond the scope of some specialist nurses; clinical decision-making is more complex, and a higher level of clinical skills is often required.

This is illustrated in the findings from study 1 where 62 (78.5%) nurses ran their nurse-led clinics independently from doctors, although a large proportion of patients attending nurse-led clinics also had regular appointments in medical clinics. In addition, doctors alone prescribed in 46 (58.2%) nurse-led clinics, which raise questions regarding the independence of nurses within many nurse-led clinics. The findings from study 1 also suggest the possibility of tensions between medical and nursing staff in relation to nurses extending their role and also nurse-led clinics. One of the main barriers to developing more nurse-led clinics was considered to be the reluctance of medical staff to relinquish part of their role, which shows concordance with the literature regarding nurse-doctor relationships.

Conflict between doctors and nurses have existed for over eighty years, where the status and power of the medical profession have influenced the professional development of nursing (Keddy et al, 1986). Historians suggest that this began with Florence Nightingale, where doctors were responsible for allocating tasks to the nurses and *"had the power to either prove or disprove nursing's worth"* (Keddy et al, 1986 p746). The authors propose that worthiness of nurses was equated with helpfulness to the doctors; nurses depended on doctors for approval which gave doctors power and control over nurses (Keddy et al, 1986).

The sociological analysis of the doctor-nurse relationship is of a patriarchal relationship which reflects the stereotypical differences in gender roles and divisions of labour (Sweet and Norman, 1995). This casts women as passive

and dependent, and suggests that nursing is subordinate to medicine (Darbyshire, 1987). However recent studies suggest improvements over time with nurse-doctor relationships (Stein et al, 1990), and where junior doctors relied on senior nurses for advice, although the 'doctor-nurse game' may still occur between nurses and medical consultants (Hughes, 1988; Sweet and Norman, 1995).

Nevertheless, doctor-nurse relationships have changed over time, with an increase in nurses' autonomy and involvement in clinical decision-making (Porter, 1991; Stein et al, 1990). This goes some way to explain current tensions between the professions with the expansion of nurses' roles, and Keddy et al (1986) propose that this may threaten the medical profession since it represents a loss of power and status. This warrants further investigation to understand more about professional boundaries and the potential influences of professional interactions and relationships on nurse-led clinics, which will be explored further in study 2.

Although some nurses have developed chemotherapy nurse-led services, this appears to be ad hoc in terms of the assessment and clinical management of patients, chemotherapy administration and non-medical prescribing. Research into nurse-led chemotherapy clinics has been minimal (Fitzsimmons et al., 2005), which makes it difficult to assess how such clinics operate and what impact they have made. It was impossible to gauge operational elements of nurse-led clinics within the scope of this survey, particularly in relation to chemotherapy clinics, given the variability of prescribing and clinical skills training. In addition, there was little evidence of formal evaluation; therefore it is difficult to measure the impact of such services. Given UK government recommendations for new ways of working and moving chemotherapy services closer to home, it seems important to undertake further work in this area.

#### **4.3.6 Independent nurse prescribing**

Despite recommendations in the UK NHS Cancer Plan (DH, 2000a) that most nurses would be able to prescribe by 2004, only 26 (33%) nurses in study 1 were non-medical prescribers, and were able to prescribe independently within nurse-led clinics. However, a national survey of over 1500 nurse prescribers showed that only 11% were independent prescribers and only half of these



were using their prescribing skills in clinical practice (Ryan-Woolley et al, 2007). However it should be noted that this survey was undertaken in 2004-2005, prior to the changes in legislation that greatly increased the range of medicines that oncology specialist nurses can prescribe independently (DH, 2006).

Although little prescribing is necessary during routine follow-up, an inability to prescribe could limit nurses' autonomy within some nurse-led clinics, and this may explain why few nurse-led chemotherapy clinics were undertaken during study 1. A number of nurses who ran nurse-led clinics, and were not able to prescribe, set up their clinic parallel to medical colleagues to overcome this. Aston et al. (2007) highlight the difficulties in nurse-led clinics when nurses were unable to prescribe independently, which caused frustration for staff and delays for patients. The survey of study 1 also showed that the range of medication prescribed by nurses was also limited; supportive medication was most frequently prescribed (n=22, 28%), and only 13 (16.5%) nurses within this sample prescribed chemotherapy. In addition, some nurses reported that they had completed the nurse prescribing course but did not prescribe independently following the course. Reasons for this were beyond the scope of the survey, but raise important questions regarding training needs for some roles and utilisation of clinical skills. This warrants further exploration given the time and resources invested in nurse prescribing training, which will be addressed in study 2.

Comparing nurse-led and medical management is not straightforward, often due to differences in approach and philosophy. Studies in the US highlight that advanced practice nurses' roles emphasise a model of doctor-nurse substitution rather than a patient-centred or holistic approach (Mundinger, 1999; Cameron and Masterson, 2000; Irvine et al, 2000). In a survey of hospitals in Canada, 46% of advanced practice nurse roles were developed to provide a replacement for doctors, and less than 21% were set up in response to health needs (Dunn and Nicklin, 1995). However, there is some evidence that the added value of advanced practice roles may extend beyond the transfer of medical skills and functions (Bryant-Lukosius, 2004), with increased patient satisfaction, education and communication (Brown and Grimes, 1995; Horrocks et al, 2002). It was not possible to explore such factors within this survey, although the survey did provide current information on different components of nurses' roles and nature of nurse-led clinics, which was not readily available in the literature at the time.

Few nurses in study 1 had undertaken research or audit to evaluate their roles or nurse-led clinics, and this is reflected in the current literature. Evaluating the impact of nurse-led approaches on patient care is important to determine whether outcomes are being improved (Cullum, 1995). Castledine (1995) warned that nurse developments should represent holistic care rather than merely substitution for medical tasks or a doctor's role; however it is difficult to gauge this from the survey results. Such issues are complex and further research is required to explore differences in nurses' roles and their impact on patient care. Loftus and Weston (2001) suggest the primary aim of advanced nursing practice and nurse-led services should be to improve the quality of life for patients, rather than becoming a stop-gap for doctor shortages. It does seem important to prioritise patients' needs when developing new services, and include consideration of the aims and outcomes of nurse-led service developments, together with a strategy for measuring and evaluating clinical services over time.

#### **4.3.7 Implications for clinical practice**

Crossing boundaries by taking on medical responsibilities is often difficult for nurses, even with support of medical colleagues and managers. Barton et al (2012a) describe specialist nurses as the first product of the evolution of nursing, where the foundations of advanced nursing practice were set in the US. However the introduction of nurse practitioners was more controversial and challenging since it affected the relationship of nursing to other professions (Barton et al, 2012a). There were subtle examples of this within the survey findings, which suggest that when nurses expand their clinical roles some doctors may feel that nurses are 'treading on their toes;' in addition, other nurses may feel threatened when the roles of their colleagues change. This will be explored further in study 2.

Nevertheless, there is some evidence in the literature highlighting how nurses' roles are changing and the impact this may have on others. An ethnographic study of advanced nurse practitioners highlights their role in teaching junior medical and nursing staff, which is seen to promote advanced nurse practitioners as role models for both professions (Williamson et al, 2012). However, also shows how the role of advanced nurse practitioners may de-skill

ward nurses by reducing their use of analytical skills, particularly when time is limited (Williamson et al, 2012).

Managers may also face difficulties when nurses expand their existing role if nurses' scope of practice and job description is not well-defined (Torn and McNichol, 1998); therefore clear lines of communication seem vital. Furthermore, since the majority of new cancer nursing roles have developed with little evidence of evaluation, it seems difficult to appreciate their impact and effectiveness on patients and cancer service delivery, and this may lead hospital managers to question their value.

Endorsement of nurse-led chemotherapy by the National Chemotherapy Advisory Group (NCAG, 2009) is an important landmark for oncology nursing, although it represents significant challenges for nurses themselves to deliver quality and safety improvements. Given the ad hoc developments and different models of nurse-led services it is difficult to determine their clinical impact and effectiveness, unless objective evaluation is undertaken.

The term 'nurse-led' is open to interpretation and the findings from study 1 highlight great disparities in nurses' scope of clinical practice, autonomy and responsibilities. However, outside the UK there are also crucial differences regarding role developments, nurse prescribing and delivery of cancer services (Bryant-Lukosius et al, 2004). Nevertheless, irrespective of such individual differences, specialist oncology nurses throughout Europe appear to face considerable challenges in meeting patients' needs, sustaining high quality care and clinical services whilst addressing their own educational needs and role developments.

With the current emphasis on survivorship and changes in follow up care provision, specialist nurses can play a key role in improving patients' experiences, their quality of life, psycho-social well-being and communication as well as cancer surveillance. The development and standardisation of advanced roles and associated educational preparation is important when taking forward the survivorship agenda and developing appropriate pathways for follow up care given the current shift to nurse-led follow up in many areas. Nurses are in a prime position to provide holistic assessments, continuity and ease of access

whilst tailoring follow up care to each individual, and this seems an important consideration given the current drive in the UK of moving cancer care away from tertiary centres into primary care and closer to home for patients.

#### **4.3.8 Summary**

The findings from Study 1 addressed the aims and objectives and answered the research questions, providing some additional information about different components of nurses' roles and nurse-led oncology clinics in the UK. This included the range of nurse-led clinics in oncology / chemotherapy, training undertaken for nurses' roles, perceptions of the multidisciplinary team for nurse-led clinics, and evaluations undertaken by nurses.

From the survey findings, nurses perceived that nurse-led clinics have several benefits, although these seemed weighted towards service needs, such as improving hospital targets and medical management, rather than patient needs. Benefits for nurses themselves were also identified, such as team working and good learning opportunities. However a word of caution from one nurse suggested that *"nurse-led clinics [must not] erode other components of care."* This seems an important comment, since it suggests that nurse-led developments may change the direction and priorities for nurses to the detriment of 'care', which is also reflected in the literature (Bryant-Lukosius et al, 2004; Henderson, 2006).

The literature review and findings from study 1 highlighted current gaps in knowledge and understanding of nurses' roles in nurse-led clinics. One of the greatest gaps was in relation to nurse-led chemotherapy clinics, which had recently started to develop after encouragement from cancer policy, although without appropriate research evidence. However, research evidence is limited in relation to chemotherapy services, and no studies to date have focused on nurse-led chemotherapy clinics. This raises some important questions about nurses' roles and nurse-led chemotherapy clinics in relation to how they operate in practice, nurses' roles and responsibilities within the clinics, and the nature of nurses' interactions with patients and their families. Therefore study 2 will focus more in-depth on nurse-led chemotherapy clinics, aiming to explore these gaps in understanding nurses' roles within nurse-led chemotherapy clinics.

The following aims and objectives, including research questions have been identified from issues raised in study 1 and current gaps in evidence from the literature.

#### **4.3.9 Study 2: Aims and objectives**

Study 2 aims to address the following aims and objectives, and answer the following research questions for nurse-led chemotherapy clinics.

##### **Aims and objectives:**

- To understand nurses' perspectives on the rationale for setting up nurse-led chemotherapy clinics
- To understand the nature of nurses' roles within nurse-led clinics
- To understand issues of autonomy within nurse-led clinics
- To understand how nurses interact and communicate with patients who attend nurse-led clinics
- To understand how nurses interact and communicate with colleagues within nurse-led clinics

##### **Research questions**

1. What are nurses' roles within nurse-led chemotherapy clinics?
2. What factors affect nurses' autonomy within nurse-led clinics?
3. How do nurses communicate with patients within nurse-led clinics?
4. How do nurses communicate with colleagues within nurse-led clinics?

Study 2 is presented in the following chapter, which aims to increase understanding of nurses' roles within oncology by focusing more in-depth on nurses who undertake nurse-led chemotherapy clinics, using qualitative methods for data collection and analysis. The chapter is divided into three sections covering the methodology, findings and discussion of study 2, and begins with an outline of possible qualitative approaches that could be used for study 2.

## **Chapter Five**

## **Study 2**

## **Section one:       Methods for Study 2**

### **5.1.1 Introduction**

Building from the foundations of Study 1, which provided a general overview of nurses' roles and oncology nurse-led clinics, Study 2 aims to gain an in-depth understanding of nurses' roles within nurse-led chemotherapy clinics. The literature review identified a lack of research in this area, despite government recommendations for more nurse-led chemotherapy clinics. Study 1 identified a growing number of nurses in the UK undertaking nurse-led chemotherapy clinics, although there are disparities in nurses' roles and scope of practice, including nurse prescribing and clinical examination.

Although the findings from study 1 have provided information on certain aspects of nurses' roles and nurse-led clinics, it lacks the depth of understanding required to appreciate the complexity of nurse-led chemotherapy clinics. Therefore an interpretative approach seems essential, using qualitative methods for data collection and analysis. Other empirical approaches may be used; however they would not take into account the context and nurses' behaviour to the same extent as a qualitative study. Several interpretative approaches were considered, and this chapter will begin by discussing each in more detail to determine the most appropriate design for this study. Following this the methodological procedures are discussed.

### **5.1.2 Strategies in qualitative research**

Murphy et al (1998) argue that the strength of qualitative research is that it facilitates understanding of the data in its original context. This reinforces the need for an interpretative approach for this study, and the next step is deciding which strategy to use. There are four main strategies in qualitative research (Denzin and Lincoln, 1998):

- Grounded theory
- Symbolic interactionism
- Phenomenology
- Ethnography

The nature of these strategies are now discussed in more detail to determine which is the most appropriate to address the questions of study 2.

### **5.1.2.1      *Grounded theory***

The grounded theory approach is concerned with discovering the meaning of events for individuals based on social processes and interactions (Backman and Kyngas 1999). This proposes that as people move from one situation to another there is a continual process that involves making interpretations about their actions and interactions (Eaves 2001). The underlying belief is that all researchers have the capacity to generate theory, and that theoretical perspectives should be 'grounded' in the empirical world (Grbich 1999). A grounded theory approach builds the data inductively then tests it in successive cases to establish whether the new pattern matches that found earlier (Glaser 1978 cited in Denzin and Lincoln 1998 p195). In principle a grounded theory approach could develop theory and new knowledge about nurses' roles and nurse-led chemotherapy clinics. However, the researcher's pre-existing knowledge of the topic could compromise the implementation of this method during data collection and analysis.

### **5.1.2.2      *Symbolic interactionism***

Symbolic interactionism is based on three premises:

- humans act towards people or objects in their environment according to the meanings they hold for them
- meanings are derived from social interactions, or communication, with people (communication may be symbolic)
- meanings are established and modified through an interpretive process (Schwandt 1998 p233).

In symbolic interactionism it is crucial to enter the subject's world to see it from their perspective in terms of what information is processed and how it is interpreted. Researchers can then use the subject's *rich* descriptions to formulate an interpretation of their experience (Schwandt 1998). In symbolic interactionism, the premise is that people structure their world by their perceptions and interpretations, and this influences their behaviour (Blumer 1969). Underpinning symbolic interactionism is the assumption that people act according to the meaning they have placed on things, based on social interactions and interpretations (Benzies and Allen 2001). Although this



approach seems feasible for this study, an emphasis on the interpretation of meanings from social interactions / communication may exclude other important phenomena within nurse-led chemotherapy clinics.

### **5.1.2.3      *Phenomenology***

The pivotal concept in phenomenology is interpretation, with emphasis on subjectivity, maintaining the context and clarification of biases (Cohen et al 2000). The authors propose that phenomenology differs from other qualitative approaches because phenomenology asks about meaning and the interpretation of people's experiences, whereas grounded theorists study social processes and ethnographers aim to understand cultures and traditions (Cohen et al 2000). However, Priest (2002) argues that it is important to distinguish between Husserlian phenomenology, which is descriptive, and Heideggerian phenomenology, which is interpretive:

- Husserlian phenomenology (root of the direct approach) studies the essences of phenomena and people's reflections
- Heideggerian phenomenology (root of the indirect approach) is more concerned with how people interpret and obtain meaning from their world (Titchen and Hobson 2005).

Phenomenology is concerned with understanding a phenomenon and the surrounding world within its context, rather than just explaining it. (Sadala and Adorno, 2002, Cohen et al, 2000). Titchen and Hobson (2005) consider two approaches - direct and indirect:

- A direct approach would be to ask participants about their subjective experiences, make interpretations and present objective constructions from the findings. This incorporates a sense of the researcher 'being in the world' and having shared meanings, however does not incorporate background knowledge.
- An indirect approach acknowledges that the research comes from within a pre-cognitive background, which is used cognitively to inform data collection. This uses participants' subjective experiences to look for unspoken, shared background meanings, whilst the researcher becomes

immersed in the person's 'life-world' and observes, records and interprets what occurs. (Titchen and Hobson 2005).

Although a phenomenological approach will enable in-depth interviews with nurse participants, this does not include observations of nurses within nurse-led clinics, therefore findings are based solely on what nurses say they do with no understanding of what they actually do and important context might be lost.

#### **5.1.2.4      *Ethnography***

Ethnography incorporates a descriptive approach to studying people and their culture, also referred to as descriptive anthropology (Vidich and Lyman 1998). Ethnographic research has changed over time from historical descriptive studies towards a greater range of subject matter, although exploring social and cultural understanding remain the main tenets underpinning ethnography (Vidich and Lyman 1998). It is primarily concerned with studying people and their interpretations, normally utilising participant observation (Goldbart and Hustler 2005). Ethnographic research features the researcher as being detached from society to study others and understand social processes (Vidich and Lyman 1998). This contrasts with symbolic interactionism, which holds that people can only be understood by considering relationships to the self. Table 5.1 outlines the possible advantages and disadvantages of each approach for this study of nurse-led chemotherapy clinics.

**Table 5.1 Interpretative approaches**

Research approach	Rationale	Data collection methods	Advantages and disadvantages for this study
Grounded Theory	Explains social processes.	Interviews, observations, diaries	In-depth approach. Observations and interviews would be very useful to explore different aspects of nurses' roles and nurse-led clinics. However pre-existing knowledge may compromise this study design
Phenomenology	Investigates the nature of human experiences.	In-depth interviews	In-depth interviews would provide subjective information on nurses' roles and nurse-led clinics from nurse participants. However observing nurses in clinic would not be possible, and this seems crucial to objectively understanding nurses' roles within the clinics.
Symbolic interaction	Humans act towards things according to the meaning they have attached to them.	Interviews, observations	In-depth approach. Observations and interviews would be very useful to explore different aspects of nurses' roles and nurse-led clinics. However the researcher is integral to determining meaning of interactions, not objective, which may add bias
Ethnography	Is concerned with understanding cultures.	Observations, interviews, documents	Observations and interviews would be very useful to explore the complex components within nurses' roles and the cultural aspects of nurse-led clinics. However the researcher's role is objective. This also takes into account other factors, such as documentation, which is important for this study.

### **5.1.3 Choice of research method for this study**

Considering the different qualitative approaches, ethnography seems the most appropriate for study 2 to explore the complexities within nurses' roles and nurse-led chemotherapy clinics. Observation of nurse-led clinics is crucial to understand nurses' roles and interactions with patients and colleagues. A key advantage is the ability to observe nurses within their clinical environment, which enables increased understanding of the culture and context of nurse-led chemotherapy clinics, including operational aspects. This will provide valuable information that cannot be obtained from interviews alone. Building on the findings from the preliminary survey, this will add greater depth to understanding nurses' roles within nurse-led clinics in the UK. The principles of ethnography are apt to guide this study, considering the complex inter-related factors within such cancer services, and limited evidence from current literature.

The key principles of ethnography are explained with evidence from the literature to support its use for this study, and the methodological approaches and perspectives for the study design, data collection and analysis are discussed. This is in line with recommendations from the consolidated criteria for reporting qualitative research (COREQ) (Tong et al, 2007). The findings for Study 2 and discussion are reported in sections two and three.

Using an ethnographic framework facilitates the identification of key factors related to nurses' roles within nurse-led chemotherapy clinics, and potential impact for patients. The following sections explain how this is achieved.

### **5.1.4 Ethnography**

Ethnographic research is based on studying people in their own environment, within everyday contexts, to understand their experiences, therefore research takes place 'in the field' (Hammersley and Atkinson, 2007 p3).

Hammersley and Atkinson (1995) suggest that ethnography has two distinct characteristics:

- It focuses on understanding the participants' perspective
- It observes participants' activities in everyday life, rather than an artificial setting or personal accounts of behaviour.

Whilst ethnography encompasses a variety of research perspectives, the aim is to conduct research in the 'natural context', which takes into account the flaws and restrictions of the participants' lives (Serrant-Green, 2007), and being immersed in the setting in order to understand the activities and processes within it (Wolcott, 1995).

In order to understand a culture, ethnographers aim to capture the breadth of activities, behaviour, knowledge and beliefs of the group to understand the meaning of events for participants within the context of the setting (Roper and Shapira, 2000). This requires intensive face-to-face contact with the group over an extended time period, however there is no general rule regarding how much time to spend with participants (Roper and Shapira, 2000). However, Gagliari (1991) suggests that the amount of time required is determined by obtaining sufficient information to answer the research question and should cease when no new information is obtained (saturation).

#### **5.1.5 Ethnography in healthcare**

Ethnographers in clinical settings focus their inquiries on local settings and practices of individuals to address specific issues within healthcare (Kleinman, 1992). In nursing, ethnographic techniques are used to study aspects of nursing and healthcare (Roper and Shapira, 2000); and nursing practice is described as a rich environment for ethnographic research (Dreher and Heyes, 1993; Street, 1992).

Research questions are formulated prior to fieldwork and focused, therefore the research can be conducted in a shorter time, although retain the characteristics of traditional ethnographies (Roper and Shapira, 2000). However, although research questions may be formulated before fieldwork begins, they may change as the study progresses (Morse, 1991). Within this, careful attention is paid to the participants' "*emic*" view of the world, yet includes the "*etic*" insight into meanings behind participants' actions to understand "*why people do what they do or believe as they do*" (Roper and Shapira, 2000 p9).

Ethnography is widely used by nurse researchers since such approaches are considered to be well suited to issues of interest to nurses (Borbasi et al, 2005), given the parallels between nurses' clinical skills and ethnography (Roper and

Shapira, 2000). Nurses' clinical skills reflect the essential skills for observational research, such as careful listening, good interviewing, astute observation and simultaneous interpretation (Lipson, 1989). The transition of nurse to participant observer is also considered easier than for other social researchers (Bonner and Tolhurst, 2002; Borbasi et al, 2005). This suggests that observational methods of research are well suited to nurses.

Early examples of observational methods in healthcare include a sanatorium for patients with tuberculosis, which developed the concept of the 'patient career' as patients moved through treatment phases (Roth, 1963). Another observational study focused on surgeons to understand their decision-making for tonsillectomy (Bloor, 1976). A number of observational studies have also focused on accident and emergency departments, where staff categorised patients into 'good' or 'rubbish' (Jeffrey, 1979); focusing on receptionists' use of discretion when prioritising patients (Hughes, 1989); or the way that children were managed in the department (Dingwall and Murray, 1983). The way that staff labelled and categorised patients was embedded in the organisation so staff were unaware of it, therefore this would not have been picked up by interviews alone (Pope and Mays, 2006).

Observational studies have focused on specific areas of care, such as cardiac catheterisation (Hughes and Griffiths, 1997), and also sensitive areas of care, including care at home for people with dementia (Briggs et al, 2003). In addition, observational studies have been used to look at the day-to-day work of health professionals (Clarke and Bowling, 1990; Fox, 1988; Smith et al, 2003), hospital clerks (Pope, 1991), and hospital managers (Strong and Robinson, 1990). Specific to nursing, Gerrish (2000) observed nurses' practice to understand how they provided individualized care to patients, which also revealed the complexities within everyday nursing practice and the influence of factors outside nurses' control. Svensson (1996) observed negotiations between doctors and nurses, which demonstrated the importance of strategies of negotiation in managing flexible boundaries between health care staff. Similarly, observation of specialist cancer nurses identified nurses' concerns regarding building relationships with medical staff and developing 'medical language' was an integral part of this (Willard and Luker, 2007).

Observational methods can be advantageous where research focuses on understanding participants' roles, actions and behaviour, including structures and processes that underpin healthcare (Walshe et al, 2011). This has included observations of team meetings to understand how specialist nurses challenge medical practice and manage specialist and non-specialist boundaries in hospice and palliative care (Arber, 2007), whilst other observations in a similar setting demonstrated meetings were medically led and suggested that palliative care nurses needed to strengthen their role to influence decision-making and benefit patients (Eagle and deVries, 2005). An ethnographic study of older patients in three elderly care wards illustrated the problems and challenges for hospital staff in developing effective communication and good terminal care (Costello, 2001). This study showed that most nurses focused on physical care and identified a lack of 'emotional engagement' with patients (Costello, 2001), which demonstrates the importance of observational methods to understand nurses' behaviour in clinical practice and nurse-patient communication. Considering evidence of observational methods in a variety of different healthcare settings indicates the potential benefits that may be achieved from observing staff in their natural setting, which supports the use of ethnography for this research.

#### **5.1.6 Methods in ethnography**

The principal methods in ethnography are participant observation, interviewing and examination of relevant documents, and these three types of information are "*a natural triangulation of investigative approaches on the same phenomenon*", which are then interwoven to enable broad and deep understandings of participants in their own settings (Roper and Shapira, 2000 p13). Triangulation can enhance the validity of qualitative research, using more than one theoretical framework or method of analysis (Denzin, 1978; Pope and Mays, 2006). In ethnography triangulation is achieved by using the three methods of data collection: participant observation, interviewing and examining documents (Scrimshaw and Gleeson, 1992; Flick, 2007b), which validates each other and provides a total picture of the participants (Roper and Shapira, 2000; Angrosino, 2007). However, triangulation is considered more than just aggregating the data (Silverman, 1993), since data from each source must be

used to judge the validity of data from the other sources (Roper and Shapira, 2000).

The overarching design of study 2 is based on the principles of ethnography. Using multiple hospital sites in the UK where nurse-led chemotherapy clinics are undertaken, the study includes observations of nurses' roles within nurse-led clinics, interviews with nurse participants and studying documentation and protocols associated with the nurses' clinics. The addition of interviews will facilitate further discussion with nurse participants regarding their perceptions of the clinic, including clarifying aspects of their roles, which adds greater depth to the study. Studying documentation associated with the clinics will also provide additional information about operational aspects of the nurse-led clinics within each hospital organisation.

#### **5.1.6.1      *Methods of observation***

Observing what people do in clinical situations can increase the accuracy of information obtained from interviews, and since it is not simply based on participants' own perceptions of what they do this can validate interview data (Robson 2002). However there are several important considerations for researchers as observers, which include their roles, behaviour, interactions, and physical position during observations. The primary reason for observational methods is to check whether what people say they do is the same as what they actually do, however unstructured observation also illustrates the whole picture, capturing the context and processes, provides insight into interactions between people and the potential influence of the physical environment (Mulhall, 2003). There are two main methods of observation: structured and unstructured (Pretzlik, 1994) (table 5.2).



**Table 5.2**     *Types of observation*

Observation type	Description
Structured	<ul style="list-style-type: none"><li>• Aims to record physical and verbal behaviour using predetermined observation schedules to a checklist of behaviours (Mulhall, 2003; Booth et al, 2001).</li><li>• Structured observers aim to remain objective and separate preconceptions from data collection (Mulhall, 2003)</li><li>• Used extensively in psychology</li><li>• Used by some nurse researchers</li></ul>
Unstructured	<ul style="list-style-type: none"><li>• Aims to understand and interpret cultural behaviour</li><li>• Subjectivity is an integral part of field work and constructing ethnographic accounts (Borbasi et al, 2005)</li><li>• Stems from anthropology and sociology (Mulhall, 2003)</li><li>• Used by some nurse researchers (Merrell and Williams, 1994).</li><li>• The researcher may have some ideas what to observe, but may change over time during data collection (Mulhall, 2003)</li></ul>

Understanding the different roles of the observer in ethnographic fieldwork is important, since this influences the way the study is conducted, reflecting a continuum from complete participant to complete observer (Pope 2005). This results in different research roles depending on the degree of participation (Mulhall, 2003 p308) (table 5.3).

**Table 5.3**     *Researcher roles during observation*

Role	Description
Complete observer	<ul style="list-style-type: none"><li>• Maintains some distance</li><li>• No interaction</li><li>• Role is concealed</li></ul>
Observer as participant	<ul style="list-style-type: none"><li>• Undertakes intermittent observation alongside interviewing</li><li>• Role is known</li></ul>
Participant as observer	<ul style="list-style-type: none"><li>• Undertakes prolonged observation</li><li>• Involved in all central activities of the organisation</li><li>• Role is known</li></ul>
Complete participant	<ul style="list-style-type: none"><li>• Interacts within the social situation</li><li>• Role is concealed</li></ul>

The four levels are placed on a continuum, and most ethnographers move back and forth among the levels (Burgess, 1984b; Pope, 2005), although the majority of information is often collected during the role of participant-as-observer or

observer-as-participant (Roper and Shapira, 2000). The choice between covert and overt observation has implications regarding validity (Mulhall, 2003), for example, if people in covert studies become aware they are being observed this would adversely affect the validity (Turnock and Gibson, 2001).

This study relied on the researcher being a non-participant observer in order to objectively observe nurses' roles and interactions with patients and colleagues. A complete participant is not possible given the participants' knowledge of the researcher's clinical role and research interests from study 1; these issues also make a complete observer role very difficult to achieve. In addition, covert research would be unethical in healthcare settings, since vulnerable patients may be observed without their consent. As a researcher, the aim is to achieve more formal observation with little interaction with nurse participants. However, maintaining a dual role as participant and researcher can be difficult at times since boundaries between the two roles could become blurred. Flick (2007) argues that the researcher is a subjective participant as well as an objective observer, which highlights the complexities of roles during observations and changes in roles that may occur over time. Agar (1986) proposes that ethnography is neither subjective nor objective, since it results from interpretations made by the researcher. Therefore this reflexive aspect of the research considers the researcher as part of the world being studied, influenced by the experiences and relationships encountered (Boyle, 1994). This will be addressed further when considering the rigour and strengths / limitations of the study.

#### **5.1.6.2      *Participant observation***

Traditional ethnographic approaches maintain a distance between observer and observed, which results in objectivity so that the results represent a true reflection of the observation (Borbasi et al, 2005). However, there is some conflict amongst researchers regarding the degree of observation versus participation (Borbasi et al, 2005), with some placing increased emphasis on intensive observation (Hodgson, 2001). It is important for nurse researchers to balance the roles of a nurse and researcher (Spradley, 1980). This includes a balance between fitting into the environment to avoid disruption, and

maintaining sufficient distance from participants to make sense of the observation (Hammersley and Atkinson, 1994).

Data collection occurs in the natural setting (Adler and Adler, 1994), where the researcher aims to understand the participants' thoughts, feelings and actions (Wiersma, 1995). However, ethnographic accounts are influenced by researchers' participation in the field, and also by their reflections of data collected (Borbasi et al, 2005). For nurses this may create dilemmas between their role as a nurse and also researcher during participant observation. Borbasi et al (2005) propose that nurses can adapt participant observation when exploring nursing research questions, however need to carefully consider the ethical and practical implications prior to undertaking fieldwork. In participant-as-observer, if researchers have a dual role within the hospital as a nurse this may confuse participants and create suspicion regarding the observation and role change (Roper and Anderson, 1991). However, observer-as-participant requires reduced participation and shorter, more formal contact with participants (Roper and Shapira, 2000).

Acting as a participant or non-participant observer facilitates a greater understanding of the participants' perspective by integrating descriptions of the whole setting with participants' interactions (Hammersley and Atkinson, 1995). For study 2 this enables greater understanding of nurses' roles by observing nurses within the context of their nurse-led chemotherapy clinics, including interactions with patients and colleagues. Interviewing nurses in addition to observations enables comparisons between what nurses' think they do and what they actually do within nurse-led chemotherapy clinics, which is not possible by interviews alone.

The strength of the participant role emerges from close involvement with the people being observed, which could yield richer data and greater authenticity of the findings. However, Mulhall (2003) argues that an insider participant role can be compromised by the researcher role. Developing close relationships with subjects being observed can create problems with potential subjectivity and bias, which arises through increased familiarity with what is being observed (Allen, 2004). This may create some tension with regard to role identity for the nurse researcher investigating a nursing environment (Murphy, 2005); one

study illustrated how boundaries between nurse and researcher can become blurred when undertaking research in a clinical area (Wilkes and Beale, 2005). This may be exacerbated if researchers undertake observation within a familiar environment. Murphy (2005) suggests that researchers need to develop competence in fieldwork, and go through stages from 'novice to expert' within the process. Researchers undertaking participant observation can also take on different roles ranging from complete insider (member of the group being studied) to complete outsider (stranger to the group) (Adler and Adler, 1994).

**Table 5.4** *Insider-outsider roles in participant observation*

<b>Role</b>	<b>Advantages</b>	<b>Disadvantages</b>
Insider	<ul style="list-style-type: none"> <li>• Seen as members of the group (Bonner and Tolhurst, 2002)</li> <li>• Greater understanding of culture being studied (Pugh et al, 2000)</li> <li>• Not altering the flow of interaction unnaturally (Adler and Adler, 1994)</li> <li>• Established relationship with participants which promotes truth telling and judging of truth (Leininger, 1985)</li> <li>• Enables the process of practice to be explored, rather than outcome (Pugh et al, 2000)</li> <li>• Facilitates access to participants (Pugh et al, 2000)</li> <li>• Easier to establish rapport with participants (Gerrish, 1997)</li> <li>• Easier to deal with any ethical concerns (Platzer and James, 1997)</li> </ul>	<ul style="list-style-type: none"> <li>• Familiarity may result in some aspects of routine practice overlooked (Lipson, 1984)</li> <li>• May make assumptions about observations rather than seeking clarification (Gerrish, 1997)</li> <li>• Easy to develop too much rapport with participants (Hammersley and Atkinson, 1995)</li> <li>• Danger of completely joining the group and becoming a non-observing participant (Miles and Huberman, 1994)</li> <li>• May experience role conflicts (Bonner and Tolhurst, 2002)</li> </ul>
Outsider	<ul style="list-style-type: none"> <li>• Free from commitment to the group (Bonner and Tolhurst, 2002)</li> <li>• Effective at building rapport with participants (Bonner and Tolhurst, 2002)</li> <li>• Increased opportunities for in-depth discussions of day to day activities (Adler and Adler, 1994)</li> <li>• Facilitates objective observations of events and gathering data (Adler and Adler, 1994)</li> <li>• May include reflections on seemingly ordinary events (Bonner and Tolhurst, 2002)</li> </ul>	<ul style="list-style-type: none"> <li>• Unfamiliar culture may interfere with research (Bonner and Tolhurst, 2002)</li> <li>• Need time to establish trust with participants (Bonner and Tolhurst, 2002)</li> <li>• Need time to understand the culture and language (jargon) (Bonner and Tolhurst, 2002)</li> <li>• The cultural distance may desensitise researcher to participants' needs / meanings (Bonner and Tolhurst, 2002)</li> <li>• May not receive true attitudes or knowledge (Bonner and Tolhurst, 2002)</li> </ul>

For this research, my position as a clinical nurse in oncology, and prior professional contact with some of the participants, may imply that I am considered an insider. This appeared to also hold true in different hospital settings and also with participants who I had not met before. In all locations I appeared to be accepted as part of the group, and trust seemed to develop much quicker than if I had been a stranger. My familiarity with oncology, chemotherapy and nurse-led clinics also enabled me to focus on nurses' patterns of practice and helped to detect subtle differences between nurses and locations. Prior knowledge of clinical and communication skills facilitated my observations since I could understand the level of skill and confidence when observing nurse-patient interactions and by interviewing nurses. However this also increased potential subjectivity and bias.

Whilst some researchers consider that using their experience will enhance interpretations during ethnography (Pellatt, 2003; Chesney, 2000), others criticise familiarity due to the increased risk of bias and subjectivity (Hodgson, 2001; Allen, 2004). In this research, my familiarity with the clinical environment could adversely affect the observational data collected, since I may overlook some areas of routine practice, or make assumptions. However, awareness of these potential problems was a constant reminder to maintain the researcher role and be objective. Practical ways to facilitate this (Bonner and Tolhurst, 2002) was not wearing a uniform, and emphasising my role as a researcher to nurse participants and patients and their relatives. I was also careful to choose my position in the consulting room, trying to sit in a corner outside the nurses' vision, but where I could observe non-verbal communication between the nurse and patient. This was important since the researcher's position during observation can influence the situation and also what is observed (Walshe et al, 2011). I also avoided participating in clinical discussions and problem-solving during data collection, which was sometimes difficult when the nurse or patient asked me a direct question. Although this involvement briefly affected my position as an observer, it did not affect the data collection since this was included in my field notes and also audio recorded.

### 5.1.6.3 Interviews

Interviews are used to validate observations and collect data on issues that haven't been observed, such as participants' thoughts, feelings and beliefs (Roper and Shapira, 2000). Table 5.5 outlines different types of interviews. Miles and Huberman (1994) propose that well collected qualitative data can increase understanding of 'real life experiences'. Keeping interviews 'grounded' in this way also maintains the context of data collected, keeping participants' experience and circumstances together, which provides a deeper level of understanding. Interviews can also obtain a richer understanding of a person's experience through non-verbal communication such as facial expressions, gestures and the use of silence (Kleiman 2004).

**Table 5.5** *Types of interviews*

Type of interview	Description / benefits
Formal (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Involves planning, covering specific, pre-determined, questions</li><li>• May use an interview guide</li><li>• Questions are open-ended, reflecting research questions</li></ul>
Informal (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Asking participants about an event or interaction immediately after it has happened</li><li>• Used to check participants' perception to compare with researcher's interpretation</li></ul>
Unstructured (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Questions are not pre-determined</li><li>• Researcher begins with one open question</li><li>• Digressions and new directions are important</li></ul>
Semi-structured (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Uses predetermined questions around area of interest</li><li>• Digressions not included in the interview plan</li></ul>
Reflexive (Hammersley and Atkinson, 1995)	<ul style="list-style-type: none"><li>• Has a list of issues that need to be addressed but do not ask each participant exactly the same questions</li><li>• Uses different modes of questioning (directive / non-directive)</li><li>• Adopts a flexible approach, allowing the interview to flow in a more natural way</li></ul>
Group interviews (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Allows participants time to reflect / recall experiences without feeling under pressure</li><li>• Comments from others may trigger memories or responses</li><li>• Contrasting opinions may be discussed</li></ul>
Oral history (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Reconstructs past through the experiences of participants</li><li>• A way for marginalised people to put their story on record</li></ul>
Life history (Roper and Shapira, 2000).	<ul style="list-style-type: none"><li>• Attempts to see the past through the eyes of one individual</li></ul>

Informal, in depth interviewing is considered a central method of data collection for qualitative research (Borbasi et al, 2005), which allows the researcher to explore the meaning that observed patterns of behaviours have for participants (Roper and Shapira, 2000). In addition, nurses' skills in knowing how to ask questions and talk to people is well recognised (Borbasi et al, 2005), which can facilitate access and the quality of interview data (Gardner, 1996). Interviews were an important part of this research, and although group interviews may facilitate comparisons between nurses, it was not feasible within this study given the different geographical settings and variety of participants at each location. Reflexive, semi-structured interviews appeared the best approach to explore nurses' perceptions and enable comparisons between nurses and locations.

The semi-structured interview was undertaken after the observation session on day one. This enabled the researcher to ask questions about particular aspects from the observational sessions and documentation in addition to understanding nurses' perceptions. The interviews focused on broad areas, including setting up the nurse-led chemotherapy clinics, clinical, administrative and managerial support, and training provision. The researcher also explored nurses' aims regarding nurse-led chemotherapy, how this fitted with broader chemotherapy service provision, perceptions regarding the impact of nurse-led chemotherapy on patients, staff and service delivery, and plans for future developments.

Interviews with nurse participants were undertaken using a semi-structured interview guide (appendix 11), which allowed nurses to discuss their own experiences more fully than if a more structured questionnaire was used. As ethnography is driven by what happens in the field, there was flexibility in the interview guide to accommodate this. The interview guide was piloted on the researcher's colleagues to ensure the questions were appropriate and captured the data required for this study. However, questions arising from clinic observation may vary according to each individual, and participants' responses can also generate other questions or areas for exploration during the interview. Interviews were conducted in a private room at the participant's place of work using an audio-recorder, and each interview lasted approximately 45 minutes. Recordings were then transcribed into a WORD document by the researcher, and then compared and contrasted with observational data during analysis.

#### **5.1.6.4      *Field notes***

Field notes can include the researcher's observations, feelings and thoughts from observations, interviews and additional sources, which are included in the analysis (Roper and Shapira, 2000). Whilst some researchers write extensive, detailed field notes, considering them to be the essence of a study (Emmerson et al, 2001), others consider field notes to be secondary, since too much time devoted to writing may lose the deeper experience of being within a culture (Mulhall, 2003). There are also implications of reliability and validity in relation to field notes, however this may be improved by ensuring an audit trail, which includes an analysis of decisions made (Clark, 2000). Waterman (1998) also suggests that this could include 'reflexive validity' which demonstrates how the researcher has influenced the focus of data collection. During this study, field notes were also taken to include aspects of non-verbal communication observed by the researcher during nurse interviews and clinical observations and interactions.

#### **5.1.6.5      *Documents***

Exploring supplementary sources of information, such as documents, reports and protocols can provide a broad perspective of the participants, setting and research issues (Roper and Shapira, 2000). Documents requested from participants included any information regarding the set up and management of their nurse-led chemotherapy clinics. The main documents provided from three locations were protocols for the nurse-led clinics, and one chemotherapy toxicity checklist; however there were no documents available at location 1. The documents (protocols) provided valuable information regarding what nurses should and should not be doing within nurse-led chemotherapy clinics, which included nurse-patient reviews, prescribing, aspects of clinical management and criteria for referral to medical clinics. The involvement of nurses in writing the protocols also gave an indication of nurses' autonomy and roles within the multidisciplinary team.

Collecting written documentation from nurse participants about their nurse-led clinics, such as protocols and guidelines aimed to provide additional



background information on nurse-led chemotherapy clinics, to add greater depth to understanding nurses' roles. This information was also triangulated with data from observations and nurse interviews during the analysis. This reflects the multifactorial approach of ethnography, where two or more different methods of data collection are used to triangulate the conclusions (Flick, 2007). Although nurses were also asked to provide the researcher with a copy of their job description, none chose to do this; and a tactful reminder failed to produce anything.

### **5.1.7 Sampling methods and procedures**

The potential sample for study 2 included 27 (26%) nurses from study 1 who had reported that they were undertaking nurse-led chemotherapy clinics. However due to time, travel and financial constraints it was not possible to include all of them in observations of nurse-led chemotherapy clinics. In addition, some nurses contacted from study 1 had changed roles or were unavailable to participate in study 2.

Four hospitals were chosen, based on geographical location and size in order to compare potential variations in chemotherapy services within cancer units and centres; covering both urban and rural locations. Comparison of different hospitals and geographical areas should increase understanding of organisational factors that may influence nurse-led chemotherapy clinics, including infrastructure and prescribing practices. This information will be useful to understand potential implications for patients, staff and service delivery.

A purposive sampling strategy was necessary to ensure representation from different geographical areas. Two hospitals were selected in the north of England and two in the south, which provided a cross-section of nurses across the UK who undertook nurse-led chemotherapy clinics. However, one hospital had to be excluded since their Research and Development (R&D) department was in disarray and R&D approval could not be obtained in time for the study; therefore an alternative hospital was selected in a similar geographical location. Discussions were also undertaken with a potential nurse participant from a fifth hospital site, who had agreed to take part if data saturation had not been achieved from the four selected hospitals.

### **5.1.7.1 Inclusion and exclusion criteria**

The study aimed to recruit 10-15 nurses from the four hospital locations in order to provide sufficient qualitative data on the nature of nurses' roles within nurse-led chemotherapy clinics. This number was considered sufficient to provide a sample that was representative of nurse-led chemotherapy clinics in the UK. The inclusion and exclusion criteria are shown in table 5.6:

**Table 5.6 Study 2 Inclusion and exclusion criteria**

	<b>Inclusion criteria</b>	<b>Exclusion criteria</b>
<b>Participants</b>	Advanced nurse practitioners Nurse clinicians Nurse consultants Chemotherapy nurses Clinical nurse specialists	Ward sisters Staff nurses
<b>Nurse-led clinics</b>	Nurse-led ambulatory chemotherapy clinics	Inpatient nurse-led chemotherapy Non-chemotherapy nurse-led clinics
<b>Intervention</b>	Consent to observation of nurse-led clinics and semi-structured interviews	No informed consent to clinic observation and interviews
<b>Location</b>	Any hospital within the UK	Hospitals outside the UK

### **5.1.7.2 Recruitment of nurse participants**

Using the list of potential participants from study 1 and based on the four selected hospital sites, emails were sent to each potential participant inviting them to take part in this study. The invitation letter for study 2 (appendix 5) was a word document attached to the email, outlining the aims of the study together with details of the proposed observation and interview. Participants were asked to complete the reply slip at the bottom of the letter and return it to the researcher by email or post, to confirm whether they wished to participate. The researcher then contacted each nurse to answer any questions about the study and arrange provisional dates for the study visits.

### **5.1.7.3 Informed consent**

Once nurses expressed an interest in taking part in the study, detailed written information and a consent form (appendix 6) were posted to each participant, with a letter requesting any documentation in relation to their nurse-led

chemotherapy clinics (appendix 9), such as protocols and guidelines. This information also informed nurses that they could withdraw from the study at any time without giving a reason; and outlined issues of anonymity and confidentiality during observations, interviews, data collection and analysis. Written informed consent was obtained to observe the nurse-led chemotherapy clinics for two days at each site, to audio-record nurses' interactions with patients attending clinic and to conduct one semi-structured interview with each nurse, which was designed to take approximately 45 minutes.

The NHS research ethics committee recommended that written informed consent was not required from patients during their consultations with nurse participants, and deemed that verbal consent only was required. It was not possible to accurately identify patients attending the nurse-led clinics in advance, therefore, patients were informed about the study by displaying information posters (appendix 8) in the chemotherapy unit on days when observations were taking place, and each patient was given an information leaflet on arrival at the clinic (appendix 9).

Patients and carers were only observed, not interviewed, and only selected to be observed if they were seeing the nurse participant that day. However, patients were made aware that they could decline to participate in the research, in which case the researcher would not observe their consultation with the nurse. Verbal consent to use an audio-recorder was also obtained from each patient prior to the consultation, however, patients were aware that they could stop the recording and ask the researcher to leave at any point.

#### **5.1.7.4      *Study tools***

A small digital recorder was used to record nurse-patient consultations and interviews with nurses. The use of an audio-recorder was essential to ensure accuracy in recording nurse-patient interactions and nurse interviews, and issues of anonymity and confidentiality were discussed prior to its use. This also allowed the researcher to focus on observing non-verbal communication and environmental factors. The recorder was placed on the desk next to the nurse at the start of each consultation, and switched off as soon as the patient left the room. A separate audio recording was made of each patient consultation, and an individual code number assigned to each recording to maintain

confidentiality. Recordings were transcribed by the researcher within seven days of the recording using WORD.

An observation guide (appendix 11) was designed to facilitate note-taking during consultations. A separate observation guide was used for each nurse-patient consultation, and the same code number assigned to the observation guide, field notes, and recording, using a simple system of consecutive numbering. The guide included contextual and operational aspects of the nurse-led clinic, contact with colleagues and potential aspects of nurses' roles. Prior to the fieldwork this information was considered to be important in addressing the research questions. However, during the first observation the semi-structured guide quickly appeared inappropriate because of its subjectivity; therefore a more inductive approach was undertaken. This enabled the researcher to focus more objectively on the individual observations. In practice the observation guide was used as a blank sheet, recording time and interactions, however data collection focused mainly on recording non-verbal communication between the nurse, patient and patient's family.

Field notes also included aspects of the clinic environment, interactions with colleagues and any interruptions to the consultations. Notes were also made of how many people accompanied the patient, their relationship to the patient, and where they sat in proximity to the patient and nurse. Notes were made of any visual events which required written descriptions, such as clinical examination, nurses' use of the computer, patient notes, and prescribing; also physical and emotional actions or interactions by patients and relatives.

Field notes included the time the consultation started and ended in order to understand chronology of events during the day. The time was also recorded for non-verbal interactions and emotions in order to accurately triangulate with audio recordings. To facilitate this, fragments of speech or actions were also noted to increase precision. Hand-written field notes were typed up within 24 hours to maintain accuracy, and used in conjunction with observational data.

#### **5.1.8 Data analysis**

The analysis of ethnographic data is inductive; starting during data collection since the researcher reflexively discovers themes from the data rather than

having preconceived ideas, then continually reviews the recordings and notes of what participants say and do (Roper and Shapira, 2000). The steps used in analysis include coding observation transcripts, field notes and interviews, sorting to identify patterns, generalizing constructs and theories, and memoing to include personal reflections and insights (Roper and Shapira, 2000). First level coding includes applying descriptive labels to chunks of text, which summarizes the content and enables the researcher to consider each individually and later combined into broader categories (Roper and Shapira, 2000).

During data collection consideration was paid to methods of data analysis, including whether to use Computer Assisted Qualitative Data Analysis (CAQDAS) software, which enables electronic storage of qualitative textual data, search and subsequent retrieval of specified items (Hammersley and Atkinson, 1995). However, generic word-processing software can also be as efficient, given the capacity to cut and paste, use bookmarks, find and highlight certain words or extracts, and add comments / notes to the margins (Hammersley and Atkinson, 1995). For study 2, generic word-processing and database software (MS WORD and MS Excel) were used to create summaries, flowcharts, diagrams and visual displays (see appendix 12).

Analysis began during data collection by systematically and repeatedly reviewing audio recordings and written transcripts from nurses' consultations with patients and research interviews. This enabled the researcher to become immersed in the data, which facilitated the identification of themes. Similar strategies were used for written records and field notes. Having one researcher undertake all data collection, including transcribing, was beneficial for the analysis since the researcher was familiar with the data from the outset. The basic principles of qualitative analysis were used (Miles and Huberman, 1994) including:

- Coding field notes and interviews
- Sorting to identify patterns
- Generalizing constructs and theories
- Memoing to note personal reflections and insights.

Observations, informal conversations and examination of documents were converted into field notes. Field notes and taped interviews were transcribed verbatim. Ethnographic data collection and analysis is an iterative process, embedded in the researcher's ideas (Hammersley and Atkinson, 1995), therefore data from study 2 were coded, classified and sorted according to '*thematic dimensions*' (Hammersley and Atkinson, 1995 p198). Sorting the data in this way creates a more organized structure to group the data, to compare and contrast, searching for patterns and themes that explain the beliefs and practices of the participants. The following steps explain this in more detail:

- Step1: First level coding helps to reduce the data into a more manageable size using codes as descriptive labels to chunks of words or paragraphs. This also allows the researcher to group all data related to the same topic. Initially codes are used to describe different aspects of the observation / interviews such as the setting, general perspectives, processes, activities and meanings. Coding initially starts using broad codes that could then be broken down into smaller concepts or ideas.
- Step 2: The data are sorted into patterns. The descriptive labels are grouped together into a smaller number of sets, including things that are similar and those that are different.
- Step 3: Constructs and theories are created to explain events and activities within the data. Diagrams and matrices are used to summarize the data and illustrate the constructs and theories.
- Step 4: Memos or reflective remarks about the data are created in order to make connections between the constructs.

However Roper and Shapira (2000) propose that this process is not linear and the process of data analysis moves back and forth through the steps. This reflects the design of study 2 since there was concurrent data collection and analysis, with memoing throughout. The large amount of data from different sources and hospital settings was challenging, however reading and re-reading facilitated coding and categorising the data to compare and contrast what happened at different sites. Hammersley and Atkinson (1995 p211) propose that this process enables the researcher to "*identify stable features....that*

*transcend local contexts*". All coding and interpretations were discussed with the research supervisors to ensure accuracy, credibility and trustworthiness of interpretations from data analysis.

In this study, coding included applying descriptive labels which were the colour coded individually and then mapped visually onto colour-coded diagrams to illustrate interactions and processes within individual nurse-patient consultations. This increased the researcher's understanding of what was happening within nurse-patient consultations, and enabled comparison within and across locations, which was then combined into broader colour-coded themes to represent the broader picture across all settings. Information from interviews, documents and field notes were combined with observational data, comparing and contrasting data from different sources throughout the analysis.

Results were synthesised using principles of data reduction and display to illustrate the findings, based on the following steps (Miles and Huberman (1994):

1. Data reduction: transforming interview data through summaries, writing memos, making codes and clusters and creating themes whilst maintaining the context of the data (Miles and Huberman (1994 p10-12).

Following transcription of the observational data separate word documents were created for each nurse-led chemotherapy clinic. This began with a summary of the clinic environment, the number of patients and nature of the clinic. The transcription and field-notes were amalgamated into a table, identifying each 'issue' separately, including who initiated the topic, the associated discussion (transcript), and observational notes. Topic categories were colour-coded to distinguish between the different aspects of nurses' consultation. The categories arose directly from the data by repeatedly reading the transcripts for each nurse-patient consultation, and were not a priori themes. Initially four categories were developed from the data to distinguish between physical and psychological aspects of the consultation, and practical aspects such as prescribing and treatment. However, as the researcher became more immersed in the data this was extended to six categories to include differences between physical symptoms and activities of daily living, such as eating. A new category was created to distinguish between social interactions / introductions and

clinical aspects of the consultation. In addition, prescribing was amended to medicines management to include broader discussions about medication and prescribing preferences, rather than just the act of prescribing. The colours used for each category were selected at random for their visual differences, although pastel colours were chosen because the text was easier to read through this rather than dark colours. The colour-coded categories are shown in table 5.7.

**Table 5.7      *Colour key for observation framework analysis***

	Exploratory / Social
	Physical Symptoms
	Psychological
	Activities of Daily Living
	Medicines Management
	Treatment / Administration

Colour-coding the framework in this way clearly showed the frequency of each category, the nature and frequency of issues within each category, and sequence of events within each consultation (see appendix 12). This produced a visual illustration of the content of individual consultations, which facilitated data reduction and enabled the researcher to compare and contrast consultations for each nurse, between nurses at the same hospital, and between different hospitals.

2. Data display: an organised assembly of information that facilitates understanding of what is happening and allows conclusions to be drawn. Displays may be graphs, charts, matrices or networks (Miles and Huberman (1994 p10-12).

Using the same colour key for step 1, data displays were created using flowcharts and matrices to show the processes within each nurse-patient consultation, focusing on issues raised and categories. The same colour-coding was used to reflect the different aspects of nurse-patient consultations and continue this through further data reduction. Using excel, a flow chart was created for each consultation using the colour-coded categories from the data, maintaining the natural order within each consultation to illustrate the flow of events. However, long consultations were divided into more than one flow chart given its size, in order to view ‘the whole consultation’ in a linear manner. This



visual display clearly illustrated patterns within nurses' consultations, highlighting the structure of consultations, the prevalence of each issue / category, including how much each nurse focused on each category. It also included patients' responses, relatives' involvement, and how this was addressed by the nurse. The individual flowcharts for each consultation facilitated comparisons between each nurse, within and between hospital locations (see appendix 13).

3. Conclusion drawing/verification: patterns or themes emerge from the data collection/analysis, which may suggest possible explanations or conclusions, although these have to be tested against the whole data set for confirmability.

This data display facilitated the early identification of visual patterns and themes, which were checked by studying the flowcharts and revisiting the transcripts within the observation frameworks. Going back to the original data in this way, whilst considering reflexivity, provided objective confirmation of the researcher's explanations and conclusions based on the whole data set, which increased study rigour.

#### **5.1.9 Quality control in qualitative research**

In qualitative research, it is essential to determine that the study is believable and accurate, which requires consideration of concepts of validity or trustworthiness of the data, reliability and generalizability (Priest 2002). However, in qualitative research it is more difficult to demonstrate validity and reliability of the research findings, although internal validity is said to exist if the study sample seems to be an accurate representation of the population group. Considerations of credibility, dependability, transferability and confirmability are more appropriate in qualitative research than measures of validity (Lincoln & Guba, 1985).

Murphy et al (1998) propose that the trustworthiness of the data can also be increased if the researchers can show that alternative explanations of their data have been considered, and credibility can be increased if negative cases are identified and inconsistencies discussed. Adopting an interpretive approach allows concepts and theories to emerge from the study by exploring the data

and gathering information (Robson 1993 p19). Hopkinson and Hallett (2001) consider this to be appropriate for studies interviewing individuals who have a unique understanding and experience.

Credibility and dependability were achieved by ensuring consistency and accuracy between data and the analysis, and by using rich descriptions. Wilkes and Beale (2005) consider that objectivity within the research process is also important during observational research to enhance quality control. In addition, transparency when outlining methods of data collection should increase credibility of the findings through an audit trail (Miles and Huberman 1994 p279). Priest (2002) suggests quality control may be improved by the following. Table 5.8 highlights how the recommendations by Priest (2002) have been incorporated into this study.

**Table 5.8 Steps taken to enhance quality control (after Priest, 2002)**

<b>Recommendation</b>	<b>Included</b>	<b>Comments</b>
Acknowledging preconceptions and presuppositions	Yes	Use of reflexivity throughout data collection and analysis
Accuracy in recording and transcribing	Yes	Use of audio tapes to record all nurse-patient consultations and nurse interviews, which were transcribed verbatim and checked with supervisor
Becoming immersed in the data	Yes	Researcher alone conducted all observations / interviews, and all transcribing. Read and re-read making constant comparisons. Creating colour-coded diagrams / flow charts / visual displays to check interpretations / findings
Feedback to the participants	No	Some of the issues that emerged seemed too sensitive to discuss with individual participants, such as poor communication skills
Using extracts from patients' verbatim accounts	Yes	Numerous direct quotes used throughout to capture the essence of observations and accuracy of participants' involvement. This increased objectivity of the findings
Peer discussions of the findings	Yes	Discussed with supervisors and other researchers within meetings and presentations. Findings also presented to nurses at UK and European conferences.

Validity refers to the accuracy of methods used in data collection and analysis (Bernard, 1994). In ethnographic research validity is established if the results reflect the reality and meanings of the group under study (LeCompte and Goetz, 1982), which is enhanced by spending longer time with participants. Validity of the research design is increased in ethnography which triangulates information from observations, interviews and documentation (Roper and Shapira, 2000). Respondent validation includes techniques to check the researcher's interpretations with participants' accounts, however there are limitations to this type of validation since the accounts are influenced by their different roles (Mays and Pope, 2006).

Participant observation enables the researcher to view nurses in practice, which assists with validation and interpretation of data during subsequent interviews (Morse and Field, 1995). Validation of the data is concerned with steps taken to ensure that the researcher's interpretations are accurate (Roper and Shapira, 2000). This can be undertaken in a number of ways, such as checking interpretations with participants, which may be undertaken during informal interviews (Roper and Shapira, 2000). However, if the time spent undertaking observation is too brief this may decrease opportunities to validate observations with participants, and could increase the risk of bias (Roper and Shapira, 2000).

In Study 2 the use of audio recordings of nurse-patient interactions ensured that the findings reflected the reality and context, since it enabled the use of direct quotes from nurse participants and patients in nurse-led chemotherapy clinics. This ensures greater accuracy of responses in comparison with observations that rely solely on the researcher's field notes. Interviewing nurses after observing their clinical practice also enhances the credibility of the findings since aspects of the observations can be fed back to the nurses during interviews in order to check accuracy of interpretations, clarify certain events or explore further to obtain more details / interpretations. However, a summary of the findings was not sent to each participant following completion of the study, which will be discussed in the limitations within chapter six. .

Reliability refers to the consistency and repeatability of data collection methods (Brink and Wood, 1994), which includes the participants' statements and the researcher's accuracy, in collecting and recording data (Brink, 1989b). In

ethnography, reliability is increased by collecting information from different participants and the inclusion of verbatim accounts of conversations and interviews (Roper and Shapira, 2000), both of which were undertaken in the present study.

Qualitative research is generally considered weak in the generalisability or transferability of the findings across populations or other settings, although there are some suggestions that limited transferability may be possible with similar participants (Priest 2002). This was addressed in study 2 by using four different locations in England, including cancer centres and chemotherapy units, and also urban and rural settings. This aimed to increase generalisability and transferability more effectively than if a single site was used. Similarly, using a range of different nurses across all locations enabled comparisons between specialist nurses and chemotherapy nurses within nurse-led chemotherapy clinics, which increased transferability of the findings.

#### **5.1.10 Reflexivity**

Although objectivity is a key element of ethnographic fieldwork, Hammersley and Atkinson (1995) propose that reflexivity is crucial to acknowledge the potential effect of the research within the field of study and take this into account when interpreting the findings. Reflexivity was an important factor during study 2 for the field observation, data collection and analysis, given the author's substantive role as a nurse clinician. This had advantages in understanding key factors within the clinic environment, chemotherapy treatments, and nurses' roles. However, increased familiarity may change the dynamics of the observations and affect interpretations by the researcher (Walshe et al, 2011). As a nurse clinician this dilemma required heightened self-awareness and reflexivity during observation and analysis to maintain the role of researcher. This is important in order to describe phenomena as they are, and understand the potential influence from the researcher's presence (Hammersley and Atkinson, 1995).

Bias can influence data collection and interpretation of the findings, which may arise from the researcher's values, beliefs, knowledge and personality (Roper and Shapira, 2000). However bias may also arise if participants block access to information / areas without explanation (Germain, 1979). Reflexivity enables

nurses to be aware of their role as ethnographers, thus identifying potential bias and their own influence on the data collected and interpretations made (Roper and Shapira, 2000). This facilitates understanding of 'normal' routines that may be taken for granted, and potential contradictions between "*intent, meaning and action*" to uncover the richness and complexity of nursing practice (Street, 1992 p11).

Within this study, being reflexive included critical analysis of any assumptions and actions / interactions during data collection and analysis in order to maintain objectivity. The process of reflection also included details of the context, non-verbal communication and personal thoughts and feelings, which were recorded in field notes.

One of the main issues was being a nurse within this specialist field, and being a researcher. This created problems of potential bias during data collection and analysis, since the research involved observing some nurses who were already known to the researcher, and one setting was the researcher's own place of work, therefore was familiar with the environment at one location. This created tensions since the researcher's primary aim was to be objective. However, awareness of this potential bias enabled the researcher to address some of the issues.

Although the environment was familiar in one location, the researcher had no prior knowledge of other nurse-led clinics at the hospital, which helped the researcher to be more objective. Observations at the other locations were not familiar, which enabled the researcher to be more objective. In some respects the researcher's familiarity with the environment was beneficial, since the researcher was not distracted by a new setting, and could focus solely on observing the consultations.

Familiarity with the nurses did seem to blur the role of researcher and nurse, since some nurses wanted to chat at times about everyday issues. However I kept this to a minimum, emphasising my research role without appearing rude and blocking the conversation. In some cases familiarity seemed advantageous since nurses appeared more open and provided more information about their feelings and perceptions of the nurse-led clinics, the hospital and colleagues during the observations, which I was able to capture in my field notes and

incorporate into the analysis. Making time for reflection after each day's fieldwork enabled me to focus on how my presence may have influenced the observation and helped to put any preconceptions to one side, which enhanced objectivity.

#### **5.1.11 Ethics and disclosure**

Research ethics committee (REC) approval for the study was obtained from the local NHS Research ethics committee prior to initiating study 2 (REC reference number 11/NW/0240 September 2011). Approval sponsorship and indemnity was also obtained from The University of Manchester (01.04.2011). Approval from the Research and Development (R&D) departments at each hospital trust was also obtained prior to starting the study in each location (April-June 2012).

Adherence to the main ethical principles of respect for persons, confidentiality, anonymity, and informed consent were ensured throughout. Participants were given at least 24 hours to consider the study before deciding whether to take part; this process was free from coercion, and participants could withdraw from the study at any time without giving any reason.

A code number was assigned to each participant to facilitate anonymity and confidentiality during observations and interviews. All data collected were held securely in the researcher's office; completed forms with personal data were kept in a locked drawer. Audiotapes and electronic data did not contain any personal identifiable information; anonymity was maintained by using codes for each participant and patients, and stored electronically on a secure server. All records will be destroyed five years after completion of the study, including digital audio recordings.

As a health professional I was aware there could be potential conflict of interest if patient or staff safety appeared to be at risk during the observational sessions. Prior to fieldwork long discussions were held with research supervisors regarding potential safety issues. This included several possible scenarios that may arise and create a conflict of interest between my objective role as a researcher and accountabilities as a nurse. For each scenario we discussed the implications and standard operating procedures regarding the initial management, with an escalation plan for more serious concerns. These issues

were outlined in the REC application and discussed at the meeting with the ethics committee, who were satisfied with the proposed action plan. For example, if I had observed poor clinical practice which breached the code of professional conduct I would have intervened immediately to protect patient safety, which would be the priority in such situations. This may include stopping an intervention to avoid patient harm and taking appropriate steps to maintain patient safety. This may necessitate approaching another nurse to take over so that I could discuss my concerns with the nurse participant and escalate to a manager as required. I would then immediately document the incident in my notes and then type it into a formal report for future use, forwarding a copy to the nurse participant and nurse manager.

#### **5.1.12 Summary**

Ethnography was chosen since this describes participants' perceptions and interactions within their own culture. This included observation of nurse-led chemotherapy clinics and semi-structured interviews with nurse participants. Non-participant observation of nurse-led chemotherapy clinics was valuable to understand nurses' roles and responsibilities in addition to observing their interactions with patients. Undertaking semi-structured interviews of nurse participants facilitated greater understanding of nurses' roles and nurse-led clinics from their own perspectives, and enabled a comparison of nurses' perceptions and clinic observations. They were also used to gather information on aspects that hadn't been observed. In addition, nurses were asked to provide a copy of their job description and any protocols, guidelines, standards or supportive documentation relating to their chemotherapy clinics. This aimed to increase understanding of nurses' roles and chemotherapy service developments.

The next section presents the findings from study 2

## **Section two: Results from Study 2**

### **5.2.1 Introduction**

The presentation of results from study 2 includes descriptive information about the sample of nurse participants, including the duration of clinical observations

and interviews. Contextual information includes the rationale for setting up nurse-led clinics, nurses' perceived priorities and essential training for nurse-led chemotherapy clinics. Following this, the qualitative findings from observations and interviews are presented, together with information from documentation, to illustrate the main themes that have emerged from data analysis. The rationale for setting up nurse-led chemotherapy clinics is included in the aims and objectives in order to understand the original drivers for nurse-led clinics, and whether this has influenced the way that nurses run the clinics on a day-to-day basis. This information, together with documentation for nurse-led clinics, also provides important background information on each location, which will be considered throughout to maintain the context.

Data presented as direct quotes from observations can be identified by 'O', whilst 'I' is used to represent data from interviews. This is placed in brackets together with 'L' for the location, plus the numerical study code for each location. In addition, letters are provided to identify the author of the quote, for example 'N' = nurse, 'P' = patient, plus their unique study number (see table 5.9). Reference to documentation will be highlighted by 'D' and the location number.

**Table 5.9**     *Key to abbreviations in observations and interviews*

Abbreviation	Description	Abbreviation	Description
I	Interview	N	Nurse
O	Observation	Ph	Pharmacist
D	Documentation	P	Patient
L	Location	H	Husband
		W	Wife
		M	Mother

The first section of the findings provides information about the sample of nurse participants in study 2 and the settings for nurse-led chemotherapy clinics.

### **5.2.2 Sample and settings**

The study was conducted in four hospital locations in England. Nurses undertaking nurse-led chemotherapy clinics were chemotherapy nurses, specialist nurses, advanced nurse practitioners or nurse consultants. All nurses



had received training in clinical examination skills at Master's level, and all but one were independent non-medical prescribers. One of the chemotherapy clinics was run jointly by a nurse and pharmacist, although the pharmacist did not see any patients during clinic observations. Table 5.10 summarises the characteristics of nurses / pharmacist undertaking nurse-led clinics at each location, however minimal data was collected on demographics. Although most of the nurses in study 2 had participated in study 1, others had not, which limited the available demographics on nurse characteristics.

**Table 5.20 Characteristics of staff undertaking nurse-led clinics**

Title	Location	Examination skills	Independent prescribing
Specialist advanced nurse practitioner	1	✓	✓
Specialist advanced nurse practitioner	1	✓	✓
Specialist advanced nurse practitioner	1	✓	✓
Specialist advanced nurse practitioner	1	✓	✓
Chemotherapy nurse manager	2	✓	✓
Chemotherapy nurse	2	✓	✓
Chemotherapy nurse	2	✓	✓
Chemotherapy nurse	2	✓	✓
Nurse consultant: chemotherapy	3	✓	✓
Chemotherapy nurse	3	✓	✓
Chemotherapy nurse	3	✓	✓
Nurse consultant: chemotherapy	4	✓	✓
Pharmacist	4	X	✓
Chemotherapy nurse	4	✓	✓
Chemotherapy nurse	4	✓	X

There were similarities and differences between the four locations regarding the setting for nurse-led chemotherapy clinics, operational aspects of each clinic, the nature of nurses' roles and their responsibilities. Each hospital location had a designated area for chemotherapy administration, and some nurse-led chemotherapy clinics operated within the same area (table 5.11).

**Table 5.11 Similarities and differences in nurse-led clinics**

	<b>Location 1</b>	<b>Location 2</b>	<b>Location 3</b>	<b>Location 4</b>
Main title of nurses	Specialist ANP	Chemotherapy	Chemotherapy	Chemotherapy
Cancer groups within nurses' role	One specialist group	All cancers	All cancers	All cancers
Cancer groups for nurse-led clinics	Gynaecology Urology Head and neck	All cancers	Breast Colorectal	Breast Colorectal Urology Lung
Administration of chemotherapy	Given by chemotherapy nurses. Separate appointment / day	Given by nurses in nurse-led clinics after patient reviews	Given by other chemotherapy nurses. Separate appointment / day	Given by other chemotherapy nurses. Separate appointment / day
Setting for nurse-led clinic	In a private consultation room in the out-patient area	In a 6 bed bay on the chemotherapy unit.	In a private consultation room on the chemotherapy unit	In a private consultation room in the out-patient area
Type of care within nurse-led clinic	Management of patients throughout chemotherapy	Administration of chemotherapy and toxicity reviews at each cycle	Shared care with medical staff. Chemotherapy reviews at specific cycles	Shared care with medical staff. Chemotherapy reviews at specific cycles
Type of consultation	Semi-structured. Medical model, replacing doctors throughout	Structured checklist.	Semi-structured. Medical model, with doctor-nurse substitution	Semi-structured. Medical model, with doctor-nurse substitution
Prescribing	Comprehensive, including chemotherapy	Limited to specific drugs and duration. Unable to prescribe chemotherapy	Comprehensive, including chemotherapy	Comprehensive, including chemotherapy
Support from a clinic nurse	Yes	No	No	No

The greatest difference was at location 2 where the nurse-led clinic focused primarily on the administration of chemotherapy in an open ward area. However nurses assessed (reviewed) toxicities from the previous cycle of chemotherapy immediately before administering the next cycle of chemotherapy. Although there were curtains between the beds they were not used; there was a lack of privacy for individual consultations between nurses and patients, with little space between the beds and nurses often sat on the patient's bed during their

consultation. As a result, consultations with patients were brief and focused on chemotherapy side-effects, which were assessed in a structured checklist, which often blocked communication.

The nurse-led review consultations were all conducted in a private room within the chemotherapy unit or in the out-patient department. This setting was similar to medical clinics, where each clinic room had an examination couch, desk with a computer and small chairs for the patient and relatives. Nurses sat at the desk, although often turned to face the patient during the consultation. This setting offered privacy during consultations between nurses and patients / relatives, and nurses referred to this as a 'closed door consultation' where patients were given an appointment to attend the nurse-led clinic. This type of setting led to a different type of consultation with patients and reflected a medical consultation.

A total of 63 hours over 12 days were spent observing nurse-led chemotherapy clinics. Thirteen nurses were observed undertaking 61 consultations with patients. Table 5.12 outlines the total number of nurses and patients at each location.

**Table 5.12** *Number of observations: nurse-led clinics at each location*

Location	Nurses observed	Days observed	Patients observed	Hours observed
1	4	6	39	22
2	4	2	7	12
3	3	2	12	12
4	2	2	3	5
<b>Total</b>	<b>13</b>	<b>12</b>	<b>61</b>	<b>63</b>

Table 5.12 shows marked differences in the number of patients and the number of hours observed between each location. More time was spent observing nurses at location 1 since nurse-led clinics were well established and patient numbers highest. In comparison, although two days were spent observing nurse-led clinics at location 4 this resulted in only three patient consultations (see table 5.13).

**Table 5.13 Nurse- patient consultations observed at each location**

This shows the number of consultations per nurse at each location. Consultation times for each nurse indicate the range, mean and total time taken, which does not include time between consultations.

Location	Nurse	Consultations observed	Time: range (minutes)	Time: mean (minutes)	Time: total (minutes)
1	1	7	11.26-56.00	28.37	198.62
	2	19	3.37-21.39	10.77	193.87
	3	13	3.04-24.36	12.94	168.16
<b>Totals</b>		<b>39</b>	<b>3.04-56.00</b>	<b>17.36</b>	<b>560.65</b>
2	4	2	20.39-39.18	29.79	59.57
	9	2	10.32-28.39	19.36	38.71
	10	1	12.48	12.48	12.48
	11	2	18.54-23.56	21.05	42.10
<b>Totals</b>		<b>7</b>	<b>10.32-39.18</b>	<b>24.23</b>	<b>152.86</b>
3	6	2	14.37-31.47	22.92	45.84
	7	4	10.25-46.57	20.39	81.54
	8	6	8.42-60.43	25.50	152.98
<b>Totals</b>		<b>12</b>	<b>8.42-60.43</b>	<b>22.94</b>	<b>280.36</b>
4	12	2	23.21-26.14	24.68	49.35
	13	1	8.32	8.32	8.32
<b>Totals</b>		<b>3</b>	<b>8.32-26.14</b>	<b>16.50</b>	<b>57.67</b>
<b>Grand Total</b>		<b>61</b>	<b>3.04-60.43</b>	<b>20.26</b>	<b>1051.54</b>

There were significant differences between the number of consultations per nurse and the average time for nurse - patient consultations. The shortest consultations were at location 1 where N3 took 3.04 minutes for one consultation and 3.37 minutes (N2) to see another patient. Time spent with each patient may be influenced by patient numbers, since consultations were longer when fewer patients attended the clinic. However the exception to this was at location 4 where the nurse-led clinic had only one patient but the consultation was quite brief.

Semi-structured interviews were conducted with 10 nurses and one pharmacist, although all were involved in nurse-led chemotherapy clinics. Table 5.14 shows the number of interviews at each location and time taken for each interview.

**Table 5.14 Duration of interviews with nurse participants**

Location	Number of interviews	Interview time (range)	Interview time (mean)	Interview time (total)
1	2	46.22-46.56	46.39	92.78
2	2	12.21-35.21	23.71	47.42
3	3	20.18-39.53	27.03	81.10
4	4	15.44-42.09	29.37	117.46
<b>Total</b>	<b>11</b>	<b>12.21-46.56</b>	<b>26.70</b>	<b>415.98</b>

Although the mean time for interviews was similar at locations 2, 3 and 4, interviews were longer at location 1 where nurses spent more time discussing how their nurse-led clinics had been set up and changed over time.

### **5.2.3 Nurse-led chemotherapy clinics**

#### **5.2.3.1 Setting up nurse-led chemotherapy clinics**

The main reason given for setting up nurse-led clinics was to alleviate problems in the medical clinics, which appeared to stem from a reduction in medical staff and increasing clinical demands.

*“The medical staff were getting a bit overwhelmed” [I.L3.N6]*

*“I think one of the big pushers was when the registrars’ training changed and we lost a lot of hands on sort of registrar presence” [I.L2.N4]*

This is supported by documentation evidence in hospital policies / protocols for nurse-led chemotherapy clinics:

*“Consultant clinics are becoming increasingly large and patients are waiting longer to be seen” [D.L4].*

*“Current Clinics are at or over full capacity” [D.L4].*

However, documentation from location 4 also indicated that specialist nurses’ skills were not being utilised, highlighting the potential for nurse-led clinics:

*“The new clinic will draw from the experience and skills that are currently underutilised due to capacity bottlenecks and delays in the consultant clinics” [D.L4]*

It was difficult to know how nurses had extended their role in relation to clinical skills and nurse-led clinics, since no nurses had provided a copy of their job description as requested. Nurse-led clinics were set up with experienced nurses, and this was concordant across data from documentation, interviews and observations. Some policies and protocols specified certain criteria for nurses working in nurse-led clinics:

*“Completed the chemotherapy course; have at least 2 years’ supervised experience in delivering chemotherapy”* [D.L2.]

Whilst other documents make generalised reference to nurses’ skills, suggesting the importance of further role development:

*“Expertise of Clinical Nurse Specialists not utilised to the full potential i.e. non-medical clinician development”* [D.L4]

However, at both locations there was evidence of the need to assess the competency of nurses within nurse-led clinics, which was either undertaken by a medical consultant or chemotherapy nurse manager.

#### **5.2.3.2      Assessing patients within nurse-led chemotherapy clinics**

The aim of nurse-led chemotherapy clinics was to assess patients during chemotherapy, ascertain treatment-related toxicities and determine whether patients were fit to continue with chemotherapy. There is concordance of data from documentation, interviews and observation to support this aim. Nurses at three locations worked to a written protocol for their nurse-led clinics. Although there were individual differences in protocols from each location, they all included specific criteria for patients who may be referred to the nurse-led clinics, and assessments that should be carried out. Examples of this included specific criteria where patients should be referred back to the medical clinics, for example:

*“unacceptable toxicities”* [D.L2]

*“toxicities level 2 or above”* [D.L4]

*“suspected disease progression.. treatment adjustment”* [D.L4]

Documentation to assess patients within nurse-led clinics was similar to documentation used by medical staff in relation to assessing the patient’s

physical performance status and chemotherapy toxicities, which was recorded in the patients' notes or electronic patient records. At each location there were examples of written documentation within hospital protocols, and/or paper chemotherapy records or symptom assessment checklists. In addition, some hospitals had electronic records which included chemotherapy toxicities; therefore nurses completed these for each patient following the consultation.

There was concordance between documentation, interviews and observations for clinical (physical) assessments at each location. However, there was discordance in other types of assessment between what the protocol said nurses should be doing, and what nurses perceived they were doing in nurse-led clinics (from interviews), compared with what nurses were observed doing in nurse-led clinics. For example, one hospital policy specified that nurses should be undertaking: *"Holistic needs assessment if appropriate"* [D.L4]. However, there was no evidence of this during observations.

Another protocol documented that nurses should be undertaking a range of assessments prior to each chemotherapy treatment. This included:

*"Clinical assessment ...and activities of daily living for nurses"* [D.L2].

*"Information...spiritual / emotional [assessment]....social assessment... financial assistance...carers / relatives [assessment of needs]..."* [D.L2]

However, there was no evidence of such assessments during observations by the majority of nurses, who focused on chemotherapy toxicities and the administration of chemotherapy. Furthermore, nurses' perceptions reflected the written documentation of hospital policies and protocols regarding holistic assessments and enhanced communication with patients. For example one policy highlights the following benefits of nurse-led chemotherapy clinics; however there was no evidence to support this from observations:

*"Enhance patient self-management, support and monitoring... Improve the interface between Nurse Specialists and patients to ensure that Holistic assessments are completed....Maintenance of consistency of advice and education for patients...Improved patient understanding and reduced treatment related anxiety....Improve continuity of care..."* [D.L4]

This highlights the potential influence of nurses when writing protocols and policies for chemotherapy and/or nurse-led clinics, with suggestions of patient and service improvements by nurse-led clinics. Although plausible, there was no evidence to support such claims from clinic observations. There are also written suggestions of improvements when comparing nurse-led and medical clinics:

*“Improve waiting time in consultant led clinics....reduced toxicity related hospital admissions...[D.L4]*

However, no audits / research had been undertaken to substantiate this, and there was no evidence to support this from clinic observations.

#### **5.2.3.3      *Skills required for nurse-led chemotherapy clinics***

Undertaking the independent nurse prescribing course also meant that nurses could prescribe chemotherapy and any supportive medication. With this framework in place the nurse-led chemotherapy clinics could operate independently from medical colleagues. However, where hospital policies and guidelines for chemotherapy or nurse-led chemotherapy clinics were written by medical consultants, this produced a very prescriptive approach with restrictions for nurses. This was particularly evident at location 2 where a separate policy existed for non-medical prescribing which identified which medicines nurse prescribers could prescribe. In addition, individual protocols specified which anti-emetics nurses could prescribe for each chemotherapy regimen. This contrasted with protocols at other locations that were written by specialist nurses in collaboration with medical consultants [L3, L4]. There were no protocols for nurse-led clinics at location 1, where nurses undertook the whole patient management for those on chemotherapy in one cancer group.

#### **5.2.3.4      *Developing protocols for nurse-led clinics***

At three locations local protocols were established to determine the type of patients doctors would refer to nurse-led clinics. The protocols included specific guidelines for nurses' clinical management during chemotherapy, such as parameters for blood results and chemotherapy toxicities. Nurses at these locations could work independently within these guidelines and refer back to the doctors if anything arose outside of them. In location 2 the protocols for the



nurse-led clinics were written by consultants alone, whilst nurses and consultants wrote protocols together for locations 3 and 4. In contrast, nurses at location 1 did not have any protocols for their nurse-led chemotherapy clinics and saw all chemotherapy patients for one cancer-specific group.

#### **5.2.3.5 Time factors**

Nurses reported that medical clinics were very busy and although nurse-led clinics were helpful, issues of clinic capacity continued to be problematic. However, nurses recognised the potential impact of their clinic numbers on the medical clinics.

*“...if we have a busy clinic then it’s taking patients out from the main clinic, which has definitely reduced the workload there” [I.L4.N14]*

*“...in a medical clinic ...they don’t have the time whereas we do. We had one patient today [laughs out loud] so I do have the time” [I.L4.N13]*

Some nurses recognised that their consultations were longer than doctors, although one nurse didn’t know the planned duration of appointments and had to refer to the protocol.

*“I’ve got the protocol.... initially each slot will be 30 minutes. I think that’s a bit longer because they only get 20 [in the medical clinics]....not much though [laughs]” [I.L4.N14]*

Several nurses perceived that their nurse-led chemotherapy clinics provided patients with more time to talk. Observations showed that the majority of nurses’ clinics were small and appointment slots were longer than medical clinics. In some cases the nurse-led clinics only had one or two patients and nurses expressed concerns regarding their viability.

*“...we don’t see enough patients and they [consultants] don’t see that we’re doing enough to alleviate....I think they see it more as a reduction in their workload so...’cause if we’re not seeing enough patients then for them that’s not an effective clinic.” [I.L4.N13]*

#### **5.2.3.6 Patient selection**

Nurses perceived that the selection of patients for nurse-led clinics was the key to success, together with careful consideration of clinic numbers. To build their confidence nurses often started off with small numbers and specific patient criteria. Protocols were created so that patients could be carefully selected from

one chemotherapy regimen, which would also reduce the number of potential patients.

*"I think it started with the adjuvant patients first. They've got no disease present ... you're basically steering them through a course of chemotherapy, monitoring the toxicities and managing the side-effects" [I.L2.N4]*

*"...we felt that adjuvant patients was the right way to go because we assumed that they would have less disease-related toxicities than metastatic patients" [I.L4.N12]*

Once the clinic was established, the aim was to increase the number of patients and expand the referral criteria to incorporate more complex regimens, and patients. However, some of the nurse-led clinics continued with small numbers due to a low volume of referrals from medical clinics.

*"...today there is only 1 patient but we have days when we have 5, 6 patients which is fine, that's manageable between two of us" [I.L4.N15]*

*"...there's still problems recruiting patients, and I think that's because the group of patients we see is quite narrow" [I.L4.N13]*

### **5.2.3.7 Improving patients' experiences**

Nurses showed strong motivations to improve patients' experiences by improving chemotherapy services.

*"...I see it more in terms of how it's improved the patients' experience than the effect that it's had on the clinics" [I.L4.N13]*

*"...one of my motivations was the waste of patients' time, especially the palliative patients, as well as a waste of resources ...[there was] often no appreciation of chemotherapy side-effects and no appreciation of on-going symptoms of their progressive diseases" [I.L1.N1]*

Nurses were keen to point out that providing additional time for patients within their clinics provided additional support for patients. Nurses perceived that doctors working in the medical clinics were always busy and had limited time to spend with patients. They felt that by giving patients more time during consultations within the nurse-led clinics they could provide additional support and improve patients' experiences.

*"I think the patients that we see are very well supported" [I.L4.N13]*

*"I think we take more time with the patients ... they're busy and doctors have a certain amount of time that they can see the patients... 'cause we're an extension of this clinic I think we can spend more time with the patients so hopefully it will improve their experience" [I.L4.N14]*

### 5.2.3.8 *Clinical dilemmas*

However, the perceived success of nurse-led clinics often brought additional demands from medical colleagues, which may create clinical dilemmas for nurses. Gaining an appropriate number of patients within each nurse-led clinic seemed particularly challenging. If numbers were too low nurses could be criticised, yet if there were too many patients nurse-led clinics would run late and increase waiting time for patients.

*“...the biggest impact has been the success... the demand from individual tumour groups for us to take it on. And that demand has presented some problems in that we at present don’t have the nurses skilled” [I.L4.N12]*

*“...they’re [nurse-led clinics] very vulnerable to come under scrutiny from other specialities and from the medical team so I think you need to maintain control of them and not just become a clinic that no-one else wants to do ... or taking on things that are too complicated” [I.L4.N13]*

Increasing demand from medical colleagues was also challenging if patients were too complex for nurses to manage effectively and safely. In many cases it seemed a fine balance to maintain appropriate numbers of patients to match the skill mix within the nurse-led clinics.

### 5.2.3.9 *Perceived priorities: nurse-led chemotherapy clinics*

In order to understand potential differences between the locations and individual nurses, each nurse was asked to list their three main priorities for nurse-led chemotherapy clinics. Based on their own perceptions, nurses’ replies have been tabulated in rank order and colour-coded for visual clarity (table 5.15), using the following legend:

	Training and experience
	Improving patients’ experience
	Assessment and practical
	Working practices & policies
	Recommendations for nurses

**Table 5.15 The three main priorities for nurse-led chemotherapy clinics**

<b>Nurse</b>	<b>First priority</b>	<b>Second priority</b>	<b>Third priority</b>
N1	Provide something additional to what a doctor would bring	Always have cross cover arrangements	Have admin infrastructure to run the clinic smoothly
N3	Support	Prescribing	Clinical supervision
N4	To have competent staff to begin with	The qualifications, experience, knowledge and skills	To be a prescriber
N5	Adequate training	Support	Clear policies
N6	Don't work in isolation	The service has to be safe fundamentally	Sustainable, on-going and functional
N7	Definitely run alongside a doctor's clinic	Nurse prescribing course and not just be looking at toxicities	Knowledge of all the things that could go wrong
N8	The patient gets the right information	Getting consent before you actually see patients	Taking time to listen
N12	To smooth the patient pathway to make it seamless	To improve patients' experience when they come to clinic	The role development of the nurse themselves
N13	Improving patients' experience	Continuity of care for a patient	Safe practice
N14	Toxicities the patient was experiencing	Proper holistic assessments	Prescribing

Two nurses considered a main priority to be improving the patient's pathway or experience, whilst other nurses placed emphasis on assessments, information, consent, and prescribing. For the remainder of nurses the priority lay in safety and the infrastructure of the clinic, and safety and support for nurses themselves.

All the nurses in this study had undertaken clinical examination skills modules at Master's level and all but one were independent nurse prescribers. During interviews nurses were asked to identify their perceived priorities in training for nurse-led chemotherapy clinics (table 5.16).

**Table 5.16 Essential Training for nurse-led chemotherapy clinics**

Nurse	Prescribing	Clinical skills	Other
N1	Prescribing	Clinical examination & history taking	Oncology / chemo experience and recognised course
N3	Prescribing	Masters – clinical skills,	Chemo / oncology experience, General medicine, Research experience
N4	Prescribing	Clinical experience	Chemo experience, Awareness of toxicities
N5	Prescribing	Assessing patients holistically	Chemotherapy course
N6	Prescribing	History taking Physical assessments	Chemo / oncology experience Communication skills
N7	Prescribing	History taking Physical examination	
N8	Prescribing	History taking	Structured training with consultant
N12	Prescribing	Advanced assessment skills	Advanced communication skills
N13	Prescribing	Clinical assessment	
N14	Prescribing	Advanced assessment skills	Chemotherapy experience Toxicity assessment
N15	Prescribing	Clinical assessment	Chemotherapy experience Trust accreditations

Nurses' responses show the main essential training to be prescribing, clinical skills and oncology or chemotherapy experience. However, only two nurses thought that communication skills' training was essential for nurse-led chemotherapy clinics.

Although all nurses appeared to have received similar training initially to undertake nurse-led chemotherapy clinics, little thought was given to on-going training in some locations. Some nurses wanted to have similar privileges as doctors in terms of continued (medical) training.

*“You’re not actually thought of as part of the medical team to actually have training. It’s kind of you have to jump on the back of it... there’s no structure as such” [I.L1.N3]*

Whilst training is definitely important, nurses suggested that outside factors may also influence nurses' roles within the clinics. In some cases nurses highlighted the importance of not only training per se, but the way that they had been trained and claimed that this defined a nurse's role.

*"... the boundaries are very blurred...to the point where it's not so much what your role is it's how you've been trained". [I.L4.N12]*

*"...you can't turn somebody into an advanced nurse practitioner overnight. It's not purely academic. It's not just with ... clinical technical skills" [I.L2.N4]*

One nurse (N4) considered the longevity of training to become an advanced nurse practitioner, implying that there was something additional to academic and clinical skills, however struggled to articulate this. This seems to highlight complexities within the expansion of nursing roles and advanced nursing practice, particularly when boundaries are blurred with other professionals such as doctors. However, further analysis using observational data sought to clarify different aspects of nurses' roles within nurse-led chemotherapy clinics.

#### **5.2.3.10      *Different levels of nurse-led chemotherapy clinics***

The findings from observations and interviews with nurse participants suggest that there are four different levels of nurse-led chemotherapy clinics, which represent four levels from novice to expert (Benner, 1984), depending on nurses' skills, clinical responsibilities and level of autonomy.

Level 1      Nurse-led chemotherapy administration. No separate appointments to see patients for assessment review. Follows a checklist to assess symptoms. Follows a structured protocol for criteria to go ahead with chemotherapy.

Level 2      Nurse-led pre-assessment undertaken as a separate consultation with patients. Follows a checklist to assess symptoms. Follows a structured protocol for criteria to go ahead with chemotherapy. However, nurses need to check with medical staff if chemotherapy needs to be deferred or dose amended. Nurses unable to prescribe chemotherapy independently, and unable to undertake clinical examinations.

- Level 3 Nurse-led chemotherapy reviews prior to chemotherapy. This is a separate consultation to assess symptoms and elicit patients' concerns. Nurses do not use a structured checklist, ask more open questions and make decisions whether to go ahead with chemotherapy or defer treatment, according to the protocol. In addition they can undertake informed consent for chemotherapy. However nurses cannot independently stop chemotherapy or amend treatment doses without discussion with medical staff. Nurses can prescribe and are trained in clinical examination skills so they can manage an episode of care, although the patient is still under the care of a medical consultant.
- Level 4 Totally nurse-led chemotherapy clinics. Nurses are completely independent and responsible for patients during the whole of their chemotherapy regimen. Can undertake comprehensive assessments of patients, take informed consent, and utilise a higher level of decision-making in that they can stop, defer or amend the dose of chemotherapy without speaking to a doctor. They can admit patients without further medical consultation, and regularly liaise with the patient's GP.

This method of levelling aims to provide a basic structure and definition for nurse-led chemotherapy clinics.

#### **5.2.4 Developing themes**

The themes were developed by combining data collected from observations of nurse-led chemotherapy clinics, interviews with nurses, and supporting documentation (protocols). Data from each location was read and re-read to understand what was happening at each location. Transcripts from observations were colour coded to identify different areas within the consultations, for example symptoms, psychological. Colour coded diagrams were then created to highlight visually how nurses communicated with patients, including processes within their consultations. This revealed not only the structure of nurses' consultations, but key areas of communication with each patient and operational processes within the nurse-led clinics. This colour coding also facilitated comparisons between nurses and also locations to search for

common elements and differences. The main themes were then developed from this process. Copies of all the transcripts, colour-coded diagrams and process maps were checked by the author's supervisor who has extensive experience in qualitative analysis. Following this a consensus for the key themes was agreed.

The results from each theme will be presented in turn, and then discussed in section three, starting with the central theme of autonomy.

### **5.2.5 Theme 1 Autonomy**

The nurse-led clinics are influenced by nurses' individual autonomy and there is clear variability across the four locations within this study. At location 1, nurses do not have written protocols guiding what they can and cannot do, and have similar freedom to medical staff regarding prescribing and the clinical management of patients, which creates greater autonomy for their clinical role. In addition nurses use their own personal autonomy by choosing whether to take on higher levels of clinical responsibilities, and this is evident by their clinical decision-making.

*"...the responsibility I sometimes struggle with is those patients that are borderline to go ahead with treatment... but because of experience and knowledge base I feel confident so I kind of overstep, work beyond a protocol because of intuition, knowledge and experience really, and so far it's usually been the right decision [laughs gently]" [I.L1.N3].*

Some nurses restrict their own autonomy by the way they work within the nurse-led clinics. This was evident in the way they structured their consultations with patients. This will be discussed further in the section on clinical and communication skills.

#### **5.2.5.1 Autonomy and advanced nursing practice**

Nurses considered there to be greater autonomy in advanced nursing practice than other levels of nursing. The main factors cited were clinical responsibilities and the level of clinical decision-making.

*"....to me working autonomously is a feature, and having the confidence and capability to achieve that, and having to take the flak if it's not right. I think it is around the decision-making, not having to rely on others to make decisions" [I.L3.N6]*



*"....to me that would be doing things really autonomously without any sort of back-up doctor wise, which I find a bit scary [laughs out loud]" [I.L3.N7]*

Here nurses associated increased autonomy with independent clinical decision-making and taking on medical responsibilities. From this several nurses perceived that medicalization of nursing roles equates to advanced nursing practice. In contrast some nurses recognised that this should be combined with nursing, rather than doctor-nurse substitution. Nevertheless nurses struggled to define specific aspects of nursing that advanced nursing practice would encompass.

*"It is additional skills beyond what would be expected of a registered nurse, taking on roles that would normally be the domain of a doctor and combining it with nursing. It should provide added value for the patient and organisation, not just a doctor replacement." [I.L1.N1]*

*"I think I see advanced nurse practice as very much a profession in their own right where they have the confidence and the ability to say 'no, and I think we should do it this way'...[if] you're doing a procedure, a procedure, a procedure, that to me is not advanced nurse practice, that's a specialist skill that you are doing and you're going to be very good at it because you're doing it all the time. The advanced bit comes in when you actually challenge how it's done, why it's done, what could we do better, [and] what evidence have you got to support that?" [I.L1.N3].*

However, some nurses saw advanced nursing practice more as a skills' set, associated more with certain courses and qualifications than responsibilities within nurses' roles. From observations it seems that the way nurses use their personal autonomy directly influences autonomy of their role, and one of the greatest influences appears to be nurses' confidence, although nurses' perceptions are underpinned by their personal beliefs. This will be addressed further in the section on beliefs.

Although autonomy is a central theme within this analysis of nurse-led chemotherapy clinics, it is closely influenced by the other themes of power, skills, knowledge and beliefs. There are two-way inter-relationships between all the themes, however each theme will be discussed separately to maintain clarity, starting with theme 2: knowledge.

## 5.2.6 Theme 2 Knowledge

The theme of knowledge has been broken down to incorporate knowledge of chemotherapy, oncology and processes, which includes signposting patients, coordinating care and other issues such as consent and emergency contact.

### 5.2.6.1 Knowledge: Chemotherapy

During clinic observations it was clear that nurses had a great deal of knowledge about chemotherapy drugs and potential side-effects, and they recognised the importance of chemotherapy experience in order to undertake nurse-led chemotherapy clinics.

*“...it’s been valuable that I’ve had chemotherapy experience, both administering it and seeing the side-effects, toxicities, and nursing neutropenic sepsis ...I think you could not run a nurse-led chemotherapy clinic without that experience, it would be foolish” [I.L1.N3]*

Nurses emphasised the importance of such knowledge and experience to assess patients and aid their clinical management during chemotherapy treatment.

*“I think you are okay to have your chemo because I think your splits [hands] are much better than what they were....your face is a lot better and your mouth is better ...do you feel up to having it?” [O.L3.N7]*

*“Yes, yes I do” [P47]*

*“I’ll keep an eye out for your kidney function and I’ll discuss with [consultant] whether we just omit that syringe full of chemo or we just dose reduce everything so that this hopefully won’t happen again. Hopefully you can carry on with the chemotherapy and not have any more of these side-effects” [N7]*

Nurses were aware of normal parameters for blood tests and used this knowledge to discuss clinical management with patients.

*“Your iron count your haemoglobin levels are a little on the low side” [O.L2.N11]*

*“What are they now?” [P41]*

*“They’re 9.9” [N11]*

*“Oh it’s not bad. It was 10 last week so it’s not gone down much” [P41]*

*“Yes it’s just trickling down, that can contribute to the tiredness. I’d say for the next couple of weeks just keep an eye on it. If you start to get more like excessive fatigue or any breathlessness then phone us through our triage number okay?” [N11]*

*“This is my last treatment” [P41]*

*“ Well done. Excellent, so it should probably just pick back up and go back to normal” [N11]*

There were numerous examples where nurses used this knowledge to educate patients and reassure them about physical side-effects of chemotherapy.

*"I do have some aches occasionally just in the lower part of my arm...and is that related to those?" [O.L3.P50]*

*Mainly we find the red coloured drug irritates the vein wall" [N8]*

*"Oh okay" [P50]*

*"And can set off sometimes like a pulling sensation?" [N8]*

*"That's right" [P50]*

*"When you outstretch your arm it can feel quite tight inside?" [N8]*

*"Yeah, yeah" [P50]*

*"Have you tried putting a warm flannel on there?" [N8]*

*"No, no. I didn't really know what it was so...if that's what it is?" [P50]*

*"Yeah some warmth will help that" [N8]*

*"Okay. I didn't know..." [P50]*

*"...with your veins we can get away with a smaller cannula because the docetaxel is diluted in a bag of fluid. It normally comes in 500 mls and goes through a pump and is pumped over an hour" [N8]*

Without using medical terminology, N8 discusses venous sclerosis with the patient, describing the symptoms and checking these with the patient's experience. The nurse then suggests a simple treatment of using a warm flannel to ease the symptoms, reassuring the patient about future venous access, since the chemotherapy will change from epirubicin to docetaxel, and finally explains how docetaxel is given.

In the next extract N2 explains about anaemia related to chemotherapy, outlining potential symptoms and the possibility of a blood transfusion.

*".... the most important thing really is the chemotherapy affects where your blood cells are made so you can become a bit anaemic which means you're a little bit pale, breathless and very occasionally we need to give a blood transfusion which with this chemo that's not common. It's unlikely that will happen" [O.L1.N2]*

Field notes: At the mention of the blood transfusion the patient puts her head in her hands and becomes tearful. Her husband reaches across to comfort her, putting his hand on her arm. The nurse looks sympathetically at the patient.

N2 continues to explain potential side-effects of chemotherapy, outlining the likelihood of them happening, based on her knowledge and experience.

*"It will also affect your platelets which are the ones that help your blood to clot...and if they're low it might mean that you will bruise a bit more easily than normal. Again it's uncommon to have a problem with that" [O.L1.N2]*

Nurses also used their knowledge of chemotherapy regimens to discuss treatment plans with patients. This is important to improve patients' understanding, as the following example shows. However, the nurse found it difficult to ascertain where the patient was up to in his chemotherapy and keep track of what he had been told by the consultant.

*"So you've had the oxaliplatin, which was the one that can cause a funny sensation in your throat, and the chemotherapy tablets?" [O.L3.N7]*

*"That was the 2<sup>nd</sup> one" [P45]*

*"The first one [W45]*

*"So you had one cycle of that only. And when you came back and saw [consultant] on the 18<sup>th</sup> of the 6<sup>th</sup> he put 'difficulty with cycle 1, sickness and diarrhoea, yeah? [N7]*

*"Yep, then he put me on that" [P45]*

*"...due to the oxaliplatin... not the chemo tablets, just the infusion" [N7]*

*"That's right" [W45]*

*"... so they've swapped you over to Cisplatin and the chemo tablets, so you've had one cycle of that. So this is now going to [pause] it will be cycle 3 altogether but 2 of the new one [N7]*

*"I'm going to have 2 of those new ones?" [P45]*

*"This will be number 2 of the new ones" [N7]*

*"Right, 'cause..." [W45]*

*"[interrupts] I was hoping this would be the last lot" [P45]*

*"No [laughs]" [N7]*

*"That's what we had to find out because obviously that first lot he had the infusion but only so many of the tablets" [W45]*

Although nurses were knowledgeable about chemotherapy, they recognised the limitations of their own professional role and the need to refer the patient on to other health professionals at times.

*"...we don't have expertise in COPD or asbestosis you know. We can look at your chest and make sure you're not infected and that sort of thing but you do need your on-going reviews for the chronic things that you have" [O.L3.N6]*

*"Now your blood pressure...you need to go and see your GP and get that sorted out" [O.L3.N7]*

*"Oh I told you you should go and see him" [W45]*

*"I would say you need to go and have your BP checked...and he's got letters from the hospital saying what medication you're on and he's the one who's sorting out your blood pressure" [N7]*

*"So you're advising me to not take nothing till I've seen him" [P45]*

*"No! I advise you to take your medication as it's prescribed at the moment, but go and see him" [N7]*

### 5.2.6.2 **Knowledge: Cancer**

Some nurses felt confident and competent with chemotherapy since they were familiar with the drugs and side-effects, but some did not feel as confident with aspects of oncology such as giving scan results to patients and knowing when patients had possible symptoms of progressive disease.

*“One of the thing that worries a couple of people is having to give them scan results and things like that, and if they’ve never done it before and they’ve never had training and that sort of thing so you’ve got to start with the basics and you know build up” [I.L3.N6]*

In contrast nurses at location 1 had gained greater knowledge of oncology within a specific disease group and were able to discuss issues of the patient’s cancer and treatment plan more freely than nurses at other locations. This appeared to be due to greater medicalization of their role. However their limitations were issues related to medical conditions other than oncology.

*“I think you need to be a very rounded person. You can’t just look at the cancer because these people are coming in with all medical conditions as well” [I.L1.N3]*

On occasion problems arose when it was the doctor’s responsibility to give scan results but the patient was seen in the nurse-led clinic. In the next extract P53 is anxious about her scan results but knows that by seeing N8 she will not get them that day. In addition no blood was taken for serum creatinine levels, and the nurse leaves the room to check with the consultant to see if this is essential prior to chemotherapy.

Field notes: The nurse leaves the room. I feel in a difficult position as the patient starts talking to me:

*“Oh God what else will treatment do to me?...My hair keeps falling out. Oh the joys of having cancer. I’m still here though. There’s a question mark over whether it’s in my bones or not. The lab think it is, consultant] thinks it might not be. I’m neutral on the subject, I haven’t decided yet but the fact that these aches are in the area where it might be bothers me, .which is why I’m still having these pigging infusions. I was saying to [consultant] the fact that it might be in my bones is bothering me and I know it is because I haven’t even looked it up on the net because I don’t think I want to know what the, you know what I mean? It’s sort of and I’m thinking ‘you’re daft’ it doesn’t make any difference whether you know or whether you don’t know, but you find yourself [pause] and then you think well if you did know you might not lie awake wondering [laughs]” [O.L3.P53]*

Field notes: N8 returns and immediately starts talking to the patient as she walks into the room. She closes the door and sits down.

*"Yes we have to do blood tests because you're on a study. I've phoned [consultant] on her mobile phone" [N8]*

Field notes: I feel uncomfortable as an observer given what the patient has just disclosed to me, since the nurse is unaware of this.

The patient doesn't bring this up again in the remainder of the consultation, however mentions to the nurse that if she'd been on the consultant's list she would have been given her scan results.

*"If I'd have come in and saw her I'd have got my scan result" [P53]*

*"I have double-checked whether she wants to go with the last one. She said because you're on the study we have to do a blood test now and send it off" [N8]*

*"Right but can you order the..." [P53]*

*"No she said she wants to see the creatinine. She wants us to..." [N8]*

*"[interrupts] Shit I'm going to be here forever! [P53]*

*"Er do you have a spare form on you or do you want me to do a form?" [N8]*

*"No..... Oh drat" [P53]*

Field notes: The patient seems angry but tries to contain it

*"I'm sorry" [N8]*

*"I told you today's not...." [P53]*

*"[interrupts] I thought I'd better double-check" [N8]*

*"It's just not worked today at all. So if I hadn't been in that traffic jam and have got here early enough I could have seen [consultant]. She'd have seen..." [P53]*

Field notes: The patient seems angry and frustrated

*"[interrupts] She would have sent you for a blood test*

*"There and then. I could also have got my scan result and then I wouldn't have needed to see her next week...." [P53]*

*"Right, I see" [N8]*

Field notes: The nurse returns to the computer to print off the blood forms

*"Because when I have to see her I'm here forever" [P53]*

*"Now will you need another set of blood forms?" [N8]*

*"No I've got loads at home.....that's 2 veins that we've got to find today. Trying to find veins in my hands is not the easiest thing in the world, especially when it's cold...they won't even order my drugs until after the blood test" [P53]*

*"I'll do it now alright" [N8]*

*"But that's at least 3 hours I'm going to be here" [P53]*

Field notes: The patient starts to get upset and begins to cry as she leaves the room. The nurse asks her to go next door for a blood test

This was a difficult consultation because P53 was expecting to see the consultant and be given her scan results. P53 felt frustrated about the blood tests, but N8 was reiterating what the consultant had told her to say. P53 was understandably anxious about the results and voiced worries about bone metastases when N8 was out of the room. However, N8 did not appear to pick up on her anxieties, even though the patient left in tears. Instead N8 focussed on the practicalities of blood results and chemotherapy, deferring the scan results to the following week when P53 would see the consultant.

In contrast, other nurses may approach difficult issues in a different way by focussing more on what the patient is saying and the implications of scan results. In this example N7 starts off with practicalities and then immediately picks up on what the patient is saying about not wanting further treatment if the scan shows progressive disease.

*“...he’ll do 4 cycles and then do a CT scan” [O.L3.N7]*

Field notes: The nurse reads aloud the last annotation on the computer, but then turns round to directly face the patient.

*“Right” [P45]*

*“Right? And see how the chemotherapy has worked” [N7]*

*“Responded?” [W45]*

*“Yeah. If the chemotherapy has responded and things have shrunk down then they would go on for another 4. Alright?” [N7]*

*“Yeah. But if it aint, I won’t be having no more anyway?” [P45]*

*“Well you don’t know” [W45]*

*“I won’t. I’m telling you. It’s my decision” [P45]*

*“He’s decided, yeah?” [N7]*

*“Okay, that’s fine yeah, whatever” [W45]*

*“I done it this time and I aint doing it a second or 3<sup>d</sup> time, as far as I’m concerned. And if it only keeps me alive for a month or maybe two” [P45]*

*“Well you don’t know. It’s one of those things” [W45]*

*“I think don’t jump the gun, don’t count all those bridges” [N7]*

*“Right” [P45]*

*“Let’s do the 4 cycles and then look at your CT scan and see how things are” [N7]*

*“Right we’ll do that” [P45]*

*“We have to. You know there’s no point in jumping the gun and saying right I’m not having anything else because we don’t know what the scan’s going to show. Also erm you know you’re saying that now but if*

*there was something like it may have a bit of mixed it might have mixed the CT scan, you might have some things that have shrunk and something might have got a little bit bigger so it might mean we might have to shift chemotherapy to a different one to see if we can make things even better"* [N7]

*"Right. Re-tuning?"* [P45]

*"Yeah, but it is your choice ultimately though"* [N7]

*"Of course"* [W45]

*"Because the side-effects can sometimes outweigh the cancer itself, alright?"* [N7]

*"And sometimes you feel that bad you think 'stuff it'"* [P45]

*"Yeah I can understand that, I really can"* [N7]

Although the nurse seems to struggle with this difficult issue, and her explanation of possible scan results lacks clarity in places, she acknowledges what P45 is saying and talks it through with the patient and his wife.

### **5.2.6.3 Knowledge: Processes**

Nurses were very knowledgeable about processes surrounding chemotherapy clinics, and often used this to inform and educate patients. Nurses spent time signposting patients regarding departments in the hospital, such as where to go for blood tests, pharmacy, chemotherapy and radiotherapy.

*"...So do you normally pick up your tablets from pharmacy or do they deliver them upstairs?"* [O.L1.N1]

*"We're not, we picked them up last week, didn't we?"* [looks across at her husband, who nods] [P1]

*"Yes?"* [N1]

*"Yes, and the week before"* [P1]

*"Yes. Before you go upstairs for your treatment just pop along to pharmacy and ... make sure things are ready, and take them up with you"* [N1]

A great deal of nurses' time involved checking to make sure patients had the appropriate blood forms.

*"And you've got one of these [forms] for next week?"* [O.L1.N3]

*"Yes, we're all organised"* [P27]

*"I'll get you a blood card for you now. That's for next time"* [O.L2.N10]

*"Yes"* [P38]

*"....now did I give you a new blood form on Monday?"* [O.L1.N1]

*"Yes. I had those done"* [P1]

*"Now did you use the form that I gave you? They haven't done one of the tests I asked for, don't worry I can work that out for you."* [N1]

*"Oh"* [P1]



There were also instances where nurses used their knowledge of the hospital, and experience within their role, to discuss other issues with patients and signpost where they should go for advice and information.

*"I told the lady yesterday I think I'm wasting your time because I can't get nowt"* [O.L1.P26]

*"He can't get any benefits"* [D26]

*"If you want to while you're here you can nip to our social work department and ask for one of those forms, and then you can take the bit that you need to fill in and I can take the other. Basically this DS1500 supersedes everything else so you don't have to fill out a disability living allowance or anything like that. When I fill the report out there may be a little bit more information on there than the information that we spoke to you about because to get you what you're entitled to this disease is serious and if we don't treat things could be difficult in another 3-4 months. Alright?"* [N3]

*"Yeah"* [P26]

#### **5.2.6.4 Co-ordinating patients' care**

Nurses also took responsibility for coordinating patients' care, which often involved checking and helping to book appointments for chemotherapy, radiotherapy, medical clinics, investigations and transport.

*"So I was going to get you booked into [consultant] clinic in about 4 weeks so that he can get the scan requested so that you can have it for the end of the 2nd cycle to see how you are getting on"* [O.L2.N9]

*"N7 And you've got your appointment to see [consultant]?"*

*P44 Yep*

*N7 And you've got your scan? .....*

Field notes: The patient nods his head

*"Do you want another set [blood forms] just in case?"*

*P44 No, no*

*"...and we'll just make sure that the transport's booked. If you just check with them on your way out today. When you get your transport check that you're booked for a pick up tomorrow, and then your next one after that will be Tuesday"* [O.L1.N1]

Coordinating different appointments during chemotherapy often took the nurse's time both during and after the clinic.

*"What I'll do I'll phone radiotherapy just to make sure we get all these dates absolutely ...spot on before you leave today"* [O.L1.N1]

*"Okay kokey"* [P2]

*"What I've been told and what the consultant wants....is she wants you to start your radiotherapy on Tuesday, okay?"* [N1]

*"Yeah. So what about tomorrow?"* [P2]

*"Tomorrow we still want you here because we could do your blood transfusion tomorrow" [N1]*  
*"Oh right" [P2]*

Nurses spent a great deal of time explaining such processes to patients, including the timing and rationale for investigations and treatments.

*"Have you had a scan date come through yet?" [O.L1.N3]*  
*"No. I know I'm due for one. When will that be? After my 2<sup>nd</sup>?" [P29]*  
*"After your 3<sup>rd</sup> cycle" [N3]*  
*"The 3<sup>rd</sup> cycle?" [P29]*  
*"Between the 3<sup>rd</sup> and 4<sup>th</sup>. It should be in the pipeline now" [N3]*

*"When she's finished in 3 weeks' time when she's finished the last of the radio does she come back for any clinics between the following week?" [O.L1.H8]*  
*"Not normally. We usually send patients away for 6 weeks to let everything settle down" [N2]*

#### **5.2.6.5      *Emergency contact***

At all locations nurses would signpost patients, explaining who to call, when to call and why they should call. All locations had a triage system for emergency or hotline calls, which was staffed by either a doctor or nurse practitioner. This was usually the first point of contact for emergencies or advice during chemotherapy.

*"And the hotline is there for any queries that you've got as well. Obviously you're coming every day so if it's something routine just ask to see me or one of the doctors and we'll come to see you. But if something is happening and you think I don't know if this is right or wrong just give the hotline a ring okay?" [O.L1.N2]*

#### **5.2.6.6      *Consent for chemotherapy***

There were differences between the four locations regarding the process of obtaining informed consent for chemotherapy. At location 2 doctors had responsibility for consenting patients whilst at location 1 the nurses had sole responsibility for this.

*"So are you happy to sign a consent form? Or if not happy, willing?" [O.L1.N2]*  
*"I'm willing" [P11]*

Field notes: The nurse shows the patient the consent form. The patient signs the consent form and gives it back to the nurse.

*"So just sign there and print your name [pause]...put the date across there. There's your copy. Your bloods are fine" [N2]*

Field notes: The nurse tears off the top copy and hands it back to the patient, then puts the other copy in the patient's notes.

However, the process for obtaining informed consent varied at locations 3 and 4. Sometimes this was undertaken by the nurse and other times by the doctors, although nurses sometimes had to check with the patient to see if this had been undertaken.

*"...and you signed a consent form with him [consultant]?" [O.L2.N9]*

*"Yes" [P37]*

*"Did he give you the gemcitabine leaflet?" [N9]*

*"Yes" [P37]*

*"You didn't sign a consent form did you? ...for the Herceptin?" [O.L3.N7]*

*"He asked me to get you to sign it today. He said [N7] will get you to sign a consent form" [P45]*

*"Oh yes he did mention it" [W45]*

*"I know him so well. Have you had the information on Herceptin?" [N7]*

*"No" [P45]*

*"I bet you haven't" [N7]*

*"No, no I assure you" [W45]*

*"I know, I know him very well" [N7]*

*"Well he might have done. I'm not sure 'cause all the paperwork is at home" [P45]*

*"No he won't have done" [N7]*

Here it seemed that the consultant knew it was his responsibility to consent the patient, but wanted N7 to do it when she saw the patient. By the tone of her voice N7 didn't seem irritated that the consultant hadn't done the consent form, but her sarcasm implied that this was a regular occurrence, which she accepted.

### **5.2.7 Theme 3 Skills**

The theme of skills has been broken down into three main skills: prescribing, clinical skills and communication skills. However, in all of these areas there are relationships with the other themes of power, autonomy and beliefs.

### 5.2.7.1 Prescribing

Prescribing practices varied across all four locations. At location 1 nurses could prescribe freely from the British National Formulary, as long as it was within their area of competence.

*"I'll give you some more paracetamol and I'll give you some morphine solution. Okay?" [O.L1.N2]*

*"... we'd need to switch your warfarin onto daily injections" [O.L1.N1]*

At locations 3 and 4 nurses were not allowed to prescribe the first cycle of chemotherapy, although they could prescribe other cycles of chemotherapy. At location 2 nurses were restricted to prescribing from a 'P formulary' which severely restricted what they could and could not prescribe and made them more dependent on doctors.

*"We have to stick to our own protocols, our own personal P Formulary... [if] we want to add more onto our P Formulary we have to apply to do ... it's very very frustrating because the process is so slow and I think it's holding us back if you consider the amount of training that the nurses have gone through" [I.L2.N4]*

*"Well I can only prescribe 5 days of cyclizine" [O.L2.N9]*

*"So I'll ring her when I go home" [P37]*

*"Yes, but I can see if one of the other doctors would give you 10 days so that would be enough to tide you over..." [N9]*

One nurse had not completed the prescribing course, therefore had to ask colleagues to prescribe chemotherapy and any supportive medication that the patient may need, which caused delays for those patients.

*"I don't prescribe either so I do the assessment toxicity scale and then I ask the doctor to prescribe it" [I.L4.N14]*

However, alternating appointments with doctors sometimes caused difficulties for nurses if drugs had not been prescribed.

*"I saw [doctor] last month and I don't know what happened but she never ordered the pamidronate so I never got it" [O.L3.P54]*

*"Alright, I'll check" [N8]*

During observations there was good evidence that nurses had a thorough knowledge of medicines that they were prescribing, and discussed this appropriately with patients to improve their understanding.

*"We'll give you some vitamin C to put on the back of your tongue just to help. It will froth up, and then it will help with that coating at the back"* [O.L3.N7]

*"Oh right"* [P46]

*"And then your taste buds might repair a bit better"* [N7]

*"I think the sickness on Saturday was almost certainly due to radiotherapy"* [O.L1.N2]

*"Is that something that's going to get worse"* [P11]

*"No"* [N2]

*"With the radiotherapy?"* [P11]

*"...that is enough to cause pressure on the vomiting centre in the brain so that tends to make you sickly and then the usual management of that is not just classical anti-sickness tablets it's steroids"* [O.L1.N2]

*"Right"* [P11]

*"And with your chemo, as part of your anti-sickness with your chemo we'll give you some steroids so I think that will settle down anyway. So you shouldn't get sickness from the radiotherapy and it shouldn't occur again"* [N2]

Knowledge about medicines seemed to make a difference during consultations with patients even though this did not always result in a prescription being made.

*"Now your omeprazole, it can be if you're getting quite a lot of the indigestion-y type pain, then you can take 40mg once a day"* [O.L3.N7]

*"Which is what I was on before, and the other thing I haven't been able to take is my statins, what d'you call it?"* [P45]

*"Yeah that's for cholesterol"* [N7]

*"I haven't took that for months. The Macmillan nurse told me not to bother..."* [P45]

*"[interrupts] She told you not to worry about that"* [W45]

*"She said that's not important. She said if you don't feel too good with 'em 'cause I had a job swallowing 'em, because every tablet I had a job to swallow. I even stopped taking my chemo I was crushing it up, melting it down in the water and that tasted horrible, because I couldn't swallow them but now I'm swallowing them again"* [P45]

*"So you're swallowing's better isn't it?"* [N7]

*"Oh yeah"* [P45]

*"And he can eat okay now"* [W45]

*"I can eat, it's just I've got to watch what I eat"* [P45]

The above extract shows how a discussion about medication may open up the consultation into an exploration of patients' concerns and symptoms.

The following section focuses on nurses' clinical skills.

### **5.2.7.2 Clinical skills**

When nurses started to develop nurse-led chemotherapy clinics they adopted a checklist structure to record toxicities from chemotherapy, which appeared to influence the structure or style of their consultations with patients. Some nurses reported using written checklists initially, then as their confidence improved this use decreased.

*“...as it’s gone on we’re very much following like checklists and things, and I think when you become more experienced you stop using the piece of paper so much and it becomes quite natural” [I.L4.N13]*

Using a checklist seemed a quick way of assessing the severity of chemotherapy toxicities. A pharmacist reported using a very structured checklist when a nurse-pharmacist clinic was first set up and then used the same checklist from memory as she gained experience:

*“...if we go thoroughly through the list ...we have checklists – so we can go through these and it’s just to remind us that you don’t forget to ask any important questions... In the beginning you are very careful of going to ask for every single small thing and then you learn because it’s the same drugs, same side-effects, same symptoms, same problems. The more you see the more confident you are in managing them.” [I.L4.Ph15]*

Previous use of a checklist appeared to create a conditioned response in that nurses continued to use a checklist approach during interactions with patients. Consequently nurses placed greater emphasis on the physical side-effects of chemotherapy and practical aspects of treatment, with less emphasis on psycho-social concerns. However nurses perceived that they were using a holistic approach.

There were also differences in the structure of the consultation between the four locations and also individual nurses. This appeared to be influenced by several factors including training, nurses’ roles, experience, confidence and perceived autonomy.

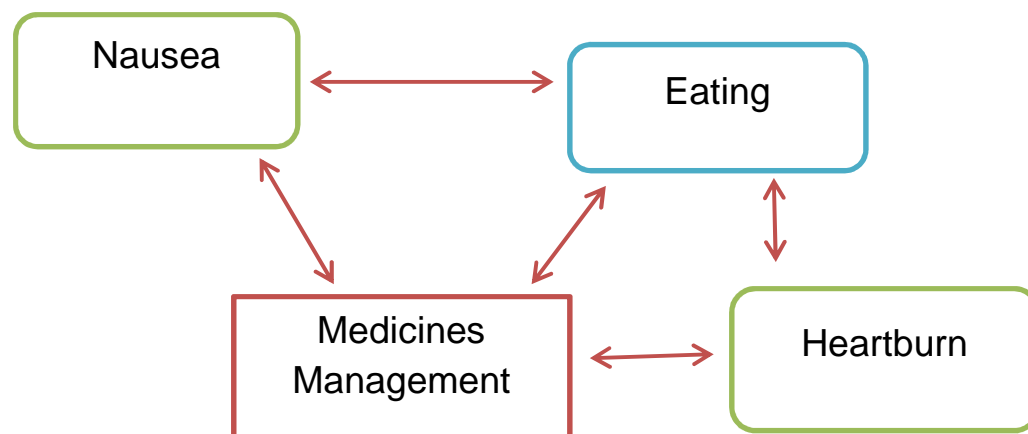
### **5.2.7.3 Clinical consultations**

There were many instances where nurse consultations lacked structure and took a circuitous route, moving back and forth between exploring physical symptoms and medicines management. The following diagram represents a consultation between N1 and P3. Starting with nausea, N1 explores the

frequency of nausea and medication, and then asks about eating, moving quickly onto medicines management. N1 then goes back and forth between eating, heartburn and medicines management in a haphazard way, which reflects the majority of nurse-patient consultations.

**Figure 5.1 Example of a consultation pathway**

Nausea [O.L1.N1.P3]



Some symptoms were more likely to prompt an immediate discussion about medicines management, such as nausea, heartburn and diarrhoea or constipation.

*“Obviously this drug capecitabine can affect the bowels”* [O.L3.N8]  
*“Yes I do get diarrhoea but I take loperamide”* [P51]

*“...has the sickness been on the Thursday?”* [O.L1.N1]  
*“Yes...and then over the week-end”* [P1]  
*“Okay have you tried taking those anti-sickness tablets 3 times a day and just keeping them regular?”* [N1]

*“I was terribly constipated, and it’s still not right but it’s at least...”*  
 [O.L1.P4]  
*“[Interrupts] Did you start the fybogel?”* [N1]

Symptoms of pain, including sore mouth, almost always resulted in a discussion of medicines, which did not address the physical and psychological impact for individual patients.

*“...it [mouth] was sore when I came in. How do I control it?”* [O.L1.P15]  
*“I think we might need to reduce the dose of one of the drugs a little”* [N2]  
*“...I tried to drink water and it was like a thousand daggers in my throat”*  
 [P15]  
*“Yeah....and I’ll also give you something for thrush...”* [N2]

In the following extract N1 asks about the patient's symptoms and then talks about medication. However the patient was referring to her cancer, which N1 doesn't acknowledge since her priority appeared to be medicines management.

*"...you mentioned having something with your tummy?" [O.L1.N1]*

*"Oh yes. It's a draggy feeling and the pain underneath" [P5]*

*"Right" [N1]*

*"Obviously from what I've got" [P5]*

*"And does the co-codamol work for you?" [N1]*

Some nurses had complex discussions with patients about pain that incorporated a number of different symptoms. In this example from the consultation between N2 and P11, N2 allows the patient to fully describe her symptoms by making small verbal encouragements. When P11 asks whether the pain will get worse, N2 answers this difficult question honestly with an explanation of the complexities regarding the patient's pain, implications for her cancer, and potential changes over time.

*"I get this pain. Complete tingling in here [throat] and up into my ear...a sort of big tingling in the back and it gives me a headache" [O.L1.P11]*

*"Yeah" [N2]*

*"And my ears go pop as well" [P11]*

*"Right" [N2]*

*"My speech is more awkward" [P11]*

*"Is it?" [N2]*

*"Is this going to happen? Is it going to get worse before it gets better?" [P11]*

*"I think some of it will get better. I think the pain in your ear will go because there's a nerve that supplies the back of your tongue and also has a branch to your ear so you get pain in your ear and your tongue. It's nothing to do with anything [cancer] spreading anywhere it's just the signalling of that nerve. I think as the tumour gets smaller the ear thing will go. Unfortunately the downside is that ...your throat will get more sore, but that's a little way in the future yet" [N2]*

N1 has a long consultation with a young patient who looked generally unwell and in pain. The patient had advanced cancer and prognosis was poor, however she was due to start a new course of chemotherapy.

*"My breathing hurts" [O.L1.P6]*

*"All the time?" [N1]*

*"...in certain positions" [P6]*

*"You're rubbing here on the right side...is that where...?" [N1]*

*"Yes that's where it's sore" [P6]*

The nurse asks whether this is a new pain, whether it's constant, if anything relieves it, whether it's worse lying down and then how she is sleeping. The



patient is on fentanyl patches and oxynorm. A few minutes later the patient suddenly looks in pain and stops the nurse:

*"I've got stomach pains again now" [P6]*

*"Where is the pain at the moment? Can you point to it?" [N1]*

*"My stomach's just gone solid" [P6]*

Field notes The nurse thinks the patient may be constipated and asks about bowel movements then examines the patient's abdomen, which is swollen. The nurse discusses analgesia and laxatives and then has difficult discussions about the patient's cancer and potential benefits of chemotherapy.

In this consultation between N1 and P6 the clinical examination was pivotal to the consultation in assessing the patient's cancer to determine her fitness for chemotherapy. Fatigue was a common symptom that either nurses asked about or patients mentioned to the nurse. However, although the extent of fatigue was discussed it appeared to be taken for granted due to its common occurrence during chemotherapy. Nurses did not discuss any strategies with patients that may help to reduce fatigue, nor did they appear to fully acknowledge the impact of it.

*"...Tired. I mean you have to remember that you are ill but I tend to ignore it and then feel absolutely exhausted" [O.L1.P22]*

*"Yes...do a bit too much?" [N2]*

*"Yeah, yeah. My wife says stop, stop..." [P22]*

#### **5.2.7.4 Nursing assessments**

A significant part of nurses' clinical assessment involved visual assessment of patients. Some of the visual assessments were not voiced, therefore it was difficult to appreciate nurses' perceptions and any nuances relied on the skills of the observer. For example nurses rarely commented on patients' general appearance, how they walked in or out of the clinic room, how they sat and what their facial expressions appeared to signify. During the observations it was impossible to know how many times the nurses picked up that certain patients were tired, in pain, anxious or distressed unless there was some verbal acknowledgement of this.

However there were instances where some nurses failed to notice a patient or relative becoming distressed because they were not looking directly at them. In

this example N7 was looking at the computer screen whilst talking about a sensitive issue and did not notice that the patient's wife was becoming distressed.

*"In yourself...are you okay or a bit like that at the moment because you've got a scan coming up?" [O.L3.N7]*

*"When...where?" [P44]*

*"He's a bit deaf you see" [W44]*

*"Oh a bit deaf [laughs]... No how are you feeling about your scan?" [N7]*

*"Oh no that's fine" [P44]*

*"Are you going with the flow?" [N7]*

*"Oh yes you just gotta go with the flow. There's nothing I can do. There's nothing I can do is there? I'm in everybody's hands...some are better than others I can tell you but [laughs]" [P44]*

*"I think Carole's going to have a laugh when she listens to this" [N7]*

Field notes: 'The patient jokes about the scan but his wife looks upset. He taps her arm but she moves away trying not to cry and then dabs her eyes. The nurse does not pick up on any of this as she is checking the bloods on the computer and her back is to the patient and his wife. I feel uncomfortable watching and doing nothing'.

#### **5.2.7.5 Visual assessments**

Visual assessments occurred frequently during patient consultations. In the chemotherapy clinics the most common areas that nurses inspected were the patient's mouth, skin, hands and feet. Using a pen torch nurses examined patients' mouths for ulcers, erythema and thrush, although on selected patients and mainly when patients had raised concerns about their mouth.

*"Let me just have a look at the top of your mouth then...oh yeah it's a bit patchy at the top there..is it sore when you swallow?" [O.L3.N7]*

*"No...stinks don't it?" [P45]*

*"What?" [N7]*

*"It stinks me breath?" [P45]*

*"Stick your tongue out...it's a bit coated...what I'm going to prescribe...it looks like there might be....let me just have a little...put your tongue back in and say ahh....yeah it looks a bit thrush-y at the back there..." [N7]*

Skin on the arms, legs and face were sometimes inspected for rashes and discoloration. Hands and feet were inspected for erythema, discoloration, skin peeling and nail changes, and veins on the hands and forearms were sometimes inspected for venous access, phlebitis, sclerosis and discoloration.

"Okay. Can I just have a look at your hands to make sure they're not going too red" [O.L3.N7]  
 "They're freezing" [P45]  
 "Yeah you are cold, aren't you?" [N7]  
 "Yeah" [P45]  
 "He's always cold" [W45]  
 "And for some reason even this one feels as though I've dug something right through there, like a nail gone through it's hurting a bit" [P45]  
 "Tender he said" [W45]  
 "Tender? Yeah?" [N7]  
 "Only today. I'm always cold...my hands and feet are always freezing" [P45]  
 "But no what we call red hands or feet from the tablets?" [N7]  
 "No" [P45]

Field notes: The nurse holds the patient's hands whilst she examines them. This seemed to serve a dual purpose of inspecting the patient's hands and therapeutic touch.

"And last time the hands were a bit pink so..." [O.L3.N8]  
 "[interrupts] That's always been a bit different since the chemo when I had it 4 or 5 years ago" [P51]

Field notes: The patient shows the nurse her hands, and the nurse holds the patient's hands whilst she examines them

"Right, so it's always been..." [N8]  
 "[interrupts] It's always been slightly purple, but not too bad" [P51]  
 "They're warm aren't they?" [N8]  
 "Yeah....and my feet are actually a lot better than they were" [P51]

Field notes: The patient takes the shoe off her left foot to show the nurse the skin on her foot

"Oh yes they are aren't they?" [N8]  
 "Yes a lot better now" [P51]  
 "They're very dry aren't they?" [N8]  
 "Yes I've been putting cream on so they're a lot better, so I'm having no problems" [P51]  
 "So have you managed...what sort of cream have you been using?" [N8]  
 "E45" [P51]  
 "Good" [N8]  
 "It works a treat so..." [P51]  
 "And I can see they haven't got any worse from where they were" [N8]  
 "No, no...they feel fine" [P51]  
 "They haven't cracked at all?" [N8]  
 "No, no" [P51]  
 "Or peeled?" [N8]  
 "No" [P51]  
 "Excellent, brilliant" [N8]

Holding the patient's hands whilst examining them also gave nurses the opportunity of checking the temperature of the patient's hands and condition of the skin. In the above extract the nurse can feel that the patient's hands are warm and the skin is dry. She then checks what cream the patient has been using and checks on previous skin integrity, which is important during the chemotherapy. However, it also seems important to be mindful of other chronic conditions that patients' may have, rather than focussing solely on chemotherapy and cancer.

*"I notice you've got some sore knuckles? Is that long-standing?"*  
[O.L3.N6]

*"No that's arthritis darling"* [P49]

*"Oh right. Take tablets for that?"* [N6]

*"Yeah"* [P49]

*"But how does that affect you?"* [N6]

*"Well it used to be very very painful"* [N6]

*"Yeah?"* [N6]

*"I used to cry with it...and they give me this medication which I'm on now and it eases it off"* [N6]

*"Okay, good"* [N6]

#### **5.2.7.6 Clinical examination**

Some nurses recognised the importance of clinical examination skills and used them frequently, whilst others were more selective about the nature and frequency of clinical examination.

*"I think it's important if you can do an examination because you never know when you're going to have to do it. For instance if I thought the patient had a PE [pulmonary embolism] then I would get a full chest examination and go on for clinical investigations, but I wouldn't necessarily do a neurological examination unless they came with possible spinal cord compression....and if I was just doing the chemo clinic those skills would deteriorate quite quickly"* [I.L1.N3]

Having clinical examination skills allowed nurses to check out patient's symptoms during the consultation, which could be important for clinical management during chemotherapy.

*"Just show me...point to where it..."* [O.L1.N3]

*"Around there"* [P28]

*"So it's quite high up isn't it?"* [N3]

*"Yeah"* [P28]

*"So what I'm going to do, I'm going to feel all round here first then I'm going to come over there....nice and soft...I can't feel your bladder, which is good"* [N3]

*"Oh..."* [P28]

*"Because sometimes you're not passing [pause] cough [pause] again [pause] I can't feel anything that's troublesome" [N3]*  
*"No...." [P28]*  
*"Your tummy's nice and soft...does it hurt when I press?" [N3]*  
*"No, not really" [P28]*

Field notes: The nurse examines the patient's stomach

*"I am happy to carry on today. You are getting side effects. They're normal side-effects, which we would expect at this stage. If anything happens overnight or you're not so well tomorrow [consultant] is going to be seeing you tomorrow in clinic" [N3]*

Some nurses recognised the importance of clinical skills and wanted to use their skills, but lacked confidence to do so.

*"I have done a physical examination course but because I've never used it I wouldn't like to suddenly start examining patients.... I'd like to actually build my skills up again, especially about doing the lung clinic ... listening to their chests and making sure that they're okay..." [I.L3.N7]*

This suggests that although knowledge and training are important for nurse-led chemotherapy clinics, other factors warrant consideration since they may directly influence the autonomy of nurses' clinical roles. The issue of confidence and clinical examination will be discussed further within the theme of beliefs.

The next section presents the findings in relation to communication skills within nurse-patient interactions.

#### **5.2.7.7      Communication skills**

Talking to nurses it seemed clear that knowledge alongside experience was crucial for nurse-led chemotherapy. However, developing nurses' roles in this way appeared to add different layers of subtle complexities that were less tangible but equally important to the nurses in this study. Although communication skills have implications for several themes within this analysis, the main presentation will be within this section.

Some nurses recognised the complexity of communication with patients, discussing different depths to communication skills such as breaking bad news and handling uncertainty. N6 conveyed differences in 'closed door' consultations that arose from seeing patients in a consulting room rather than on the chemotherapy unit. She reported that this changed the nature of nurses' communication with patients, and this required additional skills and confidence.

*“.....also the kind of like breaking bad news and managing uncertainty, the more you do it and the more experienced you get. It's very different to being in the treatment room to coming having this closed door conversation you know it's about confidence and er developing those skills” [I.L3.N6]*

## **Communication styles**

Nurses' communication style appeared to have a significant influence on the consultation with patients and nurses reported this to be one of the main differences between nursing and medical consultations, suggesting that nursing care was holistic.

*“It's more clinically driven [doctors' consultations] perhaps than my approach is with the patients” [I.L4.N13]*

*“I think more sort of important than that is actually looking at the patients holistically ... rather than sort of medically managing them. I see nurse-led clinics as being a nursing model, not a medical model to be honest...as a minimum to care for a patient who's receiving chemo, with care being the important element of it” [I.L2.N5]*

However, N3 suggests that external factors may influence her consultations with patients, and she can switch between medical and nursing models of care.

*“...the patients say 'oh he [doctor] said he was a bit rushed and he was a bit short with me, he didn't listen to this' so I think they just do kind of the...the bloods, chemo, ok, prescribe. Where a nurse I feel will go in and say open question: 'how are you today?' Erm... not just did you have, did you have, did you have. Yes, so I think the structure of the consultation with the patients can be different and I'm very well aware when I'm busy that I will change into a medical mode. Erm and when I'm not so busy or the patients... [if] I can see that patients need me to be less medical then I would change.” [I.L1.N3]*

Observing nurses at all four locations it was clear that when nurses focussed more on physical symptoms and medicines management there was little or no discussion of psychological concerns or feelings. This was particularly apparent at location 2 where nurses used written checklists and focussed mainly on the chemotherapy and its toxicities. There were several examples of poor communication with patients, as shown in this extract:

Field notes: [O.L2.N10] N10 immediately starts setting up the infusion pump for a new patient and then walks away without saying anything. The patient and relatives sit quietly. Another nurse attends to the patient in the next chair and you can hear all the conversation very clearly,

including detailed information about problems with the patient's bowels.

Two minutes later N10 returns and sits down facing the patient.

*"So what I'm going to do is I'm going to put a needle in your arm. I'm going to give you some anti-sickness first, then your chemo. It will take about an hour. Would you like to ask any questions before I start the treatment?"* [O.L2.N10]

*"No thank you"* [P38]

Field notes: 'The patient sits quietly, looking very anxious'

*"Okay do you fully understand what's happening with you about side-effects and everything?"* [N10]

*"I beg your pardon?"* [P38]

*"Do you fully understand about your side-effects?"* [N10]

*"Yeah"* [P38]

*"Okay. Date of birth please?"* [N10]

Field notes: 'The nurse picks up the prescription and checks the patient's details against it'

*"Can I give you some anti-sickness tablets to take now?"* [O.L2.N10]

*"Do I have them now?"* [P38]

*"Yes please"* [N10]

Field notes: The nurse gives the patient some tablets in a medicine pot, which she takes without asking what they are. The nurse puts a cannula in the patient's left arm then connects the infusion and attaches it to the infusion pump. The patient's husband asks':

*"Is it just the one bag?"* [H38]

*"No that's just the flush. What I'm going to do I'm going to put up her chemo in a minute. That's okay now"* [N10]

Field notes: The nurse barely glances at the patient, putting used needles in the sharps bin, and then turns back to the patient'.

*"Do you feel okay? Are you feeling fine? Is it sore or anything? No? Okay. If you feel any sore or pain or stinging at any time you need to let me know straight away, alright?"* [N10]

Field notes: The patient doesn't speak, she just nods and shakes her head to indicate yes and no, then nods her head slowly looking anxious. The nurse doesn't seem to be aware of the patient's feelings and continues with the infusion.

*"Okay, so I'm going to put the chemo up...if you feel any different, any abnormal you let us know straight away alright?...okay date of birth again please?"* [O.L2.N10]

*"\*\*\*\*\*"* [P38]

*"Thank you.....okay I'm going to put the chemo up now. It takes about an hour" [N10]*

Field notes: The nurse checks the chemotherapy bag against the patient's details, then takes down the bag of saline and replaces it with the chemotherapy, attaching it to the infusion pump.

Although the nurse had the technical skills to cannulate the patient and commence her chemotherapy safely, nursing care and compassion were neglected.

### **Communication as a skill**

Although nurses had received training in history-taking to assess patients, it was not clear whether nurses had undertaken advanced communication skills training. In addition, some nurses felt that doctors were more skilled in communicating with patients about certain aspects.

*"I can see that when I go down if there's a complicated case or something when you get a doctor involved their approach is different and it...depends on the doctor but sometimes it's really interesting to watch because they seem to find the problem, the clinical problem, faster and look at a wider scope than I would" [I.L4.N13]*

In contrast, some nurses felt that their communication skills were better than doctors and discussed how this was beneficial in chemotherapy clinics:

*"I think as a nurse I probably get more out of my patients than what a doctor does ... patients open more up to you and they would tell you what's worrying you, rather than tell the doctor" [I.L3.N7]*

*"...when patients you know obviously come in and say to me 'I don't want to have any more chemo' and I think as a nurse you can actually talk to them in words that they understand so they can make the right decision whether they want to stop or not" [I.L3.N7]*

Nevertheless, at all four locations nurses perceived the nurse clinic had advantages over medical clinics, and some nurses thought the benefits were related to communication skills and holistic approaches.

*"...better documentation of the toxicities associated with their treatment ... better evidence of a more holistic assessment of those patients" [I.L4.N12]*

However, nurses did not elaborate on their definition of holistic and there appears to be variability in their interpretation.

*"I feel that it's a bit more personal... I wish I could explain it ... it's not so much hierarchical I would say in the relationship...I think it's a bit more of*



*an overall care that they get....often ask about their families 'cause we see the families come up with them and things like that so I think it's a bit more of a holistic approach in the nurse-led clinics" [I.L4.N13]*

At times nurses appeared to struggle to define their own role and potential differences between medical clinics, suggesting that differences may not always be tangible or quantifiable.

*"[it's] the subtle things....I often like touch patients, hold their hand and just talk to them...and I think that's what the difference is, that they do start talking about lots of things" [I.L4.N13]*

However, this was not seen in the clinic where N13's consultation was brief. In the following interview the nurse seemed defensive yet appeared to show a great deal of insight and empathy for the patients.

*"That consultation was very quick, and normally we can be here for like an hour and not talking about the chemotherapy, it's talking about everything else that goes on in their lives, particularly with this group of patients I've found that a lot of it is just getting it through...getting through the treatment rather than...the physical things that don't.... aren't always the things that are holding it back. That was very unusual for it to be that quick...normally, yeah and it's not, it's not the complicated...it's not the nausea and vomiting, and things like that often, it's the anxiety, the fear, and that's what we end up talking about even though I'm not an expert on it, but I think sometimes just talking about it is...but I think as a nurse...you wouldn't get that in a medical clinic because they don't have the time either whereas we do.... we had one patient today [laughs out loud] so I do have the time" [I.L4.N13]*

In the main nurses used a physical or practical approach focussing on physical symptoms, medicines management and operational aspects of treatment, such as blood forms and results.

### **Communicating with patients**

When nurses were assessing patients' side-effects they often used closed questions, leading questions, multiple questions or a negative style of questioning patients. Asking a series of closed questions in this way made the consultation appear stilted and produced minimal responses from the patient.

*"And has your hair completely gone now?" [O.L2.N9]*

*"No strangely enough I've still got hair but I just got it all cut" [P39]*

*"Very patchy or....?" [N9]*

*"No it's been coming out in handfuls, just mainly on this side" [P39]*

Field notes: The patient laughs quietly and looks slightly upset. The nurse doesn't pause and continues with her checklist.

*"Erm did you have any constipation with your last treatment?" [N9]*

*"No" [P39]*

*"Good. Did you have any diarrhoea?" [N9]*

*"No" [P39]*

*"Good. And how has your tiredness been?" [N9]*

*"It fluctuates..." [P39]*

*"And have you had any sores in your mouth?" [N9]*

*"No" [P39]*

At all four locations there were examples where nurses showed basic errors in communication skills. Some nurses asked multiple questions and sometimes paid little attention to the patient's response.

*"What about your hands and feet? Are they dry or are they not too bad?"*

*[O.L2.N11]*

*"No they're fine. I can just feel a little tingling" [P41]*

*"Hands and feet? Any problems with your bowels?" [O.L2.N4]*

*"No. No" [P42]*

*"...you're saying that you feel sleepy all the time? Are you actually able to sleep through? Do you sleep at night time?" [O.L1.N1]*

Some nurses asked negative questions or leading questions, which some patients may find difficult to interpret:

*"No difficulty in swallowing?" [O.L3.N7]*

*"And you don't need any anti-sickness?" [O.L2.N4]*

*"No" [P42]*

*"And you're alright for the diarrhoea tablets?" [N4]*

Leading questions sometimes produced confusing replies from the patient:

*"You're eating alright?" [O.L2.N4]*

*"No" [P42]*

*"What's your appetite been like?" [N4]*

*"Brilliant..." [P42]*

There were many examples in observations where nurses failed to pick up on patient's psychological concerns or missed cues. The following patient at location 2 had metastatic cancer and was due to start the first cycle of Gemcitabine and Carboplatin. When the patient openly questioned her own decision whether to have chemotherapy in order to live longer, the nurse hesitated as though she was unsure how to respond. The nurse then blocked further discussion of the patient's feelings or concerns by asking about the chemotherapy regimen.

*"So do you understand why you've come here today?" [O.L2.N9]*

*"Yes" [P37]*

*"Can you tell me?" [N9]*

*[laughs] "I've chosen to come here. I don't know if I've done the right thing but I would like to live a bit longer" [P39]*

*"Yes and what. Do you know the name of the chemotherapy that you'll be receiving?" [N9]*

During observation at location 1 the nurse focuses on physical aspects of insomnia and fatigue as she tries to reassure the patient.

*"I had no sleep at all..." [O.L1.P3]*

*"...so you've got a bit of catching up to do" [N1]*

*"I think that's probably what it is... and I'll get strong...I'll get better" [P3]*

*"...I'm hoping you're going to be absolutely fine this week" [N1]*

*"I will be fine...I will be..." [P3]*

However, the patient looks anxious as she tries to reassure herself, but her manner suggests that she feels the opposite and her replies don't sound convincing. The nurse doesn't pick this up and continues to focus on physical and practical actions, suggesting that the patient should phone the emergency number if she becomes ill again, and then interrupts as the patient tries to explain:

*"Yes I know...it was just..." [O.L1.P3]*

*"We could have taken you in earlier" [N1]*

The patient and her husband try to explain to the nurse how difficult things have been, but although the nurse expresses sympathy she blocks the discussion and changes the subject by giving the patient a blood form.

*"It's hard work when you're not bedridden and you do everything" [O.L1.P3]*

*"When you're used to doing everything it's hard isn't it?" [N1 interrupts]*

*"It's horrible ...you've got to just blank everything out and make yourself better really" [P3]*

*"Well her main priority is to get herself put right no matter what...it's her that comes first not us" [H3]*

*"So this is your blood form for next Tuesday" [N1]*

Field notes: The patient's husband looks upset but it's not clear whether the nurse notices this as she hands over a blood form and fails to address any psychological concerns.

The nurse focuses on medicines management for the remainder of the consultation. When she asks the patient if she has any questions at the end, P3 again expresses doubts about getting better but the nurse seems to brush her

concerns to one side even though the patient's husband tries to emphasise the shock of what happened:

*"No that's okay...we're alright aren't we? Just as long as it will get better"* [O.L1.P3]

*"Yeah you'll get better...don't worry you'll get better"* [H3]

*"It's just....I felt....I just couldn't believe how it just took me off my feet... you think 'that won't happen to me' but...."* [P3]

*"It was quite a shock"* [H3 interrupts]

*"If it happens again phone the hotline....that's what they're there for"* [N1]

### **Information exchange**

In the following example the patient clearly expresses that she feels anxious about too much information, yet the nurse blocks this by changing the subject:

*"Yeah you'll have to pardon me because you know I'm getting so much information and you can't take it all in at once."* [O.L1.P4]

*"By the end of these four weeks you'll feel like it all fits into place"* [N1]

*"Yes"* [P4]

*"But it will take...by the time it all fits into place we'll be finishing"* [N1]

*"Oh it seems a long way to go ...well it's the nausea that's been..."* [P4]

*"Let's try these extra tablets ...because it's been quite helpful in a lot of patients in curbing the nausea"* [N1]

The nurse gives the patient false reassurance by trying to predict how the patient will feel in four weeks, and then interrupts the patient as she tries to explain how the nausea has been. This blocks the patient from talking about her concerns since the nurse talks about medicines management and then starts discussing the chemotherapy.

Some nurses may acknowledge that patients are struggling psychologically, yet fail to address it.

*"Are you struggling to take information in at the moment or...?"* [O.L1.N1]

*"Yes....I'm struggling to take information in. I don't have that much medical knowledge anyway but I'm struggling to take stuff in at the moment"* [P6]

Field notes When the nurse goes out of the room for a minute the patient says to her mother with great sadness:

*"This is not how it's supposed to be. I'm supposed to be getting better all the time".* [O.L1.P6]

Her mother replies:

*"You just take it, take it all the time. It's how bad you feel. You just don't know."* [M6]

However, when the nurse returns the patient and her mother don't say anything.

Field notes The nurse discusses the chemotherapy regimen and side-effects. The patient sits with her head in her hands, trying to cover her ears as though to block out what the nurse is saying to her.

*"I want to go home now"* [O.L1.P6]

*"Pardon?"* [N1]

*"I can't take any more"* [P6]

*"Right"* [N1]

Field notes The patient's mother looks concerned with uncertainty across her face.

*"This talk is so immediately before the treatment isn't it? It's difficult to think... we thought we were just coming in for the treatment...what do you want to do?"* [turns to her daughter] [O.L1.M6]

*"I don't know what to do, what I want to do. I want to get better. Oh shit!"* [P6]

Field notes The patient leans back in the chair and puts her hand across her eyes, grimacing as she does so. Her mother holds her hand at the side of her daughter's face and looks very anxious. The nurse picks up on their anxieties:

*"I'm not sure that today's the day to be talking about it but you've said a couple of times about getting better"* [O.L1.N1]

*"I know"* [P6]

*"What would you be hoping for in terms of getting better from this treatment?"* [N1]

*"This would be the worst time, and then slowly getting better...then the next treatment....maybe try to get better..."* [P6]

Field notes: However the nurse suddenly interrupts the patient and blocks these emotional discussions by changing the subject, which seems inappropriate and makes me feel uncomfortable as an observer.

*"I think that if you're constipated now then you need to take some laxatives"* [N1]

*"I'm uncomfortable"* [P6]

The nurse questions whether the patient is fit for chemotherapy, then seems to pick up on her emotional state, but her interruptions stop the patient talking about her feelings:

*"I don't know how much that's affected you coming out and having a discussion today?"* [N6]

*"I don't think we were expecting this today. We just thought we were coming in for treatment"* [M6]

*"Yeah I wasn't expecting that. I was thinking that..."* [P6]  
[interrupts] *"Well because..."* [N1]

Field notes The patient tries to interrupt the nurse to explain how she is feeling, but the nurse carries on talking about the treatment and side-effects. The patient looks irritated. The nurse leaves to check on appointments for chemotherapy. The atmosphere in the room is tense and I feel in an uncomfortable position as mother and daughter talk quietly together.

*"Anything that helps to do that"* [P6]  
*"Anything that helps. My only comment is that this conversation should have happened before. Is this just constipation?"* [M6]  
*"I don't know if it is just constipation"* [P6]

Field notes: The patient winces in pain and looks uncomfortable. I feel helpless watching. A buzzer sounds repeatedly from another part of the clinic. The patient and her mother sit quietly, subdued, whilst outside chatter from HCAs in the corridor seems out of place. The mother reaches across to hold her daughter's hand, looking anguished. The patient holds her stomach, shifting uncomfortably in her wheelchair, then holds her head in her hands and groans as the pain seems to worsen. The loud chatter and laughter from the HCAs outside the room seem inappropriate and when someone starts singing outside the room I inwardly cringe at their lack of respect. Ten minutes later the nurse returns.

Field notes: The nurse mentions about the patient being unsteady when she was walking and asks if anyone has mentioned a CT scan. The mother asks if it could be because her daughter has not walked much recently and the nurse says that it could be that, but also said it may be due to the cancer spreading to the head. As the nurse says this she wheels her chair backwards, away from the patient. At that point a HCA knocks and enters the room to speak to the nurse who goes out. The patient says sarcastically *"Oh fabulous"*. The nurse returns and apologises before discussing the possibility of cranial metastases with the patient:

*"Just very occasionally these tumours can travel to the brain....so just to be on the cautious side....scan of your brain ..."* [N1]  
*"Just bang another one in!"* [P6]

Field notes The patient replies angrily, which the nurse doesn't seem to pick up on. Then the patient sighs deeply with sadness, looking defeated as she says:

*"No. I know you're just doing your job"* [P6]

Field notes: The nurse talks about the chemotherapy and side-effects. When she leaves the room again to get a consent form the patient's mother turns to me with a worried expression on her face, and says:

*"I really think this conversation shouldn't be immediately....and we weren't expecting it. We thought we were just coming for treatment....and it's a lot to throw at you isn't it?"* [M6]

Field notes: I nod sympathetically, feeling inadequate in my role as observer since this meant I couldn't engage properly with her, and I felt in a dilemma between being a nurse and a researcher.

This was a very emotionally charged consultation for the patient and her mother, which posed obvious difficulties for the nurse. However, it seemed to leave them with unfinished questions and concerns that hadn't been fully addressed during the consultation. At times the nurse seemed unaware of the depth of the patient and the mother's discomfort, which made me feel very uncomfortable as an observer.

The following theme covers the impact of power and control on nurses' roles within nurse-led chemotherapy clinics, which centres on influence by, and relationships with, medical consultants.

## **5.2.8 Theme 4 Power**

### **5.2.8.1 Doctors controlling referrals to nurse-led clinics**

At all four locations doctors directly controlled referrals to nurse-led chemotherapy clinics. However, at location 1 the majority of patients requiring chemotherapy were referred to the nurse-led clinics, although increasing numbers placed additional pressures on the nurses.

*"...it's grown from a 20 slot patient clinic to nearly a 30 slot patient, and that can't continue"* [I.L1.N3]

At locations 2, 3 and 4 doctors appeared to exercise selectivity regarding referrals, which restricted clinic numbers.

*“...doctors do keep in mind which patients they actually refer to us and if there are any other issues they tend to keep them for themselves”*  
[I.L4.Ph15]

*“...if the doctor sees somebody that he feels shouldn’t come our way they won’t come our way, and will re-book them for the medical clinic”*  
[I.L3.N6]

*“...the doctors could indicate at the beginning of the treatment when they were consenting the patient where they wanted to do the medical reviews. So they’d say okay this is 24 weeks of 5FU I want to see them at the beginning, middle and end”* [I.L2.N4]

In the majority of cases the control of referrals to nurse-led chemotherapy clinics appeared to be set out in protocols and agreed by nurses and consultants. However there were some instances where protocols for referring patients did not seem to have been followed, but it is difficult to ascertain whether this was a conscious decision.

*“...we have a patient suitability criteria that’s laid down in the protocols ... the doctors are supposed to identify these patients and then refer them into the nurse-led clinic. That doesn’t always happen so the patients remain in the medical clinic. So there’s quite a few suitable patients that don’t come through into the nurse-led clinic.”* [I.L4.N12]

Nurses speculated about doctors’ reasons for not referring patients to the nurse-led clinics, although did not appear to challenge them directly.

*“...sometimes I think it’s that doctors not wanting to let go because maybe it’s if we’re doing more of their job, what are they going to do?”*  
[I.L3.N7]

In some cases the doctors’ rationale seemed flawed when circumstances rather than clinical criteria dictated whether patients were seen in the nurse-led clinics. For example when the medical clinic was particularly busy or when the consultants were on leave.

*“...if the doctor’s clinic is very busy and there is a patient with a scan result that is showing stable disease or good result and continue with treatment they may say ‘well I’m quite happy for you to see this patient and tell them the scan is as it is and come back to us if there are any problems’”* [I.L4.Ph15]

*“...the rules change when all the medical staff are away and suddenly we see more”* [I.L3.N6]

Some nurses checked the medical clinic lists and selected patients from this to supplement their own clinic and regain some control over patient numbers. This



was often done before the start of clinic so that patients could be moved over to the nurse-led clinic after they had booked in.

*"I had a spare 5 minutes yesterday to look at his [consultant] list to see if there's any suitable patients I could see so I could go and offer help off his list. But if he pre-empted that ...obviously it's time consuming isn't it to think whether they're suitable to see the nurse or not?" [I.L3.N8]*

At location 2 consultants exerted the greatest power over nurse-led clinics through written directives governing their clinical guidelines and restricting the range of medicines that they could prescribe. As a result the nurses operated their nurse-led clinics with little flexibility and within a very narrow remit that was directly controlled by doctors. Although this created feelings of frustration for nurses, they recognised the importance of support from their hospital Trust and developing good relationships with the consultants. This was reiterated at other locations as nurses acknowledged how this could influence referrals to their nurse-led chemotherapy clinics.

*"...you need the support of your own Trust and a good relationship with the consultants" [I.L2.N4]*

*"...if you're not keeping your eye on the ball, or are not communicating with these people [doctors] all the time, then the patients don't come through" [I.L4.N12]*

The concept of power and its impact on nurses' roles and autonomy of practice seemed heavily influenced by the relationships with medical consultants, which will be outlined in the next section.

#### **5.2.8.2 Relationships with doctors**

At location 1 specialist nurses appeared to have a stronger relationship with consultants, which seemed to develop from several years of working closely with them in one disease group. N3 described the value of this bond in generating mutual respect and understanding of each other's roles.

*"I think if I'd come out with my masters into a nurse-led clinic I wouldn't have had that ability to bond with the consultants like I have, and they wouldn't know my practice where they do now. We had those 3 or 4 years, we all worked together" [I.L1.N3]*

Specialist nurses also displayed greater autonomy than the chemotherapy nurses at other locations. Nurses described how their relationship with the consultants could influence their confidence and clinical responsibilities, and

this seemed evident in the way nurses spoke of their relationship with doctors, their own role expansion and from observations of both clinical autonomy and decision-making. In addition, some specialist nurses viewed themselves to be on a more equal footing with their consultant colleagues, and this was reflected in the autonomy of their clinical practice.

*"I don't see (consultants) as above me...I see them as equal" [I.L1.N3]*

*"...the consultants will very much say to me ... you're the best person to make that decision, so if I want to stop chemotherapy you know they will respect my decision" [I.L1.N3]*

The following section focuses on the impact of nurse-led chemotherapy clinics on nurses' roles and relationships with medical colleagues.

### **5.2.8.3 Roles**

Although some consultants recognised and accepted nurses' clinical roles and responsibilities some tensions arose over the name of the clinic and patient numbers, which seems to highlight power tensions between specialist nurses and medical consultants.

*"....the only opposition there was, was about the change of name on the clinic" [I.L1.N1]*

*"...they were worried about their kind of overall patient numbers as to how it would impact on that." [I.L1.N1]*

Changing dynamics between specialist nurses and junior medical colleagues were also evident at location 1 with nurses leading the chemotherapy service for their patient group. In addition there was evidence of role reversal in that some nurses were supervising and training registrars on their team and registrars came to help nurses in their nurse-led chemotherapy clinics.

*"I much prefer to do the clinic with a registrar present so that kind of teaching and ensure that when they are cross covering that they can do that safely" [I.L1.N1]*

*"I always make it very clear to them [registrars] that 'this is what I can do, this is what I can't do...and this is where I'll need you... and if you have a problem with a chemo patient you come to me before you come to the consultants even'" [I.L1.N3]*

*"I suppose what I won't do is kind of take on their [doctors] clinical decision-making. I've learnt also to say you know if they ask me a question 'well what would you do in that circumstance?'...because they have to learn, otherwise I'll just be taking all the decisions and then they won't learn" [I.L1.N3]*

However, at locations 2, 3 and 4, the position between consultants, registrars and chemotherapy nurses seemed more hierarchical. Some nurses spoke of tensions where role expansion had changed team dynamics and relationships with consultants, leaving registrars feeling threatened.

*“...you get resistance from registrars to be honest who see clinical nurse specialists’ relationships with consultants as slightly threatening towards their place in the hierarchy” [I.L4.N12]*

*“... a lot of doctors, especially new consultants, do see the doctors as the pinnacle and the rest of us are there to support” [I.L4.N12]*

Expanding nurses’ skills to take on medical responsibilities brought concerns that medical colleagues would become deskilled. This appeared proportional to the degree of medicalization in nurses’ roles and responsibilities. At location 1, nurses perceived that their roles had the potential to deskill consultants, whereas at the other locations the concern from nurses was the potential to deskill junior medical staff, such as registrars.

*“....probably one of the downsides of now providing a more nurse-led service is possibly some of the consultants have lost touch with how demanding some of the chemotherapy regimes are..... so there’s a possibility that in doing this we’ve deskilled consultants, if they were skilled to deskill in the first place” [I.L1.N1]*

#### **5.2.8.4 Responsibilities**

One of the greatest changes to power dynamics between nurses and doctors has been independent prescribing. This seems to be the lynch pin to developing nurse-led clinics and becoming less dependent on medical staff.

*“You don’t feel as though you are giving a seamless service if you’ve got to stop everything, go and get a consultant or a registrar out of the clinic where they’re busy themselves to write a prescription for something that you know you’re not able to prescribe and erm that consultant may never have set eyes on the patient that they’re prescribing for” [I.L2.N4]*

However, at times the nurses themselves seemed complicit in perpetuating the consultants’ power over nurses’ roles and responsibilities within the nurse-led clinics by allowing them to have the final control over nurses’ clinical assessments. Although N12 suggested that competency-based assessments were a way of protecting the nurse, the main value was perceived to be developing trust between nurses and the consultants. In contrast this process

may also be influenced by the personal beliefs and perceptions of individual nurses, and in some circumstances appears to hand power and control back to the medical staff.

*"The competency-based assessments ...to protect the nurse ...but the main benefit of it is to develop that trust relationship between the consultant. We have purposely kept it that that final sign off of those competencies is from the consultants. We felt it was better that the doctors retain that final sign off so they have control with this aspect"* [I.L4.N12]

However, as autonomy increases some nurses appeared more cynical about doctors and mutual perceptions of nurse-led chemotherapy clinics.

*"...now it's a numbers game and nurses are much more professional and better educated and trained, taking accountability and ownership of their skills and their own skill set, not having to be dictated to by the doctors' point of view"* [I.L3.N6]

*"I don't think that we should just do it to help the doctors' clinic because you know it's a busy clinic. I don't want to just be seen as 'good the nurses are coming so we can hop off early'"* [I.L4.N14]

One nurse considered role expansion had changed the nursing role into 'a clinician', implying that this was something different to nursing. However this appears to be semantics muddying the waters as well as blurring the boundaries.

*"I see my role as a clinician rather than a nurse. I'm a nurse by training, I'm a nurse by background but I see my role as a clinician role than as a nurse".* [I.L4.N12]

The nurse described some tensions between nurses and medical colleagues regarding role definition and perceptions, however this was not seen during clinical observations.

*"I think sometimes we're stuck in this this outdated concept that the team providing care for patients is just doctors, and I think some doctors think multi-professional means different strands of doctors. I think we need to have recognition that multi-professional is multi-professional, so we need to up our game. We need to stop being little handmaidens who will do everything for doctors and get ourselves seen as clinicians so we need the skills sets to do that. We need the academic qualifications to do that. We also need the confidence and the communication skills to be able to do that"* [I.L4.N12]

Nurses were happy to make decisions whether to go ahead with chemotherapy if the patient's blood results were satisfactory. However, there were some instances where there were borderline indications for stopping chemotherapy,

which created clinical dilemmas for nurses. In addition there were a few occasions where nurses wanted to discuss clinical management with a consultant during the clinic.

*“...I don’t know if we’ll go ahead with chemo today anyway. I need to speak to (consultant) I think” [O.L1.N2]*

*“Right” [P9]*

*“Your temperature’s okay. If your bloods are fine I’m happy to go ahead at that dose reduction today” [O.L1.N3]*

*“The decision today is that ‘are they so severe that we should stop the Gemcitabine?’ ‘or are they part and parcel of normal expectations that we would expect?’...and what you’re telling me is it’s normal.” [O.L1.N3]*

*“Yeah well that’s what’s happening like you know” [P28]*

It seems that as nurses increase their knowledge, advance their clinical skills and take on medical responsibilities, this can change the power dynamics within multi-disciplinary teams. Blurring the boundaries of professional roles may create tensions between nurses, junior doctors and medical consultants, however, nurses’ autonomy and beliefs may also provide significant influences.

The next section presents the findings from study 2 in relation to theme 5: beliefs, highlighting how this can influence nurses’ autonomy.

## **5.2.9 Theme 5 Beliefs**

### **5.2.9.1 Abilities**

There were several examples where nurses had received training in clinical examination skills and independent nurse prescribing, but failed to use these skills in clinical practice. Some nurse discussed their lack of confidence in using advanced clinical skills to examine patients. The close proximity of medical colleagues appeared to exacerbate this, since nurses could use their medical colleagues rather than utilise their new clinical skills. This decreases nurses’ independence as they depend on doctors for aspects of their role, and deferring to the doctors in this way would increase waiting times for patients.

*“I’ve done the ... advanced assessment skills course but I haven’t practiced that much since being in the clinical area, so I don’t feel confident enough to do it myself at the moment but I do think it’s quite important for us to be able to do it... we work alongside the doctors so we can ask them” [I.L4.N14]*

When nurses were asked to define advanced nursing practice, and consider their role as a nurse within nurse-led chemotherapy clinics, they appeared to find this difficult. Some nurses reported that their beliefs changed over time as their roles developed.

*“....it’s a nursing role where you’ve took on medical things but you’ve made them a nursing thing. If you asked me 20 years ago .I would have looked at what they call now is a doctor’s handmaiden. That to me now is not advanced nurse practice when you actually follow a doctor round and you’re doing what the doctor says to do” [I.L1.N3]*

Some nurses found it hard to distinguish between advanced and specialist levels of nursing practice, and part of the difficulty seems to be in relation to the way that advanced nursing practice has developed, together with the lack of clarity with job titles.

*“I think it’s all advanced nursing practice, to become a specialist nurse within a tumour speciality or a specialist nurse in diabetes, I think that’s all advanced nursing practice. It’s just under a different label to me” [I.L2.N4]*

However, other nurses perceived clear distinctions between clinical nurse specialists (CNS) and advanced nurse practitioners (ANP), based on their clinical practice and clinical responsibilities.

*“Ability to take history, clinical examination, diagnose and prescribe would not normally be part of the CNS role and this is all backed up with MSc level education” [I.L1.N1]*

*“... they’ve [CNS] got a structured defined role I would say. I feel mine is less structured. It’s more maverick or more pushing boundaries or more bending boundaries or moving boundaries” [I.L1.N3]*

*“...advanced nurses may be able to carry out slightly more, not necessarily procedures, that’s the wrong thing, but having a little bit more responsibility but still being a bit more hands on” [I.L2.N5]*

Nurses’ beliefs seem closely linked with their personal autonomy and self-confidence. When nurses believed that their role involved pushing professional boundaries, and if they had the desire and confidence to take on those responsibilities, they appeared to strive to achieve that. However, when nurses believed that their role had clinical restrictions and doctors could do certain clinical aspects better, they seemed to stay within the boundaries that they had set, limiting their own role and autonomy. The next section shows how nurses’ confidence can influence their roles in clinical practice.

### 5.2.9.2 Confidence

Despite similar levels of training and role expansion some nurses appeared to have less autonomy than others, which appeared to be influenced by a lack of confidence. For example, N5 had completed the nurse prescribing course and felt it was beneficial, although reported feeling scared of actually prescribing medicines and delegated her autonomy for prescribing onto medical colleagues. The close proximity with medical clinics / colleagues meant that some nurses could rely on doctors rather than building up their own clinical skills.

*“...we’re still a little bit fearful of prescribing. When you make your first prescription you’re still a little bit scared that .... what am I doing? Have I given the right thing there? I think it has been beneficial though, yeah. Although there is always a doctor here so you can always quite easily go and ask them to prescribe something for you” [I.L2.N5]*

Similarly some nurses did not utilise their clinical examination skills because they lacked confidence, and this seemed to be influenced by how frequently they examined patients. Whilst some nurses lacked confidence to undertake any kind of clinical examination, others recognised that their confidence varied according to the nature and familiarity of clinical examination.

*“I think your confidence takes a plummet initially...I may not feel that confident with medical emergencies...like PEs, DVTs.” [I.L1.N3]*

*“... (N7) is skilled in examination but she hardly ever uses it ... [I.L3.N6]*

If nurses lacked confidence, the close proximity of medical colleagues provided nurses with the option of asking them for advice or to examine a patient instead of undertaking it themselves.

*“...we do all operate differently and have different confidence levels ... you might find that the support they get from the medical staff for one person might not be needed with another person. You know they’re confident and happy to make that decision themselves...but actually because of concurrent clinics it’s there and I don’t want to stifle them just checking that out if that’s if that’s what they need to do.” [I.L3.N6]*

The following interview extract highlights the dilemma for one nurse, who recognises the potential benefits of examining the patient herself, but acknowledges her lack of confidence and doesn’t want to start examining patients.

*“I think probably...probably if I did use them more... I wouldn’t have to call on the doctor to come and listen to a chest and prescribe the antibiotics. I can already prescribe antibiotics but it’s just getting those skills to say yes I think it is an upper respiratory tract infection...yes more*

*really to listening to chests.... So I think it would be a good idea, although in some ways I'm quite happy doing it like I am doing it" [I.L3.N7]*

Whilst observing nurse-led clinics there were differences between the four locations. All nurses at location 1 examined patients within their clinics when necessary and did not choose to call a doctor. However the nurses acknowledged that confidence can be affected if they did not use certain skills regularly:

*"If there's something that I'm not confident at... it may be that if someone said to me to do a full cranial nerve assessment you know I may not be that confident ....I can't lie it wouldn't be fresh in my mind." [I.L1.N3]*

In contrast the nurses in location 2 did not undertake any physical examinations although they had been trained to do so. In location 3 N8 suspected that a patient may have a chest infection but asked one of the doctors to listen to the patient's chest.

*"I'll just go and see which doctor's available to listen to your chest, alright?....see what they say, alright?...I won't be a minute" [O.L3.N8]*

Field notes: The nurse goes out and returns a minute later, informing the patient that the consultant's clinic is running an hour late so she was going to arrange for the patient to see another doctor:

*"Now....is it okay if I sit you back outside and I'll go and talk to the [doctor]" [O.L3.N8]*

*"It's okay. I've got nothing on today" [P51]*

Field notes: The nurse goes to ask one of the doctors to see the patient, interrupting the doctor's clinic to put her patient in next.

In location 4 the nurse seems more confident when talking about the importance of clinical examination skills. Observing the nurse in clinic seemed initially to confirm this confidence as the nurse listens to a patient's chest and explores her symptoms:

*"Is the cough a constant one?" [O.L4.N12]*

*"No not really, no" [P56]*

*"Okay deep breath in....and out...good...okay I'm just going to give you a bit of a tap now....er there's just a bit of dullness down at the bottom of your right lung....are you bringing anything up when you cough?" [N12]*

*"I do bring up a bit of phlegm that's white" [P56]*

*"Okay.... Does anyone notice that before...the dullness in the chest?" [N12]*

*"They usually say it's clear" [P56]*

*"That's what I've read" [N12]*



The nurse checks with the patient and then appears uncertain when the patient reports that her chest has usually been clear. The nurse continues to ask the patient about side-effects from the chemotherapy then summarises for the patient:

*“Well everything seems pretty good. I think you’ve got a little bit of dullness there so I’ll just get one of the doctors to just have a listen to that as well erm just with the cough and everything it might be that you have a little bit of consolidation in there so we don’t want that to get anything serious. I’ll just grab one of the doctors. I’ll be back in a minute”*  
[O.L4.N12]

Field notes: The nurse goes out and returns two minutes later followed by a doctor. The nurse introduces the patient, summarising her case and physical condition:

*“...she’s got lung and liver mets and she’s coming up to her 7<sup>th</sup> cycle of Kapox, which she’s tolerating very well but she’s got a little bit of a cough and she’s got dullness ...erm...reduced air entry on the right base”*  
[O.L4.N12]

*“Right”* [Dr]

*“I wondered if you wanted to have a listen or...?”* [N12]

*“Yes....I’d better. Do you want to come over here?”* [Dr]

Field notes: The doctor goes over to the patient and examines her chest from the back. However he picks up a low quality stethoscope from the trolley and tries to use it to listen to the patient’s chest. When he realises his mistake he picks up the nurse’s stethoscope, which is a better quality and re-examines the patient’s chest’.

*“Well let’s see if using a better stethoscope can pick anything up ....deep breath in....you thought you had what at the right base? Decreased?”* [Dr]

*“Decreased air entry ...bit of dullness”* [N12]

*“On the right?... probably just the liver is pushing it up a bit. I think it’s clear.”* [Dr]

Field notes: The doctor leaves and N12 and P56 sit down. It seems like the nurse needs to justify calling the doctor, remarking to the patient:

*“That’s good that there’s nothing of note there, I just wanted to be sure”*  
[O.L4.N12]

However, this contrasted with the nurses’ earlier confidence of a differential diagnosis, and bringing a doctor in to also examine the patient seemed to undermine the nurses’ examination skills, which was uncomfortable to witness.

The next section shows how nurses’ perceptions can also influence autonomy.

### 5.2.9.3 *Perceptions*

Some nurses suggested certain boundaries exist in nurse-led chemotherapy clinics regarding the nature of their role and that of doctors, implying that doctors focus on the cancer whilst nurses focus more on how the patient is coping. However, in some cases the boundaries appear to be set by the nurses themselves based on their individual beliefs and confidence. For example, if nurses believe that their role focuses on managing the chemotherapy and side-effects of treatment rather than their cancer they will adjust their autonomy and clinical decision-making accordingly.

*“...because there are wider issues as than just their cancer sometimes and I think it’s about convincing nurses that you’re not technically er.... managing their cancer, you’re managing their drugs and their side-effects and you’re getting them through their regimen, not having to make decisions” [I.L3.N6]*

Nurses’ perceptions of how much contact patients wish to have with doctors may also directly influence their nurse-led clinics. N6 shows how her beliefs have changed over time regarding what she believes nurses should and should not be doing within nurse-led clinics.

*“... I think patients want to stay in touch with the doctor generally. I used to think ‘oh the nurses can do all this’ and I don’t think that’s the best thing or a good thing now.” [N6]*

Some nurses may also restrict their clinical practice if they believe doctors can do it better. N7 believes that doctors are more knowledgeable about oncology and can have more precise discussions with patients, such as CT scan results and prognosis. This seems to affect her confidence and makes her reluctant to discuss such information with patients.

*“I have given CT scan results but the doctors know the ins and outs of a CT scan to be able to explain it better... and doctors always talk in terms of percentages whereas I don’t. Patients always ask you percentages and I’m afraid I don’t do that. The doctors, that’s for them...I know where my level is...do you understand what I mean” [I.L3.N7]*

However, other nurses believe their knowledge and experience are similar to doctors. During observations they appear to have more complex discussions with patients about the patient’s cancer, prognosis and treatment, and show greater autonomy within their clinical role. For example, N3 sees an elderly patient on chemotherapy who mentions problems with his leg and mobility difficulties. The nurse considers the priorities in terms of arterial surgery instead

of continuing with chemotherapy. She discusses stopping chemotherapy and changing to a different drug, outlining the potential implications for the patient so that he can be involved in the decision-making.

*"I just think if I was going to give you a drug today that had no impact on your health I would not have a worry.... but because this drug is so dangerous... And we've already had that evidence [but] you were very good because you got to [hospital] very quick, but if it happened a second time round sometimes you don't recover as quick and sometimes it stops us ever giving that type of drug in the future" [O.L1.N3]*

*"Hmm" [P26]*

*"As we've got your PSA down from what three hundred and something to 63 and you've no symptoms with your cancer ...so what I propose is don't give chemo today. If we decide that we want to go with the arterial route we can get them to give us a proper estimation of time when it can be done. We can put you on abiraterone because you've had 3 courses of docetaxel so you become eligible for abiraterone. That will keep the disease stable. That might be all you need. You might be better than the chemo because they are parallel to each other, we just have to give one before we give the other, and we can rechallenge you with chemo because we know you already respond to chemo in the future" [N3]*

N3 clearly has knowledge and experience to have such a complex discussion with P26, however it was difficult to know whether the patient was fully able to assimilate all the medical information and make a decision. Nevertheless the nurse was confident in her own beliefs and this resulted in a higher level of clinical decision-making.

The final theme that emerged from the data focuses on the essence of nursing and compassionate care, demonstrating the implications for nurses' roles and nurse-led chemotherapy clinics.

## **5.2.10 Theme 6 The essence of nursing**

### **5.2.10.1 Blurred boundaries**

Blurring the boundaries between nursing and medicine appeared to cause role conflict for several nurses. This seemed more apparent with a greater expansion of nursing roles towards a medical role. However, some nurses were keen to defend nursing values, although failed to define what this meant.

*"I am definitely a nurse so I feel very strongly that I'm a nurse. I'm not a doctor, I'm not a mini doctor, I'm not substituting for the doctor...so I believe in the nursing value" [I.L3.N6]*

Nurses also discussed having a different approach to doctors, which was more about how the patient and family were coping with the cancer diagnosis and chemotherapy treatment.

*"I don't see myself as a doctor or wanting to be anything like a doctor. It's very different the approach that I do with the patients ..."* [I.L4.N13]

*"I'm looking at how they're [patients] how they're managing and how they're surviving. I'm not looking at their disease progression...I don't particularly think that is my role. My role is around seeing how they are doing, seeing how the family is doing, the coping with, living with cancer, and if there's anything thing that I can do to help them through that. As well as giving tips on their symptom management and making sure they're fit for their treatment or not".* [N6]

There was some evidence of this during clinical observations when the nurse asked about the patient's family, although sadly such instances were few.

*"And have you been able to get out and about and do whatever it is you need to do?"* [O.L3.N6]

*"Hmm...hmm"* [P49]

*"Are you looking after yourself?"* [N6]

*"Hmm"* [P49]

*"Who's at home with you?"* [N6]

*"Grand-daughter"* [P49]

*"Yeah?"* [N6]

*"She's the carer"* [P49]

*"Yeah?...She's your carer is she? How old is she?"* [N6]

*"23 in September"* [P49]

*"Alright, yeah?"* [N6]

*"Well I'd rather have somebody that I know and that I can trust 'cause outsiders, you know strangers I'm a bit cagey of..."* [P49]

*"You're a bit nervy of?"* [N6]

*"Yeah. So it has to be somebody that I know and trust and close to me"* [P49]

#### **5.2.10.2 Nursing values**

Some nurses suggested that nursing values were important, including the language nurses used to communicate with patients, perceiving that nurses were more on the 'patient's level' than doctors.

*"When patients you know obviously come in and say to me 'I don't want to have any more chemo' and I think as a nurse you can actually talk to them in words that they understand so they can make the right decision whether they want to stop or not"* [I.L3.N7]

Other nurses suggested that it was the way that they communicated with patients, for example the use of touch was considered important. During observations nurses showed compassion and empathy by reaching out to touch

a patient's arm or holding their hand, and perceived that this encouraged patients to talk about their feelings. However this happened infrequently.

*"I often like....touch patients, hold their hand and just talk to them, rather than...and I think that's what the difference is...that they do start talking about lots of things" [I.L4.N13]*

There were other examples where nurses would shake the patient's hand in greeting and/or departure from the clinic. Occasionally patients themselves would initiate this or hug the nurse on leaving to express their gratitude. Observing the non-verbal behaviours of nurses reinforced this, for example positive aspects of their body language and facial expressions. Quite often it was subtle things which appeared to make a difference and encouraged patients to open up about their feelings; however these are difficult to quantify. Some nurses appeared more open than others, which was evident by the way they sat: leaning forward towards the patient, smiling, nodding, showing that they were listening, and indicating from their facial expressions and posture that they cared. This was reinforced by hand movements, such as reaching out to touch the patient's hand or arm, acknowledging distress by a reassuring touch and sympathetic smile.

Such expressions conveyed warmth: care and compassion that patients obviously appreciated and openly expressed genuine gratitude to the nurse at the end of the consultation. In contrast, some nurses appeared more distant, rarely smiling and leaning back in their chair with their legs crossed, which appeared to put up a barrier between them and the patient. These were subtle differences between different nurses, yet as an observer it seemed to influence the atmosphere within the consultation. Sometimes nurse-patient communication seemed easier when the nurse had previously seen the patient; however this was not always the case. As an observer it seemed to be influenced more by the nurses themselves, their inter-personal skills, communication skills and communication style.

#### **5.2.10.3      *Medicalization of nursing roles***

Traditionally an integral part of a nurse's role has been changing dressings for patients. However, as nurses' roles have expanded some of these more traditional tasks appear to become lost, delegated to more junior nurses or healthcare assistants.

*"So...I think er I'll get somebody to dress it, and I'll have a look at your blood tests" [O.L1.N2]*

*"Right" [P9]*

*" Yes. Are you okay sitting outside? I'll just see if [HCA] has found anybody to do your dressing. Do you want me to put a little bit of gauze on? ...Shouldn't be long anyway" [N2]*

At location 1, nurses had greater clinical responsibilities and more of a medical role involving cancer surveillance. During the observational sessions nurses undertook more clinical examinations, complex prescribing and higher levels of decision-making. This showed greater similarities with medical models of care since nurses appeared to mirror the consultation styles of doctors.

*"I can't just stop. I don't have the luxury of sitting there for 15 minutes, 20 minutes while they're in tears...I'm constantly aware that the pressure is building up outside the clinic ... it is hard to try and be empathetic in a 10 minute interview when you've got another 20 patients waiting outside" [I.L1.N3].*

*"I feel that we have the advantage that we have the nursing kind of slant on a patient's feelings, perceptions... the total patient but we have the medical knowledge behind what's happening to them" [I.L1.N3]*

The emphasis on medical / clinical/ physical aspects seemed to change the dynamics within the consultation. Nurses became more prescriptive and informative about symptom management and clinical management of the patient's cancer. Such nurses showed greater autonomy with decision-making around chemotherapy, for example dose reduction and deferral, yet at times did not seem to show empathy for the psychological impact this may have. As an observer it seemed that with greater expansion into the medical domain core nursing values may become lost.

### **5.2.11 Summary**

The data revealed a central theme of autonomy, surrounded by four main themes of knowledge, skills, power and beliefs. The data identified that nurses were very knowledgeable about chemotherapy, which was evident in the information discussed with patients about the chemotherapy drugs and their side-effects. There did not appear to be a difference in knowledge of chemotherapy between chemotherapy and specialist nurses. However specialist nurses appeared more knowledgeable about aspects of cancer than chemotherapy nurses, which may be because specialist nurses worked within one cancer disease group, unlike chemotherapy nurses. At times this presented

difficulty, for example if patients asked chemotherapy nurses specific questions about their cancer or scan results within the nurse-led chemotherapy clinics.

Interview data revealed that nurses were skilled, having undertaken courses in clinical examination skills and nurse prescribing, which they considered to be essential for their role. However, observational data showed disparities between the utilisation of clinical skills across the different locations. At location 1, specialist nurses were advanced nurse practitioners who regularly used clinical examination skills and appeared confident, however nurses at other locations lacked confidence regarding examination skills and either devolved this responsibility to doctors, or needed a doctor to check if their examination was correct. In addition, some nurses reported that they had not used their examination skills after the training course, and now felt they needed re-training due to a loss of confidence in their abilities. In contrast, all nurses who had undertaken nurse prescribing training were prescribing independently in clinical practice, and most were prescribing chemotherapy. However, at location 2 medical consultants placed severe restrictions on the range of medicines that nurses could prescribe; which adversely affected nurses' clinical practice and increased waiting time for patients.

The theme of beliefs was closely entwined with skills, since the implementation of nurses' clinical skills was influenced by their beliefs. In addition to beliefs and self-confidence regarding clinical skills, nurses' beliefs regarding their communication in comparison to colleagues showed interesting disparities. For example, some nurses believed they were better than doctors, whilst other nurses considered that doctors were better at discussing aspects of cancer and scan results with patients. There were also several occasions where nurses' perceptions of their communication skills showed clear disparities with observational data, which nurses did not appear to be aware of.

Observational data highlighted that communication skills were variable across all locations and all nurse participants, and there was no correlation between communication skills and the duration of consultations. The majority of nurses displayed empathy during nurse-patient interactions, demonstrated by non-verbal communication such as touching the patient's arm, holding their hand, smiling, and leaning forward towards the patient in an open posture, however

there were also many examples where nurses' communication skills were poor. This was evident in nurses' blocking behaviours to avoid answering or addressing emotional issues, failing to pick up patients' cues and concerns, and asking closed, leading, or multiple questions. The study also identified that nurses focused mainly on physical aspects of treatment, physical side-effects, and giving information, rather than psychological and social issues. Although nurses perceived that they were providing holistic care, there was no evidence of this during observation of nurse-led chemotherapy clinics in study 2.

The theme of power within nurse-led chemotherapy clinics was unexpected and complex. The data identified strong influences by medical consultants over nurse-led chemotherapy clinics. There were many examples where doctors directly controlled aspects of nurse-led clinics, for example what nurses could and could not prescribe, and what type of patients / chemotherapy regimens nurses could see independently through the nurse-led clinics. There were also examples of indirect influences by doctors where they failed to refer eligible patients to nurse-led clinics, or failed to complete the appointment proforma correctly for nurse-led clinics where care was shared between nurse-led and medically-led clinics. In contrast, specialist nurses at location 1 were granted additional responsibilities by the medical consultants, where they devolved responsibility for chemotherapy patients to the nurse-led clinics for the whole of patients' chemotherapy treatment.

Autonomy appears complex and influenced by several factors. The main themes were power, skills, knowledge and beliefs. However, the emergence of a final theme: the essence of nursing care revealed a gap in the provision of nursing care within nurse-led chemotherapy clinics. Although some nurses displayed empathy when communicating with patients, this was less evident with advanced nurse practitioners than chemotherapy nurses. This may suggest that compassionate care could be influenced by the medicalisation of nurses' roles and increasing clinical / medical responsibilities. Figure 5.2 illustrates a synthesis of the main themes identified from the data with key components, highlighting their inter-relationships.

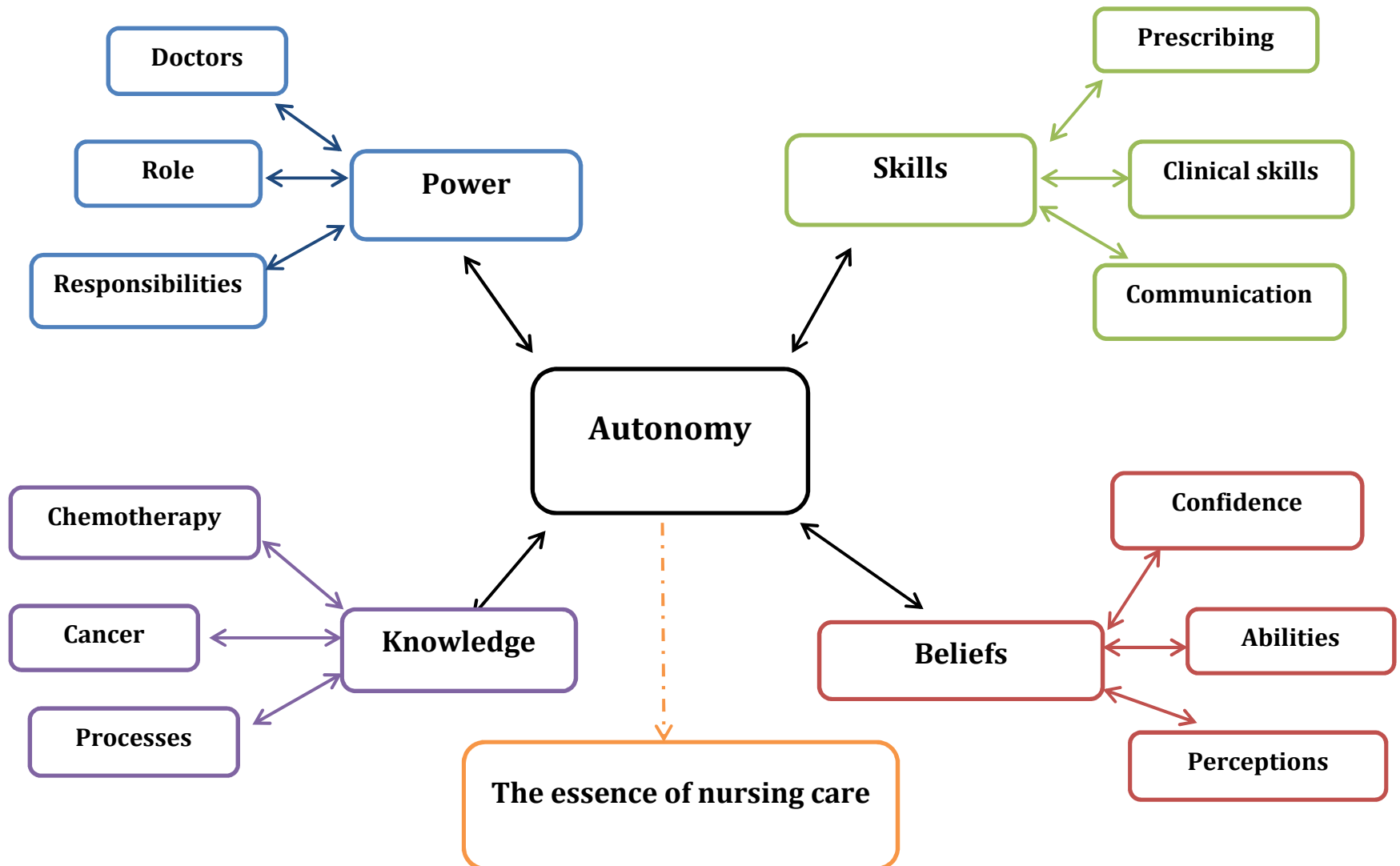
Observing nurses' behaviour in nurse-led clinics alongside the operational processes and settings identified different levels of nurse-led chemotherapy



clinics across the four locations. However, there are variations within each clinic depending on the skills, competencies and roles of individual nurses. Time spent on administrative tasks and coordination of care is important for efficiency, however could be undertaken by non-nurses. This suggests that nursing the clinic has to be balanced with nursing the patient.

The findings from study 2 are discussed in section three of this chapter, drawing comparisons with evidence from the literature.

**Figure 5.2** *Autonomy and nursing care in nurse-led chemotherapy clinics*



## **Section three:                      Discussion of Study 2**

### **5.3.1 Introduction**

This chapter forms a discussion of the key issues within oncology specialist nurses' roles and chemotherapy nurse-led clinics, which are identified from the findings of study 2. This includes the practical issues for nurse-led chemotherapy, implications for clinical practice, communication issues and the essence of nursing. Chapter six will bring the findings from the two studies together to discuss the key issues and implications for nurses in advanced roles and nurse-led chemotherapy clinics alongside current cancer policies.

### **5.3.2 Developments in nurse-led chemotherapy services**

In 2008, when study 1 was conducted, few nurses undertook nurse-led chemotherapy clinics, although this had started to rise (Fitzsimmons et al, 2005). However by 2012, and the start of study 2, there had been a rapid increase in nurse-led chemotherapy clinics within the UK. In addition, government policies endorse developing nurse-led or nurse / pharmacist-led chemotherapy clinics, with favourable statements from the National Cancer Action Team (NCAT) and National Chemotherapy Advisory Group (NCAG). The policies highlight benefits of nurse-led chemotherapy clinics, including reduced waiting times, increased capacity and opportunities to deliver care closer to patients' homes (NCAT, 2010; NCAG, 2009). However, in reality nurse-led developments have been ad hoc with no regulations or evaluations, and disparate levels of clinical practice (Lennan et al, 2012).

Study 2 shows that the main reason for setting up nurse-led chemotherapy clinics stems from a reduction in medical staff and increasing clinical demands, which is reflected in the literature (NAO, 2001). However, nurses' roles and practical elements of nurse-led clinics vary throughout the four locations, showing different levels of autonomy and clinical practice. This highlights the need for clear definitions regarding nurses' roles (RCN, 2007) and nurse-led chemotherapy clinics, since the current blanket term of 'nurse-led chemotherapy' lacks precision and may result in misunderstanding. Research evidence on chemotherapy nurse-led clinics, and nurses' roles within them, is

sparse (Fitzsimmons et al, 2005; Wiseman et al, 2005; Griffiths et al, 2012), therefore the findings from this study are novel and timely.

Differences are marked between the four locations, highlighting a wide range of nurses' autonomy and scope of clinical practice within four clearly defined levels of nurse-led chemotherapy clinics. The development of protocols to guide the nurse-led clinics were available at three locations, however these documents identify considerable influence by medical staff in some locations, with examples of biomedical models of care, prescriptive clinical management and restrictive nursing practice. This seems to resemble aspects of historical patriarchal doctor-nurse games that have restricted the nursing profession for many years (Stein, 1967; Stein et al, 1990).

Whilst protocols may be beneficial regarding understanding certain aspects of clinical management during chemotherapy, for example operational processes, and determining when to refer back to medical staff, the role of 'nursing assessments' and psychosocial aspects of care during chemotherapy are not addressed in these documents. This contrasts with the position statement by the UK Oncology Nursing Society (UKONS), which recommends that nurse-led clinics should not duplicate a medical model, but provide additional benefits for patients in terms of holistic care and family support (Lennan et al, 2012). Furthermore, the National Cancer Action Team (2012) recommend that chemotherapy nurses should also ensure that patients' "*wider holistic needs*" are addressed within nursing assessments and care (NCAT, 2012). Clearly this is not happening in this sample of nurse-led clinics. However, it is concerning that nurses perceive their practice to be holistic when this does not match independent observations of their actual practice.

Chemotherapy nurses have been responsible for administering chemotherapy for many years, taking over the role from medical staff within the UK (Lennan and McPhelim, 2012). Chemotherapy nurses' expertise and training is well recognised in the literature, and considered to provide a safe, acceptable service for patients (Kelly and Crowe, 2004; Wiseman et al, 2004). Therefore it seems unsurprising that the National Chemotherapy Advisory Group recommend developing more nurse-led chemotherapy clinics (NCAG, 2009). However, the lack of definition of 'nurse-led chemotherapy' leaves nurse-led

chemotherapy clinics open to interpretation, which may promote disparate levels of practice and a lack of national standardisation. Greater transparency is needed, with structural frameworks to identify different levels of practice, associated competencies and training for nurse-led chemotherapy clinics.

### **5.3.3 Operational factors for nurse-led chemotherapy clinics**

The findings from study 2 identify an important issue for nurse-led clinics regarding patient throughput, skill mix, efficiency and sustainability. Determining the appropriate number of patients for nurse-led clinics is challenging; if numbers are too low, nurses may face criticism from medical colleagues, and if numbers are too high this may leave nurses feeling overwhelmed. The findings from study 2 highlight that this issue is not just a local problem, since similar issues occurred at each location, demonstrating the difficulties when developing ad hoc nurse-led services; coupled with a lack of research, no forward planning, and insufficient resources. These issues reflect findings in the literature, where ad hoc developments of new chemotherapy service models have created challenges for nurses and hospitals within the NHS (Lennan and McPhelim, 2012).

#### **5.3.3.1 Professional relationships**

Professional relationships with medical colleagues are vital to the success of nurse-led clinics, and medical consultants have the power to make or break nurse-led clinics through the number of patient referrals and the degree of their professional control over nurse-led clinics. However, conflict within doctor-nurse relationships is long-standing, with evidence that a lack of collaboration can have a negative impact on patient care (Benner, 1984; Stein, 1967; Stein et al, 1990). There are also many examples in the literature that highlight the subservience of nurses to doctors (Mackay, 1993; Baumann et al, 1998; Lockhart-Wood, 2000), outlining how this can undermine nurses' confidence (Mackay, 1993) and create conflict between the professions (Benner, 1984; Mackay, 1993; Stein et al, 1990).

Based on the findings from study 2, this can happen directly by not allowing nurse-led clinics to be set up, or limiting nurses' responsibilities within the clinic through restrictive protocols. However it can also happen indirectly where

doctors fail to refer appropriate patients to the nurse-led clinic unintentionally, or intentionally want to keep certain patients in their clinic that are suitable for nurse-led management, thus maintaining more control. However the system of booking chemotherapy appointments was often flawed in that patients could be booked into the wrong clinic by ticking the wrong box on the appointment sheet, which reduced patient numbers in the nurse-led clinic.

The findings from study 1 also identify great variability in the number of patients in each nurse-led clinic, the duration of appointments, and the nature of nurse-led clinics in oncology. This reflects evidence in the literature where consultations in nurse-led clinics were longer than doctor-led consultations (Beaver et al, 2009; Coughlan, 2005; Faithfull et al, 2001; Kimman et al, 2010; McFarlane et al, 2011; Palmer and Thain, 2010; Warren, 2007; Wells et al, 2008). There are similar findings in study 2, where nurses reported that some nurse-led chemotherapy clinics had little impact on reducing patient numbers in the medical clinics. This raises questions regarding the viability of nurse-led clinics where patient numbers are small, particularly given the salary costs of specialist and chemotherapy nurses. This is important in the current financial climate where nurse specialist roles are vulnerable, and greater attention is being paid to the activity of specialist nurses to ensure that current specialist roles and clinical services are providing value for money (Kelly and Trevatt, 2006; Barlow and Jackson, 2007).

Whilst nurses in study 1 identified a variety of different barriers for their role and their nurse-led clinics, the majority of barriers came from doctors and managers within their organisation. However it was not possible to obtain further detail due to the nature of the survey questions. Interviewing and observing nurses in study 2 revealed greater details regarding barriers to nurses' roles and nurse-led chemotherapy clinics. Nurses in study 2 reported that some consultants were inconsistent regarding the delegation of clinical responsibilities, and although nurses found this difficult to deal with, they failed to challenge the medical consultants. For example, nurses reported that some consultants had different 'rules' for when they are on annual leave and need nurses to provide additional cover for their clinics. This sort of behaviour seems unacceptable and undermines nurses' autonomy. However it reflects evidence in the literature of disparities in power and status between nurses and doctors (Stein, 1967;

Benner, 1984; Stein et al, 1990; Mackay, 1993; Baumann et al, 1998; Lockhart-Wood, 2000).

Although this highlights disparities in the balance of power between medical consultants and nurses, in study 2 some nurses just accepted it as the way it was, even when the data demonstrated that their clinic numbers were consistently small because of limited referrals by medical colleagues, and they were concerned about this. Hawk (1991) proposes two concepts of power: the ability to exercise control, and the capacity for action; identifying how power is influenced by a person's self-confidence. This reflects the findings from study 2, which identified power tensions between medical consultants and nurses in relation to operational aspects of nurse-led chemotherapy clinics. The data from nurse-led chemotherapy clinics revealed clear differences between doctors and nurses; whilst doctors have both the ability to exercise control and capacity for action, there are several examples in the findings where nurses' ability to exercise control was restricted by medical staff, and nurses' capacity for action was compromised by their lack of self-confidence. These findings are supported by evidence in the literature on power relationships between nurses and doctors, illustrating the influence this may have on nurses' clinical practice (Benner, 1984; Stein et al, 1990; Mackay, 1993; Baumann et al, 1998; Lockhart-Wood, 2000) and nurses' self-confidence (Mackay, 1993).

The data revealed that although nurses in study 2 ran their own nurse-led clinics, all nurses remained dependent on medical colleagues to some extent, irrespective of the degree of collaboration. Even where nurses had a good relationship with consultants and greater responsibilities during a patient's chemotherapy, patients will still 'belong' to medical consultants. There are additional implications for accountability and legislation for nurses running nurse-led clinics and medical consultants. Nurses are accountable for their own clinical actions and behaviour, and must adhere to the professional 'Code of Conduct' (NMC, 2008). However, medical consultants are also accountable for nurses' actions within nurse-led clinics, since they have ultimate clinical responsibility for patients seen in nurse-led clinics. In terms of litigation, the hospital has vicarious liability, which involves taking on responsibility for hospital staff in cases of negligence. However, in law, clinical nurses can also face

potential charges of negligence, and this risk seems likely to increase with the expansion of nurses' roles and involvement in nurse-led clinics.

Nurse-led chemotherapy clinics rely on referrals by medical staff, therefore if the referrals stop the nurse-led clinic will fail. This process is influenced by professional relationships between medical consultants and nurses, however the findings from study 2 show that issues are more frequent where nurses share chemotherapy management with medical staff. This highlights the potential vulnerability of nurses who undertake nurse-led clinics, in that no matter how autonomous the role is perceived to be, or how skilled nurses are, nurses and their nurse-led clinics are dependent on medical staff.

The findings showed that the majority of nurses developing their nurse-led chemotherapy clinics chose to undertake patient reviews on a separate day to their chemotherapy treatment. This had positive benefits for nurses, giving them more time to check blood results and complete prescriptions; however this meant that patients attended twice in one week, which increased their travel costs and may not be acceptable for some patients. Nevertheless, there is support for this practice in the literature, where the benefits of reduced patient waiting are emphasised (Lennan and McPhelim, 2012).

However, having two separate appointments also changed the nature of the nurse-led chemotherapy clinics from the administration of chemotherapy to a more detailed assessment of the patient's condition and clinical review. Changing the nurse-patient interaction into a formal consultation had several implications for nurses, including requirements for additional knowledge, clinical skills and independent prescribing (Lennan et al, 2012). It also changed the nature of communication with patients; nurses in the study acknowledged the difference of having 'closed door' consultations with patients in a private consultation room, rather than reviewing them in an open area on the chemotherapy unit. This has implications for nurses, since some nurse participants considered the 'closed door consultations' to be different and more difficult than interactions on an open chemotherapy unit. Nurses had not received training for changes in the nature of consultations with patients, and implied that they felt unprepared.



The importance of good communication skills is well recognised in oncology, with implications for patient well-being and programmes of research to improve health professionals' communication with patients (CRC, 1997). The impact of cancer is multifaceted and can generate numerous concerns for patients. The number and severity of those concerns is associated with the later development of anxiety and depression (Parle et al 1996), and high levels of emotional distress (Weisman and Worden 1977, Harrison et al 1994). Accurate assessment of patients' concerns is, therefore, important, however patients may be selective about disclosing concerns to different health professionals, particularly regarding concerns about feeling a burden, worries about the future, or lack of independence (Heaven and Maguire 1997). Maguire and Pitceathly (2002) identify 6 key tasks in communicating with patients, which includes tailoring information to each individual and assessing, acknowledging and exploring patients' concerns. If patients' concerns are not identified this can lead to psychological distress, a lack of understanding of information and reduction in information recall (CRC, 1997). In contrast, good communication can reduce patients' psychological distress, anxiety, and/or depression (Maguire and Pitceathly, 2002). Patients rarely openly disclose their feelings unless asked; instead they drop 'cues' or hints to their concerns / feelings for the health professional to pick up, and such cues should be acknowledged and explored (CRC, 1997; Schofield et al, 2008). Asking patients 'what is your main concern/problem' will clarify the patient's priorities, however studies have identified discrepancies between the patient's main concerns and perceptions of health care professionals (Heaven and Maguire 1997, Farrell et al 2005).

The Manual for Cancer Service Standards (2008) recommends that core members of the multidisciplinary team who have contact with patients should attend advanced communication skills training. However, it is not mandatory for chemotherapy nurses to undertake advanced communication skills' training, although recommended by the UK Oncology Nursing Society (Lennan et al, 2012). Nurses in this study had a wide range of communication skills, yet most demonstrated blocking and distancing behaviours that they did not appear to be aware of. This reflects evidence from over 20 years of research on communication skills from one unit in Manchester (CRC, 1997), highlighting nurses' poor communication skills (Wilkinson et al, 1991; Schofield et al, 2008),

and poor identification of patients' concerns by hospice nurses (Heaven and Maguire, 1996; 1997), and nurses on chemotherapy wards (Farrell et al, 2005).

Reflecting on the nurse-patient observations and nurses' perceptions, it does not seem appropriate to expand nurses' roles within nurse-led clinics with the expectation that nurses will automatically have good communication skills without providing appropriate training to facilitate this. There are several National and local educational initiatives designed to improve communication skills of health professionals. The Connected national programme for Advanced Communication Skills was developed in accordance with the National Cancer Plan (2000a) and NICE Guidance for Supportive and Palliative Care (2004), and is available in a two or three day format. In addition, a wide variety of local and national communication skills training is available for NHS staff, from half day to three day sessions, standard and bespoke training by groups such as the Maguire Communication Skills Team in Manchester (Schofield et al, 2008). However, there are no current communication skills courses specifically for chemotherapy nurses.

Within the current NHS there is increasing pressure on chemotherapy services from rising numbers of patients needing chemotherapy. Whilst nurse-led chemotherapy clinics may seem to provide the quick fix from a government perspective, greater investment is required if this is to be a sustainable solution, given the complexities involved. It seems foolhardy to make recommendations for more nurse-led chemotherapy clinics in the absence of transparent definitions, particularly given the lack of research and disparate levels of clinical practice.

#### **5.3.4 Defining levels of nurse-led chemotherapy clinics**

Nurses running nurse-led clinics may be criticised for undertaking the 'easy option' in terms of patients that they can see independently, such as those on routine follow-up. However, treatment management, such as radiotherapy and chemotherapy increases the complexities for nurses, and often demands higher level decision-making and greater considerations of patient safety. This was illustrated during the observations of nurse-led chemotherapy clinics and interviews with nurse participants.

Considering nurse-led chemotherapy clinics as a collective term is inappropriate, since the findings from study 2 identify four different levels of nurse-led practice within the chemotherapy clinics. This finding is novel, and will be valuable for patients, health professionals, commissioners and policy-makers in defining chemotherapy services. The use of a framework incorporating the four levels of nurse-led chemotherapy clinics will provide greater transparency and clear definitions for clinical practice. This seems more appropriate than using a blanket term of nurse-led chemotherapy clinics, which lacks descriptive detail and is open to interpretation. Awareness of the different levels of chemotherapy nurse-led clinics is important for health professionals and clinical services to provide some structure and facilitate service developments. It is also important for policy-makers to understand the complexities within chemotherapy service provision and different levels of nurse-led chemotherapy clinics in order to make appropriate recommendations for the future.

However, the addition of a competency framework would provide additional benefits, with important safeguards for patients and health professionals. Incorporating this will mean that each of the four levels of nurse-led chemotherapy clinic has its own competency framework for training, clinical skills, assessments and evaluation. This will provide a robust system with increased transparency of clinical expertise and services. In addition it will provide a framework for career progression for nurses towards advanced nursing practice.

### **5.3.5 Autonomy and the role of the nurse**

Autonomy plays a pivotal role in nurse-led chemotherapy clinics, although it may be influenced by a number of factors such as knowledge, skills, power and beliefs. In nursing practice, autonomy is generally considered synonymous with independence in nursing practice, and a crucial factor for advanced practice (RCN, 2010; NMC, 2008). However the concept of autonomy is often poorly defined and understood, incorporating several types of autonomy with similar features but different contextual meanings (Gagnon et al 2010). This seems important when considering interpretations of autonomy and nurses' roles, and understanding the inter-relationships between personal, professional, clinical and organisational aspects of autonomy.

Definitions of advanced nursing practice include references to “*professionally autonomous decisions*” (RCN, 2010) and accountability (RCN, 2010; NMC, 2008). This suggests that it is the nurses’ actions regarding decision-making that are important rather than the nurse’s personal autonomy, however interpreting the concept of autonomy is more complex than a simple explanation of an act or omission. Philosophers propose that three factors are essential for autonomy

- Liberty (freedom from controlling influences)
  - Agency (capacity for intentional action)
  - Understanding (regarding disclosure of information)
- (Beauchamp and Childress, 1994 p121-3)

This indicates that it is more than just actions and capacity that signify autonomy, and that full understanding and freedom from distorting / controlling influences are also conditions that must be met.

Nurses in study 2 perceived that their roles were autonomous based on their ability to work independently within clinical practice, however definitions and factors of autonomy illustrate this is not so straightforward. Using the above factors, all of the nurses in study 2 had the capacity for intentional action and understanding; however liberty was often compromised by direct and indirect influences from medical colleagues, managers and also nurses themselves, which adversely affected the autonomy of individual nurses. For example, in relation to setting up nurse-led clinics, medical staff influenced who nurses could see, what they could do, and what they should not do within their nurse-led clinics. Although nurses appeared to acknowledge and accept the limitations of their role imposed by doctors, they failed to recognise how this may affect their autonomy. In addition, nurses’ individual beliefs may influence their autonomy, for example nurses’ confidence in their clinical examination skills and levels of decision-making in clinical practice. However, Lindley (1986) argues that to be totally autonomous is unrealistic, since the degree of autonomy a person may have can vary according to a number of different factors and contexts).

The literature suggests that although nurses' training, clinical knowledge and understanding enable autonomous decision-making within the scope of professional practice, if approval or permission is required from someone "above" the nurse then the nurse is not acting with autonomy (Lewis, 2006). In a systematic review of specialist and advanced practice roles, Lloyd-Jones (2005) stated that autonomy was one of the factors that facilitated role development and effective practice. Given this evidence, autonomy was considered to be an important a priori theme prior to fieldwork, however the degree of autonomy for individual nurses was not known for study 2 participants, therefore this was included in the research questions. From data collected in study 2, the variability of nurses' autonomy and influencing factors suggest that a sliding scale of autonomy, accountability and responsibilities may be more representative of nurses' roles, rather than a single measure. This appears to reflect the levels of clinical practice from novice to expert, and would fit within the four levels of nurse-led chemotherapy clinics identified in data from study 2.

The findings illustrate how nurses' professional relationships with medical consultants can have a crucial influence on nurses' roles. For example, the data showed that nurses who had worked with consultants for several years developed greater trust and autonomy, and these nurses saw themselves more on an equal footing to medical consultants. Other nurses spoke of role tensions with medical colleagues and changing team dynamics arising from the expansion of nurses' roles. This was more apparent in the data from observations and interviews where specialist nurses worked with consultants in one cancer group, rather than generic chemotherapy nurses who worked with several consultants. Observational data showed that although chemotherapy nurses seemed to be held in high regard by the consultants, their relationship appeared more distant and the consultants exerted more control over what nurses could and should not do within their clinics, which was also reflected in protocol documents for the nurse-led clinics. This is highlighted in the literature, where relationships between doctors and nurses have been described as games, illustrating power struggles and clinical conflict (Stein, 1967). More recently, there are indications of a strong synergistic association between teamwork and autonomy, in that nurses who displayed greater teamwork also had higher levels of autonomy and were more involved in decision-making

(Rafferty et al, 2001). Although this was not revealed in the data collected, it has implications for nurse-led clinics, given that support from doctors is vital for success.

This is an important issue in terms of improving clinical services to benefit patients. There is evidence in the literature where greater autonomy enabled nurses to be more flexible and creative with their nurse-led clinics (Faithfull et al, 2001; Wells et al, 2008), rather than simply using a medical model with doctor-nurse substitution (Campbell et al, 1999). However, this choice is down to individual nurses who may feel more comfortable a model of doctor-nurse substitution. This reflects the findings in study 2 where some nurses had opportunities to develop different models of care, but preferred a biomedical model of care, with little emphasis on psycho-social issues and nursing assessments.

#### **5.3.5.1      *Expanding nurses' roles in nurse-led chemotherapy clinics***

During observations of nurse-led chemotherapy clinics, patients seemed to accept the expansion of nurses' roles and nurse-led chemotherapy clinics without question. However, it was not possible to ascertain patients' opinions within the scope of this study. The lack of research evidence on this topic means that it is difficult to appreciate patients' understanding of nurses' roles within the nurse-led clinics; although anecdotal evidence suggests there is a general lack of understanding of nurses' roles by patients, therefore greater transparency is needed.

Data from study 2 also showed disparities in nurses' perceptions of advanced practice, and essential requirements for nurses' roles within nurse-led chemotherapy clinics. Within this data, nurses' perceptions of advanced nursing practice seems to reflect a 'skills set', comprising a collection of skills and certificates that focus on medical tasks, such as clinical examination, clinical procedures and prescribing. In turn, this may place emphasis on the technical aspects of clinical care and provide less priority for nursing. McIlfatrick et al, (2006) highlight the difficulties that chemotherapy nurses face in trying to maintain a balance between performing multiple tasks and providing emotional support for patients. However, being with patients was reported to be the most

satisfying aspect of chemotherapy nurses' roles, whilst insufficient time for psycho-social care and inability to form nurse-patient relationships were reported as the least satisfying (McIlfatrick et al, 2006).

The findings from study 2 reflect the literature evidence, since nurses in study 2 report difficulties trying to 'marry up' their technical role with their caring role, which resulted in frustrations. McIlfatrick et al, (2006) suggests that nurses perceived that their actual role placed priority on the technical aspects, whilst their caring role was what they aspired to. Although there appear to be obvious tensions between the two, this suggests that these two aspects must remain separate and this devalues caring within the context of chemotherapy. Barnard and Sandelowski (2001) propose that the conflict between technical and caring roles represents issues with nurses' professional identity rather than nursing care. This proposal reflects the tensions that can arise with the expansion of nurses' traditional roles when boundaries become blurred between nursing and medical practice, which was prevalent in the findings from study 2. A greater focus on technical aspects of care may also be viewed as a distraction or blocking behaviour when faced with emotional distress, which was evident in the findings from study 2. However, in study 2 it was not clear whether nurses were aware of this, or to what extent it applied to individual nurses.

Whilst clinical or technical skills may be required for some roles at an advanced level, placing emphasis on medical skills appears to give the wrong impression of advanced nursing practice. Advanced nursing practice is more than just technical skills, and placing more weight on achieving practical skills rather than communication and patient-centred care seems to devalue nursing. In expanding nurses' roles and focusing more on biomedical models of care it seems that we have forgotten the fundamentals that constitute nursing, which was clearly reflected in the data.

There are also implications for patient experiences and satisfaction. Sitzia and Wood (1998a) identify two main components to patient satisfaction with outpatient chemotherapy: the interpersonal manner of health professionals, and the technical quality of care. Although there is limited evidence on the satisfaction of chemotherapy nursing care (Sitzia and Wood, 1998a), patients receiving chemotherapy expressed dissatisfaction with doctors, highlighting

poor communication skills, a lack of empathy and insufficient time to talk in consultations (Sitzia and Wood, 1998b). This emphasises that good communication skills, empathy and time to talk seem important for nurse-led chemotherapy clinics. However, the findings from study 2 identified problems with some aspects of nurse-patient communication.

#### **5.3.5.2      *Meeting clinical needs***

The findings of study 2 highlighted the clinical pressures and service demands within chemotherapy services and some nurse-led clinics, which were causing concern for several nurses. Within the data collection, nurses reported that medical clinics regularly exceeded capacity, which increased waiting times for patients and may cause consultations to be rushed. However, there was no scope for comparisons with medical clinics in this study; therefore there is no objective evidence of this. This reflects evidence in the literature with several reports of rushed medical consultations in comparison to nurse-led clinics, where patients reported having more time to talk and discuss information (Pennery and Mallet, 2000; Baildam et al, 2004; Allison, 2004; Wells et al, 2008; Strand et al, 2011). However, despite longer consultations in nurse-led clinics the waiting time for patients was shorter because nurse-led clinics had been set up (Campbell et al, 1999; Baildam et al, 2004; Wells et al, 2008; Strand et al, 2011). .

The findings from study 2 also illustrate the importance of ensuring that nurses have the appropriate skills and knowledge to manage patients who attend nurse-led clinics. This reflects evidence from research studies which demonstrate that nurse-led clinics are safe and efficient (Knowles et al, 2007; Baildam et al, 2004; Corner et al, 2002; Moore et al, 2002; Wells et al, 2008; Faithfull et al, 2001) and that patients are satisfied with nurses' skills within nurse-led clinics (Egan and Dowling, 2005; Corner et al, 2002; Baildam et al, 2004). However, if patients are too complex nurses will need to refer back to doctors and may become disillusioned or frustrated, and there were examples of this during observations. Referring patients within nurse-led clinics to medical staff also has implications, with increased waiting time for patients, and possible loss of confidence in the nurse's abilities, which was evident in some observations during study 2. Some nurses in study 2 received training in



clinical examination, but did not use their skills in clinical practice, whilst others lacked confidence in their clinical skills and asked medical staff to examine the patient as well, or instead. This suggests that training in clinical examination skills can be a waste of time and resources if nurses fail to use the skills in clinical practice, or lack confidence in their abilities. Findings were similar in relation to independent nurse prescribing; however this was primarily caused by restrictions placed on nurses' prescribing by medical staff and managers, rather than nurses' lack of confidence. From the literature review there is little evidence of how nurses use their clinical examination skills in practice within nurse-led clinics, although there are some examples of medical procedures undertaken by nurses, such as central line insertion (Alexandrou et al, 2012; Fitzsimmons, 1997), abdominal paracentesis (Hill et al, 2012), and minor surgical procedures (Martin, 2002).

Changes to legislation for independent nurse prescribing have had the greatest impact on nurse-led chemotherapy clinics by enabling nurses to prescribe supportive medication for chemotherapy (Farrell and Lennan, 2013; Lennan et al, 2012). In addition, the findings from study 2 revealed that some nurses were also able to prescribe chemotherapy, although there were differences in what they could and should not prescribe. The UK Oncology Nursing Society (Lennan et al, 2012) proposes that nurse prescribing within the clinic is the 'gold standard' for nurse-led chemotherapy review. However, despite the national legislation for nurse prescribing, data from this study identified local disparities which influenced operational factors within nurse-led clinics. The data showed that whilst some nurses could prescribe freely, in the same way as medical colleagues, others were restricted to prescribing certain regimens or being unable to prescribe the first cycle of chemotherapy. Data from observations also revealed other implications around prescribing and amending chemotherapy; in some cases nurses could defer a patient's chemotherapy, others may have to refer back to medical staff if they want to reduce the dose of chemotherapy, whilst other nurses are able to do this independently. In addition the data revealed similar restrictions with supportive medication in that some nurses could only prescribe certain medicines, such as specific anti-emetics or growth factors, whilst other nurses could prescribe freely from the British National Formulary. The findings from study 2 demonstrated that in some cases

prescribing requirements were hospital policy and applicable to medical staff as well as nurses, however in other cases the range of prescribing for nurses was much less than doctors; during observations and interviews this often caused frustration for nurses who could not use the full range of their skills. The implications of this were seen during clinical observations, since it resulted in increased waiting times for patients whilst nurses went to find a doctor to write the prescription. The lack of current evidence in the literature on nurse-led chemotherapy clinics and nurse prescribing within clinical practice mean that these findings from study 2 are novel and have important considerations for nurses' roles within nurse-led clinics.

The findings from study 2 also showed that although nurses acknowledged the degree of 'control' by medical staff, they treated the consultants with respect and did not challenge their decisions directly. Although nurses openly expressed their feelings of frustration within the study, it was not clear to what extent medical staff and managers were aware of this. This not only illustrates disparities in power and control between doctors and nurses; it also highlights the implications for clinical management when restrictions are placed on nurse prescribing.

#### **5.3.5.3      *Meeting patients' needs***

It is difficult to know to what extent nurse-led chemotherapy clinics met patients' needs, since this study did not focus on patients' experiences. Although there is some evidence in the literature regarding patients' experience of nurse-led chemotherapy administration (Wiseman et al, 2005; McIlfatrick et al, 2006); this does not take into account the greater complexities of nurse review consultations and the nursing management of patients during chemotherapy treatment.

From the literature, Griffiths et al (2012) highlight ambulatory chemotherapy as a nurse-led service where the quality of nursing care may have a 'significant impact on patient outcomes and experiences. However, the National Chemotherapy Advisory Group reports that the quality of services within the UK is variable (NCAG, 2009). The contribution of nursing to patient outcomes during chemotherapy relies on presumed links between patient problems and

nursing actions; however this depends on the precise roles of nurses, such as independent nurse prescribing (Griffiths et al, 2012). The authors identified five outcome areas that appear the most sensitive to measuring the quality of nursing in ambulatory chemotherapy: patient experiences, nausea, vomiting, oral mucositis and safe medication administration (Griffiths et al, 2012). Whilst symptom management and safe administration of medicines may appear quite easy to measure as part of nurses' clinical practice, evaluation of patients' experiences appears more complex.

Assessing patient satisfaction per se may not provide sufficient detail of complexities within patients' experiences during chemotherapy, therefore robust qualitative research seems required to facilitate meaningful information and understanding. However, McGee and Castledine (2002) propose the lack of consideration for outcomes that can be demonstrated in terms of nursing and improved patient care (McGee and Castledine, 2002).

Data collected during study 2 clearly demonstrates nurses' skills at providing information for patients about chemotherapy drugs and side-effects of treatment; however nurses often failed to check patients' understanding of written or verbal information. During observations of nurse-patient consultations, there were also instances where patients expressed feeling overburdened by the amount of information; however this was seldom acknowledged and certainly not addressed. This seems an important omission since information is crucial during chemotherapy clinics so that patients understand their treatment, can safely manage the potential side-effects and know who to contact in an emergency.

There is evidence in the literature demonstrating that nurses are comfortable communicating with patients about chemotherapy, however many nurses identified a need for more education to help them support patients and their family with the emotional and psychological consequences of chemotherapy (Wiseman et al, 2005). Information and communication are reported to be important factors in the management of patients' anxiety during chemotherapy (Meyerowitz et al, 1983). Therefore it seems surprising that a study of chemotherapy outpatients in the US found that nurses were seldom used as a source of information or support (Dodd et al, 1992). Determining how much

information is sufficient for each individual seems a fine art (Fallowfield et al 1990, 1995; Luker et al, 1996; Van der Molen 2000). It is well known that providing information for chemotherapy treatment is crucial and links directly with patient satisfaction; however it is more than just giving information since nurses need to establish patients' understanding, psychological concerns and their ability to make informed decisions about potentially life-threatening treatment.

### **5.3.6 Nurse-patient consultations**

#### **5.3.6.1 *Duration of consultations during chemotherapy***

Data from study 2 showed disparities in the duration of nurse-patient consultations within nurse-led chemotherapy clinics, ranging from 3 to 56 minutes. The mean consultation time for individual nurses ranged from 8.32 minutes to 29.79 minutes, and the mean consultation time across all four locations was 20.26 minutes. This reflects findings in the literature; Brataas et al (2009) recorded naturally occurring consultations between patients with cancer and outpatient nurses, which varied from 15-45 minutes. However, the observations in study 2 suggest that interpersonal skills of individual nurses may influence the consultation and patients' perceptions more than the duration of the consultation itself, since observational data showed that patients appeared to appreciate brief consultations as much as long consultations when nurses' interpersonal skills conveyed empathy and compassion. This is supported by evidence in the literature, where patients' perception of time spent with nurse practitioners is influenced by the nature of the consultation rather than the amount of time nurses spend with patients (Torn and McNichol, 1998).

However, based on nurses' narratives during observations and interviews, the findings also demonstrate that a common feature of nurse-led clinics is the longer duration of appointments in comparison to medical clinics, which is reflected in the literature from other nurse-led clinics (Faithfull et al, 2001; Coughlan, 2005; Warren, 2007; Wells et al, 2008; Beaver et al, 2009; Palmer and Thain, 2010). The data from some nurses in study 2 indicates that this allows more time for patients to talk, which nurse participants perceived would improve their experience. However, observational data analysis highlights the

importance of the nature and quality of the consultation, suggesting that this should be carefully balanced against efficiency of nurse-led chemotherapy clinics. Observational data revealed that the majority of consultations observed were semi-structured. Nurses appeared to adopt similar methods for assessing patients' symptoms, referring to a list of common chemotherapy toxicities where they would grade each symptom according to a universal scale. In all consultations observed, checking and managing patients' physical symptoms was the main focus of the consultation. However, in one location the use of very structured checklists appeared to hinder the consultation, where observational data showed that this often turned into a quick sequence of closed or leading questions and negative questioning. Examples of this from the data collected include: 'any sickness?', 'bowels okay?', 'no problems with...?' which resulted in minimal responses from patients. However, the data revealed great variability in other aspects of nurses' consultations when comparing and contrasting between different nurses and locations. Data analysis indicates that the way nurses communicated with patients is crucial, for example how nurse asked questions, the way that nurses' explored symptoms, whether they picked up patients' cues, and how they elicited and explored patients' concerns.

#### **5.3.6.2      *Essential skills for nurses***

The findings from study 2 illustrate disparities in nurses' communication with patients in the nurse-led chemotherapy clinics. Although there are national recommendations for core members of the multi-disciplinary team to undertake training in advanced communication skills (NICE, 2004), this does not extend to chemotherapy nurses, despite many nurses extending their role and increasing the complexity of their communication with patients. During interviews with nurse participants they were asked to identify what training they perceived was essential for their role, and whilst some nurses included advanced communication skills training in this, more emphasis was placed on clinical examination skills training and independent prescribing. This suggests that nurses running nurse-led chemotherapy clinics considered improvements in practical and technical skills to be important when extending their roles and taking on medical responsibilities. However, the majority of nurses considered their communication skills were good and did not require further training. Nevertheless, observations of nurse-patient interactions indicate considerable

disparities in communication skills. Some nurses regularly used facilitative skills and techniques that are taught on communication skills courses, whilst other nurses displayed a lack of awareness and regularly used blocking behaviours, which prevented further discussion of patients' psychological concerns; however nurses appeared to lack awareness of this.

In many cases where nurses failed to pick up patients' cues, patients did not attempt to raise their concerns again later in the consultation, suggesting this may result in unresolved issues. This behaviour accords with evidence in the literature, which demonstrates that patients' concerns may be blocked by health professionals, particularly if they feel uncomfortable discussing emotional concerns (Razavi et al, 2000, 2002; Booth et al, 1996; Wilkinson, 1991). In one study, although 94% of nurses perceived it was their role to discuss patients' feelings, nurses used blocking behaviours during interactions with patients, and 70% of nurses were unaware that they had done this (Wilkinson, 1991). There is similar evidence with patients on chemotherapy, where nurses use avoidance tactics so that they do not have to consider the emotional issues regarding chemotherapy and its side-effects (Dennison, 1995). Dennison found that although nurses were competent in providing information they rarely made assessments of patients' feelings about the treatment. Other reasons for not discussing emotional issues may be linked to concerns that this may provoke strong reactions for patients that nurses cannot cope with and control (Maguire, 1999), or lack of confidence regarding their communication skills (Parle et al, 1997; Addington-Hall et al, 2006; Dunne et al, 2005). However there may be a number of other reasons, including lack of privacy and time (Arantzamendi & Kearney, 2004).

Studies have shown that patients' concerns may be missed during consultations with health professionals (Bell et al, 2002; Butow et al, 2002; Zimmermann et al, 2007). However patients may not spontaneously express their concerns and often hint about their emotions and concerns indirectly (Zimmerman et al, 2007; Maguire et al, 1996). This places onus on health professionals to pick up patients' cues and seek further details, which may be easily missed if the cues are not explicit and not associated with any expression of emotion (Zimmerman et al, 2007). There is also evidence that when emotional issues are expressed they are often handled briefly by doctors (Marvel et al, 2000) and nurses

(Wilkinson, 1991), and one study identified that nurses generally waited for patients to open discussions, with no formal tool in place to systematically assess psychological needs (Arantzamendi & Kearney, 2004).

There is also evidence that when nurses acknowledge and explore patients' cues or concerns this may increase emotional expression (Uitterhoeve et al, 2008). Patients' expression of concerns seems to occur quite early on in consultations (Marvel et al, 1999; Mjaaland et al, 2011), which suggests that patients' concerns could naturally be expressed even if the consultation was quite brief. This supports the findings of study 2 where some nurses showed empathy even in very brief consultations. Heyn et al (2013) also suggests that patients had greater expectations of discussing emotional issues with nurses, in comparison with doctors.

Brataas et al (2009) found that nurses focused on providing information for patients starting treatment, however did not check patients' understanding and sometimes failed to pick up on patients' cues and concerns. This is reflected in the findings from study 2, which illustrate emphasis on information provision during chemotherapy.

#### **5.3.6.3      *Communication skills training***

There is extensive work in the UK on communication skills' training, identifying this as the key to good care in oncology (Fallowfield and Jenkins, 1999). The value for patients is that it may improve patients' abilities to control stressful events (Zachariae et al, 2003), psychological distress and coping (Fukui et al, 2008), improve psychosocial adaptation and also quality of life (Razavi et al, 1988; Fukui et al, 2011). Studies have also highlighted that where patients have unmet needs for information and psychosocial support this may lead to increased anxiety and depression, poor psychological adjustment and decreased quality of life (Thorne et al, 2005). Communication skills training may also be valuable for nurses since insufficient training in communication skills has been linked to increased stress and burnout amongst oncology nurses (Escot et al, 2001).

The type of communication skills' training is also important; experiential workshops have been shown to improve healthcare professionals' empathy,

which facilitates emotional expression by patients with cancer (Razavi et al, 2002). In contrast, ineffective communication can increase patients' anxiety and dissatisfaction (Wilkinson et al, 2008), and adversely affect their quality of life (Kerr et al, 2003). Communication skills training has been well received in oncology, improving nurses' confidence (Wilkinson et al, 2003; Liu et al, 2007), increasing empathy (Faulkner and Maguire, 1984), increasing nurses' use of open directive questions (Booth et al, 1996; Heaven and Maguire, 1996, and nurses' use of emotional words (Razavi et al, 2002); however there is a limited evidence regarding the effect on clinical practice (Kruijver et al, 2000; Griffiths et al, 2012). Although evidence suggests that communication skills courses can improve nurses' communication skills, there may be a difference between nurses' competence (what a person can do) and performance (what a person actually does) in clinical practice (Heaven et al, 2006). Furthermore, a randomised trial demonstrated that improvements in communication skills are not automatically transferred back into the workplace, although clinical supervision may facilitate this process (Heaven et al, 2006).

#### **5.3.6.4      *Nurse-patient interactions***

The findings from study 2 highlight contradictions between nurses' perceptions of their care and communication with patients, and objective observations of their clinical practice. This is supported by findings in the literature where district nurses' descriptions of their care did not match observations of their actual practice; although nurses talked about providing holistic care they limited their care to physical aspects or 'chatting' about 'everyday matters and used blocking strategies with patients (Griffiths et al, 2007; 2010). The importance of professional communication is clearly illustrated in the literature; Brataas et al (2009) propose this to be a key aspect of caring and effective communication and reports that psychosocial care can improve patients' outcomes. Integral to this appears to be the connection between patient and nurse, or other health professional; and important elements are how much the patient is 'known' and cared for (Thorne et al, 2005).

Observational data from study 2 of nurse-patient consultations in chemotherapy clinics suggests that nurses may have preconceived ideas of patients' potential concerns based on their disease status and planned chemotherapy. Such



preconceived ideas may influence nurses' communication agenda, and may explain why nurses in study 2 focused more on chemotherapy toxicities and symptom management. If nurses adopt a biomedical consultation model that does not focus on patients' individual concerns, this may also explain nurses' inability to pick up patients' cues and explore their concerns. Data analysis also suggests that nurses' previous clinical experience may influence their communication with patients, since chemotherapy nurses appeared to focus more on physical aspects of chemotherapy than specialist nurses.

There is strong evidence that nurses are poor at identifying patients' concerns in hospice settings (Booth et al, 1996; Heaven and Maguire, 1996, 1997), in secondary care (Wilkinson, 1991), and also for patients receiving chemotherapy on hospital wards (Farrell et al, 2005). This is important since studies have demonstrated a significant association between patients' concerns and psychological distress (Harrison et al, 1994) and future affective disorders (Parle et al, 1996). Symptoms of anxiety and depression are common in patients with cancer (Hopwood and Stephens, 2000) affecting up to a third of patients (Maguire, 2000); often occurring at diagnosis (Stark et al, 2002) and during chemotherapy treatment (Browall et al, 2008; Farrell et al, 2005). This warrants further consideration for patients during chemotherapy who may be struggling to cope, given evidence that chemotherapy nurses may fail to accurately judge patients' needs (Fernsler, 1986).

Data from study 2 of nurse-led chemotherapy clinics indicates that the nature of nurses' communication with patients has changed over time, from providing support and information to incorporating aspects of clinical management, which includes reviewing patients instead of medical staff. During interviews with nurses from study 2, nurses highlighted a difference between 'closed door' consultations in a private room and previous reviews with patients on an open chemotherapy unit. Nurses suggest that this creates a different type of consultation that nurses were not familiar with, and some nurses suggested that this requires additional communication skills.

For nurses in positions of advanced practice their main role models in clinical practice are doctors, therefore it is not surprising that nurse consultations in study 2 followed a biomedical model. However, it is worrying that nurses

perceived their consultation style is based on holistic care and enhanced communication skills, since the findings from study 2 do not support this.

### **5.3.7 Summary**

The findings from study 2 accord with the literature, demonstrating similarities in professional relationships between clinical nurse specialists and doctors. Willard and Luker (2007) identified that acceptance by doctors was the main problem facing cancer clinical nurse specialists, which may impair nurses' ability to provide supportive care to patients. Acceptance was crucial since nurses relied on referrals from medical staff, and nurses devised a variety of strategies to increase acceptance, including building relationships with senior doctors, avoiding criticism and using a gentle approach to change (Willard and Luker, 2007).

The findings from study 2 have highlighted several issues regarding communication, illustrating power tensions between nursing and medical staff that have, in some cases, restricted what nurses can and cannot do in nurse-led chemotherapy clinics. Observations of nurses' consultations with patients indicate variation in communication skills; although some nurses used facilitative techniques, other nurses used blocking and distancing techniques, suggesting that mandatory communication skills may be useful for chemotherapy nurses. One of the key findings of this study is the deterioration in the essence of nursing and compassionate care with increasing medicalisation of nurses' roles. This is worrying given the current priorities for compassionate care. However, the findings also highlight the power of nurses' non-verbal behaviours during patient interactions, demonstrating the positive influence that this can have on patients' experiences even in brief consultations.

The final chapter draws together the findings from both studies to discuss the implications for nurses' roles and nurse-led chemotherapy clinics, and considering evidence from the literature and relevant national policies.

## **Chapter Six      Final discussion**

## **6.1 Introduction**

This chapter draws together both studies to outline the key findings in relation to the role of the nurse in nurse-led chemotherapy clinics. Links between the findings and current literature, together with government / professional policies will be discussed, with implications for clinical practice. The strengths and weaknesses of both studies will be discussed, followed by recommendations for the future.

Dal Pezzo (2009) outlines that nursing care refers to tasks and activities by nurses for patients. There are three main categories of activities: tasks and procedures, the nature of nursing care (for example skilled, compassionate, holistic), and the functions of nursing care (for example listening, assessing, monitoring) (Del Pezzo, 2009). The categories reflect different aspects of nurses' roles and are important factors to consider when exploring what nurses do within clinical practice. The findings from the present study will therefore be linked with these.

## **6.2 Nurses' roles in nurse-led chemotherapy clinics: Key findings**

Study 1 elicited a broad range of data on nurses' roles and nurse-led clinics in oncology, which included chemotherapy nurse-led clinics. Although this survey provided some information about different aspects of nurses' roles and 'who did what' regarding nurse-led clinics, it lacked details about 'what they did' and 'how they did it'. This was addressed in study 2, which provided more detailed information on nurses' roles within nurse-led chemotherapy clinics. This is important information given the limited literature on nurse-led chemotherapy, and lack of evidence on nurses' roles within nurse-led chemotherapy clinics.

The findings from both studies clearly showed disparities in nurses' job titles and their roles and responsibilities. This meant that nurses' job titles were not a reliable indicator of key aspects of nurses' roles and responsibilities such as clinical skills, due to individual variability within their roles. This finding is supported by evidence in the literature, where the Nursing and Midwifery Council (2007) raised concerns regarding the plethora of nurse titles, stating that they do not enable the public to understand the level of care that nurses can provide, which has been echoed by the Department of Health (2010).

Similarly, the Royal College of Nursing (2008) highlighted that some nurses are using the title nurse practitioner / advanced nurse practitioner without appropriate training. However this is difficult to action since there are no current specifications in the UK to determine what training may be considered appropriate.

Within nurse-led chemotherapy clinics, individual variability in roles and responsibilities was identified for nurses with identical job titles and also those with different job titles. For example, whilst all chemotherapy nurses administered chemotherapy, not all chemotherapy nurses could prescribe chemotherapy, and there were clear differences in the nature of nurse-patient consultations between individuals. However, there were also differences in the role of specialist advanced nurse practitioners within nurse-led chemotherapy clinics, compared with the role of chemotherapy nurses, yet on the surface they are all running similar nurse-led chemotherapy clinics. This suggests that it may be important to deconstruct nurses' roles to look at individual factors that may influence what nurses do in practice, and how they do it.

The findings from both studies demonstrate a wide range of components and complexities within nurses' roles generally. This is reflected in study 1 by the number and range of clinical and non-clinical activities that nurses undertake as part of their roles, and also the number and range of nurse-led clinics. In addition, study 2 provides a greater depth of understanding regarding how nurses implement their roles and interact with patients within the context of nurse-led chemotherapy clinics. By interviewing and also observing nurses in nurse-led chemotherapy clinics, nurses' perceptions of 'what they did' and 'how they did it' were compared with nurses' actual behaviour and activities within nurse-led chemotherapy clinics, which revealed disparities.

### **6.2.1 Utilization of clinical skills**

The time lag between undertaking study 1 and study 2 illustrates how nurses' clinical skills have generally developed over time, with an increase in the proportion of nurses trained in clinical examination skills and nurse prescribing. However there is limited evidence in the literature regarding the training required, or undertaken, by nurses running nurse-led clinics (Warren, 2007). Furthermore, although there is some evidence in the literature of the general

ways that nurses are working within nurse-led clinics (Faithfull et al, 2001; Moore et al, 2002; Beaver et al, 2009, 2010a, 2010b), there is no detailed evidence of how this is being undertaken. In study 1, none of the chemotherapy nurses who were running nurse-led chemotherapy clinics had undertaken any training in clinical examination skills, although two reported that they conducted clinical examinations. In contrast, all the nurses in study 2 had received clinical examination skills' training, which highlights changes over time. However, observational data in study 2 revealed that some nurses did not use their clinical examination skills in practice. In contrast, although study 1 had identified the range of nurses' clinical skills and activities (competence), it was not possible to determine from this whether nurses used such skills in practice (performance). In study 2, interviews with nurses running nurse-led chemotherapy clinics identified that nurses considered it important to gather a 'skills set', which included clinical examination skills and independent prescribing, since this type of skills set was perceived to represent advanced nursing practice and increased autonomy within nurses' roles. This finding is supported by evidence in the literature on advanced nursing practice, which places emphasis on skills and competencies in clinical practice (Mills and Pritchard, 2004).

However observations of nurse-led chemotherapy clinics revealed that the majority of chemotherapy nurses did not undertake any clinical examinations, therefore the majority of chemotherapy nurses did not really need to undertake a course in clinical examination skills. However, there were two examples where nurses wanted to undertake a respiratory examination but lacked confidence to do so. This indicates that nurses should consider the potential use of clinical skills within their role before undertaking training. If clinical examination rarely needs to be undertaken by nurses within their clinical practice, it seems inappropriate to undertake such training, particularly in the current financial climate. For clinical nurses, requests for additional training must be approved by hospital managers, therefore if managers are approving training that is not essential this suggests a lack of understanding of nurses' extended roles. In contrast, all advanced nurse practitioners conducted clinical examinations in nurse-led chemotherapy clinics and also had a greater level of medical responsibility within their role in comparison with chemotherapy nurses,

therefore clinical examination training appears appropriate for this group of nurses.

There was also evidence of changes over time in relation to non-medical prescribing; in study 1 there were only two (33%) chemotherapy nurses who could prescribe independently, in comparison to most of the nurses in study 2. However, changes in nurse prescribing legislation (DH, 2006) post study 1 have influenced developments in nurse prescribing, enabling more nurses to prescribe independently within an oncology / chemotherapy setting (DH, 2006). In contrast to clinical examination skills, all nurses prescribed independently in practice, indicating that nurse prescribing skills are essential for nurse-led chemotherapy clinics.

### **6.2.2 *Factors influencing nurses' roles***

There was minimal evidence in the literature review on nurses' roles and responsibilities within nurse-led clinics, including how nurses assess, manage and monitor patients' symptoms and chemotherapy toxicities to ensure care provision is safe. Similarly, there is no literature outlining the operational aspects of chemotherapy management within nurse-led chemotherapy clinics. One of the key findings within this study was the variability of nurses' autonomy and decision-making within nurse-led chemotherapy clinics, highlighting a range of factors that may influence nurses' autonomy. Perhaps the most surprising finding was the degree of power from doctors in relation to nurses' roles and nurse-led chemotherapy clinics, which influenced nurses' autonomy. Weston (2010) highlights that it is important for nurses to have responsibility and accountability in order to control their clinical practice, which includes the 'right' and 'power' to make decisions related to clinical practice. Therefore the findings from this present study have implications for nurses' roles.

However, increased understanding of associations between nurses' autonomy and accountability seems crucial to consider the implications for nurses' roles. Batey and Lewis (1982) propose that accountability cannot be considered in isolation from the concepts of autonomy (freedom to act), responsibility (a charge for which a person is answerable) and authority (the rightful power to act on the change). This reflects the findings from study 2 given the influence on nurse prescribing and nurse-led chemotherapy clinics by medical consultants.

In addition, Walsh (1997) recommends that a clear distinction should be drawn between accountability (explaining and justifying actions based on sound clinical knowledge and transparent, logical and replicable decision-making) and responsibility (performance of tasks in an accurate and timely way through delegation). This suggests that accountability requires independent thought and is therefore considered on a higher plane to responsibility, whilst accountability is considered to be a consequence of autonomy (Keenan, 1999). The concept of accountability is important for all nurses within their professional code of conduct (NMC, 2013). However there are greater implications for advanced nursing practice in relation to accountability and potential litigation, since nurses who have taken on a clinical task previously undertaken by a doctor must perform it to the same standard as a doctor (Duke, 2012).

Nevertheless, evidence in the literature demonstrates associations between nurses' autonomy and control over their practice with increased job satisfaction (Kramer and Schmalenberg, 2004), decreased staff turnover and less risk of burnout (Vahey et al, 2004), increased performance and improved patient outcomes (Weston, 2010). In addition, recognition of nurses' autonomy can reinforce autonomous clinical practice, providing benefits for junior nurses in relation to role modelling and mentorship (Weston, 2010). Study 1 provided important data on nurses' abilities, skills and aspects of clinical practice to create a profile of nurses' roles within nurse-led clinics, which suggested a high level of clinical autonomy. However, McFarlane (1980) proposed that nurses needed to develop a greater range and higher order of skills than those associated with carrying out a clinical task if their clinical practice demanded clinical decision-making and competence.

In study 2, asking questions about potential barriers to clinical practice and nurse-led clinics revealed several factors that may adversely affect nurses' autonomy. Study 2 enabled this to be addressed in greater depth during interviews obtain nurses' perceptions, and during observations of clinical practice, which highlighted some crucial differences. Study 2 illustrated autonomy to be a central component of nurses' roles within nurse-led clinics, influenced by nurses' knowledge, skills and beliefs. However, Savage et al (2004) reported that whilst nurses' roles were expanding and responsibilities increasing, they were often 'bounded by the use of protocols', unlike other



clinical colleagues. The authors called for greater research on the relationship between patients' needs and nurses' clinical judgement, and also increased understanding of the meaning and scope of nurses' professional accountability and autonomy. Although Savage et al (2004) focussed on the accountability of practice nurses, their findings show resonance with oncology specialist nurses, and reflect the findings from study 2.

In study 2, using three different data sources: namely documents, interviews and observations, provided different layers of information on nurses' roles in nurse-led chemotherapy clinics, which added strength to the findings. Data from documentation (protocols for nurse-led chemotherapy clinics) showed how doctors directly influenced nurses' roles by determining what nurses could do, including nurse prescribing. This reflects findings in the literature illustrating long-standing conflict between doctors and nurses from the 1920s (Keddy et al, 1986) and subservience of nurses when carrying out doctors' 'orders' (Kalish and Kalish, 1977). Seminal work in the 1960s described the 'doctor-nurse game' where nurses used covert decision-making strategies to offer advice during interactions with doctors (Stein, 1967). There are clear similarities with nurses in study 2 in the way that they used covert strategies to boost patient numbers in their nurse-led clinics when referrals were low. However there are suggestions in the literature that such power games may result in poor communication and conflict due to the lack of openness in communication (Keddy et al, 1986; Sweet and Norman, 1995). This certainly seems a risk for chemotherapy nurses in study 2 who failed to discuss such issues directly with medical consultants, which illustrates the disparity between specialist nurses who work closely with medical consultants and have greater autonomy. Drawing comparisons with Stein's work (1967), the doctor-nurse game is still evident in 2013, since chemotherapy nurses are more subservient to doctors in carrying out their orders, however specialist nurses are given 'special status' and 'privileges' which results in greater responsibilities and autonomy within their nurse-led chemotherapy clinics. However, this also seems tenuous since it relies on good relationships between individual nurses and medical consultants, therefore a breakdown in this professional relationship can be detrimental for the nurse and associated nurse-led clinic.

### **6.2.3 Interaction with patients**

There was no evidence in the literature detailing nurses' consultations and communication with patients in nurse-led clinics, however studies show improvements in symptom management (Faithfull et al, 2001; Brown et al, 2002; Cusack and Taylor, 2010; Beaver et al, 2006; Corner et al, 2002; Knowles et al, 2007; Lee et al, 2011; Seiback and Peterson, 2009), quality of life (Lee et al, 2011; Moore et al, 2002; Corner et al, 2002); psychological distress (Beaver et al, 2006; Cox et al, 2008; Corner et al, 2002; Seiback and Peterson, 2009); continuity of care (Faithfull and Hunt, 2005; Wells et al, 2008; Earnshaw and Stephenson, 1997; Egan and Dowling, 2005; Faithfull et al, 2001); informational needs (Beaver et al, 2006; 2009; 2010a; 2010b), and therapeutic support (Faithfull and Hunt, 2005). This indicates the importance of nurses' assessment, communication and nurses' abilities to address/ manage patients' symptoms and concerns. In addition, there is conflicting evidence from the literature to show whether nurse-led clinics have a positive impact on patients' quality of life and physical symptoms. Although study 2 did not aim to consider patient outcomes, the findings reflect the literature by illustrating that nurses' assessment, effective symptom management, information and communication are important aspects of nurse-patient consultations in chemotherapy clinics. In addition there are examples of continuity of care and therapeutic support within some nurse-led chemotherapy clinics, which patients appeared to appreciate in study 2, demonstrated by their comments and non-verbal behaviour. However separate interviews with patients was outside the scope of this study.

In the literature there is no evidence on the safety and efficacy of nurse-led chemotherapy clinics, and no evidence to show whether nurse-led chemotherapy clinics meet patients' needs. Observations of nurse-led chemotherapy clinics in study 2 highlight no issues in relation to safety within nurses' clinical practice, including nurse prescribing and the clinical management of patients during chemotherapy. Although nurse-led clinics appeared acceptable to patients, it was not possible to formally assess this by independently interviewing patients.

Data from study 1 revealed nurses' perceptions regarding the positive benefits of nurse-led clinics for patients, which included decreased waiting times, continuity, improved communication, information provision, and holistic care. This was also echoed in data collected from interviews with nurse participants during study 2, and reflected in the written protocols for nurse-led chemotherapy clinics. However, this often contrasted with observational data from nurse-patient interactions / consultations. Observing nurse-led chemotherapy clinics demonstrated that all nurses adopted a biomedical model of care, which placed greater emphasis on physical symptoms / chemotherapy toxicities, and treatment, which included prescribing and medicines management. In addition, observations of nurse-patient interactions revealed many examples of poor communication skills, although this contrasted with interview data where nurses perceived their communication skills to be good and perceived they were providing holistic care. This is supported by evidence in the literature where nurses aimed to provide holistic care in nurse-led clinics, but this did not happen in practice (Leary et al, 2014).

Observational data also identified that advanced nurse practitioners who had greater responsibilities for the medical / clinical management of patients throughout the whole course of chemotherapy, demonstrated greater medicalization of their role within nurse-led chemotherapy clinics. This is highlighted by greater attention to technical aspects of care, greater medical management during chemotherapy, ordering and interpreting investigations, and autonomous medical decision-making. This is reflected in the literature, which highlights increasing evidence of nurses claiming new 'territory' by taking on technical-medical tasks (Snelgrove & Hughes 2000), and using a medical model of care (James et al, 1994). In addition, several authors have previously warned about the danger of medicalizing the nursing profession if nurses are used to substitute for doctors rather than providing advanced nursing care (McGee, 1998b; Tye and Ross, 2000; Pearson and Peels, 2002; Mantzoukas and Watkinson, 2006). However, this is based on the presumption of a uniformly accepted definition of 'advanced nursing care' that illustrates a clear distinction with a medical model of care. Unfortunately there is a lack of clarity regarding key components of advanced nursing care and a lack of evidence drawing comparisons with medical models of care to highlight potential

differences between the two. This is highlighted in the findings of study 2 where nurses struggled to define advanced nursing practice and recount their perceptions of differences between advanced and specialist nursing practice. It seems that without clear definitions of advanced nursing care and the potential 'added value' of nursing in advanced clinical practice will not be recognised, and doctor-nurse substitution with medicalization of nurses' roles will continue without question.

This is important given that the recent Francis report (Francis, 2013) demonstrated a decline in compassionate care, drawing nurses' attention to the '6 Cs': care, compassion, courage, communication, competence and commitment, which reflect crucial nursing values. The situation seems compounded in the UK due to the absence of a national definition for nursing, although difficulties in defining nursing appear longstanding and more widespread (Spilsbury and Meyers, 2001). However, the expansion of nurses' roles appear to have exacerbated the difficulties not only in defining nursing per se, but also defining advanced nursing care and practice. This needs to be urgently addressed to fulfil recommendations within the Francis report and re-define nursing, including its philosophy and key nursing values within advanced practice.

At present, clinical skills appear to have more value within advanced practice than compassionate nursing care, which is supported by evidence in the literature. Wilkinson (2007) suggests changes have taken place within the nursing hierarchy, which now places 'medicalized nurses' at the top and traditional ward nurses at the base. Wilkinson argues that up-skilling nurses in this way has devalued basic nursing care and fragmented the nursing profession (Wilkinson, 2007). In relation to nurse-led chemotherapy, there may be tensions between technical aspects of the role and caring (Wiseman et al, 2005), although it is important that nurses do not use this as an excuse for a lack of compassion or blocking behaviours. There are similar examples in other areas of nursing that have a high degree of technology. Henderson (1980) highlighted conflict between the humane and technical aspects of nursing during observations of an intensive care unit, emphasising the importance of patient-centred care and preserving the essence of nursing in a technological age. Henderson also proposes that the concept of nursing is open-ended: *"the*

*complexity and quality of the service is limited only by the imagination and the competence of the nurse who interprets it*" (Henderson, 2006 p26). This is important considering recent changes within the nursing profession and criticisms around nursing care (Francis, 2013).

Observations of nurse-patient interactions in study 2, comparing chemotherapy nurses and advanced nurse practitioners, demonstrated a reduction in the essence of nursing (compassionate care), which appeared to be associated with increased medical (clinical) responsibilities. However, there are similar findings in the literature over the past twenty years where oncology nurses in a variety of settings have failed to pick up patients' cues and concerns (Wilkinson, 1991; Heaven and Maguire, 1996, 1997; Farrell et al, 2005). There is widespread recognition of the importance of good communication skills in oncology and palliative care, which is not limited to nursing, but transcends all healthcare professionals in all settings (NICE, 2004; Cummings and Bennett, 2012; Fallowfield and Jenkins, 1999; Razavi et al, 2002; Fukui et al, 2011; Liu et al, 2007).

### **6.3 Developing nursing and compassionate care**

Issues of communication and nurse-patient interactions are argued to be central to the essence of nursing and compassionate care (Cummings and Bennett, 2012). These are topical issues in light of the Francis Report (Francis, 2013) and the Chief Nursing Officer for England's new strategy for nursing (Cummings and Bennett, 2012). The Francis report recommends changing the culture of the NHS to put patients first and drive standards of care based on patients' needs:

*"...it should be patients- not numbers - which counted"* (Francis, 2013. p83).

Pivotal to the recommendations is an emphasis on care and compassion, dignity and respect. However, although the Francis Report was aimed at professionals and managers in the popular press, it was actually nurses who bore the brunt of criticism regarding the lack of compassionate care. Mirroring this, the new strategy for nursing (Cummings and Bennett, 2012) aims to build a culture of compassionate care for nursing, based on six nursing values: care, compassion, courage, communication, competence and commitment. Within this, communication seems at the heart of compassionate care, with

recommendations to embed compassionate care within nursing practice (Cummings and Bennett, 2012).

Studies in the 1990s assessed the impact of nursing posts designed to help reduce junior doctors' hours, however patient benefits were only seen when tasks were incorporated into nursing practice, rather than nurse-doctor substitution without any nursing aspects of care (Dowling et al, 1995). In addition, earlier discussions have suggested tensions between technical aspects of nurses' roles and compassionate care (Barnard and Sandelowski, 2001). The Francis report (DH, 2012) and the new strategy for nursing (Cummings and Bennett, 2013) have provided compelling evidence of deficiencies in nursing practice, with recommendations for change. Although the observations during study 2 did not reveal any issues where nursing practice was unsafe, it did identify differences in the quality of nursing practice, including psychological aspects of care and communication skills. There is clearly room for improvement regarding nurse-patient communication, and the promotion of compassionate care for this group of vulnerable patients during chemotherapy.

Although some may argue that the technical aspects of care have priority in this setting, or argue that chemotherapy nurses lack of time for emotional care, this seems unfounded. Observations in study 2 showed no correlation between the duration of nurses' consultations and displays of empathy and compassionate care, since this was evident in the shortest consultations. Evidence in the literature describes how nursing priorities have changed over time and highlighting that fundamental / basic nursing care holds a lower position of importance in society than technically advanced clinical nursing roles (Horton et al, 2007). It could be argued that nursing roles have developed to encompass a wide range of activities, previously undertaken by doctors, which has blurred the boundaries between the two professions, therefore what was once the 'essence of nursing' is no longer relevant in the 21<sup>st</sup> century. However, it is clear from the Francis report that communication and compassionate care should be at the forefront of care for patients from all healthcare professionals (Francis, 2013). This suggests that nurses' interpersonal skills are more important than time factors or technical aspects, which reinforces the importance of communication skills training for all frontline staff, including chemotherapy nurses.

Snellman and Gedda (2012) propose that the concept of trust is at the heart of nursing, and a lack of mutual trust between a nurse and patient makes it difficult to achieve a caring relationship. Whilst this places emphasis on communication skills, such as listening and being open with patients, it highlights how interpersonal skills such as caring, compassion, sensitivity, empathy, warmth, and sincerity can enhance mutual trust between patients and nurses (Snellman and Gedda, 2012). These traits are vital in oncology and cancer nursing, considering the life-threatening nature of cancer and its impact on patients. Observing nurse-led chemotherapy clinics indicated how nurses' interpersonal skills had a positive impact on patients, even in very brief consultations, with clear displays of mutual trust in nurse-patient interactions. In study 2, many patients expressed appreciation of individual nurses, even where the duration of the consultation was brief, or some blocking behaviour had occurred, and the crucial factor in this seems to be displays of empathy. In study 2, observing nurse-patient interactions in chemotherapy clinics illustrated how the use of empathy could enhance open communication with patients, which highlights the power of non-verbal behaviour in nurse-patient interactions.

This is reflected in the literature on chemotherapy nursing, where reassurance and support was rated the highest area of satisfaction, and positive comments covered empathy and understanding, emphasising 'kindness', 'caring' 'sensitive' and 'understanding' (Sitzia and Wood, 1998b). Krishnasamy (1996) also identified that the most helpful nurse interactions reported by patients with cancer were emotionally supportive behaviours, which supports the current emphasis on the essence of nursing and compassionate care (Cummings and Bennett, 2012). However, whilst compassionate care should be fundamental to all healthcare staff, including oncology and chemotherapy nurses, it is also vital for nurses running nurse-led chemotherapy clinics to be highly qualified with robust clinical skills and experience for the role. The key point is how to marry up the delivery of technically competent care and compassionate practice (Barnard and Sandelowski, 2001). Although the focus within this thesis is oncology and chemotherapy nurses, debates regarding communication skills, compassionate care and technical aspects of practice also applies to doctors and allied healthcare professionals.

Observing nurses' non-verbal behaviour reinforces the value of using an ethnographic design, since this evidence would not be obtained by interviews alone. This reflects a similar approach of observing nurses administering chemotherapy, with recommendations to consider professional caring within the context where it occurs (Kelly, 1998). When nurses are faced with increasing clinical demands and time pressures it seems important to understand how this may impact on clinical care. The findings from study 1 identified that a number of nurses were undertaking administrative tasks as part of their role because they did not have the appropriate infrastructure to support their role. Nurses also reported lack of administrative and secretarial support to be a barrier in maintaining and developing their roles and nurse-led clinics. Findings were similar in study 2, which showed that there are some aspects of nurse-led clinics that could be undertaken by administrative staff, such as booking appointments and chasing results. There is also evidence of this in the literature, since some areas place greater emphasis on 'nursing the clinic' (administration, efficiency, cleanliness) than 'nursing the patient' (comfort, reassurance) (Corner (2001). Integral to all this is the concept of nursing and providing compassionate care for patients.

#### **6.4 Communication in nurse-led chemotherapy clinics**

There is a national drive to improve nurses' communication skills in oncology through mandatory recommendations that core members of the multidisciplinary team receive advanced communication skills training (Manual for Cancer Service Standards, 2008; NICE, 2004). Whilst this includes specialist nurses, it does not include chemotherapy nurses. This is an important omission given chemotherapy nurses' roles in assessing and monitoring patients, and the rise in chemotherapy nurse-led clinics. However, although communication skills' training has demonstrated improvements in health professionals' abilities to communicate with simulated patients and identify patients' concerns, the impact on patients in actual clinical practice is not clear (Moore et al, 2004, Heaven et al, 2006). Nevertheless, there is clear value from teaching nurses how to communicate with cancer patients by raising awareness of facilitative and blocking behaviours; how to recognise patients' cues and identify their concerns (CRC, 1997; Schofield et al, 2008). Considering changes to chemotherapy nurses' practice, their concerns regarding 'closed door consultations', and



examples in the data of poor nurse-patient communication, this indicates that chemotherapy nurses would benefit from communication skills' training specific to their role.

## **6.5 Addressing patients' needs**

The impact of chemotherapy on patients should not be underestimated, and may generate numerous physical and psychosocial concerns (Harrison et al, 1994; Dodd et al, 1992; Dennison and Shute, 2000; Farrell et al, 2005). Given that most chemotherapy is now given in outpatient settings it is important that patients are able to express their concerns since problems may increase whilst at home. Even acknowledgement of patients' concerns without any further action by the nurse can benefit patients emotionally (Heyn et al, 2013; Uitterhoeve et al, 2008; Zimmerman et al, 2007; Maguire and Pitceathly, 2002; Schofield et al, 2008). This may not necessarily add more time within nurses' consultations if nurses know what questions to ask, when to ask, how to ask and are aware of why this is important (Maguire and Pitceathly, 2002; Farrell et al, 2005; Schofield et al, 2008). However this may require specific communication skills training (Maguire, 1999) to improve nurses' competence and confidence, which has been demonstrated with hospice nurses (Heaven and Maguire, 1996), oncology specialist nurses (Heaven et al, 2006), healthcare professionals in oncology (Liu et al, 2007; Kruijyer et al, 2000; Razavi et al, 2000, 2002), and also ward nurses (Faulkner and Maguire, 1984).

Patient satisfaction audits are commonly used for service evaluation; however may not include key information regarding patients' experiences. A report by the Picker Institute suggests that patients are becoming less satisfied with care over time because of rising expectations, even though they have trust in health professionals (Coulter, 2005). Patient experience is one of the central elements of quality in the NHS (DH, 2008), therefore determining factors that may influence this is important. A recent study suggests that the strongest predictors of satisfaction amongst outpatients is being treated with respect and dignity, and organisation of their care (Sizmur and Redding, 2010), which indicates the importance of nursing values. This is echoed by suggestions of factors related to inter-personal human skills, such as warmth and caring, although patients' perceive that nurses are more caring and approachable than doctors (Torn and

McNichol, 1998). Again this supports the concept of compassionate care and empathy, reflecting how crucial communication skills are to enhance patients' experiences.

## **6.6 Nurse-led care and advanced nursing practice**

Advanced nursing practice in the UK is in disarray, from the ad hoc development of clinical roles which creates confusion and makes many nurses' titles meaningless (RCN, 2007, 2008). Although the NMC has been trying to address this for several years by creating an advanced level of practice beyond registration (NMC, 2007), this has not materialised. This is reflected in the findings from study 1, which show great disparities between nurses' roles and responsibilities that often does not match their professional titles. Although the nursing profession may be commended for modernising nurses' roles, taking on many of the traditional medical tasks and improving patient pathways (DH 2006, 2007, 2008), the lack of structure and definition has led to haphazard developments in nurses' clinical practice.

However, it seems crucial to place less emphasis on individual titles, given that advanced nursing practice is defined as a level of practice rather than a person's role or job title (RCN, 2010, 2012). However, there should be greater transparency in nurses' roles, responsibilities, and competencies to provide clarity for patients and staff (NMC, 2007; Mills and Pritchard, 2004). Debates continue regarding definitions of advanced practice, and whilst some describe it vaguely in terms of 'developing both personally and professionally within nursing (Elson et al, 2005), a definition by the NMC (2005) proposes that nurses should be highly experienced and educated, able to diagnose, treat and/or refer patients to a specialist if needed. Whilst this appears an accurate reflection of current nursing practice, it places greater emphasis on the value of clinical / technical skills and processes rather than good communication skills and compassionate nursing care. This appears to reinforce the development of technical aspects of nurses' roles within advanced practice, which reflects previous discussions regarding doctor-nurse substitution and medicalization of nurses' roles (Pearson and Peels, 2002; Mantzoukas and Watkinson, 2006).

Some authors recommended caution when implementing new practice, including nurse-led clinics, to ensure that new developments incorporate holistic care rather than just substitution for medical tasks (Castledine, 1995; Brown, 1995). More recently, greater attention has been paid to developing holistic care in nurse-led clinics for patients with lung cancer (Corner et al, 2002; Moore et al, 2002; Ford, 2012), and there is clear evidence outlining the importance of holistic care in advanced nursing practice (NLIAH, 2011b; Reed, 2010; Summers and Jacobs-Summers, 2010; Plager and Conger, 2006). It is clear from the findings of study 1 that many nurses have extended their clinic role and are working at a higher level of practice beyond registration. Furthermore the proportion of nurses prescribing independently within study 1 is greater than reported in previous surveys (Ryan-Woolley et al, 2007), which may reflect changes in nurse prescribing legislation. The expansion of nurses' roles is clearly evident in study 2, where nurses worked independently in nurse-led chemotherapy clinics, although there was variability in the level of nurses' autonomy. However, the concept of holistic care was sadly lacking with models of doctor-nurse substitution, despite nurses' perceptions to the contrary.

Briggs (1997) suggestion that scope for autonomous decision-making and practice may be key elements to distinguish nurse-led services from doctor-nurse substitution for medical tasks seems too simplistic and outdated. Richardson and Cunliffe (2003) suggest three different levels of nurse-led services, depending on nurses' expertise and 'level of trust' from the consultant, which seems a more appropriate match for current clinical services. However, nurse-led care has also been described as a continuum with protocol-driven technical tasks at one end and at the other end nurses undertake diverse challenges in terms of clinical decision-making (Cullum et al, 2005). This process of clinical progression reflects the framework identified in study 2.

## **6.7 A framework for nurse-led chemotherapy clinics**

Regarding nurse-led clinics, the lack of clear definition has resulted in different interpretations of nurse-led services, which is evident in the findings of study 1 where there were great disparities in the nature of nurse-led clinics, nurses' roles, their level of autonomy and responsibilities. Study 1 identified that nurses were undertaking a wide range of nurse-led clinics, including chemotherapy

clinics, however there were disparities in nurses' clinical skills and apparent levels of autonomy. For example the majority of prescribing in nurse-led clinics was undertaken by doctors, which may have decreased nurses' autonomy. The results from study 1 provided broad information on nurses' roles within nurse-led chemotherapy clinics, which was explored in greater depth during study 2.

Nurse-led chemotherapy clinics are currently identified by one blanket term, which lacks clarity given the hidden depths within nurse-led chemotherapy clinics and disparate levels of clinical practice, uncovered by the present study. Study 2 identified four different levels of nurse-led chemotherapy clinics across the locations in England; therefore the utilisation of only one term to represent nurse-led chemotherapy clinics is inappropriate and misleading. The findings from study 2 identifying four levels of clinical practice are novel and provide important information for clinical practice and policy. This suggests a new model of nurse-led chemotherapy clinics depending on nurses' clinical activities and skills. This would increase transparency and facilitate movement and career progression through the different levels when required.

Richardson and Cunliffe (2003) recognise the need for different models of care, and challenges to the traditional medical model, given the escalation of nurse-led clinics. The authors identify three levels of nurse-led clinic, which are dependent on trust from consultants, and include six domains: assessment and technical skills, referrals, diagnostic tests, prescriptions, increased autonomy, and discharge (Richardson and Cunliffe, 2003). Within this structure, nurses at Level 1 rely heavily on medical staff for ordering investigations, prescriptions and decision-making; Level 2 share some responsibilities with medical colleagues and can only prescribe within clear protocols; and Level 3 represents nurses who have greater autonomy, including independent prescribing and autonomous decision-making. (Richardson and Cunliffe, 2003). Whilst there are some similarities with the findings from study 2 regarding different levels of nurses' autonomy, there are also some disparities which support the suggestion of a four stage framework within nurse-led chemotherapy clinics.

The findings from study 2 indicate that Levels 1 and 2 are similar since nurses rely on medical staff for prescribing, examination and decision-making, and

follow a structured checklist to review chemotherapy toxicities prior to chemotherapy administration. However, in Level 2 nurses undertake pre-assessments as a separate 'closed door' consultation, which occurs prior to cycle 1. At some locations chemotherapy nurses do not undertake a separate pre-assessment, but provide similar information to patients on an open ward / chemotherapy unit. Whilst it is possible to combine levels 1 and 2 into a single level, the observational and interview data identified that nurses required additional communication skills to undertake effective 'closed door' consultations. Therefore creating two separate levels would highlight the importance of communication skills when assessing patients prior to chemotherapy, rather than focusing solely on the current practice of information provision. Level 3 of the chemotherapy framework reflects level 2 of Richardson and Cunliffe's (2003) framework, since this involves an increase in nurses' autonomy, although clinical care is shared with medical staff. Similarly the highest level in both models compares well, representing fully autonomous clinical practice, including independent prescribing and decision-making.

This structure could be incorporated into current clinical services to create a national model for nurse-led chemotherapy clinics. A competency framework could also be created and embedded in this framework to provide on-going assessments alongside requirements for training and role development for each of the four levels of practice. This will enable a transparency of advanced nursing practice within the domain of nurse-led chemotherapy clinics, facilitate competency-based training, and enable comparison of services throughout the UK. This would provide crucial benchmarks for nurse-led chemotherapy, which could become a beacon of high quality care within the UK with worldwide applicability.

Competency based assessments are well established for undergraduate nurses during nurse training where they are required to complete a log of their competencies during clinical placements. Intravenous training is also well established for oncology nurses in relation to phlebotomy and cannulation where nurses' skills are assessed to ensure competency. Competency assessments are also used for oncology / chemotherapy nurses who are involved in administering chemotherapy (Viddall, 2014). In addition, the latest recommendations from the National Cancer Action Team, Chemotherapy

Measures are to introduce competency-based individual training records for chemotherapy nurses, although this is not a mandatory requirement (DH, 2013).

## **6.8 Nursing outcomes**

There is variability in the quality of chemotherapy services in the UK (NCAG, 2009), although it is well recognised that quality of care may have a significant impact on patient experiences and outcomes (DH, 2008; 2007; 2000a). However identifying appropriate nurse-sensitive outcomes has been difficult. The US Oncology Nursing Society defined nurse-sensitive outcomes as *“outcomes arrived at, or significantly impacted by, nursing interventions”* (Given et al, 2004), which included broad domains, such as symptom experience. Griffiths et al (2012) undertook a scoping review of published literature to determine how patient outcomes related to nursing practice in ambulatory chemotherapy, and the strength of that relationship. This indicated the sensitivity of each outcome to nursing care. Potential indicators were grouped into outcome domains and five were assessed as ‘likely’ to be sensitive to nursing, with a strong recommendation and moderate evidence (Griffiths et al, 2012). The five outcomes were communication and knowledge, patient experience, nausea and vomiting, oral mucositis, and safe medication administration (Griffiths et al, 2012). Considering the findings from study 2, the domains proposed by Griffiths et al (2012) appear appropriate, however there are clear differences between knowledge and communication that suggest separate outcomes would be more appropriate.

In study 2 all nurses had extensive knowledge of chemotherapy, and the outcome from this could be measured by information exchange with patients. Similarly, some chemotherapy nurses lacked sufficient knowledge of specific cancers to answer patients’ questions regarding scan results, prognosis and future treatment plans. However, in some cases the possession of knowledge did not reflect nurses’ communication skills, which should be considered as a separate domain with separate outcomes, given the potential impact on patients from poor communication skills. Although Griffiths et al (2012) suggests only two symptoms ‘likely’ to be sensitive to nursing, the findings from study 2 suggest that this is limited, given the wider range of potential symptoms associated with chemotherapy and potential influence by experienced nurses.

Whilst symptoms of nausea and vomiting and oral mucositis may be simple to measure, other symptoms such as fatigue, diarrhoea, constipation, hand-foot syndrome and skin irritations could be regarded as outcome measures influenced by nursing / healthcare interventions, which is reflected in the data from study 2. However, it should also be noted that the proposed outcome measures associated with chemotherapy are not exclusively the domain of nursing, but applicable to medical staff working within oncology and chemotherapy.

In addition, focusing on quantitative outcome measures such as specific symptoms does not take into account qualitative aspects of nursing care that may influence broader aspects of symptom management, including the psychosocial impact of physical symptoms. This suggests that research should incorporate both quantitative and qualitative approaches in relation to complex issues and interventions within healthcare to obtain a deeper perspective on patient outcomes than numerical data alone can provide.

Although Griffiths et al (2012) include the domain of patients' experiences as a key outcome measure; the evidence provided appears to focus on satisfaction rather than explicit accounts of patients' experiences during chemotherapy. In addition, Griffiths et al (2012) highlight the lack of evidence regarding what nurses do to influence positive / negative patient experience, and what aspects of experience matter most. Based on the data from study 2 it appeared that nurses' interpersonal skills, compassion, empathy, and kindness were valued highly by patients in nurse-led chemotherapy clinics, although patients' trust and confidence in the nurse was equally important. This indicates a complexity of different factors are involved in determining patient satisfaction / experiences, however further research is required to explore this further.

## **6.9 Strengths and limitations of both studies**

The strengths of study 1 lie in its providing increased understanding of oncology specialist nurses' roles and nurse-led clinics. This provided up to date information to form the foundation of study 2. The findings highlight components of nurses' roles that seem important, and which suggest implications for nursing practice, nurse-doctor relationships and nurse-patient interactions within nurse-

led clinics. These findings influenced the design of study 2 and enabled a more detailed exploration within a qualitative study. There is evidence in the literature to support the findings of study 1 in relation to the development of nurses' roles and disparities in training, role expansion and nurse-led clinics. However, the main weakness of the study are limited generalizability of the findings due to the relatively small sample size, and a lack of clear definition of the number of specialist oncology nurses undertaking nurse-led clinics in the UK. Nevertheless, congruence of the findings with literature evidence is reassuring, and the survey findings add to current knowledge on this topic. Furthermore, the survey identified aspects of nurses' clinical roles that were then explored further in study 2. However, if study 1 were repeated today an internet survey may be the preferred method of administration, although the increased security of many hospital firewalls may restrict access for some nurses.

Study 2 focused on four locations in the UK, which reflected differences in geographical variations, and disparities in the size of hospitals, chemotherapy units, nurse-led clinics, and nurses' roles. However, incorporating more locations and nurse-led clinics would enhance the findings. The time spent at each location was sufficient to identify key components of nurses' roles and aspects of their nurse-led chemotherapy clinics, illustrating differences between the locations. However, there were limitations in the allocated time for clinical observations and allocated resources for this study, therefore spending more time at each location would have strengthened the findings.

The combination of observing nurse-led chemotherapy clinics, interviewing nurse-participants and studying documentation proved to be an important combination of methods to address the aims of the study and answer the research questions. However, the study would be enhanced by obtaining doctors' and managers' perceptions of nurse-led chemotherapy clinics at each location. There was no scope within this study to interview patients given time factors and resource restrictions. In a future study evaluation of patients' experiences would be valuable to ascertain their perceptions of nurse-led chemotherapy clinics and determine whether their needs had been met. The main strength of study 2 is the identification of new information on nurse-led chemotherapy clinics and nurses' roles, which have implications for nursing practice, service development and policy-makers. Identifying a national



framework for nurse-led chemotherapy clinics will provide structure and clarity to dispel misleading terminology and disparate levels of clinical practice. Discovering that increased medicalization of nursing appears to decrease in the essence of nursing is an important finding, and one that reflects current professional tensions and recommendations to increase compassionate care.

A weakness of study 2 is that demographic data were not collected for nurse participants. If nurses had been asked whether they had undertaken any training in communication skills, this would have provided a greater understanding of the quality of nurse-patient communication and the possible influence of communication skills training. It may also have been useful to ask nurses to rate their own communication skills during the observations; however this may have influenced their behaviour during observations.

## **6.10 Recommendations**

### **6.10.1 *Recommendations for practice***

Greater transparency is required for nurses' titles, roles and responsibilities, within the area of specialist and advanced nursing practice. This should include transparency in nurses' skills and competencies, which should provide important safeguards for nurses, patients and other health professionals.

The identification of four different levels of nurse-led chemotherapy clinics is a key finding, which has implications for nurses, patients, and chemotherapy services. Implementation of this framework would provide national standards to benchmark nurse-led chemotherapy services in the UK, although it may have relevance for other countries. The framework would also facilitate the development of competencies and training for each of the four levels, which may lead to national recognition of skills and competencies within each level of clinical practice. Further development of a chemotherapy skills passport would enable nurses to transfer their skills to different organisations within the UK, which would save time and resources for training, providing greater benefits for patients and clinical services.

Mandatory communication skills' training for chemotherapy nurses would have crucial benefits for patients by improving their experience of nurse-patient

interactions within nurse-led chemotherapy clinics. There is also the potential to improve nurses' self-confidence regarding their communication skills, and enhance nurses' communication with medical colleagues and other health professionals. Although national courses are available in advanced communication skills, there is also the opportunity to develop bespoke models of communication skills' training specifically for chemotherapy nurses. This would enable nurses to appreciate different communication strategies to manage 'closed door consultations', including breaking bad news, facilitating decision-making, and obtaining informed consent.

### **6.10.2        *Recommendations for policy***

Current policy recommendations for more nurse-led chemotherapy clinics (DH, 2009) are misleading and inappropriate without first defining nurse-led chemotherapy and ensuring consistency in understanding. Clear policy directives are required to endorse a national framework for nurse-led chemotherapy clinics that reflect the findings of study 2. This will also facilitate comparisons of chemotherapy units across the UK, ensuring greater standardisation. Similarly, national recognition for independent and supplementary non-medical prescribing will facilitate transferability between organisations and eradicate inconsistencies in regional nurse prescribing. This will also negate inappropriate control by medical staff for nurse prescribing, and disparities within nurses' clinical practice.

### **6.10.3        *Recommendations for research and education***

It would also be useful to evaluate international differences by comparing practice in the UK with other countries. This would enable greater understanding of chemotherapy nurses' roles and issues within clinical practice. Further research is recommended to understand patients' perspectives of nurse-led chemotherapy clinics and nurse-patient consultations, drawing comparisons with the perceptions of doctors and nurses. This will increase understanding of patients' experiences during chemotherapy, and identify any potential issues from nurse-led chemotherapy clinics. This research evidence could be important to policy-makers, commissioners and health service managers to develop new national communication skills courses.

A bespoke national communication skills' training course could be developed for chemotherapy nurses undertaking nurse-led clinics, and make it a mandatory requirement. This would target specific communication skills required by chemotherapy nurses who develop their role to undertake nurse-led chemotherapy reviews. This will teach nurses how to undertake 'closed door consultations', how to elicit patients' concerns pick up patients' cues, and assess psychological distress. In addition the course could discuss more advanced skills including breaking bad news.

## **6.11 Conclusions**

Both studies have achieved the aims and objectives to answer the research questions and increase understanding of nurses' roles in nurse-led chemotherapy clinics. The findings from both studies add to current knowledge by supporting evidence within current literature on advanced nursing practice, nurses' roles in oncology, and oncology nurse-led clinics. Study 2 has demonstrated novel findings in relation to nurse-led chemotherapy clinics, by the identification of four different levels of nurse-led chemotherapy clinics, and suggesting ways that this can be incorporated into clinical practice to benefit patients, staff, service delivery and policy-makers. In addition, the discovery that greater medicalization of nurses' roles may erode the essence of nursing is an important original finding and has implications for nurses developing their clinical practice and undertaking nurse-led clinics. This is particularly relevant given current concerns regarding compassionate care in nursing.

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## **Appendices**

## Appendix 1 An extract from Medline search

This is an extract from one of the database searches on nurses' roles in oncology

Database(s): Ovid MEDLINE(R) 1946 to November Week 3 2012

Search Strategy:

#	Searches	Results
1	exp Nurse Practitioners/ or exp Advanced Practice Nursing/ or exp Nurse Clinicians/	21196
2	exp Nurse's Role/ or exp Role/	85222
3	exp Oncologic Nursing/ or exp Specialties, Nursing/	128751
4	nurse specialist*.mp.	2637
5	clinical nurse specialist*.mp.	1794
6	specialist, clinical nurs*.mp.	2
7	advanced nurse practitioner.mp.	71
8	1 or 2 or 3 or 4 or 5 or 6 or 7	212354
9	limit 8 to (english language and humans and yr="2000 -Current")	84580
10	Patient centered care.mp. or exp Patient-Centered Care/	9354
11	nursing assessment.mp. or exp Nursing Assessment/	30248
12	nursing diagnosis.mp. or exp Nursing Diagnosis/	4133
13	10 or 11 or 12	39541
14	limit 13 to (english language and humans and yr="2000 -Current")	20021
15	9 or 14	96079
16	(nurse led or nurse-led).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	1496
17	exp Nurse's Practice Patterns/	611
18	(nurse-led clinic* or nurse led clinic*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, protocol supplementary concept, rare disease supplementary concept, unique identifier]	184
19	16 or 17 or 18	2029
20	limit 19 to (english language and humans and yr="2000 -Current")	1827
21	9 and 20	885
22	neoplasms.mp. or exp Neoplasms/	2417055
23	exp drug therapy/ or exp chemotherapy, adjuvant/ or exp consolidation chemotherapy/	1009726
24	exp Antineoplastic Agents/	764965
25	cytotoxins.mp. or exp Cytotoxins/	21026
26	cytostatic agents.mp. or exp Cytostatic Agents/	1348
27	23 or 24 or 25 or 26	1614989
28	limit 27 to (english language and humans and yr="2000 -Current")	529055
29	outpatient clinics, hospital.mp. or exp Outpatient Clinics, Hospital/	15014
30	ambulatory care.mp. or exp Ambulatory Care/	58020
31	oncology services, hospital.mp. or exp Oncology Service, Hospital/	1079
32	cancer care facilities.mp. or exp Cancer Care Facilities/	3517
33	29 or 30 or 31 or 32	75385
34	limit 33 to (english language and humans and yr="2000 -Current")	25269
35	28 or 34	551537
36	21 and 35	165
37	from 36 keep 4, 6, 12, 18, 21, 29...	23

## Appendix 2                      The full quality criteria for the 9 domains

1. Abstract and title: Did they provide a clear description of the study?

- Good                      Structured abstract with full information and clear title.
- Fair                      Abstract with most of the information.
- Poor                      Inadequate abstract.
- Very Poor              No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

- Good                      Full but concise background to discussion/study containing up-to date literature review and highlighting gaps in knowledge.  
Clear statement of aim AND objectives including research questions.
- Fair                      Some background and literature review.  
Research questions outlined.
- Poor                      Some background but no aim/objectives/questions, OR  
Aims/objectives but inadequate background.
- Very Poor              No mention of aims/objectives.  
No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?

- Good                      Method is appropriate and described clearly (e.g., questionnaires included).  
Clear details of the data collection and recording.
- Fair                      Method appropriate, description could be better.  
Data described.
- Poor                      Questionable whether method is appropriate.  
Method described inadequately.  
Little description of data.
- Very Poor              No mention of method, AND/OR  
Method inappropriate, AND/OR  
No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?

- Good                      Details (age/gender/race/context) of who was studied and how they were recruited.  
Why this group was targeted.  
The sample size was justified for the study.  
Response rates shown and explained.
- Fair                      Sample size justified.  
Most information given, but some missing.
- Poor                      Sampling mentioned but few descriptive details.
- Very Poor              No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?
- |      |  |
|------|--|
| Good | Clear description of how analysis was done.<br>Qualitative studies: Description of how themes derived/respondent validation or triangulation.<br>Quantitative studies: Reasons for tests selected hypothesis driven/numbers add up/statistical significance discussed. |
| Fair | Qualitative: Descriptive discussion of analysis.<br>Quantitative.  |
| Poor | Minimal details about analysis.  |
6. Ethics and bias: Have ethical issues been addressed, and what has necessary ethical approval gained? Has the relationship between researchers and participants been adequately considered?
- |           |   |
|-----------|---|
| Good      | Ethics: Where necessary issues of confidentiality, sensitivity, and consent were addressed.<br>Bias: Researcher was reflexive and/or aware of own bias. |
| Fair      | Lip service was paid to above (i.e., these issues were acknowledged).   |
| Poor      | Brief mention of issues.  |
| Very Poor | No mention of issues.   |
7. Results: Is there a clear statement of the findings?
- |           |  |
|-----------|--|
| Good      | Findings explicit, easy to understand, and in logical progression.<br>Tables, if present, are explained in text.<br>Results relate directly to aims.<br>Sufficient data are presented to support findings. |
| Fair      | Findings mentioned but more explanation could be given.<br>Data presented relate directly to results.  |
| Poor      | Findings presented haphazardly, not explained, and do not progress logically from results.   |
| Very Poor | Findings not mentioned or do not relate to aims.   |
8. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?
- |           |  |
|-----------|--|
| Good      | Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling). |
| Fair      | Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4.                |
| Poor      | Minimal description of context/setting.  |
| Very Poor | No description of context/setting.   |
9. Implications and usefulness: How important are these findings to policy and practice?
- |           |   |
|-----------|---|
| Good      | Contributes something new and/or different in terms of understanding/insight or perspective.<br>Suggests ideas for further research.<br>Suggests implications for policy and/or practice. |
| Fair      | Two of the above (state what is missing in comments).   |
| Poor      | Only one of the above.  |
| Very Poor | None of the above.  |

## Appendix 3

## Survey questionnaire for study 1

### Questionnaire survey: Exploring the impact of nurse-led clinics in oncology

*If completing electronically please note the following: To check a selected box left click on the box, then place an x within it. Alternatively please print off, complete and post to me.*

Hospital..... Job Title.....

Name ..... Age.....

Time in current post ..... Salary grade.....

1. What disease groups do you work with?
- All types of cancer ☐
- One or two cancers only ☐ which?.....

2. Based on your job description what proportion of your time is **allocated** to your patients?.....

3. In reality, what proportion of your time is **actually spent** with patients?.....

4. What do you think about the amount of clinical time you spend with patients?

It is just right ☐

It is not enough ☐

It is too much ☐

5. Are you an independent prescriber? Yes ☐ No ☐

- 5b. If yes, how often do you prescribe in your practice?

Often ☐

Some of the time ☐

Rarely ☐

Never ☐

- 5c. If you are a prescriber, what types of medicines do you prescribe?[tick all that apply]

Supportive medication ☐

Chemotherapy ☐

Other treatments ☐

Examples?.....

6. Have you received any specific training in order to undertake your current role?
- Yes ☐ No ☐

Comments on type of training

7. Do you undertake any medical assessments in your work? Yes ☐ No ☐

7b. If yes, what does this include? [tick all that apply]

History taking

☐

Assessing toxicities / side-effects

☐

Assessing response to treatment

☐

Clinical examination

☐

Other

☐

Examples.....

8. Have you received any formal training in clinical examination skills? Yes ☐ No ☐

9. Do you undertake any clinical examinations within your role? Yes ☐ No ☐

9b. If yes, to what extent do you examine patients? [tick all that apply]

Observation only eg skin

☐

Limited local (disease specific) examination

☐

Respiratory examination eg auscultation

☐

Cardiovascular examination eg auscultation

☐

Abdominal examination eg palpation

☐

Full clinical examination top to toe

☐

10. What are the main components of your job / role?

Comments

11. Are there other people in your organisation with a similar role Yes ☐ No ☐

11b. If yes, how many?.....

12. Who are you directly accountable to within your organisation?

Senior nurse manager

☐

Director of nursing / Chief nurse

☐

Non nurse manager

☐

Medical consultant

☐

Other

☐

who.....

13. To what extent do you think your role is valued within the multidisciplinary team in your organisation?

Highly valued ☐ Moderately valued ☐ Occasionally valued ☐ Not valued ☐

Comments

14. What level of autonomy do you have within your clinical practice?

Fully autonomous (can make all clinical decisions independently)

Significant autonomy (can make many clinical decisions independently)

Some autonomy (can make some clinical decisions independently)

Indirect supervision for clinical practice

Direct supervision for clinical practice

☐  
☐  
☐  
☐  
☐

15. Do you feel there are any barriers that currently limit your practice? Yes ☐ No ☐

15b. If yes, where do they come from? [tick all that apply]

The organisation

☐

Nursing directorate

☐

Medical directorate

☐

Other

☐

Example.....

Comments

16. Do you undertake any nurse-led clinics? Yes ☐ No ☐

**If you have ticked 'No' please answer the following question then go to question 18**

16a. Would you like to set up a nurse-led clinic? Yes ☐ No ☐

Comments

**If you have ticked 'Yes' please answer the following questions:**

16b. How many clinics do you have each week?.....

16c. Approximately how many patients in each clinic?.....

16d. How long do you allocate for each appointment?.....

16e. What type of nurse-led clinics do you undertake? [tick all that apply]

Follow up

☐

Chemotherapy

☐

Radiotherapy

☐

Other

☐

Examples.....

16f. Can you run these clinics independently (without doctors)

Yes ☐ No ☐ At times ☐

16g. Do patients need to attend medical clinics as well? Yes ☐ No ☐ At times ☐

16h. Who prescribes within your clinics? [tick all that apply]

You	<input type="checkbox"/>
Other nurses	<input type="checkbox"/>
Doctors	<input type="checkbox"/>
Combination of nurses and doctors	<input type="checkbox"/>

16i. What cover do you have for your nurse-led clinic if you are off?

Another nurse	<input type="checkbox"/>
Doctor	<input type="checkbox"/>
No cover available	<input type="checkbox"/>

16j. What practical support do you have for your nurse-led clinics? [tick all that apply]

Clinic nurse / assistant	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Secretarial support	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Admin / clerical support	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>

16k. How would you rate the support that you have for nurse-led clinics?

Just right	<input type="checkbox"/>
Not enough	<input type="checkbox"/>

Comments
----------

17. Would you like to have more nurse-led clinics? Yes ☐ No ☐

18. Are there any barriers to you setting up any [more] nurse-led clinics? Yes ☐ No ☐

18b. If yes, where do they come from? [tick all that apply]

The organisation	<input type="checkbox"/>
Nursing directorate	<input type="checkbox"/>
Medical directorate	<input type="checkbox"/>
Other	<input type="checkbox"/>

Example.....

Comments
----------



19. What do you think are the benefits of nurse-led clinics? [tick all that apply]

- |   |                          |                          |
|---|--------------------------|--------------------------|
| Improve services                            | <input type="checkbox"/> | Comments.....            |
| Benefit patients                            | <input type="checkbox"/> |                          |
| Benefit staff                               | <input type="checkbox"/> |                          |
| Other                                       | <input type="checkbox"/> |                          |
| None (I do not feel there are any benefits) |                          | <input type="checkbox"/> |

20. What additional responsibilities do you have within your role? [tick all that apply]

- |                                |                          |
|--------------------------------|--------------------------|
| Teaching                       | <input type="checkbox"/> |
| Staff development              | <input type="checkbox"/> |
| Management                     | <input type="checkbox"/> |
| Audits                         | <input type="checkbox"/> |
| Research                       | <input type="checkbox"/> |
| Develop guidelines / protocols | <input type="checkbox"/> |

21. Have you undertaken any audits on your current role? Yes ☐ No ☐

21b. Have you undertaken any audits on your nurse-led clinics? Yes ☐ No ☐ N/A ☐

22. Have you undertaken any nursing research? Yes ☐ No ☐

22b. Is this something you would like to do? Yes ☐ No ☐ Not sure ☐

23. Have you any publications? Yes ☐ No ☐

23b. If yes, was this in relation to your current role? Yes ☐ No ☐

24. Have you presented at any conferences? Yes ☐ No ☐

24b. If yes, was this in relation to your current role? Yes ☐ No ☐

**Thank you for completing this questionnaire. Your comments are greatly appreciated.**

**Please email to [carole.farrell@christie.nhs.uk](mailto:carole.farrell@christie.nhs.uk) or post to:**

**Mrs Carole Farrell, Nurse Clinician, Christie Hospital NHS Foundation Trust,  
Wilmslow Road, Withington, Manchester. M20 4BX**

**If you have any comments please email or telephone me on 0161 446 8397**

**Exploring the impact of nurse-led clinics in oncology**

Dear Colleagues,

I am a Nurse Clinician in breast medical oncology at the Christie Hospital and am also doing a part-time PhD at Manchester University to look at advanced nursing practice in oncology.

My research will include different methods to look at how we are developing services as oncology nurses. I want to start off by finding out what nurses throughout the country are doing in relation to extending their practice, with particular emphasis on nurse-led clinics in oncology. It's crucial for me to find out other nurses' experiences, rather than just staying close to home and considering my own practice, so your views are important to me.

I would be grateful if you could take a few minutes to complete the attached questionnaire. This should only take 5-10 minutes, but it would give me a lot of valuable information about the scope of nurses' practice. The information that you provide will be confidential. Emailed questionnaires will be printed, then deleted and paper questionnaires will be kept in a locked drawer and destroyed after completing this study.

I am trying to contact as many oncology nurses as I can in the UK who are involved in nurse-led clinics and/or have an advanced role. This first phase is not limited to one oncology disease group as I want to keep it as broad as possible.

The questionnaire can either be emailed or posted back to me. If you are posting it, I have enclosed a stamped self-addressed envelope for your convenience.

If you would like further information please do not hesitate to contact me by phone or email. Also, if you know of any other colleagues who may be interested in taking part in this survey please let me have their details so that I may contact them.

Many thanks for your time, I do appreciate it.

**Carole Farrell**

Nurse Clinician

Christie Hospital NHS Foundation Trust, Wilmslow Road, Withington, Manchester M20 4BX Tel: 0161 446 8397 [carole.farrell@christie.nhs.uk](mailto:carole.farrell@christie.nhs.uk)

My supervisors are:

Professor Alex Molassiotis, Professor Kinta Beaver (Manchester University)

Dr Cathy Heaven (Director of the Maguire Communications Unit, Christie Hospital)



Wilmslow Road  
Withington  
Manchester  
M20 4BX

**A qualitative exploration of  
Nurse-led chemotherapy clinics  
Information for oncology nurses**

I am a nurse clinician in breast medical oncology at The Christie hospital and am also doing a part-time PhD at the University of Manchester.

You are invited to take part in a research study looking at nurse-led chemotherapy clinics. Before you decide whether to take part it is important that you understand why this research is being undertaken and what it will involve. Please take your time to read the following information and decide whether or not you wish to take part. If there is anything that is not clear, or if you would like further information, please let us know.

Thank you for reading this information sheet.

*Carole Farrell*

### **Why have I been invited?**

You have been invited because you completed my initial survey questionnaire and indicated that you are involved in nurse-led chemotherapy clinics, which is the area I am interested in for the second stage of my study. I am hoping to visit 4-6 senior oncology specialist nurses in the UK who run nurse-led chemotherapy clinics.

### **What is the purpose of the study?**

This second stage of my research aims to increase understanding of nurse-led chemotherapy clinics by looking at why clinics were initially set up, how they operate in clinical practice, and how they may vary in different areas and settings in the UK.

### **Do I have to take part?**

You are under no obligation to take part in this study, and are free to withdraw at any time. However, if you do want to take part please complete the reply slip at the end of this letter and return by email or post. I'll then contact you to discuss possible dates when the study could take place in your hospital. Following this I will send you a copy of the consent form and a further letter of confirmation for the study visit. With your permission, I would also like a copy of your job description and any supportive information about your nurse-led chemotherapy clinics, such as proformas, protocols, checklists, care pathways, standards, guidelines, operating policies etc. This will provide useful background information about nurse-led clinics. However, if you have any concerns regarding this, or would like to discuss this further by email or telephone please contact me, or speak to one of my supervisors.

### **What will happen if I take part?**

The second stage of this study will focus on nurse-led chemotherapy clinics at four different locations within the UK. It is based on observing nurse-led chemotherapy clinics and interviewing nurses who undertake such clinics.

#### Observing clinics

I would like to spend 2-3 days observing your nurse-led chemotherapy clinic, at a time convenient to you. I would like to observe your consultations with patients; however this will rely on your agreement and also depend on verbal consent from each patient that you see.

Verbal consent would need to be obtained from each patient prior to observation of the consultation, and this may be obtained by you or a chemotherapy nurse / specialist nurse within the clinic. During the consultations I will stand / sit quietly in the background and make no interruptions. However, with your permission, and that of the patient, I would like to use an audio tape to record your consultations with patients, which will ensure my records are

accurate and will facilitate subsequent analysis. In addition I may make brief notes during the clinical sessions, although this will not take place during your consultations with patients.

### Nurse interviews

After observing your clinic on the first day I would like to interview you to talk about your clinics. This could take place in your office or in a private room and will take approximately an hour. With your permission I would like to use an audio-tape so that I can accurately capture your replies. I will want to ask you about how your clinics were set up, how they fit within ambulatory chemotherapy services, how they have developed and plans for the future. I may also want to ask you some questions based on the clinic observations.

Observing nurse-led chemotherapy clinics and doing face-to-face interviews with nurses like you will provide a greater understanding than doing interviews alone. In addition I would like to look at any documents in relation to your nurse-led chemotherapy clinics, such as protocols, proformas, checklists, care pathways and your job description. These would provide important background information before I come to observe your nurse-led chemotherapy clinics.

### **Confidentiality**

All observations made within clinics, data collected during the interview and all documentation supplied in relation to your nurse-led clinics will be kept confidential. Any information about you, your patients and your organisation will be anonymised, including electronic data. All data collected will be kept securely in the research office and audio-tape recordings will be destroyed after a period of time after the study.

### **What are the advantages of taking part?**

The advantage of taking part in this study is that you are given an opportunity to share your views of nurse-led chemotherapy services and to highlight the achievements you have made in relation to developing your own practice. The data collected from this study will help to inform nurses in the UK and internationally about nurse-led clinical practice in oncology, particularly in relation to chemotherapy.

### **What are the disadvantages of taking part?**

One disadvantage of taking part is that you may raise issues that you feel are sensitive in nature. There is also a possibility that stress may arise as a result of the observations. If this were to happen, or if you have any other concerns during the observation and/or face-to-face interview, you can choose to stop the observation and withdraw from the study at any time. If you did experience problems with ongoing stress as a result of the observations you could discuss this with your occupational health department, or contact one of the research supervisors for further advice.

### **What if there is a problem?**

It is unlikely that you will come to any harm by taking part in this study. However, if you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure.

### **What will happen to the results from the study?**

This study will form part of a thesis towards a PhD in Nursing at the University of Manchester.

A report will be generated from the results of this study, which will be presented internally to staff at the Christie Hospital and staff/students at the University of Manchester. Conference presentations and publications will also take place on completion of the study to disseminate the findings. If you decide to take part in this study I will write to you with details of any such presentations and publications.

### **Who has reviewed this study?**

This study has been reviewed by the NRES Committee North West – Greater Manchester South, and a favourable opinion obtained.

### **What if I have further questions?**

If you do have any further questions about this study please do not hesitate to contact me.

Many thanks for your time, I do appreciate it.

Kind regards,

*Carole Farrell*

Carole Farrell

Nurse Clinician



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My supervisors are:

Professor Alex Molassiotis, University of Manchester  
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### REPLY SLIP

#### **A qualitative exploration of nurse-led chemotherapy clinics**

I would like to take part in this study, please send further information

Name:

Title / designation:

Work address:

Telephone:

Email

## Appendix 6

## Consent form for study 2

### A qualitative exploration of nurse-led chemotherapy clinics

#### Consent form for nurses

**Name of researcher: Mrs Carole Farrell**

*Please read each statement and place your initials in the box:*

	Yes	No
1. I confirm that I have read and understand the information sheet [v1.6 05.09.2011] for the above study	<input type="checkbox"/>	<input type="checkbox"/>
2. I confirm that I have had the opportunity to ask questions	<input type="checkbox"/>	<input type="checkbox"/>
3. I confirm that I have had sufficient time to consider the advantages and disadvantages of this study	<input type="checkbox"/>	<input type="checkbox"/>
4. I understand that my participation is voluntary and I am free to withdraw at any time, without giving any reason.	<input type="checkbox"/>	<input type="checkbox"/>
5. I understand that what I say will be treated in confidence and information collected and published will be anonymised.	<input type="checkbox"/>	<input type="checkbox"/>
6. I give permission to use quotes, from what I have said, in publications.	<input type="checkbox"/>	<input type="checkbox"/>
7. I agree to take part in this study and give permission for a researcher to observe my nurse-led chemotherapy clinics for 2-3 days.	<input type="checkbox"/>	<input type="checkbox"/>
8. I agree to take part in an audio taped interview.	<input type="checkbox"/>	<input type="checkbox"/>
9. I agree to provide copies of written documentation in relation to my nurse-led chemotherapy clinics, such as protocols and my job description.	<input type="checkbox"/>	<input type="checkbox"/>
10. I understand that all data collected for this study will be confidential, anonymised and held securely.	<input type="checkbox"/>	<input type="checkbox"/>
11. I agree to take part in this study	<input type="checkbox"/>	<input type="checkbox"/>

\_\_\_\_\_  
Name participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

Christie Hospital NHS Foundation Trust, Wilmslow Road, Withington, Manchester M20 4BX  
Tel: 0161 446 8397 [carole.farrell@christie.nhs.uk](mailto:carole.farrell@christie.nhs.uk)



**A qualitative exploration of nurse-led chemotherapy clinics**

**Confirmation of study visit for nurses**

Dear

Thank you for agreeing to take part in the second stage of this study.

I am writing to confirm that observation of your nurse-led chemotherapy clinic will take place on:

1. Date: Time: Location:

2. Date: Time: Location:

3. Date: Time: Location:

The audio taped interview will last for approximately one hour and will take place on:

Date: Time: Location:

I would be grateful if you could forward a copy of your job description and any supportive information in relation to your nurse-led chemotherapy clinics, such as proformas, protocols, checklists, care pathways, standards, guidelines, operating policies etc.

If there is any problem regarding the above, or if you would like to discuss anything further please do not hesitate to let me know.

Kind regards,

***Carole Farrell***

Carole Farrell  
Nurse clinician

The Christie NHS Foundation Trust, Wilmslow Road, Withington, Manchester M20 4BX Tel: 0161 446 8397 [carole.farrell@christie.nhs.uk](mailto:carole.farrell@christie.nhs.uk)

**A qualitative exploration of nurse-led chemotherapy clinics****Information for patients**

A research study will be taking place on .....  
in the Out Patient Department and Chemotherapy clinic. The purpose of this research is to study a sample of nurses who run nurse-led chemotherapy clinics in order to look at their role and how they work within chemotherapy services in the UK.

..... has agreed to take part in this study and a researcher (Carole Farrell) will be observing some of her clinics.

We would like your permission to observe the nurses during your consultation, and to use an audio tape to record what the nurse is saying to you. However this observation of the consultation is concerned with observing the nurse, not you (the patient). The researcher will stand in the background and not take any part in the consultation itself – she is only there to observe the nurse.

If you agree to the researcher being present during your consultation, all information from the consultation will remain confidential and anonymous. The study does not involve your medical records and will not affect your care. If you do not want the researcher present during your consultation and/or do not want her to use an audio tape please let the nurse know. This will not affect your care or treatment.

This study has been reviewed by the NRES Committee North West – Greater Manchester South

Thank you for reading this.

**Carole Farrell**

Carole Farrell is a nurse clinician at The Christie Hospital, Manchester and PhD student at The University of Manchester.



If you would like further information please contact:

Mrs Carole Farrell [carole.farrell@christie.nhs.uk](mailto:carole.farrell@christie.nhs.uk)

Prof Alex Molassiotis [Alex.Molassiotis@manchester.ac.uk](mailto:Alex.Molassiotis@manchester.ac.uk)

## **Appendix 9 Information leaflet for patients**

### **A qualitative exploration of nurse-led chemotherapy clinics**

#### **Information sheet for patients**

A study is taking place today in the Out Patient Department and Chemotherapy clinic, looking at nurses who run nurse-led chemotherapy clinics.

The purpose of this research is to study a sample of nurses who run nurse-led chemotherapy clinics in order to increase understanding of their role and clinical practice within chemotherapy services. Although there are many skilled nurses in the UK who run clinics independent of medical staff, there may be differences in their individual skills and also the way they run their clinics. This research will look at different areas and clinical settings in the UK. The current lack of research on nurse-led chemotherapy clinics means that this research study will provide important information for patients, health care professionals and service managers.

This study has been reviewed by the NRES Committee North West – Greater Manchester South

..... has agreed to take part in this study and a researcher (Carole Farrell) will be observing her clinic on.....

We would like your permission to observe the nurses during your consultation, and to use an audio tape to record what the nurse is saying to you. Your chemotherapy nurse will discuss this with you before your consultation, and will ask your permission for the researcher to observe your consultation with the nurse. If you agree, she will then ask your permission to use an audiotape to record the consultation.

If you do not want the researcher to be present during your consultation, or you do not want an audiotape to be used during your consultation, please let the nurse know. This will not affect your care in any way.

However, please note that the researcher's observation of the consultation is concerned with observing the nurse, not you (the patient). The researcher will

stand in the background and not take any part in the consultation itself – she is only there to observe the nurse.

All information from your consultation will remain confidential and anonymous. The study does not involve your medical records and will not affect your care.

The audio tape is used to accurately record what the nurse is saying to you about your chemotherapy treatment. This will help the researcher to obtain accurate information and results from this study. Using an audiotape will also mean that the researcher does not need to take any notes during your consultation, however if you do not want the researcher to use an audio tape please let the nurse know.

Thank you for reading this.

*Carole Farrell*



Carole Farrell is a nurse clinician at The Christie Hospital, Manchester and PhD student at The University of Manchester.

If you would like further information please contact:

Mrs Carole Farrell      [carole.farrell@christie.nhs.uk](mailto:carole.farrell@christie.nhs.uk)

Prof Alex Molassiotis      [Alex.Molassiotis@manchester.ac.uk](mailto:Alex.Molassiotis@manchester.ac.uk)

## INTERVIEW GUIDE

### **A qualitative exploration of nurse-led chemotherapy clinics**

The interview will be semi-structured, however additional questions may arise from observation of clinical practice and responses may also generate other questions. Questions in italics could be used to initiate the interview and explore areas of interest:

*How was your nurse-led chemotherapy clinic set up initially?*

- Initial drivers for nurse-led chemotherapy clinics and changes to service delivery
- Fit with existing care pathways / medical clinics

*How has your clinic developed over time?*

- Changes over time, telephone clinics, other nurse interactions
- Training, support, skill mix

*What do you think has been the impact of your nurse-led clinic?*

- Impact on patients, staff and service delivery
- Implications for nurses undertaking nurse-led clinics

*Have you undertaken any evaluations of your nurse-led clinics?*

- Standards / guidelines
- Audits, research, presentations, publications

*How do you see the service developing in the future?*

- Funding, support, implications
- Future developments / plans

*When I surveyed nurses in the UK the majority of nurses doing nurse-led clinics had limited examination skills: local examination not top-to-toe. Do you think that's important for a nurse-led chemotherapy clinic?*

- What type of clinical skills are important?

*In my survey there was a wide variation in training. What training do you think is important for nurses undertaking nurse-led clinics?*

- Academic courses, professional courses
- On the job training....how and who by?
- Competencies....how do we ensure nurses are competent in chemo clinics?

*How do you see your role as a nurse within this chemotherapy clinic?*

- Autonomy and scope of practice within nurse-led clinics – strengths, barriers
- Contact, support / patient interactions outside the clinic

*What do you think are the differences between a nurse doing a chemotherapy clinic and a doctor?*

- Explore perceptions

*If I asked you to make a list of the 3 main priorities for nurse-led chemotherapy what would this be?*

- From observation, focus on medicines management – where does this rank?
- What about psychological care?

*Why did you want to take this role on?*

- Explore nurse-led developments
- Advanced nursing practice

*What is advanced nursing practice in your mind?*

- Explore perceptions
- What are the key elements of advanced nursing practice?

*What makes your role advanced in terms of nursing practice?*

- Explore links with above definitions

*How would you distinguish between advanced and other levels of specialist nursing practice?*

- Explore links with above perceptions

**OBSERVATION GUIDE**

**Study title:** A qualitative exploration of nurse-led chemotherapy clinics

**Study number:**

**Date:**

Length of consultation

Clinic environment

Clinic support

Chemo process

Chemo admin

Prescribing

Contact with other nurses

Contact with doctors

Contact with other staff

Independence

Knowledge

Confidence

Decisions

Additional skills

## Appendix 12 Example of summaries and visual displays

Physical Symptoms	N	Nurse	M	Mother
Psychological	P	Patient	Si	Sister
Activities of Daily Living	H	Husband	D	Daughter
Medicines Management	W	Wife	So	Son
Treatment / Admin				
Exploratory / Social				

**Observation 2**      **Nurse: 1**      **Patient: 3**      **Consultation time:** 15.31 minutes

0957 The first patient comes in with her husband. The nurse stands up by her chair waiting for the patient and husband to sit down before returning to her seat. She sits facing the patient with her legs crossed and arms folded. The notes are on the desk beside her.			
Issue	Initiated by	Speech	Observations
Greeting	N	N1 "So I bumped into you on...was it on Monday? ...You were going home?.. P3 "Yeah" N1 "How have you been since Monday?"	
Sore legs	P	P3 "I've been alright but I felt that ...er...me body movement has...erm...been a lot more sore...in my legs" N1 "Right"	
Feeling 'in slow motion'	P	P3 "It's like having slow motion...but I wonder if that's the...er...sorry I can't think what it's..." H3 "Radio?" P3 "No...er" H3 "Chemo?" P3 "No...the stuff they give me..."	
Morphine	H	H3 "Oh...morphine?" P3 "Morphine...could it be the morphine what's slowed me down?" N1 "Are you taking liquid morphine at home?"	
Back pain	P	P3 "Hmm...not at the moment, but when I was in hospital they give me some in me hand, and they give me 3 in me arm, and I were in pain...because I had a bad back"	The patient gesticulates with her hands to describe the



		N1 "Right...so did you come in with a bad back or...did that happen while you were in hospital?" P3 "No I didn't come in with a bad back...I just had the pain afterwards"	pain
Morphine	N	N1 "And did they send you home with some morphine to take at home afterwards?" P3 "Yes....but I've not needed it at home" N1 "You've not needed it at home?...okay"	
Bleeding	N	N1 "How's the bleeding been?" P3 "It's stopped" N1 "It's stopped?" P3 "Yes...just..." N1 "Altogether?" P3 "Yes...I need a pad on...it's just slightly...like water" N1 "Right...so it's slightly...brownny..or just like water?" P3 "Just like water" N1 "Right....okay..." P3 "It's comfortable now" N1 "Right..." P3 "After 5 months"	The nurse interrupts the patient
Antibiotics	N	N1 "Okay...and we just gave you a week of antibiotics, didn't we?" P3 "Yes" N1 "So..are you on your last day of those?" P3 "Yes...I'm fine on them now" N1 "Okay"	
Steroids	P	P3 "And I've took my steroids..they give me some...like steroid tablets..I think" N1 "They gave you the little white ones for 2 days afterwards?" P3 "When I was in hospital...they sent me home with some" N1 "They sent you home with some? Have you carried on those?" P3 "I've carried on with them...2 a day...morning and night" N1 "Right...okay"	The nurse turns round to look at the computer screen, then checks in the patient's notes

Anti-emetics	P	<p>P3 "And they've give me an anti-sick tablet, and I've kept on that...they give me that in hospital"</p> <p>N1 "A different one?"</p> <p>P3 "Yeah...I've got it in me bag..."</p> <p>N1 "Have you got them with you so I can just..."</p> <p>P3 "Yes..."</p> <p>N1 "...check what you've been taking?"</p>	The patient looks in her handbag for the tablets. Husband sits quietly, looking at his wife and glancing across at the nurse. The patient interrupts the nurse
Nausea	N	<p>N1 "So from what you were telling me on Monday...the sickness ...you first of all got up Thursday morning and thought you were fine?"</p> <p>P3 "Yeah..."</p> <p>N1 "And then how long was it before you started feeling sick?"</p> <p>P3 "Er...that morning...er..."</p>	<p>The nurse interrupts the patient</p> <p>The patient looks hesitant</p>
Eating	N	<p>N1 "Did you manage to eat?"</p> <p>P3 "No...nothing at all"</p>	The nurse interrupts the patient
Nausea & Vomiting	N	<p>N1 "No...because you felt sick?"</p> <p>P3 "I felt sick...went home...got in bed at 1 o'clock Thursday afternoon...sick every hour...and then all night"</p> <p>N1 "Yeah"</p> <p>P3 "And Friday morning I can't even remember coming here...I were that bad"</p>	
Admission	N	<p>N1 "Okay...and then we admitted you..."</p> <p>P3 "Yeah"</p> <p>N1 "...on the Friday morning?"</p>	
Chemo	P	P03 "...that chemo just knocked me off my feet...it...it..."	The patient looks anxious
Anti-emetics	N	<p>N1 "Well let's try quite a different combination of anti-sickness this week"</p> <p>P3 "Yeah...that's good"</p>	The nurse interrupts the patient
Radiotherapy	N	<p>N1 "What time is your radiotherapy each day? Do you tend to be a morning appointment?"</p> <p>H3 "It's on..."</p> <p>P3 "It's..yeah..."</p>	The patient speaks at the same time as her husband

## Appendix 13 Example of consultation visual display

A visual summary of a consultation at location 2 with N9 and P37. The consultation flows from left to right, top to bottom.

