
The National Lung Cancer Forum for Nurses

MANAGING THE IMPACT OF LUNG CANCER



Contents

Contents.....	2
About this report.....	3
The National Lung Cancer Forum for Nurses	3
The UK Lung Cancer Coalition.....	3
Introduction	4
The lung cancer patient journey	5
Pre-diagnosis and referral	6
Diagnosis.....	12
Treatment	14
Follow-up and end of life care.....	20
Reducing the deficit in Clinical Nurse Specialists.....	23
Development of key performance metrics.....	24
Useful information	25
References	26

About this report

This report has been produced by the National Lung Cancer Forum for Nurses with the support of an unrestricted educational grant from Roche Products Ltd. It has been endorsed by members of the UK Lung Cancer Coalition. Editorial control rests with the National Lung Cancer Forum for Nurses.

The National Lung Cancer Forum for Nurses

The National Lung Cancer Forum for Nurses (NLCFN), established in 1999, aims to provide education, a communication network and support for lung cancer Clinical Nurse Specialists. With over 250 members, who are all specialist nurses spending more than 50% of their working week on clinical activities in caring for lung cancer patients, the forum represents virtually all lung Clinical Nurse Specialists in the UK.

The purpose of the Forum is to improve lung cancer care through:

- Sharing best practice
- Providing a forum to discuss research
- Giving its members a voice on clinical and strategic issues in lung cancer services and care

For further information, please visit our website: www.nlcfn.org.uk

The UK Lung Cancer Coalition

The United Kingdom Lung Cancer Coalition (UKLCC) is a partnership of charities, clinicians, senior NHS professionals and healthcare companies with a commitment to double lung cancer survival.

The UKLCC believes that every lung cancer patient should have access to a lung cancer specialist nurse, and is concerned that there are severe shortages of and variations in numbers of nurses across the country. At present one in ten lung cancer patients currently does not have access to a specialist nurse. To find out more about the UKLCC, please visit:

<http://www.uklcc.org.uk>

Introduction

Clinical Nurse Specialists (CNSs) play a vital role in caring for and supporting patients and their carers throughout their cancer journey. From providing advice and support on treatments, through to making sure patients' care needs are met, the CNS is often the vital link in the care pathway. CNSs can also play an important role in improving the quality and productivity of cancer services by minimising adverse events, avoiding hospital admission, reducing length of stay and helping patients with self-management.

However, there is a shortfall in access to CNSs, which is particularly acute for lung cancer. Estimates suggest that the average newly diagnosed caseload of a lung cancer CNS can be as much as double that for some other common forms of cancerⁱ. The result is that there is only one lung cancer nurse in England for every 132 patients with lung cancerⁱⁱ. This is concerning given the particularly complex needs of lung cancer patients.

Overall, the Department of Health has estimated that the CNS workforce will need to double over the next five years if every patient is to have access to a CNS. This is a challenging goal, particularly in the current NHS financial environment. However, feedback from patients shows that improving access to CNSs could make a significant difference to their experience of treatment and care.

The National Lung Cancer Forum for Nurses has developed this report to showcase the contribution that can be made by nurses to all aspects of a patient's treatment and care and to make recommendations on how lung cancer services could be improved, building on the expertise of nurses and maximising their impact. We hope the report will stimulate further discussion amongst policymakers, commissioners, service providers and healthcare professionals about how the role of CNSs can be further strengthened to improve patient outcomes and experience.

The National Lung Cancer Forum for Nurses would like to thank all those CNSs, patients and carers who have contributed their time and experiences to the development of this report.

The lung cancer patient journey

Every year, 39,750 people are diagnosed with lung cancerⁱⁱⁱ. It can have a devastating impact on the lives of both the patient and carer. Lung cancer remains one of the biggest cancer killers, accounting for 7% of all deaths and 22% of all cancer deaths^{iv}. Approximately 109 people a day lose their lives to lung cancer^v.

For many patients diagnosed with lung cancer the prognosis is very poor. After diagnosis only one in four will live beyond one year and this falls to less than one in ten who will survive for five years or more^{vi}.

A major explanation for the poor outcomes experienced by lung cancer patients is the late stage at which many patients are diagnosed. Over two thirds of cases are detected once curative treatment is no longer possible^{vii}.

However, there is cause for optimism. If detected early, lung cancer is curable. Developments in surgery, radiotherapy and drug treatment have improved the survival chances and the quality of life of many patients.

While each lung cancer patient, and his or her carer, has a unique experience of the disease, there are a number of steps which are common to most lung cancer patients throughout their treatment and care pathway. Broadly, these are:

- Pre-diagnosis and referral
- Investigation
- Diagnosis and identifying the initial needs of patients and carers
- Treatment
- Follow-up and end of life care^{viii}

This section will address the contribution lung cancer CNSs can make to each stage of the patient and carer's journey.

Pre-diagnosis and referral

CNS role in awareness

A lung cancer patient's journey begins before they have even received their diagnosis of lung cancer. Often patients may be suffering from breathlessness, recurring chest infections and/or a persistent cough and consequently visit their GP. However, public awareness of the signs and symptoms of lung cancer remains low. This can mean that patients delay seeking help, compounding the problem of late diagnosis.

Example of good practice:

In Stockton, CNSs have been involved in raising awareness amongst secondary school children about lung cancer. The CNSs presented to either specific year groups or whole school assemblies using PowerPoint presentations of facts and graphic images with a question and answer session at the end to address any specific issues or concerns the children had. The CNS was also available if the children wanted to speak in private and in confidence at the end of each session.

Feedback from the nine secondary schools which accepted the invitation for the CNS to come and speak has been extremely positive, with OFSTED highlighting it in their report as an example of good practice^x.

Ensuring that signs and symptoms of lung cancer are identified at the earliest possible opportunity is crucial to improving survival rates. We have welcomed the work of the National Awareness and Early Diagnosis Initiative to improve awareness of the signs and symptoms of lung cancer. However, there is a role the CNS can play in improving both professional and public awareness of the symptoms of lung cancer, particularly through activity during Lung Cancer Awareness Month, and advising on community based initiatives.

Common signs and symptoms of lung cancer^x

- Repeated chest infections that do not respond to antibiotics within three weeks
- Coughing more frequently
- Signs of blood in the spit
- Hoarseness and loss of voice, although the throat feels normal
- Breathlessness
- Pains in the chest and/or shoulder
- Swelling of the face and/or neck
- Weight loss or tiredness without an obvious cause
- Change in the shape of the ends of the fingers (known as 'clubbing')

Once patients report to their GP with one or a number of these symptoms which have been persistent for three weeks or more, they should be urgently referred for a chest x-ray or chest computed tomography scan (CT)^{xi}. Most GPs follow good practice and are proactive in assessing all of a patient's physical symptoms, even those which may not have prompted them to see their GP:

"I was in my doctor's and all of a sudden she said to me 'let me look at your fingers'. And she came round and she said to me, 'see that where your nails all turn down, we call that clubbing and that suggests to me that there's something badly wrong inside your body. I'm going to put you down to see a specialist'^{xii}."

(Male patient, North West)

However, not all patients are as lucky. One patient's carer described the experience pre-diagnosis:

"They don't listen. Not in our case they didn't. In our case he was a fit person. He went to the doctor's and said why am I breathless? And he was more or less told to go away and stop worrying about it and get on with living^{xiii}."

(Carer, Bishop Auckland)

Although patients rarely come into contact with a CNS during the pre-diagnosis stage, our members report that missed opportunities to diagnose cancer, as well as inadequate information at the point of diagnosis can significantly damage a patient's experience, as well as compromising their outcomes.

Key recommendations:

Efforts to support primary care professionals in diagnosing cancer earlier should be prioritised

GPs should explain the possible causes of the patient's symptoms sensitively to patients and carers

Activity to improve awareness of the signs and symptoms of lung cancer, through Lung Cancer Awareness Month and the National Awareness and Early Diagnosis Initiative (NAEDI) are to be applauded. PCTs now need to match this national commitment by investing significant resources in awareness campaigns, learning from the experience of national pilots

The 'downstream' benefits of raising awareness should be evaluated, assessing the extent to which improved awareness of signs and symptoms can help patients make more informed choices about treatment and care

Referral

If the chest x-ray or CT scan suggests lung cancer, the patient should be referred to the lung cancer multidisciplinary team (MDT). The lung cancer MDT is vital to ensuring high quality treatment and care throughout the patient pathway. The team consists of medical and nursing staff with specialised knowledge of the diagnosis and treatment of lung cancer, and commonly comprises of an oncologist, respiratory physician with a special interest in lung cancer, a radiologist, a pathologist, a palliative care specialist, thoracic surgeon and a lung cancer CNS^{xiv}. The MDT should also have a system for informing the patient's GP about the outcome of the investigations to ensure that there is coordination in their care^{xv}.

Example of good practice:

The Rotherham General Hospital has introduced an abnormal x-ray tracking system whereby radiologists at the hospital apply alerts to reports containing suspicion of lung cancer to prevent delays or missed diagnosis. The x-ray reports are collected weekly, added to a tracking database and audited to ensure that timely and appropriate referrals are made. It also ensures that GPs and referring clinicians are aware of the need for referral to the specialist team. Four potential missed diagnoses have been identified and dealt with through the tracking system to date^{xvi}.

It is usually the chest physician who is the first member of the lung cancer MDT to have contact with the patient pre-diagnosis. However, the lung CNS plays a vital role alongside the respiratory physician in co-ordinating the patient's investigative period, ensuring the flow of information between primary, secondary care and the patient, and the provision of support and information^{xvii}. This provides continuity not only for the patient, but also the staff working for the patient. The CNS refers to other members of the health and social care team at the earliest opportunity if required, and acts as a point of reference for all health care professionals involved in the patient's care.

However, there is evidence to suggest that the national guidance on MDT working for high quality lung cancer treatment and care is not being implemented consistently across the country. The Improving Outcomes Guidance for lung cancer is designed to guide commissioning, planning and developing lung cancer services. It states that there should be a named clinician for the patient to have as a first point of contact, as well as clear information for the patient on the members making up the team and regular reviews of patients' cases^{xviii}.

Example of good practice:

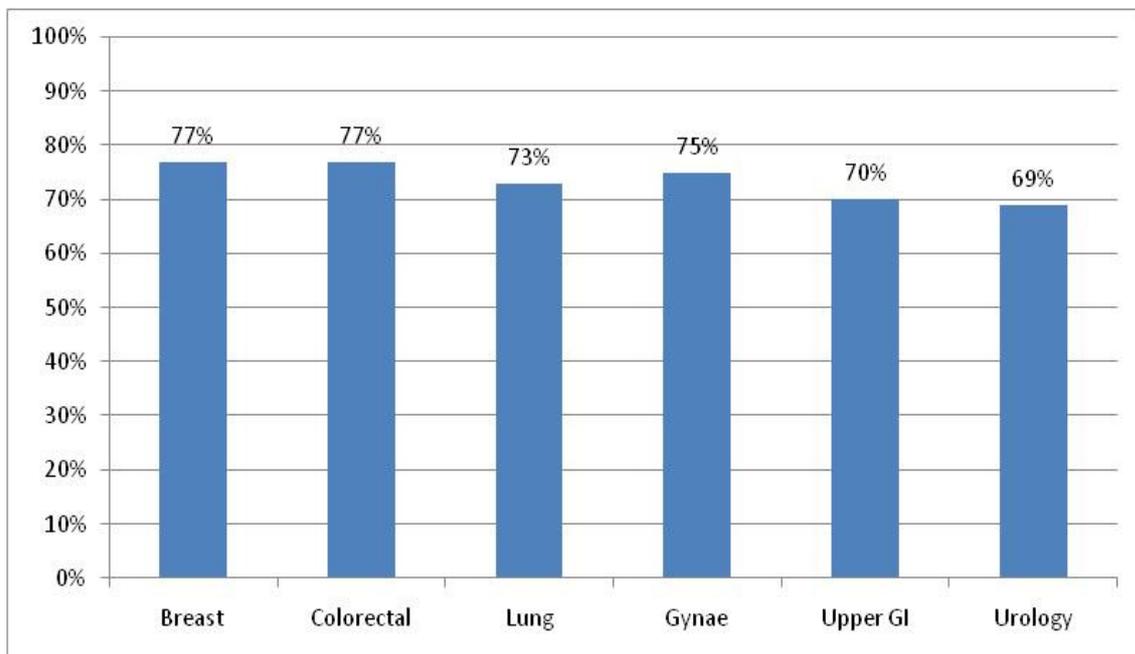
To improve continuity of care and access to specialist services, Walsgrave Hospital has introduced a clinic for all urgent referrals. Previously, urgent referrals were seen in a variety of clinics across three different hospital sites.

The clinic is managed by doctors who all have a specialist interest in lung cancer and are part of the lung cancer MDT. At the first appointment, the CNS is present and provides the patient with information on what to expect and treatment options, the details of the MDT and the contact details of their key worker. An appointment is also booked at the same time for their results so that where possible the same nurse is present.

As a result of the introduction of the clinic, the hospital has experienced improvements in waiting times with most patients seen, investigated and diagnosed within two weeks^{xi}.

The National Cancer Peer Review programme found that over the period from 2004 to 2007, overall compliance with the Improving Outcomes Guidance was achieved by 73 per cent of lung cancer MDTs. This is less than the compliance achieved by breast, colorectal and gynaecological cancer MDTs with their relevant IOG^{xx}.

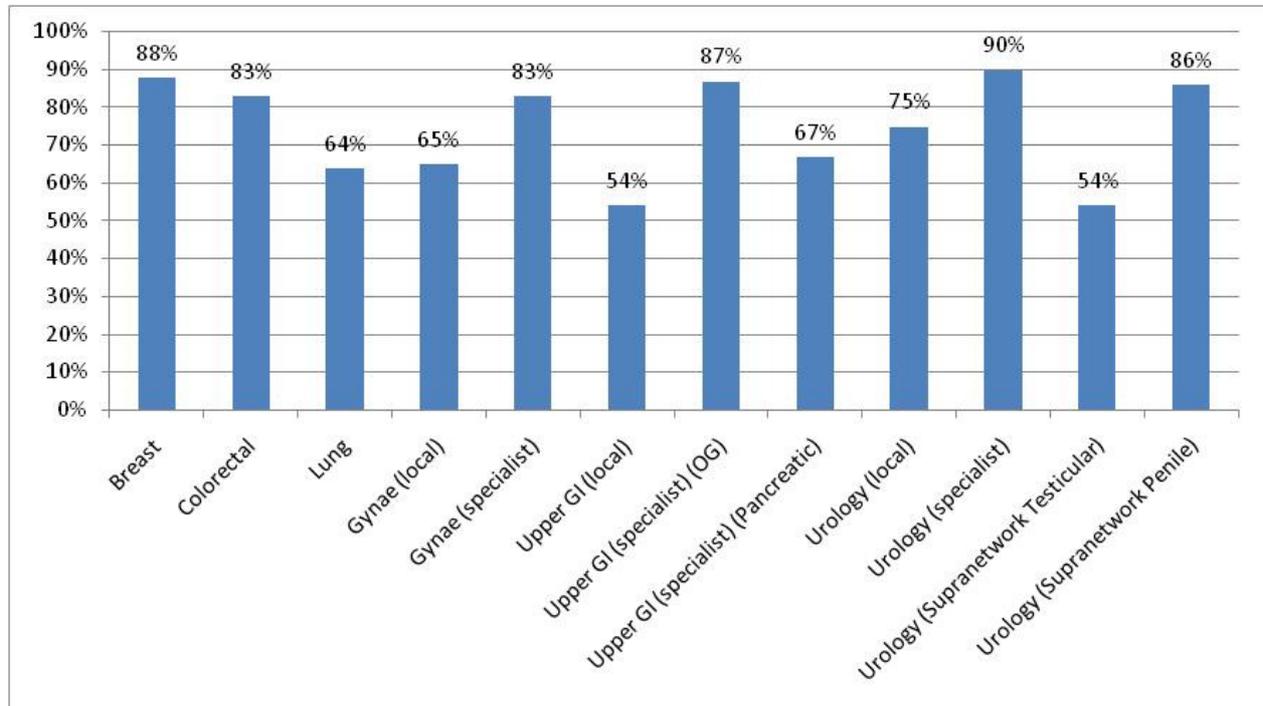
Overall compliance by MDT Tumour Site (Local & Specialist Teams)



Source: National Cancer Action Team, National Cancer Peer Review Programme 2004-07, June 2008^{xxi}

Lung cancer MDT compliance was particularly poor compared to that for other tumour type MDTs, when measuring the level of MDTs which had named core team members. Lung cancer came 10th out of the 12 most common cancers on this measure, with 64 per cent compliance^{xxii}.

Named Core Team Members - Overall Compliance



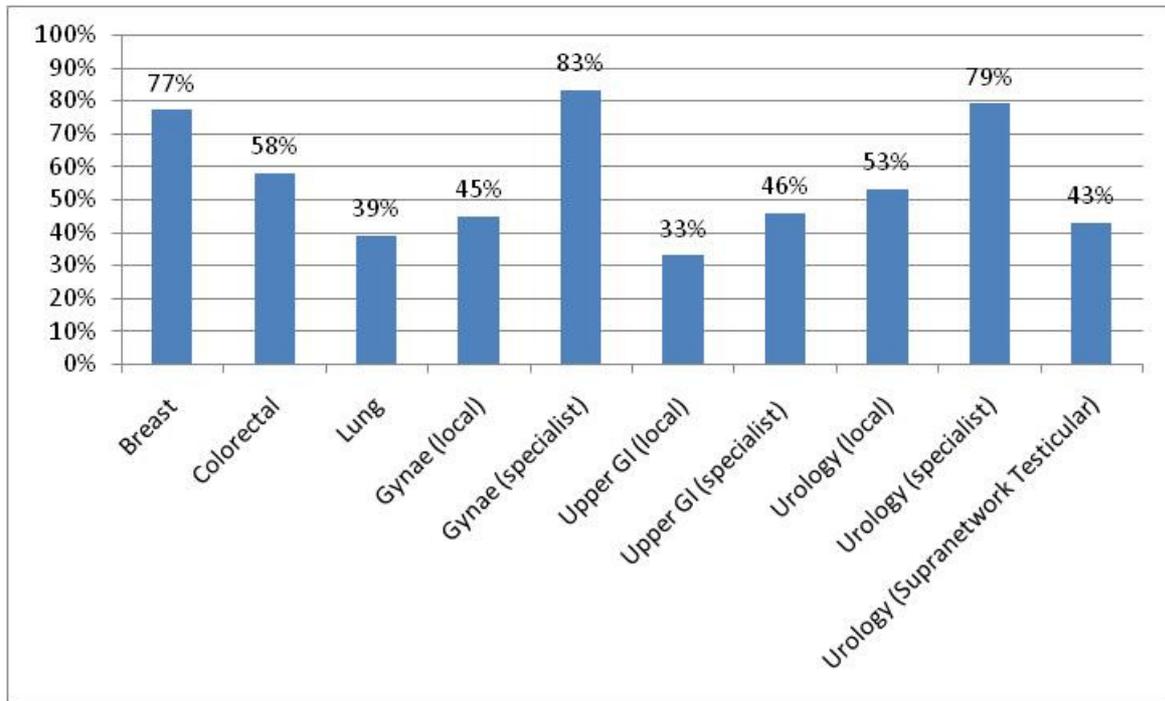
Source: National Cancer Action Team, National Cancer Peer Review Programme 2004-07, June 2008^{xxiii}

It is of concern that lung cancer patients are less likely than many other cancer patients to benefit from having named core MDT members. Patients with a lung tumour are generally more symptomatic than patients with other cancers, and so need high levels of medical care coordination for extra support and symptom control.

The peer review programme also found that only 39 per cent of lung cancer MDTs complied with the guidance on core MDT members being present for at least half of team meetings^{xxiv}. It is vital for coordination of a patient's care that as many MDT members as possible have input in discussing the options for the patient as their disease progresses. This informs a holistic view of the patient's needs.

However, as the chart below shows, lung cancer compliance with this aspect of the guidance is particularly poor compared to MDTs for other tumour types.

Core Member or Cover present for 1/2 meetings - overall compliance



Source: National Cancer Action Team, National Cancer Peer Review Programme 2004-07, June 2008^{xxv}

Diagnosis

Helping patients understand their diagnosis and prepare for treatment

During the diagnosis period, the CNS should undertake a holistic assessment of the patient; putting their illness into the context of their individual circumstances and considering the physical, psychological, social, spiritual and emotional needs of their patient^{xxvi}. The CNS is then able to determine the nature of the follow-up consultations depending on the complexity of the patient's needs. This can also be undertaken pre-diagnosis should the need arise.

However, even when information has been provided to patients and their carers throughout the course of the investigations, the diagnosis of lung cancer will generally come as a shock to most patients. It is therefore critical that the diagnosis is given in a sensitive manner. Unfortunately this is not always the case:

"He was probably very nice and it was just he was very busy and I felt he was a bit abrupt...I mean, XX was devastated and he started rambling a bit and I just got the impression this chap was thinking 'oh for goodness sake, shut up and go'. But I mean, what do you say, really?"^{xxvii}

(Female carer, South)

Ideally, the patient and carer should both be present when the news is given so that they can support each other. However, sometimes carers are excluded from the conversation, or even the room. This can make coming to terms with a lung cancer diagnosis more difficult for both patients and carers:

"The consultant, when they were giving him the news that he had the lung cancer, I was sent out...I could hear from outside because I thought 'there's no way I'm going away from here' and that's how he broke the news. 'You've got lung cancer and there may not be a lot we can do about it but we can maybe give you a little bit longer' is how he put it. And then he wafted off, never said anything to me"^{xxviii}.

(Female carer, North West)

It is crucial that patients and carers are provided with clear information in both a verbal and written form on the disease and their treatment at the time of diagnosis. Patients who are well-informed are less likely to suffer anxiety. Furthermore, a record should be kept of this so that all healthcare professionals involved in the patient's journey, including the patient's GP are aware of what information has been provided.

The CNS can play an important role in the provision of information and support at this stage, ensuring any questions the patients and carers might have are answered. However, it is concerning that only 37.8 per cent of patients had a CNS present at their time of diagnosis^{xxix}.

Key recommendations:

Primary Care Trusts should put measures in place to ensure that all patients have access to a lung cancer CNS during the investigation of their symptoms, before a diagnosis of lung cancer is confirmed

Ideally the CNS should be present when the patient receives their diagnosis

The findings of the first round of Peer Review should be addressed as a priority. All providers should be required to put in place an action plan to address any issues identified

There should be a coordinated approach to investigating the patient's symptoms through the MDT

Patients should be informed of the situation at all stages in clear language and with the opportunity to ask questions at later stages

Holistic assessment should commence pre-diagnosis

The patient should be given their diagnosis in a way which is sensitive to the needs of them and their carers

Patients and carers should receive written information which is explained to them to help them understand their situation

Work to develop national information pathways for lung cancer is extremely welcome. All providers should be encouraged to make use of this valuable resource

Treatment

Enabling patients to make an informed choice

There are a variety of different treatments for lung cancer, depending how advanced a tumour is, as well as how fit the patient is. At various times during treatment, a patient may have to choose what type of intervention (if any) to have, as well as which team they would like to deliver it. Patients may also have different preferences about the best location for their treatment. Some treatments can be taken at home or in a community setting, whilst others require hospital administration. Ensuring that care is delivered in the most appropriate setting is not only crucial to improving the experience reported by patients of their care, as well as their outcomes, but can also ensure that NHS resources are used as efficiently as possible.

When making decisions, it is important that patients have access to balanced information and advice so that they can evaluate the relative benefits and drawbacks of different options and make a decision which best reflects their priorities. CNSs can play a vital role in advising and supporting patients on their decision.

Example of good practice:

At the Papworth Hospital NHS Trust, conversations between patients and carers and consultant chest physicians, oncologists and specialist registrars are taped so that patients could take the record of the conversation away to listen to again.

Often discussions about treatment options are very complex and patients and carers may not take in all the information. Although some patients did find it distressing to have the bad news contained in the consultations on record, most found the tape helpful as an aid in recalling the discussion, prompting questions to ask the doctors, and clarifying the treatment plan and possible side effects.^{xxx}

Patients and their carers should be provided with comprehensive information about treatment options, ideally during a face-to-face consultation with the medical team so that the different options and what they involve can be explained, and their possible side-effects highlighted. Printed information produced by Macmillan and the Roy Castle Lung Cancer Foundation as well as DVDs and information packs from the pharmaceutical company producing the treatment can help patients and carers understand what a treatment entails.

We welcome the Department of Health's work in developing information prescriptions for cancer patients as part of the Cancer Reform Strategy. The national lung cancer patient information pathway, developed during the first year of the strategy's implementation, has been valuable in identifying the different information needs of lung cancer patients throughout their pathway and providing a library of content for a personalised information prescription to be developed. This means that patients can have a wide choice of information which can be tailored to their needs. It also allows for better coordination amongst the clinical team about the information which the patient has received because this is recorded at the consultation.

The role of the CNS in treatment

The importance of the CNS in ensuring the patient receives active treatment was highlighted by the National Lung Cancer Audit 2008. Data from the audit demonstrated that patients with access to a CNS were twice as likely to receive treatment compared to those without support^{xxx1}. However, the audit found that only 51 per cent of patients were seen by a Clinical Nurse Specialist during their cancer journey^{xxxii}.

CNSs also have a critical role to play in ensuring the safe delivery of chemotherapy. The National Chemotherapy Advisory Group report recommended the development of nurse-led chemotherapy to improve the safety and quality of services. It also identified that this has the potential to increase capacity and flexibility, and help to reduce waiting times and emergency admissions^{xxxiii}.

It is important to note that patients may have other illnesses which are not directly linked to their lung cancer. Handling such co-morbidities requires careful coordination with healthcare professionals outside the lung cancer MDT. Unfortunately, this does not always happen:

“I went to my haematologist... I told him about this tumour and he says ‘well whatever happens you’re going to have a problem because you can’t have chemotherapy’... Now the following week I had to go and see this [oncologist] and straightway he said to me, ‘we’ve worked out all your programme of chemotherapy’. I said I can’t have chemotherapy^{xxxiv}”.

(Male patient, North West)

One of the most difficult parts of treatment for both patients and carers will be managing the side-effects. Having one contact name and phone number to call if they are worried can be a great re-assurance and support for patients and carers. This is ideally the CNS who will have helped them prepare in advance for the side-effects of treatment.

Example of good practice:

At the United Lincolnshire Hospitals and North Tees Hospital, CNSs created a health record, held by the patient, which includes information such as contact numbers, test results, treatments, therapies, symptom management, support and advice, as well as documenting hospital attendance. This became a resource which patients and carers could draw on when necessary, such as providing information on treatment options specific to that patient^{xxxv}.

We support many of the recommendations on the management of side-effects contained in the recent report by the National Chemotherapy Advisory Group. These include:

- Written information on serious and common toxicities associated with a particular treatment should be provided and discussed with the patient before they give their consent to the treatment
- All patients should have access to 24 hour telephone advice with systems in place for access to appropriate emergency care
- All hospitals with an accident and emergency department should have an emergency oncology team in place to oversee emergency admissions from cancer patients
- Patients should know which hospital or unit they should go to if they develop complications at any time of the day or night
- Hospitals should have arrangements in place for access to urgent specialist oncology advice^{xxxvi}.

Key recommendations:

Patients should be given clear information about the treatment options available to them in a sensitive way

Accessibility to the CNS for the lung cancer patient is crucial for advice and support

There should be continuity in the medical team treating the patient, and clear communication between its members. Patients should be provided with a 'key worker' as a unified point of contact for all their care needs

Where appropriate, patients should be offered a choice of where to receive their treatment. If they opt for home or community-based treatment, they should still be provided with appropriate information and support

Education about the side effects of treatment is vital. CNSs can play an important role in ensuring that patients and carers understand what to expect and how to seek help

Supporting families

Providing emotional support to the patient and carer throughout their cancer journey is an important part of a CNS's role. Patients value knowing that the CNS is available if they need someone to talk to. Sometimes patients can feel guilty about the emotional and physical impact which their lung cancer may have on those around them, and the CNS is seen as someone sufficiently removed from the patient's domestic situation to be able to be a trusted source of advice:

"The nurse...phoned me yesterday, to see how I was. Ask questions and she's there. She'll sit and talk to you...When I first came out I went into depression and I have very bad depression and I just rang her and she was there^{xxxvii}."

(Patient, Bishop Auckland)

It is also important to recognise that patients and carers may have very different emotional needs at this point. Carers can often feel socially isolated because of the focus by medical teams, and perhaps other members of the family, on the patient, yet the diagnosis of lung cancer can be as much of a crisis for them as for their loved one:

"I don't shout and scream, I suppose I just get very upset and cry but I try not to. I've never liked crying as a release because it's always made me feel worse so probably I bottle things up. I don't suppose I have [a release mechanism] really".^{xxxviii}

(Female carer, South)

Sometimes carers can feel guilty about wanting other people to acknowledge their own needs, or mask their need for support by caring for the patient. At this point, by holding a separate consultation with the carer, the CNS can address the carer's emotional needs. The carer may be coming to terms with the likely day-to-day implications of caring for the patient, as the brunt of providing care at home and help with everyday living will most probably fall on them.

Supporting patients wider needs

In addition, the CNS can be a source of advice for other difficulties patients and their carers might be facing during treatment. The financial impact of lung cancer can be considerable. Macmillan's research has shown that 91 per cent of cancer patients' households suffer a loss of income and/or increased costs as a direct result of cancer^{xxxix}.

Example of good practice:

Lung cancer CNSs at the Churchill Hospital in Oxford set up a non-medical support clinic for lung cancer patients. This service is designed to enable lung cancer CNSs to spend more time with patients who may need it, who may be particularly anxious, or who may need advice about benefits, have their symptoms monitored, or who would benefit from psychosocial counselling.^{xi} Patients have responded to the service very positively:

"She explained things that I found I didn't have enough time to ask the doctor and put me on the right round for making up my mind regarding the next step for me".

(Patient, Oxford)

NHS patients who receive specified means-tested benefits are entitled to reimbursement of their travel and parking costs under the Hospital Travel Costs Scheme. However, there is evidence that only 19 per cent of health professionals report that patients are being informed about the schemes in line with guidance^{xii}. CNSs can help families to meet financial shortfalls during their cancer treatment by directing them to appropriate sources of information, and working with social services where this is suitable. This can help to reduce emotional stress on the patient and carer by relieving financial pressures.

"We have had one grant because she [Macmillan Nurse] said to us 'is there anything else?' and I was laughing and saying to her 'we just need a holiday, we have never had one' and she said 'actually I can help with that' and we got £500 to go on holiday^{xiii}".

(Female carer, North East)

During their cancer journey, patients may feel socially isolated because of the impact their treatment might have on their ability to work, and its effect on their relationships with family and friends. Patients may be feeling very unwell and will probably not be physically able to take part in the activities which they used to do for relaxation, or may be lonely through not being able to leave their home, apart from visits to the hospital for treatment. In these cases, many patients find the work of the lung cancer CNS in facilitating a lung cancer support group very helpful.

Example of good practice:

At the Walsgrave hospital in Coventry, the CNS set up a support group to meet each month in a pleasant room in the oncology department, away from the clinical area. At each meeting, around 15-25 people attend and guests are invited to speak, including chest physicians, oncologists, dieticians, information radiographers and physiotherapists. This fulfils not only a social role for patients and carers, but takes a holistic view of their needs and provides appropriate information^{xliii}.

Lung cancer CNSs, often supported by charities, such as Macmillan Cancer Support and the Roy Castle Lung Cancer Foundation, have set up support groups around the country to give patients, their carers and others affected by the disease the opportunity to meet regularly and provide support and advice to those who are going through a similar situation.

Key recommendations:

There should be greater recognition of the value of CNSs in providing information, advice and support for lung cancer patients' and carers' emotional, physical, social, spiritual and financial needs

CNSs can help support the different needs of patients and carers

Providers should prioritise ensuring that all patients are offered good continuity of care

Lung cancer CNSs should provide information to patients and carers in order to reduce the financial burden of attending treatment

Patients and carers should be provided with information about access to support groups and other social activities to relieve isolation

Follow-up and end of life care

After treatment

Many patients will have periods where they are not undergoing active treatment, and so may be discharged to the care of their GP. Cancer treatment is often intensive and patients will form a strong bond with the team who has cared for them. Follow-up appointments are important for providing reassurance to patients and carers that they are still being cared for, and that their condition is being monitored. However, some patients have reported feeling that they were under-supported when their treatment finished, particularly when compared to the many healthcare interventions they were receiving from different members of the medical team. They can feel uncertain and scared about what they should do, and who they should contact if they have worries about their disease^{xliv}.

Example of good practice:

Macmillan lung cancer CNSs at Guys and St Thomas' Hospital NHS Trust developed a nurse-led follow-up service, rather than conventional follow-up protocol. They found that there was no difference in the safety of the two follow-up systems, and that patients were significantly more satisfied with care than patients receiving conventional medical follow-up^{xlv}.

Access to the lung cancer CNS can be crucial during the follow-up to treatment in order to maintain a coordinated approach in caring for the patient, as primary responsibility for care should remain with the medical team that provided treatment.

Example of good practice:

Lung cancer patients at the University Hospital in North Durham particularly appreciated improvements in telephone access with the CNS, which reduced frustration and anxiety for them and their carers.

At the hospital, the lung cancer CNS set aside two hours a week when it would be guaranteed that she would be available to take phone calls from patients requiring support or advice. Information leaflets were developed for patients with all the relevant contact details, as well as stating that patients could call outside these hours and if the nurse was unavailable, she would call them back if they left a message^{xlvi}.

In order to meet the patient's physical needs at this point, the lung cancer CNS can provide practical advice, using resources such as Macmillan's leaflet on *Coping with shortness of breath* and *Practical help in advanced cancer*. The emotional and social support which CNSs provide at this point should also not be understated: they provide a link for the patient to express their concerns and talk through their feelings:

"[Contact from the nurse] makes you feel as though you are not forgotten... You know they've given you your treatment and right get on with it... It makes you feel you're a person and it's nice to know that somebody cares".^{xlvii}

(Patient, Bishop Auckland)

For carers, the follow-up period can be a period of isolation and uncertainty about the future. Macmillan research has found that although most carers want to look after the patient themselves, they still appreciate the offer of support. This is particularly the case during the early stages of treatment when they are still adjusting to the situation^{xlviii}.

Key recommendations:

The variety of functions that follow-up appointments fulfil should be recognised, including monitoring for signs of recurrence, managing ongoing side effects or the late effects of treatment and providing emotional support and reassurance

Patients should be able to tailor their follow up according to their needs

Lung cancer CNSs should be accessible to patients and provide information to enable patients to manage their symptoms and any side-effects of treatment

End of life care

Despite innovations in treatment, many patients who are diagnosed with lung cancer will ultimately die from the disease. High quality end of life care is every bit as important as effective treatment earlier in the pathway. CNSs can play a vital role in supporting patients as they near the end of their life, helping consider different options and ensuring that they receive appropriate advice and support from specialist palliative care teams. The Department of Health's *End of Life Care Strategy*, published in 2008, made clear that every patient should receive an end of life care plan, setting out their wishes and ensuring that physical, psychological and spiritual needs are met^{xlix}. CNSs can play an important role in ensuring continuity of care throughout this phase of the pathway.

Example of good practice:

At the Sunderland Royal Hospital, carers had reported that they felt a lack of bereavement support after the patient's death. This was exacerbated by the fact that they had built up a close relationship with the lung cancer CNS and medical team throughout the patient's treatment, and they felt this had suddenly been withdrawn.

To address these deficiencies, the Sunderland Royal Hospital developed core nurse ward teaching in communication skills for the sensitive conversations which are required at the end of a patient's life. In practical terms, an area of the respiratory ward was set aside for patients with potentially terminal illnesses where care is less intense and noise is less intrusive. Discharge planning was discussed much earlier in the patient journey so that patients and carers could make choices about the place of death, and a second lung cancer CNS was appointed to assist with bereavement counselling^l.

The lung cancer CNS can also provide emotional support by acknowledging the death of the patient preferably over the phone, or offering their condolences in a letter. They also continue their coordination role to address the different impacts of bereavement on the carer. The carer and family may benefit from advice on the financial implications of bereavement, and being talked through the booklet produced by the Department for Work and Pensions, "*What to do after death*".

Key recommendations:

The *End of Life Care Strategy* should be implemented as a matter of urgency

The wishes of patients and carers should be taken into account when planning for the end of the patient's life

The lung cancer CNS should coordinate acknowledging the carer's bereavement and responding to their needs when the patient has passed away

Reducing the deficit in Clinical Nurse Specialists

The CNS plays a critical role throughout the patient's lung cancer journey. They are not only able to ensure that the patient's care and treatment is co-ordinated but can also provide emotional support to both patients and their carers. CNSs can reduce the burden of lung cancer on NHS resources by reducing the length of the patients stay and the number of unplanned emergency admissions.

Key national guidance, including the Cancer Reform Strategy and the Improving Outcomes Guidance for Lung Cancer makes clear that access to a CNS should be standard as part of an MDT.

However, there remains a significant shortfall in CNSs for lung cancer. Some patients do not get access to a CNS. For others, the input of a CNS will be limited due to an unrealistic caseload.

It is estimated that there are approximately 225 lung cancer CNSs around the UK^{li}. Despite the significant burden of the disease on the NHS, as well as its impact on the 39,750 people who are diagnosed with the disease every year, on average, there is only one lung cancer nurse in England for every 132 patients with lung cancer, yet there are 82 breast cancer patients per breast cancer nurse^{lii}.

We welcomed the commitment made by the previous government for every cancer patient in England to have access to a cancer nurse specialist in their own home in the next five years. We hope that the new Coalition Government will also recognise this as a priority and invest to ensure that enough CNSs will be recruited and trained to meet this important commitment.

Further work is also required to maximise the effectiveness of CNS roles, ensuring that specialist expertise is targeted at addressing patients' unmet needs and not replicating the role of a general ward nurse.

In addition, research is required to understand how best CNSs can improve patient care. In order to further develop the contribution of CNSs to lung cancer patient treatment and care, the National Lung Cancer Forum for Nurses has identified the areas which should be key priorities for research in the future, based on an extensive questionnaire of its members undertaken in 2007. This report itself grew out of the findings of the survey, as the main area identified by nurses was exploring the impact of lung cancer on patients and their families.

Other priorities identified by CNSs for research include exploring the information needs of patients and carers; as well as examining the role of CNSs in managing symptoms, organising care and the particular needs of lung cancer patients who are undergoing surgery. The Forum would like to hear from CNSs and local NHS organisations who are interested in pursuing these areas of research.

Development of key performance metrics

There are a number of important ways in which lung cancer CNSs can contribute to improving the quality of care lung cancer patients receive. However, at present there is an absence of key performance metrics to assess the areas on which CNSs will have the greatest impact. The Cancer Reform Strategy commitment to undertake an annual cancer patient experience survey is therefore extremely welcome and should be used to inform service development and investment decisions about future CNS provision. Results should also be published so that commissioners can use the findings as a key part of performance management and so that patients are able to make choices based on the experience of people who have been in the same situation as them.

Key recommendations for building a better future for lung cancer patients:

CNS workforce capacity audits should be published and repeated on an annual basis

Commissioners should hold providers to account for ensuring the adequate provision of CNSs

Caseload guidelines should be developed for CNSs, ensuring there is clarity about the level of provision required to meet patients' needs

Further research is required to identify what CNS interventions matter most to patients and have the greatest impact on the quality of care

Regular surveys of the experience reported by patients should be undertaken and the results should be used to inform decisions about service development, performance management and patient choice

Useful information

Case studies

For more information about the good practice examples used in this report, please contact Liz Darlison at the National Lung Cancer Forum for Nurses on 0116 250 2615 or liz.darlison@uhl-tr.nhs.uk

Macmillan Cancer Support

To learn more about Macmillan's services, please visit the website www.macmillan.org.uk

Information helplines

Macmillan operates a free and confidential helpline for people who have concerns or questions about living with cancer:

9am-9pm Mon-Fri: 0808 808 2020

The following free and confidential Macmillan helpline offers nurse information on cancer types, treatments and what to expect:

9am-8pm Mon-Fri: 0808 800 1234

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