Exploring the impact of the lung cancer Clinical Nurse Specialist role on patient care in a regional hospital in New Zealand

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Abstract

Background

The aging population and the need for health systems to manage an ever-increasing numbers of patients with chronic conditions has been identified as one of the greatest challenges for health care providers worldwide. New Zealand is no exception, with chronic conditions causing over 80% of all deaths per year (Connolly et al., 2010). Cancer is one such chronic condition, where, the devastating effect of a diagnosis is often coupled with difficulties in navigating the complex health-care setting. Hence some areas have seen the development of specialized nursing roles to accommodate the needs of this group of patients. One such role to emerge is that of the Lung Cancer Clinical Nurse Specialist. The question naturally arises as to whether such nurses are indeed assisting patients and demonstrating Advanced Nursing Practice (ANP) in the care they give. Within the literature it is suggested that an evaluation of these roles is necessary, if they are to be fully recognised and valued (Bryant-Lukosius, DiCenso, Browne & Pinelli, 2004; Oliver & Leary, 2012; Vaz & Small, 2007). It is to this area that this study is directed.

Aim

The aim of this study was to explore the impact of an advanced nursing role on lung cancer patient care. In particular eliciting information regarding the functionality of the Clinical Nurse Specialist (CNS) role within the multi-disciplinary team (MDT) within a regional lung cancer service was an important aspect of the research.

Method

There was a need for the study to provide insight into how the role of the Lung Cancer Clinical Nurse Specialist (LC CNS) was viewed and understood by those that work with them (Cowman et al., 2010; Moore et al. 2006).
Phase one was a questionnaire which was sent out to 50 members of the MDT, with the express purpose to elicit information from a variety of health professionals. The questionnaire contained both quantitative and qualitative questions.

Phase two was an audit which involved a quantitative observational, retrospective study of five months of clinical data relating to patients cared for by the LC CNS’s. The data was audited against the Standards of Service Provision for Lung cancer Patients in New Zealand (MOH, 2011).

**Findings**

From the respondents questionnaire (76%. N=38) the overall opinion was that the LC CNS role was meeting the expected standards. The audit data revealed an age range of patients from 41-79yrs with a median of 60yrs. In terms of the LC CNS the audit data likewise suggested that the role was being fulfilled as expected including psychosocial support, provision of information and care co-ordination.

**Conclusion**

The LC CNS role clearly fulfills the expectation of the MOH Standards, the MDT with whom they work identify the role as crucial and have suggested that the LC CNS’s are the “glue that makes the system work much better and be more patient centered”. There is recognition that planning is essential when developing advanced nursing practice (ANP) roles, to ensure robust processes are put in place at the beginning of the process. There is evidence that development of these roles in an ad hoc fashion can lead to confusion regarding the intention of the role. The nurses who work within these ANP roles must be able to articulate and clearly define their role (Lewandowski & Adamle, 2009). There is also a need to evaluate the effectiveness of the role, as without robust evaluation there is a tendency to underestimate their crucial clinical contribution Oliver & Leary, 2012).
Dedication

I dedicate this thesis in memory of Sue Teague, whose vision and tenacity were instrumental in the development of the lung cancer CNS role.
Acknowledgements

The completion of a thesis not only impacts on the person undertaking the body of work, it impacts on all those who are part of their life, both at work and at home. I would like to acknowledge the unfailing support I have received over the past two years from a wide range of people.

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I am very fortunate to manage two wonderful teams made up of Clinical Nurse Specialists, Registered Nurses, Maori Health Workers, a Clinical Psychologist and Secretaries. It is because of you that I have undertaken this thesis. When I researched the subject of advanced nursing roles and multi-disciplinary teams, I felt nothing but immense pride to be associated with you all. The support that each and every one of you have given me over this period has been so appreciated. I have watched with pride the study many of you have undertaken, this has again inspired me to complete this thesis.

To the Lung Cancer CNS’s, thank you for trusting me to evaluate your roles. The results speak volumes to your commitment and passion, and shows the true value of your role.

I wish to acknowledge the patients and their whanau. Their information was critical in the completion of this thesis.

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<th>Description</th>
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<tbody>
<tr>
<td>ACP</td>
<td>Advance Care Plan</td>
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<td>ANP</td>
<td>Advanced Nursing Practice</td>
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<tr>
<td>CINAHL</td>
<td>Cumulative Index of Nursing and Allied Health Literature</td>
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<tr>
<td>CNS</td>
<td>Clinical Nurse Specialist</td>
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<td>DHB</td>
<td>District Health Board</td>
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<td>FSA</td>
<td>First Specialist Appointment</td>
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<td>FTE</td>
<td>Full Time Equivalent</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>HIIRC</td>
<td>Health Improvement and Innovation Resource Centre</td>
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<td>HWNZ</td>
<td>Health Workforce New Zealand</td>
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<td>ICN</td>
<td>International Council of Nurses</td>
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<td>IOM</td>
<td>Institute of Medicines</td>
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<tr>
<td>LC</td>
<td>Lung Cancer</td>
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<tr>
<td>LCNS</td>
<td>Lung Cancer Nurse Specialist</td>
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<tr>
<td>LC CNS</td>
<td>Lung Cancer Clinical Nurse Specialist</td>
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<tr>
<td>MDM</td>
<td>Multi-disciplinary Meeting</td>
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<td>MDT</td>
<td>Multi-disciplinary Team</td>
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<td>MECA</td>
<td>Multi-Employer Collective Agreement</td>
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<td>MOH</td>
<td>Ministry of Health</td>
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<td>NCCN</td>
<td>National Comprehensive Cancer Network</td>
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<td>NCNZ</td>
<td>Nursing Council of New Zealand</td>
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<td>NHS</td>
<td>National Health Service</td>
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<td>NICE</td>
<td>National Institute for Health and Care Excellence</td>
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<td>NLCFN</td>
<td>National Lung Cancer Forum for Nurses</td>
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<td>NPCR</td>
<td>National Program of Cancer Registries</td>
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<tr>
<td>NP</td>
<td>Nurse Practitioner</td>
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<td>Acronym</td>
<td>Description</td>
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<td>NZ</td>
<td>New Zealand</td>
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<td>NZNO</td>
<td>New Zealand Nurses Organization</td>
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<tr>
<td>OECD</td>
<td>The Organisation for Economic Co-operation and Development</td>
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<tr>
<td>PEPPA</td>
<td>Participatory Evidence-Based Patient Focused Process for Advanced Practice Nursing</td>
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<tr>
<td>PCNEG</td>
<td>Palliative Care and Cancer Nurses Education Group</td>
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<tr>
<td>RNS</td>
<td>Rheumatology Nurse Specialist</td>
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<tr>
<td>SEER</td>
<td>Surveillance, Epidemiology, and End Results</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>UKLCC</td>
<td>United Kingdom Lung Cancer Coalition</td>
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Chapter 1: Introduction

1.1 Introduction

Within this thesis the author explores the impact of an advanced nursing role in a specialty area, namely oncology nursing. The Advanced Nursing Practice (ANP) role within nursing has experienced exponential growth over the past years, (Barton, Bevan, Morgannwg & Mooney, 2012; Bryant-Lukosius et al., 2004; De Geest et al., 2008). This role has been well utilised since the 1940s in the realm of American nursing where the discipline of psychiatric care was the first specialty area to embrace the concept (Hamric, Spross, & Hanson, 2009). Likewise, the development of the ANP role in New Zealand has been gaining momentum since 2001 (MOH, 1998; Nursing Council of New Zealand, 2009).

The ANP role has evolved due to health care need. Peplau (1965 as cited in Hamric et al., 2009, p15) identified three social forces that preceded the development of specialist nursing roles, “(1) an increase in specialty-related information, (2) new technological advances, and (3) a response to public need and interest”. This rings true in the history of the development of advanced practice roles in New Zealand. In 1998 the Ministerial Taskforce for Nursing was formed, with the following terms of reference:

To recommend strategies to remove the barriers which currently prevent registered nurses from contributing to a more responsive, innovative, effective, efficient, accessible and collaborative health care service for New Zealanders (MOH, 1998, p.8).

The Taskforce sought to clarify the scopes of practice for nursing roles and to develop a specialist nursing framework for advanced and specialist roles in nursing. The Taskforce recognised the hidden potential of the largest professional workforce in New Zealand healthcare, suggesting that nursing should have major input into service development and planning, the delivery of integrated services and taking a lead in providing health care to those groups who fail to engage with health care services (MOH, 1998).

In Schober and Affara’s work (2007) the International Council of Nurses (ICN) suggestion that in order to have clear boundaries around practice and to identify the associated role of advanced practice nurses, it is essential to have clear definitions relating to this. Schober and Affara, (2007), posit that if ANP roles are to be effective, they must be developed to meet the needs of the health of the population they are developed for, resulting in many different but in some cases similar ANP roles across the international context.
The ICN definition of the nurse practitioner/advanced practice nurse, including Nurse Practitioners (NP) and Clinical Nurse Specialists (CNS) roles, is

...a registered nurse who has acquired the expert knowledge base, complex decision-making and clinical competencies for expanded practice, the characteristic 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 2002 (Schober & Affara, 2007, p. 12).

The Nurse Practitioner (NP) is one of the ANP roles recognised in New Zealand, following its formal introduction in 2001. The pathway for other specialty roles has been less clear, with a plethora of titles emerging such as Clinical Nurse Specialist (CNS), Nurse Consultant, Nurse Anesthetist and others. Holloway, Baker and Lumby (2009) identify the lack of a consistent specialist nursing framework, which led to different models of care throughout New Zealand (Holloway et al., 2009). Holloway has developed a ‘Specialist Nursing Framework’, which consists of three components, role adequacy, role legitimacy and role support. The framework developed by Holloway has influenced the work of the National Nursing Consortium, which was established in 2011, with the purpose of providing a national nursing endorsement mechanism for specialty standards and knowledge and skills frameworks, within New Zealand (HIIRC, 2010).

While there are a range of advanced practice roles described in the literature, within this study the focus is limited to the two most commonly described, those of Nurse Practitioner (NP) and Clinical Nurse Specialist (CNS). Registered Nurses and NPs have a defined scope of practice, which describes how they will deliver their care, where they will work and the population for whom they will be responsible for (MOH, 2002; NCNZ, 2010). The New Zealand Nurses Organization (NZNO) definition of the scope of advanced practice identifies that it is “...distinguished by autonomy to practice at the edges of the expanding boundaries of nursing. It is firmly grounded in the unique body of knowledge that is nursing” (NZNO, 2008).

The New Zealand NP is defined as a registered nurse with a minimum of four years’ experience in the area for which credentialing is sought, who has undertaken advanced education, to achieve a clinically focused master’s degree (NCNZ, 2012). The NP will have had extensive experience within a specific area of practice, using advanced nursing knowledge. The NP practices both independently and in collaboration with individuals, families and others in the health care team. This role includes a focus on health promotion, disease prevention, and the ability to diagnose, assess and manage the patient group within their specific area of practice. This role has been very effective in the management of chronic conditions;
NPs work across a wide range of health settings including hospitals, aged care, mental health and primary care (MOH 2002, 2009). The NP scope of practice was announced by the Ministry of Health and the Nursing Council of New Zealand in May 2001 (MOH, 2009). To date, as of 23rd July 2013, there are 80 NPs working across varied health settings in New Zealand, including five working within the Canterbury Region. The specialties in which the NPs work covers the health care continuum and includes child and youth, neonatal, Whānau Ora, chronic disease management, cardiology and respiratory (College of Nurses Aotearoa NZ, 2013).

The role of the New Zealand CNS is not a credentialed position, with the only requirement being that the individual is qualified as a registered nurse (NCNZ, 2010). The CNS role is identified as a senior role within the District Health Board (DHB) Multi-Employer Collective Agreement (MECA). Roberts, Floyd and Thompson (2011), discussed a study, which set out to identify how the CNS role was defined by the DHB’s who employ them. The study involved critiquing 15 CNS job descriptions from eight DHB’s, identifying qualitative and quantitative data. The study showed very little similarity as to how each CNS role was viewed by their employing DHB. There was marked difference in how each DHB viewed postgraduate education for the CNS role, with some citing post graduate qualifications as a prerequisite to these senior roles while others saw them as desirable only. Roberts et al. (2011) go so far as to suggest that for the CNS role to reach its full potential in New Zealand, the prerequisite for all CNS positions should be a postgraduate qualification at Master’s level. The Ministerial Taskforce on Nursing, 1998, was explicit in its direction to the DHB’s to develop and support the CNS role. They identified the potential of this role to enhance health outcomes for those they provided care to. They also sent a clear message to the NCNZ that they should recognise and endorse the CNS role, to date, this has not occurred (MOH, 1998). The NZNO suggest that while the nursing profession recognise the potential of nursing to influence better health outcomes for the populations they care for, this is often not the case for the public, medical colleagues or the government (NZNO, 2011). It has been suggested that ANPs lead the way in terms of innovation within nursing, however, this can challenge the deep-seated views and traditions of others health professions and the services with whom they are employed (Barton, Bevan, Morgannwg & Mooney, 2012). Given this development of advancing nursing practice it is to this end that this study is focused and explores the role further as this research was focused on the effectiveness and impact of the CNS role within the area of lung cancer.
1.2 Background

Lung cancer is one clinical setting where it has been suggested that the advanced nursing role could facilitate care. Deaths from lung cancer in New Zealand contribute 18% of all cancer related deaths in any one year (MOH, 2010). Lung Cancer in New Zealand has a five year cancer survival rate of 10.4%. This differs from Australia and Canada, where the five year survival rate is over 14% (MOH, 2011). In 2011 the National Lung Cancer Standards were developed, with the express purpose of improving outcomes for patients with lung cancer; they also identified the need to reduce disparity associated with the lung cancer diagnosis (MOH, 2011). The New Zealand Cancer Control Strategy set out to address the disparity in cancer care. The overarching principles of the Strategy are to “reduce the incidence and impact of cancer [and to] reduce inequalities with respect to cancer” (MOH, 2003, p.1).

The New Zealand Cancer Control Strategy identified that Māori and Pacific people were disproportionately represented in cancer statistics, including lung cancer (MOH, 2003). The Access to cancer services for Māori report states that lung cancer is one of the six cancers that carry a greater risk for Māori than non-Māori, with the statistics showing 30 more cases per 100,000 for Māori compared to non-Māori (Cormack, Robson, Purdie, Ratima & Brown, 2005). The very nature of how lung cancer manifests also contributes to the poor outcomes in treatment. The cancer is often well established before the patient seeks medical intervention; it is often too late for curative treatment (MOH, 2011; Spiro & Silvestri, 2005; Frizelle, 2009). There is evidence to suggest that Māori and Pacific People have greater issues with access to health care that is culturally appropriate, which may cause them to further delay seeking treatment (Cormack et al., 2005). The ability of those in the health care sector to engage with Māori is crucial in preventing and treating cancer (Cormack et al., 2005). The utilization of the Whare Tapa Wha model, developed by Mason Durie in 1994 can be of benefit (MOH, 2000). The model includes four dimensions that are attributed to wellbeing, te taha wairua (spiritual aspects), te taha hinengaro (mental and emotional aspects), te taha whānau (family and community aspects), and te taha tinana (physical aspects). Durie posited that these four cornerstones of Māori health need to be in place to ensure good health (MOH, 2000). Further to this, to ensure the principles of the Treaty of Waitangi are met, the nursing profession in New Zealand honors the principles of Te Tiriti o Waitangi of partnership, participation and protection. These three principles are embedded in the four articles of Te Tiriti o Waitangi are:

- Article One – Kawanatanga (Governance)
- Article Two – Rangatiratanga (Self-determination)
- Article three – Oritetanga (Equity)
- Article four – Wairuatanga (Spiritual Freedom) (NZNO, 2011).
Further to this, Clendon, (2011) suggests nursing within New Zealand has embraced the concept of cultural safety, a concept introduced by Irihapeti Ramsden in the 1990’s. The Māori perspective of whakawānanga (relationships), manaakitanga (caring), rangatiratanga (self-determination), and wairuatanga (spirituality) also need to guide and define the nursing profession within New Zealand to ensure they are practicing in a culturally safe manner (Clendon, 2011).

Such disparity is not unique to New Zealand. Fairley et al. (2010) analysed the data on lung cancer incidence from the National Program of Cancer Registries (NPCR) and the National Cancer Institute’s Surveillance, Epidemiology, and End Results (SEER) programme from 1998 – 2006 in America. The incidence per 100,000 population was highest among African Americans (76.1%) compared to Caucasians (69.7%). The authors suggest the reasons for this disparity in lung cancer incidence could be attributed to differences in socio-economic status, smoking prevalence and susceptibility to tobacco, and lack of smoking cessation programmes (Fairley et al., 2010). Further to this, Colice states that fewer African Americans receive timely surgical intervention for curative intent, citing a prospective study by Cykert et al (2010) of patients diagnosed with non-small cell lung cancer. The surgical resection rates were 63% for African-American compared to 75% for Caucasians (Colice, 2010).

One effort to reduce such inequalities resulted in a unique CNS role in lung cancer being established at a New Zealand tertiary hospital in 2009. The aim of this full time CNS role was to improve the lung cancer service by providing advice, support, information and advocacy to patients with a diagnosis of lung cancer. In 2010, a further 0.5 FTE lung cancer CNS position was added to the service, due to work load need. The lung cancer CNS works in collaboration with the Māori Health Workers where appropriate. It is not clear to date whether these CNS roles have impacted to improve service in relation to these areas. It is important to evaluate the effectiveness of advanced practice roles, and to identify the impact associated with these.

Some efforts to evaluate advanced nursing roles have been described in the international literature. Delamaire and Lafortune (2010) looked at the literature from 12 countries, including Australia, United States and the United Kingdom. As part of their study, they viewed a number of articles which showed that nurses within ANP roles can deliver quality care with high levels of patient satisfaction. The ANP often spends more time with the patient, which allowed for greater patient education and advice. The role of the ANP can improve access to services and reduce overall waiting times for the patient seeking care (Delamaire & Lafortune, 2010).
A study undertaken by Cowman et al. (2010), evaluated the role of the CNS in cancer care in Ireland. These authors sought to gain information from the perspective of the CNS, the patient and other health professionals. The findings from this study demonstrated that the majority of the members of the Multi-Disciplinary Team (MDT) viewed the CNS role in a positive way. The aspects of the CNS role seen as the most beneficial to the patient were in relation to education, symptom management and the ability to link all members of the MDT to the patient. Permission was obtained from Cowman et al. (2010) to utilise aspects of their survey for members of the MDT and to adapt this for the New Zealand context.

The regional lung cancer CNS role in the local setting was established in 2009. This position has not so far been formally reviewed, and it is timely to consider the effectiveness of the role. This study utilises a survey and audit process designed to contribute to that aim.

1.3 Aim

The aim of this thesis is to explore the impact of the lung cancer CNS role on patient care and elicit the functionality of the role within the MDT in a regional hospital in New Zealand.

- As per the research questions, the study will investigate how the CNS roles, established in a regional tertiary level health service, impact on patient care in the lung cancer service in relation to:
  - Contact time with patients
  - Psychosocial aspects of care
  - Support with negotiating the health system
- The functionality of the CNS roles within the context of the Multi-Disciplinary Team (MDT) will also be examined in relation to:
  - How the CNS’s are perceived by colleagues in terms of communication, referrals and caseload management

1.4 Structure of the Thesis

Chapter 1: Introduction
Chapter one provides the context which supports this thesis, and introduces the key concepts that underpin the discussion. The development of ANP roles is outlined in both the international and national context. The disparity relating to patients with a lung cancer diagnosis is discussed, and the resulting establishment of CNS roles in New Zealand to provide care for this group is outlined. The need to evaluate the effectiveness and impact of advanced practice roles has led to this research.

Chapter 2: Literature Review

The literature review presents a comprehensive search of the literature relating to the development of ANP roles, in both the international and local context. This includes literature related to educational preparedness for the ANP roles and how this is viewed by the ANP and the wider health sector. The literature review also investigates how ANP roles are currently evaluated as to their effectiveness in provision of patient care, and how ANP roles function as part of the MDT.

Chapter 3: Methodology

The details of the study design and the rationale for selection of the same, is presented in chapter 3. A mixed methods approach was utilised. The literature cites the value of this methodology as effective in capturing a more complete picture of the study subject (Polit & Beck, 2008; Schneider, Whitehead & Elliot, 2010). The study involved a two-staged approach, including a retrospective notes audit and a survey.

Chapter 4: Results

The findings which emerged from the two phases of the study are presented in this chapter. The audit phase consisted of exploration and interpretation of six months of data previously collected, identifying the impact of the CNS role on patients. This data was compared to the national standards for lung cancer care.

The survey phase involved distribution of a questionnaire to all members of the MDT involved in lung cancer care. The number of staff asked to complete the questionnaire was 50. The purpose of the questionnaire was to explore the views and perceptions of members of the MDT in relation to the CNS role in the area of lung cancer diagnosis and treatment. The number and sample of participants was chosen to ensure a representative population of those who work with the CNS’s.
Chapter 5: Discussion

This chapter focuses on the findings of the research, identifying the significance of the results of audit and the questionnaire. The author considers what this means for service delivery and for future development of the Lung Cancer Clinical Nurse Specialist roles. This chapter also acknowledges the strengths and limitations of the research.

Chapter 6: Conclusion

The final section summarises the work presented and identifies practice implications for the LC CNS role. Recommendations for future planning for the service and the development of advanced practice roles for oncology nursing are also identified.

Prior to undertaking collection of data to inform this research, a broad review of the available literature on the topic provides necessary context. In line with this, a review of the literature regarding the history and progress of the ANP role in a national and international framework is presented.
Chapter 2: Literature Review

2.1 - Introduction
The establishment of ANP roles within the New Zealand health sector has flourished in the past decade (Holloway et al., 2009; NCNZ, 2009). However, there is evidence of confusion regarding the range of roles and what each title means in the practice context. This is evident in both the local and global health sector setting (Holloway et al., 2009; Lloyd Jones, 2005). The literature review outlines key elements around the history of ANP roles, in the international and national health care settings. It also considers the establishment of ANP roles within the specialty area of lung cancer care, with emphasis on the development of Standards of Care within lung cancer.

With the proliferation of advanced practice nursing roles there is also a need to evaluate these, to determine their effectiveness (Bryant-Lukosius & DiCenso, 2004; Pollard et al., 2010). The forms of evaluation currently undertaken to determine effectiveness of such roles are outlined, with acknowledgement of the variation associated with this. A further area of interest is how the ANP role functions in the context of the MDT and the need to ensure nurses in ANP roles have appropriate advanced education to equip them for the rigor of the role (Fagerstrom, 2009; De Geest et al., 2008; Richardson, Halliday & Wilson-Barnett, 2002). The current international trends within education around advanced practice roles are also considered.

2.2 – Search Strategy
Comprehensive and systematic searches of OVID, CINAHL, Medline and Pub Med were undertaken. Key words included in the search were, Clinical Nurse Specialist, Nurse Practitioner, Advanced Nursing Practice, Advanced Practice Nursing, Nurse Clinician, Nurse Consultant, Cancer Nursing, Lung Cancer and Lung Neoplasm. Truncation symbols and Boolean connectors AND/OR were used to combine terms and widen the search. The search was limited to articles published in English, from January 2000 to February 2013. Articles were also sourced from reference lists in other publications. All literature reviewed was from peer reviewed articles, books and Government Publications.

The literature found during this review can be categorized into eight distinct areas. These were,

- Advanced Practice Roles
- Evaluation of Advanced Practice roles
Effectiveness of Advanced Practice roles  
Educational preparedness for Advanced Practice roles  
Lung Cancer Nurse Specialist, information related to Multidisciplinary teams  
Lung Cancer information and statistics, including information related to financial aspects of Advanced Practice roles.

2.3- History of the establishment of advanced nursing practice roles

2.3.1 Development of the ANP

There is historical reference to nurses working in advanced practice roles since the late 19th century, particularly in remote and sparsely populated areas, often due to a shortage of physicians (Kaasalainen et al., 2010). Literature relating to the ANP role dates back to the early 1940’s (Reiter cited in Lewandowski & Adamle, 2009). Lewandowski and Adamle (2009) posit that the development of the ANP role has been one of the most influential changes within the nursing profession, suggesting that their ability to work as change agents by leading and informing nursing teams and utilizing evidence based practice will ensure better outcomes for the patients they care for.

Factors influencing the emergence of specific ANP roles include changing societal expectations, political, professional and individual influences. The ANP role has developed in part as a response to changes in the socio-political landscape in healthcare. These changes include aging populations, increases in the number of patients with chronic diseases and a shortage of physicians, especially in the area of Primary Care (Bryant-Lukosius et al., 2010; DeGeest et al., 2008; Holloway et al., 2009; Ketefian, Redman, Hanucharukul, Masterton & Neves, 2001). Hernandez et al. (2009) suggest that healthcare teams will need to work in collaboration to achieve integrated care strategies between the primary and secondary care sectors, if they are to effectively manage the increasing population with chronic disorders.

Lewandowski and Adamle (2009) suggest that nurses working within advanced practice roles provide care for patients with complex health needs, influence the socio-political context within health and provide education and support to the multidisciplinary team. They contend that nurses working in ANP roles must be able to clearly define and articulate their scope of practice (Lewandowski & Adamle, 2009). There has also been a growing impetus to retain highly qualified nurses within areas of clinical practice. In the past many of these nurses gravitated to education and managerial roles within nursing, due to a lack of defined pathways for clinical senior nursing roles (Oliver & Leary, 2012). The establishment of advanced
nursing practice, with its base firmly in clinical practice, has provided an opportunity for these nurses to remain ‘hands on’ practitioners.

The International Council of Nurses (ICN) states that nursing is responsible for the definition of nursing roles and for the scope of nursing practice. ICN’s responsibilities lie in ensuring a clearly articulated definition of nursing and the plethora of roles they work within is shared with all involved in delivering nursing care (Royal College of Nursing, 2003). The New Zealand Nursing Council recognises three scopes of practice, Enrolled Nurse, Registered Nurse and Nurse Practitioner. The role of the NP is clearly defined, with four domains of practice outlined: professional responsibility and leadership, management of nursing care, interpersonal and interprofessional practice and quality improvement and prescribing practice (NCNZ, 2012). The competencies for the Nurse Practitioner role in New Zealand are as follows

- Professional responsibility and leadership, including accountability for their practice, ability to influence health outcomes and the ability to clearly define the nurse practitioner role they have undertaken
- Management of nursing care, including advanced clinical decision making, critical thinking and advanced clinical skills.
- Interpersonal and Interprofessional practice and quality improvement, including, advocacy, clinical collaboration with the multidisciplinary team and change management.
- Prescribing practice, including in depth knowledge of the laws that govern prescribing within New Zealand, the use, contraindications and indications for prescribing prescription medicines (NCNZ, 2012).

In addition to the NP, there are other advanced nursing practice roles possible in the New Zealand health care setting. These are centered on expansion of the existing Registered Nurse scope of practice. The following competencies underpin the expanded practice role in New Zealand, which includes the role of the CNS, along with the competencies expected for Registered Nurses.

- Demonstrates initial and ongoing knowledge and skills for specific expanded practice role/activities through postgraduate education, clinical training and competence assessment.
- Participates in the evaluation of the outcomes of expanded practice, e.g. case Review, clinical audit, multidisciplinary peer review.
- Integrates and evaluates knowledge and resources from different disciplines and health-care teams to effectively meet the health needs of individuals and groups. (NCNZ, 2010).
A number of different roles and scopes of practice have emerged as part of the wider advanced practice movement. There has also been international confusion over the titles given to ANP roles including, Nurse Practitioner, Clinical Nurse Specialist, Community Health Nurse Practitioner, Advanced Nurse Practitioner, Nurse Specialist and Advanced Practice Nurse (Schober & Affara, 2007). As stated earlier, for the purposes of this study, the focus is on NP and CNS roles.

2.3.2 ANP and Practice Contexts
As stated in the introduction, ANP roles have been well utilised internationally in the area of psychiatry since the 1940’s (Hamric et al., 2009). The international NP role was established in the 1960’s in the American health setting, initially to counteract the shortage of primary care physicians. This was not without challenges, as these NPs were viewed by some as crossing boundaries into previously held physician roles, (Hamric et al., 2009; Schober & Affara, 2007). The NP role was established in Canada in the mid 60’s and early 70’s, due to physician shortage, the introduction of publically funded medical insurance, increased need for primary health care and increased medical specialization (Kaasalainen et al., 2010).

Schober and Affara, (2007) suggest that ANP roles originated with the need to provide services to the remote populations of Australia. These roles became CNS roles, with the further expansion of practice to NP roles in 2001 (Schober & Affara, 2007).

The ANP role in New Zealand was firmly established in the 1990’s, predominantly in the areas of diabetes, respiratory and neonatal specialist nursing (MOH, 1998). The NP role was formally introduced by the NCNZ and the Ministry of Health in 2001. NPs work throughout the health sector, including acute emergency nursing, rural, mental health, neonatal and primary care (MOH, 2009).

2.3.3 ANP Role in Cancer Care
The first specific ANP roles within oncology dates back to the early 1970s, in America. The progression from research nurses to clinically focused nurses marked the beginning of specialized oncology nursing roles (Quinn, 2008). Quinn discusses the ever changing science that informs cancer treatment, including the emerging targeted and combination therapies for specific cancers. Quinn suggests that the ANP’s working within these fields need to undertake appropriate post graduate education, work in collaboration with the cancer care team and have the ability to work in an autonomous manner (Quinn, 2008). However,
the specific role of the ANP within lung cancer care was developed in the early 1990s (McPhelim, 2009; Moore et al., 2006). For countries where ANP roles are in the early stages of development, particularly in Asia and the Middle East, there is the opportunity for information sharing with the development of global standards of care within ANP roles (Schober & Affara, 2007; Quinn, 2008).

The concept of autonomy is not a new phenomenon; Gagnon, Bakker, Montgomery & Polkovitis (2010), describe how Florence Nightingale attributed ‘autonomy’ to being the single most important factor which differentiated professional nurses from lay people within health care. These authors conducted research on the concept of autonomy and its application within nursing practice. The findings concluded that high levels of autonomous practice and collaborative clinical decision making contributed to better clinical outcomes (Gagnon et al., 2010). Mrayyan (2004) suggests having autonomy within clinical practice rates highly in role satisfaction for nurses, but in order for them to achieve this, there needs to be support from nurse managers in the first instance. The three most influential factors that promote autonomy are clinical expertise, postgraduate education and support from management. In contrast the three most influential factors that detract from autonomy are high workload, unsupportive physicians and autocratic management (Mrayyan, 2004).

The emergence of ANP roles within the field of lung cancer can be traced back to the mid 1990’s; the role was established to provide support, education and symptom management for patients with a lung cancer diagnosis. There had been recognition that this group of patients received fragmented and unsupported care prior to this development (Leary, Bell, Darlison & Guerin, 2008; McPhelim et al., 2009; Moore et al., 2006).

2.3.4 Future direction for ANP roles

The ANP role is well established within the health care setting. The next challenge for the profession is to have robust plans in place for succession planning. Shirey (2008) posits that nurses in ANP roles are in the best position to tell others what their role encompasses; she has developed a five step succession planning model which includes:

1 – Organizational factors

- Requiring commitment from all in the plan, including the CEO of the organization
- Vision of what the ANP role means to the organization
- Assessment of what is needed e.g. job rotation
2 – Individual factors

- Identification of the candidates for the succession planning process

3 – Development

- Job rotation
- Mentoring
- Coaching

4 – Execution

- The plan of how the process will be achieved

5 – Evaluation and dissemination

- Comparing outcomes with the development plan
- Information regarding the success of the process needs to be shared via journal articles, presentations and within professional organizations (Shirey, 2008, p.215).

Another important factor in succession planning is to ensure that sharing of knowledge with others involved in caring for the patient occurs. This will continue to gain in importance, as nurses struggle to care for the growing numbers of patients with chronic diseases. This is further exacerbated by a lack of robust integrated working processes between primary and secondary care. The following extract from research conducted by Graham, Fielding, Rooke & Keen (2006) epitomizes this fact:

Even though I have an extended knowledge base in one part of the human body, I am constantly giving that knowledge to others as I can’t see every patient in the total area, so it’s my responsibility to share knowledge with others, educate others…we would deskill them if we didn’t and just told them what to do. (Graham et al., 2006 p. 983).

This extract underpins all that nurses must strive to do within their services; collaboration with others is crucial for the future development of the nursing profession.

Currie suggests the ability to identify key staff members who are ready to undertake advanced practice roles is crucial for ongoing development and sustainability of the specialty (Currie, 2010). Currie & Grundy (2011) suggest the development of ANP roles internationally has often been unplanned and haphazard in some cases, with no thought to succession planning. They posit that there needs to be widespread agreement from the organization regarding succession planning, backed up with financial
commitment and analytical processes to assess the service requirements for ANP roles (Currie & Grundy 2011).

2.4 - Evaluation of ANP roles

As stated previously, there is confusion regarding the plethora of titles for ANP roles (Bryant-Lukosius et al., 2004; Lloyd Jones, 2005; Trevatt & Leary, 2010). This discussion focuses on two of the most commonly used ANP roles, those of the CNS and the NP. The ANP roles have often been established as a result of unmet need in the health sector, with little planning and less evaluation of the roles (Richardson et al., 2002; Vaz & Small 2007; Lloyd Jones, 2005). This has led to resistance by medical staff, members of the multidisciplinary team and nursing colleagues towards acceptance of these roles, as others in the health workforce are unsure of the clinical expectations of these new positions. Differing expectations can lead to frustration from the ANP and members of the MDT and healthcare managers. The expectations of other disciplines include perceiving the ANP as a physician replacement or a Physician’s Assistant, with concern over the credibility of the education underpinning such roles and in particular that leading to prescribing rights (Graham et al., 2006; Lloyd Jones, 2005; Oliver & Leary, 2012). Failure to evaluate the effectiveness of the ANP roles has been suggested as one cause of confusion over roles (McPhelim et al., 2009; Vaz & Small 2007). Delamaire and Lafortune (2010) go so far as to speculate that the failure to evaluate ANP roles in the context of their impact on patient care and health costs will result in the failure of potential patient centered services. The common evaluation practice of comparing the ANP role to that of doctors does not go far enough, all aspects of health care delivery need to be included in reviews, including the impact they make in patient care (Delamaire & Lafortune, 2010).

Bryant-Lukosius et al. (2004) suggest while there will be marked differences within the broad concept of ANP roles, it is essential that the roles all have core characteristics that identify the advanced nursing role. These characteristics include, the ability to provide specialized care for patients with complex health care needs, the acquisition of advanced education and skills for the role and the ability to advance and expand the role (Bryant-Lukosius et al., 2004). There is a global move towards developing tools to evaluate these roles with the intent of evidencing their value within the health care setting (Cowman et al., 2010; Graham et al., 2006; Oliver & Leary 2012).

Lewis et al. (2009) suggests that while ANP roles appear to be effective, there needs to be further research and evaluation to substantiate these claims. Without robust evaluation of ANP roles, there is a tendency
to underestimate their crucial clinical contribution. The ANP role can be seen as expendable in the face of rising health care costs (Oliver & Leary, 2012; Shirey, 2008; Vaz & Small, 2007). This could be attributed to a lack of knowledge of the true value of the ANP on the part of financial planners in the health sector (Fox & White, 2013; Leary et al., 2008; Pollard et al., 2010).

A seminal document in the development of this study sought to evaluate the role of the CNS in St Luke’s Hospital in Ireland. Cowman et al. (2010), recognised the CNS’s as expert practitioners, who played a key role in patient care, as part of the multidisciplinary team. They also recognised the lack of formal evaluation of the CNS role and sought to rectify this by using questionnaires and focus groups, taking into account the complexity of the role. The findings from the evaluation process identified that the CNS’s were very active participants of the MDT, 47% of their time was attributed to patient care, and patient education was one of the main functions of the CNS. It was also shown that the nurse’s holding these roles were highly educated, with many holding Masters of Science degrees within their area of specialty (Cowman et al., 2010).

Within the United Kingdom, the Calman-Hine report on cancer care was released in 1995. This report sought to ensure cancer services were high quality, patient centered and equitable for all. The ANP role within cancer care did not evolve directly as a result of this report, but was established to improve cancer services (Haward, 2006; Kirshbaum, Booth, & Luker, 2004). In 2004 Kirshbaum et al. (2004) endeavored to evaluate the role of lead cancer nurse in Britain. They sought to highlight the main benefits of the ANP role within cancer care, following the establishment of these posts. The study utilised a two stage case study as the methodology. Stage one involved gathering information from the ANP’s, senior nurses and clinicians regarding the aims of the role and perceptions of achievements within the role. Stage two looked at the factors that enhance or inhibit the effectiveness of ANP roles. The factors that enhanced the role included the ability to make clinical decisions and the formation of collegial relationships. The factors that inhibited growth of the role included budgetary constraints and ongoing changes within service and policy decisions. The authors posit that while the post holder must have the required attributes to undertake the role, it is paramount that there is a strong organizational partnership between the clinician and the health care facility for the role to be successful (Kirshbaum et al., 2004).

In Britain a project to evaluate the effectiveness of lung cancer Nurse Specialists has been undertaken, with the Roy Castle Lung Foundation and the National Lung Cancer Forum for Nurses joining forces to conduct this body of work in 2012. The National Lung Cancer Forum for Nurses has been in existence
since 1999, membership is made up of Specialist Nurses who provide clinical care to patients with lung cancer for more than 50% of their working week. The Specialist Nurses can work within respiratory medicine, oncology, and palliative care and within the community (Fox & White, 2013). The project included a survey of patients with lung cancer and those who cared for them, with the purpose of illustrating the experiences these people had when working with the Lung Cancer Nurse Specialists (LCNS). The project also included a survey of the lung cancer Specialist Nurses, seeking their perceptions about how they contributed to patient outcomes.

The outcome from this project has led to the following recommendations relating to the nursing input into lung cancer care:

- Recommendation 1: LCNS’s should be involved in the pre-diagnostic phase of care of suspected patients with lung cancer. This will ensure patients are supported from initial presentation, through investigations to diagnosis, to treatment and thereafter. This will allow for the effective management of symptoms at an early stage, which optimizes potential treatment options and improves quality of life.
- Recommendation 2: all lung cancer patients should be able to access LCNS support and advocacy when they need it throughout their whole patient journey to support their holistic needs,
- Recommendation 3: LCNS’s should be involved with pre-diagnosis care of suspected lung cancer patients, from the point of detailed investigations in secondary care,
- Recommendation 4: LCNS’s need to work closely with MDT coordinators, trackers and audit staff to ensure they are not taking on unnecessary administrative roles
- Recommendation 5: despite the financial pressure facing the NHS, the role of the LCNS in ensuring optimal care for patients, must be protected, (UK Lung Cancer Coalition, 2012).

This sends a strong message of support for the effectiveness of the ANP role within the care of patients with lung cancer.

Bryant-Lukosius et al. (2004), developed a framework to identify and prevent implementation barriers when establishing ANP roles. They identified the need to ensure clear understanding of the ANP role and the clinical area, where the role functions were non-negotiable when establishing the role. They developed the participatory, evidence based, patient centered process (PEPPA) to ensure ANP role development, implementation and evaluation. The authors posit that all ANP roles require continual robust evaluation, in the context of achievable key outcomes. The ability to engage all stakeholders at the start of the process
of developing ANP roles will ensure the role is clearly defined and effective (Bryant-Lukosius et al., 2004).

Hamric et al. (2009) identify ANP’s as being in the best position to evaluate the effectiveness of their role. They suggest ANP’s frequently monitor their performance against inefficiencies, barriers to provision of continuity of care and patient outcomes. By undertaking quality initiatives to evaluate their practice, the ANP can make substantial changes to how health care is delivered, to both the patient and for the health care facility (Hamric et al., 2005). These authors identify three phases in the process for data analysis:

1)  – Define the core Questions
   - Clarify purpose of the ANP role
   - Define the target population for study
   - Identify the stakeholders
   - Articulate programme goals and incentives

2)  – Define the Data Elements
   - Identify selection criteria for the population of interest
   - Establish performance and outcome indicators
   - Identify and evaluate data elements, collection instruments and processes

3)  - Derive meaning from data and act on results
   - Analyze data and interpret findings
   - Present and disseminate findings
   - Identify improvement opportunities
   - Formulate a plan for implementation and evaluation

They go on to suggest that for ANP’s the process of undertaking robust quality initiatives not only evidences their practice, it shows those they care for and work with the value of the ANP role within the health care continuum (Hamric et al., 2009).

2.5 - Lung Cancer Globally
The history of smoking originated in the late 1800’s, cigarettes were rolled by hand at this time. James Bonsack was responsible for developing a machine that could make 70,000 cigarettes in a ten hour day. The commercial use of these machines by James Duke resulted in the establishment of the American Tobacco Company; Duke was the president of this company (Witschi, 2001).
There was an initial wide disbelief within the medical world that smoking could cause lung cancer, with blame being put on causative agents such as asphalt on the roads and industrial dusts. The ability to collect exceedingly vast tobacco taxes by Government did not encourage research regarding links between smoking and lung cancer (Proctor, 2001; Witschi, 2001). With an increase in lung malignancies, smoking as the main causative agent was suspected. The first research into this was in 1939, when Franz Hermann Muller, a German physician conducted the world’s first case control epidemiological study; the results showed that smoking was the main cause of lung cancer (Proctor, 2001). Spiro and Silvestri (2005) quote the historic nature of an article by Doll and Hill, which appeared in the British Medical Journal in 1950, again attributing smoking to lung cancer. This article was historically significant, as smoking rates were at an all-time high, post-World War Two. There was very little challenge against tobacco companies at this time; revenue was needed by governments recovering from the cost of war (Proctor, 2001; Spiro & Silvestri, 2005).

In spite of the well-publicized risks associated with smoking, there remains a global epidemic of smoking related diseases. Alberts discusses the staggering numbers of global lung cancer deaths, approximately 1.2 million people died from lung cancer in 2002. He goes on to state that there are more people who smoke in China than there are people in the United States (Alberts, 2007).

Lung cancer has become the most common cause of death for both men and women in the Western world. It is predicted that this will also be the case in the developing world in the near future (Spiro & Silvestri, 2005). Lung cancer contributes the highest percentage of all cancer related deaths in New Zealand (18%) (MOH, 2006). The five year survival rate of 10.4% is lower in New Zealand than other Western nations; Australia and Canada have a five year survival rate of 14% (MOH, 2011). The National Lung Cancer Working Group in New Zealand has identified the disparity in incidence and outcome for a diagnosis of lung cancer for Māori and Pacific people. They attribute this to higher tobacco use and late presentation to medical services once symptoms of the disease occur (MOH, 2011). The physical signs and symptoms of the disease are not identified until the disease is well established, making treatment less effective (Frizelle, 2009; Spiro & Silvestri, 2005).

While 90% of lung cancer is attributed to smoking, the remaining 10% of lung cancer affects people who have never smoked. The incidence for women in this category is higher than for men. The cause of this could be attributed to genetics, ethnicity or environmental pollution, but the literature states that this requires further investigation to determine cause and trends (Gazdar & Thun, 2007; Wakelee et al., 2007).
This information compares to local statistics, with 62% of all lung cancers attributed to ex-smokers, 28% to current smokers and 10% to non-smokers (Personal communication, C. Smith, LC CNS, 2013).

To address the spiraling statistics for cancer globally, there is an international momentum to develop cancer control strategies, including for lung cancer. In 2003 the Ministry of Health and the New Zealand Cancer Control Trust combined to produce the New Zealand Cancer Control Strategy, with the aim of reducing inequalities and the impact of a cancer diagnosis (Cancer Control Taskforce, 2005). Australia has been involved in developing cancer control strategies since the 1980’s, including the National Cancer Prevention Policy 2004 – 2006, with the express purpose of developing a national approach to cancer control (Anderiesz, Elwood, & Hill, 2006). The comparable document in America is the National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology (NCCN Guidelines), with the purpose of providing clinical guidelines to those involved in cancer care. These strategies and guidelines set out to prevent and detect cancer early through screening, education, smoking cessation and vaccinations (MOH, 2011; Anderiesz et al., 2006).

Spiro and Silvestri (2005) discuss the fact that lung cancer is the most common cause of cancer deaths in men and women in the developed world; this will be replicated in the developing world in the near future. Treatment for lung cancer offers low survival rates; however, research is focused on achieving better outcomes with targeted chemotherapy. Smoking cessation offers the most effective protection against developing lung cancer (Alberts, 2007; Spiro & Silvestri, 2005).

2.6 – Standards of Care in ANP roles in Cancer care
The establishment of the Lung Cancer CNS (LC CNS) roles to improve the quality of care for patients with lung cancer have been well received both nationally and internationally (Lewis et al., 2009; McPhelim et al., 2009; MOH, 2011; Richardson et al., 2002). The role of the LC CNS was established in 1995 in Britain as a result of Government reports whose findings related to lack of support and fragmented care for patients with lung cancer. The development of the LC CNS role provided an alternative model to traditional specialist follow up. The role was established to coordinate follow up care, provide education, manage symptoms and provide emotional support, with the ability to refer back to specialists, palliative care and home based services. Moore et al., undertook a study in the UK, which compared traditional follow up to LC CNS follow up. The study identified that LC CNS follow up is safe, effective and can result in higher levels of patient satisfaction (Moore et al., 2006). In 2004 the National Lung Cancer Forum
for Nurses (NLCFN) and the MacMillan Cancer Support in the UK, produced the Good Practice Guide for nurses caring for patients with a diagnosis of cancer. The publication was rewritten in 2009. The NLCFN was developed using information from LC CNS’s working in different areas throughout the UK. The examples of nurse initiated practice were incorporated in the document, to produce a comprehensive guide to those working in lung cancer care, ensuring the highest standard of care and uniform treatment was provided. From this work the NLCFN has formulated a definition for a LC CNS:

A Lung Cancer Nurse Specialist is a first level nurse, locally recognized as part of the specialist lung cancer multi-disciplinary team and designated as a specialist in lung cancer. The nurse should spend at least 50% of his or her time caring for lung cancer patients. It is recognized that the Lung Cancer Nurse may be practicing within a sub-specialty of oncology, respiratory nursing, thoracic nursing or palliative care. A consultation with the lung cancer nurse specialist should include a detailed assessment of the patient’s physical, psychological, social and emotional concerns either during or following the diagnostic process. The nature of follow up consultations will depend on the complexity of the patient’s needs and also local arrangements covering the sub-specialty already mentioned within this definition (Darlison & Beattie, 2009 p5).

The majority of the UK’s LC CNS’s are members of the NLCFN, which ensures standards in care are maintained (Darlison & Beattie, 2009).

In 2011 the Ministry of Health, NZ, issued standards of care for patients with lung cancer, with the aim to improve the care and to reduce inequalities for patients with lung cancer. Standard 11 states

All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specializes in cancer care, to provide psychosocial support, information and coordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with a specialist” (MOH, 2011). The objective of developing national standards was to improve the overall care for patients with lung cancer, with each region implementing them within their local and regional services

(MOH, 2011, pg. 13).

The British National Institute for Health and Care Excellence (NICE) has also issued quality standards for lung cancer care. This document has identified fifteen quality standards with the express purpose of improving the safety, patient experience of care and effectiveness of treatment, for all people with a lung cancer diagnosis. As identified in the New Zealand Standards of Care, the NICE standards have identified
the importance of all lung cancer patients having access to a named CNS in lung cancer, to provide support and expert nursing intervention throughout the trajectory of the lung cancer pathway. The CNS is seen as pivotal in ensuring communication regarding the patient with a lung cancer diagnosis between Secondary and Primary care is maintained (National Institute for Health and Clinical Excellence, 2012; NICE Pathway 2012).

Australia has also developed a cancer control policy in an effort to reduce the impact and improve outcomes for cancer patients. The estimated cost of cancer care in Australia in 2000-2001 was 5.5% of the total health care cost of 2.7 billion dollars. The aims of the cancer control policy in Australia is identical to those of all countries, with the express purpose of ensuring cancer care is approached in a coordinated and cohesive manner (Anderiesz et al, 2006). In 2006 the Australian Government established Cancer Australia.

The mandate for this agency is to,

... provide national leadership in cancer control, guide scientific improvements to cancer prevention, treatment and care; coordinate and liaise between the wide range groups and health care providers with an interest in cancer care; provide advice and make recommendations to the Australian Government on cancer polices and priorities’ and oversee a dedicated budget for research into cancer care (Cancer Australia, 2009, p.538).

To achieve this, the agency works with patients, health professionals, cancer organizations, researchers and Government. The work of this agency is aligned to internationally agreed cancer control policies (Cancer Australia, 2009).

In 2007 the MOH of New Zealand established the Palliative Care and Cancer Nurses Education Group (PCNEG), with the express purpose of having nursing input in to meeting the objectives of the New Zealand Cancer Control Strategy (MOH, 2003) and the New Zealand Cancer Control Strategy Action Plan 2005 – 2010. The outcome from this group was the development of the National Professional Development Framework for Cancer Nursing in New Zealand. Seven principles underpin the cancer nursing framework. They are as follows:

The priorities, needs and experiences of people affected by cancer and their family/whānau are central to this framework’s development

The New Zealand Cancer Control Strategy and its action plan guide this framework’s development, with the framework building on and promoting their goals, objectives and actions
The framework guides the professional development of nurses working in cancer control and care. The framework assists nursing education providers in the development of generalist and specialty cancer nursing education programs. The cancer nursing competences enable nurses to articulate their practice in a way that is consistent with, and builds on, the Nursing Council of New Zealand’s Competencies for Registered Nurses (Nursing Council of New Zealand 2007, pg. 4). The cancer nursing competencies are evidence based and can be used by registered nurses who practice in a variety of health care settings.

Efforts to reduce the burden of cancer in our community require a population-based approach to health service planning and delivery. The particular geographical, social and cultural needs of people affected by cancer (including the needs of specific population groups such as Māori and Pacific peoples, socioeconomically disadvantaged people, people from non-English speaking backgrounds and people in rural and remote areas) must be considered to ensure a responsive and inclusive approach to cancer control (MOH, 2009, p2).

The priority of meeting the seventh principle with lung cancer care for Māori is crucial, considering the incidence of lung cancer is higher for Māori than non-Māori. There are 30 more Māori diagnosed per 100,000 than non-Māori (Cormack et al., 2005; MOH, 2009). It is with the development of frameworks and recommendations such as these that a strong nursing workforce is developed, to ensure optimum care for those most vulnerable (MOH, 2009; MOH, 2011; UK Lung Cancer Coalition 2012).

2.7 – Multidisciplinary Team (MDT)

The LC CNS’s evaluated within this current study are part of the MDT, which includes respiratory physicians, thoracic surgeons, radiation oncologists, oncologists, palliative care, physiotherapists, social workers, Māori health workers, clerical and management staff. The LC CNS’s identified within this study, work across sectors and disciplines, providing a point of contact for the patients with lung cancer.

The effective function of the MDT requires collaboration between all members and with those they care for. Hamric et al. (2009) define collaboration within the MDT as the ability to recognise the importance of each member’s contribution to the function of the team. They suggest that the ANP should be instrumental in teams achieving transdisciplinary collaboration. This type of collaboration encourages teams to share knowledge, skills and information across disciplines, leading to more effective clinical outcomes. Hamric et al., suggest that there are seven characteristics of collaboration:
• Clinical competence and accountability
• Common purpose
• Interpersonal competence and effective communication
• Trust
• Mutual respect
• Recognition and valuing of diverse, complementary knowledge and skills
• Humour (Hamric et al., 2009, p 288).

Horvath et al. (2010) suggest that there are many advantages for health care teams from working within the MDT model of care. The advantages include improvement of time to treatment for cancer patients, coordinated services and increased patient and health professional satisfaction. Horvath et al. (2010) discussed a trial that compared standard care with the MDT approach; review of the MDT care showed better symptom control and satisfaction with the service, compared to the standard approach. The MDT included physicians, surgeons, nurses, social workers, radiologists, who conducted multidisciplinary meetings where each case was discussed and a plan of action was agreed. Horvath et al. (2010) posit that a functional MDT will achieve a superior result compared to that of a sole practitioner.

The Standards of Service Provision for Lung Cancer Patients in New Zealand have identified the MDT as the cornerstone of best practice in cancer care, citing the MDT as instrumental in achieving improved survival benefits, appropriate recruitment to clinical trials, reduction in duplication of care and better coordination of cancer care (MOH, 2011). The NICE pathway for lung cancer treatment also discusses the importance of all patients with a known or suspected diagnosis of lung cancer having access to the MDT as crucial in ensuring all avenues for treatment decisions are identified (NICE Pathways, 2012).

The ANP role is viewed as a pivotal one within the context of the MDT, (McPhelim et al., 2009; Cowman et al., 2010). The role of the lung cancer CNS fits very well with this view. The literature clearly sees the lung cancer CNS as instrumental in guiding the patient through the labyrinth of the treatment pathway for a lung cancer diagnosis. The CNS can be involved from pre-diagnosis to the point of palliation if required. Each part of this journey involves the MDT; however, the CNS is the one constant health professional involved with the patient, guiding, supporting and advising on all aspects of lung cancer care (Peake & Steyn, 2012; MOH Standards, 2011; Fox & White, 2013; Darlison & Beattie, 2009).
2.8 – Education and preparation for ANP roles

The International Council of Nurses (ICN) recommends ANP’s educational preparation should be at Master’s level; however, the ICN concedes that opportunities for education will be different across nations. Schober and Affara (2007) discuss the need to have flexible options for education for ANP roles, with recognition of appropriate experience and prior learning. They cite advanced education as the key way forward in identifying ANP’s from generalist nurses. The education must reflect the scope of practice and the required standards for the ANP role. This will change as more ANP educational programmes are established (Schober & Affara, 2007). Mirr Jensen suggests that the most important word in the ANP title is ‘nursing’, arguing that advanced education and nursing’s effectiveness in improving patient outcomes differentiates nurses from all other health professionals (Mirr Jensen, 2006).

The value of ANP roles in improving patient outcomes is widely recognised (Furlong & Smith, 2005; De Geest et al., 2008; Fox & White 2013). Furlong and Smith (2005) posit that the core components of the ANP role are that the practitioner is autonomous in practice, an expert clinician, has research, professional and clinical leadership skills. They suggest that ANP’s must undergo postgraduate education to ensure they develop advanced theoretical and clinical skills, (Furlong & Smith, 2005). Internationally the recommendation is for all nurses who undertake an ANP role to be prepared at Master’s level, given the expectation of the roles is to show clinical leadership and utilise critical decision making (Schober & Affara, 2007). However, in reality the educational preparation for ANP roles is often unclear. Vaz and Small, argue that ANP roles are often in place before thought has been put into support and educational requirements for the role (Vaz & Small, 2007). Aiken discusses the American Institute of Medicines (IOM) recommendation that by 2020, the numbers of nurses who hold at least a bachelor’s degree should be increased from 50% to 80%. This is to ensure there are enough qualified nurses to provide cost effective, safe and effective healthcare for an ever increasing population. Currently in America 60% of nurse’s graduate with an associate’s degree, 36% with a bachelor’s degree and 3% with hospital based diplomas. Aiken posits that this percentage has the resulting consequence of fewer nurses completing ANP education. To ensure the IOM changes occur, Aitkin suggests the current Medicare funding of $160 million per year for nursing education should be used to provide clinical training for ANP roles, rather than continue to fund diploma nursing programmes (Aiken, 2011).

The ability to retain senior nurses within clinical areas has spurred the development and proliferation of ANP roles. However, to undertake the required academic study has presented challenges to some
registered nurses, the cost of the study and the time commitment can present major barriers (Aiken, 2011; Furlong & Smith, 2005).

The Australian health sector recognizes two ANP roles, that of the CNS and NP. As in New Zealand, the NP title is formally recognised by the governing body, but the CNS role is not. The educational qualifications for the CNS role are recommended at Graduate Diploma or Master’s level. The requirement for the NP role is Master’s level, as it is in New Zealand. The Australian Government has identified the benefits of supporting the expansion of nursing roles. This has been driven by a looming shortage of health professionals and the geographical isolation for primary care health delivery (Delamaire and Laforraine, 2010). The Trans-Tasman Mutual Recognition Agreement between Australia and New Zealand has led to the development of joint standards and competencies for the NP role (Schober & Affara, 2007).

The establishment of ANP roles in Canada is much imbedded, with the formation of both the NP and CNS roles in the 1960’s. Postgraduate education programmes for ANP roles commenced in Canada over 40 years age (Martin-Misener et al., 2010). The NP role was established due to a geographical shortage of doctors. Interestingly, once the doctor shortage was addressed, the NP role was largely disestablished. The NP role returned to favor in the 1990’s, again due to a doctor shortage in both the Primary and Acute care settings. The educational level required for the NP in Canada is that of a Master’s degree. In 2008 there were 1,626 NP’s in Canada, which makes up 0.6% of the nursing workforce. The NP role in Canada is defined by the ability to provide definitive diagnostics, prescribe medications, order and interpret tests and perform specific procedures, within their legislative scope of practice (Delamaire and Laforraine, 2010; Schober & Affara, 2007).

The Canadian CNS role was also established in the 1960’s, with many of these positions being disestablished in the 1980’s and 1990’s as a result of financial constraints in the health sector (Delamaire and Laforraine, 2010). In 2008 there were 2,222 CNS’s in Canada, which made up 0.9% of the nursing workforce. The educational requirement for the CNS is a Master’s degree. The characteristic that defines the CNS role in Canada is the specialist nature of their role; they practice within a designated area or specialty. The role is further defined by the identification of the population for whom care is provided; the CNS needing to define where they practice and the type of care they provide (Delamaire and Laforraine, 2010; Schober & Affara, 2007).

While the ANP role has a long well documented history in Canada, Di Censo et al., suggest that the full potential of the role has not been realized. The ability to provide standardized education for ANP roles is
challenged, with each Province and Territory having individual policies on how they administer health care (Di Censo et al., 2009).

The ANP role in the UK has also been in place for a number of years. The first NP roles were established by the National Health Service (NHS) in the early 1970’s, their numbers have grown substantially in the past 10 years (Delamaire and Lafortune, 2010). The title of ANP is associated with four distinct roles, those of CNS, Advanced NP, Nurse Consultant and Matron. The impetus in developing these roles in the UK mirrors those described in other countries that is, improving access to services, continuity of care and changing demographics of patient need. There is a mix in the level of education required for these roles in the UK. The CNS needs to exhibit extensive experience in the field of practice, with a University first degree or master’s degree. The expectation for NP’s is to have at least a bachelor’s degree; however, most are educated to master’s level. The Nurse Consultants have either a master’s degree or doctorate and the Matron’s are educated to master’s level or have extensive experience in a related field (Delamaire and Lafortune, 2010).

Education for ANP roles will need to become more accessible to enable training for the projected numbers of ANP’s required to address the burgeoning health care need, for the chronically ill and within primary care (Fagerstrom, 2009; Furlong & Smith, 2005; Onishi, Sasaki, Najata & Kanda, 2008; Delamaire & Lafortune, 2010). Delamaire and Lafortune suggest that by providing interprofessional educational modules for doctors and nurses, the benefit would be preparation for closer working collaboration across the professions (Delamaire and Lafortune, 2010).

2.9 - Cost effectiveness of ANP roles

It is often difficult to quantify the cost effectiveness of ANP roles in purely monetary terms. Hamric et al., seek to clarify this when they describe cost effectiveness as having two distinct elements, monetary and positive clinical outcomes. They go on to discuss the difficulty associated with assigning monetary value to positive clinical outcome (Hamric et al., 2009). Leary et al., undertook a study to identify the workload of six LC CNS’s in the NHS, including “telephone work, unrecognized contribution to the health economy and complexity of workload and fiscal value”. The results concluded that on average each LC CNS worked 6.6 hours of unpaid overtime per week. They also saw 15 new and 59 follow-up patients over the eight days of the study, which they estimated would have saved £8,330 if these patients had been seen by an Oncologist (Leary et al., 2008).
A further study by Oliver and Leary in 2012 looked at the return in investment of the CNS role. They undertook the study due to mounting pressure from the perceived view that the CNS role was not cost effective and largely undefined, particularly the role of the rheumatology CNS (RNS). The study identified that the RNS role did represent value for money in NHS trusts. The annual cost of an RNS was approximately 50,000 pounds, which equates to savings of 225,000 pounds in GP and specialist time. The RNS role was shown to be highly valued by those they cared for (Oliver & Leary, 2012).

As stated earlier, it is imperative that ANP roles are rigorously evaluated to ensure the difference these roles make in the health care setting is transparent to management and to the fiscal team (McPhelim, et al., 2009; Vaz & Small, 2007). The introduction of ANP roles has often been as a result of physician shortage, particularly within primary care (Fairman, Rowe, Hassmiller & Shalala, 2011; Fagerstrom, 2009). The introduction of ANP roles, particularly to provide health care to those with chronic diseases, has increased substantially in the past years. De Geest et al. (2008) go so far as to posit that the ANP roles will have more impact on managing the chronically ill than any others in the health care setting. Fairman et al., suggest that training more nurses in ANP roles is the way forward in addressing the shortage of primary care physicians; this would be cost effective and time efficient (Fairman et al., 2011).

All roles within health are scrutinized with regard to cost effectiveness, in particular as a result of increasing health costs and the aging populations. This often leads to apprehension and stress regarding the security of roles (Cowman et al., 2010; Fairman et al., 2011; Leary et. al., 2008; Oliver & Leary, 2012; Pollard et al., 2010). There is a need for nurses in all areas of the health sector to become more fiscally aware of the costs related to providing health care, particularly those in ANP roles (Bryant-Lukosius et al., 2004; De Geest et al., 2008; Graham et al., 2006).

As stated earlier, historically the establishment of ANP roles has evolved due to doctor shortage and with the intention of cost savings. DiCenso et al. (2010) conducted a review of the evaluations conducted by a number of OECD countries on ANP roles in the primary care sector and within hospitals. They reviewed 78 studies, with the following findings. The studies concluded that in the main nurses in ANP roles provided effective safe care, with improved patient satisfaction and outcomes. The ANP spent more time in consultation, providing education and ensuring the patient fully understood their health issues. The outcome of this was fewer hospital admissions, due to better management of often chronic conditions. While the motivation was to save revenue, this was not always achieved. Where the ANP role was established with substitution of tasks usually undertaken by a doctor, the results were cost reducing or
cost neutral. However, where the role involved supplementary tasks including ordering of tests, longer consultations and more frequent recall, the costs increased. The author acknowledged that there was a limitation on the studies as they did not go on to look at the potential cost savings including reduced hospital admissions, less complications from chronic illnesses and improved patient understanding of their condition (Delamaire & Lafortune, 2010).

The study undertaken by Cowman et al. (2010), identified the LC CNS role as instrumental in providing quality cancer care, which was well regarded by the patient and all members of the MDT. The authors identified ongoing anxiety regarding role security, in the face of constant review of services, within the study group (Cowman et al., 2010). LaSala, Connors, Pedro and Phipps (2007) suggest it is imperative for CNS’s to articulate what it is they actually do, to ensure their role is transparent and valued by all, giving greater security for the future of CNS roles within health.

Having reviewed the literature, it is important to identify the most appropriate methodology to address the research question and to capture the required data for the study. Acknowledgment of the underlying paradigm and its associated methodology provides the reader with an understanding of the wider context from which the researcher has approached the subject matter.
Chapter 3: Methodology

3.1 Introduction
Within the nursing literature, scholars identify that there has been a proliferation of research within the profession (Schneider et al., 2010; Polit & Beck, 2008). The assumption appears to be that this is a relatively new phenomenon, a position decried by the evidence of Florence Nightingale’s research regarding mortality and morbidity of soldiers during the Crimean war in the 1800’s (Polit & Beck., 2008). It is increasingly recognised by nurses that there is an expectation of engaging with and initiating research, associated with being a member of a profession. Hamric et al. (2009) identify research skills as a core competency for all ANP roles. They suggest the ANPs must know how to collaborate with others in the health care setting, to utilise research findings, to elicit changes to clinical practice, with the express purpose of improved health outcomes (Hamric et al., 2009). Schober and Affara (2007) suggest further research is required to show how the ANP role fits in the health continuum, including in relation to improved patient care and in a financial context. They posit that this is where further research should be aimed, if ANP roles are to expand and flourish (Schober & Affara, 2007).

3.2 Paradigm identification
The first stage of developing a research study is to decide which paradigm will be utilised. Bergman describes the paradigm as “an organizing framework that contains theories, assumptions, beliefs, values and principles that inform a discipline on how to interpret subject matter of concern”, (Bergman, 2010, p.172).

This study utilised a mixed methods approach, combining the qualitative and quantitative paradigms. Polit and Beck (2008) define mixed methods research as the analysis of both qualitative and quantitative data. The literature cites the value of this type of methodology as its effectiveness at capturing a more complete picture of the study subject (Creswell, Klassen, Plano Clark & Smith, 2011; Hanson, Creswell, Plano Clark, Petska & Creswell, 2005; Polit & Beck, 2008; Schneider et al., 2010; Tashakkori, Teddlie & Sines, 2012). Schneider et al., suggest that utilizing a single method within research can limit research findings. The researcher needs to understand the strengths of each type of research methodology and how they complement each other, resulting in a robust strategy to undertake research of a topic (Schneider et al., 2010). Feilzer (2010) posits that the utilization of mixed methods research allows a richer, more pragmatic meaning to emerge following data capture, ensuring new and deeper dimensions emerge from
the study (Feilzer, 2010). There are critics of the mixed methods approach, however, who suggest that qualitative and quantitative are two distinct paradigms and are not compatible. The mixed method approach tends to be favoured more by qualitative researchers than those from the quantitative paradigm (Brannen (2005) cited in Creswell & Tashakkori, 2007; Cresswell & Tashakkori, 2007; Sale et al, (2002) cited in Creswell & Tashakkori, 2007). Creswell and Tashakkori suggest that the utilization of the mixed methods approach to research is pivotal in understanding and addressing the major health problems facing health care provision. These authors suggest that a multifaceted approach will assist in identifying issues such as ethnic disparity and the reasons behind poor adherence to established health treatments. They define mixed methods as a paradigm that has the potential to inform the researcher of multiple viewpoints, with the ability to reach a deep understanding of the topic under study (Creswell et al., 2011). Tashakkori et al. (2012) identify mixed methods research as an approach widely favoured within health and medical sciences, with the potential to gain a better understanding of the subject under scrutiny within the research.

Mixed methodology can also be referred to as methodological triangulation, plural or simply mixed methods, (Schneider et al., 2010; Polit & Beck, 2008). Greene, Caracelli and Graham (2010) suggest that to prevent limitations within the research, utilization of mixed methods can offset or counteract biases and give added weight to the results. Schneider et al., (2010) view the qualitative approach as searching for meaning within the data, utilizing an integrative approach; whereas the quantitative approach is looking at the data with the express purpose of finding ‘truth’ in an objective and controlled manner. Creswell and Tashakkori explore the concept of how the two paradigms must integrate, in order for true understanding of the phenomenon of interest to occur (Creswell & Tashakkori 2007).

This study utilises Cresswell and Plano Clarke’s definition of Concurrent Design, which allows the generation of different but complementary data about the central phenomenon under study. This category of design is described as involving “one phase of data collection gathered concurrently” (p103), and involves the simultaneous collection of both qualitative and quantitative data, with each given equal priority. Hanson et al., identify three sub-types of concurrent design: concurrent triangulation; concurrent nested and concurrent transformative. The concurrent triangulation design is described as incorporating simultaneous collection of both qualitative and quantitative data, with equal priority given to both types of data, separate analysis of the data and with integration occurring at the interpretation stage. Using this approach, the collection of data within the survey and audit has generated both qualitative and quantitative findings, which are considered separately, and then integrated.
3.3 Study Design

The choice of an integrated, mixed methods strategy for the study was guided by the need to ensure the study questions would gain insight into how the lung cancer CNS role was viewed and understood. This could not be identified by utilising a questionnaire that relied on quantitative responses alone, as this would not elicit in-depth information from the participants. The study also required open-ended questions, allowing the participant to answer in their own words, from their own experience (Schneider et al., 2010; Polit & Beck, 2008). In this way, elements from the qualitative interpretation were used to support the quantifiable data, creating a broader understanding of the central issue, the role of and response to the LC CNS.

The study involved a two-stage approach:

1. Audit Phase: Exploration and interpretation of six months of data previously collected, identifying the impact of the CNS role on patients. This was data compared to the national standards for lung cancer care.

2. Survey Phase: the distribution of a questionnaire to all members of the MDT involved in lung cancer care. A number of staff were asked to complete the questionnaire (n=50), targeting representatives from all professions within the MDT. The purpose of the questionnaire was to explore the views and perceptions of members of the MDT in relation to the CNS role in this area. A randomised sample of participants was chosen to ensure a representative population of those who work with the CNS’s.

3.4 Phase 1: Audit

Audit is described in the literature as being primarily either clinical audit or inquiry audit (Polit & Beck, 2008). The purpose of conducting an audit is to undertake in-depth scrutiny of the current data yielded, while measuring it against a defined set of performance indicators or clinical standards (Schneider et al., 2010; Polit & Beck, 2008). An inquiry audit is typically undertaken by an external auditor, with the intention of ensuring dependability and confirmability of the data (Polit & Beck, 2008). Audit was the main quantitative approach within the study.

In pursuit of the aim of this research study, namely to gather information about the LC CNS role, it was thought prudent to include an audit of six months of clinical data relating to the patients cared for by a LC CNS. This included review of the clinical notes that are routinely collected by the LC CNS’s as part of
their role. A clinical note is generated by the LC CNS for each interaction they have with the patient, their family or with the MDT. This current data from the LC CNS audit was compared with the expected Standards of Service Provision for Lung Cancer Patients in New Zealand, as designated by the government (MOH, 2011). All the data collected and used in this phase was anonymised, to avoid any patient being identified and thereby ensuring the confidentiality of the patient and their details. The standards for lung cancer patients consist of ten clusters. These were developed to measure the investigation, diagnosis, treatment and supportive care provided to patients with a diagnosis of lung cancer. These main clusters have been divided into thirteen standards (Appendix 1). While the lung cancer CNS has input into many aspects of the thirteen standards when providing care to this patient group, they are not responsible for the overall outcome of the majority of the standards. For the purpose of this study, the CNS role was measured against standard eleven, care co-ordination, which states:

… all patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specializes in cancer care, to provide psychological support, information and co-ordination of a patient’s cancer journey

(MOH, 2011, p13-14).

Auditing this standard involved a quantitative observational, retrospective study of the data.

The data collected as part of the audit consisted of 21 questions, which included the demographics of age, gender and ethnicity. Data was collected from existing clinical records, including discharge summaries and clinical letters relating to outpatient appointments and treatment episodes. These documents were completed by a range of health professionals including Doctors, Radiotherapists and Allied Health. These clinical records referred to input from the LC CNS’s in patient care. This information is important to capture, as it illustrates the patient population cared for by the LC CNS. This in turn ensures they are able to work with and put in place the most appropriate supports and services for the patient. The remaining questions reflected elements identified within Standard 11 (MOH, 2011), these included referral times/dates, treatment times/dates and follow up times which were all audited against the expectations within the standard. The remaining questions related to determining referral to and follow up by other health professionals. This information was used to determine the frequency of clinical input from the LC CNS. The final two audit questions addressed smoking status and date of death for any patient who died while data was being captured. In addition to the (statistical) data collected, narrative texts from the clinical material were subject to content analysis, this is described further in section 3.8. The rationale behind the audit was to explore if the CNS role was meeting the Standards (MOH, 2011), and to identify the impact their role had on the patients they cared for. This form of evaluation is valuable for identifying
in-depth information across the care continuum of the CNS role (Cowman et al., 2010; Kirshbaum et al., 2004; Moore et al., 2006).

### 3.5 Phase two: the Questionnaire

The rationale for utilising a questionnaire as part of data collection was to elicit information from a variety of participants. Polit and Beck (2008) define the questionnaire method as obtaining information regarding the prevalence, distribution and interrelations of variables within a discreet set of participants. The questionnaire may contain quantitative Likert type questions and qualitative open-ended questions, with the purpose of eliciting rich meaningful data (Schneider et al., 2010).

A study undertaken by Cowman et al. (2010), evaluated the role of the CNS in cancer care in Ireland. These authors sought to gain information from the perspective of the CNS, the patient and other health professionals. The findings from this study demonstrated that the majority of the MDT viewed the CNS role in a positive way. The areas seen as the most beneficial to the patient were education, symptom management and the CNS’s ability to link all members of the MDT to the patient (Cowman et al., 2010). Permission was granted by Cowman et al. (2010) to utilise their questionnaire for surveying the MDT, if required. This survey was adapted for the New Zealand context (see appendix 5).

This study has looked at the LC CNS role in the context of the New Zealand health setting. In June 2012 the Minister of Health announced the plan to establish a further forty to fifty ANP roles within cancer care (MOH, 2012). Prior to this announcement the Minister had sought advice from nurses working in existing advanced practice roles, including the lung cancer CNS referred to in this study. This consultation was instrumental in the decision to establish future roles. It is important to review and monitor effectiveness of ANP roles, and this survey partially achieved that aim. While the Cowman et al., (2010) tool was initially developed for use with nurses working in Ireland, the CNS role as described is very similar to that present in New Zealand.

#### 3.5.1 Development of questionnaire

The questionnaire developed for use within this study was based on that created by Cowman et al. (2010), with additional modifications to make it more relevant to aspects of the New Zealand setting. The resulting tool included nine questions, which incorporated both Likert Scale ratings and open-ended questions. The first three questions on the questionnaire related to demographics, this included, gender,
age and ethnicity of participants. The following two questions related to the recipients' profession, they were asked their occupation and how many years they had been working within health. The sixth question related to Standard 11 (2011), they were asked if they felt the LC CNS’s meet the standard and to comment on their perception of this. The final two questions were open ended, they were asked to discuss the benefit they saw of the role and to provide any additional comments they felt would be pertinent to share.

3.5.2 Distribution of questionnaire

The questionnaire was sent to clinical staff within the MDT, who had interaction with the Lung Cancer CNS’s. The distribution and collection process was managed via Survey Monkey, as all participants have computer access. This provided both quantitative and qualitative data, which yielded information about the work of the CNS. The questionnaire was sent to a broad range of health professionals, with the express purpose of selecting a non-biased sample size.

3.6 Ethical approvals and Māori consultation

3.6.1 Māori Consultation

Māori consultation was sought at the beginning of this study. In regard to the lung cancer health statistics for Māori, the Research Manager for Māori advised the researchers to include input from Māori health professionals in the research process (appendix 3). This was achieved by ensuring the questionnaire was sent to Māori staff involved in caring for patients with a diagnosis of lung cancer.

This study has potential implications for the wider population, including Māori. As acknowledged during the process of Māori Consultation, consideration was also given to the possibility that some participants may identify as being of Māori ethnicity. There is additional relevance for individuals who identify as Māori from this study, given the disparities in health outcome related to this disease.

The Ministry of Health (MOH) has identified major discrepancies with regard to cancer risk between Māori and Non-Māori. The MOH commissioned a report regarding access to cancer services for Māori in 2005. This report highlighted the lack of and incomplete nature of ethnicity data relating to the occurrence of cancer for Māori. Lung cancer among Māori is identified as one of the five cancers that attributes to 55% of all cancers for Māori. The incidence of lung cancer is three times more prevalent for Māori than Non-Māori. The report discussed the need for development of an effective cancer control policy for Māori (Cormack et al., 2005). A further MOH report in 2010 identified that the case-mortality rate for Māori is higher than for non-Māori, suggesting that Māori have an increased risk of dying when a cancer is diagnosed than non-Māori (MOH, 2010). In an attempt to address these issues, as discussed earlier, The
Standards of Service Provision for Lung Cancer Patients in New Zealand was released by the New Zealand Government in 2011, with one purpose being to address ethnic disparity among Māori and Pacific people. While this research focuses on Standard 11, it is worth noting Standard five relates to data collection, with the establishment of a lung cancer database, addressing the issue of incomplete data collection for all, more specifically for Māori (MOH, 2011).

### 3.6.2 Ethics approval

Formal ethics approval was sought for this research project, from the University of Otago Ethics Committee. The committee identified the potential for concern regarding the role of the study author as direct manager of the LC CNS’s, whose role is central to the research. The author was able to reassure the committee that the LC CNS’s were aware of the proposed study and had indicated that they welcomed the opportunity for the role to be reviewed. In addition, the LC CNS’s had access to the management team within the service, with direct access to the Director of Nursing, and were advised to approach this group, should any issues arise.

The introduction for the questionnaire utilised in the study was amended as per the ethics committee’s instructions, resulting in approval to proceed (Appendix 5). The participant information sheet informed participants that all responses would be treated anonymously and in confidence (Appendix 4).

### 3.7 Sampling – for the MDT Questionnaire

For the purpose of this study the following inclusion and exclusion criteria was utilised when selecting participants to take part in the multidisciplinary questionnaire:

- **Inclusion Criteria** – must be a health professional who interacts with the Lung cancer CNS’s, as part of the patient trajectory.
- **Exclusion Criteria** – any health professional, who has only recently, (i.e. less than three months) commenced working within Oncology, Respiratory, Cardiothoracic and Palliative Care.

### Sample size

The sample size of 50 participants was chosen, the majority of the population who interacted on a regular basis with the LC CNS’s. This was determined after discussion with the Biostatistician and the thesis supervisors. The number of 50 was agreed as giving enough information to determine how the role of the
LC CNS was viewed by those who worked both clinically and clerically with them. The response rate to the questionnaire was 76% (N=38), this was well over three quarters of the total respondents.

### 3.8 Data Analysis

A mixed methodology was used to collect both quantitative and qualitative data. Quantitative data is described as being data that is measurable, quantifiable and collected in a numeric form. This form of data capture has its roots in scientific backgrounds, where the data is viewed as being collected in a controlled way that ensures accuracy and objective observation (Schneider et al., 2010; Polit & Beck, 2008). Qualitative data capture is the collection of rich, subjective experiences, perceptions, thoughts and feelings, which are interpreted to gain in-depth insight into the study subject. Qualitative data capture is utilised widely within the discipline of nursing and midwifery, as the results often inform the need for change within the study area (Schneider et al., 2010; Polit & Beck, 2008).

The quantitative data from the audit and the closed questions on the questionnaire was analysed utilizing descriptive statistics. Descriptive statistics is used to identify trends in data collection, while providing the ability to condense the data into meaningful units (Schneider et al., 2010). Advice was sought from the biostatistician regarding possible statistical analysis, however as the numbers were small it was determined that detailed statistical testing may not be meaningful with the size of the study.

Thematic analysis was used for the qualitative data, collected in the form of written responses to open-ended questions. Thematic analysis identifies patterns and regularities appearing in the data, which can aid understanding of the main concepts presenting, it may also identify inconsistencies within the data (Polit & Beck, 2008). Braun and Clarke (2006), suggest that thematic analysis should be seen as a research methodology in its own right and not be viewed merely as part of other qualitative research methods. They have developed a six phase guide to conducting thematic analysis, which is;

- **Phase 1: Familiarising yourself with your data:** this involves immersing yourself in the data to ensure complete understanding of the detail and content of the study material.
- **Phase 2: Generating initial codes:** the codes identify the content in the data that is of interest to the researcher.
- **Phase 3: Searching for themes:** this phase requires the researcher to sort the different codes into potential themes.
• Phase 4: Reviewing themes: this phase requires the researcher to refine the themes and determine how these sets of themes fit together. This is where the overall information of the thematic analysis starts to emerge.

• Phase 5: Defining and naming themes: This phase requires the researcher to define and refine the themes to extract the true meaning of each theme.

• Phase 6: Producing the report: Once the themes are identified, the researcher analyses the content and produces a report of the findings. (Braun & Clarke, 2006).

This process was followed for data analysis for this thesis.

Polit and Beck (2008) suggest that the challenges of presenting meaningful data within qualitative research are the lack of universal results when analyzing qualitative data, the sheer volume of work required in the analysis and the vast amount of data, which must be reduced to a manageable quantity for the final presentation of data for analysis (Polit & Beck, 2008).

The choice of a mixed methodology produced a broad picture of the LC CNS’s role within the regional lung cancer service, a process that had not been previously undertaken. The findings from this process are presented in the following chapter.
Chapter 4: Results

4.1 Introduction
As described in the previous chapters there were two sources from which the data has been collected, the results of which are reported here. Firstly, descriptive statistics are used to describe the results of the audit of the lung cancer CNS’s clinical notes and electronic entries, which were compared to the standards set by the National Lung Cancer Standards for New Zealand (MOH, 2011). All further reference to the National Standards within the results chapter will be abbreviated to the Standards (2011), the full copy of this document is provided within appendix 1. Secondly, the results from the questionnaire sent to all of the multidisciplinary team who work with the lung cancer CNS’s are portrayed.

4.2 Findings: Audit
This encompassed the exploration and interpretation of data that had been routinely documented by the CNS’s over the previous six months. This was explored in order to identify the impact of the CNS role on patients. Data was identified and accessed for 32 of the total number of patients seen by the LC CNS during the designated six month period. The 32 were randomly chosen from the total number of patients seen in the multidisciplinary meeting (MDM), with a potential or confirmed diagnosis of lung cancer over the six month period (n=128). Randomisation was achieved by printing a list of sequential patients who met the inclusion criteria, and selecting every fourth patient from this list.

The specific features able to be extracted from the CNS documents and compared with the standards included:

- Demographics – age, gender, ethnicity
- Admission status- In-patient, Out-patient
- Referral Date
- First Specialist appointment – with Respiratory or Oncology services
- CNS contact – whether face to face, phone/email
- Diagnosis
- Multidisciplinary Meeting
- Multidisciplinary Decision
- Treatment intent – Curative or Palliative
- Start Date for treatment
- Mortality Data
• Advance Care Planning
• Referral to another Service
• Number of other Health Care Providers involved in their care
• Illustrations of LC CNS Involvement.

The data collected are included in appendix 1. The data was analysed against Standard 11 (MOH, 2011, p 4).

4.3 Demographics
The data was screened in order to identify the demographics of this cohort of patients including age, gender, ethnicity and smoking/non-smoking status. This provides an overview of the population being studied and identifies trends within this data set, (Statistics NZ, 2013).

4.3.1 Age
The age range represented in the audit data was from 41 – 79 years. The average age was 60 years, the median was 60 years and the most frequently occurring age (mode) was 63 years (n=5). (Refer figure 1).

Figure 1 Demographics: Age
4.3.2 Gender
Of the 32 sets of data, results demonstrated a predominance of males in the cohort (n=21, 66%) with the remaining being female (n=11, 44%). (Refer figure 2)

![Gender Distribution of Patients (percentage)](image)

*Figure 2 Demographics: Gender*

4.3.3 Ethnicity
Data relating to the ethnic distribution of health care populations is routinely collected within New Zealand District Health Boards. Ethnicity identification is based on the census data collection tool (Statistics New Zealand, 2013). The results of the data from this sample showed that a majority identified themselves as New Zealand European (n=22, 69%), followed by ‘other’ (n=5, 16%) and 6% identified as New Zealand Māori (n=2). (Refer figure 3).
4.4 Clinical data

The following tables refer to the clinical data of the study group (N=32)

4.4.1 Smoking History

The population data was analysed to determine smoking status at time of admission to the service. The data showed that the majority had a smoking history, 44% (n=14) of the patients were current smokers, 34% (n=11) were ex-smokers and 21% (n=7) had never smoked. The 2013 Census showed that the number of smokers in New Zealand has decreased by nearly a quarter since the 2006 Census, showing that 15% of the adult population were smoking, a reduction from 20.7% in 2006 (Statistics New Zealand, 2013). (Refer Figure 4).

Figure 3 Demographics: Ethnicity

Ethnicity Distribution (percentage)

- Other: 16%
- Chinese: 3%
- NZ European: 69%
- NZ Maori: 6%
- Russian: 3%
- Samoan: 3%

Figure 4 shows the decrease in smoking rates from 20.7% in 2006 to 15% in 2013.
4.4.2 Admitted as an In-Patient or Outpatient

The population was assessed to determine how many patients were admitted as in-patients in contrast to being outpatients. The patients admitted to the service as in-patients, were often in hospital as a result of an acute illness, with lung cancer diagnosed as an incidental finding during diagnostics. The patients admitted as outpatients were referred by their General Practitioner (GP) to specialist services to determine the cause of their ongoing symptoms, for example, long standing cough. The sample population showed that 25% (n=8) were admitted to the lung cancer services whilst they were in hospital as in-patients and 27% (n=24) were outpatients when admitted. (Refer figure 5).
4.4.3 Access to Cancer Services

The population data was analysed to determine key time points in the patient journey. These included time from referral to First Specialist Appointment (FSA), time from FSA to CNS contact and time from referral to treatment. A summary of this information can be found in Table 1.

Table 1 Access to cancer service

<table>
<thead>
<tr>
<th>Time from referral to FSA – (within 14 calendar days of secondary care receiving the referral)</th>
<th>Mean (days)</th>
<th>Range (days)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8.69</td>
<td>0 - 61</td>
</tr>
<tr>
<td>Time from FSA to CNS contact – (within seven calendar of the initial assessment with a specialist)</td>
<td>0.5</td>
<td>0 - 44</td>
</tr>
<tr>
<td>Time from referral to treatment if indicated – (within 62 calendar days of secondary care receiving a referral)</td>
<td>43.92</td>
<td>4 - 90</td>
</tr>
</tbody>
</table>
4.4.4 Referral to other Services

The data was analysed to determine how many patients were referred to other services by the LC CNS. The sample population identified that 75% (n=24) were referred to other services, leaving 25% (n=8) who were not referred elsewhere. Of the patients referred, six were referred to one other service, four to two and 13 to three other services. The services the patients were referred to included palliative care, Cancer Society, social worker and dietician. (Refer to figures 6 & 7).

![Referral to Other Services](image)

*Figure 6 Referral to other services (pie chart)*
4.4.5 Number of other health professionals involved in the care of patients with lung cancer

The population data was analysed to determine the number of other health professionals involved in the care of this patient population. One patient had 14 other health professionals involved in their care, while three had no contact with other professionals (refer to figure 8).

Figure 7 Referral to other services (bar graph)
4.4.6 Diagnosis and Treatment Intent

The population was assessed to determine the most commonly identified lung cancer diagnosis and whether treatment was intended to be curative or palliative. The most prevalent cancer diagnosis was Adenocarcinoma with 31% (n=10), the least prevalent was Large Cell Neuroendocrine at 3% (n=1). A summary of this diagnostic information can be found in Table 2. The intent to treat\(^1\) data showed 69% (n=22) of the study population was identified as appropriate for palliative care and for 31% (n=10) the intent was for curative treatment (refer to Figure 9).

---

\(^1\) Intent to treat refers to the decision whether curative intent is appropriate, which is based on the likelihood of treatment achieving a cure and the fitness of the patient (National Collaborating Centre for Cancer (2011)).
Table 2. Lung cancer diagnosis

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adenocarcinoma</td>
<td>10 (31)</td>
</tr>
<tr>
<td>Metastatic Adenocarcinoma</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Mesothelioma</td>
<td>6 (19)</td>
</tr>
<tr>
<td>Small Cell Carcinoma</td>
<td>3 (9)</td>
</tr>
<tr>
<td>Metastatic Small Cell Carcinoma</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Non-Small Cell Carcinoma</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Squamous Cell Carcinoma</td>
<td>6 (19)</td>
</tr>
<tr>
<td>Large Cell Neuroendocrine Carcinoma</td>
<td>1 (3)</td>
</tr>
</tbody>
</table>
**4.4.7 Mortality Data**

Figure 10 demonstrates how many of the patients cared for by the LC CNS were alive or deceased at the conclusion of data analysis. The data reflected that 62% (n=20) of the patients were alive at the conclusion of data collection, while 38% (n=12) were deceased. (Refer to table 10).
4.5 Role of the LC CNS

4.5.1 Contact with Clinical Nurse Specialist

The data was analysed to determine how many contacts occurred between the LC CNS and the patient. For telephone/email contact, the range was between zero and 18. The most frequently occurring number of telephone/email contacts was four, with a median of seven. The range for face-to-face contact was between two and 17. The most frequently occurring number of face-to-face contacts was ten, with a median of nine. This is reflected in Figure 11.
4.5.2 Illustration of LC CNS Involvement

As the LC CNS clinical notes were reviewed, data was collected and analysed regarding care co-ordination as per the Standards (MOH, 2011). The content analysis of this data was guided by the three main requirements of this standard, namely psychosocial support, information and co-ordination. As demonstrated in Figure 12, the most frequent contact was to provide psychosocial support, at 47.5% (152 interactions), followed by provision of information, 26.5% (85 interactions) and co-ordination at 26% (84 interactions).
4.5.3 National Lung Cancer Standards

The population data specific to the Regional Lung Cancer Service was compared to the Standards (MOH, 2011). Information is summarised in Table 3. The data identified that in 84% of cases, the first contact with the LC CNS was achieved within the seven day target specified. There was 100% compliance in meeting the MDM Standard and 81% of those patients who were suitable and who agreed to treatment received treatment within 62 days. (Refer to table 3).
Table 3  Meeting national lung cancer standards

<table>
<thead>
<tr>
<th>Variable</th>
<th>National Standard</th>
<th>N (%) Yes</th>
<th>N (%) No</th>
<th>Declined treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>First CNS Contact</td>
<td>Contact within 7 days of FSA</td>
<td>27 (84)</td>
<td>5 (16)</td>
<td>-</td>
</tr>
<tr>
<td>Multidisciplinary Care</td>
<td>Discussed at a multidisciplinary meeting</td>
<td>32 (100)</td>
<td>0 (0)</td>
<td>-</td>
</tr>
<tr>
<td>Commence Treatment</td>
<td>Treatment within 62 days of referral</td>
<td>22 (68)</td>
<td>5 (16)</td>
<td>5 (16)</td>
</tr>
</tbody>
</table>

4.5.4 Advance Care Planning\(^2\) (ACP)

The data was analysed to determine if the LC CNS had discussed advance care planning with the patient. The data showed that 88% (n=28) of the patients had discussed ACP with the LC CNS, there was no evidence of the ACP being discussed with the remaining 12% (n=4) of patients. (Refer to figure 13).

\(^2\) Advance Care Planning (ACP) is a process that enables an individual to think about, discuss and document their wishes about the type of care and medical treatment they would like to receive in the future (Advance Care Planning Cooperative, 2011).
4.5.5 Standard 11: Good Practice Points

The LC CNS’s clinical notes were reviewed, data was collected to provide evidence of the LC CNS’s meeting the “Good Practice Points” of Standard 11 (MOH, 2011).

The points for consideration are:

**Presence of a Lung Cancer CNS (7.1)**

This point is clearly fulfilled, refer to *Figure 11*, Contact with LC CNS. There is evidence of a commitment by the regional lung cancer service to provide dedicated LC CNS positions; currently there are 1.5 FTE within this position.

**Keeping Patients Informed (7.2)**

There is evidence of the LC CNS’s meeting this standard within their role, refer to *Figure 12*, LC CNS involvement in patient care. The review of the LC CNS notes, involved the researcher compiling evidential notes highlighting the key components presented. Examples of comments made include:
“Evidence that the CNS’s had multiple conversations with the patient and family explaining treatments and giving advice regarding symptom management”

“Evidence of the LC CNS giving ongoing advice and instruction regarding medication management, e.g. prevention of constipation, pain relief and management of nausea”

“Evidence of advice on symptom management being given by the LC CNS, e.g. use of antiemetic’s and pain relief, including xylocaine for painful swallowing post radiotherapy”.

**Psychosocial Needs (7.3)**

There is evidence of the LC CNS’s meeting this standard within their role, refer to *Figure 12*, LC CNS involvement in patient care. This aspect of care was the most strongly represented. In identifying assessment and response to psychosocial needs, the following examples were identified:

Evidence of the LC CNS support of patients prior to First Specialist appointment. “*The patient thought she would be told she only had two weeks to live, LC CNS reassured her that that would not be the case*”.

Evidence that the LC CNS was in attendance when the diagnosis of recurrent Small cell lung cancer was given to the patient and his wife. “*The family were extremely upset with this devastating news and the Radiation Oncologist asked the LC CNS to spend time with the family when they came in to pick up their father*”.

Evidence the LC CNS provided advice and support to the patient, his wife and his children in the UK. “*Email was used by the UK family, which proved effective. The patient gave his permission for the LC CNS to discuss his lung cancer diagnosis with family. The patient’s wife found this period extremely lonely, as she had limited support in New Zealand, which made the constant contact by the LC CNS’s all the more important*”.

**Culturally Appropriate Interactions (7.4)**

There is evidence of the LC CNS’s meeting this standard within their role. The data identified the following examples
The patient had very limited English, Cantonese first choice, Mandarin second choice, his children spoke fluent English. “Evidence that the LC CNS arranged for an interpreter for any clinic appointments his children could not attend”.

Another example of caring for a patient where English is a second language was described for a Samoan patient. The son acted as an interpreter for his father or if the son was unable to attend outpatient appointments, an interpreter was present. “Evidence that the LC CNS worked with the patient’s wife and son to arrange diagnostic appointments due to the language barrier”.

**Advance Care Directives (7.5)**

The New Zealand Medical Association is guided by the Code of Health and Disability, to define advance care directives. An advance directive may be a written or an oral directive which covers the following points:

a) By which a consumer makes a choice about a possible future health care procedure, and

b) That is intended to be effective only when he or she is not competent”.

The clinical audit identified that the LC CNS’s were meeting this standard within their role, refer to Figure 13, Advance Care Planning. The data identified the following examples:

*Evidence that the patient discussed (with the LC CNS) what she was likely to die from, discussion regarding advance care directives commenced at this point.*

*Evidence of the LC CNS helping the patient with organizing appropriate policy papers to claim on end of life insurance policy.*

*Evidence that at Medical Oncology appointment the decision was made not to have any further treatment. The LC CNS had conversations with the children regarding how the disease would progress and how their father was likely to die. Advance care directives discussed at this point with the patient and family.*

**4.6 Survey**

The questionnaire was distributed to 50 members of the MDT involved in lung cancer care with a response rate of 76% (n=38). A reminder was sent at the two week mark and a further two replies were received, bringing the overall response rate to 76%. The survey questions were designed to explore the views and perceptions of the members of the MDT in relation to the CNS role within lung cancer care.

A number of questions related to demographics were included, to allow a profile of respondents to be developed. These included gender, age, ethnicity and occupation.
4.6.1 Gender
Of the 38 responses to the survey, 63.2% were female (n=24), 36.8% male (n=14). (Refer to figure 14).

![Gender Distribution of Survey Respondants (percentage)](image)

*Figure 14 Survey: Gender of participants*

4.6.2 Age of Health Professionals who participated in the survey
Participants were asked to indicate which age band they identified with, presented in five year increments. The age of those who responded to the survey ranged from 25 – 60+ years. The majority of those who completed the survey were aged 50 – 59 years, 36.8% (n=14), with the lowest representation in the 25 – 29 year category, 2.6% (n=1). (Refer to figure 15).
4.6.3 Ethnicity of Survey Participants

The survey participants were asked to identify their ethnicity. Of the 38 participants who completed the survey, 32 answered this question. The majority of the participants identified as New Zealand European, 31 (97%), with one (3%) participant identifying as of Maori ethnicity.

4.6.4 Role of Health Professional

The survey asked the respondents to identify their role within the health system. The largest group of participants were medical staff, 47.4% (n=18).

Of the health professionals who completed the survey 20 (40%) were male and 30 (60%) were female. Of note the medical staff were predominately male, while all nursing staff were female. Table four shows the response rate to the survey invitations, by occupation.
Table 4  *Survey response rate by occupation*

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Number of invitations sent N (%)</th>
<th>Number of responses received N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical Staff</td>
<td>24 (48%)</td>
<td>18 (47.5%)</td>
</tr>
<tr>
<td>Nursing Staff</td>
<td>16 (32%)</td>
<td>13 (34.5%)</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Psychologist</td>
<td>1 (2%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Maori Health Worker</td>
<td>2 (4%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2 (4%)</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>1 (2%)</td>
<td>0</td>
</tr>
<tr>
<td>Radiation Therapist</td>
<td>1 (2%)</td>
<td>0</td>
</tr>
<tr>
<td>Other (Administration</td>
<td>2 (4%)</td>
<td>2 (5%)</td>
</tr>
<tr>
<td>staff)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 16 displays the occupation of the respondents, number of invitations sent and received.
4.6.5 Number of Years working in Cancer Care

Respondents were asked to identify the number of years they had worked in the specialty service, within five year time bands. For the survey, the time bands ranged from less than five to greater than 20 years. The majority of the respondents had spent 5 – 15 years (n=27, 71%), with the lowest representation in the 16 – 20 year category (n=4, 10.4%) (Refer to Table 5)

Table 5. Number of years worked in cancer care

<table>
<thead>
<tr>
<th>Years</th>
<th>%</th>
<th>(n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;5 years</td>
<td>23.7%</td>
<td>(n=9)</td>
</tr>
<tr>
<td>6 – 10 years</td>
<td>23.7%</td>
<td>(n=9)</td>
</tr>
<tr>
<td>11-15 years</td>
<td>23.7%</td>
<td>(n=9)</td>
</tr>
<tr>
<td>16 – 20 years</td>
<td>10.5%</td>
<td>(n=4)</td>
</tr>
<tr>
<td>&gt;20 years</td>
<td>18.4%</td>
<td>(n=7)</td>
</tr>
</tbody>
</table>

Figure 17 identifies the number of years the health professionals have spent working within the cancer care setting.
The health professionals who took part in the survey were asked to consider aspects of the LC CNS role. The final four questions contained both Likert-type questions and free text sections.

Participants were asked to consider Standard 11 (2011) and to rate their responses to the following question:

*All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialises in cancer care, to provide psychosocial support, information and coordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with the specialist (MOH, 2011, p. 4).*

As displayed in Figure 18, of the respondents who completed the survey, 93% (n=36) felt the LC CNS’s were meeting standard 11, with 2.7% (n=1) stating they were not, and one participant did not answer this particular question. However, the one negative response did not appear to be congruent with that participant’s other answers.
In addition, a number of individual statements relating to specific aspects of the role were presented. Respondents were asked to use a five point Likert-type scale to rate their level of agreement with each of these. These are described in the text below and summarized in Figure 19.

a) Do the LC CNS’s play an integral role in co-ordination of patient care?

- 37 of the 38 participants responded to this question
- The majority of respondents agreed or strongly agreed with the statement (n=36; 95%)
- One indicated disagreement
- One omitted to answer the question.

b) Do the LC CNS’s keep the patient informed about diagnosis and treatment?

- 38 people responded to this question
- The majority of respondents agreed or strongly agreed with the statement (n=35; 92%)
- One indicated disagreement
- Two held no strong opinion.

c) The patients’ needs in terms of supportive care and psychological needs are assessed on an ongoing basis by the LC CNS?
d) Are patients treated in a culturally sensitive manner?

- 38 people responded to this question
- The majority of respondents agreed or strongly agreed with the statement (n=33; 86%)
- One indicated disagreement
- Four held no strong opinion.

e) Consideration of advance care planning is encouraged by the LC CNS?

- 37 people responded to the question
- The majority of respondents agreed or strongly agreed with the statement (n=27; 71%)
- One indicated disagreement
- Nine held no strong opinion
- One omitted to answer the question.

f) There is value in the LC CNS attending clinical appointments with lung cancer patients?

- 38 people responded to the question
- The majority of respondents agreed or strongly agreed with the statement (n=34; 89%)
- One disagreed
- Three held no strong opinion.

g) All patients with a diagnosis of lung cancer have equal access to the LC CNS service?

- 38 people responded to the question
- The majority of respondents agreed or strongly agreed to the statement (n= 29; 76%)
- Four disagreed
- Five held no strong opinion.

Figure 19 and Table six describe the health care professional’s beliefs regarding the LC CNS role.
Figure 19  Health care professionals beliefs regarding the LC CNS service

Table 6  Health professionals’ beliefs regarding the role of the LC CNS

<table>
<thead>
<tr>
<th>Belief</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree or Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
<th>Rating Average</th>
<th>Response Count</th>
<th>% Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>CNS’s play an integral role in coordination of patient care</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>8</td>
<td>28</td>
<td>3.08</td>
<td>38</td>
<td>91.45%</td>
</tr>
<tr>
<td>Patients are kept well informed about diagnosis and treatment</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>14</td>
<td>21</td>
<td>4.00</td>
<td>38</td>
<td>85.53%</td>
</tr>
<tr>
<td>Patients’ needs are assessed on an on-going basis by the CNS</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>12</td>
<td>21</td>
<td>3.77</td>
<td>38</td>
<td>84.87%</td>
</tr>
<tr>
<td>Patients are treated in a culturally sensitive manner</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>16</td>
<td>17</td>
<td>4.18</td>
<td>38</td>
<td>82.24%</td>
</tr>
<tr>
<td>Advance care planning is encouraged by the CNS</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>16</td>
<td>17</td>
<td>4.11</td>
<td>37</td>
<td>75.00%</td>
</tr>
<tr>
<td>There is value in the CNS’s attending clinic appointments</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>7</td>
<td>27</td>
<td>3.80</td>
<td>38</td>
<td>89.47%</td>
</tr>
<tr>
<td>There is equal access to the LC CNS service</td>
<td>0</td>
<td>4</td>
<td>5</td>
<td>15</td>
<td>14</td>
<td>4.09</td>
<td>38</td>
<td>75.66%</td>
</tr>
</tbody>
</table>
4.7 Participant narrative response

As stated earlier, the respondents were also given the opportunity to provide a narrative comment, using a free text box. The data was reviewed and analysed to identify if the responses provided evidence that the LC CNS’s were meeting Standard 11 (MOH, 2011).

From the data analysis the following four broad themes, related to the standard, were identified as being consistent across each of the four questions:

1. Service Perspective – this theme related to the participants perception of how the LC CNS role influenced the cancer treatment pathway for the patient with a diagnosis of lung cancer.

2. Being present for the patient – this theme included reference to both physical and emotional ‘presence’ and identified that the LC CNS was perceived as ‘being there’ in terms of availability to provide information, coordinate care and to maintain contact with the patient.

3. Interaction with the patient – this theme identifies the participants’ perceptions of how well the LC CNS related to the patient.

4. Interaction with the family – this theme related to how well the LC CNS related to and supported the family of the patient with a lung cancer diagnosis.

4.7.1 Perception of whether the LC CNS met standard 11. Question six related to a statement from Standard 11 (MOH, 2011, p. 4)

All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialises in cancer care, to provide psychological support, information and coordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with a specialist.
The participants were asked to comment on how they saw this being met or why they thought it was not being met. This question resulted in 19 (50%) comments from the 38 respondents. The main theme to emerge showed that from a service perspective, the respondents felt the LC CNS’s provided very clear evidence that they were the key contact person for the patient. There was evidence that the respondents felt the LC CNS’s provided very prompt and consistent care for the patients, ensuring all care was coordinated with the teams involved in their care.

Responses to this question strongly emphasized the element of service perspective, as can be seen in the following quotes: …

“Providing a skilled person to help the patient through their interaction with multiple medical specialists who have intense periods of care followed by referral top another specialty”.

“From a community point of view we receive a thorough handover and have a clear point of contact, which is invaluable. The knowledge of the patient’s social, emotional and treatment needs is well communicated to the community team”.

In addition to this, emphasis was given to ‘being present’ and interaction with the patient, as seen in the following quotes: …

“Providing that initial care and psychological support particularly in the early stages just after diagnosis, where the patient and their family are particularly vulnerable”.

“The single point of contact to navigate a patient’s way through a complex system”.

“Yes they provide very prompt contact with the patient providing support to the patient and family, while also providing relevant information and expectations in their care”.

While less emphasis was given to describing or acknowledging interaction with family, there were a number of statements which identified this element of practice, for example:
“Lung cancer CNS’s bring the greatest benefit to Maori patients by being positive, showing aroha not just to the patient but to their Whānau”.

“I have observed patients and their families making contact with them to ask questions or raise concerns prior to post clinical appointments or following treatment”.

Table 7 shows the number of themes identified within the data for question six.

Table 7 Does the CNS role meet Standard 11?

<table>
<thead>
<tr>
<th>Themes</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service perspective</td>
<td>30</td>
</tr>
<tr>
<td>Being present for the patient</td>
<td>13</td>
</tr>
<tr>
<td>Interaction with the patient</td>
<td>12</td>
</tr>
<tr>
<td>Interaction with the family</td>
<td>4</td>
</tr>
</tbody>
</table>

4.7.2 Perception of the LC CNS role in improving outcomes

This question resulted in 11 (29%) comments. The respondents were asked to add any further comments regarding their responses to question seven (rated statements) relating to how the LC CNS role improved the outcomes for patients with lung cancer. This question showed the respondents felt the LC CNS’s did improve outcomes from a service perspective, but identified some constraints within the service due to resource. This will be explored further in the discussion section of this thesis.

“Whilst most lung cancer patients are identified by the lung cancer nurses, there are a few that slip through – for example in General Medicine or at Princess Margaret Hospital, particularly if the patient is not referred for chemo or radiotherapy”.

Table 8 identifies the themes from the data relating to the perception of the participants of if the LC CNS role improves the outcomes for the patient with lung cancer.
Table 8 Does the LC CNS role improve the outcomes for patients with lung cancer?

<table>
<thead>
<tr>
<th>Themes</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service perspective</td>
<td>11</td>
</tr>
<tr>
<td>Being present for the patient</td>
<td>2</td>
</tr>
<tr>
<td>Interaction with the patient</td>
<td>2</td>
</tr>
<tr>
<td>Interaction with the family</td>
<td>0</td>
</tr>
</tbody>
</table>

4.7.3 Perceptions regarding the greatest benefit that LC CNSs brought to patient care

Question eight asked respondents what was the greatest benefit the LC CNS’s brought to patient care. Of the 38 participants, 33 (87%) provided comments. The comments all offered positive assessment of the role, with examples including:

“Providing that initial care and psychological support particularly in the early stages just after diagnosis, where the patient and their family are particularly vulnerable. They are able to answer any questions that they may not have had answered or were not able to ask due to the news they had received. The one on one contact I feel is particularly important”.

“To ensure that patients have a smooth patient journey from initial appointment, testing, discussion and treatment in a supportive and timely manner. To help and support patients through a very difficult time in their lives”.

The main theme to emerge from the data was the feeling that the LC CNS’s provide a high level of psychological support and continuity of care for the patient, as demonstrated in table 9. The LC CNS’s also work with all other staff involved in the care of the patient to ensure best outcomes are achieved.

Table 9 The greatest benefit the CNSs bring to patient care

<table>
<thead>
<tr>
<th>Themes</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Service perspective</td>
<td>16</td>
</tr>
<tr>
<td>Being present for the patient</td>
<td>20</td>
</tr>
<tr>
<td>Interaction with the patient</td>
<td>8</td>
</tr>
<tr>
<td>Interaction with the family</td>
<td>5</td>
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</tbody>
</table>
4.7.4 Additional comments relating to the LC CNS role

In question 9 participants were also invited to provide any additional comments regarding the role of the LC CNS’s. A total of 13 responses were received (34%) from the participants. The comments provided were again supportive of the role and the effect it had on the lung cancer patients. The following comment is indicative of these responses:

“The role likely reduces stress for the patient and their family by there being a clear communication and information pathway. Provides an available and easily identified contact person to promptly answer queries/concerns and someone who can facilitate timely assessment and treatment. Someone who can co-ordinate/communicate with all key healthcare providers involved so resources are available but not doubled up”.

The main theme to emerge from the data related to question nine was that the LC CNS’s provided a highly coordinated service for the patient, as evidenced in Table 10. There was concern that the role was stressful and that the LC CNS’s should be provided with appropriate support to minimize burnout and stress.

Table 10  Additional comments

<table>
<thead>
<tr>
<th>Themes</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Service perspective</td>
<td>17</td>
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<td>Being present</td>
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<td>Interaction with patient</td>
<td>7</td>
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<td>Interaction with family</td>
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4.5 Summary

The results from the audit and the questionnaire utilised in this study demonstrated agreement between how both the patients and the health professionals viewed the role of the LC CNS. Both groups identified that the role met the ‘good practice’ points of Standard 11, care co-ordination (MOH, 2011), which are, psychosocial support, information provision and co-ordination of the patients cancer trajectory. The data gathered suggests that the role of the LC CNS was perceived as providing care in a timely and culturally appropriate manner.

Review of the evidential notes from the LC CNS’s identified examples of the provision of in-depth, ongoing education of the patient regarding their diagnosis and treatment. This was also evident in relation to the families involved. The overarching information identified from the notes was evidence of the time and reassurance given by the LC CNS’s to ensure the patient understood what was happening for them throughout their treatment pathway.

The survey which was sent to 50 health care professionals resulted in a response rate of 80%, and overall was highly supportive of the role, which was demonstrated with 93% of the respondents indicating that they felt the LC CNS’s fulfilled the key priority of meeting standard 11 (MOH, 2011). This was reflected in their comments, including recognition of how the LC CNS’s were “there for” the patient in the midst of an overwhelming and confusing time, with diagnosis and treatment.

One of the greatest benefits the health care professionals recognised in the LC CNS role was the provision of continuity of care, with the ability to co-ordinate care for a streamlined cancer pathway. The ability to have one point of contact with a known health care provider was also identified as a positive for the LC CNS role.

The impact on the LC CNS’s was also acknowledged, with the health care providers identifying the need to ensure the nurses were provided with support for a very busy and stressful role. They recognised the potential for burnout within this most challenging role.

The data from both the audit and survey provided evidence that these specialist nurses are providing a valuable and necessary service to a vulnerable high needs population. This role is relatively new to the regional service within this study. It has been timely to investigate how this role is functioning and how
it is perceived. The following chapter will discuss the findings in detail, identify limitations of the study and provide suggestions for future role development.
Chapter 5: Discussion

5.1 – Introduction

This research has explored the impact of an advanced nursing role within a specialty area, that of the LC CNS. The role within the regional service where the research was conducted is a relatively new one and evaluation of the role, as of January, 2014, had not been undertaken following its establishment in 2009.

The founding documents that influenced this study were the Standards of Service Provision for Lung Cancer Patients in New Zealand (2011) and a study undertaken in Ireland which evaluated the role of the CNS in cancer care (MOH, 2011; Cowman et al., 2010).

The literature review, identified the proliferation of ANP roles within New Zealand and internationally, citing the need to evaluate these to ensure they were effective in what they set out to achieve (Bryant-Lukosius et al., 2004; Polland et al., 2008). Further to this, the literature identified ongoing confusion around role title and scope of practice, and what this actually means in the practice context (Holloway et al., 2009; Lloyd Jones, 2005). Lowe, Plummer, O’Brien & Boyd (2011) expanded on this debate by suggesting that lack of role clarity affects others perception of the actual contribution to ANP each role offers. The need for establishment of ANP roles has been influenced by the socio-political sphere of healthcare, including the aging population, burgeoning numbers of patients with chronic diseases and physician shortage (Bryant-Lukosius, et al., 2010; De Geest et al., 2008; Holloway et al., 2009; Ketefian et al., 2001).

When a service undertakes the establishment of an ANP role, there is a need to ensure they understand the population for which the service is being developed and how this will impact on health care provision (Schober & Affara, 2007). Within New Zealand, the service must also underpin development of the ANP role by taking into consideration the NZNO definition which states that such a role is “...distinguished by autonomy to practice at the edges of the expanding boundaries of nursing. It is firmly grounded in the unique body of knowledge that is nursing” (NZNO, 2011). The literature review clearly identified the difference ANP roles make to the populations they care for. This is articulated by Lewandowski et al. (2009) who suggest the development of the ANP role has been one of the most influential changes within the nursing profession within recent times.
The emergence of the ANP role within lung cancer care can be linked back to the mid 1990’s. Such roles were initially established with the intent of providing support, education and symptom management (Leary et al., 2008; McPhelim et al., 2009; Moore et al., 2006). The audit data captured for analysis within this study looked at these three aspects in relation to the LC CNS role, but also included psychosocial support, co-ordination of care, culturally appropriate interactions and discussion regarding advance care directives.

The survey undertaken within this study identified four broad themes, which related to the Standards (2011). These were:

- service provision
- being present for the patient
- interaction with the patient
- Interaction with the family.

This chapter will look in detail at the findings, considering the implications and significance associated with them, in addition discussion identifying the strengths and limitations of the research is presented, together with suggestions for future research. The final aspect of this study will be to develop recommendations for future planning related to the further development of the LC CNS role.

5.2 – Specific aspects of the audit

The audit for this study consisted of exploration and interpretation of six months worth of data, which had been documented by the LC CNS’s. The data from 32 patients was audited against Standard 11; this included the LC CNS clinical notes and electronic entries. The specific features that were compared with the standard are discussed in this chapter.

5.2.1 – Patient Demographics

The data from this cohort of patients was screened to identify age, gender, ethnicity and smoking/non-smoking status. The intention was to determine whether this group of patients was reflective of the wider population of patients with diagnoses of Lung Cancer, seen within the specialty service. There are a number of implications associated with the demographic data, and the relevance of these to the LC CNS and the New Zealand healthcare setting is considered.
Age

The median age of the patients diagnosed with lung cancer was 60 years, with the range from 41 – 79 years. This is in line with the generic data relating to cancer, for example the majority of cancers are diagnosed in people over the age of 55, with a third of all cancers being diagnosed in those over 75 years of age (American Cancer Society, 2014; MOH, 2014).

The reality of caring for patients within this age range, where 47% of individuals are between the ages of 40-60, is that many will be younger or of similar age to the CNS’s caring for them. This is based on the average age of a nurse working in New Zealand being 46.4 years, and which increases for nurses working within specialty areas to 53 years (MOH, 2014). Working with a patient group who have serious, life-threatening conditions is inevitably emotionally challenging, and this is further exacerbated when other points of mutual identity, such as age, are present. To manage the highly stressful situations within their role, nurses often need to employ strategies to function effectively. The literature identifies the concept of emotional intelligence, suggesting that nurses utilise a specific set of skills to care for their patients and when working with the MDT. This form of intelligence is also referred to as social intelligence, which enables the nurse to develop effective therapeutic relationships (Codier, Muneno, & Freitas, 2011, McQueen, 2004). Codier et al. (2011) suggest that it is crucial for the nurse to be able to utilise emotional intelligence in order for effective patient care, team functioning, organizational effectiveness and self-care for the nurse (Codier et al., 2011). While it is important for the nurse to employ emotional intelligence within their working environment, prolonged or intense therapeutic relationships can cause burnout for the health practitioner (McQueen, 2004).

It is acknowledged that while the role of caring for patients with a diagnosis of lung cancer can be rewarding, it can also be extremely demanding and stressful; in particular the high mortality rate for this type of cancer makes the role extremely challenging (Moore et al., 2006). Research relating to a nurse led follow-up role for patients with a lung cancer diagnosis, identified four key themes. These included: training for the role; becoming credible within the role; the emotional burden of the role; and the perception of making a difference for their patients. These authors recommended specific training and ongoing support for nurses working in the LC CNS role. They also posit that there needs to be additional

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3 Emotional intelligence has been defined as the ability to correctly identify emotions in self and others, to use emotions to facilitate resonating, to understand emotions and the ability to manage emotions (Codier, Muneno, & Freitas, 2011).
in-depth research conducted regarding the role and the impact of the lung cancer role on the CNS (Moore et al., 2006).

**Gender**

The data identified males as having predominance within the study cohort (66%) with females representing 44%. While more males than females were present in the study, which remains representative of the wider picture, the statistics for lung cancer show that nationally the incidence for men has fallen. In 2011, 1046 men in New Zealand were diagnosed with lung cancer compared to 1002 in 2013; at the same time the number of women has increased, from 970 in 2011 to 982 in 2013 (MOH, 2014). This indicates a 52:48% ratio between males and females in 2011, and a 51:49% ratio for 2013. From this, it appears that there is a higher than national average percentage of males represented in the Christchurch cohort, however, it needs to be remembered that in addition to the small sample size the national figures are for new diagnoses, while some of those in the study cohort were already diagnosed with lung cancer.

**Ethnicity**

The population within this study identified predominantly as being of New Zealand European ethnicity (69%), 6% identified as New Zealand Māori with 16% identifying as ‘other’. The 2013 Census identified the Māori population within the study region as being 8.5%; this is lower than the national average of 14.9% (Statistics NZ, 2013). While the numbers of Māori patients are low within this study, this may be accounted for in part by the small number of patients within the cohort. Given that the national incidence for lung cancer for Māori people is three times higher than for non-Māori (MOH, 2003), the sample does not appear representative of the population for the region. The New Zealand European population accounts for 83.9% of the population in the region within this study (Statistics New Zealand, 2013). The sample size within this study may account for this disparity in representation.

In 2003 the MOH produced the New Zealand Cancer Control Strategy, with the dual purpose of reducing the incidence and impact of cancer. They also sought to reduce inequalities with respect to cancer. The project identified how cancer had a disproportionate impact on Māori (MOH, 2003). This project informed the development of the 2005 MOH report *Access to cancer services for Māori*. The purpose of this project was to ensure equitable and timely access to cancer services for Māori, which fits with the Crown’s obligations under the Treaty of Waitangi. The findings of this MOH project identified the need to utilise a clear Māori focus, rather than a population focus to ensure engagement at service level. The need to
work with Māori in partnership when developing health services was identified as crucial in the success of any initiatives. The project identified the need to ensure those involved in the workforce had adequate training to enable them to deliver health care in a culturally sensitive manner. Where the workforce could, it was suggested they employ Māori health care providers, ensuring they were fully supported with professional development and training opportunities. The report also identified that once a person has entered the health care system, there is a need for ongoing support throughout the cancer care continuum (Cormack et al., 2005). The CNS’s within this study work closely with the Māori Health Workers within the team to ensure they meet this commitment.

There are also challenges within the lung cancer service for patients identifying with other ethnic groups, particularly where English is a second language. An example of this is the Asian population, which contributes 9.4% of the total population within the study area. The number of people who identified as being of Asian ethnicity within the study was 3% (n=1). This is not representative of the population data, but again is likely accounted for by the study size. There is a need to ensure culturally sensitive management is incorporated with all care, including adequate translation services when required.

**Smoking/ Non-Smoking status**

Questions relating to smoking status are of particular relevance with regard to a diagnoses of lung cancer. This represents a well-known risk factor, although the disease can also present in life long non-smokers. There is a higher incidence of females who have never smoked developing lung cancer than males. Lung cancer is identified as one of the most preventable cancers, due to the fact that 85% to 90% of the deaths attributed to lung cancer are as a result of a smoking history (Gazdar & Thun, 2007; Wakelee et al., 2007). The data from the study population showed that the majority had a smoking history, of which 34% were current smokers and 44% were ex-smokers, 21% had never smoked. The census data reported a 20.7% reduction in smoking from 2006 to 2013 (Statistics NZ, 2013). Action on Smoking and Health (ASH), is a registered charity with the mission to eliminate death and disease caused by tobacco. They have conducted an annual survey of year 10 pupils to ascertain trends in smoking and tobacco use among school children aged 14 – 15 years since 1999. In 2013 27,921 students took part in the study. The data showed a significant drop in the numbers of students smoking, compared to previous years. Figures from 1999 identified that 28.6% of students surveyed identified as smokers, with 42.8% of Māori identifying as regular smokers. The figures have significantly decreased in 2013, with 6.8% of all students identifying as smokers and 14.7% of Māori (ASH, 2013). While the decrease in smoking is positive, the significance of the disparity between Māori and Non-Māori smokers needs to be acknowledged, with Māori smoking
statistics nationally double the European population. The overall statistic for smoking within New Zealand is 13.7% of total population, the region within this study has a smoking population of 13.3%, slightly below the national average. This 13.3% is based on the overall population of 52,212 people, 7,395 of whom identify as Māori, with 29.9% of this population reported as smokers (Casswell, Wall, Lin & Adams, 2014).

A study by Li to identify the uptake of Quitline by Asian people living in New Zealand identified that they had the lowest smoking rate of all the main ethnic groups in New Zealand, with prevalence at 11%. However, Li suggests that this rate will grow significantly with the predicted rate of growth of the Asian population in New Zealand in the next decade (Li, 2009). The data from this study was not representative of these statistics, however, the numbers would be explained by the sample size of the study.

The Government has recognised the need to employ dedicated staff to address smoking cessation, both within the primary and secondary care sectors. Quitline is the national provider of smoking cessation, with the government funding local contracts with smoking cessation providers. These include Aukati Kaipaipa, a cessation programme run by Māori for Māori, there are 32 such programmes throughout New Zealand. In addition there are four Pacific programmes, and providers to work with pregnant women as well as other DHB based programmes (Casswell et al., 2014). The LC CNS’s and the Maori Health Providers within this study refer patients to the appropriate programme, encouraging cessation to all smokers.

While there are declining numbers within smoking statistics, of the 13.3% of the population who do smoke, a significant number will develop lung cancer. The 2013 statistics identified that around 5,000 people die each year in New Zealand from smoking or from exposure to second hand smoke. This equates to 13 people per day throughout New Zealand (Statistics New Zealand, 2013). This does not take into account those who develop lung cancer from exposure to a carcinogenics such as asbestos. With statistics like these, the high workload of the LC CNS will remain unchanged.

5.2.2 – Admitted as an In-Patient or Outpatient

The majority of patients included in the audit were admitted to the lung cancer service as outpatients 75%, (n=24) with 25%, (n=8) admitted whilst they were inpatients. Those patients who were diagnosed with lung cancer as an in-patient had often been admitted due to an acute episode, with lung cancer diagnosed
as an incidental finding. The data showed that the LC CNS’s were frequently involved as soon as a diagnosis was made, a very stressful time for the patient and their family, as evidenced in section 4.7.4, where the respondent identified the LC CNS as providing timely and pertinent information at a crucial time for the patient and their family. Figures 18 & 19 and Table 6 also demonstrate the pivotal role the LC CNS’s play in providing psychosocial support, information and co-ordination of the patients cancer journey. The pathway for those patients seen as outpatients was usually a result of referral from their GP for specialist review. There is evidence that the LC CNS frequently made contact prior to the first specialist appointment to ensure the patient had received the correct information regarding diagnostics and planned appointments. While this group of patients had some idea that a diagnosis of lung cancer was suspected, the need for input and support from the LC CNS was just as warranted, as patients are often stressed and extremely vulnerable at this point in the lung cancer trajectory.

The audit data clearly articulates the extent of the LC CNS involvement regarding provision of education around the required diagnostics, diagnosis, treatment and follow up plans. There are multiple episodes documented of the LC CNS’s arranging diagnostic tests and ongoing follow up tests. There are many incidents of the LC CNS’s discussing symptom management and arranging for the patient to receive the correct prescriptions to manage their symptoms. The literature discusses the importance of that single point of contact, to ensure the patient knows who and how to contact their lead healthcare provider, going on to suggest the ideal person for this role is the nurse within the ANP role (McPhelim et al., 2009; Moore et al., 2006; National Institute for Health and Clinical Excellence, 2012, NICE Pathway, 2012). Within New Zealand, the Standards (2011) have also recognised the benefit of having a single point of contact for those patients with a lung cancer diagnosis; they suggest the ideal person for this is the nurse who specialises in cancer care (MOH, 2011).

5.2.3 – Access to Cancer Services

The Standard (2011) states that all patients who are referred for urgent follow-up, should be seen in a timely manner to enable diagnostics to be completed and their treatment commenced. This section of the document is made up of three standards:

- Standard 1: ‘patients requiring active treatment should start treatment within 62 calendar days of secondary care receiving a referral’
- Standard 2: ‘Patients with clinical and/or radiological signs and symptoms suggestive of lung cancer should be seen by a specialist with an interest in respiratory medicine within 14 calendar days of secondary care referral’
• Standard 3: ‘Chest X-Rays should be performed for all patients with symptoms suggestive of lung cancer and should be reported back to the referrer within seven calendar days of the radiology service provider receiving the referral’ (MOH, p.5).

The establishment of National Health Standards and the faster cancer treatment target of 62 days are of national significance to the population of New Zealand. The data within this study identified that the DHB (here) is achieving well. The mean waiting time for treatment for lung cancer is 49.5 days, meeting the target of less than 62 days in the majority of cases (National Lung Cancer Working Group, 2012). With any data capture, there needs to be acknowledgement that there is a possibility of potential inaccuracy with data collection. While these standards do not all directly relate to the LC CNS role, the survey data identified that the perception of the health professionals who work with the LC CNS’s is that they are pivotal in ensuring patients with a diagnosis of lung cancer are seen in a timely manner, including coordinating the lung cancer MDM. There is a need to ensure there is recognition of health disparities for some patients, the LC CNS’s play a significant role in ensuring these people are not disadvantaged, for example, ensuring interpreters are available for clinical appointments for those with English as a second language, working in collaboration with Māori Health Workers where necessary. The establishment of the LC CNS role in 2009 has assisted in meeting these standards. There are other specialty areas where ANP roles are equally successful, for example, Gynecology, Respiratory and Cardiology services.

5.2.4 – Referral to other Services

Of the data for the 32 patients audited, 75% (n=24) were referred to other services and 25% (n=8) were not referred to other health professionals by the LC CNS. The other services involved in their care included palliative care, dietician and social worker. Patients diagnosed with cancer are often still in the workforce, which impacts on treatment regimes and ongoing follow-up. The LC CNS needs to work closely with all involved in the lung cancer trajectory to ensure these patients are able to remain in the workforce while undergoing treatment. The LC CNS is often the health care professional who coordinates all appointments and treatment times to ensure the patient is able to maintain as much normality within their life as possible. The LC CNS works as part of the multi-disciplinary team and ensures the patient receives timely and accurate advice by referring them on to the appropriate person. Collaboration between the multidisciplinary team is crucial in the provision of effective patient care, resulting in better outcomes, timely treatment for cancer patients, coordinated services and increased patient and health professional satisfaction (Hamric et al., 2009; Horvath et al., 2010; MOH, 2011). The literature suggests that while the MDT is pivotal for the care pathway, the ANP remains the one constant health professional for the patient, ensuring seamless provision of service (Darlison & Beattie, 2009; Fox & White, 2013; MOH, 2011; Peake...
& Steyn, 2012). The data screened for this audit captures this aspect of the role for practically every patient, including referral to bereavement services for a family member, referral to the Cancer Society to arrange accommodation and referral to Occupational Therapy for the provision of equipment for the patient to manage independently at home. This suggests that the LC CNS is actively involved in co-ordination of care across a range of settings and services, and acts as a central point of contact within the healthcare system.

5.2.5 – Diagnosis and Treatment Intent

The data from this cohort of patients was screened to determine the most commonly identified lung cancer and whether treatment was intended to be curative or palliative. The most prevalent lung cancer was Adenocarcinoma, with this being identified in 31% (n=10) of cases. The type of lung cancer diagnosed does not usually impact directly on the role of the LC CNS; they still have input at the time of diagnosis, during the treatment phase and with follow-up. However, with the diagnosis of small cell lung cancer, initiating treatment promptly is critical, as there is a smaller window of time for treatment to commence. The LC CNS’s would have increased input ensuring the patient received timely education regarding treatment processes, making sure all appointments were coordinated and that the patient was booked in to commence chemotherapy at the earliest time possible. The patient is usually very unwell at the time of diagnosis, but typically feels marked improvement from treatment (Personal comment, LC CNS).

The intent to treat data identified that 69% (n=22) of the study population were designated as being for palliative intervention; the remaining group 31%, (n=10) were for curative treatment. The designation of palliative intent does not dictate ‘no further follow-up’, as both chemotherapy and radiotherapy are used for palliative treatment. The LC CNS’s care for the patient while they are on active treatment and whilst they are on follow-up from specialist services. The LC CNS’s may refer the patient to palliative care during this period or wait until they require further input from the palliative care team. This is done in collaboration with the patient and their family.

5.2.6 – Mortality Data

Over the six month period during which the audit was undertaken, the data showed that 38% (n=12) were deceased by the conclusion of data collection. Of the 62% (n=20) of the patients who were alive, 44% (n=14) were for palliative care and 19 % (n=6) for further curative intervention. At the completion of this
project (December 2014), 37.5% (n=12) of this cohort were still alive and receiving care from the oncology service.

The high incidence of mortality needs to be taken into consideration when managing the LC CNS’s role, as this is an identified risk factor in relation to stress and burnout (Moore et al., 2006). Palmer & Thain (2010) conclude that the role of the LC CNS carries a highly emotional load, where the continual giving of bad news can take its toll. They, as others have suggested, recommend peer support and clinical supervision for the LC CNS to manage their own psychological health and wellbeing (Palmer & Thain 2010).

5.3 – Role of the LC CNS
The overall data collected was analysed to ascertain how well the role of the LC CNS functioned, when compared with the Standards (2011)

5.3.1 Contact with the Clinical Nurse Specialist
Key to the role, as indicated both within the Standards but also from the literature, is the establishment of a therapeutic relationship between the LC CNS and the recipient of care (Fox & White, 2013; Cowman et al, 2010). The data identified that interaction occurred as a result of direct face-to-face contact as well as by telephone or email. The number of face-to-face contacts documented per patient was between two and 17, with a median of nine; the LC CNS’s had at least two face-to-face meetings with all the patients within the study group. The data identified a wide range of contact, which was dictated by patient and family need. The LC CNS’s ensure their contact details, both work phone and pager are given to the patient at the time of their admission to the service, to enable the patient to decide on the level of contact. The employment of a second LC CNS has ensured clinical cover for leave. The range of telephone/email contact was between zero and 18, the median was seven. The patients, family and other health care professionals have telephone access to the LC CNS’s throughout work hours, the high demand on their time needs to be monitored and measured, as this time is often not fully captured within clinical statistics (Moore et al., 2006).

A number of studies have looked at the efficacy of telephone based follow up when working with lung cancer patients, with findings suggested this is generally seen as appropriate and effective. Lewis et al. (2009) undertook a study in the UK which identified that patients with a diagnosis of lung cancer were
satisfied with nurse-led telephone follow-up. They went on to suggest that telephone follow-up could provide a practical alternative to routine hospital based clinics, but concluded that a more robust study would need to be conducted before this could be conclusive. The patients within this study came from a wide geographical area, this dictated that contact by the LC CNS was frequently by telephone to provide symptom management, coordination of appointments and ongoing support. Cowman et al. (2010) conducted a prospective audit over a period of 11 weeks which examined the telephone conversations between the LC CNS and the patients they cared for. The results identified 91 contacts; of these 42 affected the ongoing clinical care for the patient, including symptom management and coordination of care, while the remaining calls involved the CNS providing reassurance and emotional support.

The data within this study identifies that the LC CNSs often utilise telephone and email contact to communicate with the patient. This type of communication is often lengthy and not well accounted for within the LC CNS clinical load (Leary et al., 2008). Much of the ‘caring’ work that nurses undertake is difficult to quantify, and therefore difficult to take into account. Further to this, the art of caring within nursing has often been misunderstood and underestimated by others within health. Nursing is a mixture of art and science, which enables the nurse to develop therapeutic relationships with those patients he/she cares for. While the technical aspect of the nursing role is important, it needs to be underpinned with care and compassion (Jasmine, 2009). Fry et al., (2013), suggest while task orientated nursing is seen by others as ‘real nursing’, it is impossible and counterproductive (not to mention undesirable) to remove the caring aspects of the nursing role from the advanced clinical nature of the role (Fry et al., 2013). While patients clearly value caring aspects of practice, such as emotional support, these can be hard to measure and therefore to factor into a job description or work load.

A study by Leary et al., (2008) in the UK concluded that the LC CNS spent 26-30% of their time on the telephone; the predominant aspect of this telephone triage was organizing clinical intervention. A further aspect of their telephone work was to provide advice to other health care professionals caring for the patient with lung cancer, which often resulted in the patient not needing to be admitted. They conclude that much of this work is unaccounted for, which needs to change so that the role can be fully recognised (Leary et al., 2008).

5.3.2 Psychosocial support

The Standard (2011) identifies three key components to the LC CNS role, these being psychosocial support, provision of information and co-ordination of care. Of the three, the most frequent interactions
identified within the audit related to the provision of psychosocial support (47.5%, n=152). This reflects similar results to those identified in other studies within the literature and has been acknowledged as an influencing factor in the establishment of LC CNS posts, both nationally and internationally (Fox & White, 2013; Cowman et al., 2010; Williamson, Collinson & Withers, 2007). Fox et al., suggest that having the involvement of the LC CNS at the time the patient is diagnosed with lung cancer ensures that the person’s physical, social and emotional needs are met at a very overwhelming time (Fox & White, 2013). There is a perception that the nursing role is one that allows for mediation of the medical knowledge and transfer of this into language that is more easily understandable by the lay person, together with the provision of emotional support (Peake & Steyn, 2012).

The LC CNS documentation reviewed for the audit highlighted numerous examples of psychosocial support being offered at the time of diagnosis, with this support often extended to the family of the patient. One concern which was reiterated by the majority of the study cohort was anxiety regarding who would follow them up post treatment. The LC CNS’s reassured them that they would remain on their case load and be followed up by them. This suggests the need for personal connection and continuity in regard to the care provided.

5.3.3 Provision of Information

Provision of information by the LC CNS was also identified in 26.5% (n=85) of the interactions identified. There is often a plethora of information given to patients at the time of diagnosis, it is therefore important to ensure they understand exactly what they have been told and know what the next steps in the pathway will be. The literature identifies the LC CNS as pivotal in this process, as ongoing contact is often required to ensure the patient has grasped the information and the plan of care required (Peake & Steyn, 2012; McPhelim et al., 2009; Williamson et al., 2007). This has implications in terms of the depth and breadth of knowledge required by the LC CNS, and the importance of being able to share this in an effective manner. The ANP role requires nurses who have considerable clinical experience and have undertaken the appropriate post graduate education to allow them to work with autonomy and utilise critical thinking within their practice. These health professionals are in the ideal position to not only provide skilled care to their patients, but to educate others to ensure their knowledge and skill is shared (Schober & Affara, 2007; Graham et al., 2006).
5.3.4 Care Co-ordination

The final aspect of LC CNS involvement typically identified is in relation to care co-ordination. This was recognised in 26% (n=84) of interactions examined. The data identified the LC CNS ensuring the patient knew about appointments for diagnostic procedures, ongoing treatment and follow-up appointments. This included Echo Cardio Grams, Computed Tomography’s (CT), Fine Needle Aspiration’s, and spirometry. The LC CNS coordinated any appointments required for treatment or to manage ongoing symptoms. The literature recognised this aspect of the LC CNS as crucial for the success of the care pathway (Fox & White, 2013; Pollard et al., 2010; Lewis et al., 2009). McPhelim et al., (2009) suggests that the LC CNS is the health professional who is best placed to ensure a coordinated approach to patient management, ensuring symptom control and management.

5.4 Relation to National Lung Cancer Standards

In 2011 the New Zealand Ministry of Health published the Standards of Service Provision for Lung Cancer Patients in New Zealand. The data from this study was compared to three aspects of the Standards (2011); first CNS contact within seven calendar days, evidence of multidisciplinary care and timely access to services. First contact with the LC CNS was achieved within the required seven days in 84% (n=27) of cases. The 16% (n=5) of cases where first contact was not achieved within the specified time frame may be linked to which type of clinic the patient was first seen, for example, if the patient was seen in an ordinary Respiratory clinic for routine investigations, the LC CNS would not be notified of the suspicion of lung cancer until diagnostics were underway or completed. The patient may also have been seen in regards to recurrence of a different type of cancer, with the diagnosis of lung cancer made following additional diagnostics.

5.4.1 Involvement in multi-disciplinary team

The data identified 100% compliance with meeting Standard 9, which states that all patients with lung cancer should be discussed at a multidisciplinary meeting. The Standards (2011) suggest an effective multidisciplinary approach may improve survival, ensure services are not duplicated, result in the patient being considered for clinical trials and enhance co-ordination of services (MOH, 2011). The LC CNS’s within this study are involved in the co-ordination of the weekly lung cancer MDM, where all patients with a suspected diagnosis of lung cancer are discussed. Currently the LC CNS’s ensure all relevant diagnostics and data is available for discussion at the MDM, this streamlines the process and prevents delays within the lung cancer pathway.
Standard one refers to timely access to service, which states the patient should be seen within 14 calendar days by a specialist with an interest in respiratory medicine; have received a chest x-ray which is then reported back to the referrer within seven calendar days; patients requiring active treatment should start this treatment within 62 days; the data identified a 68% (n=22) compliance with this standard. The variance can be attributed for 16% (n=5) of the patients who declined treatment. Of the following 16% (n=5), four were candidates for surgery, therefore did not require either radiotherapy of chemotherapy. While 10 of the 32 patients within this study did not undergo either radiotherapy of chemotherapy treatment, they were all seen by a specialist, where the decision to have surgery or no treatment was discussed and appropriate referrals were made at this stage. One patient had a reoccurrence of lung cancer, which was too advanced at the time of their appointment to undergo treatment, and they were referred directly to palliative care services.

5.4.2 Advance Care Planning (ACP)

There is an expectation that a discussion relating to Advance Care Planning will occur, as part of the LC CNS role. While the introduction of ACP to the patient and their family is not solely the responsibility of the LC CNS, it is suggested that it is better to initiate these discussions in an outpatient setting, with the opportunity to add to and expand on the ACP at subsequent appointments and admissions (MOH, 2011). The Standards (2011) address the need to provide ongoing discussion regarding the patient’s preferred choices within the context of end of life decisions. Standard 11, 7.5 (2011) suggests this should not be left until the terminal stages of the illness.

The literature identifies that the concept of advance care planning and advanced directives have been in existence since the late 1970’s, however, they have not been utilised in New Zealand until relatively recently (MOH, 2011). Advance Directives usually take the form of written documents, generated when the person is fully competent. These are intended to allow the patient to make decisions about the treatment they would want, should they subsequently experience diminished competency. The Advance Care Plan (ACP) is the process of achieving this (Kass-Bartelmes & Hughes, 2003; MOH, 2011; Pearlman, 2013). Pearlman suggests the process involves four steps –

1. Thinking through one’s relevant values and preferences,
2. Talking about one’s values and preferences with one’s spokesperson, close family members and health care providers,
(3) Documenting them with an advance directive, and

(4) Reviewing them periodically and updating them as needed (Pearlman, 2013).

While this viewpoint is also present within the New Zealand context, the unique culture and medico-legal framework were recognised when the guide for ACP was developed by The National Advance Care Cooperative. The development of the framework was governed by five specific codes from the New Zealand Code of Rights, which state that the health care consumer has the right to:

- dignity and independence (Right 3)
- services of an appropriate standard (Right 4)
- effective communication (Right 5)
- be fully informed (Right 6)
- make an informed choice and give informed consent (Right 7) (MOH, 2011).

The LC CNS is the health professional who routinely sees the patient and their family in an outpatient setting, so are in an ideal position to initiate these discussions (Pearlman et al, 2013). The data was analysed for evidence that the LC CNS’s had discussed advance care planning with the patients. The LC CNS initiated discussion relating to ACP for 88% (n=28) of the patients. For the remaining 12% (n=4), there was no indication this had been discussed, however, due to the high volume of telephone consultations, this may have been discussed, but not documented. The examples relating to ACP included the LC CNS assisting the patient with organizing appropriate papers to claim on end of life insurance policies and discussing the need to involve palliative care services in their care. The ability to encourage patients to discuss ACP is a highly important skill. There is now specific training to enable health professionals to work with patients to ensure they know how to promote ACP with the patients they care for. Moore et al., suggest that the intense nature of the CNS role within cancer care is a highly stressful role and that for the health professional to be able to meet the needs of the patients they care for, they need to have ongoing support and supervision themselves (Moore et al., 2006). The service within which this study occurred provides external supervision for the LC CNS’s.

The National Advance Care Cooperative developed ACP education and training modules for clinicians, in the form of an online programme, which gives an overview of what ACP involves (referred to as level/module one). Additional education follows, which is more in depth. This includes teaching communication skills that prepare participants on how to approach difficult conversations (referred to as
level/module two). Moore et al., suggest that staff without the skills to encourage patients to discuss emotional concerns and worries can consciously or subconsciously block the conversation required to deal with the issue (Moore et al., 2006). To date, one of the LC CNS’s and one of the Māori Health Workers from the regional service within this study have attended module two of the ACP programme. The modules are designed to ensure a ‘train the trainer’ approach is achieved, thus ensuring the knowledge is widely dispersed. The level/module one programme has only recently become available online, the staff from the regional service were not required to complete level one, prior to undertaking level/module two. However, any one undertaking level two currently would need to have completed level/module one first. The audit identified many instances of the LC CNSs instigating ACP for the patients within the service. They also demonstrated inclusion of the Māori Health Worker as part of ACP discussions, to ensure awhi (help), tautoko (support), and manaaki (care) were provided for the patient (MOH, 2011).

5.4.3 – Good Practice Points
The New Zealand Cancer Control Strategy identified six good practice points that needed to be adhered to in order to improve continuity and co-ordination of care for the patient on the cancer care pathway.

1. Reduce the incidence of cancer through primary prevention
2. Ensure effective screening and early detection to reduce cancer incidence and mortality
3. Ensure effective diagnosis and treatment of cancer to reduce cancer morbidity and mortality
4. Improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care
5. Improve delivery of services across the continuum of cancer control, through effective planning, co-ordination and integration of resources and activity, monitoring and evaluation
6. Improve the effectiveness of cancer control in New Zealand through research and surveillance (MOH, 2003)

In relation to the study setting, the need for a LC CNS was acknowledged in 2009, when the regional service recognised the need to employ an expert nurse within the specialty of lung cancer. The decision to employ the LC CNS was influenced by the publication of the New Zealand Cancer Control Strategy (MOH, 2003) and the New Zealand Cancer Control Action Plan 2005 – 2010 (Cancer Control Taskforce, 2005). This move was seen as a means of working towards achievement of the national goals.
The full time role was established in 2009, with a further 0.5 position added in 2010 due to work load need. The development of the Standards (2011) to improve outcomes for patients with lung cancer have further shaped the role of the LC CNS (MOH, 2011). The employment of the LC CNS’s demonstrates that the service within this study is meeting the good practice point of 7.1, presence of a LC CNS. The role of the LC CNS also fits with the proposal of the Medical Oncology National Implementation Plan 2012/13, which recommends specialist nurses are utilised more effectively, in order to free up Senior Medical Officer (SMO) time for essential clinical SMO activities. This also reflects the targets of the Faster Cancer Treatment programme, namely to improve cancer diagnostics and treatment (MOH, 2012). A number of years ago the Ministerial Taskforce for Nursing recognised the potential for nurses to take a lead in the provision of health services (MOH, 1998), with the LC CNS’s fulfilling this potential in the role they undertake, to ensure the patient has access to a dedicated lung cancer nurse (MOH, 2011).

**5.4.4 Keeping Patients informed**

The New Zealand Cancer Control Strategy (2003) and the Standards (2011) state that patients should be kept informed throughout their cancer care trajectory. This includes information prior to diagnosis, during treatment and once treatment is either ceased or completed (MOH, 2003; MOH, 2011). This was identified as a good practice point in the Standards (2011) citing that patients should be kept informed about the processes involved in diagnosing and treating lung cancer (MOH, 2011). The audit data identified numerous examples of the LC CNS’s interactions with the patients and their families, and their involvement in imparting information and advice related to the cancer diagnosis. The literature suggests that the CNS is often the health professional in the best place to ensure the patient is given the correct information, in a holistic and individualized manner (Fox & White, 2013; Williamson et al., 2007; McPhelim et al., 2009; Cowman et al., 2010).

**5.4.5 Psychosocial Needs**

In 2003, the New Zealand Cancer Control Strategy identified that supportive care for patients with a diagnosis of cancer was poorly addressed, suggesting that there were inequalities across cancer care centers within New Zealand. The development of The Standards (2011) identified that the patient should have their supportive care and psychosocial needs assessed throughout their cancer care trajectory (MOH, 2011). The audit data identified that the LC CNS’s clearly met this standard. There were numerous examples of the LC CNS providing ongoing support and reassurance to their patients. This included being at appointments where initial diagnosis of lung cancer was given, subsequent appointments when devastating news regarding treatment progress was given, and examples of discussions held with the
patient, family and whānau. The literature identifies LC CNS’s as pivotal in meeting the psychosocial needs of the patient with a diagnosis of lung cancer, suggesting their care is given in a non-rushed, patient centered manner (Cowman et al., 2010; Fox & White, 2013). However, there is also awareness of the need for these staff to have adequate support systems in place, to address the high burden of stress this role can have, including the availability of clinical supervision for these practitioners. While the role of formal clinical supervision is well recognised within the international context (Palmer & Thain, 2010; Leary et al., 2008; Vaz & Small 2007), there is a lack of a robust process within the New Zealand setting. The development of specialist roles across all areas of health suggests it would be timely for New Zealand and Australia to emulate the clinical supervision programmes on offer within the United States and the UK. There is evidence to suggest that the availability of clinical supervision for health practitioners leads to improved patient care and better health outcomes (Walker, 2009). The NZNO suggests that clinical supervision is a critical component of professional development for all nurses and midwives, which ensures quality patient services (NZNO, 2005).

5.4.6 Culturally Appropriate Interactions
The Standards (2011) identify the need for information, treatment and care to be culturally appropriate for Māori, Pacific people and for those of other ethnicities. While the data numbers audited for this study were not large, there was enough evidence to show the LC CNS’s were addressing this standard. This included examples where interpreters were arranged, ensuring that appointments were made so that family could attend and help decipher the information provided, and ensuring adequate support and follow-up was arranged from additional services when the patient and their whānau returned to their region of domicile.

The New Zealand Cancer Control Strategy worked with the founding document in New Zealand, the Treaty of Waitangi, when developing the strategy. The three principles of the Treaty guided the development and implementation of the strategy. The principle of partnership was applied, which ensured close work with Māori in developing appropriate health services. They also utilised the principle of participation by ensuring Māori were involved with planning development and delivery of health services. The final principle of protection was upheld by developing a strategy that acknowledged Māori cultural concepts, values and principles. The development of the strategy was underpinned by recognition of the need to reduce inequalities and ensure Māori were offered the same level of health care as non-Māori (MOH, 2003). The regional service within this study have addressed the principles of the Treaty by employing dedicated Māori Health Workers to ensure Māori patients are supported and guided within the
service. The LC CNS’s work in collaboration to ensure their Māori patients receive timely and appropriate health care during diagnosis, treatment and follow-up.

5.5 Survey

The questionnaire was distributed with a response rate of 76% (38). The questionnaire was derived from the Cowman study; permission for this was sought and granted from the authors, and adaptation to the NZ context occurred (Cowman et al., 2010). The questionnaire contained both quantitative Likert type questions and qualitative open ended questions. This form of questionnaire is purported to elicit the most meaningful data capture and to ensure data is captured from a wide variety of participants (Polit et al., 2008, Schneider et al., 2010).

The initial five questions from the questionnaire related to demographics to allow a profile of the respondents to become apparent and to identify representativeness of the survey respondents. The questionnaire gave explicit information regarding the reason for capturing demographics, reassuring participants that this information would be anonymised. These questions included gender, age, occupation and number of years worked within cancer care.

The respondents of the survey were asked to identify what their occupation was within the health care system. The largest group to respond to the survey were medical staff, however, as 56% of the total surveys (n=28) were sent to medical staff, this is not unexpected. Of the 38 responses to the survey, 63.2% were from females (n=24) and 36.8% were from males (n=14). It is recognised that nursing is a predominantly female workforce, with a gender split of 91.7% female and 8.2% male (MOH, 2014), while the largest group of respondents identified as medical staff, the second largest group were nurses. The gender gap within the medical workforce is now much narrower. Female doctors now number 41.3% of the total workforce, an increase of 2.2% from 2009. This could account for the predominance of female respondents to the survey (MOH, 2014). The literature identifies under-representation of Māori and Pacific people within both medicine and nursing, but suggest this is changing with gains in numbers across both disciplines (MOH 2014).

Working with patients in oncology services requires senior and experienced practitioners. Quinn suggests nurses working within the field of oncology need to have undergone specific education relating to the specialty and be able to practice with autonomy (Quinn, 2008). This would require extensive experience,
including relevant postgraduate education. The questionnaire presented age bands of five year increments, with participants asked to identify which band they were in. The overall age range of the participants was between 25 – 60+ years. The majority of respondents identified with the 50 -59 year range, (36.8%, n=14 with the lowest representation within the 25 – 29 year category, (2.6%, n=1). This suggests that participants were predominantly senior clinicians; this result was not unexpected.

A recent publication from the MOH, *Health of the Health Workforce 2013-2014* reports that both the medical and nursing workforce is aging, with 40 percent of doctors aged over 50 and 46% of nurses. For nurses, the average age of those within specialty areas is 53 (MOH, 2014). This is further supported by the data which shows that 20 out of the 38 respondents have worked for more than 11 years in the specialty of oncology and within this group, seven have worked for more than 20 years. This shows that the LC CNS’s are part of a highly skilled and professional workforce, where the consolidation of knowledge contributes to better outcomes for the patients they care for. The benefits for the patient include faster times to diagnosis and treatment, better processes for symptom management and more robust follow up procedures (Horvath et al., 2010; McPhelim et al., 2009; Richardson, Halliday & Wilson-Barnett, 2002).

5.5.1 – Health Professionals Beliefs regarding the role of the Lung Cancer CNS’s

The respondents of the survey were asked a number of qualitative questions in relation to their beliefs regarding the role of the LC CNS’s. The questions were in relation to whether or not the participants felt the LC CNS’s were meeting Standard 11 within the Standards of Service Provision for Lung Cancer Patients in New Zealand (MOH, 2010),

“All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialists in cancer care, to provide psychological support, information and coordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with a specialist”.

The literature discusses the need for patients to have continuity of care provision, particularly for patients with a diagnosis of cancer. The volume of information and the range of diagnostic tests and treatment make the trajectory for the patient with cancer complex and often frightening, as this is foreign territory for the majority. The literature identifies the CNS as the health care professional who is the ideal person to fulfill this role, ensuring optimal treatment options are considered, with the potential of improvement
of quality of life and patient satisfaction (Fox & White, 2013; Moore et al., 2006; Leary et al., 2008; Williamson et al., 2007). According to Cowman et al. (2010), the CNS is central to patient care, working within the MDT and providing input to aspects including diagnosis, treatment and follow-up, with members of the MDT viewing them as highly qualified expert practitioners (Cowman et al., 2010). This is also true of many other ANP roles, both internationally and nationally. The ANP has been established throughout the health sector, providing innovative health care across the health care continuum. The health sector faces rapid and challenging growth, those responsible for the nursing workforce need to respond to this challenge by ensuring nurses are prepared with ongoing post graduate education, provision of support from nursing leaders and others in the health care team, including medical teams (Carter et al., 2010; Martin-Misener et al., 2010; DiCenso et al., 2010).

The results showed that the respondents to this survey viewed the LC CNS role as fulfilling Standard 11, identifying the LC CNS as the team member consulted by others to determine where the patient was within the cancer treatment pathway, ensuring a seamless process, including communication and collaboration with the community teams. The comments included recognition that the role of the LC CNS provides personal continuity for the patient during a stressful and overwhelming process. The participants also recognised the input the LC CNS’s have with family/whānau, providing information and reassurance to those closest to the patient. The LC CNS’s work in collaboration with the Māori Health Workers to ensure Māori and Pacific people are supported within the lung cancer pathway. Jansen & Sorrensen (2002) suggest for Māori and Pacific people, “cultural competency is just as important as clinical competence…cultural competence requires a commitment to continuous improvement through continuing education, review and feedback, in the same way the clinical competence does” (Jansen & Sorrensen, 2002, p306, p311).

The cancer journey not only affects the person diagnosed with cancer, but also those closest to them. The survey respondents identified the input the LC CNS had with the patient and with the families, recognizing the importance of this within the care continuum. The audit showed the LC CNS’s had multiple conversations with the family of the patient diagnosed with lung cancer. The LC CNS’s acknowledged the major role of the family in caring for the patient on a day to day basis, giving them the support and contact they needed to carry out what is an extremely difficult role. The literature recognises the extreme pressure faced by the family and care givers of a patient with a diagnosis of cancer, suggesting these people need as much support as the person diagnosed with cancer (Fox & White, 2013; Tse Man Wah, 2007).
A further aspect of the role acknowledged through the survey was the expectation and ability of the LC CNS’s to triage patients who were unwell, ensuring they received appropriate and timely treatment. The participant’s within this survey recognised the risk of patients falling through the cracks of the health care system, citing the LC CNS as the health professional who ensures this does not happen. The survey elicited a comment regarding how difficult it is for patients having to tell their health story time and time again, suggesting that the LC CNS provides a constant presence, which often prevents this from occurring. However, there were also comments that identified the impossibility of the LC CNS’s attending every clinic, thus having some patients without the support of the LC CNS. This was not a criticism of the role, but an observation of the sheer volume of patient clinics, and the scarce resource that the 1.5 FTE LC CNS represents. Another comment discussed the lack of LC CNS input for those patients admitted to General Medicine or to other hospitals; they could potentially fall through the cracks if they were not referred on for chemotherapy or radiotherapy, as the LC CNS would not know of their diagnosis. Again, this was not a criticism, but highlighted a potential issue with the need to develop robust measure to ensure each patient has the opportunity for input from the LC CNS. The Standard (2011) states that the patient should be seen by a dedicated lung cancer nurse within seven days of the initial assessment with a specialist, this was achieved with 84% of the patients within the audit. The instigation of a defined nurse led lung cancer clinic would go some way to addressing these issues. This will be an area to focus on to ensure compliance with the Standard (MOH, 2011).

The role of the LC CNS within the New Zealand context compares very favorably with the role described within international literature. It is suggested the individualized care provided by LC CNS’s is safe and effective; they work well with medical colleagues and within the MDT. Some studies suggest patients with LC CNS follow-up are provided with better symptom control and fare better psychologically than those seen by solely medical teams (Williamson et al, 2007). Huhmann & Camporeale (2012), identify the nursing role as pivotal in providing assessment and intervention to facilitate symptom management for patients with a diagnosis of lung cancer (Huhmann & Camporeale, 2012). The respondents within the survey in this study identified the significant role the LC CNS’s have in managing symptoms, arranging timely intervention and providing psychological support to the patients they care for.

Patient satisfaction with the support offered by LC CNSs at the time of diagnosis and the continuity and coordination of care throughout the cancer pathway has been identified (Richardson et al., 2002). In addition, it has been suggested that the role of the LC CNS could contribute to substantial cost savings by
reducing hospital admissions, reducing length of stay and by reducing the number of follow-up appointments including medical follow-up. This can be seen where LC CNSs adopt a proactive management approach, with reduction in admissions demonstrated in one study for those patients with non-acute issues from four per month to 0.3 per month (Fox & White, 2013).

The United Kingdom Lung Cancer Coalition (UKLCC) (2012) undertook a project to improve the outcome of patients with a diagnosis of lung cancer (Peake & Steyn, 2012). They believed that all patients with a diagnosis of lung cancer should be managed by the ‘dream MDT’, to improve the quality of care and clinical outcomes for patients with lung cancer. The members of the UKLCC’s consisted of respiratory consultants, general practitioners, a university professor, oncologists, a radiologist, a pathologist and a lung cancer CNS. The project identified 30 recommendations, four of which related specifically to the LC CNS role, including the finding that while many LC CNS’s meet the patient at the time of diagnosis, they were of the opinion that they should also be involved pre-diagnosis (Peake & Steyn 2012). This finding was captured in the survey results within this study, identifying the pivotal role the LC CNS undertakes in ensuring the Multi-disciplinary Meeting Coordinators (MDM) of the MDM for lung cancer receive notice of the patients to be discussed. The LC CNS were also responsible for collaborating with the Consultant to ensure relevant referral forms were completed, allowing diagnostics to occur in a timely manner.

5.6 Implications for the regional service
The establishment of the dedicated Lung Cancer Clinic in 2012 for the regional service within this study has ensured that the majority of patients with a suspicion of lung cancer or mesothelioma are seen in the appropriate clinic. The LC CNS’s are the only health professionals involved with each lung cancer clinic, ensuring continuity for these patients. Palmer and Thain, (2010) discuss the effect of the patient receiving bad news in the clinic situation. They suggest that given the statistics for poor prognosis and the high symptom load, a diagnosis of lung cancer or mesothelioma is almost always likely to be bad news. They suggest the establishment of nurse-led clinics would be an advantage when dealing with the fallout from the initial news of the diagnosis and very good use of the LC CNS’s expert knowledge and skills (Palmer & Thain, 2010). Roberts et al. (2011) identify nurse led clinics as a way to care for patients in a holistic manner, by providing patient centered care to improve quality of life. They caution that the development of nurse led clinics should be established to improve the outcomes for patients, not to fill the gap created by doctor shortages (Roberts et al., 2011).
To date the LC CNS’s within this study do not provide a specific nurse led clinic, however, this is a future plan within the service. This may well address the issue identified in the survey of some patients not receiving follow-up from the LC CNS, as a dedicated clinic is a very efficient use of CNS time. The literature identifies the real issue of the future shortage of health care professionals needed to deal with the burgeoning number of patients with a cancer diagnosis or with a chronic illness. Discussion of the projected shortage of health professionals to deal with a population that is aging, being offered wider treatment options and with increasing survivorship for cancer sufferers is occurring. One suggestion is a need to utilise more fully non-medical practitioners, such as NP and CNS, in order to deal with the changes within the health care setting (Nevidjon et al., 2010). Comments from the survey suggest this is already happening to some degree within the study setting, while recognizing the need to ensure systems are strengthened to ensure all patients have equal access to the input from the LC CNS. The comments also included suggestions that the patient and family often found it easier to discuss their concerns with the LC CNS, rather than medical teams. One respondent in the survey viewed the role of the LC CNS as a positive advance for patients with lung cancer or mesothelioma, stating ‘Nurses are the glue – makes the system work much better and be more patient centered’. The role of the nurse within cancer care is well documented, as is the importance of utilizing good communication skills when dealing with the patient and the family. The role of the nurse dictates more time is spent by them with the patient than any other health professional. The patient often will not verbalize anxiety, however, a nurse with the right level of training and skills will pick up on this without the patient needing to disclose their worry and fears. For the nurse to develop therapeutic relationships with their patients requires a high level of clinical competence and communication skills (Collins, 2009; Uitterhoeve et al., 2009).

In 2013 the Ministry of Health (MOH) published a document that discussed the progress to date with the six health targets they had developed, three of which focus on patient access and three on health prevention. One of these targets is shorter waiting times for cancer treatment. The target has been set at ‘all patients ready-for-treatment, wait less than four weeks for radiotherapy or chemotherapy’. The document discusses the typical pathway for cancer patients as seeing up to 28 doctors and even more nursing staff. The navigation of the health care system can be a minefield for these patients. The survey results clearly showed that having a single point of contact is preferable, and does occur with the interaction with the LC CNS’s. The appointment of 57 nurses into cancer nurse coordinator roles across New Zealand has been a major success in helping these patients deal with the stress that a cancer diagnosis engenders (MOH, 2013). These roles were developed following discussion with one of the LC CNS’s within this study. There have been four nurse cancer coordinators appointed within the region, who work in collaboration with the LC CNS’s where appropriate.
A study conducted by Moore et al. (2006), looked at the experience of developing and delivering nurse specialist follow-up for patients with lung cancer. They set out to describe the process of developing this service, identifying four themes crucial to establishing nurse led follow-up. These were, ‘training’, ‘becoming credible’, ‘emotional burden’, and ‘making a difference’. While they concluded that the role is very rewarding, there is also a high emotional demand placed on the LC CNS, they suggest adequate training and support is paramount in ensuring these roles are sustainable (Moore et al., 2006). Palmer & Thain (2010), suggest that the role within lung cancer care carries a very high emotional burden, the fact that clinicians are involved in giving diagnosis which are often terminal can lead to burn out and high levels of stress. They encourage the clinician to undergo routine clinical supervision to ensure their own psychological health and wellbeing are kept intact (Palmer & Thain, 2010).

Similar concerns were identified in the survey, with respondents suggesting that while the role provided an excellent service for the patient, the risk of burnout from an emotionally challenging role was very real and there was a need to ensure that debriefing and clinical supervision occurred on a regular basis. There is also the need to ensure adequate leave is taken on a regular basis, this is much easier to achieve now there are two LC CNS’s within the regional service. There is a movement towards a more appropriate term for the phenomenon of burnout, with the suggestion that this should be ‘compassion fatigue’. The literature suggests that the constant exposure to the grief of patients and family can take a toll of the nurse’s physical, emotional, mental and spiritual health. Longevity of working within this stressful area offers no protection, as the effects can be cumulative. The nurses working within this environment need to have strong support networks and coping mechanisms in place to prevent compassion fatigue, self-care is identified as a crucial in managing what is an extremely stressful role (Aycock & Boyle 2009; McSteen, 2010; Codier, Muneno & Freitas, 2011; Corso, 2012).

5.6.1 Role development
There are a number of common themes regarding the establishment of the APN role, definition of the role, workload sustainability, and protection of the role within financial constraints, educational requirements, performance evaluation and succession planning for these senior roles. These factors also relate to the LC CNS role (Leary et al., 2008; Vaz & Small 2007; Williamson et al., 2007; Fox & White, 2013; Cowman et al., 2010; Peake & Steyn, 2012; Scarpa & Connelly, 2011). It is suggested that without regular quality monitoring of an ANP role, there is no way of ensuring the organizational goals and objectives are met, although to achieve this can be extremely challenging (Scarpa & Connelly, 2011). One response
to this was to develop a criterion-based job performance assessment tool to evaluate practice at an advanced level, working with ANP’s, Nurse Managers, a Nurse Educator and a Physician. The findings of this process identified peer review as one of the most robust ways of monitoring and improving practice, resulting in accountability for practice and quality improvement (Scarpa & Connelly, 2011). These authors suggest evaluation that lacks peer review only measures the tasks expected of an ANP role, not the in-depth practice that defines the role. This process encourages ANPs to have input into the development and definition of their roles, ultimately resulting in improvement in patient care (Scarpa & Connelly, 2011). While the results from the survey were predominantly positive regarding the LC CNS role, aspects of these themes were identified, including workload sustainability and lack of resource to see every patient with lung cancer, which suggests nursing services within New Zealand have the same issues as international services. The regional service within this study would need to ensure clarity around the establishment of any new services associated with the LC CNS role, for example, nurse-led clinics. The international literature informed the establishment of the current LC CNS role within the regional service; an advantage over those services who set up these roles in the 1990’s.

A study by Lloyd Jones (2005), which looked at role development of specialist and advanced practice roles, identified role ambiguity as one of the most negative factors when trying to establish these positions, suggesting clear role definition and communication with others in the health care team as crucial to the success of the project (Lloyd Jones, 2005). Definition of the role is crucial for credibility from others in the health workforce. In order for the role to become embedded in the health care setting, nurses need to ensure they are able to articulate what it is that defines their role. There is also a need to ensure these advance practice roles remain nursing orientated, not medically focused. The literature identifies that one of the main obstacles in establishing and maintaining new roles within nursing is the lack of clarity around what it is that the role is intended to achieve (Bryant-Lukosius et al., 2004; Lowe et al., 2011). Donald et al., (2010) suggest lack of understanding of a role by others in the health workforce and from the public leads to unrealistic expectations. They suggest there is a need to ensure clear communication of intent with health professionals and the public prior to any new initiatives being established should be employed (Donald et al., 2010). The role of the ANP is extremely autonomous, Lukosius et al. (2004), suggest ANPs must function with independence to ensure the role is fully functional and responsive to patient needs (Bryant-Lukosius et al., 2004). The LC CNS’s in the study setting practice with autonomy, an aspect that came through very strongly both within the audit and the questionnaire.
Currie & Grundy (2011) suggest there are three categories which influence the push to establish ANP roles, ‘enthusiastic individuals creating roles when money was available, medical replacement roles and less frequently, nurse led initiatives’. They posit that historically the ANP roles have been established with little planning. They recognise the key role ANPs need to play within the current health care workforce, urging leaders to take a more consistent approach to the development of these senior roles (Currie & Grundy, 2011). The successful establishment of ANP roles depends on support from others within the multidisciplinary team, especially medical teams. The ability to establish clinical relationships is fundamental to the ongoing success and growth of the role, ensuring others in the workforce understand the function and dimension of the ANP role (De Geest et al., 2008; Bryant-Lukosius et al., 2004; Richardson et al., 2002).

5.6.2 Succession planning

The survey identified the age of the majority of respondents was in the 50 – 59 year age range (n=14), while the data did not specify occupation within this demographic, it could be assumed some of this cohort were nursing staff. Given recent workforce information released from the MOH regarding specialist nursing roles, the need to address the issue of succession planning within nursing is pressing (MOH, 2014). There are currently no formal plans to address this issue for the sector, although the regional service is aware of the need to protect the resource that is specialist nursing knowledge. One of the main barriers to establishing a program is the financial implication. However, Trepanier & Crenshaw (2013) suggest it is crucial for organizations to have robust succession plans in place for sustainability and operational viability. They posit that the aging workforce, shortage of nurses, projected increase of patients with chronic diseases and the increasing complexity of health care are all risks to the organization and succession planning cannot be ignored. Currie (2010), also identifies a lack of funding within the UK setting as a barrier to establishing robust succession plans. An Australian study by Brunero, Kerr & Jastrzab (2009), suggest historically succession planning has been only utilised for executive management level, ignoring the need to address this for the clinically focused workforce. They identify Nurse Managers as being in the best position to develop programmes to identify potential leaders within the health care setting. Bolton et al. (2004, p. 577), cited in Brunero have developed ‘five key components of succession planning’

- Identifying key positions
- Identifying potential candidates
- Developing potential candidates
- Appointing successors and
Committing resources.

They suggest a transparent approach to succession planning, where all staff are aware of opportunities for career advancement, not just a select few (Brunero et al., 2009).

The hierarchical framework of the medical profession has been established to ensure expertise is grown from within. This has not been replicated within nursing, which will lead to severe shortages within senior posts in the years to come. However, the MOH is well aware of the issue and to address this Health Workforce New Zealand (HWNZ) has set up a nursing workforce programme with the purpose of:

- Improving the integrity of nursing data
- Improving graduate nursing recruitment
- Improving nurse retention
- Workforce planning

The establishment of robust a robust succession plan for the regional service is an area that would benefit from further research within the local context. There needs to be an organizational approach to succession planning, which involves recognition of future leaders and the provision of mentoring, coaching and support to undergo relevant post graduate study in preparation for the role. This would ensure ANP roles were developed in a coordinated, systematic way, dictated by clinical need and not before the infrastructures necessary to support them are in place (Vaz & Small 2007; McPhelim et al., 2009; Ketefian al., 2001; Furlong & Smith, 2005).

### 5.6.3 Workload recognition and management

The typical workload associated with the LC CNS role has been evaluated by Leary et al. (2008). The study measured the workload in terms of clinical, consultation, education, research and administration of six LC CNS’s. The findings showed their activity as 65% clinical, 28% administration, 4% education, 2% consultation and 1% research. Much of the administration role was clinical in nature, as the LC CNS was arranging follow up for the patient, which required their level of expertise to ensure correct diagnostics were ordered. There were other aspects of the role that were difficult to account for, this included clinical telephone calls and advice to community services regarding the patient. The six LC CNS’s were surveyed over a period of eight days, which identified 352 events or 44 events per day (Leary et al., 2008). The survey and audit within this study identified similar interactions for the LC CNS, including extensive clinical work conducted via the telephone.
A key finding across many studies highlighted the lack of cover for the LC CNS role when they are on leave. This results in lack of care for the patient during this absence and heavy workload for the LC CNS when they return to work (Leary et al., 2008; McPhelim et al., 2009; Richardson et al., 2002). The regional service within this study recognised the risk of having a sole LC CNS within the service and established a further 0.5 LC CNS position in 2010. This role not only ensures cover for the service, but provides crucial peer support for this very stressful role. McPhelim et al., (2009) suggest there is inequitable service provision when there is a sole LC CNS, with no cover to ensure service provision.

The development of ANP roles in some settings was historically to address the shortage of medical staff and to reduce the costs of health care provision (Leary et al., 2008; De Geest et al., 2008; Holloway et al., 2009). The health sector has incorporated the ANP role widely across all sectors, providing specialist care and influencing health outcomes for those they care for. With the ever increasing cost of health care, there is a need to ensure ANP roles are protected in times of fiscal downturn. The challenge for nursing is to ensure they articulate the value of their contribution to the health arena with robust evaluation processes and input into developing strategies to meet the challenges of health care provision (Fox & White, 2013; Peake & Steyn, 2012; Pollard et al., 2010).

The LC CNS’s within this study exhibit a passion for their role, always striving to ensure the very best clinical outcome they can for the patients they care for and for their families. This is one of the very most challenging ANP roles within health care. The results from the survey identified those health professionals that work with them view them as highly motivated and effective Clinical Nurse Specialists.

**Limitations of the Study**

One of the limitations of the study was the small sample size of the audit. There were 32 sets of clinical notes audited, which gave a picture of the workload of the LC CNS, however, this was a comparatively small sample. Future research could audit a larger sample size, giving a more in-depth picture of the demographics of the population cared for by the LC CNS’s. This would be particularly pertinent for ethnicity data, as the 2013 Census showed the Asian ethnic group has increased in proportion in every region throughout New Zealand at 11.8%, and for the region within this study to 9.4% of total population (Statistics New Zealand, 2013).
The limitation of the survey for this study include the fact that the participants were predominantly from one site only. The response to the questionnaire from external Cancer Care facilities was very small. Future study could include other large tertiary facilities. The researcher for this study worked as a manager within the study setting, therefore, the risk of bias and conflict of interest must be taken into account.

**Implications for further research**

There is a need to establish robust succession planning programmes throughout the nursing profession. This is an area that would warrant further research, with the purpose of establishing a succession plan for all the ANP roles within the region. This will need to be undertaken with support of hospital management, if it is to succeed, there would need to be commitment to financial support for the programme (Trepanier & Crenshaw, 2013; Currie & Grundy 2011).

The final chapter of this thesis presents an overview of the study outcomes. In particular it acknowledges the implications for practice arising from this study and summarises recommendations for the continued development of ANP roles in New Zealand, and for the LC CNS in particular.
Chapter 6: Summary

6.1 Introduction

Conclusion
The overarching intent of this study was to explore the impact of an advanced nursing role within a specialty area, namely, that of the lung cancer CNS. The aging population and the never ending demand for health care workers to manage the burgeoning numbers of patients with chronic diseases has been identified as the greatest challenge yet for health care providers worldwide (De-Geest et al., 2008, Fagerstrom, 2009, Fairman et al., 2011) The literature identified that exponential growth has occurred within the advanced nursing role within the nursing profession, to manage the burgeoning numbers of patients diagnosed with chronic diseases.

A review of the literature was conducted to research the history of the development of the ANP role. The International literature identified the role as having its origins within psychiatric care in the 1940’s (Hamric et al., 2009). The New Zealand 1998 Ministerial Taskforce for Nursing recognised the hidden potential within the nursing workforce, with the aim of utilizing this group to engage with those patients who failed to seek appropriate health care (MOH, 1998). This document has been widely recognised as the springboard for the development of ANP roles within New Zealand.

Lung cancer is one such area that it has been recognised that the role of the ANP can provide support and facilitate care. The statistics for the diagnosis of lung cancer within New Zealand make for grim reading, with 18% of all cancer related deaths being attributed to lung cancer, with a five year cancer survival rate of only 10.4%. Lung cancer has a five year survival rate of 10.4% in New Zealand (MOH, 2006). The role of the Lung Cancer Clinical Nurse Specialist (LC CNS) was introduced in the region within this study in 2009, to provide specialist care and support to this group of patients.

In 2011 the MOH developed national lung cancer standards with the express purpose of improving outcomes for patients with lung cancer and to address the inequalities associated with a diagnosis of lung cancer (MOH, 2011). Further to this, the MOH have developed six national health targets, which are a set
of national performance measures to improve health outcomes for patients. Three of these targets focus on patient access and three on prevention. One of these health targets is to ensure shorter waiting times for cancer treatment, including lung cancer. This includes the 62 days to treatment target and the introduction of a senior nurse to provide a single point of contact (MOH, 2014). Within the region of study, this role was already in place, however, these targets have resulted in the instigation of the dedicated lung cancer clinic, an initiative which has seen improved compliance with meeting the Standards and the targeted waiting times. The LC CNS’s are involved in the function of the lung cancer clinic, coordinating appointments and follow up for patients.

6.2 Practice implications
Standard 11 of the Standards (MOH, 2011) states that “all patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialises in cancer care” (MOH, 2011). The employment of the LC CNS within the region of study was forward thinking and well established prior to these standards being released, realising the value and the necessity of the role by employing a further LC CNS in a 0.5 FTE position in 2010. The standard also states that the specialist nurse should provide psychosocial support, information for the patient and their family and provide co-ordination for the patients on the lung cancer pathway. The audit and the survey data both captured the workload of the LC CNS, The results identified that the LC CNS’s were meeting all of these standards.

The instigation of the lung cancer clinic has proven to be very effective for diagnostics, treatment and follow up for patients with lung cancer. The next progression will be to develop nurse led lung cancer clinics, where the LC CNS’s can see patients, provide symptom management and ongoing follow up. This would be a very productive use of LC CNS time and would enable the Senior Medical Officers to concentrate on seeing more new patients in the lung cancer clinics.

The role requires managerial support to ensure the LC CNS’s are able to practice with autonomy, with the ability to engage in collaborative clinical decision making. The LC CNS’s also require clinical supervision from appropriate providers to ensure the nurses in these extremely stressful roles do not develop burnout, from the intense therapeutic relationships they develop with the patients and their families. The health professionals who responded to the questionnaire discussed the need to ensure these nurses were supported and given appropriate professional supervision to manage what they perceived as a very demanding nursing role.
It is very sobering to note that at the conclusion of this study, of the 32 patients whose clinical notes were audited for this research, only eleven patients are still alive. The LC CNS is the single point of contact for these patients and their families, providing a constant voice throughout what is a truly devastating diagnosis and treatment process.

6.3 Recommendations
The following recommendations are derived from the study findings and consideration of the implications associated with these:

Advanced practice roles and opportunities

1. There is a need for continued exploration and evaluation of existing ANP roles
2. Consideration should be given to the opportunities for developing additional specialty roles, for example the role of ANP in case management and nurse led clinics

Lung Cancer specialty roles

1. Identification of the elements contributing to these specialty roles and the value they add to the patient’s journey needs to be undertaken.
2. Education of staff, colleagues and patient population regarding these roles.
3. Additional support for those staff engaged in emotionally challenging roles, in the form of clinical supervision and opportunities for debriefing need to be explored.
4. Explore additional opportunities for expanding nursing roles, integrating advanced skills while retaining and developing the nursing focus within these.

The overarching results from both the audit and the questionnaire identified the very real difference the LC CNS’s make for those patients with a diagnosis of lung cancer. The survival rate for those diagnosed with lung cancer is grim, with less than a third of people surviving for more than three years after diagnosis (Fox & White, 2013), making it imperative for these people to have clinical support from a nominated LC CNS. This study has validated the LC CNS role, with the research reinforcing the fact that the service needs to be supported and maintained to ensure it continues into the future.
References


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Appendices
Appendix 1

Standards of Service Provision for Lung Cancer Patients in New Zealand

Standards of Service Provision for Lung Cancer Patients in New Zealand

National Lung Cancer Working Group

2011
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Standards of Service Provision for Lung Cancer Patients in New Zealand
Introduction

Background

Lung cancer has a significant social impact due to the high rates of morbidity and mortality associated with the disease. Lung cancer mortality is higher in New Zealand than in some other Western nations. For example, New Zealand has a five-year relative survival of 10.4%, whereas Australia and Canada have five-year relative survivals of over 14%.

There are also significant variations in outcomes across New Zealand, with a range in five-year relative survivals of approximately 4–5% to 14%. Part of this variation in local outcomes is likely to be due to different standards of care.

Large ethnic disparities are seen not only in the incidence of lung cancer but also in outcomes. While some of these disparities can be explained by the lower relative socioeconomic status of minority ethnic groups in New Zealand, it is likely that higher tobacco use among Māori and Pacific people is an important contributor to the increased incidence of lung cancer in these populations. Mortality disparities are largely due to a significant number of cases not being diagnosed until the disease is well advanced.

The National Lung Cancer Working Group (NLCWG) has been charged with developing national standards of care for lung cancer patients in a bid to improve outcomes for lung cancer and reduce inequalities associated with this disease. The NLCWG has developed these standards for service provision based on the assumption that the various clinical staff, laboratories and other special investigations are credentialed by the appropriate governing bodies.

Objective

By developing national standards for the investigation, diagnosis, treatment and supportive care of lung cancer we aim to improve the overall care of all patients with lung cancer. The intention is that these national high-level standards will be implemented locally or regionally.
We envisage that the four regional cancer network lung cancer work groups will develop models of care with supporting systems and processes for how standards and good practice are implemented. This is in recognition of the fact that local processes and resources may vary, yet end up achieving the same overall result.

The standards will be the same for all ethnic groups. However, we expect that in implementing the standards district health boards (DHBs) may need to tailor their efforts to meet the specific needs of populations with comparatively poorer health outcomes, such as Māori and Pacific people.

The standards apply to any person or organisation that provides care and services to patients with lung cancer in New Zealand. It is also the intention of the NLCWG that these standards be used to develop key performance indicators that will be audited and used to drive improvements in services.

The NLCWG would like to emphasise the importance of patients being given the opportunity to participate in clinical trials.
How the lung cancer service standards were developed

The need for evidence-based practice has been recognised in the development of these standards. Numerous evidence-based guidelines and standards already exist, and so the standards in this document have largely been developed by referring to established international guidelines. These include:

• Australian Government National Health and Research Council and Australian Cancer Network, *Clinical Practice Guidelines for the Prevention, Diagnosis and Management of Lung Cancer* (referred to as ACN 2004)


Where no clear evidence is available, expert opinion has been obtained through the NLCWG. Wider consultation has taken place with key lung cancer sector stakeholders and relevant professional organisations (including the New Zealand branch of the Thoracic Society of Australia and New Zealand, New Zealand Association of Cancer Specialists and the Royal New Zealand College of General Practitioners).
These standards will be reviewed annually by the NLCWG. Researchers and other stakeholders should advise the chair of the NLCWG if important new information becomes available that might make standards and aspects of good practice out of date. The NLCWG will review the evidence and information and decide if the information is potentially important.

Summary of the clinical standards for the management of lung cancer services

The standards for the management of lung cancer have been divided into 10 clusters:

- timely access to services
- communication and referral
- data collection
- investigations
- multidisciplinary care
- smoking cessation
Standards of Service Provision for Lung Cancer Patients in New Zealand

- care co-ordination
- palliative care
- anticancer treatment
- follow-up.

The standards are as follows.

1. Timely access to services

Standard 1: Patients requiring active treatment should start treatment within 62 calendar days of secondary care receiving a referral.

Standard 2: Patients with clinical and/or radiological signs and symptoms suggestive of lung cancer should be seen by a specialist with an interest in respiratory medicine within 14 calendar days of secondary care receiving a referral.

Standard 3: Chest X-rays should be performed for all patients with symptoms suggestive of lung cancer and should be reported back to the referrer within seven calendar days of the radiology service provider receiving a referral.

2. Communication and referral

Standard 4: The formal referral pathway and required information should be agreed between primary, secondary and tertiary care. Communications between health care providers should include the patient’s name, date of birth and National Health Index (NHI) number, and ideally should be electronic.

3. Data collection
Standard 5: All patients with lung cancer should be entered into a lung cancer database.

4. Investigations

Standard 6: Computed tomography (CT) should be performed before a bronchoscopy.

Standard 7: All cancer centres should have timely access to endobronchial ultrasound (EBUS).

Standard 8: Staging positron emission tomography and computed tomography (PET-CT) should be performed in patients with suspected or confirmed non-small-cell lung cancer suitable for potentially radical treatment, with the exception of peripheral T1aN0 tumours.

5. Multidisciplinary care

Standard 9: All patients with lung cancer should be discussed at a multidisciplinary meeting.
6. Smoking cessation

Standard 10: All current smokers and their family/whānau should be offered smoking cessation advice and support to quit, where appropriate.

7. Care co-ordination

Standard 11: All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialises in cancer care, to provide psychosocial support, information and co-ordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with a specialist.

8. Palliative care

Standard 12: Patients who cannot be offered curative treatment, as well as those with a significant symptom burden, should be offered early access to palliative care services.

9. Active anti-cancer treatment

There is no specific standard for active anti-cancer treatment. However timely active anti-cancer treatment is important and is incorporated in the 62 calendar day wait time target between receiving a referral and start of treatment (see Standard 1).

10. Follow-up

Standard 13: All patients and their general practitioners should be given written information regarding a follow-up plan (including frequency of visits, tests required, and with which designated service), together with a nominated point of contact if there is a clinical concern.
Format of the standards

Each cluster of standards has a title that summarises the step of the patient journey or the area on which the standards are focused. This is followed by the standard itself, which explains the level of performance to be achieved. The rationale section explains why the standard is considered to be important.

Attached to most of the clusters of standards are good practice points. Good practice points are either supported by the international literature, the opinion of the NLCWG or the consensus of feedback from consultation with New Zealand clinicians involved in providing care to patients with lung cancer.
1. **Timely Access to Services**

**Standard 1** Patients requiring active treatment should start treatment within 62 calendar days of secondary care receiving a referral. (Expert opinion; NICE 2011)

**Standard 2** Patients with clinical and/or radiological signs and symptoms suggestive of lung cancer should be seen by a specialist with an interest in respiratory medicine within 14 calendar days of secondary care receiving a referral. (Expert opinion; NHS Scotland 2008)

**Standard 3** Chest X-rays should be performed for all patients with symptoms suggestive of lung cancer and should be reported back to the referrer within seven calendar days of the radiology service provider receiving a referral. (Expert opinion; Ministry of Health and New Zealand Guidelines Group 2009)

**Rationale**

Patients referred urgently with suspected cancer should be seen promptly and should complete their diagnostic investigations and start treatment within an acceptable timeframe. This is because delayed treatment can result in disease progression, resulting in some potentially curable patients becoming incurable. Palliative patients also require timely treatment, as most of the benefit from systemic treatment is achieved in patients with good performance.

The degree of benefit varies according to prognostic factors and performance status. The most significant gains in outcomes will be with early-stage non-small-cell lung cancer and small-cell lung cancer, and these patients should be prioritised for treatment.

The aim in setting waiting time targets is to encourage a culture of timely workup
and treatment and to work towards continual improvement. Where waiting times are longer than the time specified in the standard, local or regional services should work to reduce them to achieve the target. If the service is already meeting the target, then performance needs to be maintained and further improved.

**Good practice points**

1.1 The general practitioner (GP) practice should refer to secondary care services within one working day of receiving a diagnostic result indicating lung cancer. (Expert opinion)

1.2 Open access (same-day or no-wait service within the public system) for chest X-rays should be available inside working hours.

1.3 A contrast-enhanced CT scan of the lower neck, chest and upper abdomen should be performed as early as possible, where appropriate. Referral could be from primary or secondary care. (Expert opinion; NICE 2011)
1.4 Imaging reports should be received by the referrer within one working day of the examination being performed. (Expert opinion)

1.5 Electronic report distribution is desirable. (Expert opinion)

1.6 Systems should be developed at a local level to manage the further investigation and treatment of incidentally found abnormalities suggestive of lung cancer on radiological imaging.

Key references

2. Communication and Referral

**Standard 4** The formal referral pathway and required information should be agreed between primary, secondary and tertiary care. Communications between health care providers should include the patient’s name, date of birth and National Health Index (NHI) number, and ideally should be electronic. (Expert opinion)

**Rationale**

The purpose of the referral pathway is to ensure that all patients with suspected lung cancer are referred to the most appropriate health care service, and that appropriate standardised information is available in the referral.

**Good practice points**

2.1 The referral should contain the words ‘suspected lung cancer’ to help with prioritisation. (Expert opinion)

2.2 Electronic proforma-based referral is desirable. (Expert opinion)

2.3 Two-way communication between primary, secondary and tertiary care should be encouraged during the patient’s lung cancer journey.

**Key references**


Note: these guidelines are no longer supported by the Ministry of Health because they are not up to date. The elective services section of the Ministry of Health has advised that the guidelines be reviewed by local specialists and GPs before they are adopted.


Note: the radiation treatment booking priorities are being reviewed by the Radiation Oncology Advisory Group.
3. Data Collection

**Standard 5**  
All patients with lung cancer should be entered into a lung cancer database. (Expert opinion; National Lung Cancer Audit in England and Wales)

There is currently no national cancer database other than the New Zealand Cancer Registry, so information on patients with lung cancer should be collected systematically on local or regional lung cancer databases to support multidisciplinary cancer care and to allow future local, regional and national collation and analysis.

The NLCWG is currently developing a lung cancer data set to help with service and clinical monitoring.

The multidisciplinary team will be responsible for collecting and managing the information relating to patients with lung cancer.

**Rationale**

The aim of this standard is to construct a database for lung cancer to integrate demographic, diagnostic, treatment, outcome and other medical information to contribute to service and clinical performance monitoring and research to improve patient outcomes.

**Good practice points**

3.1 Patients should be informed that information is being recorded in a lung cancer database to help the multidisciplinary team propose a treatment plan and to monitor and evaluate access to services.
3.2 Where data is collected, it should be done in accordance with the National Cancer Core Data Definition.

**Key references**

4. **Investigations**

**Standard 6**  
Computed tomography (CT) should be performed before a bronchoscopy. (BTS 2010; NICE 2011)

**Standard 7**  
All cancer centres should have timely access to endobronchial ultrasound (EBUS). (Expert opinion)

**Standard 8**  
Staging positron emission tomography and computed tomography (PET-CT) should be performed in patients with suspected or confirmed non-small-cell lung cancer suitable for potentially radical treatment, with the exception of peripheral T1aN0 tumours. (BTS 2010; NICE 2011)

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**Rationale**

Successful treatment of lung cancer depends on the accurate diagnosis and staging of the lung cancer.

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**Good practice points**

4.1 Choose investigations that give the most information about diagnosis and staging with least risk to the patient. Think carefully before performing a test that gives only diagnostic pathology when information on staging is also needed to guide treatment. (NICE 2011)

4.2 Non-ultrasound guided transbronchial needle aspiration (non-US TBNA) should be carried out at the time of bronchoscopy in appropriate patients, guided by CT or PET scans. (NICE 2011)
4.3 Use endobronchial ultrasound-transbronchial needle aspiration (EBUS-TBNA) or non-US TBNA as the preferred diagnosis and staging tests, in appropriate patients, based on information provided by CT or PET-CT scans. (NICE 2011)

4.4 Patients thought to have N2/N3 disease, based on information provided by the PET-CT scan, should have their disease pathologically confirmed unless they have obvious distant metastatic disease or multiple nodal stations, in keeping with locally advanced lung cancer. (BTS 2010; NICE 2011)

4.5 Patients considered suitable for potentially radical treatment should have lung function assessment including gas transfer DLCO studies performed. (BTS 2010; NICE 2011)

4.6 Selected patients undergoing surgery for lung cancer will require cardiopulmonary exercise testing. (Expert opinion)

4.7 Consider CT of the head as part of staging investigation in patients with small-cell lung cancer or locally advanced non-small-cell lung cancer. (BTS 2010; NICE 2011)
Key references


5. Multidisciplinary Care

Standard 9  All patients with lung cancer should be discussed at a multidisciplinary meeting. (Expert opinion)

Rationale

The cornerstone of best practice in cancer care is multidisciplinary treatment planning and multidisciplinary care. An effective multidisciplinary approach can result in survival benefits, increased recruitment into clinical trials, reduction in service duplication and improved co-ordination of services.

Good practice points

5.1 All referrals to a multidisciplinary meeting should include demographic data, provisional staging, and clinical factors such as: current symptoms, performance status, weight loss, medical co-morbidity, bronchoscopy, relevant imaging, pathological diagnosis (if available) and lung function to maximise the chance of making appropriate clinical decisions. (Expert opinion)

5.2 The multidisciplinary team should record information in a database that can be collated and analysed locally, regionally and nationally. (Expert opinion)

5.3 The multidisciplinary discussion report should include treatment recommendations and intent, where possible, as well as reasons for any variation from standard practice. (Expert opinion)

5.4 The treating clinician should record the reason for not following the treatment plan recommended by the multidisciplinary team. (Expert opinion)
5.5 Patients and their GP should be informed of the recommendations of the multidisciplinary discussion within two working days of the meeting. (Expert opinion)

5.6 The recommendations of the multidisciplinary discussion should be available as an electronic record and accessible to other members of the health care team. (Expert opinion)

Key references


6. Smoking Cessation

**Standard 10** All current smokers and their family/whānau should be offered smoking cessation advice and support to quit, where appropriate.

**Rationale**

There is evidence for improved outcomes in patients with lung cancer who stop smoking. This is self-evident for those patients who are treated with curative intent. Patients with advanced disease who are being treated with palliative intent, particularly those being treated with tyrosine kinase inhibitors, also have improved outcomes if they stop smoking. The greatest gains from smoking cessation will be for family/whānau who are current smokers.

Smoking cessation needs to be approached with sensitivity. It is important that patients and family/whānau do not experience a sense of blame regarding their smoking status.

This standard is in line with the Government health target ‘Better help for smokers to quit’.

**Good practice point**

6.1 Inform patients that smoking increases the risk of post-treatment complications and may decrease the effectiveness of some anti-cancer treatments. (NICE 2011; expert opinion)

6.2 Patients and family/whānau should be provided with smoking cessation advice in keeping with the ‘ABC’ approach as set out in the Ministry of Health’s guidance on smoking cessation.
6.3 Referral to quit smoking treatment services such as Quitline and Aukati KaiPaipa is a key component of the ‘ABC’ approach.

More information on quitting smoking can be found at http://www.moh.govt.nz/tobacco

Key references


7. Care Co-ordination

Standard 11  All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialises in cancer care, to provide psychosocial support, information and co-ordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with a specialist.

Rationale

The cancer journey is complex and it is not uncommon for a patient to be seen by many specialists within and across multiple DHBs and across the public and private sectors.

Care co-ordination refers to a system or a role primarily intended to expedite patient access to services and resources, improve communication and the transfer of information between services, address patients’ informational needs and improve continuity and co-ordination of care throughout the cancer continuum. Services need to ensure they have strategies in place that improve the co-ordination of care.

There should be a single point of contact for patients and caregivers through the various stages of the lung cancer journey. A key priority in the NICE clinical guideline for the diagnosis and treatment of lung cancer is to ensure that a lung cancer clinical nurse specialist is available at all stages of care to support patients and their carers.

Good practice points

7.1  All regional cancer centres should have a dedicated lung cancer nurse specialist. (Expert opinion; NICE 2011)
7.2 Patients should be kept informed about all the processes involved in diagnosing and treating lung cancer, in a manner appropriate to their individual needs.

7.3 Patients should have their supportive care and psychosocial needs assessed at each stage of their lung cancer journey.

7.4 The information, treatment and care patients are given should be culturally appropriate for Māori, Pacific people and other ethnicities.

7.5 Consideration of preferred priorities of care (advance care directives) is encouraged in those for whom cure is not possible. Wherever possible, avoid leaving this discussion until the terminal stages of the illness. (Expert opinion; NICE 2011)
Key references


(accessed 17 April 2011).

8. **Palliative Care**

**Standard 12** Patients who cannot be offered curative treatment, as well as those with a significant symptom burden, should be offered early access to palliative care services. (Expert opinion; NICE 2011)

**Rationale**

The majority of patients with lung cancer will ultimately die of their disease. Most will experience a significant symptom burden during their cancer journey, emphasising the important role of palliative care in patients with lung cancer. Palliative care interventions can prolong survival in non-small-cell lung cancer.

**Good practice points**

8.1 Most patients with lung cancer would benefit from a palliative care team helping with symptom management, psychosocial support and attention to spiritual needs. (Expert opinion)

8.2 Supportive and palliative care of the patient should be provided by general and specialist palliative care providers. (NICE 2011)

8.3 Patients who may benefit from specialist palliative care services should be identified and referred without delay. (NICE 2011)

8.4 An integrated care pathway for the dying should be implemented in hospitals, hospices and other care settings (residential care homes and patients’ homes).

8.5 Cultural and spiritual support should be made available, if required.
Key references


9. **Active Anti-Cancer Treatment**

Although no specific standards have been defined for active treatment, timely active anti-cancer treatment is important and is incorporated in the 62 calendar day waiting time target between receiving a referral and start of treatment (see Standard 1).

The degree of benefit varies according to prognostic factors and performance status. The most significant gains in improved outcomes will be with early-stage non-small-cell lung cancer and small-cell lung cancer, and therefore these patients should be prioritised for treatment.

**Good practice points**

Good practice promotes best clinical practice in relation to the care and management of patients with lung cancer. The adoption of the following good practice points is encouraged.

**Surgery**

9.1 Surgery should be performed by an appropriately credentialed thoracic surgeon. (Expert opinion)

9.2 An assessment of the operative risks using standard scoring tools should be undertaken and recorded for audit purposes. (NICE 2011)

9.3 Systematic nodal dissection should be performed in all patients undergoing resection for lung cancer. A minimum of six nodes/nodal stations should be sampled at the time of surgery to improve the accuracy of pathological staging. (BTS 2010)

9.4 A multidisciplinary team review of post-surgical pathological findings should be undertaken for all patients other than T1aN0. (Expert opinion)
Radiation therapy

9.5 All radical patients should be planned with 3D technology. (BTS 2010)

9.6 External and internal motion should be considered and managed, particularly in radical settings. (Expert opinion)

9.7 The prescribed dose to the planning target volume and at-risk organs (at least the volume of lung receiving greater than 20 Gy, mean lung dose) should be recorded for future analysis. (Expert opinion)

9.8 Patients with stage II or III non-small-cell lung cancer receiving radiation with curative intent should be considered for concurrent chemotherapy. (NICE 2011; NCCN 2011)

9.9 Patients with limited-stage small-cell lung cancer (broadly staged as T1-4, N0-3, M0) should be considered for concurrent or sequential chemoradiation if they are fit enough. Radiotherapy should ideally be started during the first or second cycle of chemotherapy. (NICE 2011)
9.10 Patients with small-cell lung cancer should be considered for prophylactic cranial irradiation if their disease has not progressed on first-line treatment. (ACN 2004; NCCN 2011; NICE 2011)

**Systemic therapy**

9.11 **Chemotherapy** should be prescribed, administered and monitored by appropriately trained clinicians. (Expert opinion)

9.12 Post-surgical non-small-cell lung cancer patients with good performance status and T1-3, N1-2, M0 pathological disease should be offered post-operative platinum-based combination chemotherapy. (NICE 2011)

9.13 Patients with stage II or III non-small-cell lung cancer and good performance who are not candidates for surgery by virtue of stage or co-morbidity should be considered for concurrent chemoradiation. (NCCN 2011; NICE 2011)

9.14 Patients with stage III or IV non-small-cell lung cancer and good performance status should be considered for platinum-based combination chemotherapy to improve survival, disease control and quality of life. Patients who cannot tolerate platinum-based combination chemotherapy may be offered single-agent chemotherapy with a third-generation drug. (NICE 2011)

9.15 Patients with T1-4, N0-3, M0 small-cell lung cancer and good performance status should be considered for concurrent chemoradiation. (NICE 2011)

9.16 Patients with extensive-stage small-cell lung cancer should be considered for platinum-based combination chemotherapy up to a maximum of six cycles. (NICE 2011)

**Key references**


10. Follow-up

**Standard 13** All patients and their general practitioners should be given written information regarding a follow-up plan (including frequency of visits, tests required and with which designated service), together with a nominated point of contact if there is a clinical concern. (Expert opinion)

**Rationale**

Follow-up care is sometimes offered, with the main objective being to detect distant recurrence at an early stage so that treatment for any relapse can be started. However, there is insufficient evidence to recommend any particular schedule of patient follow-up after treatment for lung cancer.

There is no convincing proof that intensive follow-up approaches based on regular laboratory and radiological investigations improves outcomes in asymptomatic patients. Routine testing beyond a plain chest X-ray in asymptomatic patients should be discouraged to free up resources and reduce delays in diagnosing new cancers.

**Good practice points**

10.1 There is no evidence that the routine use of CT and PET-CT, tumour markers or bronchoscopy in asymptomatic patients has any effect on outcome. Routine use of these tests in follow-up of asymptomatic patients should therefore be discouraged. (Expert opinion)

10.2 Patients should be informed whether they will be offered regular follow-up appointments after completing treatment and whether the clinical follow-up will be carried out through a hospital outpatient service or in the community by a GP. (Expert opinion)
10.3 If the GP is responsible for longer-term follow-up, there needs to be an agreed assessment and investigation plan documented. (Expert opinion)

Key references


URL: http://www.nice.org.uk/nicemedia/live/13465/54199/54199.pdf

(accessed 19 May 2011).
Appendix 1:

National Lung Cancer Working Group Membership

Chair

Dr Charles de Groot, Clinical Oncologist, Waikato Hospital

Members

Dr Scott Babington, Radiation Oncologist, Christchurch Hospital

Dr Ben Brockway, MB BS BSc (Hons) MRCP (Lond), Consultant and Senior Lecturer in Respiratory Medicine, Dunedin Hospital and Dunedin School of Medicine, University of Otago, Dunedin

Professor Richard Edwards, MB BCHIR, MRCP, MFPH (UK), MD, Professor of Public Health and Head of Department, University of Otago, Wellington School of Medicine and Health Services (joined in June 2011)

Dr James Entwistle, Clinical Leader, Radiology Department, Wellington Hospital, Capital and Coast DHB

Dr Tana Fishman FRNZCGP (Dist), Senior Lecturer, University of Auckland Department of General Practice and Primary Health Care; Greenstone Family Clinic, Manurewa, Auckland

Dr Greg Frazer, Respiratory and General Physician, Christchurch Hospital; Clinical Senior Lecturer, University of Otago, Christchurch

Dr Jeffrey Garrett, Associate Professor, Respiratory Physician, Middlemore Hospital, Auckland

Dr David Hamilton, Radiation Oncologist, Capital and Coast DHB
Dr Willem Landman, Palliative Medicine Specialist, Middlemore Hospital and Hospice South Auckland, Counties Manukau DHB

Mrs Bubsie Macfarlane, Arohai Mai Cancer Support Services, Rotorua (joined in June 2011)

Dr Kim McAnulty, Radiologist, Waikato Hospital, Waikato Clinical School, University of Auckland

Mr Glen McKay, bsc mb chb fracs (General & Cardiothoracic), Department of Cardiothoracic Surgery, Capital and Coast DHB

Linda O’Grady, Clinical Nurse Specialist Lung Cancer, Northland DHB

Dr Andrew Simpson md, fracp, Medical Oncologist, Clinical Director Central Cancer Network; Executive Director, Medicine, Cancer, Community Capital and Coast DHB

Dr Wendy Stevens mbbs, phd, Dip Grad (Stats), Senior Researcher Northern Cancer Network and Discipline of Oncology, Faculty of Medical and Health Sciences, University of Auckland (November 2009 – June 2011).

Dr Ziad Thotathil, md dnbr mnams frcr, Radiation Oncologist, Regional Cancer Centre, Waikato Hospital
Appendix 2:
Terms of Reference of the National Lung Cancer Working Group

Purpose

1. To ensure the development of efficient and sustainable best practice management of primary thoracic malignancy in the New Zealand health system

2. To promote a nationally co-ordinated and consistent approach to the delivery of care for primary thoracic malignancy patients, promoting equitable, timely and quality care for all patients and family/whānau.

Aims

• To develop/adopt lung cancer specific patient management frameworks to guide service provision and promote uniform standards of service provision across New Zealand

• To develop and agree on national clinical minimum standards and protocols drawn from evidence-based international guidelines including prevention, diagnosis, treatment, palliative and supportive care for all patients with primary thoracic malignancy

• To agree on appropriate minimum datasets/metrics for measuring service and treatment effectiveness. This would include advice for establishing appropriate key performance indicators

• To identify systemic barriers and gaps in services and provide advice to appropriate fora and groups to support successful resolution

• To promote fora for discussion to advise on and make recommendations on new treatments and technologies that may impact on primary thoracic malignancy
• To develop and maintain a list of priority initiatives to feed into the national cancer prioritisation process

• To promote lung cancer research and advise on appropriate directions for research in the New Zealand context

• To act as a representative and advocacy body for all stakeholders with an interest in primary thoracic malignancy.

Membership

1. The National Clinical Director of Cancer, the interim chair and the four regional lung cancer working group chairs will appoint members to the working group following an appropriate nomination process within each of the related disciplines.

2. The Chair of the National Lung Cancer Working Group will be elected by the members of the working group. The Chair will be appointed for a two-year term and may be reconfirmed for a further two years as agreed by the members of the working group.
3. Membership will comprise some elected members and some appointed members to ensure that professional disciplines, geographical coverage and the continuum of representatives are included. The following disciplines should be included in the membership of the working group:

- chairs of the regional lung cancer working groups (who can also be one of the specialties listed below)
- disciplinary physicians
- radiation oncologist
- medical oncologist
- thoracic surgeon
- clinical nurse specialist
- radiologist
- regional cancer network clinical director (if already not included)
- primary health representative
- consumer representative
- Māori representative
- palliative care
- research
- public health
• pathologist by invitation.

4. Membership of the working group will be for two years initially, with the option of reappointment for a further two years.

5. If a member is absent from three consecutive meetings, that member can be removed and another can be elected/appointed in their place.

Work programme

6. The National Lung Cancer Working Group will provide a high-level work-plan to the Cancer Treatment Advisory Group as soon as possible following its establishment and at the beginning of each financial year.

Meetings

7. The working group will meet quarterly, either face to face or by teleconference.

Funding

8. The National Lung Cancer Working Group is not a fund-holding organisation.
Support

9. The Ministry of Health will contribute funding to support the chair of the National Lung Cancer Working Group in his/her role.

10. During the establishment phase, the Ministry of Health will provide secretariat and analyst support to the Working Group, including arranging the meetings, and the distribution of agendas and minutes.

11. Travel and time will be funded through the representative’s employer for DHB employees. The Ministry of Health will fund travel and appropriate costs for people not employed by DHBs.

12. A national primary thoracic malignancy stakeholder database will be developed and maintained by the National Lung Cancer Working Group secretariat (Ministry of Health).

13. A communications plan will be developed and maintained to ensure that there is appropriate and timely communication to stakeholders and strong links with the regional/local lung cancer working groups.

Reporting

14. The National Lung Cancer Working Group will provide its recommendations to the Cancer Treatment Advisory Group and via this process to the joint DHB/Ministry of Health Cancer Control Steering Group.

15. The National Lung Cancer Working Group will also report back to its various stakeholder groups and organisations on progress.
Appendix 3:
Governance Structure for the Cancer Control Programme

District Health Boards
Four Regional Cancer Networks

Ministry of Health

Cancer Control Steering Group
(joint DHB and Ministry of Health group)

Cancer Control Programme
Advisory Groups
Cancer Treatment Advisory Group
Palliative Care Advisory Group

National Lung Cancer Working Group

Northern Regional Lung Cancer
Midland Regional Lung Cancer
Central Regional Lung Cancer
Southern Regional Lung Cancer

Palliative Care
Control
(sub group)
**Appendix 4:**

**Abbreviations used in this document**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>3D</td>
<td>three-dimensional</td>
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<tr>
<td>ACN</td>
<td>Australian Cancer Network</td>
</tr>
<tr>
<td>BTS</td>
<td>British Thoracic Society</td>
</tr>
<tr>
<td>CT</td>
<td>computed tomography</td>
</tr>
<tr>
<td>DHB</td>
<td>district health board</td>
</tr>
<tr>
<td>DLCO</td>
<td>diffusing capacity of the lung for carbon monoxide</td>
</tr>
<tr>
<td>EBUS</td>
<td>endobronchial ultrasound</td>
</tr>
<tr>
<td>EBUS-TBNA</td>
<td>endobronchial ultrasound–transbronchial needle aspiration</td>
</tr>
<tr>
<td>GP</td>
<td>general practitioner</td>
</tr>
<tr>
<td>Gy</td>
<td>Gray (unit), an international unit of absorbed radiation dose of ionising radiation</td>
</tr>
<tr>
<td>IT</td>
<td>information technology</td>
</tr>
<tr>
<td>NCCN</td>
<td>National Comprehensive Cancer Network</td>
</tr>
<tr>
<td>NHI</td>
<td>National Health Index</td>
</tr>
<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute of Clinical Excellence</td>
</tr>
<tr>
<td>NL-CWG</td>
<td>National Lung Cancer Working Group</td>
</tr>
<tr>
<td>non-US TBNA</td>
<td>non-ultrasound guided transbronchial needle aspiration</td>
</tr>
<tr>
<td>NZGG</td>
<td>New Zealand Guidelines Group</td>
</tr>
<tr>
<td>PET-CT</td>
<td>positron emission tomography and computed tomography</td>
</tr>
<tr>
<td>TNM</td>
<td>tumour node metastasis cancer staging system</td>
</tr>
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</table>
References


Appendix 2
Ethics Approval

Ms G Halksworth-Smith
Centre for Postgraduate Nursing Studies (Chch)
72 Oxford Terrace, Levels 2 and 3
University of Otago, Christchurch

6 November 2013

Dear Ms Halksworth-Smith,

I am again writing to you concerning your proposal entitled "Exploring the Advanced Nursing Role within a Regional Lung Cancer Service", Ethics Committee reference number 13/114.

Thank you for your letter dated 24 October 2013 addressing the issues raised by the Committee.

The Committee thanks you for the comments made in relation to the potential sensitive outcome for the Clinical Nurse Specialist (CNS) noting that she is aware of the project and welcomes the opportunity for the role to be reviewed. The Committee further appreciates the confirmation that the CNS will have the full support of the management team who will be available should the CNS require any support.

With regard to the issue of safeguards to manage any employment issues the Committee appreciates that any management issues will be managed by the management team headed by the Director of Nursing.

The Committee is also grateful to note that the study has been peer reviewed and asks that a copy is sent to me.

The Committee is grateful for the amended introduction to the questionnaire as requested.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.
Yours sincerely,

[Signature]

Mr Gary Witte  
Manager, Academic Committees  
Tel: 479 8256  
Email: gary.witte@otago.ac.nz

c.c. Assoc. Prof. L Whitehead  Director  Centre for Postgraduate Nursing Studies (Chch)
Appendix 3

Maori Consultation

19 November 2012

Ms Gill Halksworth-Smith
Centre for Postgraduate Nursing Studies
University of Otago, Christchurch

Mā te rangahau hauora e taukoko te whakapiti ake te hauora Māori
All health research in Aotearoa New Zealand benefits the hauora (health and wellbeing)
of tangata whenua

Tena koe Gill,

Thank you to you and Maureen Trewhin, for taking the time to meet with me at the University of
Otago, Christchurch on Monday 5 November 2012, to discuss your research study titled:

*Exploring the Advanced Nursing role within a Regional Lung Cancer Service*

I note that your research is a 2 year Masters thesis that aims to explore the role of lung cancer
CNS and its impact on patient care.

As your research is an audit/survey, it is always challenging to make comment in terms of
achievement for improving health status and in particular Maori health status. However, I note
in your discussion that you made reference that the leading cause of cancer deaths for Maori
between 1996 and 2006.

It was apparent in your research summary, that there could be a small number of Maori
participants and that this research may have impact on Maori health, which is important.

Maori health workers, Maori health providers and Maori health professionals should be relatively
accessible and well placed to advise you as to a relevance of your research and the outcomes
which can be achieved for Maori health and the population overall.

We also discussed the relevance of the research in regard to improving Maori health status and
referred to the 1. HRC’s Nga Pou Rangahau Hauora Kia Whakapiti Ake Te Hauora Māori 2004-
The other reference that is available is 3. Hauora Māori Standards of Health IV: A Study of the
Years 2000-2005 by Bridget Robson and Ricci Harris, Maori Health Research Unit, Wellington
School of Medicine, University of Otago, Wellington. All provide Maori specific information on a
range of health issues.

The recent publication *Tatau Kahukura: Maori Health Chart Book 2010*, Ministry of Health, 2010
(2nd edition), is an update relating to the socio economic determinants of health, health status
and service utilization of the Maori population. Further references are available from the HRC’s
*Guidelines for Researchers on Health Research Involving Maori* (page 22), www.hrc.govt.nz

It was agreed that there is a need to acknowledge the issues pertaining to ethnicity and to consider how ethnicity data will be collected in your study. Also, given the poor ethnicity data collection in hospital databases, this information is collected in demographic information and supplied to the Ministry of Health, as part of the research. Through our discussion, the Census 2006 ethnicity question was considered to be the preferred tool in recording ethnicity.

It is a requirement of the ethics approval process, that a final report be submitted when the research is complete. A copy of the report should also be supplied to me at that time, as findings from this project may contribute to the development of future research hypotheses or projects. It is therefore important that appropriate Maori organisations, Maori health professionals and Maori researchers are aware of your findings. The Research Office of the University of Otago, Christchurch and in particular myself as the Research Manager - Maori would be willing to assist in the dissemination of your findings once your project has reached a successful conclusion.

My suggestions do not necessarily relate to ethical issues with your research, including methodology. Other committees may also provide feedback in these areas. Please contact me should you need any other information that may not have been included in this letter that was relevant to our conversation.

I wish you well in your research.

"Mo tatou a mo ka uri a muri ake nei" Ngai Tahu 2025
For us and our children after us

Ka nui tonu nga mihi

[Signature]

Elizabeth Cunningham
Research Manager - Maori
Appendix 4

Information Sheet for Participants

PARTICIPANT INFORMATION SHEET

Study title: Exploring the Advanced Nursing Role within a Regional Lung Cancer Service

Ethics committee ref:
Lead Investigator: Gillian Halkworth-Smith,
Senior Lecturer,
University of Otago
Contact phone number: (03)364 865

Thank you for taking the time to read this information sheet. You are invited to take part in an online survey which explores the role of the Cancer Nurse Specialist.
Please make sure you have read and understood the information provided here before deciding whether to take part in this study.

WHAT IS THE PURPOSE OF THE STUDY?

This study explores the impact of an advanced nursing role in a specialty area, that of lung cancer. The lung cancer Clinical Nurse Specialist (CNS) is a member of the multi-disciplinary team, it is important to evaluate this role to ensure on-going development of the service.

Up to 50 members of the wider multidisciplinary cancer team are being invited to complete this survey. You have received this invitation because of the position you hold within this team.

WHAT WILL MY PARTICIPATION IN THE STUDY INVOLVE?

You will be invited to complete an online survey, consisting of nine questions. It is anticipated that this will take approximately 10 minutes.

POSSIBLE BENEFITS AND RISKS OF THIS STUDY?

While there is no direct benefit to you from participating in this study, it is hoped that the findings from this study will be used to inform future strategic development of the lung cancer CNS role. Your participation allows you to take part in this process.

We do not anticipate any risks for you personally, from completing this questionnaire.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

The findings from this study may be used for publications/presentations. Please be assured that all responses will be treated anonymously and in confidence.
If you have any questions, concerns or complaints about the study at any stage, you can contact:

Maureen Trewin
364 0167, Ex 88141
maureen.trewin@cdhb.health.nz

Or - Dr Sandra Richardson, Senior Lecturer, University of Otago. Ph – (03) 364 865
Appendix 5
Survey Questionnaire

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**Lung Cancer Clinical Nurse Specialist**

This survey is currently being undertaken as part of a Master of Health Sciences (Nursing) thesis, to explore the advanced practice role of nurses in the speciality area of lung cancer. The lung cancer Clinical Nurse Specialist (CNS) is a member of the multi-disciplinary team, and it is important to evaluate this role so that future service developments can be strategically planned. Members of the wider health care team providing care for cancer patients, who work alongside the CNS, are being approached to provide feedback on the role.

The survey findings will be presented with any individual identifiers removed, and while demographic information is being collected, this is to identify the representativeness of the survey respondents and will not be used in a way that will identify participants.

Please complete the following demographic questions:

1. **Gender**
   - [ ] Male
   - [ ] Female

2. **Age**
   - [ ] 20-24
   - [ ] 25-29
   - [ ] 30-39
   - [ ] 40-49
   - [ ] 50-59
   - [ ] 50+

3. **Ethnicity (you may select more than one answer)**
   - [ ] NZ European
   - [ ] Maori
   - [ ] Samoan
   - [ ] Cook Island Maori
   - [ ] Other (please specify)

4. **Please select your occupation from the following list:**
   - [ ] Medical Staff
   - [ ] Physiotherapist
   - [ ] Radiation Therapist
   - [ ] Social Worker
   - [ ] Psychologist
   - [ ] Maori Health Worker
   - [ ] Occupational Therapist
   - [ ] Nursing - (please state below)
   - [ ] Other - (please state below)

If you selected either ‘nursing’ or ‘other’ above, please specify below, e.g. the area of nursing you work in, e.g. Palliative Care, Oncology; or state any other role you may hold, e.g. speech language therapist
5. Please identify how many years you have been working in community/hospital cancer care

- □ <5 yrs
- □ 6-10 yrs
- □ 11-15 yrs
- □ >15 yrs
- □ 16-20 yrs
- □ >20 yrs

6. Standard 11 from the Standards of Service Provision for Lung Cancer Patients in New Zealand states:

“All patients with suspected lung cancer should have a nominated single point of contact, ideally a nurse who specialises in cancer care, to provide psychological support, information and co-ordination of a patient’s cancer journey. Contact will be made with the patient within seven calendar days of the initial assessment with a specialist”.

Do you believe the lung cancer CNS’s fulfill this key priority?

- □ Yes
- □ No

Please comment on how you see this being met, or why you think it is not met!
### Lung Cancer Clinical Nurse Specialist

#### 7. Q 7 CHANGED QUESTION AFTER SURVEY COMPLETION

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
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<th>Neither Agree or Disagree</th>
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<tr>
<td>1. The CNS plays an integral role in co-ordination of patient care</td>
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<tr>
<td>2. Patients are kept well informed about the diagnosis and treatment of their lung cancer, in a manner appropriate to their individual needs, by the lung cancer CNS</td>
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<td></td>
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<td>3. The patient’s needs in terms of supportive care and psychological needs are assessed on an ongoing basis, by the lung cancer CNS</td>
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<td>4. Patients are treated in a culturally appropriate manner</td>
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<td>5. Consideration of advanced care planning is encouraged by the lung cancer CNS</td>
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<tr>
<td>6. There is value in the lung cancer CNS attending clinical appointments with lung cancer patients</td>
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<td>7. All patients with a diagnosis of lung cancer have equal access to the lung cancer CNS service</td>
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</table>

Please add any other comments you feel relevant to understanding your responses
8. The lung cancer CNS is involved in many aspects of patient care and service delivery. In 2011 the MOH released the National Lung Cancer Standards with the express purpose of improving outcomes for patients with lung cancer.

Please consider each of the following statements and state your level of agreement with each of them:

- The CNS plays an integral role in co-ordination of patient care
- Patients are kept well informed about the diagnosis and treatment of their lung cancer, in a manner appropriate to their individual needs, by the lung cancer CNS
- The patient's needs in terms of supportive care and psychological needs are assessed on an ongoing basis, by the lung cancer CNS
- Patients are treated in a culturally appropriate manner
- Consideration of advanced care planning is encouraged by the lung cancer CNS
- There is value in the lung cancer CNS attending clinical appointments with lung cancer patients
- All patients with a diagnosis of lung cancer have equal access to the lung cancer CNS service

Please add any other comments you feel relevant to understanding your responses.
9. What do you consider the greatest benefit the lung cancer CNS’s bring to patient care?

10. Please provide any additional comments regarding the role of the CNS, with regards to the care of a lung cancer patient
## Appendix 6

### Audit Tool Example

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<td>FSA – by Whom</td>
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**Frequency of follow-up (face-to-face or email/phon)**

- 12 face to face

<table>
<thead>
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<td>MDM Decision</td>
<td>Further investigations</td>
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<td>Treatment Intent</td>
<td>Palliative treatment</td>
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<td>Start date for Tx (e.g. chemo)</td>
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<td>Rad Onc</td>
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<td>Deceased</td>
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<tr>
<td>Discussed ACP</td>
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<tr>
<td>Referral to other services- i.e. Pall care</td>
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</table>

**Illustrations of Involvement**

Pt supported by xxxx. Evidence that the CNS had multiple conversations with the family regarding treatment and symptoms. Evidence that the LC CNS discussed and explained Chemo treatment and medications with Pt. both pre and during Chemo regime. The LC CNS also offered advice regarding symptom management – i.e. fatigue, BNO, hoarse voice.

**Total Number of Other Health Professionals**

S/B total of 7 other health professionals