The Changing Landscape for Lung Cancer Nurse Specialists
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ACKNOWLEDGEMENT

On behalf of the NLCFN committee, Jackie Fenemore and Carol Davies would like to thank members of the forum for supporting the development of this third edition Good Practice Guide. We are indebted to those nurses who have sent in examples of improvements and changes in their practice, some of which are also included in the Scottish Lung Cancer Forum for Nurses Electronic Directory for Sharing Practice.

FORWARD

Lung cancer nurse specialists have led the way with the Good Practice Guide since 2004 and it is wonderful to see a fourth edition reflecting progress in cancer nursing practice.

Lung cancer remains a challenging speciality, and the health service is becoming a more challenging working environment in which to provide excellent cancer care. This changing landscape is reflected in the title. The Changing Landscape for Lung Cancer Nurse Specialists is apt, for despite the challenges, lung cancer nurse specialists strive to provide the highest level of care as this document clearly shows. This fourth edition of the Good Practice Guide will act as a great resource. It is full of information and exemplars of good practice drawn from the real world of lung cancer care.

This Good Practice Guide also demonstrates the extremely diverse and complex work of lung cancer specialist nurses and the contribution they make to the team. This is becoming increasingly important as all four countries of the United Kingdom face workforce and resource challenges. This means that the examples in the Guide are not only describing excellence in practice, but also serve as examples of working smarter and more efficiently across many specialisms—this guide reaches out beyond lung cancer practice to the wider nursing community, by showing what can be achieved.

It is very good to see the contribution specialist nursing makes to the pre diagnosis phase of the lung cancer pathway articulated so clearly. This contribution is all too often hidden, but the Good Practice Guide shines a light on this contribution alongside the rest of the examples of excellence.

It is clear from this edition of the Guide that lung cancer nurse specialists are driving change, leading innovation and facing challenges with tenacity and enthusiasm. In doing so they are improving care for patients and families across the UK.

Professor Alison Leary
London South Bank University
This 4th Edition Good Practice Guide published on behalf of the National Lung Cancer Forum for Nurses seeks to highlight the essential contribution made by lung cancer nurses to the experience and care of lung cancer patients throughout the UK in the NHS. The guide has gone from strength to strength as a useful reference for good practice initiatives across the United Kingdom.

The 1st Good Practice Guide The 1st Integrated Lung Cancer Nursing: A Good Practice Guide (2004) brought together examples of good practice, in lung cancer nursing, from across the UK to be shared with all members of the multi-disciplinary team (MDTs), but particularly lung cancer nurse specialists to help develop their roles within their own MDTs.

Following the success of this publication, a 2nd Good Practice Guide was developed in 2009 by the National Lung Cancer Forum for Nurses in collaboration with Macmillan Cancer Support. This new publication: Leading the Way towards an Ideal Lung Cancer Service (2009) built on the good work demonstrated so well by contributions from lung cancer nurses across the UK in the first edition of the Good Practice Guide.

The 3rd Good Practice Guide: Excellence and Innovation in Specialist Lung Cancer Nursing Services (2014) continued to focus on everyday examples of good practice across the NHS in lung cancer nursing and to inspire lung nurses to always strive to improve the pathway and care of their lung cancer patients.

These guides have provided a framework for showcasing examples of good nursing practice to help identify a patient and carer focused approach to provide excellence in lung cancer care in an always challenging and changing environment.

This new guide: The Changing Landscape for Lung Cancer Nurse Specialists (2017) hopes to build on the work already being performed so successfully by LCNS all over the UK and highlight the ever changing workload and role of lung cancer nurses.

The stages of the patient pathway are:
1. Pre-diagnosis and referral
2. Investigation process
3. Diagnosis and initial needs
4. Treatment
5. Follow-up and end-of-life care
The purpose of this guide is to provide a user friendly, informative guide for all lung cancer nurses and their colleagues. Contact details are provided with the examples of good practice to enable networking and to promote working towards the highest standards of delivery of care.

The majority of the examples of good practice have been provided by members of the National Lung Cancer Forum for Nurses. The Good Practice Guide published by the National Lung Cancer Forum for Nurses is now an established guide to excellent practice and could be extended to be a guide for all tumour sites and other CNS roles in the NHS as examples of developing good practice. A great deal of the work highlighted in these Good Practice Guides is transferable and the NLCFN are keen to share their good practice and encourage other CNS's working to promote good practice to share their ideas.
The National Lung Cancer Forum for Nurses defines the role as:

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

GP

- Abnormal CXR
- 2 week wait referral

CT scan

- Pre clinic radiology meeting
- CT scan

Options:

- Day case biopsy
  - Bronchoscopy (EBUS/TBNA)
  - CT guided biopsy
  - Surgical biopsy

- Rapid access lung clinic
  - Ultrasound fine needle aspiration neck
  - Plural drainage
  - Further imaging (e.g., PET/MRI)

MDT

- Treatment
  - Oncology
  - Surgery
  - Watch & Wait

UHL existing patient

Rapid access lung clinic

CNS Telephone contact
In 2010, there were 42,026 recorded new cases of lung cancer in the UK, which equates to over 100 new cases every day. (Cancer Research UK 2012). Lung cancer is a devastating diagnosis which can have a huge impact on patients and their carer’s lives. As healthcare professionals we all have a responsibility to improve outcomes and provide an excellent service including communication and support of the highest standard.

Since the introduction of the clinical nurse specialist role, following the Calman-Hine report (1995), there has been an increase in the number of lung cancer nurse specialists in the UK, and the majority are members of the National Lung Cancer Forum for Nurses (NLCFN). The NLCFN was established in 1999 with the aim of providing a community for networking, shared education and general support for nurse specialists working in lung cancer. The function of the forum has since evolved to include extensive partnership working to ensure equitable access and improved outcomes for lung cancer patients and their carers.

There is a growing body of evidence which supports the involvement of specialist nurses in the care of lung cancer patients (Corner et al 2000, Moore 2002). In 2004 the National Audit Office conducted a survey of patient experience which provided evidence of improvement with regard to patients getting information they need, being treated with dignity and respect, and having trust and confidence in their doctors and nurses (National Audit Office 2004). In an interview in 2009 Professor Mike Richards, stated that improvements are down to two key elements – better MDT working and specifically the role of Clinical Nurse Specialists, ‘Clinical Nurse Specialists are the largest single element of the specialist cancer workforce. Most of the patients talked to welcome the role, and doctors have also said they would not want their MDT to be without a nurse specialist – that's fairly powerful support’ (Nursing Times 2009).

Despite this there is inequitable access to cancer nurse specialists; a study mapping the cancer clinical nurse specialist workforce concluded that the number of CNSs is not consistent with the incidence of cancers across English cancer networks with lung and urology CNSs being under represented (Trevatt et al 2008).

Department of Health policy includes clear support for Cancer Nurse Specialists in Lung Cancer. Guidelines for the Diagnosis and Treatment of Lung Cancer (National Institute for Clinical Excellence 2005) strongly recommend that all cancer units should have a nurse specialist available to see patients before and after diagnosis to provide continuing support and to facilitate communication between the secondary care team, the general practitioner, the community team and tertiary care team were appropriate.
However, in recent years despite widespread support and acknowledgment and evidence of the benefit provided by Cancer Nurse Specialists, the role and the function of the CNS has been subject to an increasing amount of debate as the NHS strives to reduce expenditure. This guide may in some part help lung cancer nurses demonstrate how they can make a difference by working effectively.

References


Cancer Research UK (2013) cancerresearchuk.org/cancer.info

Guidelines for the Diagnosis and Treatment of Lung Cancer (2005) NICE.


Further Reading


Setting up a nurse-led post MDT diagnostic clinic

**Problem identified:** Patient being investigated at Maidstone and Tunbridge Wells NHS Trust were facing delays waiting for their results and treatment plan after the MDT. This was impacting on the 62 day target.

**Intervention:** Setting up of a nurse-led clinic the day after the MDT to streamline the service. The Lung CNS' liaised with the consultant chest physicians and the medical directorate general manager and developed a protocol to ensure safe and streamlined review of patients. At that time the lung cancer pathway was changing so that the Lung CNS' were in the initial 2ww clinic appointment to meet and support the patients throughout their investigations.

**How it changed my practice:** The Lung CNS' now routinely meet patients in the 2ww clinic and support them throughout their investigations. Following the MDT patients are contacted via the secretaries and an appointment is arranged for the following day. The lung CNS's have completed their consultation and clinical examination module together with non-medical prescribing course to enable them to review patients in this clinic.

**Resource/cost implications:** Income generating clinic and also freeing up consultant slots to enable more new patients to be seen.

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Abnormal x-ray tracking

Problem identified: Due to the increasing numbers of chest x-rays requested from many different areas, delays are occurring and potentially abnormal x-rays are missed. To prevent delays or missed diagnosis of lung cancer, we commenced an abnormal x-ray tracking system whereby radiologists apply an alert system to reports containing any suspicion of lung cancer. Reports are collected and audited to ensure appropriate and timely referrals are made to respiratory physicians within the trust.

Intervention: Tracking the x-ray reports ensures that general practitioners (GPs) and referring clinicians are aware of the need for referral to the specialist team. This enables GPs to clarify the referral criteria for abnormal x-rays. Weekly collection of x-ray reports, maintenance of a tracking database and auditing has become normal procedure. To date four potential missed diagnosis have been identified and dealt with appropriately through this tracking system.

How it changed my practice: The system has been clearly identified within the trust as a risk prevention measure and this has now been applied to all tumour site specific areas. The system creates approximately 3 hours work a week and is now a routine part of the workload. It ensures timely referral but also provides insight into why patients may not have been referred to the specialist team.

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Lung cancer pathway study day

Problem identified: The Lung CNS’s identified that there appeared to be a lack of knowledge and understanding of the lung cancer diagnostic and treatment pathways, within both primary and secondary care.

Intervention: A study day was organised at the Trust with members of the multi-disciplinary team delivering presentation’s on their speciality. We looked at the whole patient pathway from first referral to a chest physician, through diagnostic investigations, including radiology and pathology, surgery, role of the lung cancer CNS, oncological treatments and emergencies and palliative care.

How has this changed your practice: Significantly, we feel it has raised our profile and made us more accessible to health care professionals outside the MDT. We have always been happy to be a resource for others to guide and advise on matters pertaining to the care of our patients. With the commencement of the study day, providing education sessions to primary and secondary health care professionals we are improving the services that current and future patients receive.

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Macmillan lung cancer specialist supportive service

Problem identified: Patients with lung cancer are often travelling great distances to hospital clinics appointments for routine follow up when they may only be seen for a 10 minute appointment and many of their psychological, emotional and social care needs for quality of life and survivorship care will not be met. The geography of the Health Board makes travel difficult and journey times long. Transport links are poor and many travel long distances on minor roads. Patients say they would like to be treated closer to home.

Intervention: A bid was put forward to Macmillan to develop the lung cancer specialist support service, this included funding for a band 7 lung cancer nurse specialist to set up an outreach service for patients with lung cancer in primary care. The outreach service includes clinics in local hospitals, GP surgeries and various community settings and provides specialist lung cancer nursing support to patients and families closer to home at all points of the patient pathway. Outreach clinics and home visits, where appropriate, are offered to patients who have stable disease following treatment or are managed for best supportive care, and those who are being monitored for progression or recurrence and for patients needing pain and symptom control management. The focus was on quality of life for patients with non-curable disease and survivorship care for those post radical treatment.

How has this changed your practice: Prior to the development of the outreach service it was not possible to offer adequate and/or equitable support to patients throughout the lung cancer patient journey. Patients at the beginning of the diagnostic pathway were adequately supported by the hospital LCNS, and patients with complex needs nearing the end of life were well supported by the palliative care team. However, patients who, having completed their treatment and were being monitored for progression and/or recurrence in respiratory and oncology clinics, were inequitably supported in their complex holistic needs. The instigation of the lung cancer specialist nurse outreach service has provided support for patients throughout their cancer journey at the right time, by the right person, in the right place. This has, prevented unnecessary trips to hospital for patients and families and enabled patients to be cared for closer to home. The influence of specialist liaison and communication between the acute and primary care sectors has transformed communication ensuring a seamless service for patients between hospital and community.

Resource/cost implications New Band 7 post funded by Macmillan

References:
Right Care, Right Time, Right place… Every Time. Hywel Dda Health Board Five Year Plan 2010/2015 http://howis.wales.nhs.uk

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Preventing inappropriate admission to hospital through nurse-led telephone consultation clinic

**Problem identified:** With the increasing numbers of patients being investigated for lung cancer/mesothelioma, patients need accurate information at all stages of the cancer pathway. Following MDM discussion patients traditionally attended clinic to be informed of the need for further investigation or indeed information giving. This was creating capacity problems in terms of clinic availability and consultant time. To address this a formalised nurse-led telephone clinic was implemented to prevent unnecessary hospital attendance.

**Intervention:** An electronic template was required to capture activity / audit discussion and communication with all MDM team to gain agreement and inform of the process of change.

**How it changed my practice:** The aim will be to further develop this initiative through implementing a “virtual reality” clinic consultation as technology develops within the NHS.

**Funding/cost implications:** Consultation appointment slots freed up - therefore allowing effective usage of clinic time.

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**Fast-track clinic**

**Problem identified:** New suspected lung cancer referrals were being seen in several clinics across the Trust, at one time across 3 hospital sites. The service was not an effective use of lung CNS time as it created difficulty covering all the designated clinics.

**Intervention:** The problem was discussed within the lung cancer team and it was agreed that there should be a dedicated fast track lung cancer clinic where all patients referred with suspected lung cancer were seen. Since moving to a new site we have been able to develop the fast track clinic further enabling a more efficient service. The clinic runs on 2 days a week giving more flexibility for follow up appointments and avoiding unnecessary delays. Dedicated CT slots are available and the majority of fast track referrals have a CT scan performed, prior to being seen in clinic. Bronchoscopy appointments are also made available within 7 days so that, if appropriate, patients can be provided with date and information about the procedure.
The clinic is facilitated within the respiratory out-patient department where patients can undergo other diagnostic and screening tests such as spirometry, blood tests and chest x-rays.

**How it changed my practice:** Patients have benefited from improved continuity and access to specialist care from their first appointment. All patients see a Macmillan LCNS who is introduced as their key worker. Any additional investigations that may be needed will be requested at the MDT ensuring rapid progression along the lung cancer pathway. Patients are contacted by the CNS following the MDT meeting and appropriate onward referrals/further investigations are discussed/arrange. This way of working has improved the patient pathway, reducing waiting times and helps achieve national targets. Patients receive the right information at the right time and are supported by the CNS throughout their lung cancer journey.

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**Facilitating and tracking investigations for patients with lung cancer**

**Problem identified:** Patients with lung cancer can present through multiple points of entry to the service, and many different health professionals can be involved in their care. Problems with care pathways have been identified in previous audits of lung cancer management in South-East Scotland. Improving and streamlining the process of care for patients with lung cancer through the pathway in a timely fashion presents a major challenge to all healthcare professionals.

**Intervention:** To streamline the pathway and keep patients on our ‘radar’ during the investigative period, we developed a proforma to enable patients to be tracked. This enables the LCNS to be more proactive in chasing results or dates for investigations ensures patients are seen quickly and within recognised waiting times.

**How it changed my practice:** Completing the proforma on a weekly basis is time consuming but it ensures patients are discussed by the team regularly and pathways are more efficient. This also helps us to prevent patients from breaching waiting times. In the last year we have developed a shared drive where the proforma is housed with other relevant documents. This ensures accessibility for all members of the team. This invaluable tool helps to streamline the processes of care and provide optimal management for patients with lung cancer.

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The development of lung cancer nursing documentation: An integral part of patient care

Problem identified: The lung cancer nursing team in Lanarkshire work across 3 acute hospitals delivering a team approach to patient care facing new issues and problems each day and regularly making decisions on patient care. We decided to evaluate the nursing documentation currently in use to reflect cross site working and standardisation of the nursing documentation.

Intervention: The lung cancer nursing team reviewed the existing documentation, identifying areas that were not covered as part of a holistic patient’s assessment. It was developed to include the recommendations from the NMC (2002c) regarding what documentation should be included and to provide a holistic approach to the assessment. Therefore the documentation would reflect the following:

- Investigations
- Diagnosis
- Treatment
- Signposting to additional services
- Education/information
- Follow up

How it changed my practice: The lung cancer nursing team agreed that record keeping was one area where it was essential to always make documentation robust and accurate despite the time constraints of a busy job. It was decided to base the new documentation on the SMART (Hoban 2005) model of care planning to avoid any problems related to record-keeping.

The SMART model ensured that the document was:

- Specific
- Measurable
- Accurate
- Realistic
- Time-based

The documentation design was sectioned into the various aspects of the patient pathway for easy navigation. The sections reflected patient care where the lung cancer nurse specialists roles and responsibilities lay these includes:

- Patient demographics
- Pre-diagnostic patient assessment
- Pre- and post-diagnostic patient information
- Diagnostic investigations
- MDT treatment planning
- Community referrals
- Toxicity and symptom assessment scoring tools

This change in practice has also enabled the lung cancer nursing team to utilise an evidence based tool that demonstrates:
Quality Care
- Seamless continuum
- Identification of issues/observations in relation to patient care with actions and outcomes for resolution

Patient Assessment
- Would enable accurate assessment
- Holistic approach
- Validated treatment assessment tools

Service Audit
- Easy access to information/data for audit/research purposes
- Monitor quality of care and nursing activity

By maintaining good quality documentation the lung cancer nursing team within Lanarkshire have utilised this evidence based tool to promote communication, continuity, consistency and efficiency, with the reinforcement of documented communication within the team. In the long term it will be helpful evidence for the team and ensure the professional and legal standing of the nursing team is not compromised by absent or incomplete records.

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Assistance in investigative procedures

Problem identified: The need to improve timeliness and patient experience of undergoing investigations for lung cancer.

Intervention: The lung CNSs now assist in bronchoscopy, thoracoscopy and pleural aspiration procedures on a regular basis. Patients and carers are encouraged to contact the CNS early to report any problems. This enables investigations to be performed regularly with short notice on an ad-hoc basis. This often means patients can undergo a procedure to assist with their diagnosis or to manage a symptom on the same day as their first appointment.

How it changed my practice: This has ensured timely investigations are maintained, reducing the number of hospital visits for patients and avoiding inappropriate admissions. This enables early referral, prompt treatment and enhances communication and support for patients and their carers.

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Management of patients undergoing image guided biopsies

Problem identified: Image guided biopsies were booked and a day case bed was requested. The patients were informed of the date of the biopsy and prepared for the procedure. The patient would come to the hospital on the appropriate day but if a bed was not available the biopsy would be postponed.

Intervention: After lobbying by the clinicians the Trust introduced a planned investigation & treatment unit (PITU) to facilitate day case, day care and 5 day admission.

How it changed my practice: The lung CNS liaises with the PITU co-ordinator and the radiology consultant to determine a date for the procedure. The patients are guaranteed a bed on the day of the procedure and image guided procedures are not cancelled due to bed availability. This minimises the patient distress and ensures that resources are used effectively.

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Holistic nursing assessment: Developing a comprehensive screening and assessment process

Problem identified: To introduce a self-assessment tool for patients and carers to identify their needs which may not have been discussed or addressed. The tool helps the patient and carer to identify and disclose any concerns and discuss them with their lung CNS.

Intervention: We introduced the Sheffield Profile for Assessment and Referral to Care (SPARC) tool across the Trust for all tumour sites in conjunction with national guidelines. We initially audited the use and timeliness of the tool and then audited the results for lung cancer patients. Consent and support was gained from the cancer MDTs, lead clinicians and clinical nurse specialists in introducing the tool and in on-going support.

How it changed my practice: Prior to completion of our pilot our approach to HNA screening and assessment was variable and at times we were struggling to ensure all our patients were offered an opportunity for structured assessment. Whilst all patients received a copy of our assessment tool in initial information at or around diagnosis providing structured follow up and encouraging them to return the forms was sporadic. This led to a patchy approach to HNA and acknowledgement within our service that a comprehensive pathway for screening and assessment was needed. In November 2012 we commenced a pilot to explore new ways to approach screening and assessment. We continued to use the Distress Thermometer and Needs Checklist (DT/NC) agreed and previously adapted by us for our particular patient group. We set up a weekly nurse led clinic specifically to offer structured holistic assessment and we also changed the way we had previously circulated the tool to our patients.

Patients are now sent a screening tool 4-6 weeks post diagnosis or after an episode of treatment or disease change. With the tool we send a stamped address envelope so it can be returned directly to our nursing team once completed. On receipt the score system for the DT enables us to streamline our patients for follow-up either through offering a clinic OPA or
by offering telephone follow-up. Patients scoring 5 or over on the DT/NC are automatically offered an OPA where identified areas of distress can be explored in detail during a 50 minute appointment. Those scoring 4 or less are contacted by telephone so that the form can be discussed and any matters arising can be explored at that time. All patients are asked to identify 4 key areas of concern and these guide our discussions both in the clinic and during telephone follow up. This structured approach to HNA ensures we can effectively screen and support our patients and show that we are achieving a high uptake of screening and assessment for our patient group.

**Resource/cost implications:** To support the postage for the screening tool and SAE we applied for funds provided through our Cancer Trust Fund. Clinic costs are already covered by formal funding for specialist nurse led new and follow-up patient appointments. This also supports provision of transport for patients who cannot attend otherwise. Telephone follow-up will soon be formally logged so this too is funded for HNA assessments. To support the administrative process we have a volunteer for 2 hours/week who processes all returned forms and books the OPA.

**Reference:**
Distress Thermometer & Needs Checklist (2007) Based on and adapted from the work of J. Brennan

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Developing a breathlessness booklet

**Problem identified:** Lung cancer patients expressed the need for an easy to use breathlessness aid; they reported when breathless, fatigued and anxious, they find reading breathlessness information overwhelming and confusing.

**Intervention:** The aim was to develop an easy to use breathlessness aid. An A5 four page booklet was produced; this has since been updated to include a multi-disciplinary approach. Information remains, as intended simplistic but is comprehensive. It includes breathing control, anxiety techniques/management, breathing techniques and pacing.

**How it changed practice:** The revised A5 booklet has since been used by patients and a number of multi-disciplinary teams. Feedback remains very positive. It suggests patients feel more equipped to cope with their breathless. They report it has helped them cope with pacing themselves and controlling breathing when using the stairs. Others enjoy the choice of breathing techniques and tips for managing activities in and out of the home. Initially the booklet was distributed by the Macmillan lung CNS and palliative care team which includes consultant, CNS’s and healthcare support workers. Interest in this breathlessness aid was expressed from a variety of specialities and hospitals within Aneurin Bevan University Health Board. The breathlessness leaflet is now available on intranet so that all personnel within ABUHB can access this information. The booklet has also proven useful for non-cancer patients.

**Resource/cost implications:** N/A

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**Direct access chest x-ray**

**Problem identified:** Within Eastern Cheshire there is a currently a direct access chest x-ray service, for patients referred by their GP. Research has shown that patients with lung cancer often present to their GPs late, in order to address this, the Trust is looking at widening the direct access service to include referrals from community pharmacists.

**Intervention:** Patients presenting to a pharmacy requesting medication for lung problems who fulfil specific criteria will be assessed by the registered pharmacist and offered referral directly for a chest x-ray without recourse to their GP.

**How it changed practice:** Pharmacists complete the card and the patient self presents with the card to the radiology department at Macclesfield DGH. The chest x-ray report will be sent to the lung cancer nurses for processing. Patient will be triaged depending on result of CXR and symptoms documented on pharmacy card into RALC.

If there is no suspicion of cancer a letter will be sent to the GP with recommendations for next steps and copied to referring pharmacist.

**Direct Access Flow Chart**

**Resource/cost implications:** N/A

**References:** N/A

**Name:** Karen Clayton  **Hospital:** East Cheshire  **Email:** k.clayton@nhs.net
A 'hub and spoke' approach to providing mesothelioma clinical nurse specialists across the UK

**Problem identified:** Over 2,500 people across the UK are diagnosed with mesothelioma each year with the UK having the highest incidence in the world. Access to a mesothelioma clinical nurse specialist is patchy and yet essential in supporting the NHS to drive up standards and ensure equitable access to world class treatment, trials and care.

**Intervention:** During 2015/2016 the number of mesothelioma UK specialist nurses increased to 12 with the formation of two team leader posts. Currently, there are 13 mesothelioma UK clinical nurse specialist with the aim to increase to 18 as we progress through 2017. Current posts are in Leicester (2), Portsmouth, Manchester (2), Sheffield, North East, Oxford, Glasgow, Yorkshire, Wales, Plymouth and Cambridge. However, there are still large areas without access.

**How it changed practice:** Establishing the 'hub and spoke' has enabled specialist mesothelioma nursing to be integrated into front line services within the NHS to ensure it is available at the point of need. Clear leadership has developed from the director of services/nurse consultant and the 2 team leaders, one covering the south and the other covering the north of England, Wales and Scotland.

Each nurse has a clear service level agreement with the host Trust outlining the requirement for the role to have a local, regional and national remit. The nurses have become integral to the multidisciplinary teams and team meetings and in co coordinating care, brokering and being the expert practitioner. They play a part in developing information, assessment, referral, symptom management, research, optimising function and life style advice. The nurses are able to be alongside the patient throughout their pathway.

They have been able to develop and help in sustaining support groups with 75 meetings being attended in 2016/17.

The nurses can be accessed via the Freephone helpline and dealt with 609 of the 2319 calls in 2016/17. Many of these calls were regarding access to care, support, information and clinical trials.

Practice has been changed by having the nurses in place to address the unacceptable variation in access to specialist treatment, care and clinical trials.

**Resource/cost implications:** Each of the mesothelioma clinical nurse specialist posts are funded by Mesothelioma UK for 0.4% WTE and all of this is derived from charitable donations.

**References:**
The Next 5 Years Mesothelioma UK 2016-2021 Strategy. (Mesothelioma UK)

**Name:** Lorraine Creech  **Hospital:** UHSM and North West  
**Email:** Lorraine.creech@nhs.net  **Telephone:** N/A
Macmillan lung cancer specialist supportive service
support officer

Problem identified: Patients, relatives and professionals did not have adequate access to appropriate support and information throughout the diagnostic and lung cancer pathway. Phone contact was inadequate for the support needs of patients and relatives and liaison with professionals regarding the co-ordination of tests, appointment and referrals was insufficient to ensure a smooth service. The lung cancer specialist nurses needed administration support to enable them to cover clinical areas of working more effectively.

Intervention: A bid was put forward to Macmillan to develop the lung cancer specialist support service; this included the funding of a band 4 support officer. The support officer is available 9am to 5pm, five days a week, as the point of contact for communication with patients, relatives and liaison with professionals regarding tests, appointment, transport issues, general anxieties and concerns at all the points of the diagnostic and lung cancer pathway.

How it changed the practice: The support officer is the first point of contact for patients, relatives and professionals via telephone, email, fax, and letter and in person. The accessibility of the support officer as an appropriate first point of contact to deal with queries and provide information and support at all points in the lung cancer pathway has enabled the lung cancer nurse specialist to re-prioritise their time and focus on the more complex needs of patients and families. The CNS is now able to devote more resources to the development of the lung cancer service including the educational and information needs of professionals. Accessibility to the lung cancer support service has been transformed, ensuring appropriate support for patients, families and professionals at the right time by the right person in the right place, so ensuring a seamless service for all.

Resource/cost implications: New Band 4 post funded by Macmillan.

References:
Right Care, Right Time, Right place…Every Time. Hywel Dda Health Board Five Year Plan 2010/2015 http://howis.wales.nhs.uk

Name: Sarah Morgan  Hospital: Glangwili Hospital
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Assessment of uptake of holistic needs assessment (HNA) in newly diagnosed lung cancer patients

Problem identified: The lung CNS team experienced difficulty ensuring all newly diagnosed lung cancer patients are offered a HNA to discuss concerns and information needs as per guidance. We wished to establish if all newly diagnosed lung cancer patients are being offered a HNA and to assess the uptake within this group.

Intervention: An audit was undertaken alongside the specialist palliative care team for a three month period to identify all newly diagnosed lung cancer patients to see what proportion had been offered an HNA and what proportion accepted it. There were 78 patients in the sample, 31 male and 47 female, average age 72 years, age range of 47-87 years. 15 patients had been referred directly to the hospital palliative care team as inpatients and had their HNA done by them. Of the remaining 63 patients, 57 patients had contact with a Macmillan lung nurse specialist and 6 patients had no contact with a Macmillan lung nurse specialist or the palliative care team. Out of the 63 patients, 35 (56%) were offered a HNA, 15 accepted a HNA and 13 had a HNA delivered. 2 patients who accepted a HNA didn't have it delivered - as HNA appointment clashed with oncology centre appointment/patient passed away. There was no significant difference between males and females accepting/declining HNA.

How it changed the practice: Newly diagnosed lung cancer patients are identified from the x-ray meeting and MDT meeting. Following the rapid access clinic the three Macmillan lung CNSs’ identify if any patients have not been offered an HNA. Any patients not seen by lung CNS have a nurse-led telephone appointment arranged to be offered an HNA. Inpatients will be seen on the ward to offer an HNA. We use the electronic HNA and are part of phase 2 of the eHNA project in conjunction with Macmillan cancer support. The use of the electronic HNA will make it much easier to assess data in the future to identify issues affecting patients and potential service needs. We also plan to obtain the patients views about this service.

Resource/cost implications: There are cost implications for the clinic rooms for the HNA clinic. Both the HNA and telephone clinic will generate income for the Trust. The ipad has been provided by Macmillan cancer support as part of the eHNA project. The HNA clinic has been incorporated into lung CNS working week and job plans. All three Macmillan lung nurse specialists have monthly clinical supervision according to the guidelines.

References:

Name: Joanne Brown  Hospital: Whiston Hospital  Email: joanne.brown@sthk.nhs.uk  Telephone: 0151 430 1367
Holistic needs assessment - Self assessment tools

Problem identified: To introduce a self-assessment tool for patients and carers to identify their needs, which may not have been discussed or addressed. Referral to appropriate teams for continuing care. The tool helps the patient to identify any concerns and discuss them with the Lung CNS.

Intervention: We introduced the Sheffield Profile for Assessment and Referral to Care (SPARC) tool across the trust for all tumour sites in conjunction with national guidelines. We initially audited the use and timeliness of the tool and then audited the results for lung cancer patients. Consent and support gained from cancer MDTs, lead clinicians and clinical nurse specialists in introducing the tool and in ongoing support.

How it changed the practice:
The tool is offered to patients, mainly post their initial treatment to assess for any concerns or issues that may not have been addressed. It is also offered to in-patients and is useful to discuss with the ward staff.

- The action plan can be used to fax to GP’s, palliative care teams or any further referrals required.
- Patient feedback on the tool has been positive, however it has been identified that for some areas the length of the tool could be reduced and a shorter self-assessment tool is now being piloted.
- The tool has identified that many concerns have been addressed but it enables and encourages patients and carers to discuss these concerns more openly. It helps identify any issues, not related to cancer that may not have been addressed which may require support from other agencies.
- It has clearly identified for many patients that symptoms have improved post treatment and that they are more aware and informed of the possibility of new symptoms which may occur, and further support available to them.
- The tool may take time to complete but it has helped to identify patients who need more of our time and the ones who are coping well. It needs to be extended to all patients, particularly those who do not receive active treatment and are followed up in the community.
- Initiatives to develop an electronic holistic needs assessment tool are presently ongoing.

Resource/cost implications: Photocopying the SPARC tool.

Name: Josie Roberts & Suzanne Davies  Hospital: Rotherham NHS Foundation Trust  Email: Josie.roberts@rothgen.nhs.uk  Telephone: 01709 424727
Coventry Roy Castle Lung Cancer Support Group

Problem identified: It was identified that there was a lack of support available for patients with lung cancer. There was a belief that lung cancer support groups would not be viable as lung cancer patients were of poor performance status and their prognosis was also very poor.

Intervention: Funding was obtained to attend a lung cancer conference and contacts were made with the Roy Castle Lung Cancer Foundation. The nurses were guided on how to set up a support group up and help on advertising through the media. The nurses carried out a small survey amongst patients and there was enough interest to continue with plans to set up a group. Appropriate accommodation was found and a letter sent out to all known lung cancer patients that were currently attending the oncology clinic. The nurses also advertised in the local press, GP surgeries and on the local radio station. Posters with relevant information were also sent to local libraries and appropriate clinics.

How it changed my practice: The lung cancer nurses have been facilitating the support group since 1999 and we still welcome in excess of 15 patients and carers to each meeting. All patients are invited and encouraged to attend the group at varying stages of their cancer journey as each will need different support at different stages. The meetings often welcome other health care professionals such as physiotherapist, dietician, benefits centre and radiographers as well as oncologists and chest consultants to speak to the group. Setting up the support group is very rewarding and satisfying and we would encourage any CNS to take a group forward.

Resource/cost implications: There are little resource/cost implications for the group itself. The main resource is nurses time. Currently, the group lasts 1.5 hours and the preparation time can vary but not usually more than 1 hour a month. Adequate accommodation needs to be identified with special consideration to comfort and privacy. The nurses time needed to facilitate the group is very little compared to the satisfaction of running it and knowing how much people benefit from it.

Name: Lindsey Fitzpatrick, Clinical Nurse Specialist Lung Cancer
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Home visits for patients diagnosed with mesothelioma

Problem identified: The need for home visits after a diagnosis of mesothelioma for patients and carers.

Intervention: Following a patient satisfaction survey it was identified that patients who had received a home visit really valued it. It also identified that patients would have appreciated the offer of a visit, particularly after a diagnosis or to discuss treatment options.

How it changed my practice: A home visit is now offered to all newly diagnosed patients with mesothelioma. Patients with complex needs following a diagnosis of lung cancer are offered a home visit. This service has not been required by everyone but allows time to be
dedicated to provide a visit. It enables better understanding of patients social circumstances allowing earlier identification of any particular problems and referral to community colleagues. This development adds to the quality of the service offered and a valued response to the patient satisfaction survey. This service development will have implications which will need to be addressed to continue the equity and present level of support offered.

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**Nurse-led follow-up for results - Breaking bad news within the home setting if this is the preferred option**

**Problem identified:** Choice of setting was identified as a key issue for people who were poor performance status at diagnosis and were deemed to be for "best supportive care" as treatment intervention decided at MDT meeting.

**Intervention:** Patients and carers are now given an option in terms of the location where they can be told results. A service led agreement with chest physicians has given the approval for this service to be developed and subsequently piloted. The lung CNS team has been employing this initiative for a number of months and a pilot questionnaire has been developed, due to be sent out in July to ascertain opinion.

**How it changed my practice:** Early indicators tell us that this concept and initiative is highly successful for certain categories of lung cancer patients who are symptomatic and too unwell to attend outpatient clinic follow-up. Our concept allows choice and offers sensitivity in delivering information in surroundings which suits particular patients and carers. The chest physicians are incredibly positive about this initiative, backing the process 100%. It allows the CNS to develop closeness to individuals and become an ally and companion to whom they can consult for help and advice on their cancer journey.

**Reference**


**Name:** Paul McKenna & Christine Marsden  **Hospital:** Pendle Community Hospital

**Email:** paul.mckenna@elht.nhs.uk

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**Lung cancer diagnosis and home visits**

**Problem identified:** Patients were attending busy dedicated lung cancer clinics and informed of their diagnosis by the chest physician. The patient then met with an oncologist to discuss treatment and then spent time with the nurse to clarify diagnosis and discuss ongoing support available etc. Each stage often incurred more waiting time.

**Intervention:** Macmillan have funded a 3 year post for a lung cancer nurse to make a one off home visit within a week of patients being told their lung cancer diagnosis. It is widely under-
stood that following a cancer diagnosis patients are unable to retain a majority of the information discussed (Brennan 2005). A home visit within a few days has enabled clarification as well as giving patients time to reflect and generate their own questions in a more comfortable and private environment. Continuity of care is achieved as the nurse endeavours to be present when a diagnosis is given. Family members can choose to attend.

**How it changed my practice:** Patient and lung CNS expectations have changed. By offering this service patients benefit from a more personable, private and timely holistic assessment by the lung cancer nurse specialist. Improved relationships and communication have been established with patients. Improved record keeping within the team to ensure members are aware of outcomes of home visits.

**Reference**

**Name:** Jo Phelps, Michelle Palmer & Jolly Barber  **Hospital:** Southend University Hospital  **Email:** johanna.phelps@southend.nhs.uk, michelle.palmer@southend.nhs.uk, jolly.barber@southend.nhs.uk
Incorporating assessment of patients on immunotherapy into an established nurse-led oncology clinic

**Problem identified:** At Maidstone and Tunbridge Wells NHS Trust we were seeing more patients on immunotherapy via the EAMS scheme and it was having an impact on the consultants clinics causing patients delays in being seen.

**Intervention:** In order for the lung CNS' to assess patients safely and provide standardised care we developed an electronic immunotherapy assessment tool. The lung CNS' liaised with other centres to see what assessment tools were currently being used and worked collaboratively with the consultant oncologist, chemotherapy matron and computer scientist department to produce our own version. This has been agreed by the chemotherapy group locally and is in the process of being used throughout Kent.

**How it changed my practice:** This has standardised our practice and ensured safe assessment of patients on immunotherapy. Patients are now seen in the already established nurse led oncology review clinics and the tool has been incorporated within their practice. The data is stored electronically so can be audited. An academic evening was held and was attended by lung CNS', chemotherapy nurses, consultants and pharmacists from around Kent and the tool is going to be used regionally.

**Resource/cost implications:** Nil

**References:**
- Keynote Immunotherapy Clinical Trials
- Clatterbridge Hospital Guidelines

**Name:** Sandra Wakelin  **Email:** s.wakelin@nhs.net  **Telephone:** N/A
Improving the care of patients diagnosed with cerebral metastases

Problem identified: Cerebral metastases are often associated with poor prognosis and the management of these patients was based on the experience of the individual clinician with ad hoc care planned following discharge, not only to dose reduce the steroids but also to manage the side effects these could cause.

Intervention: Concerns about the variance in practice were raised to a chest physician colleague. A quality improvement project to assess the current dexamethasone prescribing practice for cerebral metastases was undertaken. Following this, a 6 month retrospective audit identified 21 patients, their dexamethasone prescription and reduction plan. Seven patients had full written dose reduction plans documented, 5 had their reducing dose part planned and 9 patients had no plan in place to reduce their steroids. The audit also identified side effects the patients experienced and also if they had PPI cover. The performance statuses were recorded and also if any follow up care was planned.

How it changed my practice: There is limited research into the use of steroids, including dosage and duration of treatment, in the management of cerebral metastases. The audit, carried out by two junior doctors, showed that the admitting Hospital teams were excellent at prescribing steroids however there were inconsistencies when documenting a weaning programme, prescribing PPI cover or planning follow up care. There was also concern over the management of blood sugars when two patients were admitted with steroid induced diabetes mellitus.

It was recognised that a more standardised dosing regimen for dexamethasone needed to be implemented. The Edinburgh Cancer Centre policy for steroid use in patients with symptomatic cerebral metastases was considered as an excellent tool for clinicians to use. To ensure that Trust medical and nursing staff were made aware of the new guidance the original concern regarding the management of cerebral metastases raised by the Macmillan lung CNS and the subsequent audit has been presented at the Trust lead nurse/sisters meeting by the Macmillan lung CNS therefore promoting this practice throughout the nursing workforce. The junior doctors presented their audit to the medical directorate and the chest physician has had the guidance implemented on the Trust intranet site.

The management of patients who now present with cerebral metastases should follow the Edinburgh Cancer Centre Guidance with the subsequent recommendations:

- A careful assessment of the severity of any midline shift and/or oedema on the CT/MRI brain scan.
- Any symptom the patient is experiencing is recorded before the first dose of dexamethasone is prescribed.
- A PPI is prescribed as standard alongside the dexamethasone.
- A weaning regime for the dexamethasone is documented within the medical notes.
- Documentation of side effects of the dexamethasone.
- The patient is referred to the acute oncology nurses or lung cancer specialist nurses promptly, (if primary cancer is of lung origin).
- This in turn reduces variance across admitting teams and also hopefully a reduction in bed stays.
- Blood sugars are monitored as standard from commencement of the steroids.
A plan of care following discharge is formulated which includes a referral to the community Macmillan specialist palliative care nurse to manage the dose reduction of the steroids based on assessment of the symptoms (occasionally steroids may need to be reduced more slowly or even be increased again).

Each patient is also referred to the district nursing team to monitor the blood sugars and referred to the diabetic team if needing treatment to manage hyperglycaemia.

Resource/cost implications: This is a change in practice so there are no further funding, resources or cost implications. If anything this will hopefully lead to a reduced number of bed stays for patients. A more proactive management of cases with the lung CNSs’ or acute oncology nurses involvement will streamline further investigations and the diagnosis pathway.

References:
Edinburgh Cancer Centre policy for the management of cerebral metastases
Audit carried out by Dr Christopher Taylor and Dr Samantha Foreman - date of report 20.3.2017
Consultant Physician overseeing this project - Dr Benjamin Prudon.

Name: Jeanette Draffan  Email: jeanette.draffan@btinternet.com  Telephone: N/A

Developing the CNS service at a cancer treatment tertiary centre

Problem identified: The Christie Hospital, Manchester had approximately 2,000 new lung cancer patient referrals attending for treatment in 2015. The numbers had been increasing as patients diagnosed with lung cancer had better access to treatment options. The Trust only employed 2 lung CNSs’. The caseloads for these nurses had become completely unmanageable.

Intervention: The lung team developed a strategy with the help of the medical staff and a survey was undertaken by all the medical and nursing personnel in the team. Overwhelming support for new additional lung CNS posts was concluded. This information was compiled and a meeting was sort with the management team. Support for 2 new nursing posts was also secured from Macmillan by completing a partnership application form. Macmillan also agreed to fund a project manager to oversee the project development for 2 years and to ensure success in establishing the four sector model of working.

How it changed my practice: With the support from Macmillan the management agreed to fund four additional lung CNS posts. Two full time permanent and two 2 year posts. It is hoped by auditing the service and being able to prove better proactive management of patients undergoing treatment and follow up at The Christie these two additional posts will be secured. HNAs and sectorised working across Manchester’s four MDTs will help these four CNSs’ divide the caseload, leading to a more structured approach to caseload management.

Resource/cost implications: Considerable Macmillan investment in the service for 2 years.
Macmillan thoracic surgical nurse specialist post

**Problem identified:** A review of thoracic services raised concerns regarding inadequate information provision for patients prior to, during and after surgery. Also concerns rose of inadequate post-surgical support and poor information flows between the thoracic centre (Leeds) and the units. There was an increase in patient complaints and increasing pressure for the Leeds based CNS team to see non-Leeds patients attending Leeds for thoracic surgery. There was no additional capacity to be able to accommodate those requests.

**Intervention:** The Yorkshire Cancer Network approached Macmillan and secured funding for a full time thoracic surgical nurse specialist for 5 years starting September 2011. The function of the new post was to support the non-Leeds cancer unit patients attending Leeds for thoracic surgery and ensure equitable supportive care for all the lung cancer patient population at this part of their pathway of care.

**How it changed my practice:** The post-holder is based within the Leeds Teaching Hospitals NHS Trust (LTHT) and has established robust communication links with the referring units to ensure smooth patient pathways, equitable patient experience and a two way passage of information. Since the introduction of the post a number of service improvements have been implemented. This includes the patient education programme (PEP) which has been designed to bridge the deficits highlighted in a patient survey aiming to provide equity of support for any patient undergoing thoracic surgery as a treatment for lung cancer. The post-holder has been instrumental in implementing the enhanced recovery programme currently being piloted. To support both of these initiatives all written patient information has been reviewed and re-written.

**Resource/cost implications:** LTHT will commit to pick up funding following an initial 5 year funded period of the post, during which time the success of the post in improving outcomes for patients will be evaluated.

Name: Sandra Dixon. Macmillan Thoracic surgical Nurse Specialist
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Nurse-led management of pleural effusions, in patients with a lung cancer or mesothelioma

**Problem identified:** Patients frequently presented as an emergency and their pleural effusion management was often inappropriate. Symptoms patients presented with were breathlessness, anxiety, cough and pain. Patients were often frightened and aware cancer may be spreading. Lack of support for patients was apparent, lung CNS often not informed of events. The intention was to introduce a robust patient centred service.

**Intervention:** Post a diagnosis of pleural effusion patients, GPs and community palliative care team (CPCT) are encouraged to contact the Macmillan lung CNS if new or persisting symptoms. Prompt clinic review is arranged. If pleural effusion is suspected, the patient is reviewed by a respiratory advanced nurse practitioner (ANP) and during the same visit has an ultrasound scan and therapeutic aspiration.

All patients are given an information leaflet and the ANP contact details. The patient is assessed by the ANP and discussed with a respiratory consultant regarding suitability for thoracoscopy, pleurodesis, and insertion of indwelling pleural catheter or symptomatic drainage. All decisions are made on an individual basis taking into account a patient’s diagnosis, performance status, co morbidities, type of effusion and patient preference. MDT members are informed of any intervention performed.

Patients return to the ward on day 7 and are seen by the ANP, and the stitches removed. The district nurse attends this visit to meet patients and arrange future drainage.

**How it changed my practice:** Symptomatic pleural drainage by an ANP in the pleural room on the respiratory ward; frequency flexible to meet the needs of the patient. The accessibility of this service has been warmly welcomed by patients and carers. Patients tell us they feel supported. It minimises hospital admissions and outpatient clinic appointments, thus reducing travel and hospital transportation costs. This resource is an example of how a service can be adapted to meet the needs of the patient and provides evidence of seamless working through primary and secondary care. Reducing emergency hospital admissions for the management of pleural effusions in patients with a lung cancer or mesothelioma

The patient is informed of suspicion of cancer, further investigations arranged and information given. The patient is seen by the lung CNS and given date to return for results.

**Resource/cost implications:** Advanced nurse practitioner with appropriate training and an interest in the management of pleural infusions. Conversion of the pleural room on the respiratory ward with ward based ultrasound machine. Running an educational teaching session for primary and secondary care.

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Developing a concurrent chemo/radiotherapy treatment patient focus checklist/patient hand held schedule and management of symptoms/side effects of treatment by the lung CNS

Problem identified: Concurrent chemotherapy with radiotherapy for non small cell lung cancer patients is the optimal treatment for patients with inoperable stage 3 non metastatic disease and a good performance status. Concurrent chemotherapy/radiotherapy is also the gold standard treatment for patients with limited stage/non metastatic small cell lung cancer. Patients have a more complex treatment pathway and various screening and diagnosis/patient safety tests are performed prior to commencement of treatment. The lung nurse specialist is the key worker for all patients receiving concurrent chemotherapy/radiotherapy and is a vital part of the pathway co-ordination and selection. Patient selection for this treatment is vital and the CNS is in a pivotal role to help the patient and medical team decide if the patient is fit to commence on this often tiring and toxic treatment regime. A concurrent patient checklist has been developed by the CNS team at The Christie Hospital to expedite these procedures and tests and have them performed in a timeframe to minimise a patient’s visits to hospital if possible.

Intervention: A checklist and patient handheld treatment record has been developed with the medical team so at any point the clinician or CNS can see at what stage in the screening process the patient is up to. This is to increase the chances of the patient commencing treatment within a 3 week timeframe from first being considered for concurrent treatment. The CNS will meet with the patient in clinic, discuss their suitability for treatment with the medical team and go through all the requirement and planned treatment dates with the patient.

How it changed my practice: The CNS is able to book treatment for chemotherapy based on screening information and ensures all the necessary tests and procedures are booked at the correct time. The patient hand held record has been helpful for patients and gives them a treatment plan of where they need to attend at a specific time or date. It empowers the patient to help them understand the treatment plan better. Often at first, patients have been disorientated prior to treatment commencement and patients have given the team positive feedback about the handheld record helping them understand the treatment plan. This streamlines the process for the patient and enhances communication to all personnel involved in the patient’s treatment. The CNS is the keyworker for all patients undergoing concurrent treatment and this ensures all the patients have a point of contact during treatment and then follow up. The CNS is a major point of contact should a patient develop toxicities from treatment. All the CNSs’ in the team are prescribers and can prescribe supportive medications to help with toxicities, such as oesophagitis, pain, lethargy, shortness of breath and pneumonitis. This ensures symptoms can be managed better sometimes preventing the need for hospital admission.

Name: Jackie Fenemore & Emma Halkyard, Lung Cancer Nurse Clinicians
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A nurse-led erlotinib toxicity assessment clinic within the lung oncology clinic

Problem identified: During reorganisation of the lung oncology clinic (2011) it was identified that inconsistencies within the follow up and management of those prescribed a tyrosine kinase inhibitor (TKI), such as erlotinib existed. It was agreed to be a suitable group for nurse led follow up and stratifying of the pathway. The lung cancer nursing team wished to apply their knowledge and experience within the patient pathway for toxicity management and assessment.

Intervention: The evidence for the nurse-led clinic was based on guidance on managing patients receiving erlotinib therapy published by McPhelim et al. 2011 and utilising the expert consensus pathway. This was utilised to support the lung cancer nurses in developing local services by providing a workable management algorithm. Following discussions with the lung oncology team it was agreed to implement the guidance and include telephone assessment. This was agreed as the lung CNS managed toxicities, scheduled clinic appointments, utilising the erlotinib toxicity management guidelines.

An erlotinib prescription checklist was developed to be incorporated as part of the nurse led assessment. This assisted medical staff and pharmacists to have an accurate record of medication requirements based on the full nursing assessment ensuring safe patient management.

How it changed my practice: This has changed practice by demonstrating integration of healthcare professionals within the lung oncology clinic, enabling the delivery of clinically effective care by utilising a team approach to care delivery. It has enabled the delivery of care and management to be:
1. patient centred
2. efficient
3. effective
4. safe
5. timely
6. equitable

This development has structured the assessment and time with patients and carers ensuring a baseline assessment is carried out before commencing treatments, supported by appropriate patient education.

This incorporates the aim of treatment and monitors:
1. side effects
2. storage of medication
3. contra-indications
4. when and how to take therapy
5. frequency of measuring treatment response

The change to practice has also standardised follow up and assessment within this patient group allowing extended clinic follow up and telephone assessment at various time points whilst on therapy depending on toxicities experienced. It also gives the flexibility when patients are doing well with toxicity free periods to alter from pathway steps to either 4 weekly, 8 weekly or 12 weekly reviews.
It has also facilitated the close monitoring of patients receiving TKIs’ as it is important for early detection of toxicities and complications allowing prompt intervention.

The overall aims are therefore achieved by:
1. Improving the patient experience at the clinic
2. Maximising the lung CNS expertise at the lung cancer oncology clinic, giving recognition for a nurse led service within a shared care approach
3. Maintaining therapy at the prescribed dose and reducing the amount of treatment breaks in patients receiving TKI therapy

This model is underpinned by the Key Quality Indicators enabling the delivery of clinically effective care and treatment to service users and consistent with The West of Scotland Managed Clinical Network for lung cancer; follow up guidelines.

Resource/cost implications: No resource or cost implications. Reconfiguration of the lung CNS’ job plans to support the initiative was required. Utilisation of skills within a shared care approach to patient care and management was achieved at no cost.

References
West of Scotland Lung Cancer Managed Clinical Network Follow up Guidelines; Oct 2011

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Enhanced recovery programme

Problem identified: Enhanced recovery after surgery (ERAS) is an approach to the care of patients undergoing surgery involving a number of evidence-based interventions which collectively improve patient outcomes. It has been applied to colorectal, gynaecology, urology and musculoskeletal surgical specialities. It is now being piloted within thoracic surgery at LTHT to enable patients to recover from surgery and leave hospital sooner by minimising the stress responses on the body during surgery.

Intervention: All patients meeting the inclusion criteria are identified in clinic by the surgeon. Patients are given a diary in clinic and given an explanation of the programme. Patients then attend the patient education programme 1-2 weeks before surgery. On the day of admission the patients are given a preload drink at 6pm and again at 10pm. A further third preload drink is given on the day of surgery up to 2 hours before the procedure. Ward staff give patients the incentive spirometry on admission, with explanation of how to use it as part of the breathing exercises in the diary. 30-60 minutes pre-operatively a Bair Paws warming gown is put on the patient and remains in situ throughout surgery. Ward staff encourage the patients to complete the diary which is handed in to the ward on discharge and used for audit purposes.

How it changed my practice: This intervention will enhance patients experience both pre and post operatively and should ensure a better recovery.
**Resource/cost implications:** The cost implication for each patient is approx £22.50, this includes the warming gown, incentive spirometry and the preload drinks.

**References:**

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**Patient education programme**

**Problem identified:** To provide focus and direction for service improvement a patient survey was conducted. The results showed that patients wished for improvement in information regarding their expectations – especially at admission and discharge. Patients asked for one to one support and to have the opportunity to talk to others. Providing written information alone did not guarantee patients were informed.

In response to the results of the survey a weekly 2 hour session of patient education was set up to encompass issues such as pre and post exercises and mobility, post operative pain management, nutrition, smoking cessation, explanation of adjuvant therapy, discharge advice and provide a brief overview of the patient’s surgical pathway. Patients are given a diary of exercise to commence prior to admission, continuing right through surgery to recovery post discharge. The programme is co-ordinated by the thoracic surgical nurse specialist with the specialist sessions being delivered by the physiotherapists, dieticians, pharmacists, surgeons, nurse specialists and ward sisters.

**How it changed my practice:** Each week 10 patients and a companion will attend the programme. This initiative will improve patient readiness for surgery, provide a realistic overview of the hospital experience and recovery, pre-empt and decrease the anxiety that comes with elective surgery. The programme will help communicate to patients that thoracic surgery for lung cancer has a predictable course of recovery and helps prepare the patient and their family for their post discharge care needs.

The venue is within the hospital with refreshments being funded from a charitable fund. There is no cost implication for the speakers as this is incorporated into existing roles and responsibilities. To ensure those who require hospital transport in order to attend the session the programme has been set up as a clinic session. It is estimated that it will cost £80,000 per year by running the course in this format.

**References:**

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Virtual follow-up clinic for patients following high dose radiotherapy (HDRT) for lung cancer

Problem identified: In the Edinburgh Cancer Centre, patients with lung cancer who undergo high dose radiotherapy with or without chemotherapy are reviewed weekly during treatment and followed up in clinic 4-6 weeks later. In that 4-6 week period some patients may struggle with side effects of treatment and anecdotally, the lung cancer team felt that some patients did not seek help during this time. It is widely recognised that patients feel isolated following an intense period of contact with healthcare professionals at a time when they are dealing with significant toxicities from complex treatment and that toxicity associated with treatment can adversely affect quality of life (Bulsara 2004). Anecdotally, the lung cancer team felt that some patients struggled with side effects of their treatment but did not seek help during this time.

Intervention: During treatment, patients are reviewed and assessed by a radiotherapy nurse on a weekly basis and toxicities from treatment are graded using the Common Toxicity Criteria version 4.0 (National Cancer Institute 2010). On completion of HDRT all patients are directed by the radiotherapy team to make an appointment for the virtual clinic. To improve continuity the same proforma used by the radiotherapy nurse is used by the lung CNS team. The team phones patients on a weekly basis offering assessment of toxicities, support and reassurance for approximately 4 weeks depending on toxicity or longer if deemed necessary by the nurse. Other interventions can include referral to GPs in a timely fashion, administrative issues around appointments, other agencies such as rehabilitation or arranging admission if required. At the end of the review period a letter is generated to the GP detailing toxicities and any nursing interventions.

How it changed my practice: By supporting patients to anticipate and pre-empt problems you empower them to take a more active role in the management of their care (Hibbard et al 2006). Patients are now offered advice and support during a time when they may feel "cast adrift". Continuity of care has improved and patients like the regular contact by the hospital. In addition, liaison between the tertiary and primary services has improved. An audit of this initiative has shown that the lung cancer nursing team has provided an effective service to this group of patients and their service is now embedded in practice. As this intervention has been so successful, we now include patients undergoing high dose palliative radiotherapy.

In the last couple of years one of the radiographers has joined our team and helps us with the telephone review. We benefit as a team learning more about radiotherapy as does he in his professional development.

References:

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The introduction of the radiotherapy practitioner

**Problem identified:** Care of patients undergoing radiotherapy was not consistent within the Trust. Patients were assessed by the medical team on a weekly basis.

**Intervention:** Introduction of role of the radiotherapy practitioner within the Trust. To ensure safe, continuous care during the entirety of radiotherapy, from the decision to treat, through planning and simulation to post-treatment follow-up. This includes an outreach service to inpatients.

**How it changed my practice:** Patients who are attending for radiotherapy are assessed daily by the radiotherapy practitioners (RTP) and any necessary treatment is provided according to protocols. The RTP liaises with the lung CNS to prevent and manage any issues for the patient and carers.

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Pilot to gather information regarding patient concerns following surgery for lung cancer and to assess uptake for holistic needs assessment (HNA) within this group

**Problem identified:** All lung cancer patients should be offered a HNA post primary treatment. The Macmillan lung nurse specialists felt that there was less support available for the surgical group of patients as they are not always present in the surgical clinic, because of other clinics running in parallel.

**Intervention:** We offered an HNA to the first 8 patients from March 2012 who had had surgery for lung cancer. All patients had been seen as outpatients by the thoracic surgical team post-operatively. Three patients accepted HNA, and 4 declined. Of the 4 patients who declined, 2 were going to have adjuvant chemotherapy and the other 2 felt that it wasn’t needed. One patient was considering whether to complete an HNA.

Of the 3 patients who accepted HNA, one patient had the Macmillan lung nurse specialist (MLNS) present at the time of diagnosis, one patient had contact with a CNS during the investigative period before the cancer was diagnosed and one patient had had no contact with the MLNS at all. The time interval from surgery to HNA was 6 to 12 weeks. For all 3 patients the assessment was performed using the paper format of the patient concerns checklist. The initial scores of the 3 patients on the distress thermometer were two at score 6, and one at score 7. The main concern for each of the 3 patients was shortness of breath on exertion, shortness of breath on exertion and reduced activity levels, and being unable to go outdoors without others. Other concerns raised were excessive thirst, money worries, difficulty bathing, inability to cut their toenails, memory problems and wound care. All 3 patients appeared to value the HNA and reported less distress when phoned a month after HNA. When asked all felt that post-op lung cancer patients should be offered an HNA as a matter of routine. The sample size was too small to identify common themes in relation to patient concerns, and it
also suggested that CNS support was variable. More work in this area would be valuable to assess the need for an HNA in this setting with a larger sample group.

**How it changed my practice:** Currently, patients who have had surgery for lung cancer are now routinely discussed on the MDT before their initial post op review by the surgeon. Any of these patients who are missed by the Macmillan lung nurse specialists in clinic are added to the nurse led telephone clinic so they can be contacted by phone to be offered a post-op HNA appointment.

For the future, it was suggested considering contacting post-op patients 2-3 weeks post discharge (i.e. before review by the surgeon) to offer support and to offer HNA appointment following review by surgeon.

This audit suggested that contact with the Macmillan lung nurse specialist was variable, as one patient had had no previous contact with a Macmillan lung nurse specialist. This was also found to be the case in a more recent audit looking at uptake of holistic needs assessment in newly diagnosed lung cancer patients. Now all newly diagnosed lung cancer patients, and post-op lung cancer patients are identified at the x-ray meeting and MDT. After the rapid access clinic, we check to see which patients have been seen and if any have been missed. Any post-op and newly diagnosed patients who are missed are booked into the nurse led telephone clinic so they can be contacted to offer support and an HNA appointment.

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### End of treatment clinic

**Problem identified:** During treatment patients are regularly reviewed by healthcare professionals. On completion of initial treatment patients often feel abandoned and anxious as to what the future holds and are fearful about cancer recurrence. Our oncologist sees patients in district general hospital (DGH) but is employed by cancer centre; as such up to date oncological documentation is not immediately available on DGH hospital IT system.

**Intervention:** We discussed the concept of introducing a nurse-led end-of-treatment clinic with multidisciplinary colleagues. All agreed it would benefit patients; another essential benefit each patient seen would have an oncology end of treatment summary. Decision made to introduce a face-to-face nurse-led end-of-treatment clinic assessment.

A template was set up to capture workload and a proforma devised to meet the needs of this specific assessment.

Assessment summary would be sent to patient, treating consultant, patient’s GP and available on DGH IT system.

**How this has changed practice:** Patients are invited to attend clinic for an end of treatment review. Discussion occurs in informal setting; a private relaxed atmosphere is provided to enable patients to talk about different aspects of their life and disclose/discuss their concerns. Follow up plans are confirmed, possible future treatment options discussed, we provide education and advice on common physical post treatment issues such as pain, fatigue and breathlessness, feelings of depression and anxiety that frequently persist after treatment are also
discussed and explored. Symptom management now and what to look out for in the future is discussed and where appropriate end of life preferences approached. Patients appear to value this assessment. Following this face-to-face end-of-treatment summary, the proforma is completed by one of the lung cancer nurse specialists; a copy is sent to the patient, GP, treating consultant and is promptly downloaded onto DGH hospital IT system. This comprehensive end of treatment summary includes each patient PS, co-morbidities, diagnosis, stage at diagnosis, treatment to date, response (or lack of response) to treatment and future treatment options or lack of options. It is a resource with many advantages; providing accurate up to date information. In the event of emergency admissions; clinicians can access this essential information to ensure appropriate clinical decisions made. It aims to provide the patient and healthcare professionals of the actions they should take in the event of new concerns, and who to contact with questions.

**Resource/cost implications:** Assessment and completion of proforma is time consuming for lung cancer nurse specialist. Patient seen in existing nurse led clinic each patient 1 hour session. Additional specialist nurse time needed to complete proforma.

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Problem identified: The Yorkshire Cancer Network (YCN) Lung Cancer Nurse Forum wrote a protocol for follow-up of lung cancer patients for implementation within the network. In Leeds this was first implemented in 2006.

Intervention: We informed the medical teams that telephone follow-up by the LCNS team was possible utilising the YCN protocol. We set up a template on the patient administration system to ensure activity was being formally recorded and set up a prospective audit database.

How it changed my practice: The follow up protocol is now well established as part of follow up practice for selected patients

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The introduction of nurse-led telephone clinic for patients on open follow-up

**Problem identified:** The lung cancer nurses identified concerns that due to increasing heavy workload; some patients with open follow up become lost in system. Historically for this subgroup of patients, emphasis is on the patient to contact the lung cancer nurse service when new symptoms present or if they have new concerns. It was recognised a proportion of individuals for various reasons may not report problems/concerns or seek advice.

**Intervention:** We introduced various nurse-led telephone clinics; with the aim to capture potential problems early enabling us to ensure appropriate support is put in place at an appropriate time for each patient. The telephone clinics give the patients access to the lung cancer nurses from the comfort of their own home which reduces the burden of hospital visits and is a cost effective method of communicating with and supporting patients.

**How this has changed practice:** Protected time was introduced for the telephone clinic. A clinic template was set up and a simple proforma has been devised and implemented. One of the nursing team now phones patients on a rotational basis to assess how they are and assess for any new changes/symptoms. A proforma is used to capture data. Patients, as a result of this new intervention, report feeling better supported and as a consequence say they are more likely to contact the lung cancer nursing team with a concern in between telephone reviews. By phone we assess symptoms and advise on the best course of action, aiming for the patient to be managed in the community whenever possible. If necessary we arrange prompt community review; or prompt referral to appropriate specialist services. Alternatively, clinic review can be arranged if patients prefer. With early identification and intervention for new symptoms we believe hospital admissions will be avoided. Telephone follow-up clinics are an efficient way of keeping contact with a large patient group, providing vital support to vulnerable people. The clinics enable us to assess the physical, psychological and social needs of the patient so we can refer the patient onto the appropriate services. The lung cancer nursing team now have better data to evidence time spent speaking to patients.

**Resource/cost implications:** Introduction of additional nurse led clinic session. Strong links with community teams required.

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CT based surveillance programme following resection of early stage lung cancer

**Problem identified:** The ideal follow-up for resected lung cancer patients remains uncertain. CXR follow-up protocols have been standard practice after thoracic surgery but are of limited benefit in picking up small abnormalities in the chest, distant disease will also be missed. CT follow-up offers improved imaging but with increased exposure to radiation and an increased workload for the Radiology department.
**Intervention:** Following discussion within the MDT we introduced standardised follow-up protocols for patients following thoracic surgery. Our initial protocol was for 6 monthly follow-up for 2 years with CT chest, abdomen and pelvis with contrast at 6 months and 18 months, then annual follow-up to 5 years postoperatively with a further CT chest abdomen and pelvis with contrast at 4 years. Following review of the first 3 years of results this has now been amended, the timing of follow-up remains the same but a CT chest, abdomen and pelvis with contrast is performed prior to every appointment.

**How this has changed practice:** The CT follow-up programme is now embedded in our MDT practice. All patient who have primary lung cancer resected and do not require adjuvant treatment follow the protocol. Patients attend for a CT one month prior to their follow-up appointment, allowing time for the images to be reported before the patient is seen. Abnormal CT results are triaged by the nurse practitioner, repeat imaging is arranged if recommended by the reporting radiologist, all other abnormal results are discussed at the lung MDT.

In the first 3 years of the programme 28% of CTs were abnormal, half of these patients went on to be diagnosed with malignancy. The non-malignant abnormalities were most commonly nodules under continuing follow-up or infection related abnormalities. The programme has detected 79% of cancers prior to the development of clinical symptoms. 5% of patients under follow-up developed recurrent lung cancer, 3.5% had new lung primaries and 1% had non-lung primaries detected. 57% of the CT detected tumours were radically treated. 85% of the radically treated patients had their disease detected in the first 18 months after surgery, compared to 45% of the palliative treatment group.

**Resource/cost implications:** Increased burden of work in the lung cancer MDT - abnormal results need to be discussed, not all of the abnormal results turn out to be recurrent/new cancers.

Increased number of CT image requests.

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**Telephone follow-up clinic for patients with resected primary lung cancer**

**Problem identified:** Introduction of a CT based follow-up programme for patients with resected primary lung cancer means that patients are required to make two trips to the hospital, one for the CT and another for the results once the images are reported. Patients find this burdensome, with traffic and parking problems causing particular concern. Some patients live a considerable distance from the hospital and can have difficulties making the journey on public transport. Most patients appreciate the increased level of surveillance offered by our CT based programme and are happy to make one journey for imaging.

**Intervention:** We have introduced a telephone follow-up clinic for patients who have undergone CT imaging. Patients are given the option of transferring to the telephone clinic or attending a face-to-face clinic for their results at each appointment. The telephone clinic is
run by the nurse practitioner who is experienced in seeing patients in the face-to-face follow-up clinic. Patients are sent a timed appointment and their contact number confirmed prior to the appointment.

The consultation is structured in the same format as a face-to-face appointment with the nurse practitioner. A record of the appointment is made in the patient’s notes and a clinic letter is sent to the GP and other relevant healthcare professionals summarising the consultation. Patients whose concerns cannot be adequately managed via the telephone can be booked into the next available face-to-face clinic appointment. A database of patients seen in the telephone clinic is completed prospectively.

**How this has changed practice:** The nurse practitioner now runs one telephone clinic per week in addition to the scheduled face-to-face clinics. This has increased overall clinic capacity within the department and reduced the waiting time for appointment for patients who need pathology results. Patient feedback in the first 3 months of the clinic has been positive.

**Resource/cost implications:** CCG approval for the change in clinic structure, with associated cost implications (tele-med appointments are charged for at a lower rate).

Reduction in the waiting time for face-to-face clinic appointment, for patients who require them.

Hands-free telecoms equipment for running the clinic.

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**Inter-hospital communication, fast and reliable patient-centred information exchange**

**Problem identified:** Thoracic surgical services in the West of Scotland centralised to the Golden Jubilee National Hospital (GJNH) in Clydebank, this included concentration of thoracic surgical services for lung cancer patients. This service reorganisation presented new challenges regarding communication between the Regional Treatment Centre and NHS Lanarkshire as a service user.

**Intervention:** The lung cancer specialist nursing team from NHSL and the thoracic specialist nurses at the regional centre identified that the communication process was on occasion suboptimal for a variety of factors. Therefore, a shared care information transfer form was developed, that is transmitted electronically from specialist nurse to specialist nurse.

**How this has changed practice:** This has changed practise by enhancing communication between the regional centre and local multi-disciplinary teams supporting a timely process to ensure appropriate patient pathways are adhered to. It also ensures that post-surgical patients are discussed at the local lung cancer MDT in an appropriate time frame to ensure access to adjuvant treatment is met.

The thoracic specialist nurse aims to visit patients 4-8 days post discharge. The visit focuses on aspects such pain control, bowel function, sleep pattern, exercise tolerance, appetite and wound assessment. Pathology results are discussed with the patient and discussion regarding future treatment and follow up takes place.
Relevant information from the home visit is included within the proforma and sent to the local CNS.
The overall aim with the change to practise ensures the maintenance of:
- Communication being carried out within 24 hours of patient discharge
- Clinical usefulness
- Improvement with communication
- Timeliness of information exchange

This service improvement and change to practise fulfils the key component roles of the CNS and their impact as suggested in key documents: Excellence in cancer care, the impact of the CNS, NHS NCAT 2010.
The tool is evidence based with regards to reliability, effectiveness and complies in the secure transfer of identifiable patient data, as the tool is sent password protected.
Since the introduction of the initiative, it is our perception that patient care and patient experience of care has improved as a result of better interpersonal links between the specialist nurse teams in NHS Lanarkshire and the Regional Thoracic Centre.

References:
1. Excellence in Cancer Care, the Impact of the CNS, NHS NCAT 2010.
2. BTS guidelines on the radical management of patients with lung cancer; Oct 2010.

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NHS lung cancer information and support sessions – A service review: A viable and modern approach in patient support

Problem identified: The lung CNS Team recognised improvements to the structure of the existing lung cancer support sessions where necessary to encourage new patients to attend and also to justify the role of their attendance at the scheduled sessions. It was also recognised by the patient group members that new patients needed to be attracted and gain access to the benefits for the group.
The group was becoming a social support group rather than a collective group of people sharing common interests and experiences on how to cope with the challenges of living with lung cancer. There was also acknowledgement that new patients who attended often did not return on subsequent sessions.

Intervention: Approval was gained from the lead lung CNS, lung cancer team members and the Maggie’s Lanarkshire team. We also gained the support on the requirement to redesign the structure of the support sessions, from the patients of the existing group.
Consideration to the session topics, the benefits to the current group and experience of the lung CNS on facilitating the sessions were also examined.
Analysis of the regular session evaluation questionnaires were reviewed, and a focus group discussion, including existing group members on how beneficial they felt the sessions were and the value to them as participants.
How it changed my practice: In redesigning the sessions it has enabled equitable access to additional support, maintaining the initial patient and carers’ needs analysis supporting evidence based patient centred approach. By streamlining the sessions it has offered support to all patients and carers wherever they are in their cancer journey. These changes now support a sustainable service, with a focus on movement through the support sessions with a supported exit strategy to continued support at Maggie’s. It also ensures the lung CNS expertise is utilised in patient education and support.

It was agreed to maintain the existing sessions once a month and rename it as “Living with Lung Cancer sessions” for social support, facilitated by the current group attendees and the input from the Maggie’s team when the sessions required support from a skilled facilitator. The structured sessions on various topics would therefore move to the 4th Wednesday of each month, supported by the lung CNS team.

A patient satisfaction questionnaire was developed for administration to attendees at the end of each CNS facilitated session. This was designed to capture information on session topics, to ensure it was meeting patient and carer’s needs and expectations. They were also asked to evaluate various aspects of the sessions including; effectiveness, delivery of information and venue.

On completion of the 6 session block analysis is carried out on the supported exit strategy into the “Living with Lung Cancer” meetings and the value of support from one another to cope with the challenges of living with lung cancer. This takes the form of a focus group. By changing practise it has aided the streamlining of the sessions and offers support to all patients and carers wherever they are in their cancer journey.

There has also been some impact on patient care, including:

- An opportunity to meet with other people living with lung cancer
- Develop new skills in self-management and coping day to day
- An opportunity to be supported and to help others
- A chance to share experiences and source information
- Support and advice within the hospital setting

Changing practise has also impacted on colleagues and the trust including:

- Being part of the development and facilitation of a patient focused service that ensures continuous focused support and advice
- Working in collaboration with Maggie’s Lanarkshire, as a 1st within NHS Scotland
- Establishing the goal of delivering a viable and modern approach to patient support
- Delivering an evidenced based initiative that is patient focused

These changes will support sustainable services, with a focus on movement through the support sessions with a supported exit strategy. It is a model of good practice that will be showed with transforming care after treatment (TCAT) a Scottish joint initiative. This initiative being based in the Maggie’s Centre encourages patients to access the wide range of support and services also available here.

Resource/cost implications: To achieve this model an additional session was required within the Maggie’s Centre monthly activities timetable. This was introduced on the ethos of delivering a supported exit strategy into the Living with Lung Cancer group, and to allow the introduction of new patients to the structured facilitated sessions. There was no resource implication to the lung CNS, as attendance would continue on a rota basis.
Reference:
Implementing patient-centred cancer care: Using experience-based co-design to improve patient experience in breast and lung cancer services; Tsianakas et al; April 2012.

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Annual report

Problem identified: The lung cancer nurse team has been considering writing an annual report that would become a useful tool in sharing our practice with other nurses and management. It is notoriously difficult to demonstrate the lung CNS role particularly as we spend so much time on the telephone.

Intervention: The nurses had previously written annual reports they lacked ‘punch’. We invited a business manager from a pharmaceutical company to look over our report and guide us to how we could make it better. Our aim was for the report to have an impact on its readers, to raise our profile and highlight the work that we do. We arranged an afternoon where we went through our report line by line looking at the wording. We were taught how write in business terms rather than nursing terms. This was very new to us. We were also advised to collect data to validate our statements.

How it changed my practice: The new annual report has changed practice in a variety of ways. The nurses were not acknowledging all patient interventions, for example, the nurses would check all the lung cancer MDT letters and make corrections as necessary. The letters and recommendations for inpatients would be actioned and necessary referrals to other services would be completed. Previously this work was not identified. The meeting we had suggested we complete a very crude data collection exercise over a one month period detailing themes in telephone consultations. We looked at number of calls, ward discharges expedited, outpatient appointments and admissions to hospital avoided. The results showed we had 814 telephone calls ranging from 1 minute up to 44 minutes. The data highlighted 27 avoided admissions, 64 clinic appointments not needed and 15 discharges expedited (we did not collect data for number of bed days). This information was valuable in demonstrating our work and was included in the annual report.

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The implementation of a nursing database to aid in the provision of care for lung cancer patients

**Problem identified:** We were looking for a process of collating information on our patients as we found that we were using multiple pieces of paper to record details of patients that we had seen. In addition we wanted some way of producing meaningful data for annual reports.

**Intervention:** A database was developed with the input from the CNS and houses information on patients referred to the nursing team. This system allows us to be paperless, helps in the collection of data for annual reports and also helps to improve case ascertainment for network and national audit.

**How it changed my practice:** The database has made a significant impact on our practice. We enter information on all patients referred to the nursing team across three hospitals. This ensures that all nurses wherever they work across Lothian have access to the patient database. This is helpful when there is cross boundary working but also when another nurse is on annual leave and a patient rings with a question. Any of the nurses can link into the database and be aware of where the patient is on the pathway and the patient understanding. This ensures a smooth and consistent pathway for patients with lung cancer. The database can also generate letters to agencies e.g.: local council departments, GPs and notes to file. This has made a huge difference in the workload for nurses when letters can be automatically generated with patient details. The database is continually being updated, upgraded and improved. We are currently adapting and improving the database to try and capture more meaningful data in order to quantify specific nursing interventions and enable outcome measures. This stems from trying to justify the CNS post and how these posts contribute to medical outcomes. Current work is looking at the KS framework and the differing levels of expertise required. In addition, to try and improve case ascertainment of the lung cancer database for the SCAN network a data feed has been established so that data is downloaded and analysed on a monthly basis from the database to the lung audit facilitator.

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Nurse-led follow-up of patients with lung cancer following treatment

**Problem identified:** Patients were travelling distances for review at either oncology or surgical clinics. By initiating a nurse-led follow-up clinic at a local district hospital, all patients whether they are following radical treatments with radiotherapy and/or chemotherapy or surgery or patients in a palliative setting were seen in a nurse-led clinic.

**Intervention:** Nurse-led protocols were agreed jointly with surgeons, oncologists and respiratory physicians. Patients are initially seen by the Respiratory physician and plan made for follow-up. Thereafter the lung CNS reviews the patient as per protocol with intervention from appropriate physician if and when required.
**How it changed my practice:** Since starting the clinic our referral rate to the clinic has ranged from 100-168 patients. As yet the nursing team have not undertaken nurse prescribing but plan to in the near future to enable a more holistic service. We also plan to undertake clinical skills assessment so that patients can be examined.

**Resource/cost implications:** Clinics are cancelled if the CNS is on annual leave. The clinic runs on a day when the LCNS visits the DGH so currently has no resource implications.

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**Email alert for acute admissions**

**Problem identified:** The patient pathway management (PPM) IT Team wanted to explore the feasibility of email alerts to key workers.

**Intervention:** The lung CNS team was asked to pilot the email keyworker alert system (KAS).

**How it changed my practice:** Patients who are admitted acutely to the Trust have an email alert sent to their keyworker. Once this is received the lung CNS contacts the ward that they have been admitted to ascertain the reason for admission and to give advice as necessary.

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**Sustaining a therapeutic lung cancer and mesothelioma support group known as ‘The Sunflower Club’. This is a group for lung cancer and mesothelioma patients and includes carers**

**Problem identified:** Patients and carers were expressing a wish to meet others in similar position and to do so regularly enough to capture the changing nature of the disease.

**Intervention:** Following a needs analysis we first run our group as a pilot project for 6 months back in 2004 testing out a core programme with ongoing evaluation through group member feedback. This group has met every 2 weeks since it was set up and although this has resource implications the value of meeting has been shown to outweigh costs.

**How this has changed my practice:** The Sunflower Club is the name of our long running Bucks Lung Cancer and Mesothelioma Support Group – now in its 12th year of existence. This group meets every two weeks for two hours and includes both patients and their carers. The group brings together between 12-16 people and is co-facilitated by two lung nurse specialists. We offer a programme through the year that includes exploration of certain shared aspects of need such as fatigue, poor appetite and breathlessness as well as emotional issues such as living with fear and worry and issues around end of treatment and end of life. To support the programme we invite local professionals to help in our discussions such as our clinical
psychologist, our dieticians and our physicians. The group become closely attached to each other which of course mean we need to deal with loss and aspects of dying throughout the year. However, the support that is experienced and shared is powerful and in spite of some intense times most meetings have a joyful spirit that enables people to feel safe and connected.

The group has a trip out each year that is funded by our Trust charitable funds and this allows us to share a social time together away from the hospital setting. We have had afternoon teas and river boat trips and these have provided wonderful memories and photos for all those that attend.

Cost implications: The Trust fully supports the group and our venue is specifically designated for patient group meetings. It has wheelchair access and funds are available for transport if needed. The group is facilitated by a minimum of one lung CNS and lung CNS cover is available to avoid cancelling the regular meeting.

Reference:
The Bereavement Model of W. Warden, Egan’s Model of Counselling underpins the nature of communication within the group. The Art of Listening and Systems Theory are all influences in the models chosen to develop and sustain the process of facilitating the group.

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Developing a network wide approach to assessing the experiences of our cancer patients in the North London Cancer Network

Problem identified: Patient experience surveys have in the past been:

- Inconsistently assessed across trusts and MDTs - no ability to benchmark.
- At tumour specific level only - does not tell us about the whole picture of cancer care within an organisation or across the sector.
- Usually developed and co-ordinated by CNSs - is this appropriate use of scarce resource.
- Little time spent on making improvements - needs to be owned by trust boards but they need robust data.
- Considerable bias in selecting patients - therefore data not representative.
- No assessment of the whole pathway experience.
- Hard to reach groups experience not gathered - not representative of the population. Can lead to more inequalities.

Intervention: Steering group of interested parties including network nurse director, CNSs and patient information officers within North London Cancer Network. A patient experience survey was compiled by the steering group with the assistance of Picker Institute, sought and obtained agreement from Trusts within the Network to use the survey. The survey was then
sent to patients within 6 months of being seen at each Trust. Results were analysed by the Picker Institute and reports sent to the network and each Trust.

**How it changed my practice:** Standardised format of patient experience survey and analysed independently.
- Helps healthcare staff understand the patient perspective.
- Stimulates competition between providers in relation to quality benchmarks.
- Monitor patients experience against explicit standards.
- Describe and explain variations in experience of different patient subgroups.
  - Motivate providers to make quality improvements. Identify "the best" providers and produce rankings.
- Inform patients when choosing a provider.

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**Nurse-led breathlessness clinic**

**Problem identified:** Breathlessness is a significant problem for lung cancer patients with around 80% of all patients experiencing it at some point. The lung cancer nurses highlighted a need for a dedicated service to enable lung cancer patients to manage and cope with this breathlessness more effectively.

**Intervention:** The lung CNSs searched for a breathlessness training course specifically for lung cancer patients and attended the MPACE course in Manchester. Funding was obtained from the Arden Cancer Network and an additional nurse was employed allowing the setting up of a breathlessness clinic. Necessary clinic space was identified ensuring it was appropriately furnished with sufficient and appropriate seating.

**How it changed my practice:** The lung cancer management of breathlessness clinic was set up to help patients manage and cope with their breathlessness and also to help their family and carers. The clinic offers four x 1 hour sessions to each patient on a one to one basis. Carers are welcome to attend allowing for patient choice. The CNS carries out a detailed assessment of the patient’s breathing problems ensuring all reversible medical conditions have been addressed. Relaxation techniques, breathing exercises and ways to conserve energy are taught. Discussions take place about planning daily activities and how to pace oneself to ensure evening activities are achievable. Feedback from the clinic suggests that patients feel more confident about managing their breathlessness and can regain some control of their abilities. The CNSs’ will accept referrals from anyone involved in the care of the lung cancer patients and also referrals from the patients themselves. Home visits are often arranged due to the nature of the clinic and this is welcomed by the patient. The clinic has made a big impact on patients lives and is rewarding to do.

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Nurse-led telephone follow up in lung cancer patients

**Problem identified:** Over a period of 18 months it became increasingly evident to the LCNS team that patients need to be offered some form of follow up support not only after treatment had been completed, but during investigations and throughout their treatment journey. Patients were highlighting their feelings to the CNS about feeling isolated and lonely and not knowing who they should contact in the first instance. The CNS plays a vital role in supporting the patient and the patient needs to know they can access this support at anytime within their pathway.

**Intervention:** As lung cancer nurse specialists we have developed a telephone follow up service to support patients throughout the lung cancer pathway.

An important component of cancer care is physical, social, and psychological rehabilitation, and a busy outpatient clinic is unlikely to provide these components (Brada, 1995).

This is supported with evidence gathered from a focus group conducted with service users and members of MALCOLM support group. In lung cancer, the key components of follow-up have been highlighted in the integrated LCN: Good Practice Guide (2004) being support, information, and communication, open access, nursing assessment, patient advocacy, multidisciplinary team membership and co-ordinating care. As lung CNSs we see these as core elements of our role.

According to the NICE guidelines, only one randomised controlled trial of nurse led follow-up for lung cancer patients appears in the literature. This study of nurse led follow up by Moore *et al* (2002) looked at nurse led clinics versus conventional medical follow up in the management of lung cancer patients. It indicated that nurse led initiatives can be more responsive to individual needs, increase patient satisfaction and reduce the burden of hospital visits. This has been indicated from our review of telephone follow up calls, and contact with patients and families during their cancer journey.

**How it changed my practice:** Our practice now consists of telephone follow up calls post diagnosis; this is discussed with the patient during their consultation so they are aware of CNS contact within the next 24-48 hours. This enables effective communication between patient, carer and lung CNS. Effective communication is known to be key to optimal health outcomes, understanding what patients need to know, when during the course of care, and from whom they receive this information becomes vital to ensuring the delivery of quality cancer care. Following patients throughout their journey enhances this process and telephone follow up is not just limited to new diagnosis, but also to the treatment phase, both oncologically and surgically.

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Rehabilitation programme post surgery

**Problem identified:** Further support required for patients having surgical intervention and radical treatment for lung cancer.

**Intervention:** A pilot for a rehabilitation programme was conducted for patients post surgery in conjunction with the existing pulmonary rehabilitation programme for patients with COPD in Rotherham.

**How it changed my practice:**
- All patients who have had surgery for lung cancer are introduced to the rehabilitation programme prior to surgery. Patients are assessed post surgery and referred to the programme at *Breathingspace* where they receive an assessment by the physiotherapists and start a 6 week exercise, educational and support programme.
- Some patients have continued on a maintenance programme and the evaluation to date has been positive and enjoyable.
- The pulmonary rehabilitation programme has been extended to patients who have completed radical radiotherapy treatments, and patients with existing respiratory problems.
- The plan is to extend the programme to include patients who may not initially be fit enough for surgery, to improve their exercise and lung function.
- Further audit and assessment is required to develop the enhanced recovery programme. Also to establish if the rehabilitation programme helps reduce hospital admissions and improve survivorship and well being for patients.

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Memorial service

**Problem identified:** Our successful monthly support group found it difficult to come to terms with the loss of members.

**Intervention:** An annual memorial service now takes place and is open to anyone who has lost a family member or friend to lung cancer or Mesothelioma regardless of whether they have been members of the support group. The service is filled with hymns, prayers and personal reflection. We usually advertise in the local press and send personal invitation to families who have lost a member within the last year. The service is held in November as part of our campaign raising awareness for lung cancer awareness month.

**How it changed my practice:** This has proved a popular event. It enables members to reflect and has proved invaluable for staff as well as relatives of patients who have died.

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Nurse re-assessment clinic - Holistic nursing assessment for patients completing initial lung cancer treatments

Problem identified: An earlier needs analysis highlighted the issue of patient abandonment on the completion of lung cancer treatments. It became apparent from this in depth study that patients with lung cancer needed to re-establish contact with the lung CNS where a detailed assessment of the patient and carer’s physical, psychological, social & financial needs could take place. At the time of the pilot there was no lung cancer nursing support on the hospital site where patients received chemotherapy and radiotherapy.

Intervention: A nurse-led re-assessment clinic for eligible lung cancer patients was piloted known as nurse re-assessment clinic (NRAC). Appointments were offered to all suitable patients over a 16 week period to have an opportunity for a detailed nurse assessment upon completion of this initial lung cancer treatment. 71 patients were offered an appointment during the pilot phase. Only 21 received the nurse re-assessment. 50 patients did not attend. Crucially 24 patients felt that they did not require the input of a lung CNS at this time which raised the question how can we capture a significant proportion of patients that have no nursing needs at the end of treatment, but are likely to develop needs in the coming months.

How it changed my practice: The NRAC clinic concept was poorly received; sadly only 21 patients underwent a nurse re-assessment. In terms of both uptake and time the clinic concept was not time or cost effective, although evidence from our own local study supported by wider literature demonstrates that patients with lung cancer can have many unmet needs which are often exacerbated at the end of treatments. Of those that did attend the feedback was positive. Following discussion with the local clinical and medical oncologist it was felt that they would benefit enormously from lung CNS input in their post treatment clinics where the detailed assessment could be undertaken if required at each of the patients follow up visits if required. Therefore the team have changed working practice and established themselves twice weekly in the oncology department on the hospital site where patients receive their treatment.

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LCNS leaflet for primary care teams - Helping primary care teams to support patients with lung cancer and those recovering from lung cancer

Problem identified: Their was a lack of two way communication between district nursing teams/nursing homes etc regarding patients with lung cancer. This was mainly around patient symptoms which may warrant further treatment or palliative management not previously highlighted.

Intervention: A leaflet was designed that we could fax with district nurse referral letters to primary care teams / nursing homes. This was particularly helpful for patients not having active treatment, but who would benefit from review / further treatment if their disease progressed.
How has this changed my practice: I have developed closer links with primary care teams. This has increased 2 way communication which has led to more enquiry calls in particular from district nursing teams. This enables patients’ symptoms to be highlighted earlier, leading to more timely review and treatment. It also supports the provision of an improved quality of life of patients. This has increased awareness of the lung cancer nurse specialist role within primary care teams in Nottingham. GPs appear to be telephoning the lung cancer nurses more, giving updates on patients they are concerned about or who they know we have close involvement with in the primary care setting.

Cost implications: Initial cost of printing / posting to all GP practices / district nursing teams when the leaflet was launched was significant. Time resource to do the initial launch is not to be underestimated particularly as the team did not have any administrative support. On-going resource cost is minimal and includes the printing and faxing of the leaflet with each district nurse referral and initial contact with care homes. Easy access to printer and fax machine is crucial.

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USEFUL CONTACTS

**National Lung Cancer Forum for Nurses**
www.nlcfn.org.uk
Email info@nlcfn.net
Telephone 01675 477607

**British Lung Foundation**
www.lunguk.org

**British Thoracic Oncology Group**
www.btog.org

**Macmillan Cancer Line**
www.macmillan.org.uk  0808 808 00 00

**Mesothelioma UK**
www.mesothelioma.uk.com
0800 169 2409

**Roy Castle**
Telephone Support Line 0800 358 7200
www.roycastle.org

**UK Lung Cancer Coalition**
www.uklcc.org.uk