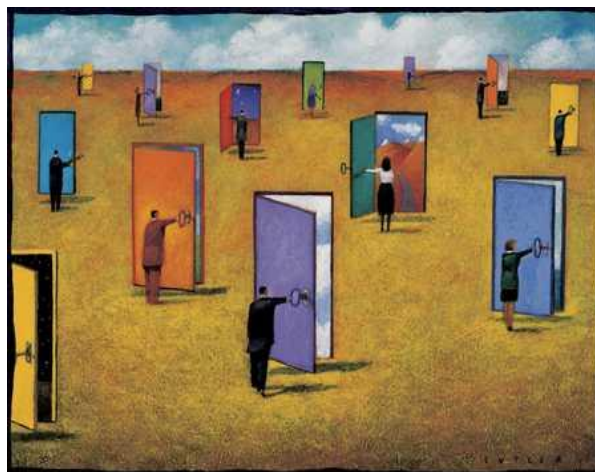# Opening doors to treatment

Exploring the impact of lung cancer specialist nurses on access to anti-cancer treatment: an exploratory case study

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Opening doors to treatment: Exploring the impact of lung cancer specialist nurses on access to anti-cancer treatment, an exploratory case study

Summary

Background

This exploratory study examined how different Lung Cancer Nurse Specialists (LCNS) worked within their Multi-disciplinary Teams (MDT) to have a positive impact on patient access to anti-cancer treatment. The study used a mix of qualitative methods including individual and group interviews, observation and documentary analysis.

The project was developed in response to the finding from the National Lung Cancer Audit (2010) that 64% of patients who saw a LCNS received anti-cancer treatment, compared to 30% of patients who did not see a LCNS. This project aims to generate insight to understand what it is the LCNS does that increases patient access to treatment.

Aim and scope

The aim of this study was to conduct an initial exploration to generate understanding of the role of the LCNS within the lung cancer multi-disciplinary team and identify factors that assist the LCNS in increasing treatment access for people with lung cancer and to generate recommendations for LCNS practice, MDT working and for future research.

Methods

Case study methods were adopted including individual interviews with the LCNS, clinical lead and up to four additional MDT members, observation of the MDT meeting and documentary analysis. NHS Research Ethics was not required as only staff were involved. NHS Research Governance and University Ethics approval was obtained.

Sample

The case was the LCNS. Four cases were purposively selected to include LCNSs working in sites with high and low treatment access as identified by the National Lung Cancer Audit (NLCA). The NLCA data was used to inform selection of sites with different treatment and LCNS access for patients. Individual interviews were conducted with up to six clinicians per case, comprising, the LCNS (n=4), the lead clinician for the MDT (n=4), plus three to five other MDT members (total for MDT members = 16). A total sample across staff groups was

24. One MDT meeting was observed for each case study site along with documentary analysis of a small sample of (n = 2-3) documents related to the LCNS role, for example job descriptions, patient pathways and protocols.

Two focus groups were held at the end of the study to expand and verify the findings amongst a broader sample of LCNSs (n=6) and wider MDT members (n=2).

Findings

The findings provide in-depth insight and understanding of the way the LCNS has an impact on treatment access, through their influence upon and work with patients, staff and organisational structures, processes and systems. The LCNS worked differently in the different sites according to local resources, geography and demographics. However, elements of the way they worked were similar and were seen to be instrumental to their impact on treatment access. The role was pervasive and had an influence across a range of people, places and structures. Unlike other MDT members, whose input was more episodic, the LCNS was the one MDT member who worked continuously with the patient across the pathway. The LCNS was referred to as the "hub", as being key to the delivery of care and the efficiency of the related systems and processes. Core themes that described this pivotal contribution were having a central role, continuity, co-ordination, and support and advice.

The specialist nurses worked flexibly and in an entrepreneurial manner in order to enhance their impact on patient care and outcomes, such as treatment access. The findings describe how the LCNS is able to enhance delivery of the whole service and function of the MDT. However, this means it is difficult to extract any one particular element which is discrete to the LCNS impact on treatment access. The picture is much more complex and the LCNS impact is symbiotic and synergistic to the working of the MDT. What is clear is that the LCNS role is crucial and at times the catalyst to patient eligibility for treatment. Some participants did not appreciate the extent of this impact until they reflected on practice due to participation in the study. The impact on treatment access is described here in terms of the tasks identified that the LCNS undertakes, for example assessment, managing symptoms and early and appropriate referral.

The co-ordination and communication aspects of the LCNS role are essential in realising the impact in increasing treatment access. The findings illustrate how the LCNS is described as the hub, the oil on the wheels, the central cog, and in this way makes things happen. Without a LCNS the MDT members highlight how continuity and advocacy is absent, and how that void can obstruct treatment access.

The LCNSs in this study clearly worked to an advanced level of clinical decision making. Whilst co-ordination, linking and liaising were crucial dimensions of the role it is important to realise that this aspect of the role isn't just administrative but involved high levels of clinical decision making e.g. ordering, interpreting and acting on tests and investigations, referrals and prescribing. The expertise the LCNS brings to the service is evident in the study in terms of knowledge of the patient population, the disease trajectory, how relevant services work and how to get the best out of those services. The LCNS could often anticipate and deal with problems that could obstruct treatment access. These problems could be patient focused, such as fear and denial or organisational, such as the need to improve tracking systems. If the LCNS did not pre-empt these issues and deal with them it is difficult to see who else would be in a position to do so.

Aspects of the LCNS role were challenging for the cases because of lack of funding and an increasing workload. Another constraint that was identified relates to reliance on the LCNS to undertake administrative tasks which hindered their ability to work efficiently and maximise patient outcomes.

In financially constrained environments it would be tempting to see the LCNS as an expensive resource, and therefore vulnerable to cuts. However, this study demonstrates how integral the role is to efficient and cost-effective care, as well as increasing treatment access. The results also indicate how the LCNS role is enhanced when the organisational structure is stable, relationships with MDT members is harmonious; they have support and supervision and information systems that are efficient and not cumbersome.

As this study emerged from an observed association from the National Lung Cancer Audit, data was extracted and analysed that provided insight into how the LCNS worked with and valued the NLCA database (sometimes referred to as LUCADA). There were mixed experiences and views regarding the Audit and database. Where there was good knowledge of the Audit and related processes, regular well-informed administrative and data entry support, and local reliable IT expertise, LCNS views were more positive. Where such resource was lacking, there was concern about the completeness and confidence in the audit findings.

Measures suggested that would improve audit data accuracy and capture included trained administrative support for LCNS and others responsible for entering data for the NLCA, clarity over who should enter data at all stages of the patient's journey and contemporaneous data entry by people trained not only in the information system but also in medical terminology.

Future research

Future research could test and evaluate the impact of factors identified here as influencing the LCNS impact on treatment access across multiple sites. Future multi-centre studies could seek to identify what aspects are most important in terms of patient outcomes. The thematic framework from the study provides the beginnings of a typology to explain the practice or impact of the LCNS on treatment access. This framework could be developed, implemented and evaluated in future multi-centre research.

There is an urgent need for an economic evaluation of the impact of the LCNS roles. Robust cost benefit and cost effectiveness studies would be a challenge but are essential.

Finally, more analysis is required of the database. Currently the NLCA only analyse two of the five fields that relate to the LCNS input to the patient pathway and outcome. It is necessary to consider if all five are necessary, if more resource is required if the NLCA is to realise its potential and if there are better fields that could be developed to evaluate the impact of the LCNS role and that of other professionals and service components.

Conclusion

This study generated clear and in-depth insight to demonstrate why and how the LCNS has an impact in access to treatment. The study reveals the centrality of the LCNS role to the MDT and continuity in relation to the patient and their journey across the pathway. This study provides the first step in understanding and evidencing the contribution this advanced practice role makes to a tangible and vital patient outcome.

Contents

Opening doors to treatment: Exploring the impact of lung cancer specialist nurses on access to anti-cancer treatment, an exploratory case study

Introduction

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The project was developed in response to the finding from the National Lung Cancer Audit (2010) that 64% of patients who saw a LCNS received anti-cancer treatment, compared to 30% of patients who did not see a LCNS. This project aims to generate insight to understand what it is the LCNS does that increases patient access to treatment.

Following a brief overview of the background literature and methods used, the findings of the study are reported here. The report concludes by outlining key messages and points for discussion, alongside recommendations for future practice and research.

Background

The Lung Cancer Nurse Specialist Role

Clinical Nurse Specialists (CNSs) provide high quality, patient-centred, timely and cost-effective care. They tailor care depending upon the patient's level of need. The CNS also provides education and support for patients to manage their symptoms (Fletcher 2011, Ball 2005).

Nurses working in these advanced and specialist roles spend time in four main areas of activity. These are clinical care, education, management and research (RCN 2010, 2012). The quality of care and support that specialist nurses offer has been instrumental in reducing unnecessary hospital admissions and re-admissions, reducing waiting times, improving access to care, educating health and social care professionals and supporting patients in the community (Fletcher 2011, Ball 2005).

Whilst many CNSs work in isolation, those working with people with cancer tend to work collaboratively through Multi-Disciplinary Teams (MDTs). The MDT model of working was endorsed in the NHS Cancer Plan (2000) and has been demonstrated to improve patient outcomes. An example is in the improvement of treatment and survival rates for patients with non-small cell lung cancer (Forrest et al 2005). The contribution of the LCNS to MDT working has been well recognised, most recently in "The Dream MDT" document, written by the United Kingdom Lung Cancer Coalition (UKLCC) (2012). The UKLCC stipulate that the LCNS is a key player within the MDT and the CNS should perform the roles outlined in Box 1.

Box 1. The Dream MDT: The role of the LCNS

- All lung cancer patients should be able to access lung CNS for support and advocacy when they need it throughout their whole patient journey to support their holistic needs.

- The LCNSs should be involved with pre-diagnosis care of suspected lung cancer patients, from the point of detailed investigations in secondary care.

- LCNSs need to work closely with MDT coordinators, trackers and audit staff to ensure they are not taking on unnecessary administrative roles.

- Despite the financial pressures facing the NHS, the role of the lung CNS in ensuring optimal care for patients, must be protected. (UKLCC, 2012)

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A recent survey of LCNSs (Brown et al, 2005) indicates that, many LCNS incorporate certain activity into their role, such as MDT follow up (Table 1). However, there is variation in the range and scope of LCNS roles and models of working differ.

The LCNS and Impact on Patient Care

Whilst no research has explicitly examined how and in what way the LCNSs may have a direct impact upon increased access to treatment, there is some evidence that illuminates the impact of the LCNS on patient care. In addition to that evidence cited above research has demonstrated that LCNSs conduct a range of activities in various clinical and community settings, using diverse communication methods (Table 1). The value of these activities has been recently highlighted by the Roy Castle Foundation and National Lung Cancer Forum for Nurses report on Understanding the role of the Lung Cancer Nurse Specialist (Roy Castle Foundation 2013). This document makes a series of recommendations that emphasise the key role the LCNS has on care quality (Box 2). An explicit claim is made regarding symptom management and treatment access. However it is difficult to evidence exactly how the LCNS role plays out in terms of access to care.

Table 1. Clinical activities performed by lung cancer nurse specialist

Activities	*MDTs where the activity existed*	*Proportion involving nurses*
Routine MDT follow-up	87/115 (76%)	82 (94%)
Diagnosis/results at a general clinic	84/113 (74%)	78 (93%)
Dedicated diagnosis/result clinic	60/110 (55%)	55 (92%)
Ward visits/review	121/126 (96%)	111 (92%)
Managing investigations	93/117 (79%)	84 (90%)
Stock taking clinic	42/103 (41%)	38 (90%)
Nurse led telephone review	90/118 (76%)	81 (90%)
Home visits	60/106 (57%)	53 (88%)
New patient clinic	84/117 (72%)	74 (88%)
Palliative care	111/122 (91%)	97 (87%)
In treatment reviews	93/117 (79%)	79 (85%)
Support groups	64/120 (53%)	53 (83%)
Rapid referral clinic	61/109 (56%)	48 (79 %)
Nurse led follow-up	34/102 (33%)	27 (79%)
Chemotherapy assessments	63/107 (59%)	46 (73%)
Breathlessness clinics	27/102 (26%)	19 (70%)
Pre assessment clinic	11/93 (12%)	5 (45 %)
Chemotherapy administration	33/99 (33%)	13 (39%)

MDT=multidisciplinary team.
Brown et al 2009

Box 2. Understanding the role of the lung CNS

1: LCNSs 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 optimises potential treatment options** and **improves quality of life.**

2: All national clinical guidelines on lung cancer treatment should reflect **the important role** played by lung cancer nurse specialists (LCNSs) in **the treatment** of patients with lung cancer, from referral to diagnosis, through treatment and survivorship, and including end of life care.

3: **NHS commissioners and/or providers should ensure that there are sufficient** numbers of LCNSs in place, taking into account the need for appropriately **skilled** nursing cover during periods of planned and unplanned LCNS absences.

4: All patients should have **equitable access** to a LCNS at the time of diagnosis to guarantee that their physical, social and emotional needs, and their treatment options, are appropriately assessed and discussed from the beginning of their cancer journey.

5: LCNS posts should be **protected**, especially during times of financial austerity to ensure that patients with lung cancer, and their families, are adequately **supported and offered informed advice** throughout the complex and varied journey.
(Roy Castle Foundation / NLCFN, 2013)

The National Lung Cancer Audit - tackling variations in treatment and patient outcomes

The National Lung Cancer Audit (NLCA) (NHS Information Centre, 2011) reports annually on services provided to 38,000 lung cancer patients in the England and Wales. The Audit was developed to improve the quality and outcomes of services for patients with lung cancer. The core data set was published in 1999 and showed that that outcomes vary widely across the UK and are poor compared to other western countries.

After five years the audit was capturing approximately 100% of the expected number of incident cases across hospitals in England, Wales, Scotland, Northern Ireland and Jersey (Beckett et al 2012; Beckett & Woolhouse 2012). The Audit indicated improvements in measures of process and outcome, such as the histological confirmation rate (64–76%), the proportion of patients discussed in a multidisciplinary team meeting (78–94%), and the proportion of patients having anti-cancer treatment (43–59%), surgical resection (9–14%) and small cell lung cancer chemotherapy (58–66%). However these are national averages. They hide wide variations between hospitals providing lung cancer care. The Audit clearly

demonstrated that these variations cannot be accounted for by differences in case mix. However, explanations for the variations are difficult to demonstrate. For example, a suggestion that better outcomes are delivered in lung cancer surgery if patients are seen by an on-site thoracic surgical team have been questioned, as has been the claim that larger centres deliver better surgical outcomes (Beckett & Woolhouse, 2012, Rich et al, 2011). A possible explanation for better outcomes is a well functioning MDT as they are more likely to have efficient pathways of care, best practice in terms of diagnosis and improved treatment access (Beckett & Woolhouse, 2012). The hypothesis that improved MDT functioning would reduce treatment and outcome variations lay behind the recent Improving Lung Cancer Outcomes Project, funded by the Health Foundation (The Health Foundation 2012).

For the 2010 audit year the NLCA reported that only 58% of lung cancer patients in England and Wales received active treatment. Such treatment includes chemotherapy, surgery and radiotherapy. Only 14% of patients in the audit received surgery.

The Lung Cancer Nurse Specialist and access to treatment

The National Lung Cancer Audit (NLCA) (NHS Information Centre, 2011) reports annually on services provided to 38,000 lung cancer patients in the England and Wales. For the 2010 audit year the NLCA reported that only 58% of lung cancer patients in England and Wales received active treatment. Such treatment includes chemotherapy, surgery and radiotherapy. Only 14% of patients in the audit received surgery. LCNSs are seen as making an important contribution to patient care and patient experience. This is reflected in the fact that LCNS input is measured in the audit. In 2010 the NLCA revealed that access to specialist nursing was a factor in whether patients received treatment: 64% of patients seen by a specialist nurse received anti-cancer treatment compared to 30% of those who did not see a nurse (Ford, 2011, The Lancet 2011). This is the first direct indication that LCNSs can increase treatment access. In the 2011 NLCA this inequality endures with 64.3% of patients seeing a LCNS receiving treatment and only 28.7% of patients who do not see a LCNS having access to anti-cancer treatment.

The reason for this startling observation of an association between being seen by a LCNS and access to treatment is not clear and cannot be explained from the information provided within the database. It may indicate a problem with the sensitivity of the audit fields used in the database to capture patient assessment by or access to a Specialist Nurse. In addition, the perceived association may be false if data on access to LCNS or receipt of treatment is incomplete or not accurately coded within the database. If any errors or omissions in data

entry happen more in some centres than others then the possibility for spurious associations is heightened. Finally, any association between access to a LCNS and access to treatment may be due to a variety of factors, including improved symptom management resulting in increased ability to tolerate treatment. An improved understanding and interpretation of the data is crucial if the benefits of specialist nursing care are to be realised for all lung cancer patients.

Dr Mick Peake, (National Clinical Lead for Lung Cancer and Audit Lead and a respiratory consultant at University Hospitals of Leicester NHS Trust) reported that his interpretation of the finding was that the association was partly explained by the impact of the nurse working as an advocate, and spending time explaining treatment options with patients (Ford, 2011). He said it might also be an indicator of the higher overall specialism of the clinical teams in question.

The NLCA also revealed that access to specialist nursing was one of the few areas of lung cancer treatment that showed a marked improvement in England and Wales last year. The percentage of patients seen by a specialist cancer nurse increased from 64% to 75% between 2009 and 2010, while the number of patients that had a nurse present at diagnosis rose from 38% to 48% (Ford 2011). However, access to a specialist nurse varies tremendously across cancer treatment centres in England and Wales and in 2010 it ranged from just 12% of patients to 90%. The NLCA adds to evidence that very different models of MDT representation and working exist. This indication is supported by anecdotal evidence from the National Lung Cancer Forum for Nurses (NLCFN). The NLCFN has a membership of nearly 300 nurses specialising in lung cancer from across the UK. Forum members vary in terms of the model of working, for example their role within the MDT when treatment decisions are made and when in the pathway they see patients. These factors may influence how the LCNS can play a role in facilitating treatment access.

This observation needs investigation outside of the audit. This exploratory case study project begins the process of developing insight and understanding into the factors that may enable the LCNS to have an impact on access to anti-cancer treatment.

Methods

Research questions:

i)   What factors contribute to the impact that LCNSs have on treatment access for people with lung cancer and what are the implications for multi-disciplinary teams?

ii)   What are the implications for future research?

Aim and scope:

The aim of this study was to conduct an initial exploration to generate understanding of the role of the LCNS within the lung cancer multi-disciplinary team and identify factors that assist the LCNS in increasing treatment access for people with lung cancer and to generate recommendations for LCNS practice, MDT working and for future research.

While there is potential for a larger case study research project incorporating more extensive data collection from a broader range of stakeholders (including other MDT members and patients) this study was limited to four short case studies due to time and financial limitations.

Design:

An exploratory observational case study methodology was adopted and a collective case study approach (Gerrish, 2007, Stake 1995) was used. This helped develop an understanding of the context in which LCNS nurses work, the people with whom they interact, and how they contribute to access to anti-cancer treatment across the patient pathway.

NHS Research Ethics was not required as only staff were involved. NHS Research Governance and University Ethics approval was obtained.

Methods:

Case study methods were adopted including individual interviews with the LCNS and clinical lead, observation of the MDT meeting and documentary analysis.

Sample:

The case was the LCNS. Four cases were purposively selected to include a LCNS working in sites with high and low treatment access as identified by the National Lung Cancer Audit (NLCA). The purpose in selecting a range of sites in terms of high and low treatment and LCNS access was to examine factors that influence access in different circumstances. The

aim was to identify those factors that applied across all sites, although the experience of the factors may differ by site. In addition, a project reference group of NLCFN members was established through the NLCFN representatives in the research team. The reference group were consulted regarding sampling of the case study sites to ensure different models of LCNS working within MDTs were incorporated. Four LCNSs working in sites that broadly fitted each of the quadrants in Diagram 1 were recruited. The NLCA data was used to inform selection of sites with different treatment and LCNS access for patients.

Diagram 1.

LTA	HTA	LTA = Low treatment access
HI	HI	HTA = High treatment access
LTA	HTA	HI = High levels of integration
LI	LI	LI = Low levels of integration
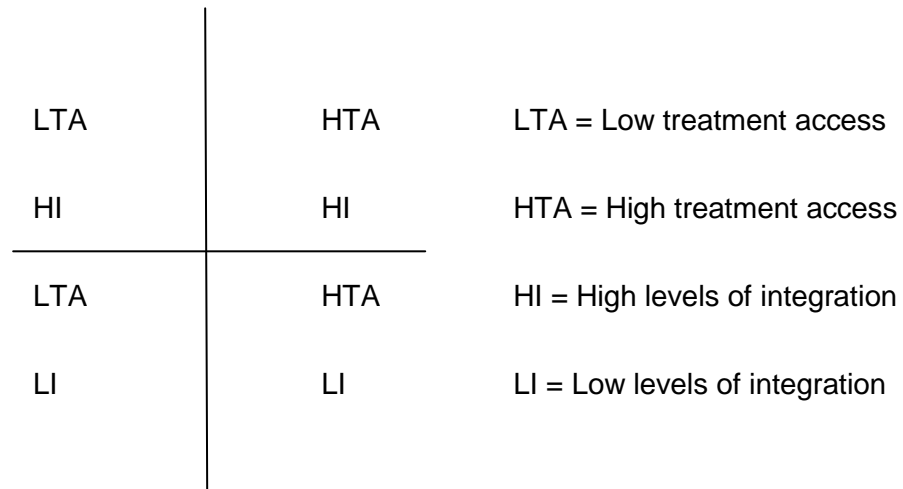
The LCNS at each site was contacted and recruited by members of the NLCFN Executive Committee who explained the study and asked if they were interested in participating. If they agreed, the research team were informed and contacted the LCNS to discuss participation further and arrange an initial visit.

Data collection for case studies:

Each case study consisted of three stages:

    Stage 1 An initial set up visit to discuss involvement, obtain consent from the LCNS, arrange the practicalities of the case study visit and conduct initial interview.

    Stage 2 A case study visit, including individual interviews and an MDT meeting observation.

    Stage 3 A follow-up interview with the LCNS to feed back to the site and clarify any points. (In two cases, this was conducted by telephone by negotiation with the LCNS).

Data collection was guided by the use of individual interview and focus group schedules, observation and document templates and pro-formas that had been developed through consideration of relevant literature and informed by discussion with the NLCFN reference

group. Informed, written consent was obtained from participants in interviews and observation.

Table 2: Characteristics of Case Study sites

Site		Patient seen by LCNS percentile		Patient having active treatment percentile		Active anti-lung cancer treatment on site		
						Surgery	Radiotherapy	Chemotherapy
A	NHS Foundation Trust	9	High	8	High	No	No	Yes - in chemotherapy unit, separate from lung cancer team.
B	NHS Foundation Trust	9	High	3	Low-mid	No	No	No Outreach chemotherapy service - palliative treatment only.
C	NHS Foundation Trust	1	Low	9	High	No	No	Yes - regime dependent; some referred to tertiary centre.
D	NHS Foundation Trust	1	Low	1	Low	No	No	Yes - regime dependent. Some on study site; some on other Trust site.

NOTE - anonymisation of sites was achieved by asking an independent person to make a blinded selection of the identifiers in the tables. Cases are attributed letters in this table summary i.e. A-D. Quotes are attributed to case study sites by numbers to help with anonymisation and prevent identification of people through sites.

Data collection combined the use of the following methods:

- Individual interviews with up to six clinicians per case, comprising, the LCNS (in stages 1,2 and 3), the lead clinician for the MDT (stage 2), plus three to five other MDT members (total for MDT members = 16). A total sample across staff groups was 24. The interviews explored the role of the LCNS and their contribution to and facilitation of anti-cancer treatment access. Aspects of facilitating anti-cancer treatment access that were explored included assessment of patients' fitness and suitability for treatment, executing fast and timely referral, development of related processes and pathways, and time and quality of input during or outside of patient consultation with medical colleagues related to treatment options. Interviews also explored the perceptions of MDT members related to the impact of the LCNS on patient and MDT decision making. Interviews were digitally recorded and transcribed verbatim.

- Observation of an MDT meeting to examine the role of the LCNS regarding decisions related to treatment access, and dynamics regarding to decision making across the MDT. Data was recorded in written form using a structured template, and transferred into a word document on a password protected computer.

- Documentary analysis of a small sample (n = 2-3) documents related to the LCNS role. These were made available by the LCNS and included a range of job descriptions, patient pathways / protocols detailing the LCNS input and reports on team activity e.g. Peer Review. Data were extracted from the documents into a template. Content was transferred into a word document on a password protected computer.

Two focus groups were held at the end of the study to expand and verify the findings amongst a broader sample of LCNSs. This will aid the transferability of findings. The first was with six NLCFN members. The group was conducted adjacent to a routine NLCFN meeting. In addition a focus group of wider MDT members was also conducted at the end of the study. Recruitment to this latter group proved challenging. In order to ensure participation it was conducted by telephone conference. Two MDT members took part, each from different Cancer Networks. The participants were a medical oncologist and a thoracic surgeon.

Following consent from focus group participants, the discussion was conducted using a topic guide generated from the findings of the case studies. The discussion was digitally recorded, transcribed and anonymised. Identifying data was removed from all Word documents and transferred into qsr NVIVO (version 10) for analysis.

Analysis

Data analysis was iterative in nature and informed by ongoing analysis of emerging data. Framework analysis was used to interpret the data and identify key themes and issues to explain the contribution of the LCNS to anti-cancer treatment access (Ritchie and Lewis, 2003; Ritchie and Spencer,1994). Framework Analysis has emerged from policy research and is a pragmatic approach to qualitative data analysis. It involves a systematic process of sifting, charting and sorting the material into key issues and themes. It allows the integration of pre-existing themes into the emerging data analysis and provides a clearly defined analytical structure that contributes to the transparency and validity of the results. The structure is developed through five analysis techniques with associated methods of data ordering, these are familiarisation, developing a thematic framework, indexing, charting, and mapping and interpretation.

These methods were used to identify cross-cutting themes shared across case studies as well as highlighting the different contextual issues which were particular to individual cases (Gerrish et al 2007).

Findings

Introduction

The study revealed that the LCNS has a profound impact on treatment decision making. Whilst data was collected more broadly on the influence of the LCNS on treatment, the focus here is on anti-cancer treatment decisions. Whilst palliative and supportive care decisions and provision are clearly important, the research question addressed here concentrates on treatment that is curative or extends length and quality of life.

The wide range of interrelating factors that help to explain the impact of the LCNS on treatment access are summarised in Table 3. An overview of the findings is provided here using the main themes of introducing the LCNSs, tasks, the impact of the LCNSs, structures, patterns, facilitators and the National Lung Cancer Audit database..

Table 3: Thematic framework

Theme	Sub-theme
Tasks	- Assessment - Holistic - Patient focus - Performance status - Symptom management - Co-ordination - Lifestyle modification - Prescribing - Service development - Optimizing function - Mobility - Respiratory function - Advanced clinical decision making - Resolving diagnostic confusion - Patient and family information provision - Counselling and psychological support - Navigating services
Impact of LCNS	- Impact on patients and families - Impact on staff - Impact on the organisation
Structure	- Pathway - Pre-diagnosis - Diagnosis - Treatment - Post treatment - Review - Re-entry - People - Patient - Carer and family - MDT

	- GP - District Nurse - Nurses - Place - Home - Hospital - Clinic - Nurse led - Out patient - MDT meeting - Telephone - Treatment centre
Patterns of working	- Hub - Central role - Continuity - Opening doors - Co-ordination - Timeliness - Speed and efficiency - Creating time - Spending time - Qualities - Patent focus - Expert practitioner - Entrepreneur
Facilitators	- Stability and structure of organisations - Working relationships - Support and supervision - Workload - Information systems
National Lung Cancer Audit Database	- Data entry - Completeness - Comprehensiveness - Usefulness

Introducing the Lung Cancer Nurse Specialists (LCNSs)

All the LCNSs who formed the four case studies were highly experienced clinical nurses although their professional backgrounds varied. Table 4 summarises the characteristics of the LCNSs. Having a breadth of both clinical and life experience was seen as vital to undertake this challenging job and the need for both maturity and emotional resilience was highlighted throughout the case studies:

> *"it is a job for a mature person, it's not something you come into at 23 is it really"?* (CS2 LCNS2)

The role of the LCNS is diverse and demanding. Spheres of practice include providing emotional and practical support for patients and their families, supporting patients to make treatment decisions, symptom management, pain control and end of life care. The care that is provided by the LCNS is based on detailed holistic assessment of a range of factors including patients' physical status and performance, social circumstances, family support, activities, interests, diet and mobility.

The way that the LCNSs enacted their roles varied considerably between case study sites. They had different working patterns and focused on different settings, with some LCNSs being mainly hospital based and some community based. While all LCNSs worked across the patient pathway, there were variations with some being involved pre-diagnosis while others picked patients up at the point of diagnosis when results of investigations were presented to patients. Table 5 gives full details of the LCNS roles in the four case study sites.

Irrespective of the variation in their roles there was remarkable consistency in how the LCNSs and their colleagues viewed the contribution of the LCNS. LCNSs were seen to add considerable value to the MDT through their in-depth knowledge of their patients which meant that they were in a unique position not only to inform treatment decisions, but also to act as the patients advocate and at times challenge the MDT:

> *"the nurse brings the patient to the MDT" (Focus Group 1).*

> *"if the cancer nurse specialist isn't there you haven't always got the patient advocate, because you're the one that's seeing the patient, talk to them, maybe seeing them at home, know what their home circumstances are like, you know, again an example from the MDT they speak about a gentleman that we're discussing about whether or not he was suitable for quite an aggressive treatment and he was caring for his wife for motor neurone disease and it's the implications of going back and to the Treatment Centre for 20 treatments every day and the clinicians aren't aware of*

those circumstances. So it is about being that advocate I think for the patient as well." (CS4 LCNS1)

LCNSs were seen to have a 'bigger picture' and could ensure the patient's voice was heard:

"this patient's got small cell lung cancer and she's performance status one, she's 50, she needs chemo, and that would be the decision, but we could say well actually yeah, she's that, but she doesn't want it or she's also got this problem or she's psychotic" (CS3 LCNS1)

There was also consistency across case studies in the value that was placed on the LCNS seeing the patients throughout the pathway. While the care pathway for lung cancer is very straightforward for some patients, for others it is very complicated and can involve different treatments at different hospital sites with different clinicians over a prolonged period of time. For patients this is characterised by anxiety and uncertainty around treatment outcomes as well as stigma about lung cancer. Contact with the LCNS began at pre-diagnosis clinics or at the point of diagnosis. The importance of building rapport with patients from the start, giving support alongside clear, accurate information and providing the opportunity to ask questions, and address uncertainties was seen as crucial at this early stage in the patient's journey:

"it's the different types of information that people are worried about as well, concerned about, they worry about when they're going to die, they'll be worried about the sort of treatment they're going to get, they'll be worried about finances and can I carry on working, family, relationships, you've got youngsters with kids. There's a whole range of things that people, different things that people will be concerned about. But as far as they're concerned they've got cancer". (Focus Group 1)

Keeping track of patient wishes, which may change over time, was also an important function of the LCNS.

The other key feature of the LCNS role which was highly valued across all case study sites was their ability to keep track of patients in the pathway and ensure that no-one 'fell through the net'. In this way the LCNS streamlined care to make sure that all investigations were done in a timely way.

Tasks

The participants clearly explained how they worked (patterns of working) within different service structures in order to increase access to treatment. For example, through their in-depth knowledge of the patients, the LCNS could be instrumental in helping patients consider their treatment options more carefully, and be more receptive to the idea of active treatment. Participants explained that without this intervention some patients dismissed treatment and considered it not worth the effort given following the delivery of a diagnosis of lung cancer. The LCNS was also seen as instrumental in helping patients both consider and tolerate treatment better.

All of the LCNS activities involved advanced clinical decision making and practice. However, a clear list of tasks emerged that were the essential activities that made a difference in terms of service and treatment access. A brief description is given below but examples of how the tasks performed increased treatment access are provided along with illustrative quotes and findings presented in the subsequent sections of this chapter.

Assessment

Clear, advanced and accurate patient assessment was seen to increase access to treatment by taking into account the whole picture, and impact of the diagnosis on the patients' psycho-social circumstances (holistic assessment). The focus on the patient was important here and helped the LCNS more accurately assess performance status, and therefore eligibility for treatment.

Symptom management and optimising function

Better management of symptoms such as breathlessness, pain and fatigue by the LCNS also improved eligibility of patients to treatment.

Co-ordination

The practical co-ordination of different services across the pathway and aspects of care helped to speed decision making and ensure all those eligible for treatment were able to access it in a timely way.

Lifestyle modification

Provision of information, support and advice to patients and carers regarding aspects of lifestyle also improved fitness and therefore eligibility for treatment. Key examples here were smoking cessation, physical activity, diet and nutrition and hydration.

Table 4. Characteristics of Case Study LCNSs

Site	Length of time in post	No of LCNSs on site	Type of post	No of years qualified	Education and experience	Focus
A	2007	2, but recently applied for a third.	Dual role - specialist palliative care and LCNS. Organisation restructured - LCNS focus only now.	>15 years	Started as a LCNS in 2002 at another Trust - a new developmental post. Variety of medical nursing roles - rheumatology, endocrinology, neurosciences, respiratory. Did care of the dying course as a staff nurse. Every Friday for an hour attends the lung learning programme which she organises. Is a nurse prescriber.	Not routinely involved with in-patients - no capacity to do this. Mostly see patients in community. Do post-diagnosis home visits. Does a lot of telephone consultations with patients.
B	2002	2	Macmillan pump primed but now funded by Trust. Called LCNS. Have developed the role themselves.	>20 years	Worked in cancer care for nearly 20 years. Started in haematology. Specialised as palliative care nurse.	Does home visits; focus on mesothelioma and lung cancer patients with complex social and psychological needs.. Work with patients post diagnosis and now setting up rehabilitation service for patients post-surgery.
C	2000	1, recently appointed second	Was a new service in 2000. She was involved in setting it up from scratch.	>30 years	Worked in A&E, trauma, orthopaedics and ITU. Then general practice, with interest in respiratory medicine then did palliative care degree. Master's degree in ethics of palliative care and done nurse prescribing.	Initially the service focused on newly diagnosed patients in clinic and acute patients on wards. Mainly clinic and telephone work; some home visits - plan to expand now second post-holder in post. Education of registered and student nurses and junior doctors.
D	3 years	2	Macmillan and Trust funding. Other LCNS was involved in setting up the service from the beginning	> 30 years	Started in cardiology then specialist work in diabetes then lung cancer. No specialist training for lung cancer, Just done degree module in mesothelioma and starting another in palliative care	Does a lot of telephone and clinic work.

NOTE - anonymisation of sites was achieved by asking an independent person to make a blinded selection of the identifiers in the tables.

Table 5. Activities of LCNS - what do they do in practice?

Case study	OPD role	In patient role	MDT meeting	Community role	Telephone contact	Point of pathway	Other activities
A	Multi-disciplinary lung cancer clinic including physicians, oncologist, dietician, physio This is when they first meet new patients. Also attends oncology clinic. This is a really useful way of picking up problems early	Not routinely involved with in-patients due to lack of capacity. Watching brief - all lung cancer in-patients tracked.	Attends the meeting	Community is their main focus. Every patient gets a post diagnosis home visit. Do a lot of home visits. For complex patients this can be 2 or 3 times a week for symptom management and palliative care. Will be handing over palliative care to the generic Macmillan team soon. Successfully negotiated agreement to continuation of home visits post-diagnosis.	Great deal of phone contact with patients around time of diagnosis - pre and post. For patients who are complex, this can mean daily phone calls. Telephone follow up after clinic appointments for some patients	Meet at diagnosis time, but not routinely involved in the pre-diagnosis clinic. Then see through the whole of the pathway. End of life care being directed to community palliative care teams with LCNS providing specialist advice in support.	Run a monthly lung cancer support group
B	One stop clinic where patients come for the day. LCNS is there all day and will be	See patients on wards	Attends the meeting	Few home visits	Does a large proportion of their work over the phone.	Sees patients from diagnosis to end of life	Covering the wards occasionally due to staff shortages

	there if good or bad news is given. Also attends respiratory clinics.						
C	See surgical patients in pre-operative clinic. Sees patients having chemo every week. Sees bronchoscopy patients pre-bronchoscopy and then in a results clinic	Visits lung cancer in-patients.	Attends the meeting.	Does home visits, but sparingly. Sees post-operative patients at home.	Telephone contact with patients and families who ring a lot while their treatment plan is being sorted out	Never discharges patients. Sees them at all points in the pathway. .	Focuses Runs the Mesothelioma Support Group. Member of the Network Clinical Site Specific Group. Teaching of registered and student nurses and junior doctors.
D	Sits in on clinic with oncologist to answer questions after consultation and provide further information. This is an active not a passive role. Encourages patients come to OPD so they are monitored and stay well at all points of the pathway.	They cover in-patients and monitor who has been admitted and support the wards by providing information to ensure early discharge where possible Review of services - no longer visit hospital wards.	Attends the meeting	No home visits. Coordination of services via telephone contact for speed of response.	Does a large proportion of their work over the phone.	Contact with patients from point of referral to chest clinic with suspicious chest X-ray.	Formal and informal teaching. Covering much of work of MDT coordinator since post-holder resigned and replacement no longer available on site.

NOTE - anonymisation of sites was achieved by asking an independent person to make a blinded selection of the identifiers in the tables.

Prescribing

Swift, accurate prescribing and titration of medication again helped to maximise fitness and reduce symptoms and thus increase potential for suitability for treatment.

Service development

LCNSs were all involved in evidence based developments in services which improved patient's medical status (e.g. pulmonary rehabilitation) or the efficiency and quality of services (nurse-led clinics). This had a subsequent impact on treatment access.

Advanced clinical decision making

The level at which the LCNS was working made the services more efficient and enabled speedy patient response to interventions. Whilst the MDT members did work collaboratively the LCNS was able to make autonomous decisions that didn't require validation or checking by senior medical colleagues. The LCNS was an advanced, but also trusted and respected senior MDT member.

Resolving diagnostic confusion

The holistic, advanced, patient focused nature of the patient assessment conducted by the LCNS enabled them to clarify whether symptoms were due to the lung cancer diagnosis or a co-morbidity. Where the latter was the problem, swift treatment of the co-morbid condition made a difference between a patient being eligible for anti-lung cancer treatment or not.

Patient and family information provision

The provision of timely, accurate, trusted and appropriate information and advice to patients and carers helped ensure they were equipped to make informed treatment decisions. This was important where they were previously misinformed about treatments and refused because they felt scared, fearful or hopeless regarding treatment. The LCNS was reported to overcome this barrier to treatment.
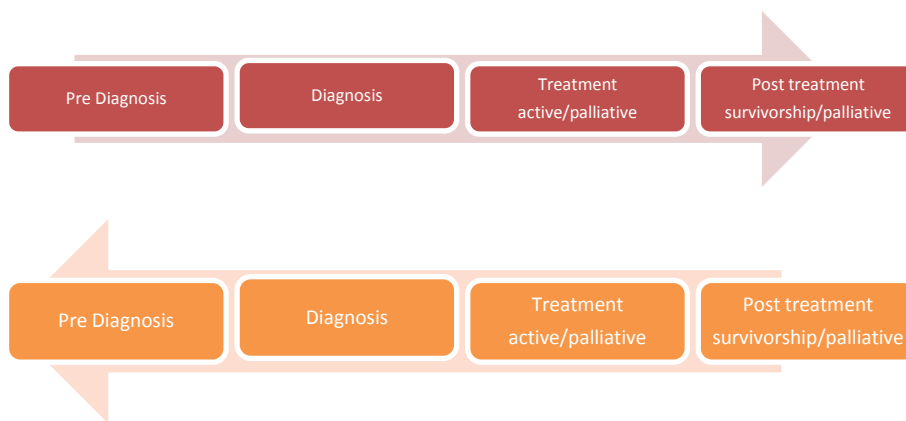
Counselling and psychological support

Provision of ongoing support in terms of the emotional, social or financial repercussions of a lung cancer diagnosis was key to the LCNS preparing patients for treatment eligibility or acceptance. Examples included overcoming fear and fatalism regarding treatment, the impact to family members, or the prohibitive cost of travel to treatment.

Navigating services

Developing systems that ensured the LCNS ordered or processed test results, reviewed patients, discussed options, or prepared patients, family and medical staff for clinical appointments were some examples of how the specialist nurse was able to help the patient navigate through to treatment. Co-ordination with colleagues within and external to the MDT was vital.

How the tasks and activities described above manifest themselves in terms of increasing access to treatment will be detailed now in relation to the structures within which the LCNS works and their patterns of working. Following this, facilitators that enabled the LCNS to work more effectively in terms of increasing treatment access are summarised.

Diagram 1. The LCNS: Continuous presence across the pathway (see page 43)

Pre Diagnosis	Diagnosis	Treatment active/palliative	Post treatment survivorship/palliative

Pre Diagnosis	Diagnosis	Treatment active/palliative	Post treatment survivorship/palliative

Impact of LCNS

In addition to their impact on access to anti-cancer treatments, a wealth of data emerged from the case studies about the wider impact of the LCNSs. As well as having a profound impact on patients and families, LCNSs were seen to have an impact on other staff and on organisational priorities and targets. These dimensions of impact are summarised below.

Impact on patients and families

The LCNSs had an impact on patients in a number of ways, notably in terms of improving the patient experience by ensuring that patients had access to timely and streamlined services which were clearly signposted and available when the patient needed them. These services ranged from anti-cancer treatments to preoperative lung fitness advice, rehabilitation services, smoking cessation services and community and palliative care services. This was achieved in part by the availability of the LCNS and the ease with which patients were able to access them at times of need.

One of the ways in which they were able to be effective in this element of their work was by being readily accessible and responsive to patients. They were available for telephone advice on an ad hoc basis as well as ensuring that regular, planned contact took place throughout the patient's journey. One outcome of this was improved symptom control. For example at one site, the LCNSs did telephone follow up after the patients had been seen by the doctor in clinic:

> *"If we're seeing the follow-ups in clinic or if we're seeing the new diagnoses who are quite symptomatic for whatever reason quite often I'll start a treatment in the clinic. But if they had to rely on either coming back to clinic or seeing their GP it just wouldn't happen, the treatment wouldn't get titrated, so you'll start it and then, you know, a week, ten days later I'll ask CS3_LCNS2 or CS3_LCNS1 oh how they doing on such and such? She's like well it wasn't really working so I changed it to this or I increased the dose. So much happens just so quickly that if they waited for us then we'd have a lot more unhappy patients or we'd have a lot more symptomatic patients out there".* (CS3 SPR1)

This also had a 'knock on' effect on the organisation in terms of averted in-patient admissions, as this example illustrates:

> *"We will always encourage, even for patients who are deemed not to be able to be well enough for treatment at diagnosis, that they contact us if they have any problems. So for example if they have a pleural effusion, we can get them seen*

quickly and get that aspirated. Which although is very symptomatic treatment for them, as long as we're aware we can get that done, which again often prevents many admissions for these patients who otherwise would be admitted". (CS1 LCNS1)

The LCNSs also improved patient's knowledge and understanding of their condition and treatment. They were seen as a primary source of information about treatment and prognosis. Being able to ask questions, to be given clear information and supported to ask questions of others or seek answers on patient's behalf were all highly valued by patients. The LCNSs were seen as able to convey complex information to patients about the rationale for treatment and therefore increase compliance as a result:

LCNSs were also able to have discussions with patients about the side effects of treatments and allay patients' fears by spending time with them and providing space to talk about the patients perceptions and concerns about what treatment might involve and their ability to tolerate it.

Participants reported how LCNSs could influence the availability of treatment on occasions. For example one LCNS felt that when patients need radiotherapy quickly, her good working relationships with the oncologists who she could talk to directly and who trusted her judgement could facilitate treatment in a timely way.

In terms of helping patients make treatment decisions, the LCNS played a key role. They were well placed to do this in view of the in-depth knowledge and the close relationships they had developed with their patients by spending time with them. In this study, the support of the LCNS was important not only to ensure that patients could access active treatment but also to ensure that those patients who decided not to be treated could also be supported:

> *"For patients who might be undecided about a course of treatment, she often has a bit more time to sit and spend talking to them about what that might entail and what impact that will have on them and their family to help them to make a decision about what the right course of treatment for them is. Or indeed no treatment, because we have a lot of patients who decide that actually they don't want to do anything at all, and having the opportunity to have a chat with CS1_LCNS1 about that and making sure that they understand the implications of that decision, but also that they won't just be abandoned having made the decision that they don't want any additional treatment, so CS1_LCNS1 really brings the whole thing and CS1_LCNS2 to that extent bring the whole thing together".* (CS1 MC3)

LCNSs also had an impact in terms of reducing anxiety and emotional distress for patients and their families throughout their journey. Emotional support was provided from diagnosis to treatment and follow up and in many cases in end of life care. Helping patients deal with their diagnosis was seen as a key role as was helping patients think through the practicalities of treatment and the implications of their diagnosis on other aspects of their life.

> *"..I can imagine when you first meet the oncologist and you're told your diagnosis and you're told, it must just be like a bombshell. So I could imagine a lot of the information just doesn't go in does it?...So then they're going to go home and they're going to have the questions. Well the first person they're going to ring is CS4_LCNS1. You know, he said about this, I can't remember what he said, or he talked about this, does this means this is going to involve that, that and that. Because when they get home and they sit down and it all sinks in, I think that's when the important questions come for most of them, because it must just be an absolute shock for a lot of them".* (CS4 C1)

Impact on staff

Evidence was generated from this study to demonstrate how the LCNSs had an impact on other staff with whom they worked on a day to day basis. This was most clearly seen in their ability to harness to efforts of the MDT through a whole systems approach by facilitating communication and team working.

> *"So CS4_MC1, if I've seen a patient, I'll ring him and say so and so's been in, this is what I've done, this is where we're up to and this the follow up I've arranged, and he'll say that's fine. If I'm not sure, I'll ring him and say I've got a patient here, this is what I think I'm going to do, do you think that's the right thing to do, happy with that, and he's always happy to give advice. As is CS4_MC2, you know, coming here at the hospice anytime and just ask advice. So it's useful to be able to complete a full episode of care, rather than having to say to the patient, I see what your problem is but actually I can't prescribe for you, so I need to send you back to your GP, or I can't organised a CT scan for you, so I need to refer you to CS4_MC1! Whereas I could organise CT or chest x-ray or, so it's quite nice to be able to do that".* (CS4 LCNS1)

The LCNSs also played a big role in brokering and navigating across both professional and organisational boundaries played a vital role in ensuring that patients didn't get stuck in the system but moved through in a timely way:

> *"I think there's a lot of things around the medical side of things that we as doctors maybe do not access as much, where the lung nurse is able to open all those doors*

and avenues, so things like you said the lung fitness side of it, preoperative lung fitness advice and clinics and rehabilitation services, things like smoking cessation services as well, things that we may not be so bothered or have time to be fair to actually refer people on to smoking cessation, which is really important, and those are things that the nurse will do. Things like OT, physio, community services, absolutely I think all things are appropriate". (Focus Group 2)

Having a LCNS in post also freed up other MDT members to spend more time using their own expertise to better effect for patients, as this consultant surgeon pointed out:

"some of what the lung nurse specialists are doing I could do as well, perhaps not as well but perhaps do as a specialist. The fact the lung nurse specialists are doing it though gives me extra time to perhaps do better with what I feel that I should be doing with my patients. So for example, I would far rather have that little bit extra time to go through working with a patient on issues around consent and whether they really want surgery, because I know some of the other aspects will be dealt with by the lung cancer nurse specialists, whereas if I had to do that, I would have to trim somewhere else. So freeing up my time is not, I don't mean that I can go off and do something else, but I can use it more effectively. So I think the patients get a much better deal, they're getting more". (Focus Group 2)

Impact on the organisation

The LCNSs were key to ensuring that organisational priorities and targets were met in terms of the national standards and performance targets. For example the LCNSs were key to reducing breaches in the '2 week wait' rule by ensuring that all relevant investigations were done within the 2 week period before the first out-patient appointment. In one site the contribution of the LCNS in ensuring that targets were met was highlighted when the LCNS was absent for a period:

"what is evident is from our 62-day pathway outcomes over the last two months when CS4_LCNS1 has been away, we tail off a little bit. And I don't think that's irrelevant; I think it's very relevant. I think the fact that CS4_LCNS1 is not present means that patients haven't got somebody to contact easily, you know, or there's not proactive contacting of the patient, do you see what I mean? Quite quickly days are lost in their pathway". (CS4 MC1)

LCNSs were also involved in the development of policies and protocols and the development of the lung cancer pathway.

By coordinating the efforts of the MDT and ensuring timely investigations and treatment decisions, and by developing systems for monitoring and keeping track of patients across the pathway, LCNSs were also seen to reduce hospital admission and in-patient length of stay.

Diagram 2. The LCNS as the "Hub" of the care team (see page 41)
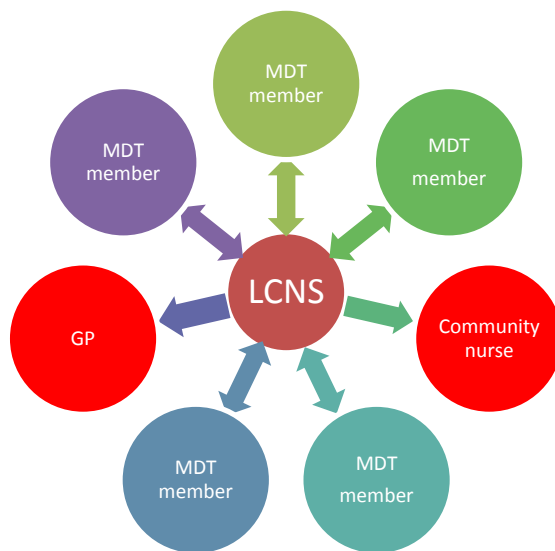
Structures

The findings from the study revealed how the nurse worked within and across certain structures in order to influence access to treatment. These findings are summarised here under the themes of pathway, people and place.

Pathway

The national target for people referred by their GP with suspected lung cancer is first outpatient appointment within 14 days ('two week wait'), and 31 days from decision to treat to commencement of treatment, within an overall target of 62 days, including diagnostic investigations, MDT meetings and any second opinion. Entry to the pathway commonly follows GP referral, but may result from identification of abnormalities in routine chest X-rays, or emergency hospital admission.

> *"It's very different from other cancers. The trajectory is...much shorter."* (CS3 LCNS1)

The LCNS mapped the lung cancer pathway to the individual patient, through multiple entry and exit points, helping everyone concerned to navigate the pathway.

> *"…if you map every single patient you will end up with spaghetti junction. I mean you've got to have the basic pathway there that we follow…but it's not clear cut …"* (CS3 LCNS1)

- *Pre-diagnosis*

> *"The most important factor is getting them here……we see too few of them and we see them all too late or most of them too late."* (CS2 LCNS2)

Following referral, achieving a diagnosis takes between days and weeks but is essential to accessing active treatment. Investigations may take place at a distance from the lung cancer unit. Increasing use of targeted therapies requires tests for genetic markers that extend the diagnostic process. By informing patients about the rationale for diagnostic tests, supporting them emotionally and practically to cope with attending and also assisting with investigations, LCNSs contributed to patients' willingness to tolerate procedures essential to opening the way to active treatment.

> *"Again it's sometimes you find without them being there it just wouldn't happen."* (CS1 MC1)

34

- *Diagnosis*

  "It is a very fast process…Sometimes within seven days they've gone from nothing to a huge diagnosis." (CS4 LCNS1)

Following diagnosis, LCNSs helped patients to consider treatment options, facilitating decision-making. LCNSs could not always be present at diagnosis, but saw patients as soon as possible in clinics, following this with home visits or telephone calls to check patients' understanding of diagnosis and treatment details required to make informed decisions.

  "...if at least you can explain it in a way that's more understandable and often again with family members, can certainly help the decision." (CS1 LCNS1)

- *Treatment*

  "You want the patient to have the best opportunity for any sort of treatment... and most patients say they want treatment anyway. So you want to make sure that they're the best optimum health that you can possibly do beforehand." (CS3 LCNS1)

Treatment options were influenced by stage, grade and type of cancer and co-morbidities, and the patient's performance status. LCNSs enhanced patients' opportunities for access to active treatments by ensuring practical interventions to optimise performance status.

  "...we might see a patient in clinic, do the home visit, realise that they actually are quite fatigued, but the fatigue is because they've lost their appetite, so by improving on symptoms, by improving their appetite, which ultimately would improve fatigue, by just introducing a small dose of steroids might bring their fitness level up to a state where they're then able to get anticancer treatment. So again it's about that holistic assessment and understanding the disease as well and knowing what works..." (CS3 LCNS1)

LCNSs' availability as a point of contact also supported patients' decisions.

  "Also I've had patients who've gone for surgery who are very unsure or have been tentative; the fact that they're offered the support following the surgery has been

helpful in that decision making. I had one lady that rang me and said oh that's helpful to know that there's something else after I've had the surgery." (CS1 LCNS1)

LCNSs supported patients' coping abilities during treatment through clinic appointments, on-treatment reviews, telephone contacts and even support groups. Patients who experienced new or recurrent symptoms sought help from LCNSs, who never discharged anyone. LCNSs also gave practical support, including carer respite and benefits advice.

"But the patients know they can just self-refer to us at any point, they don't have to go through anybody else, so they can just ring up." (CS3 LCNS1)

- *Re-entry*

LCNSs noted that it was unusual for patients to survive five-years from diagnosis, but one described a patient who had been actively treated three times. Continued contact with the LCNSs had allowed early identification of new symptoms and facilitated the patient's access to active anti-cancer treatment.

"It was because of our involvement that we picked up on it the second time for her, because she saw us every month at the support group, and it was us that said: 'This cough that you've got, can we just do a chest X-ray?'." (CS3 LCNS1)

People

The LCNS interacted with a range of people in order to impact upon treatment access.

"I imagine it as a theatre; you've got all these people waiting in the wings and they come in and play their part on the stage with the patient, and it may only be for five minutes or it may be for a full scene, and they then depart. But the people that are on the stage permanently are the patient, the carer and the lung CNS." (CS3 LCNS1)

- *Patient*

LCNSs identified lung cancer as stigmatising and patients as lacking hope.

"…they often feel that their time has come and that they shouldn't be draining the NHS…." (CS1 LCNS1)

LCNSs gave patients the opportunity to reconsider by reframing the situation and contemplate treatment:

"You've got to put everything into perspective for them, make it their disease, their treatment...And I think once that's explored with the patient they accept treatments more readily." (CS3 LCNS1)

- *Carer and family*

Enabling the patient to accept anti-cancer treatment also involved LCNS support of families.

"...their concerns might be things like finance or something, you know, how their relatives are coping I hear more than anything, how families cope. And the symptoms that we may think are a problem for them actually no, they're not, they're coping quite well." (CS1 LCNS1)

Family members' encounters with lung cancer influenced patients' propensity to accept treatment, and LCNS challenged such negative attitudes sensitively.

"...because people's perceptions of treatments vary widely, people's experiences of other members of the family going through treatments will always come to the forefront." (CS3 LCNS1)

- *The MDT members*

Within the MDT, LCNS' knowledge of patients as people complemented medical staff's technical understanding.

"And she is a key witness to what may be possible to deliver for that patient...And that in making a decision about the management of lung cancer it's crucial not just to understand the radiology, the pulmonary function test and pathology but the patient that that information belongs to..." (CS4 MC3)

LCNSs also ensured that everything necessary to access to active treatment for patients was completed.

"...it's just invaluable because it means I don't have to be constantly thinking 'Oh, I must check up on what X, Y and Z!'." (CS3 SPR1)

- *GP*

LCNSs liaised with GPs, responsible for managing patients' care in the community and complementing their role in symptom management and referral to other services. LCNSs provided advice to GPs who rarely encountered lung cancer and thus facilitated timely communication with the lung cancer team. They also identified that changes in the GPs' commissioning of services in the NHS and increasing choice for patients ('Choose and Book') were increasing the need to actively manage patient support across the pathway.

- *District Nurse*

Communication with community nurses was essential to managing co-morbidities and the prevention of patients' admission to hospital.

> *"...and I'm absolutely sure it's because of these rigorous systems of referral to district nurses, to primary care services, that we keep them out of hospital."* (CS2 LCNS2)

LCNSs' liaison with community nursing colleagues also allowed patients with carer responsibilities to take up treatment options.

- *Nurses*

LCNSs ensured the effective and seamless transfer of responsibility for patients to and from CNS colleagues in treatment centres in order to facilitate patients' acceptance of active treatment. They also provided education and advice to hospital nursing staff in order to expedite the discharge of lung cancer patients and maximise their capacity for active treatment.

Place

LCNSs varied in the balance of where they worked across the pathway depending on local circumstances regarding the service, local resources and population.

- *Home*

Not all LCNSs undertook home visits to patients. Those who did visited either all patients or particular groups, including people diagnosed with mesothelioma and patients with who had rejected treatment.

"Again they have further discussions with the treatments, but I think they need to hear it in their own environment in a timely fashion as well, not in a rushed clinic." (CS3 LCNS1)

- *Hospital*

LCNSs worked to prevent admission to and ensured timely discharge from hospital in order to maximise the patient's performance status and eligibility for active treatment.

"...we keep them out of hospital, I know we do." (CS2 LCNS2)

They aimed at appropriate transfer to a respiratory ward for emergency admissions, enabling patients not known to the lung cancer team to be brought to their attention for investigation.

- *Clinic*

LCNS led clinics were provided on one site as a flexible alternative to consultant-led clinics for on treatment and follow up reviews. Patients could 'drop in' to discuss medication or use them as an alternative to telephone contact, helping them to cope with treatment. On two further sites nurse-led clinics were being actively considered.

- *Outpatient Clinics.*

LCNSs on all sites met patients, carers and families in consultant-led outpatient clinic sessions, at first referral, during the giving of diagnosis and/or presentation of treatment options as well as to monitor and follow-up response to treatment. This contributed to patients' access to active treatment in various ways. LCNSs established relationships with patients, carers and families so facilitating later access to LCNS support. Meeting patients in outpatient clinics complemented telephone contact and home visits to provide a holistic picture of patients that enabled teams to facilitate access to active treatment - whether through enhancing patient's performance status, complementing social support or facilitating financial assistance. LCNSs contributed actively to the conversations between medical staff and patients during outpatient clinic sessions, following these with longer meetings to ensure that patients understood information about their lung cancer diagnosis and treatment options.

"I think there's a definite relationship between a CNS seeing a patient and a patient opting for treatment, because they take much more information from a CNS meeting them…" (CS4 LCNS1)

- *MDT meeting*

The MDT meeting was the central decision-making forum, where diagnostic information was examined and treatment options debated. LCNSs advocated for the patients, their professional expertise being valued by medical colleagues.

> *"We're all experts within our own field to give an opinion on what we feel is best for that patient."* (CS3 LCNS1)

LCNSs ensured that those opinions were managed to achieve a consensus.

> *"One of our roles I think is central to making that MDT work…If you just sit quietly in the corner they're probably going to fall out, aren't they…you help people to get along, by humour usually…rudeness and humour."* (CS2 LCNS2)

- *Telephone*

Telephone work allowed continuity of contact across the pathway, for patients, carers, families, and colleagues, in a way that could not be achieved with a medical consultant. The telephone allowed tracking and follow-up checks for patients during the diagnostic process, advice following diagnosis, and enabled early identification and resolution of concerns during treatment that may affect the patient's ability to complete treatments.

- *Treatment centre*

Patients whose treatments included surgery or radiotherapy received these in treatment centres, often in other Trusts. These could be located up to 100 miles from the cancer units where the LCNSs were employed. Travelling for treatment was emotionally and physically exhausting for patients and families. LCNSs usually transferred direct responsibility for patients during active treatment, but remained available for the patient to contact.

> *"Being there at pivotal points in the journey, but also being there when patients are at other hospitals is really important for us, I think."* (CS4 LCNS1)

Patterns of working

The participants identified various ways in which the LCNS worked that meant the specialist nurse role was fundamental to increasing access to treatment, as well as to the quality of care. These are conceptualised and reported here as "patterns of working". Findings are presented using the following themes; being the "hub", timeliness and qualities of the LCNS.

Being the "hub"

Across the participants the LCNS was referred to as the "hub" or being key to the delivery of care and the efficiency of the related systems and processes. Core themes that described this pivotal contribution were having a central role, continuity, co-ordination, and support and advice.

- *Having a central role*

The LCNS was depicted as central to the patient and to the MDT. This centrality meant the LCNS contribution to treatment decision making was vital. The LCNS was pivotal to allaying the patients' fears regarding treatment options as well as providing ongoing support to both the patient and efficient working of the MDT and care processes.

> *"I think lung cancer nurse specialists are both key to support the patient primarily, but also they do allow us time to concentrate on the medical aspects of things as some of the social and financial aspects are taken care of with themselves….once we've made the decision that bit of information is then fed back perhaps to the MDT via them or actually they link a lot of people, they're probably sort of the hub, and then we're all spokes around them if you like, and then we connect, and then if there's any problem we feed it back to them and they feed it back".* (CS1 MC1)

It was clear that the extent and nature of the support and guidance they offered patients was different to the interventions of other MDT members.

> *"I mean they're definitely the kingpins in the whole process. The nitty gritty they do I'm not so in detail, but patients always speak highly of them and it's always that they know they're not just being number crunched through CS3, there's somebody at the end of the phone who can speak to them. Often doctors aren't the ones they want to speak to and they've always got the liaison number to phone up to, so it's a feeling of importance and a feeling of worth and a feeling of not being left alone with a condition is one of the most important roles".* (CS3 MC2)

Each member of the MDT was seen to have their place, but the LCNS role turned individual practitioners into a team. Thus the LCNS was core to the efficient working of the MDT and collaborative treatment decision making

> *"Before the nurses were involved within the multi[disciplinary team], well, there wasn't a multidisciplinary team, there were individuals that would see patients and decide the whole pathway really, and by their own admission would say now they have no idea how they did that. So you would have a chest doctor who would diagnose and sometimes even decide on chemo and such like, and that doesn't happen now. You have the individual specialties which are glued together by the specialist nurses I think".* (CS2 LCNS2)

> *"No, I have told you, I value them. It's not only for this study I'm telling you, that's the truth; I value their role in our system. They're supportive of all the patients' journey, and also in the community and they are one of the pillars of strength in that department, where the patients can lean upon and can discuss any sort of thing, so that's quite important for the patient. It makes the whole cancer journey different for the patients".* (CS3 MC2)

Not only were the LCNS the catalyst to prompt treatment decision making they also had a core role in maintaining harmony within the clinical team (see' working relationships' p55).

Another dimension of their central role was that the LCNS was often the person who placed the patient and the disease in the context of their wider life.

> *"They* [LCNS] *hold the case. So they hold the case in context".* (CS2 MC2)

Finally the LCNS was the person at the core of the service who would influence passage through the care pathway towards treatment.

> *"It'll come back here, because we're seen as the, and that's part of the influence of the treatment really I think, it's that we're seen as the gatekeepers, the access, whatever you want to call it, to all those investigations, those treatments, those doctors, those tertiary centres, those Macmillan team, the PET scanner, whatever you mention, they know that this is the place to come for"* (CS2 LCNS1, LCNS2 Follow up)*.*

- *Continuity*

An essential aspect of the LCNS role that impacted upon treatment access was the continuity of care delivery. As seen earlier in relation to care across the pathway, the LCNS was the one constant in the patient's journey from pre-diagnosis onwards. As a result of this they had an in-depth and holistic knowledge of the patient that enabled them to tailor information, support and advice accordingly. They were therefore excellently placed to advise the MDT regarding the suitability, and acceptability of treatment options for individual patients.

> *"It's saying I've seen this patient at home, yes they had surgery previously but they've got a sick wife now that they're caring for, they're not keen to go in for surgery again, but they would cope with radiotherapy or they would cope with chemotherapy, providing we would get care in for the wife. So it's trying to influence decisions in a positive way, but also making sure that the patient's perspective I think is heard. Because with all due respect to the clinicians, they are very focused on the treatment option and what the x-ray looks like, or what the CT scan looks like, and the patient actually isn't in the room".* (CS4 LCNS1)

In addition to knowing the patient well, another aspect of continuity of the LCNS role that impacted upon treatment access was their ability to "keep track" of patients whereever they were in the pathway. This was in comparison to other MDT members whose input and knowledge of the patient tended to be episodic. The LCNS "*keep[s] a track to ensure or to see that nobody is lost as it were".* (CS1 MC1)

Shortly after diagnosis this means following the patient up at home and "keeping track" of them in terms of the impact of the diagnosis and treatment options.

> *"The nurses when patients are diagnosed they will phone the patient the next day to make sure they understood the diagnosis and if they've got any questions. So they're always in communication with the patients and families".* (CS2 C1)

This ability to keep track and have in-depth knowledge of the patient can mean they are best placed to assess performance status accurately and therefore increase eligibility for treatment.

> *"A lot of people will say to her LCNS1 have you met this patient, what do you think he would do or, and someone will say his performance status is three, and then LCNS1*

will say yeah but I've seen him this week and that's a lot better than the last time you saw him. So her opinion and what she knows about the patients is vital when they're making the decision, definitely, because she does have a lot of patient contact". (CS4 C1)

Whilst not all the LCNSs conducted home visits, those who did found this helped maintain continuity and gave them a breadth of understanding of the illness in the patient's life. A home visit enabled the patient to:

"In the past I have arranged a home visit for a patient who didn't want treatment, just couldn't see the sense in any chemotherapy treatment, because they were just so devastated at the time, but following discussion, again at the patient's home, agreed to treatment and responded well to treatment and lived for another two years at that point". (CS1 LCNS1)

All the LCNSs valued and relied heavily on phone contact to maintain continuity. This was seen as an essential element of their work. The LCNS thought phone work was sometimes undervalued by others who did not appreciate the skill and expertise required. This phone contact also impacts upon access to treatment and assessing eligibility because of the frequency and accuracy of the LCNSs patient assessment.

"Telephone-wise they can contact the nurses at any time and the nurses will get back to them and deal with any questions, queries, concerns". (CS2 C1)

"We see patients as doctors for about half an hour, 45 minutes, an hour, maybe a couple of hours. LCNS1 and LCNS2 are on the phone with the patients and seeing them directly for often longer periods of time. If they feel that a patient will benefit from a treatment in or out of the MDT they will get involved". (CS1 MC1)

- *Opening doors*

As a result of the continuity and centrality of the role of the LCNS they were able to "open doors" to treatment in various ways. In this way they were the "hub" of care and access to treatment. They adopted various mechanisms and strategies in order to open doors to treatment and these were employed across the care pathway. It was seen to be important to "be there at the start" in order to get to know, build a rapport and develop trust with the patient. However, ongoing contact and reassessment were as important in ensuring patients

were considered for all appropriate treatment. An overview of the mechanisms adopted by the LCNs is provided in Box 3.

Box 3. Mechanisms for opening doors to treatment

Expert knowledge: patient, the disease, the illness trajectory, treatments, pathways and processes.

"I think it probably gives them more confidence in their treatment because they've got somebody that they know from the beginning who is aware of what treatment they're having, where they're having it, what's likely to be involved, what the side effects are likely to be and so on". (CS4 MC2)

Expert practice: Reassessing if patient initially refuses treatment, discussing diagnosis and treatment options, linking and referring to other services.

"We sometimes get phone calls from the family to say the patient's now behaving strangely …. The nurses will then arrange with the doctor for an urgent scan and let the patient know or the family know this has been arranged and then arrange for the GP to give some steroid treatment. And if anything happens like that the nurse will deal with any situation, arranging the appropriate investigations or support that's required". (CS2 C1)

Advanced practice: Prescribing, physical assessment, managing symptoms.

"Obviously the notion of the management of symptoms is hugely important as well ….I've got case studies that I present about … how our interventions help improve people's performance status before they see an oncologist has actually allowed them to have treatment". (Focus group 1)

Psychological support: Tackling mental ill health (anxiety and depression), listening and counselling, overcoming blame and stigma, promoting self-esteem and confidence, addressing fear and denial, promoting coping mechanisms.

"their role is pretty pivotal in that, because the consultants will explain right you've got to have this done, but I think the lung cancer nurses are there to allay their fears, to support them through the process which isn't very pleasant. And I think that's quite important to get them through the investigation process, to allow them to be able to have treatment options at the end of it". (CS1 Consultant 1)

Advice and information: Lung cancer, lifestyle, treatment options, symptoms, side effects.

*"We've had several involvements with patients who've declined treatment in their clinical appointment, even though it's been encouraged by both oncologist and chest physician, who will then contact us at a later date to, who have thought about it, discussed it with their family, and asked to have another visit, and so we always accommodate that. Equally we have patients who've been offered treatment and may ring and want to cancel, but on further discussion about the reasons why, they will often at least attend for that treatment or come back and re-discuss. So I think having that opportunity where they've actually met someone and they know who they're ringing and can talk to certainly does have its benefits in that respect, certainly regarding the treatment aspec*t". (CS1 LCNS1)

Another aspect of the role that can open doors to treatment is the provision of financial advice and information to help patients unlock benefits they are entitled to. The financial burden of the illness and treatment can influence a patient's decision to have treatment.

"So it's financial information they want, and so we would also link them to Macmillan Benefits, make sure everybody gets Attendance Allowance, make sure they're not paying for prescriptions if they're under a certain age. Financial benefits are huge I think. We apply for grants through Macmillan if people haven't got money for their washing machine or, you know, there's a variety of things that they'll cover. They've actually paid some bills for someone recently, Macmillan". (CS2 LCNS2)

- Co-ordination

A final dimension of the LCNS role that places then at the hub for the patient and MDT, and has an impact on treatment access, is the co-ordination they undertake. Co-ordination was a recurrent theme and was mentioned in relation to pathway co-ordination, linking and liaising, bringing the team together and keeping records. Some examples of how these co-ordination roles play out in practice and increase treatment access are provided in Box 4.

Box 4. Co-ordination roles and treatment access

Pathway co-ordination: "*So there's a role in initial diagnosis, there's a role in communicating that, following up at home immediately afterwards, but also for a period of time during their treatment, and then re-engagement at a later stage as needed for second lots of treatment or monitoring or for facilitating things like perhaps psychological support*" (CS3 MC1)

Linking and liaising (of colleagues, tests, settings and services)
"*I guess what they are is they are the primary point of contact, aren't they, for patients and families, as they coordinate and go through their treatment*". (CS2 MC2)

"*We need to link everybody together in the way that I spoke about linking the MDT together, that's what we see very much as our role*". (CS2 LCNS2)

Bringing the team together
"*With lots of things going on, and that will all come back to us, every aspect of that journey from suspicion to death really will come back to us, will come back to one of those phones or email*". (CS2 LCNS 1&2)

Keeping records.
"*But CS4 LCNS1 certainly is one who is involved in pulling all the information together*". (CS4 MC2)

Across other dimensions of "patterns of working" but especially co-ordination, the LCNS is seen to work with a whole systems approach. The role is crucial to the efficient running of the service but also to the care of the patient and access to treatment. The impact of the LCNS permeates all aspects of the system of care as illustrated by the comment from a medical MDT member who participated in the focus group. This shows how the LCNS keeps the MDT, patient pathway, tests and investigations, and psychosocial interventions co-ordinated across the service, care settings and geographical boundaries.

> "….encouraging the patient through the pathway, things we've covered already, making sure their fears are allayed, things like bronchoscopy, CT scans, make sure appointments are not wasted, patients know to attend on time and when their appointments are. Sometimes complex tests as well, such as PET scans and EBUS

doppler and ultrasound, but those are things sometimes patients need a bit more understanding about what they're for and why they're done. Those are slightly geographical, they're geographically quite difficult to get done because tend to be centralised tests away from the local hospital. So again we require the lung nurse to explain why it's important to attend and understand the compliance regarding that. So I think the nurse has an important role regarding that….. I'll just mention about the whole pathway and the fact that the lung nurse is almost a coordinator aside from the lung cancer MDT tracker, the lung nurse will coordinate the whole pathway, make sure that patients are going for their tests and things are being done appropriately". (Focus Group1, M1)

Timeliness

There was a strong stand of data that demonstrated timeliness was a pattern of working that enabled the LCNS to improve access to treatment. This was in three ways, through speed and efficiency of working, by creating time for decision making and finally by spending time with people.

- *Speed and efficiency*

The LCNS on all case study sites were seen to speed up the system of working and the decision making processes, as indicated above. The resultant increased efficiency meant the patient received more timely diagnosis and treatment response, thus increasing treatment rates. Additional interventions that improved timely treatment were improved service structures brought about by LCNS innovations, for example one-stop shop nurse led clinics. The expertise and knowledge of the LCNS enabled them to use their judgement and know when was the right time to see a patient, inform them and discuss treatment possibilities in an accessible way.

"LCNS1 and LCNS2 a week or two later may have been in touch with the patient and they may have made a stonkingly good recovery from their pneumonia or whatever, and then things open up again and they do become maybe fit for anti-cancer treatment, and so they'll get the patients chivvied along to the relevant clinic so that they can be offered more active treatment". (CS1 MC1)

- *Creating time*

There were various ways in which the LCNS was able to "create time" for patients who struggling to make a decision regarding treatment. Participants explained that there were a number of reasons for this including being overwhelmed by the diagnosis, fatalistic in their

approach to treatments, feeling unwell. The continuous nature of the contact the LCNS has with the patient and their knowledge of them meant they were attune to when the patient may need additional time to consider treatment options.

"We're aware that patients in hospital are far less well than what they potentially were maybe a week or so earlier, and once they get home they will improve and they're always offered follow up appointments if they do improve to discuss treatment again at that stage…. I can remember several cases where we've stressed that this patient the previous week was fit and well and they really need to get back on track and we get them seen again to discuss further treatment options". (CS1 LCNS1)

In many cases the LCNS was able to appear to create time for the patient to reflect on their options - even if the pathway was still working to the same speed. On other occasions, the service pathway needed to slow down to give patients the time they needed to consider treatment options. The LCNSs have the skill and insight into the disease and the patient to identify when this change of pace was required.

"I think our role adds to that for patients who are uncertain, for patients who just need maybe a little bit more time to think about things. We tend to be very conscious that because of targets that we tend to rush into things, obviously for many of the conditions they need to be acted on very quickly and that's what the majority of people want, they want a decision and they want treatment yesterday almost, but I do think for the ones that maybe are unsure, the ones who are potentially less well, that we encourage to improve" (CS1 LCNS1)

"We often have patients who at first discussion don't want anything doing or they're very adamant against one treatment or another, but given a bit more time to have a chat about what it might entail they're able to inform patients to enable them to really stand by their decision. So rather than just a blanket no surgery, making sure that they understand what the implications of that decision or what surgery would involve and what the difference between surgery and radiotherapy is in terms of outcomes. So they have a bit more time to be able to spend, so they influence outcomes I think as much on that side as they do on the MDT side". (CS1 MC2)

Creating time for patients gave them more control and helped to allay fears related to their prognosis. The LCNS had the expertise to judge the speed of information delivery as well as tailoring the content of that information and support.

"You think well actually I've got to take this very slowly with this patient for them to adjust, for them to understand what's going on as well, and appreciate and accept why we're doing things, and ultimately the diagnosis. And I think if you rush people too quickly sometimes it becomes a jumble in their head, and that's when they misunderstand things. Where if you take it step by step and almost drip feed them, it's like if you're given a tumbler of water to drink all in one go, you don't enjoy it. But if you take a sip at a time it's much more refreshing and you appreciate it more". (CS3 LCNS1)

- *Spending time*

The LCNS worked differently across sites but all were flexible in how they spent their time with patients. Whether patient contact was in clinic, during home visits or over the phone the specialist nurse was seen as accessible and someone who had time for the patient. Despite very challenging caseloads the LCNS still provided time for patients according to need.

*"Patients have plenty of time to mull things over, they're not rushed into a decision, and it's somebody who's really accessible to turn to and to ask for, you know, not for advice but so that they can make a properly informed decision, because the consultants, with the best will in the world, just wouldn't have the time for that". (*CS1 C1)

Qualities

The final theme regarding the LCNS patterns of working relates to the qualities of that work. Three themes emerged, patient focus, expert practitioner and entrepreneurial working.

- *Patent focus*

As demonstrated above the LCNS has the most continuous contact with the patient compared to other MDT members, they know the patient well and keep track of their progress. As such they are able to accurately maintain a patient focus in their approach to the patient but also maintain a patient focus to MDT discussions.

"A MDT with CS4_LCNS1 not here, it doesn't seem to flow as well. Because sometimes they want to make a decision on the patient based on what the patient's like, and a lot of the time CS4_LCNS1 has met them, had a conversation with them, and very often she'll say I've spoken to this gentlemen this week and he's adamant

he doesn't want this, or he only wants this if it can give him this. And we wouldn't have that input if CS4_LCNS1 wasn't present at the MDT". (CS4 C1)

The timeliness of care delivery discussed above also illustrates the focus on individual care requirements of each patient rather than adherence to a generic pathway.

"Even if you just put things off for a day, it just allows them that control, they're in control as well. At the end of the day it's their disease, it's not ours". (CS3 LCNS 1)

The participants in the study provided numerous examples of how the LCNS was able to maintain a patient focus by adjusting the service speed, identifying and allaying fears, being an advocate in MDT discussions and providing trusted and appropriate advice and support. Quotations provided earlier in this section illustrate how this practice can increase access to treatment.

- *Expert practitioner*

As previously mentioned the LCNS worked at an expert level. Their knowledge of the disease, patient pathway and the range of responses to patients provides them with the judgement to tailor care in such a way that treatment possibilities are maximised. In addition the advanced nature of their clinical decision making and practice was also seen to open up treatment opportunities to patients. This was partly due to skilled communication and building rapport.

[Being at pre-diagnosis clinic] *"means that she then has a chance to build a rapport with the patient, get to know them and often it's their partner or their children that comes with them. So that it's not just suddenly somebody new introduced at diagnosis".* (CS1 MC3)

However, it may also be due to accurate and expert assessment of performance status, management of symptoms or prescribing of medications, all of which could increase eligibility of patients for treatment.

"So there's all sorts of ways of assessing and triaging on the phone, which I have to say takes a few years to be comfortable with". (CS2 LCNS2)

"They're better at sort of assessing functional status, performance status than a lot of people, and quite often they've seen them in their own home. And they quite often can advocate and say look I know you said this person's performance status two, but

I saw them a few days ago, yeah, he's out of bed, but, you know, he sits in his chair or he walks back from one room to another, it's like I've got real doubts about his fitness". (CS3 SPR1)

"Nurse prescribing gives us more autonomy. Particularly in the community, we're not having to ring up GPs and say look can you do a prescription"? (CS3 LCNS1)

- *Entrepreneur*

The LCNS was described as entrepreneurial in their approach to their work. Essential elements of this were being pro-active in terms of tracking the patient, managing symptoms and developing services. By helping patients to improve fitness levels and improve symptoms the specialist nurses were able to open up treatment to patients.

"I suppose what we try to constantly encourage is that patients do try and improve their general health, if we can manage symptoms, get them feeling fitter and weller then there always is an opportunity to consider treatment if that's an option. So we're very proactive in that". (CS1 LCNS1)

Amongst the services and innovations that the LCNS had been instrumental in developing were pulmonary rehabilitation programmes, holistic needs assessments and tracking systems. All of these helped to ensure that patients were considered for all appropriate treatment options and that patients did not slip through the net. For example in relation to a tracking system developed and run by a LCNS, one consultant remarked.

"I think, three, four, five years, every year I would be doing a medico-legal report for a patient who had a chest x-ray that was missed. When they started doing the tracking that stopped and they were very successful in preventing, they have been successful in preventing missed x-rays, so it's a very valuable service". (CS1 MC1)

Again the whole systems and creative approaches to resolving clinical challenges was highlighted as important to the LCNS effectiveness.

"I think there's something about being quite creative in dealing with problems or issues; it's just looking at multiple solutions….. we need good systems and infrastructure, but we also need flexibility, and can do attitude" (Focus Group 1)

Diagram 3: Timeliness (see page 48)
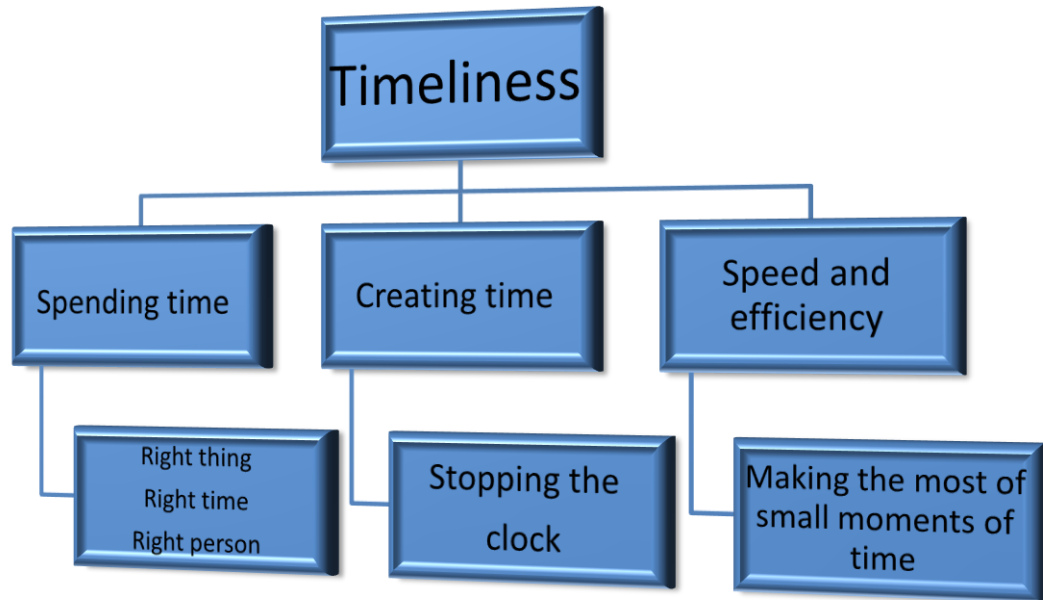
Facilitators

From the data in this study a number of factors were identified that help the LCNSs work effectively, efficiently and improve access to treatment. These factors are briefly summarised below.

Structure and stability of organisations

The fact that treatment for lung cancer could be delivered on multiple sites which may be geographically distant could result in practical and organisational difficulties not only for patients accessing services but for the MDTs trying to deliver timely care for patients and keep track of patients throughout their journey. The structure of the networks in place and the number of sites involved in the pathway made a big difference in terms of transfer of patients for diagnostic tests, delivery of treatments such as surgery, chemotherapy and radiotherapy and the links that needed to be in place between sites to ensure patient flow and exchange of information. The LCNSs were seen to have a key role to play here in developing systems and networks to keep information flowing for the patient's benefit.

Where the LCNS was located geographically within their own hospital could also have an impact on their ability to offer the best service to patients. Having the office of the LCNSs close to the outpatient clinic and the physician's office for example was a huge help in one case study site.

Not all LCNSs worked in organisations where their posts were seen to be stable and secure. In one site, all specialist nurse posts had recently been reviewed as a result of strategic changes within the Trust. Staffing shortages within the same Trust has meant that on occasion the LCNS had been asked to cover wards. However, by contrast the LCNS in another site felt very secure in her post given that the peer review process in cancer services had identified her role as pivotal to the running of the service.

The fact that services might be split between organisations and even in different parts of the same organisation could also causes difficulties when deciding who should fund the LCNS.

Working relationships

Good working relationship between the LCNSs and other MDT members were evident in all case study sites. These were seen as pivotal in harnessing the collected skills and efforts of the MDT for the benefit of patients. MDT observations revealed collegial relationships between the team at all case study sites. Informal conversation between the LCNS and other

team members were seen as vital to ensure flow of information about patients in order that treatment decisions were made with the best information available;

> "…the respiratory consultants actually, well I've got one working in the next room to me now, so if I needed any assistance, any advice at all then he's there. We've got mobile contact with the histopathologist, the radiologist. We're on first name terms with them, and they know us quite well, so they're very supportive". (CS2 LCNS1)

In some sites, the medical consultants had known the LCNSs when working as registrars and it was clear that they respected their role and the part they played in patient care:

> "I think oncology I always believe it's a team game, you know, not just lung cancer work, oncology as a whole is a team game". (CS1 MC2)

As identified above, the LCNSs were seen as the glue keeping the MDT together.

> "Well, we have to make it work. We don't have to all love each other, we have to all work together, and there are a lot of individuals that would find it very difficult to listen to what somebody else would have to say. We can all be like that, you know, and there are a lot of people that would find it hard someone else telling them the way they should be doing things. And what our role is as well as all the other things I think is to make that work. It's a bit like your role at home in a way. Which it doesn't sound like it is but it is really. Mum makes the peace everywhere really; it's a bit like that". (CS2 LCNS2)

Support and supervision

The importance of good peer support doing a difficult and demanding role was highlighted in all case studies. For many LCNSs peer support from their fellow LCNSs either on site or through national or local networks was highly valued. However, lone post holders were seen to face particular challenges.

Managerial support was also seen as highly important to sustain these demanding roles. The provision of clinical supervision was not uniform. In one site this was provided formally by a clinical psychologist on a monthly basis and prioritised, but on some sites it was more ad hoc and patchy.

The amount of administrative support varied between organisations in the case studies. MDT co-ordinators played a vital role in some sites but administration was seen as inadequately resourced in others, resulting in a heavy administrative burden for some LCNSs.

Workload

The workload for LCNSs on all case study sites was seen to be increasing over time. This was in part due to increased numbers of patients being diagnosed and in part due to the fact that patients were seldom discharged (except on sites where they were transferred to the palliative care team at the very end of life). Due to advances in treatment patients were living longer and this was seen as another reason for year on year increases in LCNS workload.

The heavy workload on all sites meant that in each case study, there were aspects of care that the LCNSs would like to undertake but were unable to due to lack of capacity. These included follow up home visits following diagnosis, visiting patients having treatment at another hospital and on one site increasing the number of nurse-led clinics.

On one site LCNSs were not able to see in-patients due to workload pressures but focused instead on patients in the community. On another site the LCNS saw their ability to see every patient at the point of diagnosis as being compromised by sheer volume of work. On one site, workload pressure meant that the LCNSs were involved in a radical reconfiguration of their role and were going to hand over the palliative care element of their work to Macmillan nurses, much to their regret:

> *"it has been heart wrenching I think because my colleague and I are passionate about the model, the care and the service we deliver. But for our own sanity something had to give, we have to give something up otherwise we'll both end up not working because of the amount of work that we've got".* (CS3 LCNS1)

At the case study site where only a single LCNS was in place the sheer number of clinics presented an organisational dilemma for the single LCNS, although plans to recruit a second LCNS were in place:

> *"she is torn between trying to be in a number of different places at once. For instance on the Tuesday morning when I'm doing my clinic and seeing new patients, seeing patients who are on chemotherapy and seeing some patients for follow up,*

that in parallel to that there is a respiratory clinic where patients with lung cancer are being given bad news or, you know, are at the start of their cancer journey or indeed are also on follow-ups so she can't be in two places at once. And in my clinic there's myself and the registrar and there are simultaneous patients with problems, and, you know, she simply cannot be in several rooms at one time". (CS4 MC3)

These lone postholders were seen to face particular challenges with little cover being available when the LCNS was either on holiday or off sick.

Workload was also affected by the amount of administration the LCNSs had to do which in part depended on contribution of the MDT co-ordinator. In some sites there was insufficient resource within the organisation to cover all tumour sites so the co-ordinator's time was limited.

The extent to which the LCNSs were involved in palliative care also affected their workload with the LCNSs who had a dual lung cancer/palliative care role highlighting that this resulted in a considerable increase in workload.

The extent to which LCNSs had to work to 'glue together' the different parts of the patient pathway and ensure streamlined timely service provision depended on both the number of sites involved, the geographical distribution of their patients (particularly if the LCNSs did home visits) and the amount of administrative support. The imperative not to breech the two week wait rule was felt keenly by LCNSs in CS1 and they expended a great deal of time on administrative functions to ensure this did not happen which was not seen as appropriate by everyone:

"What worries me is I don't think lung cancer nurse specialists should be fundamentally being involved in data collection and coordinating the patients' pathway. That's not to say they shouldn't do so as and when they are in contact with patients, of course they should, but I don't want the service dependent on the nurses being coordinators. I think their role is much more important, and so I would far rather the data clerk send the data, I'd far rather the system's working so we don't need to coordinate pathways in the same extent that sometimes happens. So actually the nurses can focus on the nursing support, care and advocacy for the patients". (Focus Group 2 M2)

The effect of workload pressures meant that if a LCNS was off sick long term or took annual leave there were gaps that were hard to fill. The result was that for patients there was a lack of continuity gaps and in service provision and for the MDT, poor co-ordination.

Information systems

There was a variety of information systems in place across the case study sites. The information systems served two broad purposes - to ensure that information was recorded for the purpose of monitoring performance against organisational targets and to ensure that patients records were complete or patients could be 'tracked' or monitored throughout the care pathway. The importance of having a good data manager on site as well as sufficient administrative support to maintain information systems was echoed across all sites.

'Somerset' was the database used in three of the case study sites to record all the cancer wait time data and the COSD (Cancer Outcomes Services Data). Somerset was seen as useful in its ability to capture patient contact including telephone contact. However, at some sites there were reservations about the Somerset system because it did not allow data to be displayed in the most useful way in MDT meetings for example with radiological images alongside other detailed information about individual patients.

Even in sites where Somerset was in place, additional information systems were in place to supplement this. For example in one site, in order to keep track of telephone conversations with patients and keep track of contacts made, the LCNSs kept their own nursing records. This was seen to provide richer and more useful data than Somerset.

Data from the focus group highlighted this variety in information systems further, with some participants reporting that they had developed their own custom built databases which print letters to GP and for blue badge applications etc. Other organisations were wholly reliant on paper records while others relied completely on electronic records.

The importance of having systems in place to ensure that each patient was captured, dealt with and picked up at the right time was paramount, given that patients dipped in and out of the pathway in unpredictable ways and often at a point of crisis. Various of systems were in place to ensure that this happened. At one site, information systems had been set up so that when a patient was referred in for any type of cancer, an electronic alert was put on their hospital record. If a patient with lung cancer was subsequently admitted to hospital, the LCNS would get an email that day to alert her to the fact.

On another site, if the radiologist reading the chest X ray of a patient referred from the GP felt the X ray was suspicious of lung cancer, s/he would indicate this on the X-ray reporting system that the patient would need fast tracking to clinic. This information then came to the secretary, consultant and the LCNSs by fax and a CT scan was requested electronically before the patient's first appointment in clinic.

The overarching issue across the case study sites was that however good the information systems in place, these could not provide all the information about an individual patients circumstances and preferences that was relevant to their care e.g. that the patient may have dementia and live in a nursing home. The role of the LCNS was seen as crucial in providing additional information to inform the treatment decision in a timely way.

National Lung Cancer Audit Database

The NLCA 2010 identified the apparent correlation between the patient's access to an LCNS and their access to active anti-lung cancer treatment (NHS Information Centre, 2011). The perceived benefits and deficiencies of the NLCA and the Audit database (sometimes referred to as LUCADA) were discussed by participants during interviews and the focus groups in relation to helping or hindering their work and the ability to capture the impact of the LCNS. Five dimensions of the NLCA were referred to and are presented here; the entry of data on LCNS activity; the completeness of data in the NLCA; comprehensiveness of the NLCA data; the usefulness of the database; and measures that might help to improve use and utility of the NLCA in relation to the role of the LCNS.

> *"Problems with the fields not being reflective of what you do. Problems with the fields having too many options so that the coordinator can't select the correct option. Problems with support of MDT coordinator...we have nobody, no administrative and no MDT coordinator, so everything that's being done is being done again within the nursing role... Problems with accuracy of data, the inputting and interpretation, there's a very fine line isn't there between the clinical and the administrative role in that scenario...So we've had occasions where they've interpreted a CT scan result that didn't particularly identify anything as being a negative result for cancer, and they've put them 'not cancer'. So our role, we're constantly checking this stuff when we shouldn't have to, so training issues".* (CS2 LCNS1&2)

Data entry to the NLCA

On one site, the LCNS had been involved in the use of the NLCA from its inception, and had contributed to the development of the fields that currently capture LCNS activity. On this site the data management team had remained stable throughout the time that the NLCA has been used. On the remaining sites, there was frustration with the process of entering data onto the local information system for the NLCA. There was uncertainty about where data on specific LCNS activities should be recorded so that it would be 'pulled through' to appear on the NLCA database.

> *"Unfortunately our IT system when we upload is not uploading information correctly, so we have been getting incorrect figures on LUCADA"* (CS2 C1)

Completeness of data on the NLCA

Uncertainty over which 'fields' to record the work of the LCNS was further complicated by instability in the teams that gathered and monitored data collection. On one site, the LCNS

was confident that the data on LCNS activity was complete and accurate. Any data missing was quickly identified by the data manager who prompted the LCNS to fill the gap. Elsewhere, different people took responsibility for recording the data. On one site, the lead clinician in the lung cancer team took the lead responsibility for data entry, but LCNS activity had been missing initially as a result. Where the MDT coordinator had health professional training it helped the accuracy of recording diagnostic test results when entering data.

Even where the LCNS took responsibility for ensuring that data on their own activity was accurate, lack of training in the completion of the fields could still result in inaccurate data on the NLCA database. One LCNS reported that it had taken the work of two staff members over a week to check through hand held records to correct errors. In three of the four study sites there was uncertainty over who should record treatment data in cases where the patient was referred from the study site to a treatment centre for their anti-cancer treatment. This was reflected in a focus group discussion involving medical staff.

> *"And sometimes it can be difficult to be sure the right data is being linked and the right information is all being collated together."* (Focus Group 2)

Comprehensiveness of the NLCA data

LCNSs noted that not all aspects of their work was captured by the NLCA. Much of their work was not overtly captured, including the telephone work that occupied a considerable proportion of patient contact time.

> *"A large percentage of what we do over the phone, I always feel it tends not to be recorded properly...a lot of the work is done by telephone, a lot of the supportive work, contacting other colleagues, liaising with GPs and actually preventing admission."* (CS1 LCNS1)

However, it was acknowledged that the Somerset system used to enter data on three sites includes fields that could reflect diverse approaches to LCNS work, but there was uncertainty about how to ensure that these would be reflected in the NLCA.

> *"...because very often when we're filling it in, we think 'oh, that's not there - we can't put that in', but then you forget what it was..."* (CS4 LCNS1)

This may also reflect lack of awareness that not all data entered locally is analysed and presented in the NLCA at present.

Usefulness of the NLCA

Our findings indicate mixed feelings about the utility of the NLCA for LCNSs. On the one hand, there is concern that incomplete data paints a falsely negative picture of the contribution made by LCNSs. Conversely, where data can be trusted, it provides visible evidence of the work of the LCNS. This has contributed to re-shaping that role and supporting a case for additional staff resources. For some LCNSs, changes in the work done by the LCNS have not been reflected in the fields used to collect data for the NLCA while for others it provides sufficient flexibility to keep pace with developments.

Summary

The findings of this study demonstrate clearly how the LCNS can increase access to treatment. Selected findings have been presented to illustrate how different structures and patterns of working can impact upon patients, staff and organisations in order to ensure appropriate treatments are provided. The findings also highlight the tasks that LCNS undertake to achieve that impact. Findings that relate to the National Lung Cancer Audit are provided in relation to its completeness, comprehensiveness, and perceived usefulness. Finally measures that might help to improve use and utility of the Audit data in relation to the role of the LCNS have been considered. The next section of this report now considers some key messages to emerge from the study, some strengths and weaknesses and recommendations for future research.

Discussion

Strengths and limitations

This study aimed to identify explanations for the reported association that patients who see a LCNS are more likely to have access to anti-cancer treatment, as reported in the NLCA. The study was successful in generating insight into how the LCNSs conducted their work, and why they may increase access to treatment. The intention was not to provide statistical data on how often this impact was experienced, but the study did provide explanations to understand how the impact plays out in clinical practice.

Data was collected from individual interviews, focus groups, observation of MDT meetings and selected documents (e.g. job descriptions, patient pathways and protocols). Whilst the study was limited to four case studies of LCNSs, the range of disciplines and data collection methods helped to strengthen the rigour of the study. The triangulation of this data helped to verify the findings. However, caution is required in making generalizable claims from this data without wider testing of the experiences and practice reported here.

One challenge encountered in terms of completion of data collection was in terms of the focus groups. Many efforts and strategies were employed to recruit participants to focus groups from other MDT disciplines e.g. targeting interested groups, attaching the focus group to pre-existing meetings. All approaches hit logistical barriers. Finally a telephone group interview was arranged but at the final event only two doctors (an oncologist and thoracic surgeon) rang in to participate. However, recruitment across disciplines at the case study sites was successful and the study was able to integrate views from across the MDT.

The process and timescales of the project were challenged because of the inordinate amount of time it took to obtain research governance approval. Whilst all the study sites were helpful, there was a lack of familiarity with the research methodology and so the process of approval was uncertain in some sites. This meant approval took four months in some sites. Conversely, we had been able to obtain ethics committee approval within weeks.

Despite this delay, the research team have been successful in early international dissemination of the findings at the prestigious World Conference on Lung Cancer in Sydney in October 2013.

Evaluation of advanced nursing practice roles

Our study has produced a wealth of qualitative data to illustrate a range of 'ways of working' which provide clear and plausible mechanisms by which LCNSs might increase access to

anti-cancer treatments. However, articulating cause and effect in a quantifiable sense would be highly problematic for any element of LCNS work, even in the context of rigorously designed experimental studies. As McDonnell et al, (2013) point out, the impact of many advanced nursing roles is inherently hard to capture. Reasons for this include the fact that the impact of these roles is often indirect i.e. through influencing the activities of another MDT member rather than direct and therefore are delayed rather than felt immediately. In addition, for nurses who work as members of large multi-disciplinary teams, attributing any change in patient or organisational outcomes to an individual team member is not only problematic from a research perspective, but does not reflect the realities or goals of day to day clinical practice.

Advanced roles in nursing, including the LCNS role, have been developed across the UK and internationally in response to a number of key drivers including the increasing number of treatment options available for many conditions, the complexity of treatment pathways, the increasing population of elderly people, increasing costs of healthcare and in Europe, the reduction in the working hours of junior doctors.

The contribution of advanced practice roles in nursing has been explored in a number of reviews of the literature. Some of these reviews have focused on particular settings such as primary care (Laurant et al. 2004). Others have focused on a particular clinical speciality, such as cardiology (Halcomb et al. 2007), critical care (Kleinpell et al. 2008), cancer (Cruickshank et al. 2009), emergency care (Carter & Chochinov, 2007), diabetes (Ingersoll et al. 2005) and multiple sclerosis (Forbes et al. 2003). Other studies have focused on a mixture of both clinical areas and patient groups (e.g. Wilson-Barnett & Beech, 1994). These reviews have contributed to an increasing evidence base for the positive impact that advanced nursing roles can have on a range of indicators including patients' symptomatology or physical outcomes, psychological wellbeing, patient satisfaction and patient knowledge/understanding (Gerrish et al 2011a, b & c).

There is however, little evidence about the impact of LCNS roles. There are no reviews of the literature which explore the impact of the LCNS. In addition, previous research has focused on the impact of the specialist nurse on follow-up care and end of life care rather than access to treatment (Moore et al 2002 & 2006, Murray et al 2002). However, there is growing interest in the value of the LCNS and their contribution to patient experience and positive outcomes of care (Roy Castle Foundation / NLCFN, 2013).

Current research indicates that impact of advanced nursing roles is diverse. Gerrish et al (2013) in a study of the impact of Nurse Consultant roles developed a framework for

capturing the impact of consultant roles which summarises impact in three domains - impact on patients, impact on staff, and impact on the organisation. Subsequent studies of the impact of advanced practice nursing roles indicates that this framework also has salience for roles other than those at consultant level (Begley et al 2013, McDonnell et al 2013 a & b).

In this current study, there was clear evidence that the LCNSs were also having an impact across the three domains (patient, staff and organisation). The focus of impact in relation to patients was on physical and psychological wellbeing (particularly in relation to symptomatology and reduction in anxiety), quality of life and patient experience. The impact on staff was particularly strong in relation to team working and impact on the organisation was felt keenly in relation to organisational priorities and targets - particularly those which related to waiting times and the National Lung Cancer Audit.

While there is evidence from our study about the wider impact of LCNSs across this broad range of domains, the focus of our work was on the impact of LCNS roles on increasing to access to anti-cancer treatments hasn't been captured before. These findings are summarized below.

Key findings

Whilst it was clear that the LCNSs worked differently across sites according to local context, resources and the population demographics, there were commonalities in terms of how the nurse specialists impacted upon treatment access. This study shows the complexity of the role, which has a diffuse and whole systems impact. This highlights a difficulty for the nurse specialist in demonstrating their impact. Nurse specialist roles are currently under pressure to demonstrate their contribution to the efficiency of the service. The findings here clearly demonstrate a contribution; however they highlight the challenge in quantifying that contribution in the climate of efficiency savings.

The LCNS has an impact on the whole system of service delivery in terms of treatment access. They worked across different structures and settings, and with a diverse range of disciplines. They adopted flexible and interchangeable patterns of working to move the patient through the pathway towards appropriate and accessible treatment options. A key feature of their working practice was to keep the patient at the centre of decision making. The role was highly respected and considered core and integral to the MDT by the members interviewed. The findings describe how the LCNS is able to enhance delivery of the whole service and function of the MDT. However, this means it is difficult to extract any one particular element which is discrete to the LCNS impact on treatment access. The picture is much more complex and the LCNS impact symbiotic and synergistic to the working of the

MDT. What is clear is that the LCNS role is crucial and at times the catalyst to patient eligibility to treatment. This is clarified in terms of the tasks identified that the LCNS undertakes, for example assessment, managing symptoms and early and appropriate referral.

The co-ordination and communication aspects of the LCNS role are essential in realising the impact in increasing treatment access. The findings illustrate how the LCNS is described as the hub, the oil on the wheels, the central cog, and in this way makes things happen. It was interesting to note that in one study site the LCNS had recently had extended absence due to sick leave. Their responses were informed by the gap they experienced when the specialist nurse was absent. The continuous nature of the LCNS contact with patients and families enabled them to really know the patient, keep track of them and where they were in the disease trajectory and pathway, accurately assess them physically and for psychosocial impact, and accurately present their views and needs at the MDT. Without a LCNS the MDT members highlight how continuity and advocacy is absent and how that void can obstruct treatment access.

The LCNSs in this study clearly worked to an advanced level of clinical decision making. Whilst co-ordination, linking and liaising were crucial dimensions of the role it is important to realise that this aspect of the role isn't just administrative but involved high levels of clinical decision making e.g. ordering, interpreting and acting on tests and investigations, referrals and prescribing. The expertise the LCNS brings to the service is evident in the study in terms of knowledge of the patient population, the disease trajectory, how relevant services work (including those linked to but external to their MDT) and how to get the best out of those services. The LCNS could often anticipate and deal with problems that could obstruct treatment access. These problems could be patient focused, such as fear and denial or organisational, such as the need to improve tracking systems. If the LCNS did not pre-empt these issues and deal with them it is difficult to see who else would be in a position to do so.

 Aspects of the LCNS role were challenging for the cases because of lack of funding and an increasing workload. The LCNS were all seeing increasing numbers of patients every year and, with financial pressures were being forced to make priorities regarding the focus of their work. For example in one case study site they were about to withdraw from doing home visits. This was despite being able to demonstrate how home visits added to the quality of the service and helped them anticipate problems in accessing treatment e.g. mobility, symptoms, transport, fatalist of families or fear of the patient. Another constraint that was identified relates to reliance on the LCNS to undertake administrative tasks. The capacity of

the LCNS to perform efficiently and undertake new aspects of service to maximum effect was hindered by the amount of time spent on administration.

In financially constrained environments it would be tempting to see the LCNS as an expensive resource, and therefore vulnerable to cuts. However, this study demonstrates the how integral the role is to efficient and cost-effective care, as well as increasing treatment access. However, to ensure best value for money investment needs to be appropriate across the MDT, including investment in administration, so each person can play to their strengths. The results also indicate how the LCNS role is enhanced when the organisational structure is stable, relationships with MDT members is harmonious; they have support and supervision and information systems that are efficient and not cumbersome.

As this study emerged from an observed association from the National Lung Cancer Audit, data was extracted and analysed that provided insight into how the LCNS worked with and valued the NLCA database. There were mixed experiences and views regarding the Audit and database. Where there was good knowledge of the audit and related processes, regular well-informed administrative and data entry support, and local reliable IT expertise, LCNS views were more positive. They were also more confident that the data shown on the NLCA regarding LCNS activity was more accurate. Where such resource was lacking, there was concern about the completeness and confidence in the audit findings. On some sites the LCNS has spent considerable time ensuring that data on their own activity was accurate. However, lack of training in the completion of the fields could still result in inaccurate data entry. The LCNSs also noted that not all aspects of their work was captured by the NLCA, including work that was highly valued and time consuming such as telephone contact and counselling. However, it was acknowledged that the Somerset system used to enter data on three sites includes fields that could reflect diverse approaches to LCNS work, but there was uncertainty about how to ensure that these would be reflected in the NLCA.

The continuous and consistent availability of trained administrative support for LCNS and others responsible for entering data into the NLCA database, whether through Somerset or another data entry system, appears as one measure to improve data accuracy and capture. Clarity over who should enter data at all stages of the patient's journey through the lung cancer pathway is also essential. Finally, contemporaneous data entry by people trained not only in the information system but also in medical terminology would assist in improving accuracy.

Future research

This study makes an early contribution in understanding how the role of the LCNS makes an impact on care and specifically on access to treatment. Collating evidence on impact is difficult because of differences across sites. This study identified those elements of practice that are common and help understand how the role can impact upon patient outcomes. Future research could test and evaluate the impact of these across multiple sites, maybe through survey methods and analysis routine data. Future multi-centre studies could seek to identify what aspects are most important in terms of patient outcomes.

The aim in this study wasn't to develop a framework or typology to explain the practice or impact of the LCNS. However, the beginnings of a framework of impact similar to that developed for Nurse Consultants, has emerged (Gerrish et al, 2013). This Framework could be developed, implemented and evaluated in future multi-centre research.

There is an urgent need for an economic evaluation of the impact of the LCNS roles (and other CNS Cancer roles). There is knowledge of how much such posts cost. However, it is more difficult to calculate the offsets to these costs and impacts of the roles. This study demonstrates how difficult it is to capture such impacts and the components of practice that contribute to them. Robust cost benefit and cost effectiveness studies would be a challenge but are essential.

Finally, more analysis is required of the database. Currently the NLCA only analyse two of the five fields that relate to the LCNS input to the patient pathway and outcome. It is necessary to consider if all five are necessary, if more resource is required if the NLCA is to realise its potential and if there are better fields that could be developed to evaluate the impact of the LCNS role and that of other professionals and service components.

The research team have linked with the University of Nottingham and other external consultants in a successful application to the Dimbleby Trust. This study will undertake secondary analysis of the NLCA, including all five nursing fields. This will be integrated with analysis of the National Cancer Action Team census, Hospital Episode Statistics data and survey findings from the National Lung Cancer Forum for Nurses. This study is due to commence in January 2014. The lead for this study is Dr Laila Tata from the Division of Epidemiology and Public Health in the Faculty of Medicine at the University of Nottingham. Professor Tod and John White are co-applicants in the study.

Dissemination

A brief summary of dissemination activity to date, and that planned for the future is presented below.

Conferences

World Conference on Lung Cancer. Sydney, Australia. October 2013. The impact of the Lung Cancer Nurse Specialist on access to treatment. Tod A. Redman J, McDonnell A, White J, Borthwick D. *(Oral presentation)*

International Thoracic Oncology Nurses Forum Annual Meeting and Workshop. Sydney, Australia. October 2013. Positive impact of Specialist Lung Cancer Nurses on better patient outcomes. Tod AM. *(Invited Keynote)*

National Lung Cancer Forum for Nurses Annual Conference. London, England. November 2013 The impact of the Lung Cancer Nurse Specialist on access to treatment. Tod A. Redman J, McDonnell A, White J, Borthwick D. *(Poster)*

British Thoracic Oncology Group Annual Conference. January 2014, Dublin Republic of Ireland. The impact of lung cancer nurse specialists on access to anti-cancer treatment - implications for the Multidisciplinary Team (MDT) Tod A. Redman J, McDonnell A, White J, Borthwick D. *(Poster)*

RCN International Nursing Research Conference, April 2014, Glasgow. The impact of lung cancer nurse specialists on access to anti-cancer treatment - implications for advanced nursing practice and patient care. Tod A. Redman J, McDonnell A, White J, Borthwick D. *(Poster)*

Publications

At least two academic peer review articles are planned, aimed for the Journal of Advanced Nursing and the European Journal of Oncology Nursing. An additional article will be prepared aimed at a clinical audience in Cancer Nursing Practice.

Report dissemination

An executive summary of the report will be disseminated to key organisations including the British Thoracic Society, British Thoracic Oncology Group, National Cancer Research Institute Clinical Studies Group: Lung Cancer, Roy Castle Foundation, Macmillan and the NLCA Committee.

Conclusion

This study generated clear and in-depth insight to demonstrate why and how the LCNS has an impact in access to treatment. The study reveals the centrality of the LCNS role to the MDT and continuity in relation to the patient and their journey across the pathway. This study provides the first step in understanding and evidencing the contribution this advanced practice role makes to a tangible and vital patient outcome. A preliminary framework has been developed that could be refined and implemented to support the performance of LCNS roles and help specialist nurses demonstrate their impact locally. Economic analysis of the impact of the LCNS role is urgently required.

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