Understanding the value of lung cancer nurse specialists
January 2013
ACKNOWLEDGEMENT

The Roy Castle Lung Cancer Foundation and National Lung Cancer Forum for Nurses would like to thank all those who have lent their support and expertise in the development of this report: Diana Borthwick; Kim Bowles; Sarah Compton; Alison Leary; Dr Mick Peake; and Dr Ian Woolhouse. We would also like to thank all the nurses, patients and carers who responded to our survey, without whom this project would not have been possible. In addition, we thank MHP Health Mandate, whom we commissioned to compile this report.

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ABOUT THE ROY CASTLE LUNG CANCER FOUNDATION

The Roy Castle Lung Cancer Foundation was founded in 1990 and is the only charity in the UK wholly dedicated to defeating lung cancer. We work to:

• Support and fund research into the early detection and prevention of lung cancer

• Provide support for people affected by lung cancer through information, advice and advocacy, and through raising awareness of the disease

• Raise awareness of the harm caused by tobacco and build capacity to reduce and prevent the harm caused by smoking through our FagEnds stop smoking services

• Campaign for more research and for better care and treatment for people affected by lung cancer, and for strong anti-tobacco measures to support reductions in smoking prevalence

ABOUT THE NATIONAL LUNG CANCER FORUM FOR NURSES

The National Lung Cancer Forum for Nurses was established in 1999, primarily to provide networking opportunities and support for nurses involved in caring for people with lung cancer. Any specialist nurse who spends more than 50 per cent of their working week or clinical activities in caring for patients with lung cancer is eligible for membership. The success of the forum since its establishment is indicative of a real need for links and networks for nurses involved in caring for people with lung cancer. The experience and clinical background of the members’ working environments are very diverse, including palliative care, oncology, respiratory medicine and community. This affords the forum a wealth of knowledge from which all its members can benefit.

Please note that the names used in case studies throughout the report have been changed to protect confidentiality.
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SUMMARY OF RECOMMENDATIONS

**Recommendation 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.

**Recommendation 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.

**Recommendation 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.

**Recommendation 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.

**Recommendation 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.

**Recommendation 6:** LCNSs should be provided with the necessary resources to give advice and support to help patients with lung cancer who are smokers to stop smoking.

**Recommendation 7:** More research should be undertaken to understand the reasons for the correlation between nursing input and receipt of active treatment so that best practice can be replicated where possible and all patients have equitable access to active treatment for lung cancer.

**Recommendation 8:** Nurse-led follow-up after treatment should be offered to all patients with lung cancer undergoing treatment to ensure that they can benefit from the improved outcomes this model of care has been shown to deliver.

**Recommendation 9:** LCNSs should be encouraged, and provided with the necessary resources, to offer all patients with lung cancer access to nurse-led clinics that improve their quality of life and functional capacity.

**Recommendation 10:** LCNSs should be recognised as the patient’s advocate at multidisciplinary team (MDT) meetings and be supported by the MDT to deliver patient-centred care that responds to the patient’s individual needs.

**Recommendation 11:** Patients with lung cancer should be able to access LCNS input at all stages of the lung cancer pathway, including towards the end of life, so that they are able to benefit from high quality palliative and end of life care that responds to their individual needs and expectations.
INTRODUCTION

The aim of this project

The Roy Castle Lung Cancer Foundation (RCLCF) and the National Lung Cancer Forum for Nurses (NLCFN) have worked together to develop this booklet with the aim of highlighting the difference lung cancer nurse specialists (LCNSs) can make to the lives of patients with lung cancer and their families and carers. We conducted a survey of LCNSs, patients with lung cancer and carers of people with lung cancer, with the aim of uncovering people’s experiences of the care delivered by LCNSs in addition to LCNSs’ own accounts of how they have helped to improve patient outcomes. The responses to the survey are used throughout this report to illustrate the value of LCNSs to patients with lung cancer and their carers.

Specialist nursing posts are often placed under threat during times of financial austerity, despite evidence that patients value the services provided by specialist nurses greatly and consistently rate them higher than other health professionals in terms of understanding patient needs, designing better personal care pathways, and obtaining patient feedback\(^1\). With the ongoing financial pressures in the NHS, we are concerned that LCNS posts may be threatened in some areas. As this report illustrates, LCNSs are essential to the delivery of high quality care and improved outcomes for patients with lung cancer. Posts must therefore be maintained and, where possible, the number of LCNSs increased so that all patients with lung cancer can have access to a LCNS.

About lung cancer

Despite improvements in the quality of care and treatment for people with lung cancer in recent years, lung cancer remains a devastating disease and the most common cause of cancer death in the UK. Each year around 41,500 people are diagnosed with lung cancer in the UK\(^2\). On average, only around a third of people survive lung cancer for three years after diagnosis, and fewer than one in ten survive beyond five years\(^3\). Awareness of the signs and symptoms of lung cancer is low and more than two thirds of patients are diagnosed at a stage when curative treatment is no longer an option\(^4\). There are significant variations around the UK in outcomes, treatment, care and patient experience for people diagnosed with lung cancer\(^5\).

About lung cancer nurse specialists

Since the introduction of the clinical nurse specialist role in 1995 there has been an increase in the number of LCNSs. There are, however, variations in access to LCNSs across the UK. LCNSs play a vital role in the delivery of high quality care and treatment to patients with lung cancer. They are in an ideal position to be able to care for patients with lung cancer in a holistic way, ensuring that all their care needs are addressed from referral to diagnosis, through treatment and survivorship, and including end of life care. Figure 1 highlights the key contributions that CNSs make to cancer care, including in-depth knowledge of the cancer they specialise in, leadership within the multidisciplinary team, and the ability to assess the patients’ holistic needs.
The most recent Cancer Patient Experience Survey in England highlighted the importance of all cancer patients, including those with lung cancer, having access to CNSs. In fact, one of the most important findings of both the 2011/12 and 2010 surveys was that, on almost all the survey questions, patients with access to a CNS gave more positive scores than patients without a CNS. The most recent report states that these findings are “the clearest possible indication of the quality of care given by specialist cancer nurses, the manifest impact that they have on the services given to cancer patients, and the substantially improved understanding of treatment options and prognosis which flow to patients from contact with their CNS”.

Figure 2 sets out the role of the LCNS in the lung cancer patient pathway. As illustrated in the diagram, the LCNS plays a key role in the pathway, from pre-diagnosis through to survivorship. LCNSs play a role prior to diagnosis, for example through raising awareness of lung cancer and supporting patients through investigative tests. Following diagnosis, LCNSs provide invaluable support to the patient at all stages of the pathway, including through information provision, holistic assessment, psychological support, care coordination and patient advocacy.
The contribution of LCNSs to efficiency savings

There is evidence to suggest that CNSs can contribute to cost-savings for the NHS – CNSs have been shown to represent good value for money by reducing the number of emergency admissions, the length of hospital stay, the number of follow-up appointments, the number of medical consultations and providing support to enable people to be cared for and die in their place of choice\(^8\).

One study in Manchester found that service improvements along the cancer pathway led by breast and lung CNSs could release about 10 per cent of cancer expenditure in the area\(^9\). Another lung cancer nursing service in London has reported that, by delegating administrative tasks and adopting a proactive management approach to patient care with the LCNS as the key worker, the rate of lung cancer admissions for non-acute problems fell from four per month to 0.3 per month, representing a significant return on investment in nurse posts\(^10\).

As further illustrated by the case studies that feature in this report, LCNSs can increase productivity and efficiency by intervening to manage lung cancer treatment side effects and symptoms, preventing costly unplanned hospital admissions. They can also provide nurse-led services that free up consultant resource, and empower patients with lung cancer to self-manage their condition, leading to additional efficiency savings.
PRE-DIAGNOSIS

The role of the LCNS begins even before a diagnosis of lung cancer is made. Many LCNSs are involved in complex activity at the pre-diagnosis stage, for example through providing information, coordinating tests, communicating with other healthcare professionals and supporting symptom management. A recent report from the UK Lung Cancer Coalition recommends that LCNSs should be involved with pre-diagnosis care of suspected patients with lung cancer. The report stresses that, in the ideal lung cancer multidisciplinary team (MDT), LCNSs should be involved at this early stage so that they can support patients from initial presentation with symptoms, through investigations to treatment, into palliation and supportive care, and are critical to ensuring continuity of care.

Awareness of the signs and symptoms of lung cancer is low and more than two thirds of people are diagnosed at a stage when curative treatment is no longer an option. LCNSs play an important role in raising awareness of lung cancer signs and symptoms. For example, they may run awareness-raising initiatives within their local area, sometimes to coincide with Lung Cancer Awareness Month.

Recommendation 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.

All the LCNSs who responded to our survey were able to provide examples of their input at the pre-diagnosis stage of the lung cancer pathway. A selection of these examples is set out below.

Examples of LCNS input at pre-diagnosis stage

“I have been involved in radio media interviews advertising the cough x-ray campaign and I also meet all patients with suspected lung cancer pre-diagnosis to start the support and information.”

“We are present from pre-diagnosis to support any patient with a possibility of cancer within the lung. About 50% of these turn out not to have cancer but have the same fears and anxieties.”

“I provide a lung cancer awareness stand in November. I support patients and provide information regarding diagnostic tests.”

“I hold awareness days and a lung cancer study day for professionals.”

“[We provide] holistic assessment of needs/interventions from first appointment/test [and act as the] key worker throughout investigations. Patients value this contact/support – this time of uncertainty they describe as the worst time for them.”

“Offering smoking cessation advice and raising awareness of symptoms in the local community.”

“I meet the patient at their two week wait appointment. Meeting patients at this first visit allows early intervention into symptoms and provides support through the diagnostic pathway.”
Understanding the value of lung cancer nurse specialists

DIAGNOSIS

Around 41,500 people are diagnosed with lung cancer each year in the UK, which is more than 100 people each day. The psychological impact on patients and their carers following the diagnosis of the disease often requires special attention. It is crucial that patients and their families are given timely and accurate information about the treatment options available, in addition to being provided with individual care and support during this difficult period. Having a LCNS present at the point of diagnosis can ensure that people's physical, social and emotional needs are appropriately assessed from the beginning of their cancer journey, in addition to ensuring that the patient and their family clearly understand how the disease will impact their lives.

Role of the LCNS at diagnosis

The National Institute for Health and Clinical Excellence (NICE) lung cancer quality standard, published in March 2012, includes a statement on ensuring LCNSs are present at diagnosis and throughout the care pathway, recommending that people with known or suspected lung cancer have access to a named LCNS who they can contact between scheduled hospital visits.

The Scottish Intercollegiate Guidelines Network (SIGN) guideline on lung cancer recognises the importance of LCNSs at diagnosis and after, stating that: “The development of clinical nurse specialist posts should be encouraged, through resourcing and training, to facilitate best practice”. The guideline also recognises the effectiveness of LCNS-led follow up care and outlines that it can lead to greater patient satisfaction than physician-led follow up. An update of the SIGN guideline on lung cancer is currently in progress and is expected to be published in Spring 2013. We would urge SIGN to recognise the important role of LCNSs at diagnosis to ensure all patients have access to the best effective care possible.

The Northern Ireland Service Framework for Cancer Prevention, Treatment and Care sets out standards in respect of the prevention, diagnosis, treatment, ongoing care, rehabilitation and palliative and end of life care of patients with cancer. It states that a LCNS should assess all patients at their time of diagnosis, at the end of each part of their treatment, and as needed throughout their cancer journey.

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

Encouragingly, the National Lung Cancer Audit has shown that the proportion of patients who had a LCNS present at diagnosis has increased steadily since 2007, as illustrated in Figure 3. However, still only 55.1 per cent of patients have a LCNS present when they are diagnosed, which means that a significant number of patients are not benefitting from the involvement and support of a LCNS from the early days of their cancer journey. (Please note that data on whether a LCNS was present at diagnosis were not available for Scotland and Northern Ireland.)
The majority of the nurses that responded to the RCLCF and NLCFN survey said that they always aimed to be present at diagnosis to ensure they can provide support, clarify information and to help patients and their families deal with the news. One nurse also said that support assessments of both patients and their families were carried out throughout the treatment process.

Those patients surveyed who had a LCNS present at diagnosis said it was very useful as they were able to answer questions and provide reassurance at a time which can be very overwhelming.

The Cancer Patient Experience Survey 2011/12 showed that 91 per cent of patients were given clear answers to important questions from the LCNS in charge of their care[19], which demonstrates the value of having a LCNS present at diagnosis to ensure patients have access to accurate and comprehensive information about their condition from the beginning. However, it also highlights the unmet need for the one in ten patients who did not find their questions answered.
Challenges to the role of the LCNS

Since the introduction of the LCNS role in 1995, there has been an increase in the absolute number of LCNSs. There is still variation, however, in access to LCNSs across the UK. According to the latest National Lung Cancer Audit, the mean percentage of people seen by a nurse specialist was 80 per cent. In addition, the Cancer Patient Experience Survey found that 90 per cent of patients with lung cancer who responded to the survey had been given a named clinical nurse specialist. However, being given the name of a LCNS does not necessarily translate into being seen by a LCNS.

The Improving Lung Cancer Outcomes Project (ILCOP), based at the Royal College of Physicians and involving eight partner organisations, found that case load and staffing levels can significantly impact patient outcomes. The same study also found that teams with higher ratios of LCNSs to patients tend to ensure that they are present during diagnosis more often than teams who have low ratios.

A number of the nurses who responded to the survey said that the increasing caseload, twinned with an increasingly complex workload and paperwork, had created barriers to the delivery of high quality care for patients. Some said that their volume of work also created difficulties in supporting patients throughout the whole care pathway, namely after treatment is completed. The NICE lung cancer clinical guideline shows that the most common case load for a LCNS is between 100-150 cases per year. However, Macmillan Cancer Support has reported that, on average, there is only one LCNS in England for every 161 people diagnosed with lung cancer, compared to 117 people per breast cancer nurse.

It is estimated that LCNSs in Scotland see an average of 200 new lung cancer cases a year.

Many of the nurses responding to the survey said that they had significantly larger numbers of cases than that recommended by NICE.

“Our biggest challenge at present is workload and time...When I started the job four years ago there were 240 live patients on our database – there are now 483 and we have no more staff or time.”

“Our greatest challenge is shortage of time which sometimes prevents us being with patients, either as long as we would wish or not being able to be with different patients at the same time.”

Some of the patients surveyed said that they did not have access to a LCNS at diagnosis. One patient said they only met their LCNS when they were admitted to hospital, which highlighted the importance of improving communication between primary and secondary cancer care services. Of these patients who did not have a LCNS present at diagnosis, many said it would have been very useful if they had been present as they recognised the real value they could bring to their treatment and care.

“I had to try on my own to get a lung nurse, who is a specialist, and this year I have succeeded. I think it should now be easier and better.”
A survey of LCNSs undertaken in Scotland in 2009 demonstrated the need for succession planning and highlighted inadequate arrangements to cover the planned and unplanned absences of the specialist nurse\(^29\). 45 per cent of those surveyed were able to obtain cover for annual leave. This was shown to significantly affect the LCNS input to the patient care pathway and lead to a deterioration in maintaining an appropriate level of service. High workload and lone working can often lead to development of burnout and frustration for many LCNSs.

The implementation guidance for the NICE lung cancer quality standard recommends that commissioners should work with providers to agree the capacity for LCNSs, and ensure that there are sufficient numbers in place, taking into account holiday cover if there is only one full-time LCNS\(^30\). The guidance also states that ensuring sufficient capacity of LCNSs contributes to putting patients and clinicians at the heart of decision-making in the NHS, and is also likely to improve patient experience.

Recommendation 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.

Recommendation 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.

The role of the LCNS in delivering holistic care

It is important that patients diagnosed with lung cancer are offered a holistic and co-ordinated approach to care. LCNSs can act as a point of contact for patients from diagnosis onwards in the lung cancer pathway and in providing information and support for the family and carers of people with lung cancer. LCNSs can assist with referrals and can contact members of the multidisciplinary team as required\(^31\). They can also improve the quality of lung cancer services by reducing adverse events, avoiding hospital admissions, reducing length of stay and helping patients with self-management\(^32\).

The role of a LCNS in helping to deliver integrated care for patients with lung cancer supports the commitment to improve joined-up care in the NHS, which is at the heart of the NHS reforms in England. It also reflects the commitment of the governments in the devolved nations in the Detect Cancer Early Initiative in Scotland and Together for Health – Cancer Delivery Plan: Our Vision, published by the Welsh Government in 2012. To achieve this, it is essential that integrated care is centred on the needs of patients, which will lead to higher quality, safer and more cost-effective services which will deliver improved outcomes for patients with lung cancer.

The most recent Cancer Patient Experience Survey showed that 91 per cent of patients said their LCNS listened carefully to them when they spoke\(^33\). Nearly all of the patients who responded to the survey said that their LCNS supported them, or the person they cared for, throughout the illness in a range of ways. They cited their LCNS as a source of helpful information and guidance about lung cancer, in addition to helping them to manage symptoms. Most of the respondents also said that their LCNS provided support throughout the care pathway, while helping to make important decisions about treatment. This was also reflected in the responses we received from carers to the survey. The role of the LCNS in improving patient experience helps commissioners and providers to deliver against Domain 4 of the NHS Outcomes Framework, which focuses on patients’ experience of services. LCNS will also help NHS boards in Scotland deliver against the lung cancer Quality Performance Indicators to ensure that care is patient-centred and is focussed on areas which improve survival and patient experience.
Understanding the value of lung cancer nurse specialists

Many of the LCNSs who responded to our survey described the role of LCNSs as multifaceted, but many highlighted their position as a trustworthy and constant point of contact throughout a complex and varied journey for both patients and carers.

The responses to the survey show the importance of ensuring that patients have access to a LCNS at diagnosis and throughout the patient pathway. They also serve to emphasise the importance that these positions are protected during the transition and while the Government strives to deliver greater efficiencies in the NHS.

**Recommendation 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.**

**Smoking cessation**

Tobacco remains the single biggest lifestyle risk factor of lung cancer, accounting for nearly nine out of ten cases. On average, a lifetime smoker is 20 times more likely to develop lung cancer compared with a lifetime non-smoker.

The link between smoking and cancer incidence is widely acknowledged in government healthcare policies. For example, the 2012 Welsh Cancer Strategy sets out the Welsh Government’s vision for NHS cancer care by 2016, stating that patients with the condition should be supported to quit smoking and have access to nurses 24 hours a day. LCNSs can play an important role in promoting healthy living and supporting patients with lung cancer who are smokers to stop smoking. Nearly all of the nurses surveyed said they provided patients with information about smoking cessation and many worked in collaboration with their local stop smoking services to increase awareness about the risks. One patient said the stop smoking advice provided by the LCNS even encouraged other family members to quit.

**Recommendation 6: LCNSs should be provided with the necessary resources to give advice and support to help patients with lung cancer who are smokers to stop smoking.**
TREATMENT

If more patients are to survive lung cancer, and UK survival rates are to match those in other parts of Europe, the numbers of patients receiving active treatment must be increased. There will always be a number of patients who are too ill at the point of diagnosis for active treatment to be an option. There will also be a small number who decide that they do not want to have active treatment. However, ongoing efforts to improve early detection and to ensure that all those fit enough are offered surgery and other treatment options should improve the numbers of patients able to benefit from treatment.

Variations in treatment

The latest figures from the National Lung Cancer Audit indicate that variations persist in the numbers of patients offered active treatment. In England and Wales, three in five patients (60 per cent) now have active treatment such as chemotherapy or radiotherapy, compared to just fewer than half of patients first seen in 2005 (45 per cent). One in five patients with confirmed non-small cell lung cancer (20 per cent) now has an operation that could potentially cure their cancer, compared to one in ten patients (10 per cent) first seen in 2005.  

In Scotland, 59.7 per cent of patients (about 2,800 people) had anti-cancer treatment in 2011 compared to 63.9 per cent (about 2,810 people) in 2010, while the proportion of patients overall who had surgery fell slightly from 11.1 per cent to 10.7 per cent. However, for patients with confirmed non-small cell lung cancer, the proportion having surgery increased from 16.3 per cent to 18.5 per cent.

While the Audit shows that care has generally improved, the figures mask significant regional variations that cannot be fully explained by either data quality or case-mix. As shown in Figure 4, the highest scoring network on active treatment rates is Central South Coast Cancer Network, where nearly 70 per cent of patients receive active treatment, compared to just over 50 per cent in Sussex Cancer Network.
Impact of LCNS on treatment

The National Lung Cancer Audit has demonstrated a correlation between the proportion of patients given access to a specialist nurse and those receiving active treatment. As shown in Figure 5, around two thirds of patients seen by a LCNS went on to receive active treatment, whereas less than a third of patients who did not see a LCNS were given active treatment.
Although not showing a causal link between nursing input and receipt of active treatment, the data show that patients seen by a LCNS were more than twice as likely to receive active treatment compared to those who were not seen by a LCNS. Further statistical analysis demonstrates that this relationship is independent of age, disease stage and performance status. With only just over half of patients having a LCNS present at the point of diagnosis, a significant number of patients are not benefitting from the involvement and support from a LCNS from the early days of their cancer journey. Given the correlation with active treatment rates, failure to see a LCNS may impact on their chance of having treatment.

**Why the LCNS makes a difference during treatment**

The reasons for the observed correlation between nursing input and receipt of active treatment require more research to be fully understood. The NLCFN has, however, conducted some work to investigate the correlation. As part of its research, the NLCFN collated case studies from its non-medical prescriber members to try to explore in more detail the role of the LCNS in symptom management and prescribing. The research found that non-medical prescribers actively prescribe for all the symptoms of lung cancer and treatment side effects. The case studies reported by LCNSs showed that symptom management intervention from the time of pre-diagnosis to seeing an oncologist has a potential impact on uptake of treatment. For example, if the patient’s condition and symptom control is improved, they are reported to be more likely to be offered treatment.
Quotes from the survey also give an indication of the different ways in which LCNSs make an impact during the treatment phase. Their impact is particularly evident in relation to shared decision-making, early intervention, managing symptoms of disease or side-effects of treatment and improving experience during treatment. The following are case studies gathered from the survey of nurses:

• “Mr W had early diagnosed, operable lung cancer but refused to have surgery because of unfounded fears about operations and a desire to be well and continue being able to play with his grandchildren. He met the respiratory consultant and the surgeon to discuss treatment options but continued to have doubts about surgery and would not make a decision. I spent a lot of time with him and his wife exploring his fears, the options available and likely consequences of each option. He eventually chose to have surgery and I have just discharged him from my nurse-led clinic five years post surgery – an extremely grateful couple as he is still gardening and playing with his grandchildren.”

• “A patient contacted me after he developed pain in his back that was becoming progressively worse. He spoke of how he felt that his legs were becoming weak. I contacted his oncologist who requested an MRI scan on the same day. He had malignant spinal cord compression and was admitted for surgery for decompression of this. He is now fully mobile.”

• “A lady with known lung cancer had completed chemotherapy and was having a period of observation. She reported new symptoms promptly as discussed by the LCNS in oncology clinic. She was quite unwell with neurological symptoms but did not wish to be admitted to hospital. The LCNS was able to recognise that this was likely disease progression and was able to liaise with the GP and oncologist to facilitate prompt investigation and management of symptoms at home whilst also being a source of support and contact for the lady and her husband. This allowed further treatment to be instigated without delay and within a few days, whilst allowing the lady to stay at home as she wished.”

• “A patient rang us to inform us that she was getting confused, unable to get her words out and falling. The LCNS was able to secure a CT head scan that day, inform that patient she has developed brain metastases, prescribe dexamethasone and lanzoprasole to control the symptoms and book in for an urgent oncology review two days later. The patient was given information and the benefits and side effects of treatments were explained. Next day, the patient was feeling considerably better, confusion and all other symptoms had gone. The patient felt fully informed and supported.”

• “Redesigning our service around the key points where we know that patients have challenges and unmet need is crucial and we as a team believe that this has a significant impact on patient care. We therefore assess all points pre-diagnosis, at the start of treatments, during treatments, end of treatments and at disease progression using a comprehensive assessment tool. We believe that this significantly cuts down on patient admissions, particularly emergency admissions and it means that patients are treated by the right person at the right time and receives their care in their preferred place.”
These examples are reflected in the survey feedback from patients:

“[She] advised time and time again on how to manage symptoms. Her advice was always useful.”

“[On] medicine control – [she] drew out a schedule so I could medicate my mum at home.”

“[She] got to know us and helped us in a way that was helpful to us, knowing what was and wasn’t important to us.”

“We called her to discuss options, ask questions, discuss possible drug trials, discuss side effects and to discuss the pros and cons of whether to have treatment and the likelihood of success.”

“I was given practical advice and referred to a nutritionist regarding weight loss.”

“[She] offered therapies with mum just to relax.”

**Recommendation 7:** More research should be undertaken to understand the reasons for the correlation between nursing input and receipt of active treatment so that best practice can be replicated where possible and all patients have equitable access to active treatment for lung cancer.

**The extended role of the LCNS**

Most patients with lung cancer are offered some form of follow-up after treatment. The NICE clinical guideline on lung cancer recommends that nurse-led follow-up should be offered to patients with lung cancer with a life expectancy of more than three months. Evidence has shown that patients with lung cancer receiving nurse-led follow-up had significantly fewer medical consultations with a hospital doctor in the three months following cancer treatment than conventional medical follow up services. It is also reported that significantly more patients who received nurse-led follow-up from LCNSs died at home rather than in a hospital or hospice: 40 per cent compared to 23 per cent receiving conventional medical follow up.

The benefits of nurse-led follow-up were highlighted in the responses to our survey. As a carer, one respondent said that her husband’s LCNS was always available to talk to her and to answer any questions she had. Many patients talked about the emotional support provided by the LCNS, in addition to effective treatment and care.
Below is a quote from a nurse who responded to our survey which provides an excellent example of the benefit of a LCNS, particularly their role in helping to deliver coordinated care and reduce hospital admissions.

• “I believe that one of the greatest benefits provided by the LCNS is having a named individual who is responsible for the coordination, communication and support provided to the patient and family throughout their diagnosis, treatment and often traumatic experiences. Working as the patient’s advocate, being accessible, providing advice, support, contacting relevant professionals to assist in the delivery of care and allowing the patient to feel listened to, is an essential part of my role as a LCNS. This not only improves the experience of a patient with lung, particularly when care is delivered across several sites, but can prevent inappropriate hospital admissions, ensures patients are admitted to hospital when necessary and provide reassurance and confidence in their understanding of the disease trajectory. Ultimately it can improve end of life care for patients and their families, which matters most when a patient is very sick.”

Case study: LCNS-led clinic for oral therapy

An erlotinib treatment pathway has been implemented by the LCNS team at Guy’s and St Thomas’ Hospital in two phases. In December 2009 the team developed a treatment pathway which included a pre-treatment consultation and telephone call (on day seven of the first treatment cycle) to all patients commenced on erlotinib.

Phase two saw the establishment of the nurse-led clinic in March 2011. At the clinic, LCNSs take responsibility for reviewing patients on erlotinib treatment, undertaking the following stages:

• Consent to treatment
• Pre-treatment talk
• Telephone call (on day seven of the first treatment cycle)
• Toxicity check (on day 14 of the first treatment cycle)
• Prescribing erlotinib together with supportive medication if required
• Conducting all on-treatment reviews excluding CT scan results

Non medical prescribing started in the clinic in July 2012. Erlotinib can be prescribed by the non-medical prescriber after the first treatment cycle together with supportive medications. Commonly prescribed supportive medications include hydrocortisone, E45 cream, clindamycin lotion, loperamide and doxycycline.

Challenges include the fact that patients with lung cancer on second line treatment have complex needs, the team only see erlotinib patients, and new specialist registrars have limited understanding of the clinic and its role.

In the period from March 2011 (when the clinic started) to July 2012, the following achievements have been recorded:

• A total of 34 patients on erlotinib have been seen
• 100 per cent adherence to the treatment and quicker response to toxicity management
• 19 patients supported by LCNS to consent to treatment
• Most patients received a telephone call on day seven of the first treatment cycle
• Every patient attended a toxicity visit on day 14 of the first treatment cycle
• None of the patients stopped treatment
• Positive verbal feedback has been received
• Non-medical prescribing was started in July 2012

The clinic is currently being expanded to include other lung cancer treatments, including gefitinib.
Recommendation 8: Nurse-led follow-up after treatment should be offered to all patients with lung cancer undergoing treatment to ensure that they can benefit from the improved outcomes this model of care has been shown to deliver.

LCNSs may also run clinics and patient education programmes to help patients manage their symptoms, for example breathlessness clinics. The focus of these clinics is on improving quality of life and educating patients about their illness. The SIGN guideline on lung cancer states that breathlessness clinics led by nurses or physiotherapists should be made available to all patients with lung cancer\(^46\).

Evidence has shown that they can improve the quality of life and functional capacity of patients with lung cancer\(^47\). Several of the nurses who responded to our survey provided examples of their work in running symptom management clinics.

“Patients are provided with the telephone number of their LCNS and are told to contact them to discuss any problems. This very often results in prompt referral to clinics, which reduces hospital admissions or home-visits by GPs. We do not provide a specific nurse-led clinic but we carry out routine telephone follow up calls for patients.”

“We have been running a follow-up clinic alongside the respiratory consultant for patients for best supportive care, and coordinated oncology treatment.”

“I run a weekly nurse led clinic where I see patients post treatment or post MDT meetings to discuss results/further investigations.”

“We are just about to start a patient education programme for patients undergoing thoracic surgery. This is to improve their information needs prior to surgery and will hopefully have an impact on length of stay and readmission rates.”

Recommendation 9: LCNSs should be encouraged, and provided with the necessary resources, to offer all patients with lung cancer access to nurse-led clinics that improve the quality of life and functional capacity of patients with lung cancer.
MULTIDISCIPLINARY CARE

The LCNS plays a key role in supporting access to the multidisciplinary team (MDT) and coordinating multidisciplinary care around the needs of patients and their carers. The NICE quality standard for lung cancer includes a number of quality statements which draw attention to the value of multidisciplinary working in caring for patients with lung cancer. The quality standard states that people with lung cancer should be “offered assessment for multimodality treatment by a multidisciplinary team comprising all specialist core members.” It also includes three further quality statements which explicitly talk about the role of the MDT in delivering high quality care.

This is reflected in the SIGN guidance on the management of patients with lung cancer, which recommends that all patients with a diagnosis of lung cancer should have their treatment and management planned and directed by a multidisciplinary team.

Role of the LCNS in coordinating multidisciplinary care

LCNSs sit at the heart of the MDT and, as a result, are able to have influence across the whole patient pathway. The National Cancer Action Team has reported that cancer nurse specialists are increasingly taking a leadership role in refining systems and smoothing care pathways, making a demonstrable contribution to effectiveness, patient experience and safety.

This was a theme that came through strongly in the responses to our survey, with some nurses talking about their role in “streamlining the patient journey” and being a constant for the patient in a complex pathway, providing reassurance, support and information, as needed by the patient.

“The journey of a lung cancer patient is very complex and varied. The LCNS is the constant throughout this. This provides support, information and guidance for patients. It is reassuring for them to know they have open access to the same person at any time.”

The National Lung Cancer Audit 2012 recommends that trusts should maintain the number of patients with lung cancer being discussed at MDT meetings at the current level of 95 per cent. The LCNS’ role in making sure that patients are discussed at MDT meetings is vital. The UK Lung Cancer Coalition highlighted in its recent report the important role the LCNS plays in advocating for patients at MDT meetings and throughout the patient pathway. This is especially important when there are a number of healthcare professionals involved in making important decisions about a patient’s treatment. The responses to our survey illustrated this, with nurses describing themselves as advocates for the patient.

“We are the patient’s advocate at MDT, speaking for them on what treatment decisions they would like made.”

“[I am] the patient’s voice at MDT and clinic appointments when they feel unable to express themselves.”
In acting as the patient’s advocate, LCNSs also play a key role in ensuring that multidisciplinary care is responsive to the patient’s individual needs and preferences, as illustrated by the quote and case study below.

“In our LCNS was often the gateway to admissions to hospital, helping us avoid the Emergency Medical Unit (EMU) by securing a bed on the cancer ward. The EMU would have been potentially disastrous for [my partner], as he was so susceptible to bugs and he would have found the chaos so hard as he was so poorly. [Our LCNS] often liaised with [my partner’s] consultant and got us earlier appointments, tests or treatment when things deteriorated / progressed.”

Case study

LCNS Laura first met Mr D when he was admitted to hospital with small cell lung cancer relapse. Laura identified a number of problems at Mr D’s first LCNS assessment – his symptom control was poor, he was suffering anxiety, panic and fear, and he had poor social support as he lived alone with no friends living locally. Laura took the following action: she reassured Mr D by providing information about his treatment; prescribed treatment for shortness of breath and panic attacks; visited Mr D every day throughout his treatment to gain trust and because he had no carer or friends locally; and set up a discharge plan to provide the maximum support given his clinical condition and isolation. Laura recently received a thank card from Mr D, which stated “Big thanks for all your organisational arrangements when I was in hospital. I am now surrounded by help, support, medication, attention and advice and I feel so much better for it. What you put in place has been brilliant.”

Recommendation 10: LCNSs should be recognised as the patient’s advocate at MDT meetings and be supported by the MDT to deliver patient-centred care that responds to the patient’s individual needs.
Palliative and end of life care

In highlighting the vital role of the LCNS, the National Lung Cancer Audit 2012 report states that LCNS input should ideally occur at all stages of the lung cancer pathway, from referral through investigation, to treatment and survivorship, and including end of life care. Recent research into complex treatment decisions for patients with advanced lung cancer showed that LCNSs play a valuable role in supporting decision making and are seen as trusted sources of information. The NICE lung cancer quality standard recommends that people with lung cancer should have access to all appropriate palliative interventions delivered by expert clinicians and teams. The NLCFN provides guidance to define the supportive and palliative care interventions required to improve the patient and carer experience in the last year of life which can be used by any healthcare professional.

The SIGN guideline on lung cancer states that after palliative therapy is completed, follow-up should be agreed between the oncologist, respiratory physician, GP and palliative care team. We would urge SIGN to recognise the key role LCNSs can play in liaising with palliative care specialists and ensuring that patients have access to the care they need in the updated guideline.

The importance of LCNSs at this stage of the disease was evident from the responses to our survey, as illustrated below.

Recommendation 11: Patients with lung cancer should be able to access LCNS input at all stages of the lung cancer pathway, including towards the end of life, so that patients are able to benefit from high quality palliative and end of life care that responds to their individual needs and expectations.
CONCLUSION

This report has examined the role of LCNSs, with the aim of helping people understand the vital contribution they make to the delivery of high quality care and to improved outcomes for patients with lung cancer.

By drawing on the real-life experiences of patients with lung cancer, carers and nurses themselves, and examining the data that are currently available on lung cancer treatment and outcomes, we hope to have made a positive contribution to ongoing efforts to improve the prognosis for patients with lung cancer in the UK.

We hope that the findings and recommendations highlighted in this report will encourage policymakers, healthcare commissioners, providers and clinicians to ensure that LCNS posts are protected and, where necessary, increased in number, so that all patients with lung cancer have equitable access to LCNS input in their lung cancer pathway. Furthermore, we hope that this report demonstrates the importance of fully supporting LCNSs with sufficient resources to carry out their work to the highest possible standards.

The RCLCF and NLCFN are committed to continuing to work together to raise awareness of the value of LCNSs and campaigning for better care and treatment for people affected by lung cancer in the UK.
USEFUL GUIDANCE

The National Lung Cancer Forum has published a number of useful guidance documents. These are listed below and are available on the NLCFN website: http://www.nlcfn.org.uk

- NLCFN Guidelines to Prepare and Support Patients Undergoing Lung Resection (2012)
- NLCFN Guidance for the Supportive and Palliative Care of Lung Cancer and Mesothelioma Patients and their Carers (2012)
- NLCFN Guidelines for the Assessment of Patients following Palliative Radiotherapy for Lung Cancer (2012)
- NLCFN Pulmonary Nodule Protocol: Improving the Patient’s Experience (2010)
- NLCFN Good Practice Guide (2009)
- NLCFN Guideline to Enable Lung Cancer Nurse Specialists to Consistently Communicate Key MDT Decisions to Patients (2009)
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