



Integrating Lung Cancer Nursing: A Good Practice Guide



**Cancer Services Collaborative
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Foreword

Despite the hard fact that there have been few significant developments in the treatment of lung cancer in recent years, in many respects the care available for these patients has improved dramatically in most areas since the 1980s.

Examples of such improvements include the widespread establishment of specialist teams, mechanisms for rapid referral and diagnosis, improved staging, MDT working and an increase in the proportion of patients receiving radical therapies.

The impact of all this on the survival statistics has yet to be clearly demonstrated but the impact on the overall quality of the care 'package' available to patients and carers beset by this dreadful disease is undoubtedly better in many parts of our country than it has ever been before. Central to this pattern of improvement in what might be called 'holistic' care has been the emergence, and then the flourishing, of the Lung Cancer Nurse Specialist.

It is hard to believe now, when we both speak at national conferences of such nurses where there are hundreds of delegates, that the first such nurse was appointed only a little over ten years ago. There are now probably approaching 300 lung cancer nurse specialists in the UK and their voice and role in the care of these patients grows stronger all the time.

This guide is the first attempt to bring together examples of good practice from around England as it has been fostered and documented by the Cancer Services Collaborative Programme. The range of the work described here is huge and the possibilities for the spread and further development of such initiatives into parts of the country that have yet to benefit from them is great.

All the contributors are to be congratulated on their groundbreaking work, no matter what its scale, and we know that they would be only too happy to share their experience and ideas with others given the opportunity. We know also that there are many nurses out there whose initiatives have not been included either for reasons of space or simply because we do not know of them. We would encourage you all to be prepared to share your experiences, good and bad for the benefit of all our patients in the future.

We commend this excellent guide to you and simply ask you to **use it!**

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Section 1 - Introduction and Background

Who is this guide aimed at?

The Guide to Integrating Lung Cancer Nursing is aimed at all members of multi-disciplinary teams particularly nurses, involved with lung cancer patients. It has been developed as a tool to help deliver high quality patient care by describing the core elements of the lung cancer nurse specialist's role and some nurse led developments in practice. Examples of these are contained in the guide along with the contact details of the nurse involved.

This document is also available on the Cancer Services Collaborative Improvement Partnership (CSC'IP') website www.modern.nhs.uk/cancer/lung and is a joint publication with the National Lung Cancer Forum for Nurses (NLCFN). The website also hosts examples of good practice some of which are featured in this guide. The examples of good practice will be regularly updated to reflect the current work and progress of service improvements and developments already implemented.

Readers are encouraged to share their own good practice with others. If you have work which you would like to be included on the website please email cancer.collaborative@npat.nhs.uk.

What is a Lung Cancer Nurse Specialist?

Following a request from the British Thoracic Society as part of the Lung Cancer Data (LUCADA) project, the National Lung Cancer Forum for Nurses drew up the following definition:

"A Lung Cancer Nurse Specialist is a first level nurse, locally recognised as part of the specialist lung cancer multidisciplinary 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 Specialist may be practising within a sub speciality of oncology, respiratory nursing, thoracic nursing or specialist palliative care. A consultation with the lung cancer nurse specialist should include a detailed assessment of the patient's physical, psychological, social and emotional concerns either during or following the diagnostic process. The nature of follow up consultations will depend on the complexity of the patient's needs and also local arrangements covering the sub specialities already mentioned within this definition."



Background

Since the publication of the Calman-Hine report (1995) there has been a huge increase in the number of tumour site-specific cancer nurse specialists. There is a growing body of evidence that particularly supports the involvement of specialist nurses in the care of lung cancer patients (Corner et al 2000, Bredin et al 1999, Moore et al 1999 and Moore 2002).

At the outset there was little to support newly appointed lung cancer nurse specialists in implementing their roles and this led them to develop their posts in very individual and unique ways, adapting their skills and defining their roles to suit the team within which they practice. The workload of each lung MDT varies depending on the local incidence of lung cancer and the population size that they serve. This also influences the model of nurse specialist contribution within the lung cancer team. One lung cancer nurse specialist can provide specialist nursing support to the patient and be the link to other specialties e.g. palliative care specialist nurse, however in larger centres it is necessary to have a team of specialist nurses who may be practising within a particular area. Irrespective of the model adopted, enquiries have shown, in keeping with the growing body of evidence that there are several core components familiar to every lung cancer nurse specialist's post. Central to all of these is the lung cancer patient and their carers.

Over the last 5 years lung cancer nurse specialists have been pivotal to many service developments in lung cancer care. Nurse-led follow-up,



breathlessness clinics, patient held records, patient information and lung cancer support groups are some examples. Some service developments, for example MDT meetings, patient tracking, open access clinics, have depended on the skill and enthusiasm of the nurse specialist to facilitate the change in practice and sustain the new way of working. It is acknowledged that whilst the nurse specialist has often been essential to implementing change, once established the actual day to day completion of some tasks can be more appropriately carried out by another member of the team.

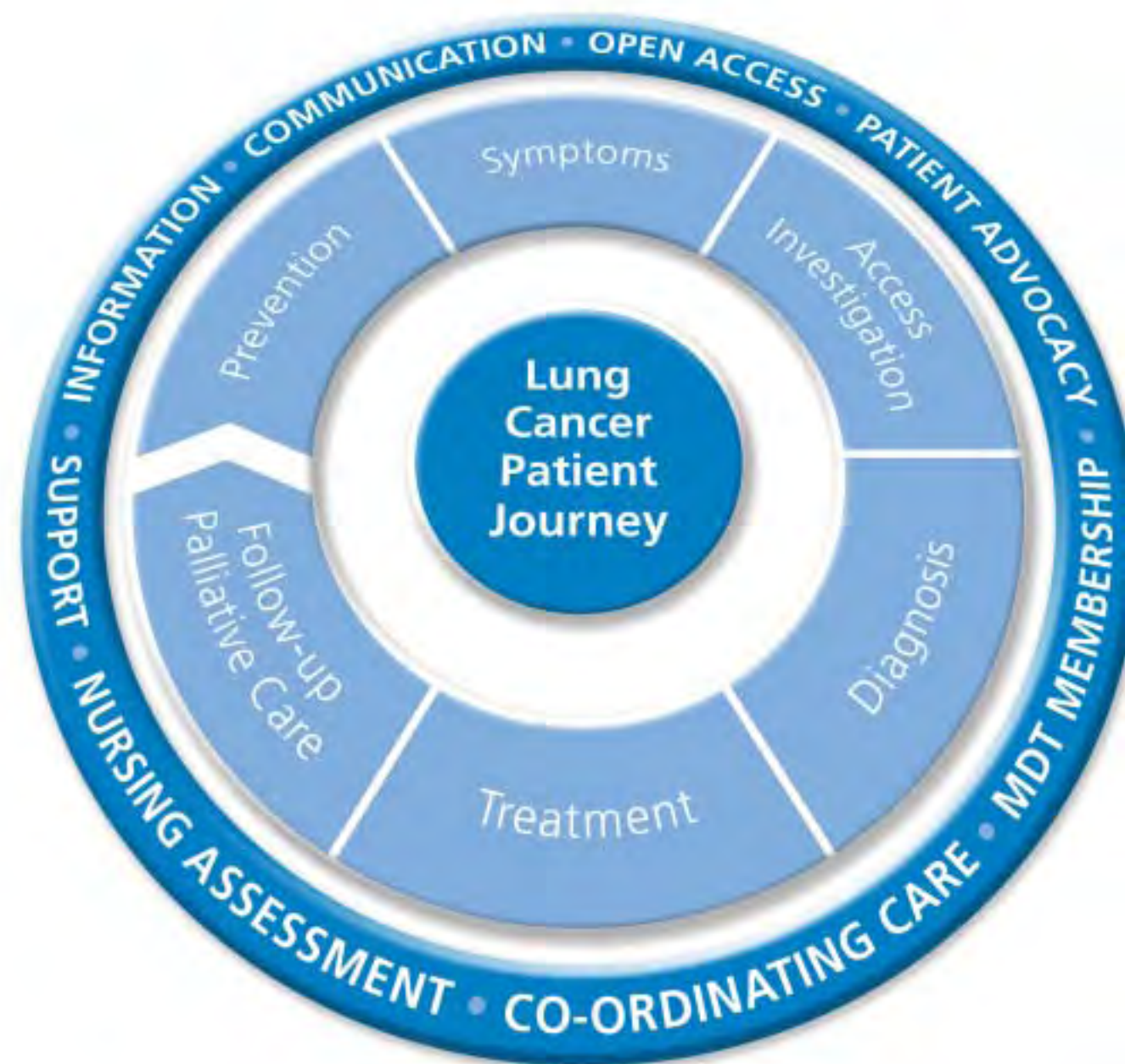
The recently published consultation draft of the National Institute for Clinical Excellence (N.I.C.E.) Guidelines for the Diagnosis and Treatment of Lung Cancer highlighted the emergence of the lung cancer nurse specialist role as a positive development in lung cancer care and strongly recommended that 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 where appropriate. The role of nurse led breathlessness clinics, protocol controlled nurse-led follow-up and the importance of smoking cessation before and after treatment are also discussed within the guidelines.



Integrating nursing across the lung cancer journey

The key components:





Section 2 - Core elements of the lung cancer nurse specialist's role

"We want patients and their families to be confident that they will receive the information, support and specialist care they need to help them cope with cancer, from the time that cancer is first suspected throughout the subsequent stages of the disease. Good communication between health professionals and patients is essential"

NHS Cancer Plan 2000

There are several core elements of a lung cancer nurse specialist's role which span the whole of the lung cancer patient pathway from health education, through diagnosis and treatment, follow-up, palliative and end of life care. These are:

- communication;
- information;
- coordinated care;
- nursing assessment;
- MDT membership;
- patient advocacy;
- accessibility;
- support.

In the pages that follow there are details of initiatives and service improvements that have been developed predominantly by lung cancer nurse specialists. Each has

been linked to an appropriate core element of the lung cancer nurse specialist's role, some could easily fit into more than one of the core elements and each may be relevant at just one stage of the patient journey or across them all. In some instances it is evident that a nurse specialist is not essential in providing the service, however achieving and sustaining the development was dependant on their skill, knowledge, ability to initiate change and enthusiasm.

Contact details of the people involved have been provided for each example.

Communication

Patients, their carers and families want:

- to know whom to contact should they have concerns;
- to establish good communication and form an effective working relationship with their health care professionals;
- to know that their GP will be kept fully informed of their care by the hospital;
- reassurance and guidance with a planned approach to ensure that services they need are in place;
- to have the option to change their mind about treatment.

The lung cancer nurse specialist is:

- central to ensuring that lung cancer patients and their carers understand the complexities of their care;

- pivotal to the flow of timely, appropriate information within the lung MDT and between primary, secondary and tertiary care;
- readily accessible to the patients and carers and all members of the health care team.

Resource

Improving communication in cancer care

Many teams across the Cancer Services Collaborative 'Improvement Partnership' (CSC'IP') have focussed on improving communication across the patient pathway. In response to this, and with the support of many professionals, patients and carers, a framework has been developed and updated by the CSC'IP' Primary care team which many teams are implementing. The framework contains details of what to communicate, when and how. The DOCTOR acronym (appendix 1) has proved a useful tool on which to base improvements. Many examples of teams work are sited in the document including templates for communication across care settings at key stages in the patient pathway. These can be downloaded from the website www.modern.nhs.uk/cancer/primarycare and adapted for local needs.



Example

Fast track referral system for suspected lung cancer patients

GPs referred patients for a chest x ray. If the x ray was found to be abnormal the report was sent to the GP and the GP would then refer the patient back to the chest clinic for an appointment. Patients could wait up to one month from the chest x ray until the first outpatient appointment and the GP was not aware of the appointment date.

Agreement was reached with the relevant parties that patients should be referred directly from radiology to the chest clinic when a suspicious x-ray was found:

- patients now wait less than 14 days between chest x-ray and the first outpatient appointment.
- this ensures patients get onto the right care pathway.
- the patient has a booked first appointment with certainty and choice.
- GPs are informed of the patient's appointment, improving communication between primary and secondary care

All GP referred patients with a suspicious chest x-ray are involved in this process.

Follow up discussions identified a need for patients entering through A&E to be fed into this system .

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Example

Nurse led pro-active approach to management of abnormal chest radiograph reports

Survival rates from lung cancer in this country are poor. Many patients present late, which can preclude radical treatment. Fear and ignorance to symptoms are difficult to monitor. However, failure of professionals to act upon abnormal chest radiographs can be addressed.

In January 2002 a 'failsafe' chest x-ray (CXR) system was established in

Whiston Hospital. This hospital serves a population of 350,000 and the majority of suspected lung cancer patients are seen in a dedicated rapid access clinic.

The system essentially revolves around coding of CXR reports. CXRs with features suggestive of carcinoma were coded TCXX, and CXR's where neoplasia could not be excluded, but a repeat film in 4-6 weeks was suggested were coded TPXX.

Copies of the CXR reports were sent to the Macmillan Lung Shadow Nurses, who also cross-checked the computer system to ensure that no CXR reports were missed.

CXR reports coded TCXX of Patients who had not been referred to the Lung Shadow Team, were discussed with the Patients GP/Consultant to arrange urgent referral to the rapid access clinic.

Reports received coded TPXX were monitored in order to ensure a repeat film was preferred as suggested in the initial report.

The system was initially audited retrospectively after the first year. The results of this audit included:

- 39% of patients diagnosed via the rapid access clinic had been identified through the failsafe system.
- patients who by passed the system had a significantly longer time interval from first CXR to date of first clinic appointment, than those who were identified via the failsafe system.
- improved liaison with radiology department and primary care, aiming to re-enforce a more positive attitude to lung cancer and encourage early referral.



Following the initial audit, the system underwent a prospective re-audit from April 2002. The re-audit included the views of local GP's and also assessed the level of radiology coding. The results of the second audit included.

- 69% of abnormal CXR receive the appropriate code.
- 86% of local GP's felt that failsafe system was helpful and should be continued.

The conclusions we made from the audits is that the system is an effective tool that helps to ensure that patients with lung cancer are seen promptly and do not "slip through the net".

The improvements appear to be sustainable with collaborative working between the radiology department and the lung shadow team but depends upon accurate coding of CXR reports and careful monitoring of the reports by the lung shadow nurses, who initiate appropriate action for rapid referral.

To date, no formal assessment of patient views of the system has been made. However, it seems reasonable to assume that most patients would prefer to be seen sooner rather than later, when investigating an illness such as lung cancer.

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Example

Taped consultations

"Patients should be offered a permanent record of consultations"

Improving Supportive and Palliative Care for Adults with Cancer (NICE 2004)

The CSC Service Improvement Guide (2001) highlights the positive patient feedback hospitals have received of taping consultations. It was decided to set up this service to see if communication could be improved for the patient. The recording process was explained to each patient by specialist nurses and a written leaflet and consent form given. Both patients and families were impressed to hear of such a service and keen to be involved

In total over an eight month period 101 new diagnosis consultations were taped. Consultant chest physicians, oncologists and specialist registrars were involved. The service was audited by questionnaire to patients

Results were very positive:

- all patients who took the tape found it beneficial
- most would have further consultations taped
- most would recommend it to others.

The benefits were:

- remembering facts and recall of discussion
- prompting questions to ask the doctors
- clarifying the treatment plan and possible side effects.

These were often very complex discussions and not all information is taken in. Much of the information given to lung cancer patients is not good news and a small number of patients and carers found it distressing listening to the tape.

Taped consultations enhance the patient care experience by improving communication of complex information. Some staff were sceptical of its benefit in such bad news consultations but from detailed comments received it was advantageous to many patients and fulfils one of the recommendations of the NICE Supportive and Palliative Care Guidance

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Resource

Patient held record toolkit

Many patients, carers and health care teams have found the Patient Held Record (PHR) to be a useful tool in communicating information throughout the patients' pathway. There has been widespread activity across these teams to develop a PHR with many teams designing these locally. In response to this a PHR toolkit has been developed by the Cancer Services Collaborative 'Improvement Partnership' bringing together much of this work to assist teams wishing to design their own. It contains a section on practical information and general guidance and tips on implementing and evaluating a PHR. The second section contains a series of templates/examples items that you



might want to make use of. These are downloadable from the website and can be customised locally.
www.modern.nhs.uk/cancer/patientexperience

"There is a widespread perception amongst primary care teams that information from hospitals reaches them too slowly, and that the delays create difficulties"

National Council for Hospice and Specialist Palliative Care Services (2002).

Example

A patient held record can improve the situation and benefit the patient and has been developed in many trusts including United Lincolnshire Hospitals and North Tees Hospital

A health record can:

- be used by patients as a resource of information.
- improve communication between all professionals caring for the patient
- inform and involve patients about their care.
- improve experience and outcomes for people diagnosed with cancer.
- be an effective information tool used in conjunction with verbal interaction?
- enable individual learning at a pace to suit the user.
- be specific to each patient's condition and treatment.
- be used by all involved in patients care
- be used as a hand held discharge.

Personal details, contact numbers, tests, treatments, therapies, symptom management, support and advice, hospital attendances can be documented. If kept by the patient and kept up to date both patient

and staff will be aware of the current situation.

Before piloting a hand held record a baseline survey should be carried out which should be repeated after the pilot to evaluate the effect and enable further improvement

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Example

Improving the care of patients dying with lung cancer

Many lung cancer patients die in hospital. By mapping the final stages of the patient journey and interviewing carers it was obvious that several improvements could be made to the last days of a patients life

Issues:

- Communication between staff, patients and carers was deficient with carers feeling that information was difficult to access and they wished for a more frank discussion around prognosis so that they might be better prepared for the eventual outcome.
- Many carers expressed a view that they wished the patient to have died in their own home but felt that the issue was left until there was insufficient time for discussion and they had doubts about their ability to provide care.

- Carers disliked the noise and lack of privacy of the acute medical ward and wished for a quieter, more peaceful environment.
- After death it was common for carers to feel a lack of bereavement support. It felt like the close relationship built up between them and hospital staff had been suddenly withdrawn.

Improvements:

- To address the deficiencies in communication greater educational input for staff has been implemented and is now part of core nurse ward teaching.
- To improve the environment an area of the respiratory ward is set aside for patients with potentially terminal illness where care is less intense and ward noise less intrusive. This has produced positive feedback from carers and patients with range of terminal respiratory illnesses.
- Bringing these patients together in one area increases the potential for greater spiritual input and will facilitate introduction of an integrated care pathway for the dying.
- To improve patient and carer choice about the place of death, discharge planning will be discussed and a decision made much earlier in the patient journey.
- Bereavement counselling is to be improved by the recent appointment of a second Macmillan lung cancer nurse specialist and shortly by a Hospital Bereavement Officer.

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**Example****Palliative Care Out Of Hours**

A hand over form has been designed by St. Albans and Harpenden PCT to improve communication with the Out of Hours Service for patients with palliative care needs. It is a single sheet of A4 paper. The information is split into four sections; patient details; patient's own GP; other care providers; and the patient's medical condition. The section outlining the patient's details gives the patient's name, address and date of birth. It also identifies whether the patient lives alone, how to gain access to the home, who the main carer is and their relationship to the patient. The section on the patient's medical condition identifies the diagnosis, any complicating conditions, present treatment, main medication, details of emergency drugs in the home, plans for future care and for anticipated problems. Two practices are using the hand over form on a regular basis and it is being rolled out to other practices in the PCT.

For more information contact:

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Information:**Patients, their carers and families want:**

- to know they can reduce the chances of getting cancer
- information on signs and symptoms to help them detect possible cancer early
- to know that they will have easy access to information throughout their journey
- to receive detailed high quality information about their condition and treatment given in an honest and sensitive manner at all stages of their journey.

The lung cancer nurse specialist is:

- responsible for ensuring that the appropriate information is available for and offered to patients at every stage of their journey
- responsible for the development of local lung cancer information resources
- key to the development of local policies ensuring information utilised is developed through a network wide coordinated approach.

People with cancer request different styles of information, in different formats and at different levels. The lung cancer nurse is able to help patients navigate the information available. Some patients may not wish to receive information and the lung cancer nurse is able to assess and discuss carefully the needs of each patient in their care.

Example**Improving patient information**

Patient information for lung cancer and other conditions was of variable quality and not always easily accessible or well understood by patients. National Opportunities Funding provided an opportunity to redesign a range of booklets specifically dealing with lung cancer.

All new patients given a diagnosis of lung cancer are interviewed by a Macmillan nurse specialist who hands out an A5 folder containing relevant information leaflets which cover general information on lung cancer and the role of the nurse specialist together with guides on CT scanning, mediastinoscopy, surgery and radiotherapy. The Roy Castle lung cancer booklet is also included in the pack to produce a comprehensive range of information.

Patients are now much better informed about their investigations and treatments and feel more confident about navigating through their journey.

Traditionally information has been produced in house and photocopied or obtained entirely from outside sources so that it frequently becomes out of date or unobtainable. Involvement with the NOF initiative has provided added credibility ensuring recurrent funding and thereby sustainability.

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**Example****Smoking Cessation Encouragement**

Poor smoking cessation rates were identified in a socially deprived community in Cheshire West PCT. Lache Health Centre in Chester encourages patients to participate in light-hearted events with a serious message. For example, "No Smoking Days" are promoted, linked to national campaigns, and fun afternoons are held in local schools, involving the Fire Brigade, smoking-linked activities, and smoking-cessation related poster competitions with good prizes.

Improved smoking cessation rates, both initially and sustained, are being seen as a result of these moves. The initiative is repeated at intervals to maintain interest, and health professionals believe that the improvement will be ongoing.

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Resource**Patient Information Made Easy**

The Cancer Services Collaborative 'Improvement Partnership' have produced a CD Toolkit to help you map your information and to create suitable information for your patients. This is available from www.modern.nhs.uk/cancer/patientexperience

Co-ordinated Care**Patients, their carers and families want:**

- to know that their care will be coordinated and available in a timely manner appropriate to them.

The lung cancer nurse specialist:

- facilitates the navigation of individual patients from the point of diagnosis onward to suit their unique need
- refers to other members of the health and social care team at the earliest opportunity
- acts as a point of reference and liaison for all health care professionals involved in the patient's care wherever that might be
- is central to influencing the redesign of processes to streamline the patient journey.

"Teams, whether hospital, hospice or primary care based, should develop mechanisms to promote clinical continuity for patients. Teams may wish to consider nominating (with the agreement of each patient) a person to act as a 'key worker'; this person might be, for instance a community nurse, allied health professional, nurse specialist or social worker".

"Patients move frequently between sectors (home, hospital and hospice) between teams (primary care, cancer and palliative care) and between NHS, local authority and voluntary agencies. Coordination among these teams and services should be proactive to enhance continuity of care"

Improving Supportive and Palliative Care for Adults with Cancer (NICE 2004)

Example

A lung cancer nurse specialist is often the main point of contact for the patient although many services are appointing an administrative contact pathway co-ordinator, MDT coordinator or tracker who can co-ordinate the journey and be available as a common access point for patients and professionals who can put patients in touch with the relevant person. There are a number of similar posts based within primary care. Primarily nurses they work with patients from diagnosis onwards throughout their journey using the same principles. These posts have been so successful that the Department of Health are now commissioning nine pilots to run over the next two years to further evaluate the role. These are Integrated Cancer Care Pilots (ICCP)

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**Example****Improved pathway for Lung Cancer Patients using tailored software package**

The lung cancer nurse specialist co-ordinated the patient journey but this led to problems when the lung cancer nurse was away:

- inconsistent assessment of patients leading to differing care
- duplication of data during patient transfers
- audit opportunities missed
- poor communication with GP.

A software package was designed by the multidisciplinary team (MDT) which enables data to be entered as the patient progresses along the pathway of care; access is provided to the MDT.

Benefits of the package are:

- improved patient care through standardised assessment and recording of data
- improved communication within primary and secondary care
- no duplication of data
- access to data entry from MDT team
- prospective audit with quality data
- database for Hospital specialist Macmillan Lung Nurses and Chemotherapy Nurses to use.

The system has led to a more streamlined and patient focussed service and is user friendly

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Example**Co-ordinating the patients' lung cancer journey from referral to treatment**

Patients were experiencing and complaining about long delays at the first non booked appointment mainly around radiology before seeing a specialist and specialists were kept waiting for patients to return from radiology with the result that clinics over ran or consultations at the end of a clinic were rushed. There was delayed access to CT staging and uncertainty around the optimum time for MDM discussion. A Nurse led pre-assessment clinic (PAC) at which medication and smoking history would be recorded together with blood pressure, height, weight and urinalysis was set up. Simple staging investigations including the chest radiograph and blood screen were ordered together with an ECG and spirometry.

Arrangements were made with other departments to ensure that appointments could be booked prior to patients attending the PAC so that delays on the first visit were minimised. Patients were seen at the first clinic following PAC, the results were all available with no delay and the specialist was in a position to request the most appropriate next investigation. It then became straightforward to schedule bronchoscopy, the staging CT scan and the MDM discussion date. A data clerk now collates all information on patients coming via the TWW route to facilitate the patient journey, maintains a database and schedules the MDM

The patients are experiencing fewer delays and have a more streamlined journey. Specialists are also experiencing fewer hold ups. A MDT management plan can now be actioned quickly with information being immediately available for handing on to the surgeon and oncologist.

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Example**The appointment of a "tracker" helps with booking and co ordination along patient pathway**

Co-ordinating and facilitating the various steps along the pathway that the cancer patient and their carers travel is fundamental to both the quality of their experience and the timeliness of their diagnosis and treatment.

In April 2002, with 3rd wave booked admissions funding to 'pump prime' it, a 'lung tracker' role was established in Leicester. As far as we know this was the first of its kind in the UK. This admin. and clerical post works in close co-operation with the nurse specialist and MDT co-ordinator and is responsible for tracking patients along their cancer journey, booking and co-ordinating all investigations and hospital appointments.



An abnormal chest x-ray flagging system was introduced in the Trust in 2000 and all abnormal reports are automatically forwarded to the lung tracker who follows a protocol to ensure a referral is received and the patient booked into the rapid referral clinic. An electronic patient diary maintained by the tracker, then monitors and records all patient events up to, and including, their first treatment. Government targets for intervals from referral to diagnosis and treatment (31 and 62 days respectively) are highlighted for each patient; potential breaches are raised within the MDT meeting and with the patient's consultant. All clinical and core administration members of the team have access to the diary. All outcomes of the weekly MDT meeting, tests, investigations, clinic appointments and referrals are organised by the tracker, results from investigations are monitored daily and once obtained, presented to appropriate members of the team and acted upon accordingly. The nurse specialist maintains the communication link with the patient, providing timely information and appropriate support.

The introduction of the 'lung tracker' post has had a major impact on:

- releasing the lung cancer nurse specialist to spend her time and expertise more appropriately in direct patient contact
- increasing the proportion of patients being seen by specialist team
- ensuring that 100% of all identified patients are presented at the MDT
- waiting times, with around 90% of our patients now being treated within 62 days and 40% within 31 days

- the pre-booking of virtually all steps along the pathway
- improved patient certainty and choice
- improving the quality of data for audit purposes.

Thus this novel post has resulted a more rapid and better planned service for patients and carers, more appropriate utilisation of specialist nursing skills and has contributed significantly to the ever increasing demands for high quality data.

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Nursing Assessment**Patients, their carers and families want:**

- to be treated as an individual, with dignity and respect for culture, lifestyle and beliefs.

The lung cancer nurse specialist:

- holistically assesses patients throughout their care journey.
- is attentive to social, psychological, physical and spiritual needs.
- refers patients to wider members of the team and voluntary agencies appropriately.

"Assessment and discussion of patients needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis, at commencement, during and at the end of treatment, at relapse and when death is approaching"

Improving Supportive and Palliative Care for Adults with Cancer (NICE 2004)

The Gold Standards Framework (GSF) Liverpool Care Pathway for the Dying Patient (LCP) and Preferred Place of Care (PPC) are tools to be used at the end stage of life and are recommended in the Improving Supportive and Palliative Care for Adults with Cancer (NICE 2004)

The Gold Standards Framework (GSF)..... in action

The Gold Standards Framework is a way of pulling together many good things that practices are often already doing. At the heart of the framework are seven 'Gold Standards' relating to seven key aspects of care, together with guidelines for good practice on teamwork and continuity of care, advanced planning, symptom control and support of patients and carers. The Gold Standards Framework is being used by over 1300 practices across the UK. All of these practices are working towards achieving the main goals of the Gold Standards Framework:

- better symptom control including psycho-social care
- better needs based care and more people dying where they choose
- better security and support with fewer crises and more information
- better support for carers
- greater staff satisfaction, awareness, team working and co-working with palliative care specialists.

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Example

Improving care in the last 48 hours of life – Liverpool Care Pathway for the Dying Patient (LCP)

The aim of this pathway is to provide a structure across an organisation for the care of the dying patient and their family. It contains three sections: initial assessment and care, ongoing care and care after death. Each section contains outcome measures (goals), which incorporate physical, social, psychological and spiritual/religious aspects around care of the dying patient.

The ongoing care focuses on four hourly observations for the control of patients' symptoms including pain, agitation and respiratory tract secretions (RTS) and patients' comfort including mouth-care, syringe driver care and administration of medication. In the majority of cases these observations are recorded by nursing staff within the health care setting ensuring that the nurse records what the variance is; why it has occurred and what action was taken.

There are symptom control guidelines attached to every pathway. These are formulated so that they can be used as a stand-alone document. There are also supporting information leaflets regarding: Use of the Syringe Driver, Relatives and Carers Information, Facilities and Bereavement Support. This pathway empowers doctors and nurses to deliver high quality care to dying patients and their relatives. It facilitates multiprofessional documentation and communication, integrating national guidelines into clinical practice.



The LCP has been implemented throughout many hospital trusts with adaptations being made for nursing & care homes, community hospitals and PHCTs. The LCP has been adapted and incorporated into GSF as standard seven.

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Preferred Place of Care

The Preferred Place of Care (PPC) framework has been designed to identify services being accessed by palliative care patients, changes that occur in care planning and the reasons why the changes occurred. It is being introduced in Lancashire & Cumbria Cancer Network to evaluate the nursing contribution to improving patient and carer choice in the place of care when an individual is receiving palliative care in the community.

The PPC is being introduced so that the changes that occur can be mapped and analysed to inform

future care planning for palliative care patients. It can be initiated in the patients home, hospice or hospital and aims to ascertain the patients understanding of their diagnosis and expected outcomes, preferred place of care and where they wish to die. The professional and patient note services available locally, any problems they may encounter and changes made to care.

For further information contact the Lancashire and Cumbria Cancer Network office – 01772 64704



MDT Membership

Patients, their carers and families want:

- to know that their views are represented
- that the MDT has access to the best evidence based practice on which to base the recommendations for treatment or care.

The lung cancer nurse specialist:

- contributes to the development of the local MDT
- contributes nursing assessment of individual patients within MDT
- acts as advocate for patient and carer
- contributes to the management of the service.

“Each multidisciplinary team should implement processes to ensure effective inter-professional communication within the teams and between them and other service providers”

Improving Supportive and Palliative Care for Adults with Cancer (NICE 2004)

The nurse specialist is a required member of the MDT and there are specific nursing standards. These can be found in the Manual of Cancer Services Quality Measures 2004 Topic 2A

Membership of the MDT enables the lung cancer nurse to contribute to the care plan for the patient and to speak on behalf of the patient. The lung cancer nurse has a relationship with the patient and carer which enables holistic assessment i.e. Patient and carer needs and wishes. The lung cancer nurse can liaise directly with the patient and the primary care team.

Example

A multidisciplinary approach to the management of breathlessness

Lung cancer accounts for around 40,000 deaths each year. 75% of these patients are affected by breathlessness, which has a devastating effect on the patient and those who care for them, adversely affecting their quality of life.

A Breathlessness Clinic for lung cancer patients and their families has been established to help them access support and symptom control. Nurse specialist, physiotherapist, occupational therapist and dietician are involved. The clinic has been available for 3 years and offers a 4 week program aiming to provide coping strategies for patients and carers. Referral can be made at any time by any member of the MDT, by patient or their carer.

Clinic Programme

Week One	<ul style="list-style-type: none"> • Overview of the program • Individual patient assessment • Realistic goal setting with patient and carer • Viewing of the breathlessness video • Basic biology of the lungs • Teaching of lower chest breathing • Visualisation technique demonstrated • Breathlessness video and written information to take away
Week Two	<ul style="list-style-type: none"> • Evaluate lower chest breathing and develop its use • Anxiety Management with relaxation and visualisation techniques demonstrated and practised • Relaxation tape and information to take way
Week Three	<ul style="list-style-type: none"> • Evaluate anxiety management • Energy conservation • Management of fatigue • Dietary advice • Information on the above to take away
Week Three	<ul style="list-style-type: none"> • Revision on any of the above • Feedback on the program by patient and carer • Individual patient assessment review • Opportunity to join support group



The Hospital Anxiety and Depression scale (HAD) (Zigmond & Snaith, 1983) was used on both patient and carer. The Canadian occupational performance measure (COPM) (Law & Baptiste, 1991) was used to assess the patients' performance status before and after the intervention.

Results from patients and carers indicate improvements in the HAD scale and COPM following intervention in these patients. Patients and carers also report increased confidence and quality of life after attending the clinic. Following the clinic they are invited to join the Lung Cancer Support Group.

To promote the clinic study days and workshops for health care professionals from both secondary and primary care have been set up. These have been positively evaluated. A video demonstrating the clinic has been produced by the team.

Difficulties have been experienced recruiting into the 4 week programme because of patient's ongoing treatments. A drop in clinic is now provided weekly in order to provide the ongoing service to patients.

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Example

Nurse-led haemoptysis clinic

Patients with haemoptysis were putting increasing pressure on already overstretched respiratory clinics because they fulfilled the

criteria for urgent referral and needed to be seen by a specialist team with 2 weeks. However it is known that haemoptysis in the presence of a normal chest x-ray or a chest x-ray, which is not suspicious of cancer, is unlikely to be a malignancy (Santiago et al, 1987).

To overcome this lack of capacity and ensure the patient received appropriate care, a nurse led haemoptysis clinic was set up. Patients are seen by trained respiratory nurses, a full medical history is taken and a clinical examination is performed. Appropriate investigations are carried out according to an approved algorithm. Patients may not be seen by a doctor on the first visit but are reviewed on subsequent visits.

Patients are now seen and investigated quickly, facilitating early diagnosis and treatment. This service gives a high quality, swift and seamless journey for the patient, improved communication and referral for primary care and enables the 2-week wait target to be met. Although the option to see a doctor is always given, no patient has refused to be seen by the nurse specialists and appear to be happy with the service. 55 patients have been seen in the clinic to date and none have subsequently been found to have a malignancy.

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Example

Development and evaluation of nurse led follow-up in the management of patients with lung cancer Sally Moore, Jessica Corner, Jo Haviland, Mary Wells et al (2002)

Current models of cancer follow-up emphasise disease surveillance and may not meet the full range of problems experienced by patients with lung cancer.

An alternative model was needed to better meet the physical, emotional and social needs of patients with lung cancer during follow-up.

Process:

- Phase I: Identification of the needs of patients with lung cancer during the follow-up period of care and identify the nature of current follow-up
- Phase II: Development of the role of lung cancer nurse specialist and an alternative model of follow-up.
- Phase III: Evaluation of the safety and effectiveness of nurse led follow-up in a randomised study comparing nurse led follow-up with conventional follow-up of patients with lung cancer.

Results:

- Acceptability of nurse led follow-up was high. 75% of eligible patients consented to participate in the trial.
- Nurse led follow-up of lung cancer patients is safe – there was no difference in survival between the two groups during the study.
- Patients receiving nurse led follow-up were significantly more satisfied with care than patients receiving conventional medical follow-up.



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Patient Advocacy

Patients, their carers and families want:

- to be treated as an individual, with dignity and respect for culture, lifestyle and beliefs.
- to know that the GP will be kept fully informed of their care by the hospital
- reassurance and guidance with a planned approach to ensure that services they need are in place
- to have the option to change their mind about treatment
- healthcare professionals to have respect for their choice regardless of what that choice may be.

The lung cancer nurse specialist:

- acts as a patient advocate in a range of settings
- develops relationships with health professionals and patients to allow them to be the patient advocate
- listens to what the patient wants and communicates this to the wider team.

Example

Raising Awareness of Lung Cancer

'No One In The World Deserves Lung Cancer'

Lung cancer fails to attract the same media and public attention as other common cancers. The Global Lung Cancer Coalition was established in 2001, and aimed to be the 'voice' for lung cancer patients. Lung Cancer Awareness month is held each November, and is co-ordinated in UK by The Roy Castle Foundation



and Macmillan Cancer Relief. Its aim is to improve outcomes for those affected by lung cancer through the following key messages:

- raise public awareness of lung cancer
- educate those at risk about symptoms and early diagnosis
- highlight sources of information
- put lung cancer on the agenda for health care authorities

The Lung Cancer Nurse Specialist (LCNS) has key role to play in all of the above. For the past 3 years at Heartlands and Solihull Hospitals they have promoted the awareness campaign both within and outside the hospital with keen members of the Roy Castle patient support group.

- information stands are set up on the hospital site, and local shopping centres
- leaflets, posters and beer mats are distributed throughout the hospital, local GP surgeries, social clubs and public houses spreading the message that early diagnosis saves lives

- the LCNS promotes dialogue with the local press to ensure maximum publicity for the month. Patients have had articles in local and national press including key women's magazines
- the West Midlands Lung Cancer Nurses Forum organised a Charity Ball in November 2003 to raise awareness and funds.

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Example

Patient Stories Improve Services for People with Lung Cancer

"People whose lives are affected by cancer can make significant contributions to the planning, evaluation and delivery of services".

Improving Supportive and Palliative Care for Adults with Cancer (NICE 20004)



- a random sample of patients were asked to take part in audio interviews and were interviewed using non-directive prompts and the tapes analysed by impartial Clinical Nurse Specialists (CNS).

Actions were identified as follows:

- increased teaching and update sessions with the Primary Health Care Teams
- concerns about parking on the hospital site have led to more frequent bus services to the hospital and timetables being made available within the hospital departments
- improved 'Breaking bad news' sessions with junior medical staff
- review follow-up time scale for patients after treatment
- setting up pilot clinic for post thoracic surgical patients
- written directions are now available for travelling to Surgical centre from Harrogate
- improved pre operative information available for patients
- all patients for radiotherapy are given information on the service and are able to book radiotherapy sessions
- improved pathway for patients referred to ENT services for Teflon injections
- work with psychology department about assessment of patients 'living with cancer' and referrals to their department
- reassurance for patients who have finished treatments, that support is still available
- positive feedback sent to, all members of thoracic surgical team, day surgery unit, radiology unit, catering manager, domestic supervisor, lung cancer team and Trust Board.

The power of the patient story is that the individual leads the content of each interview, giving views of the service, which contribute to improving patient care. These have been incorporated into the Lung Cancer Service as a yearly audit mechanism, giving feedback to the patients who have participated.

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Accessibility

Patients, their carers and families want:

- to know whom to contact should they have concerns.

The lung cancer nurse specialist:

- is accessible to patients, carers and all members of the health care team along the patient journey
- provides information and advice to patients so that they are aware of how to access local primary care and support services including the out-of- hour's service
- shares information with all care providers, inclusive of out-of-hours at key stages of the patient pathway e.g. when patients are very ill or in the terminal phase of their condition.

Example

Improved telephone access

It was hard for patients to contact the lung cancer nurse specialist by phone due to her busy schedule. It was decided that a dedicated session would best overcome this and also allow the nurse to catch up on administrative tasks during this period:

- the nurse has set aside 2 hours per week when she has guaranteed that she will be available to take phone calls from patients requiring support or advice
- a leaflet was developed with the clinical nurse specialist details, phone number and times of the session
- the leaflet also states that patients may call outside these specified hours and if the nurse is unavailable they can leave a message and she will call them back.

This has reduced frustration and anxiety for patients and carers.

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Example

Respiratory nurse specialists set up an open access clinic

There was a capacity issue for the Chest Physicians and Lung nurses were concerned about the quality of follow up for patients
The respiratory nurses agreed to set up an open access clinic once a week to which patients, relatives, and GPs can refer by telephone. Almost half of the attendees self refer.

- the clinic is advertised/promoted in GP surgeries, through community staff and on a patient information leaflet
- the clinic is used to monitor side effects of treatment, symptom management and coping skills
- there is also an opportunity for education and information provision



- the clinic ensures continuity of support and onward referral to other agencies as is appropriate
- there is an opportunity for holistic care
- there is a reduced need for unnecessary appointments
- the clinic is running well and there are plans for nurse led prescribing
- patients are asked their opinion on a regular basis.

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Support

Patients, their carers and families want:

- to know that they will have access to support from a skilled health care team throughout their journey
- continuity in the support available to them by members of the health care team who are well informed about their individual circumstances
- to die in the place of their choice
- to be assured that their family and carers will be supported throughout the illness and in bereavement.

The lung cancer nurse specialist:

- is able to develop supportive relationships having a continuous presence throughout the lung cancer journey. Patients draw on their own resources and derive emotional support from family and friends but sometimes a nurse can offer additional support
- is pivotal to the flow of information between primary and secondary care
- provides information and advice to patients so that they are aware of how to access local primary care and support services including the out-of- hour's service.

Nurses have an essential role in the provision of ongoing support to patients who have been diagnosed with cancer and their families. This support may be needed very soon after a patient has been told the diagnosis and may continue throughout primary treatment and into remission or palliative care.

"Health care teams in hospital, hospice and primary care settings should establish mechanisms to promote good working relationships with social service departments. Agreement should be reached about professional responsibility for different aspects of assessment, referral arrangements between professions or agencies and information sharing".

"Some patients and carers may require the support of authorised healthcare chaplains, appointed in accordance with NHS National guidance".

Improving Supportive and Palliative Care for Adults with Cancer (NICE 2004)

Example

Home visits from the lung cancer clinical nurse specialist

There were problems with lung cancer nurses seeing patients within clinics.:

- not all patients were seen owing to the broad range of access points to the hospital
- there were insufficient clinic rooms and resources across the service
- patients were often too upset immediately following diagnosis.



Comments from the patients about the support clinic were very positive.

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

Following a successful trial period the clinic will now be held on a permanent basis.

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Example

Setting up a Lung Cancer Support Group

People affected by cancer have a key part to play in promotion of self-help and support groups. Lung cancer nurses can be useful in setting up these groups and providing professional input.

There was a misconception that a support group for lung cancer patients would not be well attended or successful due to the poor prognosis of many patients. The lung cancer nurses identified this as a problem and asked a group of patients. The general response was that patients wanted a support group.

The Roy Castle Foundation gave the nurses great support and encouragement. The group was advertised in the local press, local radio, GP surgeries, libraries, and key departments around the Trust to try and attract as many patients and carers as possible. The group meets in the Day Centre within the Oncology department; it is a pleasant room with a conservatory away from the clinical area creating



an environment for lung cancer patients to access support from nurses and fellow patients and carers.

Anyone affected by lung cancer is welcome to attend the group. The meetings are held monthly and each meeting is attended by between 15-25 people including patients (both surgical and non-surgical), carers and friends. Most patients come regularly each month. However a few attend when they want to.

The support group is well attended and positively evaluated by all that attend. Although the nurses involved in facilitating the group stress that it is for patient support, the members have chosen to organise fund raising and social events which have raised money for the thirty nebulisers for local lung cancer patients and the Roy Castle Lung Cancer Foundation.

Guests are invited to speak at the meetings and regular visitors include chest physicians, oncologists, dieticians, carers support services, information radiographers, physiotherapist, surgeons and Cancer Backup nurses.

A patient questionnaire is completed annually to help the nurses identify topics of interest to the group. In our experience it is a very worthwhile venture As long as there is a need, there will be a support group.

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It therefore became local practice for the Clinical Nurse Specialist, present at the time of breaking bad news, to visit the patient at home. Patients were asked their opinion of this service given below:

- patients prefer home visits
- patients need information and support at the right time
- accessing clinics may be difficult for many patients with advanced disease
- cost and discomfort of getting to hospital for ill patients is reduced
- patients are more comfortable and able to speak more freely without interruptions. Patients seem more able to discuss sensitive issues and are more able to retain the information offered
- home visits have resulted in a more patients having access to the Clinical Nurse Specialist.

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Example

Nurse led non-medical support clinic

The Lung Cancer Nurse Specialist acknowledged that much of her time outside of the clinics was spent providing non-medical advice to patients and their carers, and that these needs could be addressed in a separate clinic.

A room was found and clinicians told about the support clinic and its' referral criteria.

The clinic is designed for those who need more time spent with them than it is sometimes possible to give in a busy medical clinic supporting those who:

- are particularly anxious or struggling with decision making
- require benefit guidance
- require psychosocial advice
- require monitoring of symptoms
- are newly diagnosed or those with recurrence who were not seen in the medical clinic by the Lung Cancer Nurse Specialist.



Postscript

There have been many innovative developments in the role of the lung cancer nurse specialist, which have improved the care of the lung cancer patient and carer. Some of these are contained in this document together with examples from the Cancer Services Collaborative Improvement Partnership. We are indebted to those nurses who have sent in examples of changes in their practice.

We hope that this document helps to define and support the role of the lung cancer nurse specialist and that many more developments will occur to improve the lung cancer patient's journey.

For further information contact

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Appendix 1

Information and communication between professionals

What information do consultants require from the primary health care team?

Proforma led referral following National Guidelines.

Patients prepared for a possible cancer diagnosis and investigations.

1. Has CANCER been mentioned?
2. Is an interpreter needed?
3. Past medical history/drug history.
4. Social/psychological state - where appropriate.

What do GPs require from the multidisciplinary team?

Timely, legible, quality information in bullet point, not prose:

- to referring GP;
- with information contained as in 'DOCTOR' acronym.

D agnosis and prognosis (generic)
O ptions regarding treatment
C are Plan time scale and follow up
T old - what has patient/carer been told
O ther agencies involved/referred to
R eview who, where, when



Appendix 2

Useful documents and websites

Useful documents available via
www.modern.nhs.uk/cancer

A Policy Framework for Commissioning Cancer Services
 (Calman-Hine Report)1995
 Department of Health

NHS Cancer Plan 2000
 Department of Health

Draft Guidelines for the Diagnosis and Treatment of Lung Cancer
 NICE 2003

Improving Supportive and Palliative Care for Adults with Cancer
 NICE 2004

Manual for Cancer Services (Peer Review)
 Department of Health 2004

Improving Communication in Cancer Care
 September 04 CSC'IP

Patient Held Record Toolkit
 2003 CSC'IP'

Patient Information Made Easy – a toolkit for improving delivery of patient information
 2004 CSC'IP'

www.doh.gov.uk
 Department of Health

www.doh.gov.uk/cancer/lung
 Lung specific publications and information from the Department of Health

www.rcplondon.ac.uk
 Royal College of Physicians
 Information on LUCADA –Lung Cancer a Core Data Set for the measurement of process and outcome in lung cancer management

www.brit-thoracic.org.uk
 British Thoracic Society

www.rcr.org
 Royal College of Radiologists
 Professional organisation for clinical oncologists and radiologists

www.goingfora.com
 Part of the Royal College of Radiologists website -virtual hospital site touring clinical oncology(cancer treatment) and clinical radiology(diagnostic imaging)

www.sor.org
 Society and College of Radiographers- information for patients and professionals
www.cancerresearchuk.org
 Information for patients and professionals

www.cancerbacup.org.uk
 Cancer Information for professionals, patients and carers

www.cancerline.com
 Information for patients and professionals

www.roycastle.org
 Roy Castle Lung Cancer Foundation.
 Charity energising research and providing support for patients

www.britishlungfoundation.com
 Support for patients with lung disease and their carers

www.nlcfn.co.uk
 National Lung Cancer Forum for Nurses

www.bmj.com
 British Medical Journal/Weekly publication

www.c4ci.net
 Coalition for Cancer information
 Patient Information including NHS Direct

www.cancerworld.org
 Multi-national association of supportive care in cancer

www.dipex.org
 Patient quotes about their care

www.dh.gov.uk/cancer/guidancefor NHS.htm
 Guidance for NHS – Manual of Cancer Services Standards including Improving Outcome Guidance, health service circulars and other guidance notes

www.mesothelioma.uk.com
 The National Macmillan Mesothelioma Resource Centre.
 Impartial up-to-date information relating to malignant mesothelioma for the UK

www.medicine.org.uk
 Electronic Medicine Compendium.
 Up-to-date information about prescription only and over the counter medicines. Details of the properties, effects and appearances of drugs and drug company patient information leaflets.

This site has three sections with password access:
 Patients
 Healthcare professionals
 Pharmaceutical Industry employees.

www.hospiceinformation.co.uk
 An information service for health professionals and the public, including an enquiry and signposting service ref palliative care.

www.nice.org.uk
 National Institute for Clinical Excellence

www.nursingtimes.net
 magazine for nurses

www.rcn.org.uk
 Royal College of Nursing

www.timetocare.org.uk
 National hospice charity "Help the Hospices" and Tesco have launched "caring for carers" – a support package for family carers and professionals.