Clinical Standards Board for Scotland
National Overview

NHS SCOTLAND

Lung Cancer Services

CSBS
Promoting
Public Confidence
in NHSScotland

www.clinicalstandards.org

ISBN 1-903766-51-6

First published March 2002

Further details on the process by which the Board is achieving its objectives can be found in the comprehensive Clinical Standards Board for Scotland (CSBS) *Quality Assurance & Accreditation Manual* (August 2000).

Copies of the *Clinical Standards for Lung Cancer* are also available from CSBS.

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Copies of this report and of the reports on each Trust/Island NHS Board area, and other CSBS documents, are available on the CSBS website or in print format from CSBS.

Information contained in this report has been supplied by Trusts, or taken from current Trust sources, unless otherwise stated, and is believed to be reliable on publication.

www.clinicalstandards.org

Clinical Standards Board for Scotland

National Overview

Lung Cancer Services

Introduction and Acknowledgements

The remit of the Clinical Standards Board for Scotland (CSBS) is to develop and run a national system of quality assurance and accreditation of clinical services, with the aim of promoting public confidence in the NHSScotland.

For each project, the Board establishes a project group to:

- develop and consult on the standards and self-assessment framework;
- oversee the process of external peer review; and
- report findings to the Board.

The Lung Cancer Project Group was established in January 2000 under the chairmanship of Dr Anna Gregor, Consultant Clinical Oncologist and Macmillan Lead Cancer Clinician, Lothian University Hospitals NHS Trust and, since 2001, Chairman of the Scottish Executive Health Department Scottish Cancer Group. Membership of the Project Group is given in Appendix 1.

The CSBS *Clinical Standards for Lung Cancer* were developed by this group and published in January 2001 following extensive consultation. Copies of the standards are available on request from the Board or on the CSBS website (www.clinicalstandards.org).

Peer review visits to all NHS Board areas in Scotland were conducted between March 2001 – November 2001 to assess performance against the standards and local reports on each visit to Trusts/Island NHS Boards, including a detailed assessment of performance against each standard, have been published and are available on the CSBS website.

This report presents a national overview of lung cancer services in Scotland, reporting on performance across Scotland against the standards and including examples of local initiatives relevant to them.

The CSBS gratefully acknowledges the work of the Lung Cancer Project Group for its oversight of the project from its inception to the publication of this report. In addition, the contribution made by every member of the peer review teams was crucial to the success of the visit programme.

The Board wishes to record its thanks to all the staff, who contributed to the peer review visits, and in particular the liaison co-ordinators, local review facilitators and lead clinicians in Trusts/Island NHS Boards who were responsible for preparing staff locally for peer review visits and for the compilation of comprehensive self-assessment material prior to visits.

Contents

Contents

Executive Summary

Introduction

Cancer affects everyone's lives – the 25,000 people who are diagnosed with the disease every year in Scotland, the families and friends of cancer patients and the many health professionals and others involved in the care of patients with cancer. Over the past 50 years the incidence of cancer has risen steadily with lung cancer being by far the most common cancer in the Western world. Lung cancer is closely associated with cigarette smoking and affects men and women equally. Deaths from the disease now account for about a quarter of all cancer deaths each year.

While lung cancer is a common disease with over 4,500 patients diagnosed each year in Scotland, survival is poor, with less than 6% of patients being alive five years after diagnosis. In contrast to other cancers, there has been very little improvement in survival rates over the last 20 years and while lung cancer is difficult to cure for a number of reasons, even a small improvement in survival would benefit many people.

Tackling cancer is one of the NHSScotland priorities, together with heart disease and mental health. The three most common cancers are lung, breast and colorectal, or bowel, cancer. Exploring each aspect of the patient journey from the point of diagnosis for people diagnosed with any of these three cancers, together with a fourth, ovarian cancer, formed one of the first projects tackled by the CSBS. This report sets out the findings of the Board's review of lung cancer services across Scotland and it is underpinned by the separate publication of local reports for every NHS Trust and Island NHS Board providing these services in Scotland.

The first step of the process was to develop a series of key standards against which to monitor performance and this was undertaken by a project group which included representatives of all healthcare professionals involved in the treatment of lung cancer as well as members with personal experience of services. Full membership details are given in Appendix 1.

From March to November 2001 each acute NHSScotland Trust and the three Island NHS Boards were visited by teams of healthcare professionals and members of the public to assess lung cancer services against the standards. This review has provided a unique opportunity to capture a Scotland-wide 'snapshot' of these services which can be used as a baseline against which to inform, support and measure continued improvement in the quality of these services.

Summary of Findings

Several important themes have been identified which apply specifically to lung cancer. All these are explored in detail in the section of this report describing performance against the standards, and a summary of the key findings is given below:

1. Care of Patients

- Lung cancer is a common disease which presents at a late stage and in a variety of hospital and primary care settings. Most patients cannot be cured and their treatment and care depends on a highly skilled and supportive approach from a variety of specialists. The review teams all commented on the commitment, enthusiasm and professional approach of the staff involved in the care of lung cancer patients, and their families and friends, and in particular on the support provided by palliative care teams. The role of the specialist nurse was also found to be important, acting as a link for the patient between the different health professional team members and as a source of information and support, although it was found that few such nurses are in post across the country.

2. Referral

- In general, referral arrangements are in place from primary care to hospital services. However, these are often informal, and it is important to develop and disseminate protocols that specify local arrangements to ensure the right patients are referred to the right place without unnecessary delay. Patients suspected of having lung cancer should be referred to a respiratory physician for investigation and assessment. It is also important that once in 'the system', referral between hospital departments is clearly defined to avoid delays in the journey of care and inappropriate investigations.

3. Investigation and Diagnosis

- Diagnosis of lung cancer is usually straightforward and review teams found that patients generally had good access to diagnostic investigations such as bronchoscopy, but waiting times for CT scans were unacceptably long, leading to delays in treatment. Many Trusts were not able to provide specific information on waiting times to allow review teams to assess their performance and much of what is reported was based on oral information provided during visits.

4. Multidisciplinary Approach

- All Trusts recognised the value of a multidisciplinary approach to decision-making and treatment planning although only half the Trusts visited had multidisciplinary lung cancer teams that met regularly. It was recognised that in some Trusts this presents real challenges as staff can be working on several geographically remote sites, and one clinician covers more than one Trust. Further, certain services, most notably pathology and radiology, are under severe staffing pressures and many Trusts have long-term vacancies. Palliative care services were valued by all Trusts and by those using the service and, in general, are available across Scotland, although often not involved in multidisciplinary meetings at an early stage. It was also noted that specialised pharmacy input is a valuable resource that should be core to the team. Trusts are urged to consider innovative ways of using their resources to ensure that all patients have access to multidisciplinary teams, and adopt a Trust-wide approach. At the time of visiting, very few Trusts were involved in Managed Clinical Networks, although this is being addressed through the implementation of *Cancer in Scotland*.

5. Treatment

- It has been difficult to assess Trust performance against the treatment standards, particularly where these involved waiting times, as there were inadequate data collection systems in place in most Trusts. Where figures were available, the delay between diagnosis and treatment was unacceptably long, particularly the waiting time between booking of radiotherapy and the start of radiotherapy treatment.

  Also of particular concern was the lack of protocols for diagnostic and staging assessments and for surgical technique.

6. Chemotherapy

- Most hospitals visited that prescribed chemotherapy had protocols in place and these were made available for review teams during visits. The staff providing chemotherapy services were aware of these protocols and in many places these were under review with expert input from pharmacists with a special interest in chemotherapy as they did not all cover toxic side-effects. The review teams found that there were a number of information leaflets available about chemotherapy and the nursing staff were well trained and provided information and support for patients. Hospitals that did not prescribe chemotherapy but may have to admit patients in their area who were suffering from side-effects did not always have the necessary protocols in place although it was reported that they had good access to the prescribing units for advice.

Chemotherapy services are very stretched in some areas of the country, mainly due to the number of patients in the system and to a shortage of oncologists. In these areas services are sometimes offered outwith the 'normal working hours' of 9-5 which is not in line with recognised guidelines as not all support services are available out-of-hours. Trusts were aware of this and assured the review teams that operating additional services did not compromise patient safety. There was also some concern that in the absence of an oncologist, other medical staff who may not have had the necessary training, were prescribing chemotherapy. While the services provided do strive to meet the highest standards, all staff working in this field should attend accredited training.

7. Radiotherapy

- Radiotherapy may be used to treat cancer (generally before or after surgery) and in some cases it is used as an alternative to surgery or to relieve symptoms of advanced disease. Before a patient receives radiotherapy, calculations must be made about the radiation dose and type, the area to be treated and the distribution of the dose. Treatment is prescribed by clinical oncologists, but others are involved in making the calculations, giving treatment and maintaining the machines.

  Modern radiotherapy uses machines called linear accelerators (LinAcs) which deliver high energy X-rays and electrons to kill tumour cells. At present there are not enough LinAcs in Scotland to meet patient demand within reasonable timescales and much of the equipment in use is old and subject to frequent breakdowns. This has been recognised and a national plan is now in place to address this. Some areas also have problems in recruiting key staff including clinical oncologists. These two factors, together with a need to improve care planning, have led to delays in treatment which are unacceptably long at all hospitals.

8. Communication and Information

- All Trusts had written information about lung cancer available and several had developed local leaflets with additional information about the services provided within their Trusts. The visits could not assess the degree and success with which this information reached patients and their families. One issue that arose on several visits was the limited access to private areas where sensitive issues could be discussed and Trusts are urged to address this as such consultations are recognised as an important element of the patient journey of care. It was also noted that while some staff had attended communication skills training, these courses were not generally attended by senior medical staff who are responsible for giving sensitive or bad news to patients and their families.

9. Discharge

- Much effort is directed into discharge planning, but a lot of work is still needed to make sure patients, their families, and clinicians responsible for ongoing care, have the information they need at the time of discharge.

10. Data

- One of the main problems faced throughout the lung cancer review was the lack of 'evidence' to support the evaluation of performance against standards. Much audit activity is under way, mainly at the level of individual healthcare professionals. Even where core data are collected, there was limited awareness among those treating patients about what was collected, by whom and how to access this information to monitor their performance against standards. The information systems which currently support patient care cannot provide the information which is essential to monitor performance against standards of care. This needs to be rectified if NHSScotland is to be able to monitor standards and improve the quality of care.

Conclusion

Lung cancer services in Scotland are currently variable and need to be improved. In contrast to other cancers, survival from lung cancer has not improved in the last decade. Improving the co-ordination and availability of specialist care will improve outcomes. There is no doubt that the staff providing services are committed professionals willing to consider changes that will lead to better integration and improved access to care. One of their key priorities is to develop and strengthen referral and treatment protocols, and improve waiting times for key investigations and treatment. Trusts also need to focus on the introduction of information systems that will monitor performance. This in turn will allow Trusts to monitor improvements in services. Without these systems it is difficult to provide and manage quality services as any areas that require improvement cannot easily be identified.

Key Recommendations

People with Lung Cancer

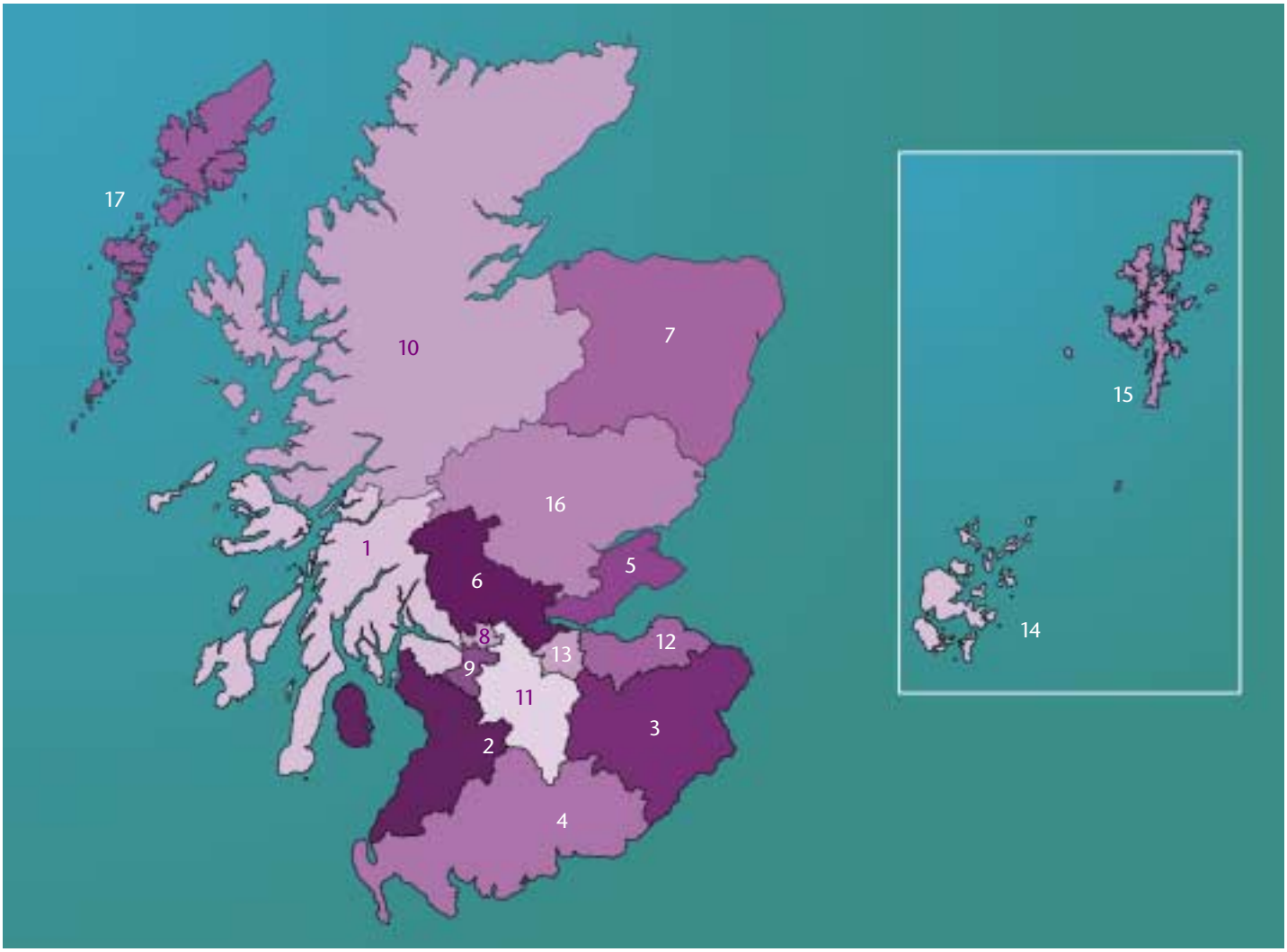
- Patients should have access to a specialist care nurse.
- Referral protocols should be in place, both between primary and acute care and within the hospital.
- There is good evidence that multidisciplinary team working improves the quality of care. All Trusts should ensure these teams are established and that there is a Trust-wide approach to multidisciplinary working.
- Protocols for the prescription and administration of chemotherapy should be in place. These should include the management of side-effects.
- All staff involved in prescribing and administering chemotherapy should have accredited training.
- Healthcare professionals working with cancer patients should have training in communication skills.
- Clinical information systems that support the monitoring of performance should be in place at every Trust. National data sets and definitions should be used.

Chapter 1

Setting the Scene

- NHSScotland Regional Breakdown and Index of Visits
- The CSBS Approach to Assessment
- An Introduction to Cancer
- Lung Cancer
- The CSBS Standards and Your Care
- Frequently Asked Questions and Useful Contacts

1 Setting the Scene



1.1 NHSScotland Regional Breakdown and Index of Visits

1	Argyll & Clyde	10	Highland
2	Ayrshire & Arran	11	Lanarkshire
3	Borders	12	Lothian
4	Dumfries & Galloway	13	Lothian (West)
5	Fife	14	Orkney
6	Forth Valley	15	Shetland
7	Grampian	16	Tayside
8	Greater Glasgow (North)	17	Western Isles
9	Greater Glasgow (South)		

The following hospitals were reviewed during March – November 2001. Local reports (for each area), containing findings of each individual peer review visit and assessments against the standards, are available on the CSBS website (www.clinical standards.org) or in print format from CSBS.

Local Report Area: Estimated Population Area (square km) Population (per square km)	**Hospitals Reviewed**
1. Argyll & Clyde 423,500 7,531 56	Inverclyde Royal Hospital, Greenock Lorn & Islands District General Hospital, Oban Royal Alexandra Hospital, Paisley Vale of Leven District General Hospital, Alexandria
2. Ayrshire & Arran 373,400 3,338 112	Ayr Hospital Crosshouse Hospital, Kilmarnock
3. Borders 106,900 4,734 23	Borders General Hospital, Melrose
4. Dumfries & Galloway 145,800 6,439 23	Dumfries & Galloway Royal Infirmary

Local Report Area	Hospitals Reviewed
5. Fife 350,400 1,323 265	Queen Margaret Hospital, Dunfermline Victoria Hospital, Kirkcaldy
6. Forth Valley 278,000 2,652 105	Falkirk & District Royal Infirmary Stirling Royal Infirmary
7. Grampian 523,400 8,742 60	Aberdeen Royal Infirmary
8. Glasgow (North) 557,520 372* **	Gartnavel General Hospital, Glasgow Glasgow Royal Infirmary Stobhill Hospital, Glasgow Western Infirmary, Glasgow
9. Glasgow (South) 346,880 186* **	Southern General Hospital, Glasgow Victoria Infirmary, Glasgow
10. Highland 208,600 25,784 8	Raigmore Hospital, Inverness

* Estimated figure supplied by NHS Greater Glasgow.
** Figure unavailable.

Local Report Area	Hospitals Reviewed
11. Lanarkshire 562,000 2,189 257	Hairmyres Hospital, East Kilbride Monklands Hospital, Airdrie Wishaw General Hospital
12. Lothian 628,920 1,296 485	Royal Infirmary of Edinburgh Western General Hospital, Edinburgh
13. Lothian (West) 154,680 425 364	St John's Hospital, Livingston
14. Orkney 19,480 992 20	Balfour Hospital, Kirkwall
15. Shetland 22,440 1,438 16	Gilbert Bain Hospital, Lerwick
16. Tayside 385,500 7,558 51	Ninewells Hospital, Dundee Perth Royal Infirmary
17. Western Isles 27,180 3,134 9	Western Isles Hospital, Stornoway

1.2 The CSBS Approach to Assessment

The CSBS has developed a methodology which draws upon other quality assurance models to enable it, in partnership with healthcare professionals and members of the public, to both develop standards for clinical services and assess performance across NHSScotland against these standards.

The Board's approach is outlined in its *Quality Assurance & Accreditation Manual* (issued August 2000). Further information and definitions of the terms used in the standards and in the assessment of performance are contained in Appendix 2.

Assessment Categories

Each review team reported its assessment of performance **at the time of the visit** using the categories detailed below:

- '**Met**': applied when the evidence, either quantitative or qualitative, demonstrated that the standard and/or criterion is being met. When the assessment was based on qualitative information, the review team confirmed this information with Trust staff during the visit.
- '**Not met**': applied when the evidence, either quantitative or qualitative did not demonstrate that the standard and/or criterion is being met.
- '**Not met (insufficient evidence)**': applied when no evidence was submitted to the review team, or where the evidence supplied was insufficient to allow an assessment to be made.
- '**Not assessable**': applied when the criterion had been written in such a way that it was not possible to measure performance in a consistent and meaningful way.
- '**Not applicable**': applied when a standard and/or criterion did not apply to the hospital being reviewed, usually because the relevant aspect of this service is not provided on that site.

1.3 Introduction to Cancer

In the past, the leading cause of death in the UK was heart attack and other cardiovascular diseases. Deaths from heart disease are now falling and over the last two years, cancer has become the main cause of death in this country accounting for 27% of total deaths in men and 23% in women. Cancer is largely a disease of the elderly with two-thirds of cases diagnosed in people over the age of 65; as the population is generally living longer, these figures are likely to rise. Over 26,000 people in Scotland are diagnosed with cancer each year and in 1999, over 14,000 Scots died from the disease.

Basic Facts about Cancer

The body is made up of many types of cells. Normally cells grow, divide, and produce more cells to keep the body healthy and functioning properly. Sometimes, however, the process fails and cells keep dividing when new cells are not needed. A cancer consists of abnormal cells that increase in number without control or order and then invade and destroy body tissue. The extra cells then form a mass which is called a growth or tumour. Tumours can be benign or malignant and malignant tumours are known as cancer as they have the potential not only to invade and destroy the tissue surrounding the growth but also to produce secondary growths elsewhere in the body.

In Summary

- Cancer is the uncontrolled and disordered growth of cells within a specific organ or tissue type.
- Most cancers (although not all) begin in a single site such as the breast or lung.
- If left untreated, cancers grow steadily often by invading surrounding areas.
- They often also produce secondary or further growths (metastases) and this is the aspect of cancer that is most difficult to treat.

Diagnosis, Assessment and Treatment

Cancer is usually diagnosed through one of two routes. The general practitioner (GP), or a hospital consultant, who thinks that symptoms are suspicious of cancer, may refer the patient to a specialist for investigation for cancer; alternatively, investigation for cancer may follow provisional identification in a screening programme. Both these routes lead to full assessment, diagnosis and treatment if required. Cancer may also present symptomatically as an emergency.

Much of the specific assessment, diagnosis and treatment of cancer takes place in the acute hospital setting (secondary care) although co-ordinated and effective communication between primary and acute care is essential both at the stage of referral and at discharge.

The treatment for each patient is approached on an individual basis; however, there are usually three specific components of treatment of cancer: chemotherapy, radiotherapy, and/or surgery. The order or combination of these will vary according to tumour, stage of disease, or if the patient is involved in a clinical trial.

Communication with patients and their family and friends is also recognised as a core element of care, and information on every aspect of the cancer journey should be available and provided in a range of ways (unless the patient makes it clear they do not want this). This applies not only among patients, so that they have the choice to participate in treatment decisions, but also among the care staff. Good communication is supported by patient-centred record-keeping of assessments of the quality of the patient's life as well as the treatment and progress of their disease.

1.4 Lung Cancer

Lung cancer is the most common cancer in men and women in Scotland and is the main cause of death from cancer.

It is overwhelmingly associated with smoking and less than 5% of lung cancer patients are lifelong non-smokers. Patients who smoke 10 – 20 cigarettes a day have a risk of lung cancer 30 times greater than non-smokers and for people who smoke 60 a day, the risk is 60 times greater. Comprehensive tobacco control would prevent, over time, most lung cancers, but there is at least a 20-year legacy before any significant reduction could be expected in the frequency of the disease.

Of the 4,500 patients newly diagnosed each year, only 6% are alive five years later and in contrast with other types of cancer this figure has not changed in Scotland over the last 20 years. Lung cancer is difficult to cure for a number of reasons, but evidence from other countries and from audits of practice in the UK suggests that there may be room for improvement in Scotland. Even a small increase in survival rates would mean that a large number of patients could benefit, and standards such as those developed by CSBS are part of the drive to improve the overall management and treatment for lung cancer patients.

There are many different types of lung cancer, which are divided into two main groups: non-small-cell lung cancer (NSCLC), which accounts for over half the cases seen, and small-cell lung cancer (SCLC). As these two groups are very different, both pathologically and in their natural history, accurate and complete diagnosis and complete work-up of the patient are essential to devise the appropriate treatment strategy. The diagnosis, treatment and management of patients with lung cancer involves a team including chest physicians, radiologists, surgeons, nurses, professions allied to medicine, radiation and medical oncologists, specialists in palliative care and crucial input from GPs.

Symptoms and Diagnosis

Lung cancer does not produce symptoms in its early stages, and when it has spread into the main airways or surrounding tissues the symptoms are common and non-specific. While typical symptoms include coughing, shortness of breath and chest pain, many patients will be used to these since smokers often suffer such respiratory problems. Symptoms such as weight loss can also occur for other reasons, and even coughing up blood (haemoptysis) can be due to infection. It is therefore important to have a high degree of clinical suspicion and investigate high-risk patients as soon as possible.

Diagnosis is usually straightforward, as most lung cancers are visible on a chest X-ray. Confirmation of an abnormal shadow can then be made either by examining sputum (spit) under a microscope, or by a technique called bronchoscopy using a small telescope which is passed under local anaesthetic into the lung, where a small tissue sample is taken for analysis. Once the diagnosis is made, most patients will need assessment of the extent of their tumour as well as their fitness for treatment. This is called staging, and will include investigations such as CT scans, lung function tests and sometimes tests on heart function.

The most suitable approach will often involve more than one treatment, and the results of the investigations will usually be discussed by the various specialists in order to agree the best approach for each patient. This multidisciplinary approach is known to lead to better results and to allow faster decision-making.

Treatment

The main decision is whether treatment can cure a patient or whether the most effective approach should be directed to control of symptoms (palliative). Patients, together with their families should, if they wish, have full input to discussions on the choice of treatment and may opt for no specific interventions.

While surgical removal of the tumour often has the greatest chance of long-term success, only a minority of cases are suitable, and it is important to ensure that surgery with its associated risks is only used where there is likely to be a benefit in survival. Radiotherapy can also be used effectively, and in patients for whom an operation is not possible it can lead to prolonged tumour control and long-term survival (30-40% at five years). Radiotherapy can also be helpful in shrinking tumours and controlling symptoms.

Chemotherapy has been the main treatment for SCLC for some time and is increasingly used for other types of lung cancer. There are a variety of drugs and treatment regimes and it is important that these are planned and delivered by trained and experienced staff. All treatments will have some side-effects, and their control and minimisation is also an important part of specialist care and management.

Support and Information

Support for patients, and their families, needs to be available at every stage. The need for information will vary, and individual patients have the right to access information at the time and level of detail they wish. Specialist nurses have an important role in providing contact and professional links, and as key members of the multidisciplinary team they are closely involved in addressing the physical, psychological and social needs of patients and their families. Finally, clear communication links between primary care, the acute sector and voluntary organisations are essential for the effective delivery of consistent, readily available and accessible care for patients with lung cancer.

1.5 The CSBS Standards and Your Care

CSBS Standards and Questions You Might Want to Ask

The lung cancer standards have been summarised and are shown below in blue. Each standard is followed by relevant questions you might want to ask about your care.

Referral guidelines are in place between primary and acute care.

- Why are you referring me?
- Who are you referring me to?

Patients who need urgent treatment get a hospital appointment within two weeks.

- How quickly will I be seen?

Patients are told about the type of test they are getting and why, when they will receive the results, and whom, they will receive them from.

- What tests will I get and what are they for?
- How many will I need?
- Who will give me the results and when?

Referrals are made to the appropriate cancer specialist and multidisciplinary team.

- Is the doctor I will be seeing a cancer specialist?
- Will that doctor have all my test results?

Those discussing the diagnoses and other sensitive issues with patients are trained in communication skills.

- Will the doctor understand my concerns and give me time to ask questions?
- Will a specialist nurse be there to speak to me?

GPs are informed, without undue delay, about a patient's diagnosis, prognosis, proposed treatment and what the patient has been told.

- Who will tell my GP about the results of my tests and the treatment that is planned?
- How quickly will this happen?

Arrangements are in place for the supply of equipment and drugs in the community as well as in hospital.

- Who will arrange for any drugs or equipment I may need when I leave hospital?
- What do I do if I need help overnight or at the weekend?

Waiting times for investigation and treatment are monitored and reduced wherever possible.

- When will my treatment start?
- What will the treatment be like and how long will it take?
- Will there be side-effects and what can I do about them?

Surgery is performed by a specialist or sub-specialist for those cancers where evidence shows this improves the result.

- Is my surgeon a specialist in my type of cancer?

Chemotherapy is prescribed by a medical or clinical oncologist and its administration is supervised by trained staff.

- Is the doctor prescribing my chemotherapy an expert in this field?
- Who will give me my chemotherapy and will they have the right training?

All treatment and care plans are discussed by a multidisciplinary team which includes cancer nurses and all the main consultants.

- Will my treatment be discussed by all the staff involved in my care? Does this team include cancer nurses as well as doctors?

There are formal interdepartmental referral arrangements in place and full records are available to all the staff involved in a patient's care. Wherever possible, integrated care pathways are developed.

- If I have to go to more than one clinic or hospital, will they know about my diagnosis and treatment?

Good supportive care is available throughout treatment and patients know how to get help including from sources outside the NHS.

- Who should I contact if I am worried about my diagnosis, treatment or prognosis?
- What help is available for my family?
- What patient support groups are there in my area?

There are formal arrangements in place for the provision of palliative care and the management of symptoms.

- Who will help me deal with symptoms like pain and tiredness during my treatment?

Patients and their families have good practical and emotional support when they need it.

- Who can I talk to about how I am feeling?
- What support is available for my family?

1.6 Frequently Asked Questions and Useful Contacts

Q. Can I do anything to prevent myself from getting cancer?

A. The cause of many cancers is not known although there is increasing evidence that certain factors do raise the risk of developing cancer. The European Union has developed a 10 point code designed to reduce your risk of getting cancer and this is detailed below:

- Stop smoking.
- Limit alcohol consumption.
- Cover up in the sun.
- Be breast aware.
- Attend screening invitations.
- Eat at least five portions of fruit and vegetables daily.
- Take regular exercise.
- Check for unusual lumps.
- Follow health and safety instructions on substances which may cause cancer.
- Consult a GP if you have continual problems such as persistent cough or a change in bowel or urinary habits.

Q. If I have had cancer are my children more at risk?

A. Very few cancers have a strong enough genetic component to put your children at high risk of developing the disease (less than 5%). The most common cancers where there is evidence of family histories are breast, colorectal and ovarian cancer and if you are concerned about your family history, you should discuss this with your doctor who can refer you to a specialist clinic if necessary.

Q. Can I ask for a second opinion from another cancer specialist?

A. It is perfectly reasonable for patients with cancer, who have several options for the treatment of their disease, to seek a second opinion. Your GP will be able to help you arrange this. A list of organisations that can provide further advice is also provided in this report.

Q. Do all chemotherapy drugs have bad side-effects?

A. A lot of progress has been made in improving the drugs used to treat cancer and there are now over 50 anti-cancer drugs that can be used in various combinations. Each drug has different side-effects which should be discussed with you by the doctor and nurses who give you the treatment. If you want to ask more about this before you agree to treatment, information on these drugs is readily available. Not all chemotherapy causes sickness and hair loss, and there are now several drugs available that can control side-effects very effectively.

Q. Is it true that clinical trials are good for you?

A. Clinical trials are good for you for two reasons: first they ensure that you receive the highest possible standards of care, and second your treatment will be fully documented and the results analysed. They also allow you to make a contribution to improving health services by being part of the evidence that is used to determine the best way to treat diseases. Your permission will always be sought and you will not be entered into a trial without your knowledge and consent. If you do not want to enter a trial this will not affect your treatment. You should always be given full information about any study or trial you are asked to consider and there is usually a specially trained nurse available to discuss this with you and to answer your questions.

Useful Contacts

The following organisations can provide information and support about all aspects of cancer. GPs and healthcare teams treating cancer can also provide you with information about local support groups.

At certain times the telephone lines may be very busy and callers are encouraged to keep trying.

1. **Cancer BACUP**
   2nd Floor
   30 Bell Street
   GLASGOW
   G1 1LG

   Tel: 0141 553 1553
   www.cancerbacup.org.uk

2. **Macmillan Cancer Relief (includes Cancerlink)**
   9 Castle Terrace
   EDINBURGH
   EH1 2DP

   Tel: 0131 229 3276
   www.macmillan.org.uk

3. **Tak Tent Cancer Support**
   Flat 5
   30 Shelley Court
   Gartnavel Complex
   GLASGOW
   G12 0YN

   Tel: 0141 211 0122
   www.taktent.org.uk

4. **Cancer Research UK**
   Federation House
   222 Queensferry Road
   EDINBURGH
   EH4 2BN

   Tel: 0131 343 1344
   www.cancerresearchuk.org

5. **Health Education Board for Scotland**
   Woodburn House
   Canaan Lane
   EDINBURGH
   EH10 4SG

   Tel: 0131 536 5500
   www.hebs.scot.nhs.uk

Lung Cancer

6. **British Lung Foundation**
   6th Floor
   New Garden House
   78 Hatton Garden
   LONDON
   EC1N 8JR

   Tel: 020-7831 5831
   www.lunguk.org

7. **Roy Castle Lung Cancer Foundation**
   5-6 Park Terrace
   GLASGOW
   G3 6BY

   Tel: 0141 231 0580
   www.roycastle.org

Chapter 2

National Performance Against the Standards

2 National Performance Against the Standards

This section presents the findings across Scotland in terms of performance against individual standards. A number of examples of innovative local solutions and areas of good practice are highlighted in boxes throughout the text. These examples are not exhaustive – every review team noted examples of good practice during visits and these were often in place in more than one Trust. Challenges are also listed and there is certainly scope for change and improvements in the process of care for lung cancer patients. This is recognised by healthcare professionals and by patients and their families and friends, and while in the past there was limited patient involvement in cancer care, there are now many examples of successful partnership working. In common with many conditions, cancer care is complex and most treatment is personally tailored to suit each patient's needs. This presents challenges when developing general patient information. It is not easy to achieve a balance between personal expectations and outcomes, and general information.

Feedback from those reviewed and those in review teams is sought after every visit and nearly 700 people have responded. Overwhelmingly, those involved in the review process report that the opportunity to network and the time to consider different ways of addressing shared issues has been valuable. Giving the public and the service the chance to review many aspects of the way in which care is provided has been fundamental to the Board's approach and is a starting-point for many activities including:

- measuring good practice;
- disseminating good practice;
- stimulating multidisciplinary working;
- involving those who use the service; and, perhaps most importantly,
- reviving the appetite to ensure that the provision of patient care is balanced by the monitoring of that care against key performance standards and that the quality of care is continually improved.

During the review of lung cancer services, 31 hospitals were reviewed based in the 14 acute Trusts and three Island NHS Boards to assess performance against the standards. This national overview summarises 28 local reports, as Trust-wide information was submitted by three of the Trusts reviewed. Accordingly the findings presented reflect the number of instances where the standard criteria were met, based on the denominator of the 28 local reports (referred to in the text as hospitals).

Information, Data Collection and Audit

Data collection and regular audit and review of the results facilitate effective healthcare as outcomes can be monitored and, where necessary, improvements made in the quality of treatment and care.

During review visits it was apparent that the methods used for data collection, audit and dissemination of information vary considerably between and within Trusts, Island NHS Boards and hospitals. A key challenge for NHSScotland is to develop systems that support the monitoring of clinical practice, and to disseminate the results of this monitoring. A further challenge is to develop common definitions and analyses so that performance can be compared within and between organisations.

There is clearly a commitment to, and an awareness of, the importance and value of data collection and audit, but too often this is taken forward by enthusiastic individuals without the necessary support when a Trust-wide approach is required.

Although Trusts tried hard to meet the requests for information about services, what was provided was often incomplete. This explains some of the gaps in information provided throughout the reports, and where information was not available to support a response, this has been assessed as 'Not met (insufficient evidence)'.

More worryingly, it suggests that the organisations responsible for cancer services, and the clinicians working within them, are not in a position to routinely monitor or account for those services, nor can they give patients information on, for example, the length of time they can expect to wait between different stages of treatment. It is not possible for a service to know its effectiveness in the delivery of care without such information. Not only are data systems poor, but also, they do not allow information about different parts of the overall process to be connected.

A national cancer registration scheme has been in operation in Scotland for the last 30 years and the SIGN core data sets are well-established. The Board has already set standards and targets and has provided self-assessment tools which will allow monitoring of performance against these. There is now an urgent need to improve the methods and systems used to collect and analyse information and this should be taken forward at national and local levels.

2.1 Standard 1: Referral Process

Standard Statement
Referral guidelines jointly agreed between primary and secondary care are used for patients suspected of having cancer. The respiratory physician is normally the clinician responsible for confirming diagnosis of lung cancer and supervising the initial investigations and management plan.

Essential Criteria

1. **Formal arrangements jointly agreed between primary care and the hospital multidisciplinary team are in place. These specify which patients are referred and to whom and the referral arrangements for a positive or suspicious result from radiology.**

This criterion was met in 13 hospitals.

2. **Formal arrangements jointly agreed between hospital departments and specialists working within the multidisciplinary team are in place. These specify which patients are referred and to whom.**

This criterion was met in nine hospitals.

3. **Respiratory physician to see within two weeks of referral, a minimum of 90% of patients referred with a strong clinical and/or radiological suspicion of lung cancer.**

This criterion was met in three hospitals.

Strength

- Most Trusts were able to demonstrate that informal arrangements jointly agreed between primary care and the hospital multidisciplinary team are in place.

Challenges

- Many Trusts did not produce formal protocols for interdepartmental referral of patients with suspected lung cancer.
- It was not possible to determine whether respiratory physicians see 90% of patients with suspected lung cancer within two weeks, as most Trusts were unable to provide audit data to support this.

Recommendations

- Trusts should develop and review with Primary Care Trusts formal pathways of care for patients suspected of having lung cancer, and these should be shared with all primary care teams.
- Waiting times in the various parts of the investigation process should be measured, evaluated and reported.
- Trusts should ensure that within two weeks of being suspected of having lung cancer, patients are referred to a respiratory physician for assessment.

Examples of local initiatives

Dumfries & Galloway
Dumfries & Galloway Royal Infirmary has developed a medical handbook for those providing services, which contains protocols for all medical conditions and essential information about the organisation of services within the hospital. In particular, the regular multidisciplinary approach to updating the handbook, local ownership and acceptance by junior medical staff are commendable.

Grampian
Grampian University Hospitals NHS Trust has a number of beds reserved on the five-day investigation ward for patients referred under suspicion of lung cancer, and this results in a faster diagnosis for the large number of patients referred to Aberdeen Royal Infirmary.

Orkney
NHS Orkney has appointed two patient co-ordinators, which it felt would not only enhance links between the Balfour Hospital, Kirkwall and Aberdeen Royal Infirmary but also provide a central point for a formal referral system.

2.2 Standard 2: Investigations

Standard Statement
All patients with suspected lung cancer have timely and appropriate investigations carried out to confirm a diagnosis of lung cancer.

Essential Criteria

1. **A minimum of 75% of all lung cancer patients have their diagnosis confirmed by histology/cytology and the reasons for not having this confirmed are recorded.**

This criterion was met in 11 hospitals.

2. **Locally agreed investigation protocols are in place.**

This criterion was met in 15 hospitals.

3. **All patients considered for curative treatment (surgery, radical radiotherapy and combined modality treatment) are to receive a CT scan of the chest, and for a minimum of 90% of patients this will be within two weeks from the request.**

This criterion was met in two hospitals.

4. **Information about the patients' diagnosis, their understanding of the diagnosis and outline of treatment options is communicated to the GP within 1-2 working days.**

This criterion was met in 17 hospitals.

Strength

- Where audit data were available, most lung cancer patients had their diagnosis pathologically confirmed.

Challenges

- The review process frequently found more than two weeks' delay for CT scanning.
- Most Trusts' data collection and processing systems are inadequate, and there were insufficient audit data to assess performance against this standard.
- Timely and comprehensive communication between hospital and primary care clinicians need to be improved.

Recommendations

- Trusts should improve access to and reduce waiting times for CT scanning. The development of clear interdepartmental referral policies should help to address this.
- Trusts should establish data collection and processing systems that allow them to assess their performance against standards.

Example of a local initiative

Fife
Queen Margaret Hospital, Dunfermline, operates a CT scanner between the hours of 9.00 am and 5.00 pm and in emergency situations. These hours allow for all patients to receive a CT scan within two weeks of the request for a scan having been made.

2.3 Standard 3: Multidisciplinary Working

Standard Statement 3(a)
There is a named lead consultant for lung cancer services.

Essential Criterion

1. Named Lead Consultant with responsibility for co-ordinating a multidisciplinary system of working.

This criterion was met in 26 hospitals.

Desirable Criterion

2. Managed Clinical Network.

This criterion was met in four hospitals.

Strengths

- Almost every Trust has nominated a lead clinician responsible for the co-ordination of lung cancer services.
- There is a commitment to multidisciplinary working in every Trust.

Challenges

- In Trusts with more than one hospital site, all staff need to be aware that there is one named lead consultant with overall responsibility for co-ordinating a multidisciplinary system of working across the whole Trust.
- At the time of the review, only four Trusts were involved in Managed Clinical Networks.

Recommendations

- Trusts should encourage and support the development of managed clinical networks for lung cancer services.
- Administrative and management support should be provided to facilitate multidisciplinary working.
- The time commitment necessary for multidisciplinary working should be formally recognised in job plans.

Standard 3: Multidisciplinary Working

Standard Statement 3(b)
Each patient is aware of the named clinician responsible for any given part of their journey.

Essential Criterion

1. **Cancer patients are told the name of the clinician responsible for their care at each stage of the patient journey.**

This criterion was met in all 28 hospitals.

Strength

- All Trusts reported patients were aware of the named clinician responsible for their care at any given part of their journey. This information is provided in a variety of ways including by letter, personally during their hospital stay, by the use of name badges and on the bedhead.

Challenge

- There is a need to formally agree roles and responsibilities of the multidisciplinary team.

Standard 3: Multidisciplinary Working

Standard Statement 3(c)
All patients with lung cancer have access to a named cancer nurse with experience and knowledge of their cancer.

Essential Criteria

1. **Patients have access to a named cancer nurse with expertise in lung cancer.**

This criterion was met in 24 hospitals.

2. **In cancer centres patients have access to a specialist cancer nurse.**

This criterion was met in four hospitals.

3. **There are locally agreed standards of care covering all aspects of cancer nursing practice and clear communication pathways between professionals.**

This criterion was met in 17 hospitals.

4. Clear links between hospital-based nursing services and those in the community and palliative care services.

This criterion was met in 28 hospitals.

Desirable Criterion

5. Access to a specialist cancer nurse for lung cancer.

This criterion was met in 18 hospitals.

Strengths

- The standard of nursing care is good, and clear communication paths have been developed between professionals. Some sites have developed standards of care specifically for the management of lung cancer, and in other sites standards of care generic to all conditions are in place.
- A number of Trusts were able to illustrate how the palliative care service is well integrated into the lung cancer patient's journey of care.
- There are posts dedicated to facilitate seamless communication pathways between professionals and discharge of patients from secondary to primary care. Hospital discharge co-ordinator roles were identified in some hospitals, and it was evident that these had a positive effect on the quality of discharge information and planning.

Challenges

- Although lung cancer patients in acute Trusts had a named nurse, the review could not confirm their training and experience in lung cancer.
- Lung cancer nurse specialists play an important role in the care of lung cancer patients, providing advice and support throughout their journey of care, and are often the communication link between different members of the multidisciplinary team. At present there are only a small number of these nurses in post, and there is a demonstrable lack of equity in access.
- Written standards of care for nursing practice are not in place specifically for lung cancer patients.

Recommendations

- All patients with lung cancer should have access to a named nurse with knowledge and experience of lung cancer.
- The number of specialist lung cancer nurses should be increased.
- The roles and responsibilities of multidisciplinary teams should be agreed formally.
- Written standards of care for nursing practice should be developed.

Standard 3: Multidisciplinary Working

Standard Statement 3(d)
The management of patients with cancer is multidisciplinary.

Essential Criteria

1. **Multidisciplinary management protocols are in place for patients with cancer, covering systems for referral (including to thoracic surgery, medical and radiation oncology and palliative care services), investigation, treatment and follow-up.**

This criterion was met in 12 hospitals.

2. **Local agreement and awareness of the membership of the lung cancer multidisciplinary team including as a minimum a respiratory physician, oncologist and specialist cancer nurse.**

This criterion was met in 17 hospitals.

3. **A documented system for working and decision-making process of the multidisciplinary team.**

This criterion was met in 19 hospitals.

4. **Cancer centres have a weekly clinical conference.**

This criterion was met in four hospitals.

5. **All patients will have a treatment plan developed and agreed jointly with the patient and communicated to the GP.**

This criterion was met in 23 hospitals.

Desirable Criteria

6. Evidence of specialisation in lung cancer within oncology, respiratory medicine, radiology and pathology services.

This criterion was met in 10 hospitals.

7. Provision of a specialist thoracic oncology clinic.

This criterion was met in 18 hospitals.

Strengths

- The benefits of collectively discussing the management of lung cancer patients in a multidisciplinary forum is recognised by all Trusts, and most were making steps towards achieving this.
- For those Trusts where multidisciplinary management protocols for patients with cancer were in place, these were comprehensive, and there was evidence to suggest that they were used in the management of patient care.

Challenges

- All Trusts need to clearly define the multidisciplinary lung cancer team for their patients.
- The majority of Trusts had no arrangements for formal documentation and dissemination of decisions made during the multidisciplinary team meetings. Where available, patient casenotes were used to document decisions. However this was not considered to be a satisfactory mechanism to ensure that all individuals involved in the care of lung cancer patients were made aware of the decisions made by the multi-disciplinary team, as not all healthcare professionals have access to notes.
- Trusts reported difficulties with finding an appropriate time for all essential members of the team to meet, particularly where members of the team provide care in remote areas, or work on more than one site. The challenge is to consider ways of overcoming this, including teleconferencing and video links.

Recommendations

- Formal protocols for treatment and management of lung cancer patients should be developed with the collaboration of all specialties involved.
- All Trusts need to develop a formal system of multidisciplinary working and decision-making.
- Systems should be developed, including teleconferencing and telemedicine, which support multi-site working and improve specialist access to patients in remote areas.

Example of a local initiative

Grampian

Aberdeen Royal Infirmary has a lung cancer specialist participating in the development of a patient information database that will record diagnosis, treatment plan, pathology details, etc. It is hoped that this database will eventually link up with community primary care databases, facilitating continuity of care between different professional groups in secondary and primary care.

2.4 Standard 4: Education and Training

Standard Statement
All health professionals in cancer services undertake cancer-specific professional education and development including the principles and philosophy of palliative care.

Essential Criteria

1. **Doctors, nurses and professions allied to medicine working in multidisciplinary teams have accredited specialist education and training in cancer.**

This criterion was met in 19 hospitals.

2. **All health professionals involved with cancer services undertake communication skills training.**

This criterion was met in 11 hospitals.

3. **There is evidence of regular discussion of work practice at a local level within the multi-professional team.**

This criterion was met in 25 hospitals.

4. **There is a multidisciplinary rolling programme of palliative care education for all staff involved in cancer care covering the physical, emotional, social and spiritual aspects of palliative care.**

This criterion was met in 17 hospitals.

5. **At least one member of a multidisciplinary team has undertaken an accredited course in palliative care.**

This criterion was met in 27 hospitals.

Strengths

- There is considerable commitment and enthusiasm from Trust staff to undertake cancer-specific education and development.
- The majority of Trusts were able to provide evidence that cancer-specific education is available to healthcare professionals.
- In-house education packages have been developed in a number of Trusts.

Challenges

- Communication skills training is not routinely available to all healthcare professionals, and in particular for senior medical staff.

Challenges

- Although there are some excellent examples of palliative care education programmes these were found to be largely focused on nursing staff. Other healthcare professionals in cancer services did not all appear to have access to palliative care courses.
- Work commitments and financial constraints were cited as major barriers to training, particularly among medical and nursing staff. The challenge is to ensure that all staff not only have access, but also the opportunity to attend. This is particularly important in remote Trusts, where travel distances and associated costs present specific challenges.
- Systems of appraisal and accreditation to measure the education and training standards of the workforce are not generally in place.

Recommendations

- Cancer education and training should be available for all members of the multidisciplinary team with particular emphasis on communication skills. This should be explored with NHSEducation.
- A national programme of appraisal and accreditation should be developed, which will allow them to measure the education and training standards of the workforce. This should be explored with NHSEducation.
- Trusts should explore the use of information technology to enhance the training opportunities available to healthcare professionals.
- An evaluation of training needs should be carried out to find out the training requirements of Trust personnel.

Examples of local initiatives

Shetland
NHS Shetland has a programme of palliative care education in place which has been developed by a local GP, and funded by Macmillan Cancer Relief. Six monthly palliative care seminars are held where local and visiting specialists provide a range of lectures and seminar sessions on palliative care issues.

West Lothian
West Lothian Healthcare NHS Trust provides the opportunity for staff to 'shadow' their peers in secondary care.

Highland
Highland Acute Hospitals NHS Trust has undertaken a training needs assessment. Following this NHS Highland and the Highland Hospice have developed a programme of palliative care education and hold seminars on cancer care.

2.5 Standard 5: Audit

Standard Statement
Prospective clinical audit is an integral part of cancer services

Essential Criteria

1. **Continuous collection of (SIGN) Lung Cancer Core Data Set to facilitate audit.**

This criterion was met in 11 hospitals.

2. **Participation in the Scottish Cancer Therapy Network (SCTN) National Data Quality Assurance Programme.**

This criterion was met in 10 hospitals.

3. **Registered number of patients with lung cancer managed by the Trust and the percentage of those managed by the respiratory physician are recorded.**

This criterion was met in 10 hospitals.

Desirable Criteria

4. **1, 2, and 5-year survival rates are audited.**

This criterion was met in eight hospitals.

5. **Regular reporting of casemix and outcome.**

This criterion was met in seven hospitals.

Strength

- All Trusts recognised the value of clinical audit as a tool to support service evaluation, and some have established data collection systems in place.

Challenges

- Most Trusts were unable to provide audit data. As a result, it was not possible to assess their performance against certain standards.
- Collection of the SIGN Lung Cancer Core Data Set is variable.
- Resource constraints are cited as a major barrier to effective clinical audit. Clinicians reported that they do not have the time, support staff, or the systems in place to support data collection activity.

Recommendations

- All Trusts should ensure collection of the SIGN National Minimum Core Data Set according to national data definitions, and participate in the SCTN National Data Quality Assurance Programme.
- All Trusts should implement sustainable, continuous and prospective collection of key data sets which will allow monitoring of service standards.

2.6 Standard 6: Clinical Trials

Standard Statement
Those involved in delivering cancer services are to try to increase the participation of patients in well-designed, ethical clinical trials.

Essential Criteria

1. Recording of patients offered a clinical trial.
This criterion was met in 10 hospitals.

2. Percentage of patients entering clinical trials is recorded.
This criterion was met in 13 hospitals.

3. Informed consent.
This criterion was met in 19 hospitals.

4. Functioning Ethics Committee.
This criterion was met in all 28 hospitals.

Strength

- All Trusts had access to a functioning Ethics Committee.

Challenges

- Overall the percentage of lung cancer patients who are being entered into clinical trials is small.
- There is a lack of systems in place to record information on the recruitment of patients into clinical trials.
- Geographical difficulties and lack of research support staff were cited as the main barrier to patient entry into clinical trials.

Recommendation

- Trusts should recognise the importance of clinical research for quality of care, and its fundamental contribution to the improvement of healthcare services by supporting the infrastructure that will enable patients to have improved access to clinical trials.

2.7 Standard 7: Communication and Information Sharing

Standard Statement
Patients are fully informed of different options for treatment and involved in decision-making to the extent they wish.

Essential Criteria

1. **Patients with cancer receive information about their illness at all stages. The treatment options are discussed and decisions taken in partnership with the patient.**

This criterion was met in 26 hospitals.

2. **Written information leaflets (including information about local support groups) are available for all patients (including those with disabilities and those requiring translation services).**

This criterion was met in 22 hospitals.

3. **The breaking of bad news is handled in a sensitive manner.**

This criterion was met in all 28 hospitals.

4. **Private areas are available in clinics and wards for communicating information.**

This criterion was met in 22 hospitals.

Strengths

- There is a growing awareness of the usefulness and need for clear, consistent and up-to-date information for patients.
- Most Trusts have arrangements in place to try and ensure that bad news is given sensitively and in private areas.

Challenges

- It was not possible to assess how bad news is broken to patients and their families.
- Information was not always readily available, and sometimes the distribution of leaflets was restricted.
- Access to private areas for communicating bad news was limited or not available in some Trusts. This is particularly sensitive for lung cancer patients, many of whom may be too ill to move out of the ward area.

Recommendations

- All Trusts should implement protocols for the breaking of bad news, and should support staff with training.
- Trusts should explore ways of ensuring that information is available to patients and their families in a range of formats, including written, Braille, pre-recorded tapes and translated into other languages. Where possible, patients should be involved in the development of this information.

Examples of local initiatives

Ayrshire & Arran

Ayrshire & Arran Acute Hospitals NHS Trust has developed a Cancer Nurse Steering Group. This group will facilitate the dissemination of best practice amongst cancer nursing services across the Trust, and consult with the Lung Cancer Multidisciplinary Team on issues relevant to communication and information provision for lung cancer patients.

Glasgow

Stobhill Hospital, Glasgow runs a dedicated clinic for breaking bad news, which is attended by both the consultant and clinical nurse specialist.

Stobhill Hospital also gives all patients receiving radiotherapy an information folder. This contains information about patients' regimes, including contact telephone numbers and what to do with each drug.

2.8 Standard 8: Assessment and Care Planning

Standard Statement
All patients with cancer have their complex needs assessed, documented and acted upon.

Essential Criteria

1. **Each patient has an individual documented care plan.**

This criterion was met in 26 hospitals.

2. **The individual care plan assesses and documents the most distressing problems as identified by the patient; whether physical, emotional, social or spiritual.**

This criterion was met in 26 hospitals.

3. **The most distressing problems are documented in patient notes.**

This criterion was met in 27 hospitals.

4. **There is a clear record of what the patient has been told.**

This criterion was met in 26 hospitals.

5. **There is evidence of regular reviews of problems, and actions taken.**

This criterion was met in all 28 hospitals.

6. **All patients have a written record given to them on discharge documenting medication and detailing: what the medication is, when it was prescribed, why it was prescribed, frequency of administration, dose and formulation.**

This criterion was met in 13 hospitals.

7. **Continuity of care for patients with specific palliative needs is ensured by the appropriate communication of those needs from secondary to primary care.**

This criterion was met in 27 hospitals.

8. **Continuity of care for patients with ongoing palliative needs is ensured by the appropriate communication of those needs between GPs and 'out-of-hours' co-operatives.**

This criterion was met in 19 hospitals.

Desirable Criteria

9. **Integrated records.**

This criterion was met in four hospitals.

10. Social work advice from a designated social worker with a special interest in palliative care.

This criterion was met in 15 hospitals.

Strength

- All Trusts provided an assurance that important events during a patient's stay in hospital, including what they have been told, are documented in the care plan.

Challenges

- Most Trusts did not provide patients with comprehensive information on medication at the time of discharge.
- Integrated records are not in use for lung cancer patients in most Trusts. Further, the term 'integrated record' was interpreted in different ways at different hospitals.
- Only half the Trusts had social work advice from a designated social worker for lung cancer or palliative care services.

Recommendations

- Trusts should ensure their immediate discharge document includes all information required for ongoing co-ordinated care and safe administration of medication.
- Those involved in care of individual patients should have access to all the relevant records. This could be achieved by integrated records. There should be improved understanding of the value of integrated records that focus on the needs of the patient.
- NHS Boards should improve the access of lung cancer patients to social work support.

Examples of local initiatives

Argyll & Clyde
Lorn and District General Hospital, Oban has an all-inclusive and concise hand-held patient record.

Shetland
NHS Shetland has a fast track assessment system in place for patients with palliative care needs. Case conferences are held to ensure rapid and seamless discharge of patients in the palliative care stage of their illness back into the community. In addition the community Macmillan nurse visits the hospital weekly and is involved with patient discharge.

2.9 Standard 9: Management

Standard Statement
All patients to be considered for treatment appropriate to their stage of disease.

Essential Criteria

1. **A decision about initial treatment to be made within 4 weeks of diagnosis.**

This criterion was met in three hospitals.

2. **All patients referred to oncology are seen by an oncologist within 1 week of referral.**

This criterion was met in five hospitals.

3. **Waiting times for patients receiving treatment are recorded, these are to remain within national guidelines.**

This criterion was met in one hospital.

4. **Percentage of patients receiving surgery, radiotherapy, chemotherapy and combined modality treatment are recorded.**

This criterion was met in 12 hospitals.

5. **Percentage of patients not receiving active treatment are recorded.**

This criterion was met in nine hospitals.

6. **Reasons for not receiving active treatment are recorded.**

This criterion was met in 16 hospitals.

Strength

- All Trusts were aware of the challenge of waiting times.

Challenges

- Where data were available, the times between diagnosis and treatment exceeded national standards.
- The evidence on which to measure compliance with waiting time targets is not currently available due to the lack of systematic data collection and processing.
- Pressure on oncology resources, and the lack of monitoring of referral waiting times, causes delays and anxiety.

Recommendations

- Measures to reduce waiting times should be introduced urgently at both national and local levels.
- Trusts should ensure that waiting times are recorded as part of routine data collection.

2.10 Standard 10: Surgical Management

Standard Statement
All surgical management for lung cancer to take place under the auspices of a consultant thoracic surgeon or consultant cardiothoracic surgeon.

Essential Criteria

1. **A minimum of 90% of patients resected within six weeks of diagnosis.**

This criterion was met in two hospitals.

2. **All lung resection for cancer to be performed or supervised by consultant thoracic or cardiothoracic surgeon.**

This criterion was met in six hospitals.

3. **Locally agreed protocols for preoperative assessment and surgical technique (including frozen section) are in place.**

This criterion was met in three hospitals.

4. **Less than 10% of patients are resected by wedge or segmentectomy.**

This criterion was met in six hospitals.

5. **All patients with incompletely resected or unresectable tumours have a clearly defined management plan prior to discharge which is communicated to the patient and the GP.**

This criterion was met in four hospitals.

Strength

- Lung cancer resections were performed by specialist surgeons in the majority of cases.

Challenges

- Most Trusts were unable to provide audit data on the waiting time between diagnosis and treatment.
- Protocols for the preoperative assessment and surgical technique were not available in half the Trusts which performed lung cancer surgery.
- Not all patients with incompletely resected or unresectable tumours have a clearly defined management plan prior to discharge.

Recommendations

- Trusts should collect data to allow them to measure waiting times.
- Trusts should improve the referral and preoperative investigation process through the development of care pathways and investigation protocols.
- Arrangements should be in place to ensure that all patients with incompletely resected or unresectable tumours know their postoperative management plan before they are discharged from the surgical unit. This information should also be provided to the patient's GP without delay.

Example of a local initiative

Lothian
Lothian University Hospitals NHS Trust uses minimally invasive surgery through the use of minimal Access VATS (Video Assisted Thorascopic Surgery). This ensures optimal chances of survival.

2.11 Standard 11: Radiotherapy Treatment

Standard Statement
All patients considered for radiotherapy will have an appropriate radiotherapy regimen.

Essential Criteria

1. **Patients not to receive preoperative radiotherapy unless it is a part of externally reviewed research protocol.**

This criterion was met in four hospitals.

2. **Patients with completely resected N0/N1 tumours not to receive postoperative radiotherapy.**

This criterion was met in four hospitals.

3. **Percentages of patients with incomplete resection receiving postoperative radiotherapy are recorded.**

This criterion was met in five hospitals.

4. **Percentage of inoperable patients with stage 1, 2 and 3A disease receiving radical radiotherapy are recorded.**

This criterion was met in four hospitals.

5. **Percentages of SCLC patients achieving good response to induction chemotherapy receiving consolidation thoracic irradiation are recorded.**

This criterion was met in nine hospitals.

6. **Percentages of SCLC patients treated with combined modality therapy are recorded.**

This criterion was met in 10 hospitals.

7. **Percentages of patients with good prognosis SCLC receiving PCI are recorded.**

This criterion was met in seven hospitals.

8. **Percentages of patients receiving palliative radiotherapy are recorded.**

This criterion was met in 10 hospitals.

Desirable Criterion

9. **Percentage of radically treated patients with NSCLC receiving CHART are recorded.**

This criterion was not met in any hospital.

Strength

- The use of pre and postoperative radiotherapy follows evidence-based guidelines in all Trusts providing radiotherapy.

Challenges

- Most Trusts could not provide audit data to allow review teams to assess performance against the radiotherapy standards. The percentages of patients receiving the regimen described in the criteria are not routinely collected or available.
- Where data were available, the waiting times between radiotherapy booking and the start of radiotherapy were outside the national standard.

Recommendations

- Sustainable audit data collection systems should be established in all Trusts.
- It is essential that long-term plans are in place to reduce the risk of building up such waiting times in the future.
- The cancer centres need to develop and implement mechanisms for radiotherapy delivery within the national standards of care.

Example of a local initiative

Glasgow

The Western Infirmary, Glasgow offers a radiotherapy helpline. This is a voluntary service provided by a radiographer during lunchtime. All calls made to this service are logged, and patient feedback is positive.

2.12 Standard 12.1: Chemotherapy Management

Standard Statement
Chemotherapy is prescribed, dispensed, administered, and supervised in a safe and effective manner.

Essential Criteria

1. **Chemotherapy to conform to JCCO (1994) guidelines, this includes the following:**

This criterion was met in 11 hospitals.

2. **Cancer chemotherapy is carried out in designated in-patient or out-patient facilities which are properly equipped for the purpose.**

This criterion was met in 18 hospitals.

3. **Cancer chemotherapy regimes are prescribed on the basis of a protocol in regular use in the department.**

This criterion was met in 24 hospitals.

4. **Protocols are readily known and available to any staff involved in the delivery of chemotherapy.**

This criterion was met in 23 hospitals.

5. **Protocols contain an account of toxic effects of the drugs used and recommendations for their management.**

This criterion was met in 18 hospitals.

6. **Chemotherapy is initiated by an accredited clinician using protocols jointly agreed between members of the multi-disciplinary team.**

This criterion was met in 21 hospitals.

7. **Chemotherapy is dispensed by trained and experienced practitioners working with suitable equipment in an appropriate environment.**

This criterion was met in 23 hospitals.

8. **Chemotherapy is administered by trained and experienced practitioners.**

This criterion was met in 24 hospitals.

9. **Departments administering cancer chemotherapy are to have access to education and training courses for all healthcare professionals administering chemotherapy.**

This criterion was met in 21 hospitals.

Strength

- The majority of Trusts in which chemotherapy is prescribed and administered ensured that it is prepared and delivered in designated facilities by appropriately trained personnel.

Challenges

- Many Trusts did not adhere to all components of the Joint Council for Clinical Oncology (JCCO) (1994) guidelines. Reasons for non-compliance were related to 'out-of-hours' drug administration, constraints on facilities and staff training.
- Not all Trusts have readily available protocols for prescribing chemotherapy and dealing with toxic effects.

Recommendations

- Trusts should ensure that all aspects of chemotherapy preparation, delivery and administration conform to national guidelines.
- Each Trust should ensure that chemotherapy protocols are developed through networks, are readily available and used by all staff involved in the administration of chemotherapy.
- Toxic effects of chemotherapy and their management need to be a part of all chemotherapy protocols.

Examples of local initiatives

Fife
Fife Acute Hospitals NHS Trust is piloting a Chemotherapy Integrated Care Pathway and items such as treatment response and toxicity will be included and expanded upon in this document.

Lothian
The cancer centre at the Western General Hospital, Edinburgh has ISO9000.

Standard 12.2: Chemotherapy Treatment

Standard Statement
All patients considered for chemotherapy to have an appropriate chemotherapy regimen prescribed and supervised by an oncologist or experienced respiratory physician.

Essential Criteria

1. **A minimum of 60% of SCLC patients to receive combination chemotherapy.**

This criterion was met in eight hospitals.

2. **A minimum of 10% of NSCLC patients to receive chemotherapy.**

This criterion was met in nine hospitals.

3. **There is written assessment of treatment response and toxicity in patient's notes and protocol for their documentation and management.**

This criterion was met in 21 hospitals.

Strength

- This standard was met in the majority of Trusts that were able to provide data.

Challenge

- Combination chemotherapy should be the standard of care for all patients with small cell lung cancer.

Recommendation

- Full multidisciplinary management and decision-making should be in place in all Trusts to ensure that patients who may benefit from chemotherapy have the opportunity to receive the necessary regimen safely.

2.13 Standard 13: Symptom Management

Standard Statement
Care is provided in accordance with relevant SIGN guidelines or, where these do not exist in accordance with good practice guidelines, which are evidence-based.

Essential Criteria

1. **Persistent poorly controlled problems are discussed with, or referred to, the specialist palliative care team.**

This criterion was met in 20 hospitals.

2. **Locally agreed policies for pain management based on the SIGN Guideline for the Control of Pain in Cancer Patients.**

This criterion was met in 17 hospitals.

3. **Locally agreed policy on the management of symptoms in particular, but not exclusively, for: agitation/confusion, anorexia, breathlessness, constipation, fatigue, insomnia, nausea/vomiting, oral care.**

This criterion was met in 11 hospitals.

Strengths

- The majority of Trusts stated that patients with persistently poorly controlled symptoms were discussed or referred to the palliative care team for management of these symptoms.
- Most of the Trusts had locally agreed policies for pain management based on the SIGN Guideline for the Control of Pain in Cancer Patients.

Challenges

- The majority of Trusts do not have established policies for the management of symptoms such as breathlessness, insomnia and oral care, although many have developed some protocols for these.
- Some palliative care teams reported that earlier involvement, as appropriate in the care of some patients with lung cancer, would be appropriate.

Recommendations

- Trusts should ensure that patients have access to palliative care throughout the patient journey, where appropriate.
- Trusts should ensure that policies are in place for palliation of symptoms referred to in the standards.

2.14 Standard 14: Drugs

Standard Statement
Prescribed essential drugs are obtainable when required (including 'out-of-hours' for patients at home).

Drugs in NHS Board Areas

Essential Criteria

1. **A list of essential drugs (including those required for syringe drivers) is agreed in each NHS Board area. These drugs are available at all times, especially out-of-hours, from designated pharmacy source(s).**

This criterion was met in 23 hospitals.

2. **There are locally agreed guidelines on the use of syringe drivers and drugs used with syringe drivers.**

This criterion was met in 25 hospitals.

Drugs in the Community

3. **This arrangement includes pharmacy advice from a specialist pharmacist with particular interest in palliative care.**

This criterion was met in 16 hospitals.

4. **These arrangements are known to palliative care staff, primary healthcare teams (GPs, district nurses) and on call co-operatives/GPs.**

This criterion was met in 15 hospitals.

Strength

- Most Trusts have systems in place to ensure that essential drugs are available at all times and also have guidelines on the use of syringe drivers in place.

Challenges

- Access to pharmacy advice from a specialist pharmacist in palliative care is limited.
- Arrangements for the supply of essential drugs, and advice on palliative care drugs, are not always made known to staff providing palliative care in the community.

Recommendation

- Trusts should ensure that drugs are available at all times, and that palliative care staff, GPs, district nurses and on-call co-operative doctors are aware of the arrangements for essential drugs, and who to access for advice about them.

2.15 Standard 15: Equipment

Standard Statement
All patients receiving palliative care have timely delivery of equipment essential to their needs.

Essential Criteria

Equipment in the Community

1. **There is an effective and efficient system to ensure the supply of equipment (including syringe drivers) and training in the use of this equipment.**

This criterion was met in 27 hospitals.

2. **There is a database established for the whereabouts of essential equipment.**

This criterion was met in 23 hospitals.

3. **There is a clear designated authority for management of the equipment store.**

This criterion was met in 26 hospitals.

4. **Equipment is labelled with a telephone number for quick uplift of items.**

This criterion was met in 14 hospitals.

5. **Basic equipment is delivered to the patient within 24 hours, seven days a week.**

This criterion was met in 16 hospitals.

6. **Arrangements are in place to ensure that syringe driver use can be established 24 hours a day, seven days a week.**

This criterion was met in 26 hospitals.

7. **Syringe drivers in the community are supplied by Primary Care Trusts and are maintained annually.**

This criterion was met in 23 hospitals.

Equipment in NHS Board Areas

8. **There is a rolling programme for replacement of syringe drivers resulting in the provision of one single type of syringe driver in each NHS Board area.**

This criterion was met in eight hospitals.

Desirable Criterion

9. NHS Boards and Trusts work with local authorities to set up a joint equipment service where this does not already exist.

This criterion was met in 25 hospitals.

Strengths

- The majority of Trusts had arrangements in place to guarantee that syringe drivers can be accessed and used at all times.
- Most NHS Boards are working towards establishing joint equipment stores with local authorities.

Challenges

- The majority of Trusts did not have systems in place to ensure that basic equipment is delivered to patients within 24 hours, seven days a week.
- There needs to be a register and a replacement programme for syringe drivers.

Recommendations

- NHS Boards and Trusts should work together to ensure that arrangements are in place so that basic equipment can be delivered to the patient within 24 hours, seven days a week.
- In each NHS Board area Trusts need to ensure there is a single type of syringe driver.

2.16 Standard 16: Generic Discharge Standards

Standard Statement
Effective discharge planning begins on or shortly after admission and is a continual process. Communication and transfer of information among healthcare professionals is essential to a seamless process.

Essential Criteria

1. **Discharge is planned and all relevant information communicated at the appropriate time to the patient and to those involved in continued provision of care.**

This criterion was met in 22 hospitals.

2. **A handheld immediate discharge document is provided.**

This criterion was met in 24 hospitals.

3. **A full discharge summary is sent to the patient's GP.**

This criterion was met in 27 hospitals.

Strengths

- Primary Care representatives from all Trusts confirmed that they receive full discharge summaries for all lung cancer patients.
- Immediate discharge documentation is provided for lung cancer patients in the majority of Trusts.

Challenges

- Patients do not routinely receive a personal copy of their immediate discharge information.
- Primary Care representatives reported that there are often delays between a patient's discharge and receipt of the full discharge summary.

Recommendations

- Trusts should ensure that all patients receive a personal copy of their immediate discharge information.
- Trusts should ensure that full discharge summaries are issued to GPs as quickly as possible, and should audit the time between discharge and the issue of full summaries to ensure this is kept to a minimum.

Example of a local initiative

West Lothian
West Lothian Healthcare NHS Trust provides patients and their GPs with a computer-generated immediate discharge document, in addition to the full discharge summary sent to the GP.

Chapter 3

Conclusions

Conclusions 3

This national overview, and the accompanying local reports, set out the performance of NHSScotland as a whole, and of each Trust/Island NHS Board, against the lung cancer standards published by the Board in 2001.

A number of general themes have emerged, and these apply to all cancers. First, without exception, each review team was struck by the commitment, dedication and hard work of staff involved in providing cancer care, frequently under considerable pressure. The services provided are responsive to patient needs and a number of innovative service developments were observed during visits. Of particular note was the multidisciplinary approach which is used in most Trusts to assess and plan treatment for cancer patients. All Trusts were enthusiastic about working together internally and across Trusts to provide rapid and 'seamless' access to care, and the next challenge is to establish regional cancer networks to support and strengthen joint working.

Second, members of the public have been involved at every stage of each cancer project. This has provided a valuable perspective on the work of project groups in setting standards and on review visits, and has also given members of the public the chance to contribute to all aspects of the review process, rather than simply to read a report prepared without their input.

Third, action is needed to improve and support clinical data systems and audit. At present these vary considerably, both between Trusts/Island NHS Boards, and between individual sites within a single Trust. Frequently systems are developed locally by enthusiasts without the necessary support and, as a result, many Trusts were unable to provide basic monitoring information about their performance against standards. In particular, Trusts face considerable challenges in monitoring waiting times throughout the patient journey, and it is important that this is addressed at a national level as well as locally.

Fourth, there is evidence that, although time-consuming for all concerned, the standards, self-assessment and review processes have already been a focus for change and improvement. In particular, the self-assessment element of the process is being used as a tool locally to monitor progress, and in many sites, its completion has brought staff together to discuss service delivery. The Board's work has re-focused the agenda in many Trusts and revived enthusiasm to work together to achieve changes and improvements. No-one believes major changes can be achieved immediately but already small steps have been taken. Teams are meeting where, before, this was difficult. Protocols are being developed and

shared with all those involved in care, primary and secondary. Change is occurring not only in sites visited – review team members are taking back new ideas to use in their practice as well. Additional funds provided through the Scottish Cancer Group have attracted bids to address problems identified during the Board's visits. The patient movement is growing and new posts for patient involvement officers are being advertised.

This report, and the local reports on each Trust/Island NHS Board, together with the examples of good practice they contain, are designed to support and encourage the process of continual improvement in services. The findings of this report will be presented to the Scottish Cancer Group in support of the work under way on the implementation of the Scottish Cancer Plan.

The Board looks to each Trust/Island NHS Board, guided by its Clinical Governance Committee, to ensure that in close collaboration with the staff responsible for providing the service, practice is reviewed in the light of the report's findings and recommendations and appropriate action taken. Considerable momentum has built up and it is important to use this enthusiasm to take forward the work of strengthening and improving cancer services.

Under the arrangements established in September 2001, each NHS Board is responsible for the performance of its local NHS services. NHS Boards are accountable to the Scottish Executive Health Department which will use the reports, and local responses to them, to monitor local and national performance. The public, both locally and nationally, also have an important role to play in ensuring that changes are made.

The Board reserves the right to revisit a Trust/Island NHS Board where it considers there are serious issues that need further external monitoring and report. The Board intends periodically to review and raise its standards, in the light of the latest evidence about best practice and the performance of the service, and to conduct further national reviews so as to encourage continuing quality improvement.

Appendices

Appendix 1

Lung Cancer Project Group

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Project Group Members

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Dr Marianne Nicolson
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Ms Margaret Stevenson
Scottish Partnership Agency for Palliative and Cancer Care

Dr Marion Storrie
General Practitioner, Lothian Primary Care NHS Trust

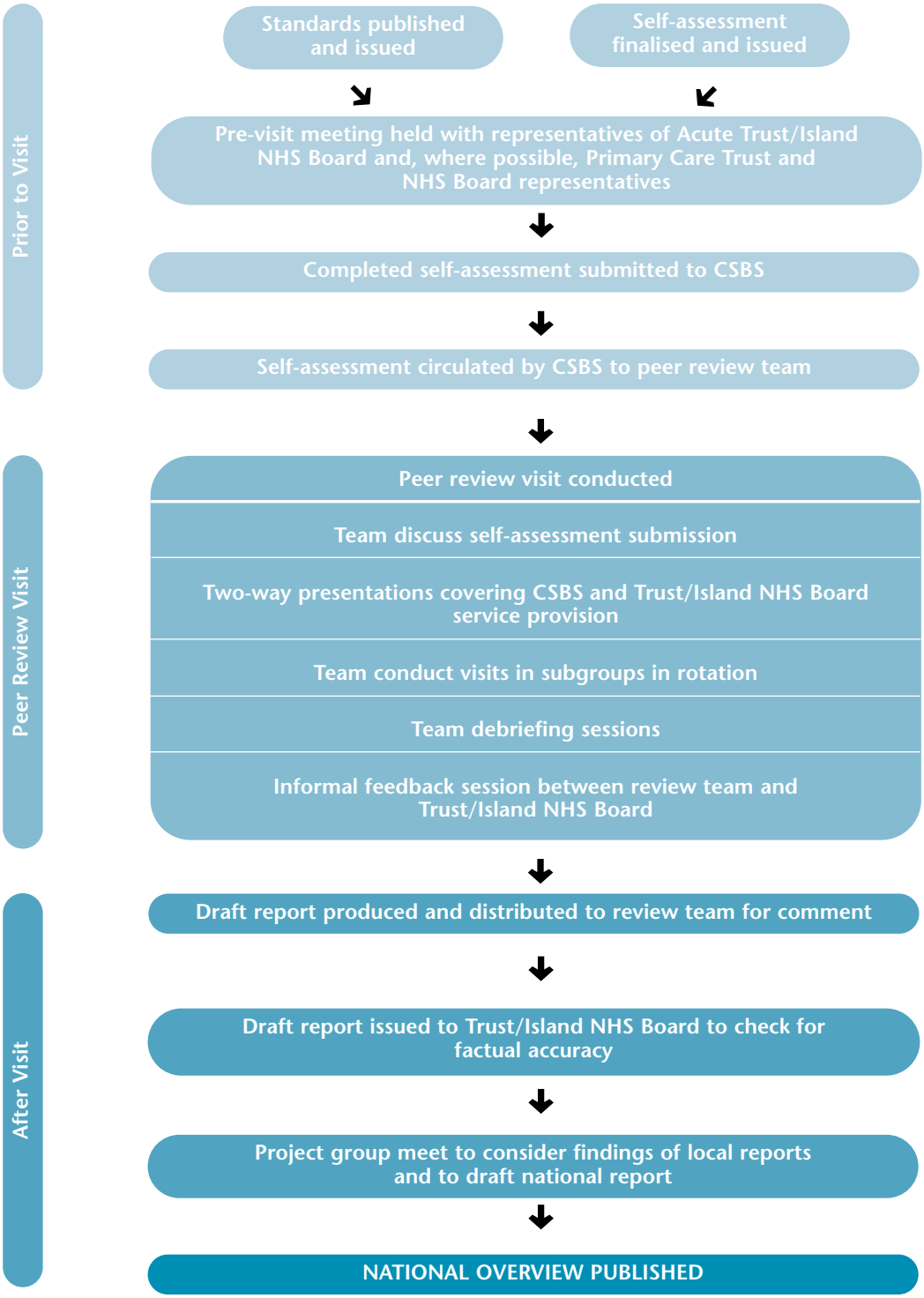
The Board member specifically working with the Lung Cancer Project Group was **Ms Margaret Williamson**.

Ms Frances Smith (Director of Nursing & Quality), **Ms Rachel McDowall** (Project Officer) and **Mr James Steven** (Project Officer) from the Clinical Standards Board for Scotland, provided support.

Appendix 2

Quality Assurance and Accreditation: the Approach Used in this Review

The CSBS accreditation process is outlined in the flow chart:



Standards

All standards set by the Board comprise a standard statement and related criteria.

Standard Statement

Describes the agreed performance for the specific area, determined by those who are involved in the delivery/receipt of the service.

Criteria

State exactly what must be done for the standard to be reached.

Some criteria are **essential** as it is expected that they will be met wherever a service is provided. Others are **desirable/aspirational** in that they will promote continuous quality improvement as they are being met in some parts of the service and demonstrate levels of quality which other providers of a similar service should strive to achieve.

Self-Assessment

Each set of clinical standards has an accompanying self-assessment framework developed by the CSBS. This framework gives guidance about the type of evidence required to demonstrate performance against the standards. It is completed and submitted to CSBS prior to a peer review visit, together with extensive additional documentation. The evidence obtained from this self-assessment exercise comprises the main source of written evidence considered by each peer review team.

Peer Review

Peer review is the process by which a multidisciplinary review team, including members of the public, carries out a hospital review to validate the quantitative data submitted through the self-assessment. This is done by gathering qualitative information through both discussions with staff in clinical areas, and observation.

During each review, the review team was guided by a clinician as team leader to ensure a multidisciplinary consensual assessment was reached. At the conclusion of the review, the review team provided feedback to the Trust/Island NHS Board giving a broad overview of its assessment, which was based on the written self-assessment, and evidence obtained during the review visit.

To enhance the consistency of the process, a CSBS manager and a project officer accompanied each visit, both of whom provided the secretariat and developmental support for the project group during the standard-setting phase of the project.

The schedule for a lung cancer external peer review visit included:

- initial meeting with key personnel responsible for the service under review;
- dialogue with clinicians, audit staff and managers based on the written evidence;
- scrutiny of documentation;
- interviews with staff members;
- regular team briefings throughout the day to assess progress and to compile the local report; and
- feedback to the Trust/Island NHS Board representatives on conclusion of the visit.

In addition, the CSBS review team met with local health council and patient representatives, GPs and representatives from the area NHS Board.

The review team for each peer review visit comprised different people. Although this presents challenges in achieving consistency of process, it promotes sharing of good practice and ensures that each review team assesses the performance of a hospital against the standards, not by comparing one hospital with another.

In order to determine whether a particular criterion is 'met' or 'not met', each review team requires to identify evidence on a variety of levels. For example, to demonstrate that a particular issue is addressed in a local protocol, evidence is sought during the peer review process as follows:

- description of the issue and how it should be managed in a local written protocol (submitted as part of the self-assessment);
- confirmation of awareness of the location and content of the protocol through staff interviews;
- evidence of a process in place for the protocol to be regularly updated; and
- collection of data through an integrated care pathway/audit sheet, leading to provision of collated audit data confirming compliance with the local protocol.

Until a legal interpretation of the Data Protection Act is made as to whether patient records can be accessed for purposes other than managing patient care, CSBS review teams are not scrutinising individual patient records. Therefore, in cases where it is stated that information is recorded in individual patient casenotes, and during the visit staff interviews corroborate the claim, an assessment of 'met' will be made.

The responsibility of the CSBS is to report whether the services provided by NHSScotland – nationally and locally – meet agreed standards, but not to review individual cases or the work of individual healthcare professionals. In achieving this aim, variations in practice (and potential quality) within a service will be encountered. Where such variation exists between hospitals (eg between hospitals within a Trust/Island NHS Board), this will be stated; treatment variations will also be reported but will not identify patients or healthcare professionals.

Reports

A local written report was drafted at the time of each visit by CSBS. The draft report was then circulated to the review team for comment, and to the Trust/Island NHS Board concerned to allow a check for factual accuracy.

On conclusion of the peer review programme, the project group reconvened to study the findings and examine trends in order to draw conclusions and make recommendations to the CSBS.

Appendix 3

Co-ordinating Cancer Care

The pathways of care for cancer are complex, often poorly co-ordinated and can be confusing.

There is no single pathway through the system and patients may move between the different stages described in the table below. The lists under each heading illustrate the wide range of services and professionals involved in cancer care.

Stage	Initial Contact and Referral	Diagnosis and Options for Treatment
What might happen	• discussion of symptoms causing concern • routine screening tests • examination in A&E	• tests: - scans, CT, MRI - X-ray - endoscopy - pathology (eg biopsy) - blood tests - sample of cells (FNA) • information and advice • discussion of options
Where	• GP surgery • screening service • A&E unit • home – may receive information/advice by post, Internet or phone from voluntary or NHS organisations	• hospital • GP surgery • home – information/advice from voluntary or NHS organisation
Who may be involved	• GP • practice nurse • screening service staff, radiographer, nurse, doctor • A&E staff	• oncologist • surgeon • physician • specialist nurse • radiographer • radiologist • pathologist • GP

Treatment and Care	Palliative and Terminal Care	Monitoring and Follow-up
• radiotherapy • chemotherapy • surgery • counselling/psychological support • information	• palliative treatment (eg non curative drug or radiotherapy treatment) • therapy (eg physiotherapy) • counselling/psychological support	• tests (scans, X-ray, pathology) • check up
• hospital • home • clinics • GP surgery	• hospital • home • hospice • private hospital/ nursing home	• GP surgery • home • hospital out-patient clinic
• oncologist (clinical or medical) • surgeon • specialist nurse • other health professionals (eg physiotherapist, dietician) • GP • palliative care nurse • palliative care doctor • social worker • psychologist or counsellor	• palliative care nurse • palliative care doctor • social worker • community nurse • psychologist or counsellor • other health professionals (eg physiotherapist, dietician) • GP • radiotherapist • radiographer	• GP • surgeon • physician • oncologist • specialist nurse • pathologist • radiographer • radiologist

Appendix 4

Lung Cancer Review Team Members

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Appendix 5

Glossary of Terms

A&E	Accident and Emergency Department.
accreditation	A process, based on a system of external peer review using written standards, designed to assess the quality of an activity, service or organisation.
acute sector	Hospital-based health services which are provided on an in-patient or out-patient basis.
adjuvant	A substance that, when added to a medicine (or treatment), speeds or improves its action which aids another, such as an auxiliary remedy.
adjuvant chemotherapy	The use of chemotherapy after initial treatment by surgery and/or radiotherapy. The aim of adjuvant therapy is to destroy any cancer that has spread.
adjuvant radiotherapy	The use of radiotherapy in association with treatment by surgery.
adjuvant therapy	Treatment given in addition to the primary therapy or a secondary remedy assisting the action of another.
antibiotic	A chemical substance produced by a microorganism which has the capacity, in dilute solutions, to inhibit the growth of or to kill other microorganisms. Antibiotics that are sufficiently nontoxic to the host are used as chemotherapeutic agents in the treatment of infectious diseases of man, animals and plants.
antibiotic prophylaxis	The administration of antibiotics to reduce the prospect of infection.
assessment	The process of measuring the quality of an activity, service or organisation.
audit	Systematic review of the procedures used for diagnosis, care, treatment, and rehabilitation, examining how associated resources are used and investigating the effect care has on the outcome and quality of life for the patient.
BASO	British Association of Surgical Oncologists.

benign	Non-cancerous, used to refer to tumours which grow slowly in one place and which, once removed by surgery, tend not to recur.
biopsy	The removal of a small piece of tissue from an organ or part of the body for histological analysis, microscopic study, or pathologic evaluation. It is an important means of diagnosing cancer from examination of a fragment of the tumour.
cancer	The name given to a group of diseases that can occur in any organ of the body, and also blood, which involve abnormal or uncontrolled growth of cells.
cancer centres	Cancer services are based in cancer centres. Such centres provide the entire spectrum of cancer care – both on-site and to associated cancer units.
cardiothoracic	Heart and chest.
care plan	A document which details the care and treatment that a patient/user receives and identifies who delivers the care and treatment.
carer	A person who looks after family, partners or friends in need of help because they are ill, frail, or have a disability. The care they provide is unpaid.
case record	Patient's notes; documentation of care.
CAT scan	Computerised axial tomography. See computerised tomography.
CDS	See core data set.
cells	The individual units from which tissues of the body are formed. All living organisms are composed of one or more cells.
CHART	Continuous Hyperfractionated Accelerated RadioTherapy: a recently developed radiotherapy technique aimed at the rapid destruction of tumour cells when they are most sensitive to radiation.
chemotherapy	Systemic therapy with medications that reach every cell in the body.

chest X-ray	Chest X-rays are commonly used to detect abnormalities in the lungs, but can also detect abnormalities in the heart, aorta, and the bones of the thoracic area. See X-ray.
clinical conference	Includes doctors/nurses/professions allied to medicine and other different specialties contributing to discussions on how to manage patients or diseases.
clinical effectiveness programme	The extent to which specific clinical interventions, when deployed, do what they are intended to do, ie maintain and improve health, securing the greatest possible health gain from the available resources. This is assessed through clinical effectiveness programmes.
clinical governance	A framework through which NHS organisations are accountable for both continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.
clinical oncologist	A doctor who specialises in the use of radiotherapy but who may also use chemotherapy.
Clinical Resource and Audit Group	The lead body within the Scottish Executive Health Department promoting clinical effectiveness in Scotland. The main committee, together with its subcommittees provides advice to the Health Department, acts as a national forum to support and facilitate the implementation of the clinical effectiveness agenda and funds a number of clinical effectiveness programmes and projects. Abbreviated as CRAG. Website address: www.show.scot.nhs.uk/crag/
clinical service	Service provided by healthcare professionals.
Clinical Standards Board for Scotland	The Clinical Standards Board for Scotland is a statutory body, established as a special Health Board in April 1999. Its role, in line with the Scottish Executive's commitment to quality, openness and public accountability, is to promote public confidence that the services provided by the NHS are safe and that they meet nationally agreed standards, and to demonstrate that, within the resources available, the NHS is delivering the highest possible standards of care. Abbreviated as CSBS.

clinical trial	Research study conducted with patients, usually to evaluate a new treatment or drug. Each trial is designed to answer scientific questions and to find better ways to treat individuals with a specific disease.
colleges	In the UK medical world the term colleges, as for example in "The Royal College of...", refers to bodies which usually combine an educational standards and examination role with promotion of professional standards.
combined modality	Use of different treatments (surgery, chemotherapy, radiotherapy).
computerised tomography	An X-ray imaging technique used in diagnosis and radiation treatment planning. This can reveal many soft tissue structures not shown by conventional radiography.
contra-indication	Any condition, past or present, which makes a particular line of treatment unsuitable or undesirable.
co-operative	A system of working where the establishment is owned and run jointly by its members.
core data set	A minimum set of information related to a specific medical condition – includes demographic, clinical management and outcome data.
CPA	Clinical Pathology Accreditation.
CPC	Clinico Pathological Conference.
CRAG	See Clinical Resource and Audit Group.
criterion/criteria	Criterion is the term used for the singular. We have one criterion, and several criteria. Criteria provide the more detailed and practical information on how to achieve a standard and can be described as structure, process and outcome criteria.
CSBS	See Clinical Standards Board for Scotland.
CT	See computerised tomography.
cytology	The study of cells under the microscope.
cytotoxic	Type of substance toxic to cells; refers to drugs used in chemotherapy to kill or slow down the reproduction of cancer cells.

cytotoxic drugs	Chemicals that are directly toxic to cells, preventing their reproduction or growth. Cytotoxic agents can, as a side effect, damage healthy, noncancerous tissues or organs which have a high proportion of actively dividing cells, for example, bone marrow, hair follicles. These side-effects limit the amount and frequency of drug administration.
data set	A list of required and specific information relating to a specific disease.
data source	The source of evidence to demonstrate whether a standard or criterion is being met.
desirable (criterion/criteria)	Good practice that is being achieved in some parts of the service and demonstrates levels of quality to which other providers of a similar service should strive.
DGH	District General Hospital (non-teaching hospital).
diagnosis	Identification of an illness or health problem by means of its signs and symptoms. This involves ruling out other illnesses and causal factors for the symptoms.
discharge	A discharge marks the end of an episode of care. Types of discharge include in-patient discharge, day-case discharge, day-patient discharge, out-patient discharge and PAM discharge.
DVT prophylaxis	Measures taken to reduce the prospect of the patient suffering from deep vein thrombosis after an operation.
efficacy	Strength, effectiveness. The ability of a drug to control or cure an illness. Efficacy should be distinguished from activity, which is limited to a drug's immediate effects on the microbe triggering the disease.
elective	Subject to the choice or decision of the patient or physician, applied to procedures that are advantageous to the patient but not urgent.
eligible	A patient is eligible for treatment if the benefits of that treatment outweigh the risks.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.

evaluation	The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity.
evidence-based	The process of systematically finding, appraising, and using current research findings as the basis for clinical decisions.
excision biopsy	Surgical biopsy that removes entire lesion.
extent of disease	This is measured in stages. See staging.
formal arrangement	Agreement in the form of a written document, forming local strategy/documentation.
generic standards	Standards that apply to most, if not all, clinical services.
GP	General Practitioner.
guidelines	Systematically developed statements which assist in decision-making about appropriate health care for specific clinical conditions.
HDL	See Health Department Letter.
HDU	High Dependency Unit.
Health Council	Each NHS Board area has a Health Council, an organisation whose aim is to promote public consultation and participation in health-related matters.
Health Department Letter	Health Department Letter (formerly known as Management Executive Letters – MELs), formal communications from the Scottish Executive Health Department to NHSScotland.
healthcare professional	A person qualified in a health discipline.
histological diagnosis	Study of what is under the microscope; the most minute branch of anatomic study; the information in a pathology report.
histological grade	The degree of similarity of the cancer cells to normal cells when examined under the microscope.
histopathology	The science concerned with the study of microscopic changes in diseased tissues.

ICP	See integrated care pathway.
imaging	The production of images of organs or tissues using radiological procedures, particularly using scanning techniques.
in situ	A cancer that is "in place": is non-invasive: has not spread beyond the initial structure.
Information and Statistics Division	The Information and Statistics Division is part of the National Health Service in Scotland, Common Services Agency. Health service activity, manpower and finance data are collected, validated, interpreted and disseminated by the division. This data is received from NHS Boards, NHS Trusts and general practices. Abbreviated as ISD. Website address: www.show.scot.nhs.uk/isd/index.htm
informed consent	The principle by which a patient/user is informed about the nature, purpose and likely effects of any treatment proposed before being asked to consent to accepting it.
in-patient	A person who is admitted to hospital for observation, examination or treatment.
integrated records	Complete medical notes relating to a patient and including information from every treatment service which they have used.
Internal validation	When an assessment of one service or procedure is made by several groups of observers, and their methods and findings carefully checked against each other for consistency, then the conclusions can be described as having undergone internal validation.
intervention	Healthcare action intended to benefit the patient.
invasive	Cancer that can or has spread from its histological original site.
investigation	A medical procedure to assist diagnosis.
irradiated	See radiotherapy.
irradiation	Radiation therapy.
irradiation	Treatment by ionising radiation, such as X-rays or radioactive sources such as radioactive iodine seeds.

ISD	See Information and Statistics Division.
Island NHS Board	Island NHS Boards do the work of both NHS Boards and Trusts in that they have a strategic and operational role. There are three Island NHS Boards, covering Shetland, Orkney, and the Western Isles.
ITU	Intensive Therapy Unit.
JCCO	Joint Council for Clinical Oncology.
jointly agreed	Where both parties involved (if one is the patient, include the carer with patient's consent) have decided together on a particular course of action/non-action, to benefit of the patient.
lead consultant	Clinician with administrative responsibilities for a specific service.
LHCC	See Local Health Care Co-operative.
LN	Lymph node.
lobe (lobes)	A section of an organ. There are lobes of the brain, thyroid, liver and lungs. The right lung has three lobes and the left only two.
lobectomy	Removal of one lobe of lung.
Local Health Care Co-operative	A grouping of general medical practices.
local information pack	Information relevant to a specific service.
lymph	Almost colourless fluid that travels through the lymphatic system, bathing body tissues and carrying cells that help fight infection; operates much like the circulatory system.
lymph nodes or glands	Small bean-shaped organs located along the lymphatic system. Nodes filter bacteria or cancer cells that might travel through the lymphatic system.
lymphoedema	The swelling of an arm, leg or another part of the body which sometimes happens when lymph nodes and vessels in the armpit or groin have been removed or damaged by surgery or radiotherapy, or have been blocked by a tumour.

malignant	Cancerous. Malignant tumours can invade and destroy surrounding tissue and have the capacity to spread.
managed clinical network	A formally organised network of clinicians. The main function is to audit performance on the basis of standards and guidelines, with the aim of improving healthcare across a wide geographic area, or for specific conditions.
margins of resection	Cut edges of the specimen taken out during biopsy; edges of the excision (excised tissue) checked for the presence of tumour cells. If no cancer has reached the edge of the tissue, margins are clean mass.
medical oncologist	A doctor who specialises in the use of chemotherapy.
medication	Drugs prescribed to treat a condition.
MEL	Management Executive Letter (now known as Health Department Letters – HDL), formal communications from the Scottish Executive Health Department to NHSScotland.
metastasis	Spread of cancer from one part of the body to another.
metastatic cancer	Cancer that has spread from its original site to other parts of the body; most commonly bone, lung, liver, brain, lymph nodes.
metastatic lesions	Cancerous lesion or tumour at another site that has the same cancer cells as the original tumour.
monitoring	The systematic process of collecting information on clinical and non-clinical performance. Monitoring may be intermittent or continuous. It may also be undertaken in relation to specific incidents of concern or to check key performance areas.
morbidity	A diseased condition or state. The incidence of a particular disease or group of diseases in a given population during a specified period of time.
mortality	The number of deaths in a given population during a specified period of time.

MRI	Magnetic resonance imaging. A special imaging technique used to image internal structures of the body, particularly the soft tissues. An MRI image is often superior to a normal X-ray image. It uses the influence of a large magnet to polarize hydrogen atoms in the tissues and then monitors the summation of the spinning energies within living cells. Images are very clear and are particularly good for soft tissue, brain and spinal cord, joints and abdomen. These scans may be used for detecting some cancers or for following their progress.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide care for patients with a particular condition. The composition of multidisciplinary teams will vary according to many factors. These include: the specific condition, the scale of the service being provided and geographical/socio-economic factors in the local area.
multidisciplinary system of working	A method of working in a multidisciplinary team with protocols in place for most, if not all, eventualities.
multifocal disease	Occurring in more than one location in an organ of the body, eg the breast.
named cancer nurse	Name of nurse, eg Staff Nurse Smith, ward 7/Macmillan cancer nurse.
named lead consultant	Named clinician with administrative responsibilities for a specific service, who is thus identified as the lead member of a team caring for a patient.
negative nodes	Lymph nodes showing no signs of cancer.
neoadjuvant chemotherapy	Chemotherapy that is given before the treatment of a primary tumour with the aim of improving the results of surgery or chemotherapy and preventing the development of metastases.

NHS Board	NHS Boards replaced the separate board structures of Health Boards and NHS Trusts. The NHS Boards cover the same geographical area as the old Health Boards. The overall purpose of unified NHS Boards is to ensure the efficient, effective and accountable governance of the local NHS system and to provide strategic leadership and direction for the system as a whole, focusing on agreed outcomes.
NHS priorities	The three national clinical priorities are mental health; coronary heart disease and stroke; and cancer.
NHSScotland	The National Health Service in Scotland.
nodal status	The presence or absence of cancer in lymph nodes draining the area where the primary tumour is found.
non-invasive	In situ cancer that does not spread outside the polyp or colon lining.
NSCLC	Non-small cell lung cancer.
nurse	A person who is specially trained to provide services that are essential to or helpful in the promotion, treatment, maintenance, and restoration of health and well being.
oncologist	A doctor who specialises in the treatment of cancer patients. A clinical oncologist, or radiotherapist, specialises in treating cancer with radiation or drugs, and a medical oncologist specialises in treating cancer with drugs.
oncology	The study of the biology and physical and chemical features of cancers. Also the study of the cause and treatment of cancers.
out-of-hours	Between 5pm – 9am Monday to Friday and also weekends (not between 9am – 5pm Monday to Friday).
outcome	The end result of care and treatment and/or rehabilitaion. In other words, the change in health, functional ability, symptoms or situation of a person, which can be used to measure the effectiveness of care and treatment, and/or rehabilitation.

out-of-hours co-operative	Arrangement where a group of general practitioners in an area cover for each other out of normal working hours by taking part in an extended rota.
out-patient	A patient reviewed in a hospital but who does not need to be admitted to the hospital.
palliative care	Palliative care is the active total care of patients and their families by a multi-professional team when the patient's disease is no longer responsive to curative treatment.
PAM	See professions allied to medicine.
pathologic diagnosis	A histological diagnosis, the microscopic assessment of the tumour.
pathological	Relating to or arising from disease.
pathologist	Doctor who identifies diseases by studying cells and tissues under a microscope.
pathology	The study of disease processes with the aim of understanding their nature and causes. This is achieved by observing samples of blood, urine, faeces, and diseased tissue obtained from the living patient or at autopsy, by the use of X-rays, and by many other techniques.
patient	A person who is receiving care or medical treatment (especially in a hospital). A person who is registered with a doctor, dentist, or other healthcare professional, and is treated by him/her when necessary. Sometimes referred to as a user.
patient journey	The pathway through the healthcare system taken by the patient (the person who is receiving treatment), and as viewed by the patient.
PCI	Prophylactic Cranial Irradiation – literally means preventative radiotherapy to the head. With some types of cancer that can spread to the brain, doctors like to give a short course of radiotherapy to the brain. The idea of this is that it kills off any microscopic spread that may already be there.
PCRG	See Primary Care Reference Group.
PCT	Primary Care Trust. See Trust and Primary Care.

peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer. In the CSBS method all members of a review team are equal.
peri	Prefix meaning near, around, or enclosing.
perioperative	Within 30 days of surgery.
pharmacist	A qualified professional who understands the nature and effect of medicines and how they may be produced and used to prevent and treat illness, relieve symptoms or assist in the diagnosis of disease. Pharmacists use their expertise for the well-being and safety of users and the public.
physician	A specialist in medicine.
pneumonectomy	The removal of one lung.
policy	An operational statement of intent in a given situation.
positive lymph nodes	Lymph nodes that contain cancer cells.
post	Prefix meaning following or after.
pre	Prefix meaning before or preceding.
prescription	Usually a written recipe of treatment.
primary care	The conventional first point of contact between a patient and the NHS. This is the component of care delivered to patients outside hospitals and is typically, though by no means exclusively, delivered through general practices. Primary care services are the most frequently used of all services provided by the NHS. Primary care encompasses a range of family health services provided by family doctors, dentists, pharmacists, optometrists and ophthalmic medical practitioners.
Primary Care Reference Group	Established to help the CSBS ensure that the component of care delivered to patients outside hospitals is included in its standards, and to promote the accreditation of general practices. Abbreviated as PCRG.
primary tumour	Original site of the cancer; the first.
procedure	The steps taken to fulfil a policy.

professions allied to medicine	Healthcare professionals directly involved in the provision of primary and secondary healthcare. Includes several groups such as physiotherapists, occupational therapists, dieticians, etc. Abbreviated as PAM.
prognosis	An assessment of the expected future course and outcome of a person's disease.
prophylaxis	The prevention of disease; preventive treatment. Intervention to prevent an unwanted outcome.
protocol	A policy or strategy which defines appropriate action. Also covers the adoption, by all staff, of national or local guidelines to meet local requirements in a specified way, resulting in what are known as local protocols.
QA	See quality assurance.
qualitative information	Qualitative data can include personal evidence or statements, samples of documentation or other output, video or sound recordings, objects, and is typically non-numerical.
quality assurance	Improving performance and preventing problems through planned and systematic activities including documentation, training and review. Abbreviated as QA.
Quality Assurance Manual	CSBS document outlining the methods and procedures to be used in setting standards and reviewing services.
quality of life	The overall appraisal of an individual's situation and subjective sense of well-being.
quantitative information	Quantitative information is data presented in numerical form.
radiation	Radiation is energy in the form of waves or particles. See radiation therapy.
radiation therapy	Treatment with high-energy rays from X-rays or other sources to kill or slow cancer cells; can also reduce pain from cancer spread to bone by killing tumour at this site.
radiology	The use of X-rays in the diagnosis, treatment and monitoring of disease.
radiotherapy	The use of radiation, usually X-rays or gamma rays, to kill tumour cells.

randomised	Randomly allocated to one of more than one different choices.
rationale	Scientific/objective reason for taking specific action.
RCGP	Royal College of General Practitioners.
RCN	Royal College of Nursing.
recurrence	Recurrence is when new cancer cells are detected at the site of the original tumour, following treatment.
referral	The process whereby a patient is transferred from one professional to another, usually for specialist advice.
regime	Treatment programme, eg for drugs, also known as a regimen.
regional oncology centre	A centre providing area-wide cancer services.
resection	Surgical removal of a portion of any part of the body. For example, a section of diseased intestine may be removed and the healthy ends sewn together.
risk factor	A clearly defined occurrence or characteristic that has been associated with the increased rate of a subsequently occurring disease or health problem. Risk factors include aspects of personal behaviour, lifestyle, environmental exposure, or inborn or inherited characteristics, which are known to be associated with the disease.
risk factor stratification	Assessing and grading of risk factors relevant to a patient. See risk factor.
SCLC	Small cell lung cancer.
Scottish Executive Health Department	The Scottish Executive Health Department is responsible for health policy and the administration of the National Health Service in Scotland. Abbreviated as SEHD.

Scottish Intercollegiate Guidelines Network	SIGN was established in 1993 by the Academy of Royal Colleges and Faculties in Scotland, to sponsor and support the development of evidence-based clinical guidelines for NHSScotland. Where a SIGN guideline exists for a specialty or service for which CSBS is setting standards, it will be referenced. For further information relating to SIGN guidelines or the methodology by which SIGN guidelines are developed, contact: SIGN Secretariat, Royal College of Physicians, 9 Queen Street, Edinburgh EH2 1JQ. Abbreviated as SIGN. Website address: www.sign.ac.uk/
SCTN	Scottish Cancer Therapy Network.
secondary care	Care provided in an acute sector setting. See acute sector.
section	In surgery this is the act of cutting (the cut or division made is also called a section).
segmentectomy	Removal of part of the lung less than a lobe.
SEHD	Scottish Executive Health Department.
self-assessment	Assessment of performance against standards by individual clinical teams and/or Trusts providing the service to which the standards are related.
sentinel lymph node	The sentinel lymph node is the lymph node near a body organ or part of an organ which is thought to be the first that the tissue fluid draining from that organ reaches. So, if there is a cancer in the organ, this lymph node may be the one most likely to contain cancer cells if the cancer has begun to spread. Different techniques for evaluating the sentinel lymph node are currently being assessed.
SIGN	See Scottish Intercollegiate Guidelines Network.
SIGN guideline	Scottish Intercollegiate Guidelines Network guideline.
social work	Social work services provide advice and practical help for problems resulting from social circumstances. A social worker is a person who has obtained a professional qualification in social work. A social worker supports vulnerable people and their carers with the aim of enhancing the quality of all aspects of their daily lives.
specialist	Person who is an expert in the subject.

staging	Process of describing whether cancer has spread from its original site to another part of the body. Staging involves clinical, surgical and pathology assessments.
standard statement	An overall statement of desired performance.
statutory	Enacted by statute; depending on statute for its authority as a statutory provision. Required by law.
symptom	A reported feeling or observable physical sign of a person's condition that indicates a physical or mental abnormality.
syringe driver	A means of administering pain-killing or chemotherapy drugs under the skin which relieves patients of the need for frequent injections.
systematic	Methodical, according to plan and not casually or at random.
systemic	Involving the whole body.
systemic therapy	Treatment that goes through the system, usually via the blood, and reaches and affects cells all over the body.
team leader	Senior clinician who leads a CSBS review team during its Trust and Island NHS Board visits and plays a key role in drawing together the assessments of all team members.
tertiary centre	A major medical centre providing complex treatments, which receives referrals from both primary and secondary care. Sometimes called a tertiary referral centre.
therapy	A word often used to mean treatment.
thoracic	Chest.
TNM classification	TNM classification provides a system for staging the extent of cancer. T refers to the size of the primary tumour. N refers to the involvement of the lymph nodes. M refers to the presence of metasteses or distant spread of the disease. See staging.

TNM staging	Tumour, Node, Metastatis. A descriptive method of assessing the spread of cancer. Staging of breast cancer is based on the TNM classification which classifies the size, site and spread of the disease. Therapeutic decisions are formulated in part according to staging. The numbers 1, 2, 3, and 4 are used to denote the stages and each number refers to a possible combination of TNM factors. For example: a Stage 1 breast cancer is defined by the TMN group: T1, N0, M0 which means: T1 – Tumour is 2cm or less in diameter, N0 – No regional lymph node metastasis, M0 – No distant metastasis.
treatment plan	Protocol of care which specifies what should be done, when and with what aim.
triple assessment	Clinical, pathological, and radiological assessment.
Trust	A Trust is an NHS organisation responsible for providing a group of healthcare services for the local population. An Acute Hospital Trust provides hospital services. A Primary Care Trust delivers primary care/community health services. Mental health services (both hospital and community based) are now usually provided by Primary Care Trusts.
tumour	A lump or mass of cells which can be either benign or malignant. Also known as a neoplasm.
ultrasound	Test that bounces sound waves off tissues and converts the echoes into pictures.
unified Board	See NHS Board.
WHO	World Health Organisation. A United Nations agency dealing with issues concerning health and disease around the globe.
X-ray	An imaging technique that uses energy beams of very short wavelengths that can penetrate most substances except heavy metals. This is the most common form of imaging technique used in clinical practice everywhere in the world, with the image captured on photographic film.

Our Commitment

The Board will:

- involve NHS staff, patients and the public in all parts of its work;
- work with and support NHS staff in improving standards;
- assist NHSScotland in delivering the highest quality of NHS care to each patient;
- base its conclusions and recommendations on the best evidence available;
- be open and transparent in all its work through wide circulation of reports written in language that can be understood by all and is jargon free;
- seek to avoid duplication of effort through working closely with other national organisations involved in improving the quality of care within the NHS;
- ensure that its own work is subject to quality assurance and evaluation.

CSBS
Promoting
Public Confidence
in NHSScotland

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