

Lung Cancer & Mesothelioma 2011- 2015

Mesothelioma

1. The vision for mesothelioma services is set out in the Mesothelioma Framework issued by DH on 26 February 2007 (supported by the British Thoracic Society's 'Statement on the Management of Malignant Mesothelioma' in 2007 and the 'Good Practice Guide' published by Mesothelioma UK in 2010).
2. The recommendations in the Mesothelioma Framework were not mandatory. However, if the NHS takes them into account as it develops, provides and commissions services for this group of patients the quality of services would improve across the country – this is vital as a peak in incidence is only around 10 years away.
3. Whilst the Lung Cancer and Mesothelioma Advisory Group recognise that there is no central funding available to support the implementation of this framework, the CRS should encourage the implementation of this framework including local investment to deliver its aims.
4. One of the main recommendations was the establishment of Specialist Mesothelioma MDTs. This has happened only to a limited extent, but the need for fewer, more specialised MDTs covering the whole range of thoracic oncology (lung cancer, mesothelioma and rarer intrathoracic cancers) is clear and should be pursued.
5. Support should be provided for one national centre to develop their expertise in treating peritoneal mesothelioma.
6. The benefit of tumour site specific clinical nurse specialists is widely acknowledged in cancer care within the NHS and yet there are just 4 such nurses in the UK with mesothelioma in their job title. It is not necessary or practical for each lung cancer MDT to have a Mesothelioma CNS attached to it but each cancer network, particularly those in areas or high incidence, should be encouraged to develop network wide Mesothelioma CNS posts.
7. Four members of the Association of British Insurers have agreed to provide, between them, £1m p.a. for the next three years to stimulate research into asbestos-related diseases of which mesothelioma is by far the most important. These funds are being administered by the British Lung Foundation and, at the request of the DH, the NCRI has recently published a review of research into asbestos-related diseases which will feed into that programme.
8. It is important that what is a relatively modest amount of money is used wisely to develop research capacity and a sustainable research programme. Whilst clearly only high quality research should be supported, it is important that government plays its part in ensuring that research resources are distributed fairly across as wide a range of disease areas as possible so efforts need to be made to support a sustainable research programme in this relatively uncommon disease.

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Lung Cancer

Prevention

9. Lung cancer is a largely preventable disease. Tobacco use is the major cause of lung cancer deaths. The ban on smoking in public was introduced in July 2007 and has worked very effectively but that is not the end. The public health white paper *Healthy Lives, Healthy People* stresses the importance of tackling smoking so as to prevent lung cancer and other major causes of death and disease. This will remain important as we approach 2015. A new Tobacco Control Plan will be published early next year.
10. The headlines that should be addressed as we approach 2015 to support the prevention of lung cancer are:
 - setting a national ambition for reducing smoking prevalence each year up to and including 2015
 - improving links between both primary care and secondary care (especially respiratory physicians and in lung cancer follow up clinics) and stop smoking services to make them as effective as possible
11. Whilst it is recognised that the impact of smoking goes beyond cancer and that the CRS is not an appropriate vehicle to address the whole smoking agenda, other key messages that should be considered as part of the wider smoking agenda include:
 - addressing where tobacco is on sale
 - ensuring support for smoking cessation services, particularly for under 18s who may want to give up
 - taking every opportunity to stop people smoking
 - encouraging behavioural change to stop people starting to smoke in the first place
 - taking efforts to educate the public that stopping smoking at virtually any age reduces the risk of lung cancer e.g., if we could persuade most 50-year olds to stop smoking, there would be a major fall in the incidence of lung cancer over the 15-20 years that followed – quantifying this fall for maximum impact
12. It should be highlighted that asbestos is thought to be responsible for up to 2000 cases of lung cancer per year and primary and secondary care teams should seek to support the voluntary sector (BLF and Asbestos Support Groups) with their awareness campaign initiatives.

Screening

13. Screening programmes exist for other common cancers such as breast and bowel but not for lung cancer, the leading killer. There are concerns about the efficacy of

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screening programmes but there is no UK trial to consider this issue further and without one it is unlikely that there will be robust evidence to support (or otherwise) screening by 2015.

14. It should also be noted that some private healthcare companies are starting to offer private CT scanning as a form of screening and this is likely to expand over the next few years. This is already leading to an increase in the number of people identified with 'incidental nodules' on lung scans being referred back into the NHS for management.
15. The headlines that should be addressed in relation to screening of lung cancer by 2015 are:
 - UK should remain fully engaged in the screening trial that we understand is shortly to begin its pilot phase; this is funded by the HTA
 - National guidelines (developed by NICE or the British Thoracic Society) should be developed on the management of lung nodules found on CT scans.

Early detection of symptomatic lung cancer and the role of Primary Care

16. There is a wealth of recent and emerging evidence that late diagnosis of a wide range of cancers is likely to be a significant factor in the poor survival statistics for patients in the UK. One estimate (Coleman et al, Brit J Cancer, December 2009) is that around 1300 cancer deaths could be avoided in England if lung cancer was detected as early as it is in the best performing areas of Europe. In another study (Holmberg et al, Thorax, 2010;65:436-441) it has been shown that if one excludes early deaths, 5 year survival for lung cancer patients is virtually identical between England, Norway and Sweden.
17. Since there is no lung cancer screening programme in Norway or Sweden, the strong implication from this work is that earlier detection and referral to specialist care of *symptomatic* patients accounts for a large part of the difference.
18. This means that efforts should be made to introduce, in a controlled and measured way, techniques that aim to increase public and primary care awareness of the early symptoms and signs of lung cancer. In parallel with this, primary care must have easy access to rapid diagnostics underpinned with clear advice about risk assessment of individual patients based both on their characteristics and their patterns of symptoms. High quality electronic active decision support is likely to be very useful in this context and should be properly evaluated.
19. The importance of this is further highlighted by recently published analysis of 'Routes to Diagnosis' of cancer, which indicated that 38% of lung cancer patients are diagnosed following emergency presentation. For those diagnosed through this route, one-year survival was substantially poorer than for those diagnosed after GP outpatient referral. By 2015, it is hoped that the proportion of lung cancer patients diagnosed following emergency presentation is significantly reduced.
20. Messages to the public about lung cancer should not be simply focussed on smoking but also the promotion of messages to raise awareness of the signs and symptoms of

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lung cancer and promoting the message that coming forward early increases the chances of lung cancer being curable.

21. It should be noted that people often do not recognise symptoms or health changes as possible signs of lung cancer, nor necessarily think of health changes as symptoms of illness. The role of patient groups in helping to convey these messages also needs consideration. It is important to acknowledge that 10-15% of patients will have never smoked and so messages should be relevant to all not only smokers and should not dismiss symptoms in never smokers
22. There has been a long history of nihilism in many professional groups, both about the value of early diagnosis and the value of an aggressive approach to the treatment of lung cancer. This is compounded by the stigma arising from the view that it is a 'self-induced' disease. Overcoming this nihilism is important both to drive improvements in the level of specialist treatment but particularly when engaging with primary care to make efforts to achieve earlier diagnosis.
23. Links should be made to the Chronic Obstructive Pulmonary Disease (COPD) strategy to ensure early recognition of lung cancer symptoms and proper referral mechanisms are built into their recommendations. Patients with COPD have a particularly high risk of developing lung cancer and primary care clinicians (GPs and nurses) should be encouraged to maintain a high index of suspicion in this patient group and refer patients on appropriately. The COPD strategy raises the possibility of introducing, promoting and evaluating surveillance strategies for earlier diagnosis of lung cancer in this particularly high-risk population
24. There is also some preliminary evidence that people diagnosed with more advanced lung cancer have had fewer chest x-rays prior to diagnosis than those with early stage lung cancer so there might be scope for considering the threshold for GPs referring patients for chest x-rays including repeat x-rays.
25. Ways should be found to incentivise efforts to diagnose lung cancer earlier in primary care using changes to the QOF framework.

Diagnosis

26. The management of lung cancer is becoming increasingly dependent upon precise staging, histological sub-typing and the identification of molecular markers. High quality pathology and molecular biological services are therefore central to treatment decision making. Examples include:
 - the optimal management of many patients with locally advanced (stage IIIA and some stage IIIB) NSCLC is very dependent on precise definition of which mediastinal lymph nodes are involved
 - decisions about the need for, and nature of, oncological treatments post surgical resection are highly dependent on the detailed pathological examination of resected specimens

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- there is now good evidence of a differential response to different types of chemotherapy in patients with advanced stage (IIB & IV) NSCLC who have squamous cell and those with non-squamous cell histologies.
- There are a number of biological markers emerging that will make the targeting of specific therapies to specific patients a reality. The most well studied example is EGFR mutation analysis enabling the identification of patients most likely to benefit from the EGFR Tyrosine Kinase Inhibitor, Gefitinib. Several more look promising, including ALK, Thymidylate Synthetase and markers of DNA repair gene activation such as ERCC1 and RRM1.

27. By 2015 it is suggested that:

- the full range of diagnostic and staging techniques such as endobronchial and endoscopic ultrasound, ultrasound of the neck and medical thoracoscopy should be available in a timely manner for all patients who require them.
- pathology departments working in thoracic oncology MDTs should have access to all the necessary immunohistochemical techniques
- there should be a network of molecular pathology laboratories able to carry out a range of high quality analyses of important biological markers that guide treatment decisions in lung (and other) cancer
- it should be clearly defined how these tests are integrated into the clinical pathway and how they are costed and funded .
- there also should be a mechanism for rapid introduction of new molecular markers as they become validated

Treatment & MDT management

28. Treatment of lung cancer is becoming more complex (e.g. parenchymal - sparing surgery, combination chemo-radiotherapy, advanced radiotherapy techniques, biological therapies, etc). It is noted from the latest round of cancer peer review that whilst there is evidence of improvement in MDT membership and attendance that there is still significant variation, with particular concerns remaining about lack of representation from some professional groups (particularly thoracic surgeons, a factor which could impact on resection rates).
29. Consideration needs to be given to reducing the number of MDTs as an appropriate way of ensuring representation from core members and encourage more specialisation, particularly for the treatment of more complex patients, such as those with stage III non small cell lung cancer (NSCLC). However, the resulting increase in caseload for remaining MDTs would need to be addressed.
30. It is our view that, despite the fact that more needs to be done, the Cancer Peer Review Programme has been very effective in driving up standards and we particularly welcome the introduction of clinical outcome measures (the Clinical Lines of Enquiry)

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in the recent round. This group strongly supports the essential ongoing role that Peer review can play in the continuous improvement of clinical standards and therefore patient outcomes.

31. By 2015 it is suggested that:
- there should be clear guidance for commissioners on the key characteristics of a high quality thoracic oncology service
 - MDTs that do not meet minimum standards of core membership or attendance of core members should develop ways of either merging with other regional MDTs or having regular video-conferencing to overcome these problems
 - it is of particular importance that only MDTs with the full complement of specialist members should manage patients with stage III NSCLC and those who need more complex surgical procedures
 - consideration should be given to how patients turned down for surgery by non-thoracic surgeons might gain access to a specialist thoracic surgical opinion
 - IT should be improved to facilitate the monitoring of clinical outcomes and working between MDTs/hospitals including independent sector services when used
 - patients should have access to the latest radiation oncology equipment and techniques
 - patients who have had curative surgery should have access to the necessary support to enable them to recover, including access to rehabilitation services post surgery

Supportive & Palliative Care

32. Specialist nursing has been one of the major improvements in the care of lung cancer patients in recent years but the current number is less than is required to provide an ideal service.
33. It is noted that important elements of supportive care such as this are sometimes seen as a “soft” target when funding is short and vigilance will be required to ensure that these vital services are maintained for lung cancer patients and their carers. Lung and specialist palliative care Cancer Nurse Specialists are the main providers of palliative care services. Cancer Nurse Specialists also offer improvements to service efficiency, for example by averting unnecessary emergency admissions.
34. LCMAG does not believe that lung cancer will have become a generally curable disease by 2015, it will therefore be vital that patients have access to appropriate palliative care, including specialist palliative care services. To support this, the lack of funding for consultant posts in palliative medicine needs to be addressed – this is so acute that we are in danger of training more SpRs in palliative medicine than will have substantive posts.

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35. A recent US study (Temel et al, NEJM, August 2010) has shown a survival advantage for patients with advanced stage NSCLC who were given regular specialist palliative care. This merits further study in the UK setting.
36. By 2015 it is suggested that:
 - all lung cancer patients should have access to a named lung cancer nurse and there should be cover for annual leave etc.
 - patients should be offered access to a lung CNS during investigations, acknowledging that some patients will not turn out to have lung cancer
 - all doctors managing lung cancer patients should have received advanced communications skills training
 - funding for consultant posts in palliative medicine should have been prioritised
 - every lung cancer MDT should have a specialist palliative care physician as a member
 - there should be multi-disciplinary palliative care services equitably across the country, with the appropriate expansion in the number of palliative medicine physicians to support this
 - carers of lung cancer patients should be supported
 - there should be easily available, high quality information to support patients and carers, including what they should expect from a high quality service – this would support the patient choice agenda as it evolves
 - patients should have access to:
 - rehabilitation services to improve their quality of life and daily living
 - specialist benefits advice – raising awareness of financial support would be useful as experience suggests that access to benefit services is low and yet socially disadvantaged groups disproportionately develop lung cancer
 - smoking cessation post thoracotomy should be encouraged
 - avoidable admissions in patients nearing the end of life should be reduced.
 - patients should be able to die in the place of their choice.

Cancer Intelligence and National Audit

37. It is vital that the quality of lung cancer services being provided is monitored routinely to enable MDTs and cancer networks to learn quickly from experience and to support effective commissioning. To do this, teams need to ensure that they routinely collect

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information on patient experience, relevant core clinical data on every patient and participate in the National Lung Cancer Audit programme.

38. By 2015 it is suggested that:

- there is a clear commitment to the long term funding for the National Lung Cancer Audit programme
- data from the National Lung Cancer Audit should be linked, under the supervision of the NCIN, to other sources of data to provide as comprehensive a picture as possible – this would include data from Cancer Registries, HES, Radiotherapy data (RTDS), Peer Review and patients surveys
- a wider range of key clinical outcome measures should be developed and both included in the Peer Review programme and fed back efficiently and regularly to clinicians and commissioners
- such outcome data needs to be effectively communicated in easily accessible forms to all those who need it, including patients and the public
- a regular programme of patient and carer surveys is undertaken to obtain users views and monitor the quality of the services provided from a user's point of view – this information should be analysed in conjunction with available quantitative data.
- There is an increase in the mesothelioma specific fields within the NLCA.

Research

39. By 2015 it is suggested that:

- the imbalance in funding between research into prevention/screening/early diagnosis and treatment is addressed i.e. increased funding for the former
- all lung cancer MDTs should be actively involved in the recruitment of patients to relevant NCRN approved clinical trials
- there should be ongoing efforts to support the increase of available funding for research in lung cancer and mesothelioma

**Lung Cancer and Mesothelioma Advisory Group (LCMAG)
December 2010**