Gateway Ref: 7316

Mesothelioma Framework

Draft advice for the NHS on how
to organise services for mesothelioma patients
to improve standards of care across the country

A Discussion Document

November 2006

DH INFORMATION READER BOX

Policy	Estates
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Contact Details	Suzanne Rowe Cancer Team Wellington House, 133-155 Waterloo Road London SE1 8UG 0207 972 4732		
For Recipient's Use			

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Introduction

Who is the framework for?

1. This framework aims to provide Strategic Health Authorities (SHAs), cancer networks, Primary Care Trusts (PCTs) and NHS Trusts in England with advice on how to organise services for mesothelioma patients in order to improve standards of care to a uniformly high level across the country. It includes advice on:

    a. Configuration of services;
    b. Clinical management, care and support;
    c. Underpinning programmes such as information, research and audit.

2. This framework is intended as service guidance rather than a detailed clinical guideline; i.e. it offers recommendations on the organisation of services to ensure improved care and outcomes for mesothelioma patients. It assumes that good practice has been followed in terms of delivering a patient centred service as set out in the guidance issued by the National Institute for Health & Clinical Excellence (NICE) on "*Improving Supportive & Palliative Care for Adults with Cancer*" issued in March 2004.

3. The uptake of this framework is not mandatory. However, the developers of the framework believe that adoption of the recommendations would make a substantial difference to mesothelioma patients and their families and that it can be implemented relatively simply and at relatively low cost.

4. This framework should be read in conjunction with the 2001 British Thoracic Society Statement on Malignant Mesothelioma in the United Kingdom (which is currently being revised).

5. This framework is not intended to be a patient information leaflet.

Reason for Framework

6. There are around 1800 new cases of mesothelioma a year in the UK and the disease is almost always fatal. More people die of mesothelioma than of cervical cancer, malignant melanoma or endometrial carcinoma. Mesothelioma incidence is still rising and is expected to peak between 2010 and 2015. Between 2006 and 2020 up to 30,000 people will die of the disease in the UK

7. A proposal for a NICE mesothelioma guideline was considered by the Department of Health in September 2002 but it was decided that there was insufficient evidence at the time for NICE to be asked to produce evidence-based guidance. This position remains unchanged. There are also no plans to produce Improving Outcomes Guidance (IOG) on this disease.

8. The Department of Health's Lung Cancer and Mesothelioma Advisory Group (LCAMAG), chaired by the National Cancer Director, and its associated Mesothelioma Working Group (MWG) therefore advised that, in the absence of a clinical guideline or an IOG, the Department should agree to the production of a framework offering advice to the NHS on how to improve services for mesothelioma patients. The department has agreed to this given the issues set out below which, when taken together, show that mesothelioma is a particularly challenging condition to manage:

   a. in parts of the country, mesothelioma is a relatively rare condition and there are few, if any, dedicated multi-disciplinary teams (MDTs) for mesothelioma - commissioners and service providers would benefit from advice about service provision;
   b. mesothelioma can be difficult to diagnose and a framework would support clinicians in this task;
   c. patients often have a short life expectancy and experience complex, debilitating symptoms. However, earlier detection could mean increased potential for radical therapy in a small minority of patients which could increase length of survival;
   d. for those patients with more advanced diseased, there may be major quality of life issues which could benefit from a range of specialist advice, for example, on symptom control – a framework would support this;
   e. in most cases, mesothelioma is an industrial disease which leads to complicated legal and financial information needs plus a coroner's inquest once a patient has died – a framework could advise the NHS on how to manage these issues;
   f. research is necessary if outcomes are to be improved and trial entry could be facilitated by more collaboration between centres;
   g. a peak in mortality is less than 10 years away so there is a real opportunity to ensure that the NHS has done all it can to provide a high quality service for the increasing number of patients that will be diagnosed with mesothelioma over the next few years.

9. This document is the resulting framework. It is not a formal evidence-based clinical paper, but service guidance based on professional consensus about what is deemed good practice in organising mesothelioma services and caring for mesothelioma patients and their families. It takes into account the key messages from the Mesothelioma Patients' Charter recently developed by the British Lung Foundation in collaboration with patients and their families along with relevant evidence where available.

10. LCAMAG advise that care for patients with mesothelioma in this country could be improved substantially by implementation of this framework.

11. The framework is endorsed by………………………………..

Key Recommendations

[To be added based on views from consultation]

Consultation Question

- ***Out of all the recommendations in this report (summarised at pages 39-44) which 6-8 would you want to see highlighted as the key ones?***

Background

What is mesothelioma?

12. Mesothelioma is a cancer which principally affects the lining of the lungs (pleura). However it can also affect the lower digestive tract (peritoneum) and, occasionally, arises in the membrane covering the testes (tunica vaginalis). Over 90% of mesothelioma with a known first site occurs as pleural mesothelioma.

What causes mesothelioma?

13. Mesothelioma has a strong association with exposure to asbestos. When asbestos fibres are inhaled or swallowed, they cause inflammation and scarring of the lung, pleura and peritoneum which in a proportion of individuals can lead to malignant change and the development of cancer in the pleura or peritoneum. It is believed that nearly all deaths caused by mesothelioma are linked to asbestos exposure.

14. There is a long ‘lag time’ between exposure to asbestos and the development of mesothelioma; this varies from a minimum of 10 years to a maximum of 60 years after exposure, the median time being of the order of 30 years.

15. Cases of mesothelioma in the UK usually occur in people who have worked in the building and manufacturing industries using asbestos or asbestos products, particularly in construction and engineering. For this reason, mesothelioma is more common in areas such as Scotland, the North East and Southern England where many industries, particularly shipbuilding and railway engineering, used significant amounts of asbestos. However, an increasing proportion of cases are being diagnosed in individuals who may have had less intense exposure such as the building industry (carpenters, electricians, demolition workers etc.) and people who have worked in buildings where asbestos construction materials have been used and become disturbed in some way. It is estimated that these now represent the majority of new cases. [Note– ref to be included] There is a large number of people who are at risk of the disease who are unaware of their exposure.

16. Men are far more likely to develop mesothelioma than women, mainly because they were more likely to have been exposed to asbestos in the course of their work than women were. However, family members of people exposed to asbestos also have a higher risk of developing mesothelioma because of fibres brought into the home on work clothes. A third group of cases probably arise because of ‘environmental’ exposure, for example in individuals who have lived in close proximity to asbestos factories or dumping sites. There is also a small number of deaths each year in people with no history of asbestos

exposure – evidence suggests that there are likely to be at least 50 of these so-called “spontaneous” mesothelioma cases each year in Great Britain. A small number of these cases occur in children.

17. The use, supply and importation of asbestos and asbestos products is now banned for all but a few exceptions by the Asbestos (prohibition) Regulations. Work with asbestos generally requires a licence and the use of strict control measures, including personal protective equipment such as respirators. The latest revision of the Control of Asbestos at Work Regulations introduced, from May 2004, a duty on those responsible for commercial premises to manage the asbestos contained in them. (source: www.HSE.gov.uk)

Epidemiology

Incidence

18. In 2003, there were 1,796 new cases of mesothelioma of which 85% (1521) were men and 15% (275) were women. In a study in the Yorkshire region between 2002 and 2005, the median age at diagnosis was 74.6 (range 36 – 93). The median age is slowly increasing because of the exposure of a cohort of individuals to asbestos in the 1960s and 1970s. Mesothelioma is predicted to become more common over the next 5-10 years as the effects of this exposure become apparent and it is estimated that around 1% of all males born between 1940 and 1950 will die of the disease (Peto, J., Hodgson, J.T., Matthews, F.E., Jones, J.R. Continuing increase in mesothelioma mortality in Britain. *Lancet* 1995; **345** (i): 535-539).

19. There is wide variation in the incidence of mesothelioma around the country as shown in the following table:

Incidence of mesothelioma (ICD10 C45), persons by SHA, 2003

Strategic Health Authorities	Incidence	Population	No. of cases per M pop	Age-standardised rates per M pop
Norfolk, Suffolk And Cambridgeshire	116	2218581	52	36.5
Bedfordshire And Hertfordshire	50	1614690	31	26.6
Essex	88	1629647	54	40.7
North West London	32	1814671	18	18.0
North Central London	24	1220221	20	19.8
North East London	61	1530792	40	40.6
South East London	54	1511793	36	34.1
South West London	27	1310391	21	17.3
Northumberland, Tyne & Wear	77	1392448	55	39.9
County Durham And Tees Valley	44	1146915	38	29.4
North And East Yorkshire And Northern Lincolnshire	58	1640835	35	25.5
West Yorkshire	97	2095862	46	36.9
Cumbria And Lancashire	73	1919041	38	27.0
Greater Manchester	84	2530956	33	27.2
Cheshire & Merseyside	88	2354535	37	27.3
Thames Valley	48	2112536	23	19.7
Hampshire And Isle Of Wight	80	1797070	45	32.5
Kent And Medway	75	1599912	47	35.7
Surrey And Sussex	126	2570762	49	33.2
Avon, Gloucestershire And Wiltshire	77	2191184	35	27.4
South West Peninsula	85	1601215	53	34.5
Somerset And Dorset	45	1206888	37	24.4
South Yorkshire	40	1272609	31	23.9
Trent	70	2670775	26	20.7
Leicestershire, Northamptonshire And Rutland	45	1581519	28	21.7
Shropshire And Staffordshire	34	1496006	23	17.8
Birmingham And The Black Country	62	2273390	27	21.9
Coventry, Warwickshire, Herefordshire And Worcestershire	36	1550496	23	17.1

Source: Office for National Statistics (ONS)

Note: Age standardised to European Standard Population

20. This shows that:

    a. 2 SHAs have less than 30 cases a year
    b. 8 SHAs have between 30-49 cases a year
    c. 10 SHAs have between 50-79 cases a year
    d. 6 SHAs have between 80-99 cases a year
    e. 2 SHAs have over 100 cases a year

In relation to cases per million, there is a threefold variation between SHAs (range 18-55).

21. Thus in some areas, mesothelioma can be considered a rare disease. This is even more noticeable if data is considered at Primary Care Trust (PCT) level. There are just over 300 PCTs at the time of writing and in the year 2003 according to ONS figures:

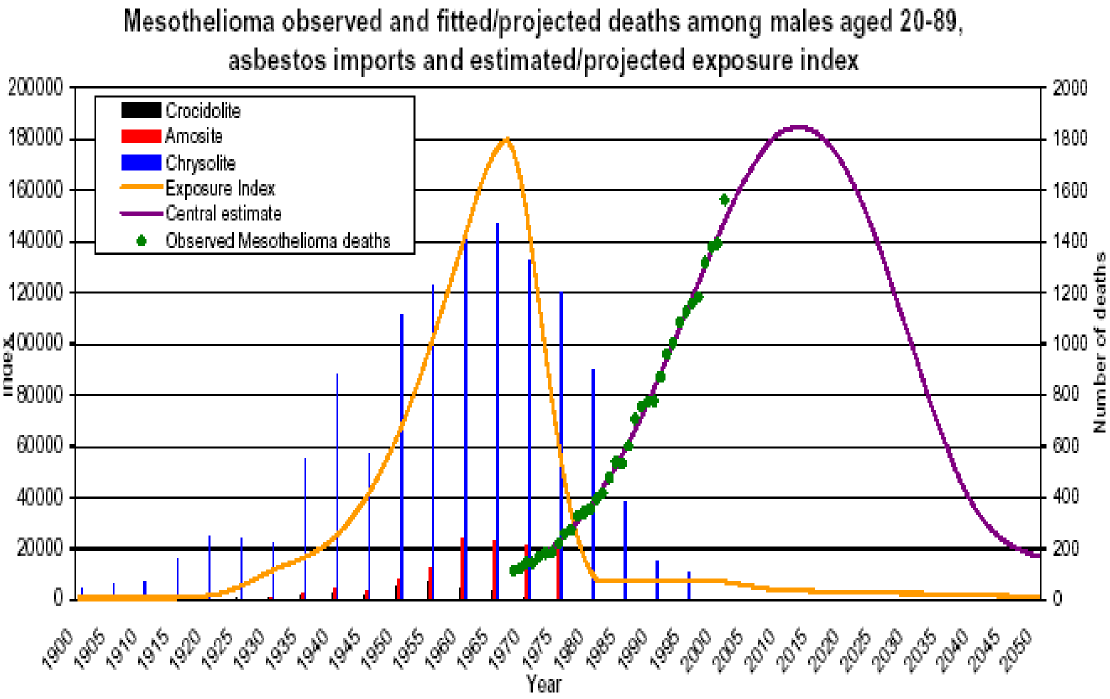
    a. 42.5% of PCTs had less than 5 cases of mesothelioma;
    b. 42.8% of PCTs had between 5-9 cases of mesothelioma;
    c. 11% of PCTs had between 10-14 cases of mesothelioma; and
    d. only 3.7% of PCTs had 15 or more cases of mesothelioma

22. The Health & Safety Executive (HSE) has found that the geographical variation in incidence is associated with the geographical locations of asbestos related industries. High risk areas tend to be those containing, or near to, industrial sites where asbestos was used extensively in the past – shipyards, asbestos manufacturing factories and railway engineering works for example (source: www.hse.gov.uk).

Mortality

23. Information from the Health & Safety Executive (HSE) also shows that the annual number of mesothelioma deaths is increasing from 153 in 1968 to 1633 in 2000 to 1874 in 2003. The annual total number of mesothelioma deaths in Great Britain is predicted to peak during the period 2011 to 2015 at a level of 1950-2450 deaths.

24. The following graph shows the number of deaths from mesothelioma since the mid 1960s and those that are predicted to take place over the next 40 years or so. It also shows how this trend correlates to asbestos imports from the 1900s to the 1980s. It can be seen that there is a lag of over 35 years from the peak of exposure to the peak in incidence.



25. At Local Authority level there is huge variation in Standardised Mortality Ratio (SMR) for mesothelioma around the country. In men, over the period 1981-2000 the SMR varied from 593 in Barrow-in-Furness to 16 in Worcester. Again, this is likely to be related to the geographical location of asbestos-related industries. The following table shows the Local Authorities (LAs) in England with the highest and lowest SMRs for men and women between 1981-2000:

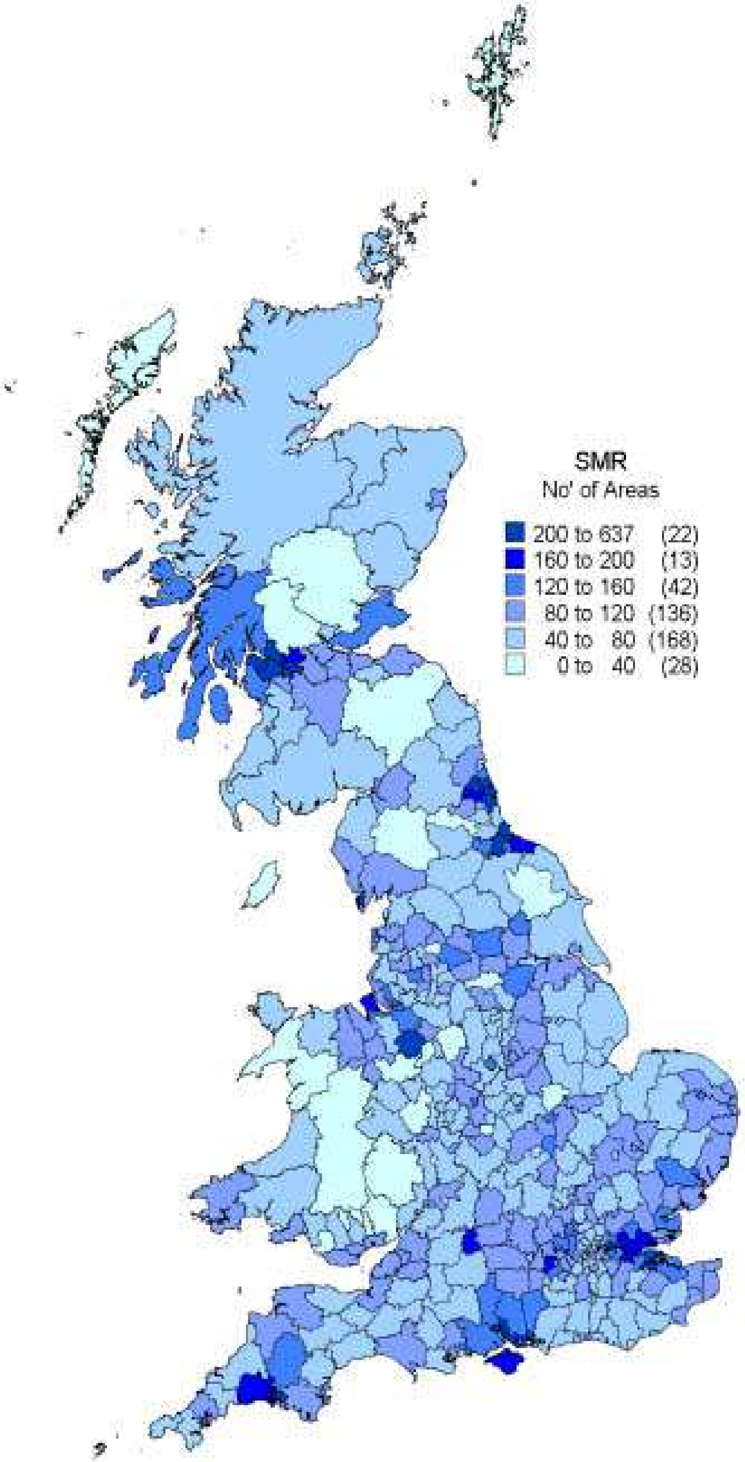
LAs in England with the highest SMRs for Mesothelioma 1981-2000					
Males			**Females**		
Area	**SMR**	**No.***	**Area**	**SMR**	**No.***
Barrow-in-Furness	593	7	Barking & Dagenham	649	2.6
Plymouth	396	15.9	Sunderland	575	4
Portsmouth	388	11.1	Blackburn	484	1.5
South Tyneside	357	9.3	Newham	348	1.4
North Tyneside	340	11	Leeds	328	5.7
Southampton	325	10.3	S Ribble	367	0.8
Eastleigh	303	4.7	Swale	297	0.8
Medway	298	9.4	Kirklees	226	2
Barking & Dagenham	294	7.3	Chorley	279	0.6
Newham	250	6.8	Southampton	221	1.1

LAs in England with lowest SMRs for Mesothelioma 1981-2000					
Males			**Females**		
Area	**SMR**	**No.***	**Area**	**SMR**	**No.***
Kensington & Chelsea	39	0.75	Canterbury	26	0.1
Herefordshire	34	1	Rotherham	26	0.15
Newcastle-u-Lyme	30	0.6	Doncaster	22	0.15
Cheltenham	29	0.5	Warwick	17	0.05
Ryedale	27	0.25	Eastbourne	15	0.05
Staffordshire	25	0.4	Brighton & Hove	14	0.1
Barnsley	22	0.8	Wealden	12	0.1
Worcester	16	0.2	Hinckley & Bosworth	0	0

*Denotes the average number of new cases per annum over the 1981-2000 time period.

Source: Health & Safety Executive

26. The following map of Great Britain shows male SMR for mesothelioma by local and unitary authorities – the areas with the highest SMRs are clear to see:



Survival

27. Mesothelioma is almost always fatal. Median survival from diagnosis varies from study to study within a range of 8 to 14 months. The one-year survival rate for adults diagnosed with cancer of the pleura (almost all mesotheliomas) during 1991-2001 was under 30% and five-year survival was 3-4%.

28. The survival rate for mesothelioma is poor compared with other cancers. This is thought to be due to the advanced nature of mesothelioma at the time of diagnosis and the lack of effective treatments. However, with earlier detection and improved services it should be possible to extend and improve the quality of life of mesothelioma patients and there is the potential for radical therapy in a small minority of patients which could significantly increase their length of survival. At the very least such early stage patients should have the opportunity to be entered into high quality trials of new therapeutic approaches.

Activity/Current Services

29. A questionnaire was sent to all the clinical and nursing mesothelioma leads in England in 2005 to find out more about local services and referral issues. 27 of the 34 Networks responded (79%). Of the approximately 155 lung cancer multidisciplinary teams (MDTs) in England, 124 (80%) were referred to in these responses although it is likely that all lung MDTs, on occasion, deal with patients with mesothelioma as well as lung cancer.

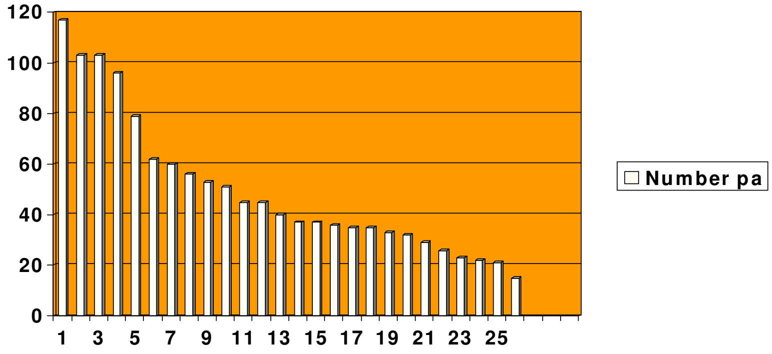
30. The following table shows the reported numbers of mesothelioma cases per annum from the 27 networks that responded to the questionnaire along with the number of MDTs that were reporting on mesothelioma patients in that period within each network:

Network	**Reported numbers pa**	**No. of MDTs reporting on mesothelioma patients pa**
3 Counties	23	4
Arden	34	3
Avon Somerset & Wilts	60	7
Black Country	15	2
Cancer Care Alliance	53	4
Central South Coast	105	4
Derby Burton	22	2
Dorset & Somerset	29	3
Greater Manchester	117	10
Kent & Medway	76	4
Lancashire & South Cumbria	50	6
Leicestershire Northampton & Rutland	37	3
Merseyside & Cheshire	85	12
Mid Anglia	26	3
Norfolk & Waveney	32	4
North London	35	6
North Trent	56	6
North West Midlands	31	4
Pan Birmingham	111	6
Peninsula	79	5
SE London	50	6
South Essex	36	2
SW London	45	1
Surrey West Sussex & Hampshire	37	4
Sussex	36	4
Thames Valley	30	1
Yorkshire	94	8
Total (27 networks)	**1404**	**124**
Average number pa	**52**	**11.3**

31. This shows that:

a. the mean number of cases being seen annually by network was 52, ranging from 15 – 117.

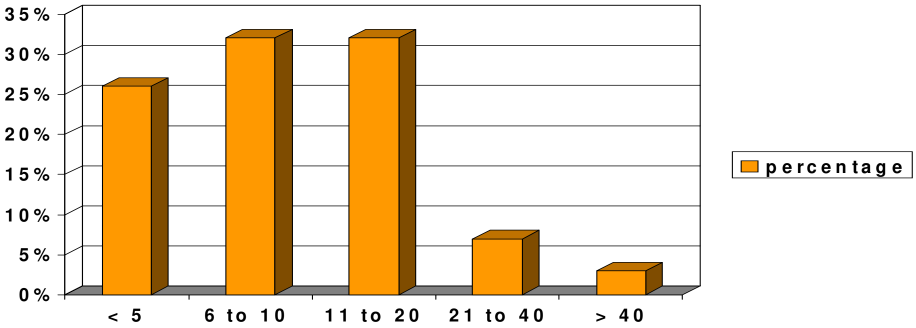
New cases per network per year



b. the mean number of cases being seen by each MDT per year was 11.3 with a range of 1 – 54 and more than half of the MDTs see 10 cases or less a year:

- 26% of MDTs see 5 cases or less a year
- 32% of MDTs see between 6-10 cases per annum
- 32% of MDTs see between 11-20 cases per annum
- 7% of MDTs see between 21-40 cases per annum
- 3% of MDTs see more than 40 cases of mesothelioma a year

Number of new cases per MDT per year



Please note – this graph will be replaced by a frequency plot in the next draft

32. In addition responses from the survey showed that:

a. 96.5% of MDTs estimated that they discuss most or all reported mesothelioma cases with 3.5% estimating that they only discuss difficult or unusual cases.
b. some MDTs may go up to 6 months without seeing a single mesothelioma case.
c. 99% had a clinical nurse specialist, 89% had an oncologist and 78% had a thoracic surgeon in regular (>50%) attendance.

Improving services for mesothelioma patients

33. The following section addresses:

a. Configuration of services:

    i. Cancer Networks
    ii. MDTs

b. Clinical management, care & support
    i. Early Presentation
    ii. Diagnosis
    iii. Treatment
    iv. Clinical Nurse Specialists
    v. Supportive & Palliative Care

c. Underpinning programmes

    i. Communication, information and support
    ii. Research/Clinical Trials
    iii. Audit

Configuration of Services

Cancer Networks

34. Cancer networks play a key role in ensuring integrated care, improved clinical outcomes, cost effective services, improved patient experience and equity of service provision. In areas such as mesothelioma where incidence is low compared to other cancers and there is no prospect of NICE or Improving Outcomes guidance, it is easy for the disease to be overlooked. To help avoid this, in 2005, each Cancer Network was asked to nominate a clinical and a nursing lead for mesothelioma. It is not intended that these lead clinicians are responsible for the clinical management of all mesothelioma patients in the network, rather they should help ensure that the network has appropriate individuals, processes and protocols in place to identify and manage these patients in accordance with this framework.

35. All but one of the 34 cancer networks already had a lead nurse and lead clinician in place for mesothelioma at the time of writing. Of the 33 lead clinicians 17 are respiratory physicians, 10 are oncologists, 3 are thoracic surgeons, 1 is a radiologist and 2 are unknown.

Recommendations

36. It is recommended that:

    a. Each cancer network should have a lead clinician and lead nurse for mesothelioma. They should have an agreed list of responsibilities (in line with the role set out at para 36b). They should also have the time available (for the clinician, expressed in whatever units are used in their contract) to carry out those responsibilities.

    b. The role of the network mesothelioma clinical and nursing leads should be:

        i. to bring together data on the incidence of mesothelioma in their network and the numbers of patients being discussed at each of their MDTs on an annual basis;

        ii. to carry out a mesothelioma needs assessment for their local population, if one has not been done in the last 12 months, to identify the nature and scale of any problems and how they might be resolved (this would include the availability of the relevant clinical expertise within their network);

        iii. to assist/support the implementation of this framework, for example by:

            - ensuring MDTs are in place;

    - ensuring referral pathways are clear & relevant protocols developed;
    - supporting cross network co-ordination/ communication;
    - ensuring that the quality of services provided are audited and progress is fed back to the network;
    - acting as a mesothelioma ‘resource’ for the local area.

iv. to contribute to the recently established network of mesothelioma leads which seeks to share experiences and good practice with the aim of improving services for this group of patients nationally.

Consultation Questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***
- ***Will the role differ in a network that has a specialist mesothelioma MDT and one that does not (see section on MDTs)***
- ***What should the role of the clinical and nursing leads be once the framework has been implemented?***

Multi-disciplinary Teams

37. A consistent theme in the "Improving Outcomes" series of cancer guidance is that cancer services are best provided by teams of clinicians who work together effectively. The NHS Cancer Plan, 2000 stated that "*the care of all patients with cancer should be formally reviewed by a specialist team*".

38. It is important that mesothelioma patients have their cases discussed by a multi-disciplinary team (MDT) to ensure optimal management. Patients managed by MDTs are more likely to:

    a. be offered a range of effective interventions rather than investigations and treatments determined by an individual doctor's specialisation
    b. receive better coordination and continuity of care through all stages of their disease
    c. be treated in accordance with locally-agreed protocols and clinical guidelines
    d. be offered appropriate and consistent information
    e. have psycho-social as well as clinical issues considered thus improving the overall experience of care.

39. In addition:

    a. staff working in multidisciplinary teams are likely to develop higher levels of knowledge, skills, expertise and experience thus ensuring higher quality diagnosis, treatment and care for mesothelioma patients
    b. establishment of multidisciplinary teams tends to reduce the variation in management and outcomes around the country and in particular avoid individual 'outliers' who may provide sub optimal care.

40. The extent to which mesothelioma patients are currently discussed in MDTs is variable. Anecdotal evidence suggests that there are few (if any) dedicated mesothelioma MDTs around the country. It is estimated that around 90% of mesothelioma patients have their case discussed as part of a lung cancer MDT but some of these MDTs only focus on the difficult or unusual cases leaving some mesothelioma cases not discussed by an MDT at all. This runs counter to the statement in the NHS cancer plan (see para 37).

Recommendations

41. It is recommended that:

    a. All mesothelioma (including peritoneal) should be included within the remit of lung cancer MDTs (although not all lung cancer MDTs are likely to see mesothelioma patients).

b. All patients with diagnosed mesothelioma or undiagnosed malignant pleural effusion should have their case discussed by a lung cancer MDT and the radiological images and pathology reports should be available at that meeting.

c. There should be two tiers of MDTs for managing mesothelioma – local (LMDT) and Specialist (SMDT):
   i. LMDTs should initially consider all patients with suspected mesothelioma to try and establish the diagnosis and plan palliative and supportive care (this may include chemotherapy and radiotherapy to the chest drain site) - a member of the palliative care team will need to be part of this MDT.

   ii. All cases should at least be registered at the SMDT. The following groups of patients should be formally discussed by the SMDT who may take on aspects of the more specialist management of the patient if appropriate:
      1. Patients in whom there are local difficulties with diagnosis or staging;
      2. those with limited disease (stage I & II);
      3. patients with a performance status (PS) of 0-2.

   Information from the LUCADA database (see para 72) indicates that in at least 20% of patients there are difficulties with diagnosis and that 43% of mesothelioma patients have a PS of 0-2 on diagnosis. The stage distribution of cases is not known. From this information, if the proposed referral criteria referred to above was adopted, it can be estimated that around 60% of all new/suspected mesothelioma (about 1080 cases a year) should be discussed by SMDTs.

d. A SMDT should discuss a minimum of 25 mesothelioma cases a year. The survey results (see para 29), indicated that all but 4 of the 27 networks that responded have this caseload and could therefore host a SMDT.

e. Where the caseload is not sufficient to support a SMDT within the boundaries of a network a protocol to support referrals to another network's SMDT should be put in place. The location of SMDTs should be a matter for local decision and do not necessarily have to be at University or Teaching Hospitals. A district general hospital could host an SMDT if that is where the necessary expertise is located. It is however expected that most SMDTs will be based around centres with thoracic surgical services or where there are visiting surgeons with expertise in this area.

f. Networks should review the mesothelioma caseload for each of its lung MDTs over the past 5 years for which figures are available. Based on this each network will need to identify which lung MDTs should also act as either mesothelioma LMDTs or SMDTs in their locality taking into account the recommended minimum caseload per annum for SMDTs and ensure that there are referral procedures in place between these teams. Networks without adequate numbers for SMDTs should work with neighbouring networks to identify a suitable SMDT.

g. Consideration could be given to the establishment of a dedicated Mesothelioma SMDT in selected areas where there is a particularly high incidence. It should also be noted that an SMDT can act as the LMDT for its own locality.

h. Both LMDTs and SMDTs should meet weekly if there is not to be an adverse impact on waiting times.

i. SMDTs should include a thoracic surgeon, medical oncologist, clinical oncologist, palliative care physician, clinical nurse specialist, radiologist and pathologist, all with an interest in mesothelioma.

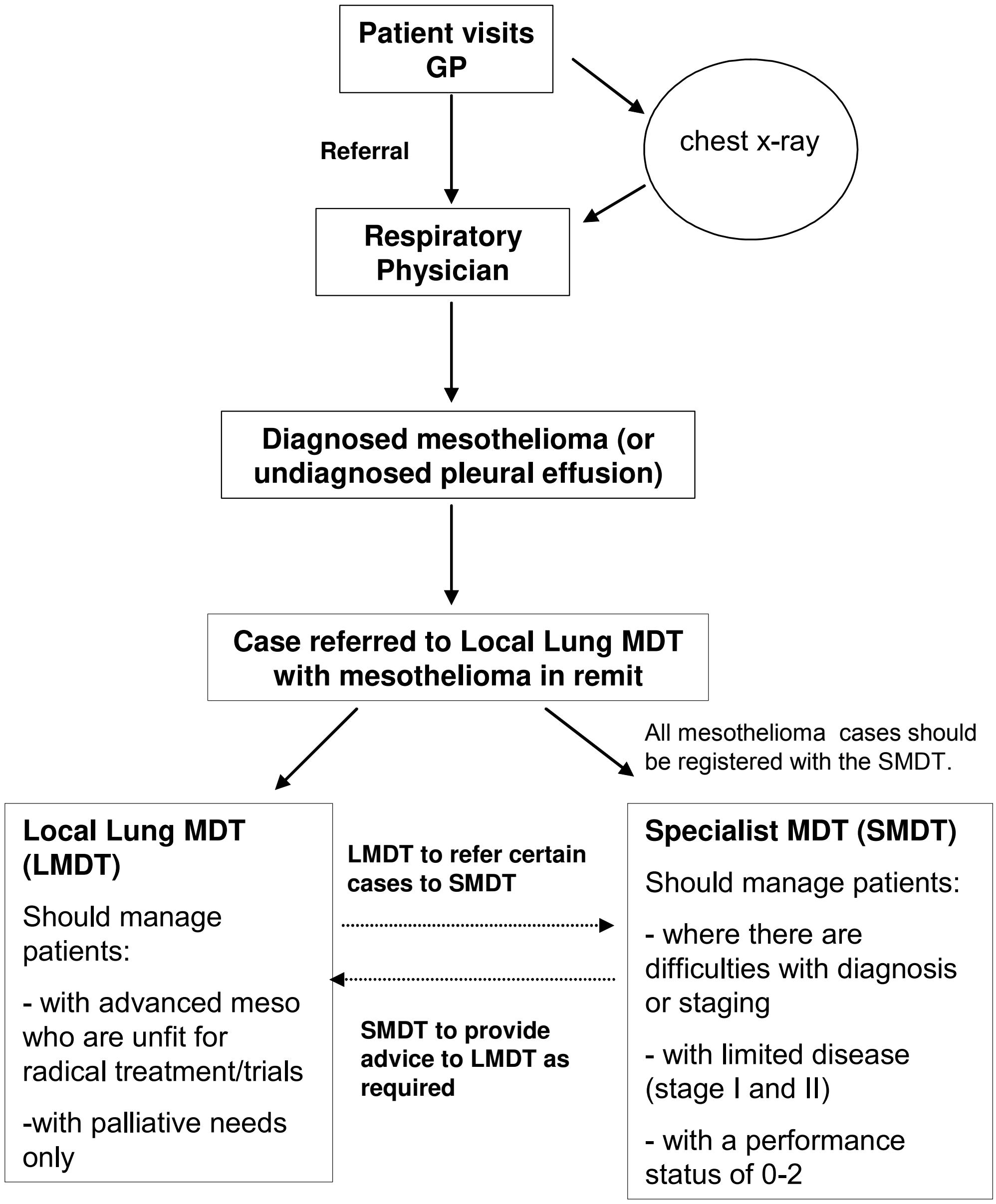
j. Both SMDTs and LMDTs should have access to an extended team including, for example, a physiotherapist, occupational therapist, medical social worker, dietician, psychologist and hospital chaplain.

k. SMDTs should be actively recruiting patients to all relevant national clinical trials.

l. All MDTs (whether LMDT or SMDT) need the support of a co-ordinator. The co-ordinator should take responsibility for organising MDT meetings and may also take the role of team secretary and/or data manager, but should not be a clinical nurse specialist as this would not be an appropriate use of the CNS’s skill or time.

42. Implementation of these recommendations would result in the following patient pathway:

Typical Care Pathway following implementation of the mesothelioma framework



Consultation Questions

- ***Do you agree with the recommendations and resulting patient pathway?***
- ***Are there any other recommendations that should be considered?***
- ***Should lung cancer MDTs which also act as mesothelioma LMDTs or SMDTs be renamed "lung cancer & mesothelioma MDTs" to clarify referral pathways?***
- ***Should all mesothelioma cases identified by the L/SMDT be reported to the network lead?***
- ***Is it desirable/feasible to register all cases with the SMDT?***
- ***Has the threshold for the minimum number of cases (see para 41d) been set at the right level?***

Clinical management, care & support

43. Although it is considered that there is insufficient evidence for NICE to be asked to produce a clinical guideline on the management of mesothelioma, there are a number of areas where there is a high level of professional consensus about patient management and these are outlined in the following sections.

Early Presentation

44. As with all cancers, it is likely that the earlier mesothelioma is diagnosed the better the outcome for the patient in terms of length of survival and improved symptom control. To ensure early presentation, there are two target audiences:

    a. the public;
    b. clinicians (particularly in primary care).

Public

45. There is very little known about public awareness of this condition and whether/if there is benefit to be gained by raising awareness of the risk given the potential psychologicial impact of knowing that, even if you were diagnosed early, mesothelioma is at present an incurable disease. That being said, further thought needs to be given to the risk/benefit of raising awareness among three sub-groups of the population:

    a. those who have worked in high risk industries and know it;
    b. those who have worked with asbestos but are unaware of the risk;
    c. the majority of the population who will be at low risk.

Consultation questions:

- ***should we try to raise awareness of mesothelioma risk factors/symptoms amongst any/all of these groups;***
- ***how might we raise awareness amongst these different groups;***
- ***what are the benefits of raising awareness for these groups given the condition is currently incurable and do these benefits outweigh possible psychological disadvantages such as anxiety and depression?***
- ***should 'raising public awareness' be included in this framework given that the remit is aimed at organising services to improve standards of care?***

Clinicians

46. GPs have a critical role in assessing any patients who present with symptoms which could be due to cancer. They need to be able to decide appropriately which patients can be reassured, which should be observed within primary care, which require routine investigations and which require urgent assessment by a specialist. NICE issued "*Referral guidelines for suspected cancer*" in June 2005 to help primary care staff identify those patients who are most likely to have cancer and who therefore require urgent assessment by a specialist. The guideline did not address mesothelioma although it did include a section on lung cancer (see ***Annex A***). The presenting symptoms suggestive of lung cancer and mesothelioma are broadly the same.

47. If primary care professionals follow the NICE referral guidelines for lung cancer then it is more likely that mesothelioma patients will be referred to a specialist in a timely manner. However, it should be noted that an individual GP is likely to see at least several hundred patients with these signs or symptoms each year but could go several years without ever having a single patient diagnosed with mesothelioma. It is therefore unlikely that a national initiative to raise awareness of mesothelioma amongst primary care staff would be desirable or feasible.

Consultation Questions

- ***should PCTs in areas associated with asbestos-related industries/high mesothelioma incidence consider targeted local initiatives in primary care (and maybe even local hospitals) to:***

    - ***maintain among local clinicians a higher level of suspicion of the disease in appropriate patients than may be necessary in other parts of the country***

      For example, PCTs could:

        - remind their GPs of those patients where they should have a high index of suspicion ie. males over 50 with:
            - a history of asbestos exposure or employment in high risk industries or those with possible 'casual' exposure such as the building industry;
            - a suspicious chest x-ray; and/or
            - the following clinical features: pleural effusion; unexplained chest pain; breathlessness and weight loss.

        - ask that primary care staff explore and document possible occupational risks or potential asbestos exposure in patients with suggestive respiratory symptoms along side birth date - it is estimated that around 1% of all males born between 1940 and 1950 will die of mesothelioma.

        - urgently refer patients with a history of employment in high risk industries – including those with ‘casual’ exposure such as the building industry - for a chest x-ray if they have pleural effusion, unexplained chest pain, breathlessness or weight loss.

        - record on patient records (in primary and secondary care) occupational history and where asbestos exposure is definite or likely.

    - ***ensure local clinicians know what to do if they have a suspicion of mesothelioma ie. when and where to refer patients for specialist advice***

- ***should ‘raising clinician awareness’ be included in this framework given that the remit is aimed at organising services to improve standards of care?***

Diagnosis

48. Mesothelioma patients present with symptoms such as breathlessness, chest pain, weight loss and fatigue which may be non-specific. It may not always be immediately apparent that the patient has a history of exposure to asbestos. The diagnosis of mesothelioma can therefore often be difficult. It is not uncommon for there to be delays in diagnosis as patients are referred to other specialties for assessment. Increasing the proportion referred directly (eg. to rapid access lung cancer clinics) would be likely to improve both the speed of diagnosis and the appropriateness of management.

49. The interpretation of imaging investigations (especially contrast-enhanced CT scans of the thorax) and biopsies of mesothelioma can be very difficult and require a high level of expertise. In addition, many patients undergo multiple procedures before a diagnosis is made.

50. Many patients present with a pleural effusion of which mesothelioma is one cause amongst many. The questionnaire referred to in para 29 revealed that only 50% of networks had a protocol for the management of pleural effusions.

Recommendations:

51. To ensure that a diagnosis of mesothelioma can be made as early as possible, it is recommended that:

    a. Rapid access lung cancer clinics, as recommended in the NICE clinical guideline on lung cancer, also accept referrals of suspected mesothelioma cases.
    b. The British Thoracic Society (BTS) in collaboration with the Royal College of GPs (RCGP), Royal College of Radiologists (RCR) and the Royal College of Pathologists (PCPath) develop national guidelines on the management of pleural effusions. Examples of what could be considered for inclusion in such a guideline are included at ***Annex B***.
    c. All networks take steps to ensure pleural effusions are investigated and managed in line with the guidelines referred to above.

Consultation Questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***
- ***Would you support the development of national guidelines by professional bodies on the management of pleural effusions or would you prefer the local development of network-wide protocols?***
- ***any views on the suggestions for inclusion in a national guideline as set out at Annex B?***

Treatment (including palliative treatment)

52. At present there is no consensus on the optimum form of management for patients with mesothelioma - there is uncertainty about how it should be treated and no treatment has been unequivocally shown to have more than a modest impact on survival.

Surgery

53. Radical surgery (extrapleural pneumonectomy) may be indicated for a small proportion of patients (some 1 to 5%) whose disease is at Stage I or occasionally Stage II using the Butchart staging system. In highly selected series, median survival duration in such patients has been up to 2 years with 5-year survival rates of 15%. Surgery of this sort is usually combined with chemotherapy and radiotherapy. Research is currently underway to try and establish if this is a real effect of the surgery or simply selection bias. Palliative surgical techniques such as de-bulking pleurectomy and surgical pleurodesis can also achieve symptomatic improvement and chest drainage should be followed by pleurodesis as soon as possible.

Chemotherapy

54. Various types of chemotherapy have been reported as offering possible modest improvements of survival and of improving symptoms. There is no ‘gold standard’ of chemotherapy that is universally accepted and there has been no study yet published comparing chemotherapy against ‘Best Supportive Care’. Having said that, many oncologists believe that chemotherapy can offer clinical benefit to a sub group of relatively fit patients. Many different combinations of drugs are used and newer agents are being developed, the most recent of which (Pemetrexed - Alimta) has recently been considered by NICE and not supported on the grounds of a low cost-benefit ratio. It is estimated that at least 60% of patients diagnosed with mesothelioma are not fit enough for chemotherapy. Wherever possible, chemotherapy in mesothelioma should be given within the context of a clinical trial.

Radiotherapy

55. Routine radiotherapy to the primary tumour is of no value, but adjuvant, radical radiotherapy is used in some centres after extrapleural pneumonectomy. This should only be carried out in the context of a clinical trial. Palliative radiotherapy to the site of chest drainage has been used for many years in the belief that it reduces the risk of developing ‘seeding’ of the tumour down the track which can lead to large, painful nodules on the chest wall. The effectiveness of this treatment has, however, recently been brought into question although the data has not yet been published in a peer review journal.

Metastatic disease

56. Metastatic disease outside the thorax is relatively uncommon, with the brain, liver, adrenals and abdominal lymph nodes being the most common sites. There is no trial evidence to support any specific management strategy in these situations, but cranial irradiation has been used for cerebral metastases in line with that administered for Non-Small Cell Lung Cancer.

Recommendations

57. It is recommended that:

    a. the LMDT or SMDT consider treatment options for all mesothelioma patients before a treatment plan is discussed and agreed with the patient;
    b. wherever possible and appropriate, entry into clinical trials should be explored with the patient. In particular, all patients with early stage disease and good performance status should be considered for the MARS trial of radical surgery;
    c. mesothelioma in-patients stay on a respiratory ward staffed by nurses with appropriate skills to manage this condition – especially with experience of managing chest drains and pleurodesis;
    d. all MDTs dealing with patients with mesothelioma should have access to thoracoscopy (either surgical or medical);
    e. although first line chemotherapy should be considered for appropriate patients, there is currently no evidence to support second line chemotherapy;
    f. on current evidence, all mesothelioma patients with chest drains should be offered superficial radiotherapy to the site of chest drainage;
    g. for longer term symptom control surgical of medical pleurodesis should be available.

Consultation questions

- ***Do you agree with the recommendations? If not, why?***
- ***Should all forms of 'clinical' guideline be excluded from this framework given that its aim is to advise on how to 'organise" services to improve standards?***
- ***Are there any other recommendations that should be considered?***

Clinical Nurse Specialists

58. The support of Clinical Nurse Specialists (CNS) is a vital part of the care pathway. Nurse specialists have established themselves across all tumour sites and are considered pivotal to:

    a. Meeting the psychological, social and spiritual needs of patients.
    b. Streamlined, responsive care pathways which are able to meet the individual needs of patients and their family / carers;
    c. The provision of information within a supportive environment (see para 67);
    d. The flow of communication to patients and across all members of the health care team.

Recommendations

59. It is recommended that:

    a. The lung cancer nurse specialist within each Lung Cancer MDT be responsible for providing nursing care, support and information for mesothelioma patients and their families as well as the lung cancer patients, and remains the key worker whilst the patient is undergoing predominantly secondary care treatment. The CNS should facilitate referrals/contact with members of the extended MDT such as physiotherapist, occupational therapist etc as required.

    b. each specialist lung cancer MDT (SMDT) has a named Lung Cancer Nurse Specialist with an interest in Mesothelioma (see para 41).

    c. the lung cancer nurse specialist assesses the patient throughout their care pathway to identify any psychological, social and spiritual needs with:

        - psychological assessment including hopes and fears for the future,
        - social assessment including the availability of family/carer support, ability to cope, appropriateness of current housing, needs of and provision for dependents, occupational history and exposure to asbestos, financial need, benefit entitlement, ability and need to work.
        - spiritual assessment including religious preferences and need, end of life issues.

    d. the CNS in the local Lung MDT works with the CNS in the specialist lung/mesothelioma MDT to develop a streamlined, responsive care pathway that is able to meet the needs of individual patients. This would require:-

  - the establishing of good communication channels within and between the local and specialist MDTs, GP, primary care nursing teams, the patient and their family;
  - access for the patient to members of the care team via the keyworker;
  - simple referral processes for other members of the health care team (incl. palliative care, physio, hospital chaplain, OT, Social Worker, Psycho-Oncology) to ensure that referrals occur as the need arises and at a time that is appropriate to the individual patient
  - comprehensive, accurate and accessible nursing documentation.

e. Patient preference and choice is considered at different stages of the patient journey (supported by accurate information) and fed back to the appropriate MDT.

Consultation questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***

Supportive and Palliative Care

60. Supportive and palliative care has a key role in the management of patients with mesothelioma as more than 60% of patients will not be fit for either surgery or chemotherapy by the time of diagnosis. In addition, as mesothelioma is almost always fatal, all patients will need palliative interventions and care at some stage of their illness. Palliative care is thought to be patchy for this group of patients and it is therefore important that the palliative care team is involved as soon as a diagnosis of mesothelioma is confirmed.

61. Patients with mesothelioma frequently suffer distressing symptoms. These may include breathlessness, chest pain, fatigue and weight loss. Intractable pain in particular is a key issue. Specialist palliative care including specific interventions such as radiotherapy to the site of chest drainage/biopsy, nerve blocks & cordotomy, are of particular importance in some patients.

62. Implementation of the NICE guidance on "*Improving Supportive & Palliative Care for Adults with Cancer"* should ensure that patients receive optimal symptom control together with psychological, social and spiritual care throughout the course of their illness.

Recommendations

63. It is recommended that:

    a. the NICE guidance on "*Improving Supportive & Palliative Care for Adults with Cancer"* should be implemented across networks as soon as possible and that in addition:

        i. every patient with mesothelioma should be reviewed by a clinical nurse specialist who would usually act as their 'key worker' during the course of their illness (see para 59).
        ii. palliative care and symptom control should be central to any management plan for mesothelioma patients.
        iii. a member of the specialist palliative care team should be a core member of any MDT discussing mesothelioma patients (see para 41).
        iv. every unit treating patients with mesothelioma should have access to a pain management team which, in turn, has access to nerve blocks and cordotomy if required.

Consultation questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***

Underpinning Programmes

Communication, information and support

64. Communication, information and support for cancer patients is addressed in the guidance issued by the National Institute for Health & Clinical Excellence on "*Improving Supportive & Palliative Care for Adults with Cancer*" in March 2004. When this guidance is fully implemented across the NHS this will greatly benefit all cancer patients including those with mesothelioma.

65. Mesothelioma is, in most cases, an industrial disease and therefore, in addition to the measures set out in the NICE guidance there is a need for high quality and timely information for both patients and carers about medico-legal and benefit-related issues. In their report on asbestos related diseases the Industrial Injuries Advisory Council (IIAC) recognised that that a proportion of mesothelioma patients who are eligible for industrial injury benefit do not claim it. They believed that one important reason for this may be a lack of awareness of the Scheme. They recommended that the provisions of the IIDB Scheme be highlighted to mesothelioma sufferers.

66. There are already a number of sources of information on mesothelioma and several charities and support groups who focus on this condition including:

    a. Mesothelioma UK
    b. British Lung Foundation (which includes the June Hancock Fund)
    c. Cancerbackup
    d. Many local asbestos support groups

Recommendations

67. It is recommended that:

    a. Cancer networks implement recommendations on information, communication and support in the NICE guidance on Improving Supportive & Palliative Care for Adults with Cancer as soon as possible.

    b. The Lung Cancer Nurse Specialists are responsible for the provision of information in a timely manner and within a supportive environment and the patient's level of understanding should be assessed, documented and communicated throughout the care pathway para 59]

    c. Network wide information, rather than unit specific information, is developed for mesothelioma where possible.

d. Mesothelioma patients have access to information on benefits and legal advice on possible compensation – to support this the CNS should have a knowledge of relevant local information services such as Asbestos Support Groups, Cancer Information Centres, Citizens Advice Bureaus and benefit advisors if patients are to be signposted appropriately.

e. Each CNS should have available a Mesothelioma Patient Information Pack that should include as a minimum, a Mesothelioma Patient Information Booklet (i.e. Mesothelioma UK, Cancer Backup, British Lung Foundation) and a local guide to Mesothelioma services.

f. A Mesothelioma Information timetable and checklist could be developed locally as a prompt to ensure vital information is conveyed at an appropriate time.

g. There should be information/support for families about what happens when a patient dies in terms of post mortem, inquest etc.

Consultation questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***
- ***Would it be useful for the information pack to contain information about claiming benefits and relevant claim forms.***

Mesothelioma research/clinical trials

68. Research can lead to improved standards of care of patients. Research funding for mesothelioma-related studies has been limited in the past. Research is vital if advances are to be made in the diagnosis and treatment of this disease. The NHS Plan announced that the Department of Health would provide an additional £20 million per year to establish a national cancer research network. The National Cancer Research Network (NCRN) and the National Translational Cancer Research Network (NTCRN) were established as a result. The NHS is currently supporting four mutually exclusive mesothelioma studies through the NCRN. These are:

    a. the ***MS01 trial*** (jointly funded by cancer charities, the British Thoracic Society and a pharmaceutical company)- a trial of chemotherapy for patients with malignant pleural mesothelioma. This has recently closed for recruitment, but planning is underway for MSO2;
    b. the ***MALCS study*** (funded by the Health and Safety Executive) – a population based case-control study of mesothelioma and lung cancer in relation to occupation in British men and women under the age of 60;
    c. the ***MARS (Mesothelioma and Radical Surgery) study*** (funded by Cancer Research UK and the June Hancock Mesothelioma Research Fund). This is a pilot study to determine the feasibility and acceptability of performing a randomised trial comparing extra-pleural pneumonectomy (EPP) against no EPP surgery within the context of trimodality therapy (chemotherapy, surgery, post-operative radiotherapy). It is currently recruiting ahead of schedule;
    d. the ***MESO-VATS study*** (funded by the BUPA foundation) – a prospective randomised controlled trial of video-assisted thoracoscopic (VATS) cytoreductive pleurectomy compared to talc pleurodesis in patients with suspected or proven malignant mesothelioma. This has been underway for 2 years and is expected to expand into further centres.

69. The National Cancer Research Institute (NCRI) Lung Clinical Studies Group has established a mesothelioma sub-group to facilitate the development of these and other clinical trials in the disease. The sub-group will produce an annual report in the autumn setting out progress and developments.

Recommendations

70. It is recommended that:

    a. all appropriate mesothelioma patients should be offered the option of entering a clinical trial, where one appropriate to their clinical condition is open for recruitment.

b. the NCRI mesothelioma sub-group and other interested clinicians are encouraged to develop protocols for new clinical trials.

Consultation questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***

Audit

71. It is important to measure the quality of service being provided to enable MDTs to learn quickly from experience. To do this, teams need to ensure that they collect relevant information on patients' cases and carry out local audits.

72. The national lung cancer audit programme (LUCADA) is also intended for the collection of data on mesothelioma. NHS Trusts managing/ treating mesothelioma patients should use this system to start to collect more detailed longitudinal data on this disease. If all centres collected this information via the LUCADA database it would be possible to have national data on:

   a. the incidence of new cases of mesothelioma by MDT and network
   b. the proportion of cases receiving surgery, radiotherapy, chemotherapy and specialist palliative care
   c. the survival of mesothelioma by MDT and network

Recommendations

73. It is recommended that:

   a. all network/trusts that manage mesothelioma patients participate in the LUCADA national audit programme.

      [Information is available via the NHS Health and Social Care Information Centre website, the url address is: http://www.icservices.nhs.uk/ncasp/pages/audit_topics/lungcancer/default.asp?om=m1.

Consultation questions

- ***Do you agree with the recommendations? If not, why?***
- ***Are there any other recommendations that should be considered?***

Conclusion

74. Your views on the consultation questions set out in this document would be very welcome. However, we would also be keen to know any other views you might have, for example, the cost associated with implementing this framework.

75. Please could you send your comments to Suzanne Rowe (suzanne.rowe@dh.gsi.gov.uk) by Thursday 18 January 2007 using the template provided if possible.

Summary of Recommendations

76. This framework recommends that:

Cancer Networks

a. Each cancer network should have a lead clinician and lead nurse for mesothelioma. They should have an agreed list of responsibilities (in line with the role set out at para 36b). They should also have the time available (for the clinician, expressed in whatever units are used in their contract) to carry out those responsibilities.

b. The role of the network mesothelioma clinical and nursing leads should be:

   i. to bring together data on the incidence of mesothelioma in their network and the numbers of patients being discussed at each of their MDTs on an annual basis;
   ii. to carry out a mesothelioma needs assessment for their local population, if one has not been done in the last 12 months, to identify the nature and scale of any problems and how they might be resolved (this would include the availability of the relevant clinical expertise within their network);
   iii. to assist/support the implementation of this framework, for example by:
      - ensuring MDTs are in place;
      - ensuring referral pathways are clear & relevant protocols developed;
      - supporting cross network co-ordination/ communication;
      - ensuring that the quality of services provided are audited and progress is fed back to the network;
      - acting as a mesothelioma 'resource' for the local area.
   iv. to contribute to the recently established network of mesothelioma leads which seeks to share experiences and good practice with the aim of improving services for this group of patients nationally.

MDTs

c. All mesothelioma (including peritoneal) should be included within the remit of lung cancer MDTs (although not all lung cancer MDTs are likely to see mesothelioma patients).

d. All patients with diagnosed mesothelioma or undiagnosed malignant pleural effusion should have their case discussed by a lung cancer MDT and the radiological images and pathology reports should be available at that meeting.

e. There should be two tiers of MDTs for managing mesothelioma – local (LMDT) and Specialist (SMDT):
   i. LMDTs should initially consider all patients with suspected mesothelioma to try and establish the diagnosis and plan palliative and supportive care (this may include chemotherapy and radiotherapy to the chest drain site) - a member of the palliative care team will need to be part of this MDT.
   ii. All cases should at least be registered at the SMDT. The following groups of patients should be formally discussed by the SMDT who may take on aspects of the more specialist management of the patient if appropriate:
      1. Patients in whom there are local difficulties with diagnosis or staging;
      2. those with limited disease (stage I & II);
      3. patients with a performance status (PS) of 0-2.

   Information from the LUCADA database (see para 72) indicates that in at least 20% of patients there are difficulties with diagnosis and that 43% of mesothelioma patients have a PS of 0-2 on diagnosis. The stage distribution of cases is not known. From this information, if the proposed referral criteria referred to above was adopted, it can be estimated that around 60% of all new/suspected mesothelioma (about 1080 cases a year) should be discussed by SMDTs.

f. A SMDT should discuss a minimum of 25 mesothelioma cases a year. The survey results (see para 29), indicated that all but 4 of the 27 networks that responded have this caseload and could therefore host a SMDT.

g. Where the caseload is not sufficient to support a SMDT within the boundaries of a network a protocol to support referrals to another network's SMDT should be put in place. The location of SMDTs should be a matter for local decision and do not necessarily have to be at University or Teaching Hospitals. A district general hospital could host an SMDT if that is where the necessary expertise is located. It is however expected that most SMDTs will be based around centres with thoracic surgical services or where there are visiting surgeons with expertise in this area.

h. Networks should review the mesothelioma caseload for each of its lung MDTs over the past 5 years for which figures are available. Based on this each network will need to identify which lung MDTs should also act as either mesothelioma LMDTs or SMDTs in their locality taking into account the recommended minimum caseload per annum for SMDTs and ensure that there are referral procedures in place between these teams. Networks without adequate numbers for SMDTs should work with neighbouring networks to identify a suitable SMDT.

i. Consideration could be given to the establishment of a dedicated Mesothelioma SMDT in selected areas where there is a particularly high incidence. It should also be noted that an SMDT can act as the LMDT for its own locality.

j. Both LMDTs and SMDTs should meet weekly if there is not to be an adverse impact on waiting times.

k. SMDTs should include a thoracic surgeon, medical oncologist, clinical oncologist, palliative care physician, clinical nurse specialist, radiologist and pathologist, all with an interest in mesothelioma.

l. Both SMDTs and LMDTs should have access to an extended team including, for example, a physiotherapist, occupational therapist, medical social worker, dietician, psychologist and hospital chaplain.

m. SMDTs should be actively recruiting patients to all relevant national clinical trials.

n. All MDTs (whether LMDT or SMDT) need the support of a co-ordinator. The co-ordinator should take responsibility for organising MDT meetings and may also take the role of team secretary and/or data manager, but should not be a clinical nurse specialist as this would not be an appropriate use of the CNS's skill or time.

Diagnosis

o. Rapid access lung cancer clinics, as recommended in the NICE clinical guideline on lung cancer, also accept referrals of suspected mesothelioma cases.

p. The British Thoracic Society (BTS) in collaboration with the Royal College of GPs (RCGP), Royal College of Radiologists (RCR) and the Royal College of Pathologists (PCPath) develop national guidelines on the management of pleural effusions.

q. All networks take steps to ensure pleural effusions are investigated and managed in line with the guidelines referred to above.

Treatment

r. the LMDT or SMDT consider treatment options for all mesothelioma patients before a treatment plan is discussed and agreed with the patient;

s. wherever possible and appropriate, entry into clinical trials should be explored with the patient. In particular, all patients with early stage disease and good performance status should be considered for the MARS trial of radical surgery;

t. mesothelioma in-patients stay on a respiratory ward staffed by nurses with appropriate skills to manage this condition – especially with experience of managing chest drains and pleurodesis;

u. all MDTs dealing with patients with mesothelioma should have access to thoracoscopy (either surgical or medical);

v. although first line chemotherapy should be considered for appropriate patients, there is currently no evidence to support second line chemotherapy;

w. on current evidence, all mesothelioma patients with chest drains should be offered superficial radiotherapy to the site of chest drainage;

x. for longer term symptom control surgical of medical pleurodesis should be available.

Clinical Nurse Specialists

y. The lung cancer nurse specialist within each Lung Cancer MDT be responsible for providing nursing care, support and information for mesothelioma patients and their families as well as the lung cancer patients, and remains the key worker whilst the patient is undergoing predominantly secondary care treatment. The CNS should facilitate referrals/contact with members of the extended MDT such as physiotherapist, occupational therapist etc as required.

z. each specialist lung cancer MDT (SMDT) has a named Lung Cancer Nurse Specialist with an interest in Mesothelioma (see para 41).

aa. the lung cancer nurse specialist assesses the patient throughout their care pathway to identify any psychological, social and spiritual needs with:
   - psychological assessment including hopes and fears for the future,
   - social assessment including the availability of family/carer support, ability to cope, appropriateness of current housing, needs of and provision for dependents, occupational history and exposure to asbestos, financial need, benefit entitlement, ability and need to work.
   - spiritual assessment including religious preferences and need, end of life issues.

bb. the CNS in the local Lung MDT works with the CNS in the specialist lung/mesothelioma MDT to develop a streamlined, responsive care pathway that is able to meet the needs of individual patients. This would require:-

- the establishing of good communication channels within and between the local and specialist MDTs, GP, primary care nursing teams, the patient and their family;
- access for the patient to members of the care team via the keyworker;
- simple referral processes for other members of the health care team (incl. palliative care, physio, hospital chaplain, OT, Social Worker, Psycho-Oncology) to ensure that referrals occur as the need arises and at a time that is appropriate to the individual patient
- comprehensive, accurate and accessible nursing documentation.

cc. Patient preference and choice is considered at different stages of the patient journey (supported by accurate information) and fed back to the appropriate MDT.

Supportive and Palliative Care

dd. the NICE guidance on "*Improving Supportive & Palliative Care for Adults with Cancer"* should be implemented across networks as soon as possible and that in addition:

  i. every patient with mesothelioma should be reviewed by a clinical nurse specialist who would usually act as their 'key worker' during the course of their illness (see para 59).
  ii. palliative care and symptom control should be central to any management plan for mesothelioma patients.
  iii. a member of the specialist palliative care team should be a core member of any MDT discussing mesothelioma patients (see para 41).
  iv. every unit treating patients with mesothelioma should have access to a pain management team which, in turn, has access to nerve blocks and cordotomy if required.

Communication, information and support

ee. Cancer networks implement recommendations on information, communication and support in the NICE guidance on Improving Supportive & Palliative Care for Adults with Cancer as soon as possible.

ff. The Lung Cancer Nurse Specialists are responsible for the provision of information in a timely manner and within a supportive environment and the patient's level of understanding should be assessed, documented and communicated throughout the care pathway para 59]

gg. Network wide information, rather than unit specific information, is developed for mesothelioma where possible.

hh. Mesothelioma patients have access to information on benefits and legal advice on possible compensation – to support this the CNS should have a knowledge of relevant local information services such as Asbestos Support Groups, Cancer Information Centres, Citizens Advice Bureaus and benefit advisors if patients are to be signposted appropriately.

ii. Each CNS should have available a Mesothelioma Patient Information Pack that should include as a minimum, a Mesothelioma Patient Information Booklet (i.e. Mesothelioma UK, Cancer Backup, British Lung Foundation) and a local guide to Mesothelioma services.

jj. A Mesothelioma Information timetable and checklist could be developed locally as a prompt to ensure vital information is conveyed at an appropriate time.

kk. There should be information/support for families about what happens when a patient dies in terms of post mortem, inquest etc.

Mesothelioma research/clinical trials

ll. all appropriate mesothelioma patients should be offered the option of entering a clinical trial, where one appropriate to their clinical condition is open for recruitment.

mm. the NCRI mesothelioma sub-group and other interested clinicians are encouraged to develop protocols for new clinical trials.

Audit

nn. all network/trusts that manage mesothelioma patients participate in the LUCADA national audit programme.

Annex A

NICE Guideline on Referral for Suspected Cancer
Extract on Lung cancer

General recommendations

1.3.1 A patient who presents with symptoms suggestive of lung cancer should be referred to a team specialising in the management of lung cancer, depending on local arrangements.

Specific recommendations

1.3.2 An urgent referral for a chest X-ray should be made when a patient presents with:

- haemoptysis, or
- any of the following unexplained persistent (that is, lasting more than 3 weeks) symptoms and signs:
    - chest and/or shoulder pain
    - dyspnoea
    - weight loss
    - chest signs
    - hoarseness
    - finger clubbing
    - cervical and/or supraclavicular lymphadenopathy
    - cough with or without any of the above
    - features suggestive of metastasis from a lung cancer (for example, in brain, bone, liver or skin).

A report should be made back to the referring primary healthcare professional within 5 days of referral.

1.3.3 An urgent referral should be made for either of the following:

- persistent haemoptysis in smokers or ex-smokers who are aged 40 years and older
- a chest X-ray suggestive of lung cancer (including pleural effusion and slowly resolving consolidation).

1.3.4 Immediate referral should be considered for the following:

- signs of superior vena caval obstruction (swelling of the face and/or neck with fixed elevation of jugular venous pressure)
- stridor.

Risk factors

1.3.5 Patients in the following categories have a higher risk of developing lung cancer:

- are current or ex-smokers
- have smoking-related chronic obstructive pulmonary disease (COPD)
- have been exposed to asbestos
- have had a previous history of cancer (especially head and neck).

An urgent referral for a chest X-ray or to a team specialising in the management of lung cancer should be made as for other patients (see 1.3.1 above) but may be considered sooner, for example if symptoms or signs have lasted for less than 3 weeks.

Investigations

1.3.6 Unexplained changes in existing symptoms in patients with underlying chronic respiratory problems should prompt an urgent referral for chest X-ray.

1.3.7 If the chest X-ray is normal, but there is a high suspicion of lung cancer, patients should be offered an urgent referral.

1.3.8 In individuals with a history of asbestos exposure and recent onset of chest pain, shortness of breath or unexplained systemic symptoms, lung cancer should be considered and a chest X-ray arranged. If this indicates a pleural effusion, pleural mass or any suspicious lung pathology, an urgent referral should be made.

Annex B

Possible inclusions for a national guideline on the management of pleural effusion

i. a specialist pleural effusion diagnosis service should be set up in each Trust and centred around its Lung Cancer MDT(s).

ii. referral protocols for primary care, A&E, inpatient departments etc

iii. Clinical advice such as:

  - patients with undiagnosed pleural effusion are referred to a rapid access clinic run by a respiratory physician with an interest in lung cancer or mesothelioma.

  - x-rays suspicious of a malignant pleural effusion should be ‘flagged’ to the trust’s specialist pleural effusion diagnosis service as well as to the referring clinician.

  - simple diagnostic pleural tap with a fine needle for protein analysis and cytology can be carried out at the outset, but rarely gives a definitive diagnosis of mesothelioma.

  - most patients with a unilateral pleural effusion without a clear non-malignant cause will require a contrast-enhanced CT scan of the thorax (it is a misconception that you need to remove the fluid from the lungs before imaging

  - punctures into the pleural space should kept to a minimum and the areas marked with an ink tattoo to facilitate superficial radiotherapy at a later date.

  - blind biopsies (eg. Abram’s or COPE) should be avoided where mesothelioma is a possibility

  - biopsy of the pleura should, wherever possible, be image guided – either CT guided biopsy or via thoracoscopy.