Clinical Standards Board for Scotland

National Overview

NHS SCOTLAND

Breast Cancer Services

CSBS
Promoting
Public Confidence
in NHSScotland

www.clinicalstandards.org

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Further details on the process by which the Board will achieve 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 Breast Cancer are also available from CSBS.

Clinical Standards Board for Scotland
Elliott House
8-10 Hillside Crescent
Edinburgh
EH7 5EA

Copies of this report and of the reports on each Trust/Island Health 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

Breast 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 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;
- report findings to the Board.

The Breast Cancer Project Group was established in January 2000 under the chairmanship of Miss Philippa Whitford, Consultant Surgeon, Ayrshire & Arran Acute Hospitals NHS Trust. Membership of the Group is given in Appendix 1.

The CSBS *Clinical Standards for Breast 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.clinical standards.org).

Peer review visits, to all NHS Board areas in Scotland, were conducted during March – November 2001 to assess performance against the standards. Local reports on each visit to a Trust/Island NHS Board, 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 breast 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 Breast 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: 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.

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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 and this is particularly noticeable for breast cancer following the introduction in the UK of the world's first national breast screening programme. This programme aims to diagnose breast cancer early so that women can benefit from the advances that have been made in the treatment for breast cancer and such are these advances that there has been a 30% decrease in the number of breast cancer deaths over the last 10 years. The latest figures published in 2001 showed that of the 3,500 cases of breast cancer diagnosed each year in Scotland, over 75% are still alive and well five years after diagnosis.

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 breast cancer services across Scotland and it is underpinned by the separate publication of local reports for every NHS Trust/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. This was undertaken by a project group which included representatives of all the healthcare professionals involved in the treatment of breast cancer as well as members of the public with personal experience of these services. Full membership details are given in Appendix 1. From March to November 2001 all acute NHSScotland Trusts and the three Island NHS Boards were visited by a team of health professionals and members of the public to assess breast 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 to cancer services generally, others more specifically to breast 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 relating to breast cancer is given below:

1. Care of Patients

- All review teams commented on the commitment, enthusiasm and professional approach of the staff involved in the care of breast cancer patients, and their families and friends. The role of the specialist nurse was found to be particularly important as the link for the patient between the different health professional team members and as a source of information and support. These nurses were in post in most Trusts although access for patients can be limited due to geography and to the deployment of these nurses across hospital sites.

2. Referral

- In general, robust referral arrangements are in place across the country from primary care and screening services to hospital services. However, these are often informal between primary and secondary care 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. 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

- Teams were struck by the efforts that have been made to drive up the quality of services most notably through the introduction of 'one-stop' clinics run by multidisciplinary teams that aim to carry out all the necessary investigations during one clinic visit, to support rapid diagnosis and to reduce the anxiety caused by waiting for the outcome of tests. Most women referred to these breast clinics will not have breast cancer and it is important that this can be confirmed for them as quickly as possible. For those who do require further investigation and possibly treatment, early investigation and rapid results mean that a treatment plan can be discussed and developed as soon as possible.

4. Multidisciplinary Approach

- All Trusts recognised the value of a multidisciplinary approach to decision making and treatment planning. Wherever possible, patients were central to this process and encouraged to participate in decisions about their care and their options. It was recognised that in some Trusts this presents real challenges as staff can be working on several geographically remote sites, and can sometimes cover more than one Trust. Further, certain services, most notably pathology and imaging, are under extreme pressure and many Trusts are carrying long-term vacancies. Palliative care services were valued by all Trusts and by those using the service. In general these services are available across Scotland although they are 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 ways of using their resources more effectively to ensure that all patients have access to multidisciplinary teams and to ensure that a Trust-wide approach is taken to this. At the time of the visits, most Trusts were not participating in Managed Clinical Networks although this is now being addressed through the implementation of *Cancer in Scotland*.

5. Treatment

- There was good evidence that the treatment for patients with breast cancer follows current, evidence-based guidelines. Chemotherapy services are well developed although further work is needed on developing protocols for the management of all symptoms and the side-effects of chemotherapy.

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 shock 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. Sites 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 available about breast cancer 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 in which this information reached patients and their families. One issue that arose on several visits was the 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 discussing sensitive or bad news with patients and their families. Review Teams reported that staff were very aware of the value of communication and information both among those caring for patients and with patients and their families and it was clear that every effort is made to achieve a high level of support.

It is recommended that those providing palliative care are involved in discussions about treatment planning and management at an early stage, particularly as they can assist with the management of distressing symptoms.

9. Discharge

- Much effort is directed to discharge planning and management but a lot of work is still needed to make sure patients, their families and the 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 breast cancer review was the lack of data and 'evidence' to support the measurement of performance against standards. Some audit activity is under way, much of which is at the level of individual health professionals. Even where core data are collected, there was limited awareness amongst those treating patients about what was collected, by whom and how to access this information to monitor their performance against standards. There is no doubt that there are robust information systems in place to support direct patient care, but very few of these systems can also provide monitoring information which is essential if the risks involved in treating cancer patients are to be well managed and the quality of care is to improve.

Conclusion

Breast cancer services have led the way in introducing a multidisciplinary, standards-based approach and there has been a lot of investment across Scotland to ensure that high-quality care is provided. Those providing these services offer a patient-focused, responsive service that is based on current, evidence-based guidance and, as a result, deaths from breast cancer are falling and survival from the disease is improving. As with all services there are areas where further work and investment will support continued improvement. For breast cancer services the Board found that workforce planning and service redesign were two of the key factors in addressing the main issues identified in this review, namely pressures on certain services such as pathology and imaging, and the challenge of providing truly multidisciplinary services. It is also important that data collection and analysis systems are established to allow Trusts to continually monitor performance.

Key Recommendations

People with Breast Cancer

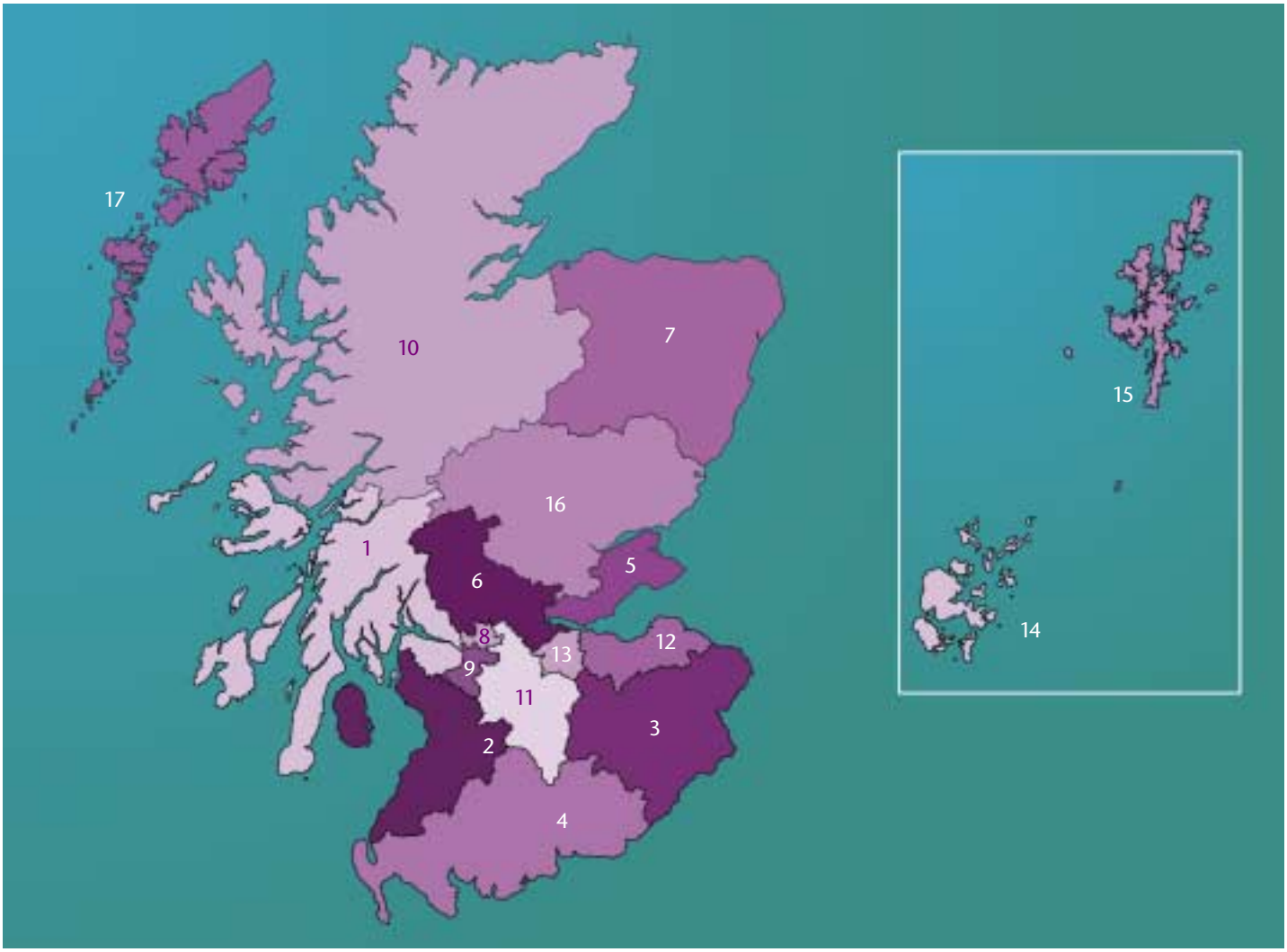
- Patients should have access to a specialist breast care nurse.
- Referral protocols should be in place, both between primary and acute care and within the hospital.
- There is good evidence that multidisciplinary team working improves the quality of care. All Trusts should ensure these teams are established 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
- Breast 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
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 Dr Gray's Hospital, Elgin
8. Glasgow (North) 557,520 372* **	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	Belford Hospital, Fort William Caithness General Hospital, Wick 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	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 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 with 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 Breast Cancer

Breast cancer is the commonest cancer in Scottish women with 3,000 patients diagnosed each year. At least one in 12 will be diagnosed with the disease in their lifetime and over 80% of cases are diagnosed in women aged over 50. Survival from breast cancer has improved significantly over the last 30 years and 75% of women are now still alive and well five years after diagnosis.

Women may be diagnosed through the NHS Breast Screening Programme or may notice a symptom in the breast and attend their GP. The most important symptom is a new lump in the breast and will usually result in referral to a specialist breast clinic where the lump will be examined and investigated. Women with other breast symptoms, such as nipple discharge or breast pain, may also be referred to a breast clinic or dealt with by their GP although these symptoms are rarely associated with breast cancer.

Most Common Symptoms of Breast Cancer

- Lump 90%
- Painful lump 20%
- Nipple change 10%
- Nipple discharge 3%
- Skin contour change 5%

Diagnosis of Breast Cancer

Breast cancer is usually diagnosed using 'triple assessment'. This comprises clinical examination of the breast, imaging using mammography (X-ray of the breast) or ultrasound scan and microscopic examination of cells or tissue pieces taken using a needle to remove a sample. Many specialist clinics for patients with breast symptoms try to provide all of these investigations on the same day to allow speedy diagnosis. These are known as 'one-stop' clinics.

Management of Breast Cancer

There are four main treatments for breast cancer:

- Surgery
- Radiotherapy
- Chemotherapy
- Hormonal treatment

Surgery and radiotherapy are used to treat the region of the breast cancer, which includes the breast and armpit (axilla), while chemotherapy and hormone therapy circulate through the blood system to treat cancer cells that have escaped from the original tumour and are, therefore, known as systemic treatment.

Treatment

Surgery

Breast cancer is most commonly removed by surgery. This may involve removing part of the breast (preservation or lumpectomy) or the whole breast (mastectomy). During the same operation some or all of the lymph nodes in the armpit are removed to check if cancer cells have spread to them. As well as removing the tumour, surgery allows the cancer and the lymph glands to be studied by the pathologist to see what type of cancer is involved and whether it has spread.

Pathology

The tissue removed by surgery is studied by the pathologist to find out what type of breast cancer it is, and whether it has spread to the lymph nodes in the armpit. Some features of the cancer will influence the treatment used to back up the initial surgery. The pathology of each cancer should be discussed at a clinical meeting by the whole breast cancer team, and this information is used to plan the best treatment to eliminate the cancer and reduce the risk of it coming back.

Radiotherapy

Radiotherapy complements surgery in the control of cancer within the cancer region (breast and local lymph nodes). This is commonly used when less radical surgery is performed such as a lumpectomy or when only a few lymph nodes from the armpit have been sampled and contain cancer. Other indications apart from preservation surgery are if the cancer is felt to be at higher risk of recurring even after a mastectomy has been carried out (based on features of the cancer noted by the pathologist).

Systemic Treatment

Chemotherapy

Chemotherapy, along with hormone therapy, is a systemic treatment. This means that it enters the blood system and travels through the body destroying cancer cells. Chemotherapy usually consists of a mixture of strong anti-cancer drugs that are given every few weeks by injection. These drugs attack cells that are growing and dividing quickly. This applies to many healthy cells within the body, such as blood cells as well as the cancer cells, and this is why patients require a few weeks between treatments to allow normal cells to recover. Cancer cells do not recover as well and so are progressively destroyed.

Hormone Therapy

If cancer cells are sensitive to oestrogen (female hormone) they will be stimulated by any oestrogen whether naturally produced by the body or produced by hormone replacement therapy (HRT). Hormonal treatment of breast cancer involves giving drugs that work either by blocking oestrogen from stimulating the cancer, or by lowering the body's production of oestrogen. The most commonly used hormone treatment for breast cancer is Tamoxifen which works as an oestrogen blocker.

Conclusion

Breast cancer trials over the last 20 years suggest that the appropriate use of these various treatments can make a big impact on survival after breast cancer. While the contribution of each treatment alone may be fairly small, it appears that these small advances added together produce a big improvement in outlook. This is exactly what has happened in Scotland where five-year survival has improved from only 53% in 1971 to almost 75% in 1993.

Breast cancer has long had a high political and media profile in the UK as so many women die from the disease. As part of the fight against breast cancer the Scottish Breast Screening Programme was phased in from 1988 and is now well established. From the outset the programme has carefully monitored every aspect of screening from calling people for mammography, through further assessment, diagnosis and treatment and the standards set within breast screening have led the way in improving breast services generally.

The CSBS *Clinical Standards for Breast Cancer*, while not exhaustive, follow the patient's journey through referral, diagnosis and cancer treatment, focusing on key areas. They aim to assess what services are provided by breast cancer teams in Scotland, how they are provided and whether teams have the facilities they need to offer these services. It is hoped that by setting, monitoring and achieving these standards it will be possible to further improve the quality of breast cancer care across Scotland and further reduce the number of deaths from the disease.

This is the first national report of the assessment of breast cancer care across Scotland and has involved the health service and the public in a process that includes self assessment and external peer review visits. Over 20 hospital sites have been visited.

1.5 The CSBS Standards and Your Care

CSBS Standards and Questions You Might Want to Ask

The breast 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

Breast Cancer

6. **Scottish Breast Cancer Campaign**
   PO Box 26191
   DUNFERMLINE
   KY11 3YG

   Tel: 0131 623 0037
   www.scottishbreastcancercampaign.org

Chapter 2

National Performance Against the Standards

2 National Performance Against the Standards

The findings across Scotland in terms of performance against the standards are presented in this section. A number of examples of innovative local solutions and areas of good practice are described in boxes throughout the text. These examples are not exhaustive – indeed, individual review teams highlighted many innovative examples of good practice across Scotland. It is often the case that the example cited also exists in another location.

It should be noted that a total of 31 hospitals were reviewed to assess performance against the standards. This national overview summarises 27 local reports as Trust wide reports were submitted by four of the Trusts visited and these incorporate all hospital sites within that Trust. This is reflected in the findings by providing information on the number of instances where the criteria were met, based on the denominator of the 27 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 level.

2.1 Standard 1: Referral Process

Standard Statement
Breast units collaborate with GPs to achieve appropriate referral rapidity.

Essential Criteria

1. **Clear evidence of consultation between primary and secondary care to produce referral guidance and system of referral for GPs.**

This criterion was met in 22 hospitals.

2. **A minimum of 70% of patients referred to a symptomatic clinic are seen within 4 weeks from date of GP referral.**

Where data were available to assess this criterion it was met in 6 hospitals.

Desirable Criteria

3. **A minimum of 80% of patients are seen within 2 weeks from date of GP referral.**

Where data were available to assess this criterion it was met in 3 hospitals.

Strengths

- There was widespread evidence of SIGN guideline based referral protocols in use.
- There is an obvious commitment across all the units to maintain short waiting times for the first clinic appointment although this is difficult as a result of increasing patient numbers.

Challenges

- The increasing numbers of patients referred to breast clinics result in pressure within the service making it very difficult for clinic staff to keep up with demand. This is exacerbated by shortages in the diagnostic specialties, radiology and pathology. While the SIGN guidelines are used as the basis for most referral protocols, there was less evidence of actual collaboration with primary care colleagues and such collaboration might be fruitful in avoiding unnecessary referrals while ensuring easy access for patients with suspicious symptoms.

Challenges

- This standard applies to all patients referred to the breast clinic and not just cancer patients. It includes the vast majority (about 90%) who are subsequently shown not to have breast cancer. With regard to the actual waiting times, the vast majority of Trusts were unable to produce the data for this standard from their records departments and could only obtain them from the core data set, which only shows the waiting times for cancer patients. As some patients with clinically obvious cancer may be seen urgently this could give an overly optimistic impression of the clinic waiting times. However, studies have shown that as many as one-third of cancer patients are diagnosed among the 'routine' patients and it is therefore important that all patients are seen within a reasonable time. This is also important in reducing the anxiety of the many women who attend with a benign symptom.

Recommendations

- This standard was set to include time from referral, and not from receipt of referral letter, to encourage collaboration between primary and secondary care to streamline their referral system and create a formalised referral protocol. The Electronic Clinical Communications Implementation (ECCI) programme may allow the use of electronic interactive referral protocols, which could be used to audit, and if possible minimise, inappropriate referral to breast clinics.
- All Trusts should have audit data of diagnostic breast clinics, as this is an early step on their journey for cancer patients, and may be the only experience of the breast service for those with benign disease.

Examples of local initiatives

Dumfries & Galloway

A cyst register has been set up to ease the review of patients with recurrent cysts while avoiding them coming to the one-stop clinic. Patients who have been through the one-stop clinic and diagnosed as having significant fibrocystic disease are listed in a 'cyst register' and can contact the unit directly. An ultrasound is arranged by the radiologist, and if a cyst is confirmed this is aspirated under ultrasound guidance. If a cyst is not found the patient is then referred to the one-stop clinic for further investigation.

Greater Glasgow

Stobhill Hospital has a primary care clinic co-ordinator to increase the collaboration between primary and secondary care regarding clinic referral.

2.2 Standard 2: Time to Diagnosis of Cancer

Standard Statement
Breast clinics are established and served by staff trained in breast disease. Where a localised abnormality is present, patients undergo imaging, usually followed by fine needle aspiration (FNA) or core biopsy (triple assessment).

Essential Criteria

1. Breast clinics are staffed by personnel trained in breast disease.

This criterion was met in 25 hospitals.

2. All main diagnostic modalities are available with immediate reporting: Mammography (report); Ultrasound; FNA; Core Biopsy (not reported immediately).

This criterion was met in 12 hospitals.

3. A minimum of 80% of patients with diagnosis within 2 weeks of first clinic visit (including image-guided needle biopsy or excision biopsy).

Where data were available to assess this criterion it was met in 16 hospitals.

4. A minimum of 70% of patients with preoperative diagnosis (FNA or core biopsy).

Where data were available to assess this criterion it was met in 19 hospitals.

Desirable Criteria

5. A minimum of 90% of patients with diagnosis within 2 weeks of first clinic appointment.

Where data were available to assess this criterion it was met in 8 hospitals.

6. A minimum of 90% of patients with pre-operative diagnosis.

Where data were available to assess this criterion it was met in 6 hospitals.

Strengths

- In most units, breast clinics are led by experienced consultants with a special interest in breast cancer care, supported in some units by staff grade doctors or breast physicians.
- The majority of hospitals now provide 'one-stop' diagnostic breast clinics although there are variations in how they are set up. These clinics allow access to all the diagnostic tests required at the same visit. They may also lead to the patient receiving the diagnosis on the same day. A specific breast clinic would not be appropriate in a small rural unit nor could they provide a 'one-stop' service due to the lack of on-site pathology. However, they should be able to show that despite a different clinic structure, more appropriate to their setting, they are able to meet the 'Time to Diagnosis' standard.
- Of the 21 units able to provide data regarding the time to diagnosis, 16 of these achieved a diagnosis in more than 80% of cancer patients within two weeks with eight units achieving this standard in 90% of breast cancer patients.
- Of the 20 units who could provide evidence of preoperative diagnosis, 19 met the standard in more than 70% of patients with six units achieving a preoperative diagnosis in more than 90% of their breast cancer patients.

Challenges

- One-stop clinics are under considerable pressure not only from the increased numbers of patients but also as a result of the shortage of breast cancer specialists. While this applies to breast surgeons and pathologists, the greatest shortage affecting the diagnostic service is breast radiologists.
- Despite the small numbers of patients treated in most rural units, some were unable to produce evidence that they met the 'Time to Diagnosis' standard or indeed the standard for preoperative diagnosis. It is not the role of the CSBS to suggest where patients should be treated, particularly for common conditions, but patients should be treated to the same standards irrespective of the size of the unit. It is incumbent upon smaller units to demonstrate that they are able to deliver the standards of care even if in an alternative way.

Recommendations

- While it is important that manpower issues are addressed nationally, local units should ensure their services are set up to make the best use of the specialist staff available and avoid delays in diagnosis. Innovative solutions to ease the pressure on diagnostic clinics may have to be sought.
- Permanent middle grade doctors (staff grades) and breast physicians (who are often GPs) may give the possibility of achieving stability of expertise within the diagnostic team. Junior staff could join the team for training in breast cancer diagnosis without being exposed to unsupervised working. At present there are no formal training courses for breast physicians in Scotland who must travel to the South of England to access these. The development of a Scottish training centre should be considered.
- To achieve high preoperative diagnosis rates requires collaboration of the full diagnostic team. An increase in image-guided needle biopsies is necessary in cases where free-hand needle biopsies have failed to achieve a diagnosis. It is important to achieve a high preoperative diagnosis rate to avoid unnecessary surgery in benign cases and to allow preoperative discussion and consultation with patients who require surgery for breast cancer.

Examples of local initiatives

Ayrshire & Arran, Dumfries & Galloway
In Ayr Hospital and Dumfries & Galloway Royal Infirmary the role of the breast care nurse is being extended in the assessment of young patients with presumed benign disease. This requires radiology support and clinical protocols. In both instances, where any concern remains, patients are referred back to the consultant-led breast clinic.

2.3 Standard 3: Multidisciplinary Working

Standard Statement 3(a)
Patients with breast cancer are managed by a multidisciplinary team within a designated breast unit. There is a named lead consultant for breast cancer services.

Essential Criteria

Multidisciplinary Team – Surgery

1. Specialised breast surgeon/s.
This criterion was met in 24 hospitals.

2. Access to plastic surgeon (with special interest).
This criterion was met in 25 hospitals.

3. Access to orthopaedic surgeon (with special interest).
This criterion was met in 22 hospitals.

Multidisciplinary Team – Oncology

4. Specialised oncologist/s.
This criterion was met in 26 hospitals.

5. Access to palliative care specialist.
This criterion was met in 26 hospitals.

Multidisciplinary Team – Pathology

6. Lead pathologist.
This criterion was met in 21 hospitals.

7. Clinical Pathology Accreditation (CPA) of pathology laboratory.
This criterion was met in 17 hospitals.

Multidisciplinary Team – Radiology

8. Lead radiologist.
This criterion was met in 21 hospitals.

9. Mammography accreditation for radiographers.
This criterion was met in 19 hospitals.

Multidisciplinary Team – Breast Care Nurse (BCN)

10. Less than 150 new breast cancers per year for each BCN (1WTE).
This criterion was met in 23 hospitals.

Multidisciplinary Team – Physiotherapy

11. Shoulder exercises.
This criterion was met in 27 hospitals.

12. Lymphoedema services.
This criterion was met in 27 hospitals.

Desirable Criteria

13. Specialisation in pathology and radiology.
This criterion was met in 15 hospitals.

14. Participation of pathologist in National Breast Screening Histopathology External Quality Assessment Slide Circulation.
This criterion was met in 21 hospitals.

15. Participation of radiologist in PERFORMS (Personal Performance in Mammographic Screening) external radiology quality assurance (currently available to Breast Screening Programme radiologists, wider availability under review).
This criterion was met in 10 hospitals.

16. Membership of a Managed Clinical Network for Breast Cancer.
This criterion was met in 6 hospitals.

Standard 3: Multidisciplinary Working

Standard Statement 3(b)
Prior to performing any definitive treatment the patient is fully discussed by a multidisciplinary team.

Essential Criteria

1. **Meeting of the team with full postoperative pathology where adjuvant treatment planning is carried out (this may be physical or by a variety of forms of communication).**

This criterion was met in 9 hospitals.

2. **Detailed records of Clinical Pathological Conference (CPC) meetings to be kept.**

This criterion was met in 15 hospitals.

Desirable Criterion

3. **Discussion of:**
   - **newly diagnosed cancers preoperatively**
   - **full postoperative pathology**
   - **adjuvant treatment planning**
   - **discussion of patients with metastatic disease.**

This criterion was met in 9 hospitals.

Strengths

- Breast cancer has been at the forefront of multidisciplinary team working for several years and this was evident in the majority of units visited with degrees of sub-specialisation evident in all their team members. Breast care nurses are by definition specialised. Surgeons were most commonly sub-specialised, while radiologists and oncologists showed varying degrees of sub-specialisation. Pathologists sub-specialised least often because of their small numbers in each Trust and the range of pathology to be covered.
- The majority of units held some form of clinical pathological conference (CPC) to allow the team to plan each patient's treatment. Some units keep detailed minutes of the meetings as well as documenting each patient's case sheet.

Challenges

- While there was evidence of increasing sub-specialisation there were obvious shortages appearing, particularly in radiology and pathology. Many new consultant appointments are filled by those who were already consultants elsewhere. The recruitment problem is therefore not solved, the gaps are just moved around between Trusts.

Challenges

- The biggest challenge in team working was the clinical pathological conference. In many sites one key member of the team is missing from the meeting and therefore their contribution to treatment discussion is lost. In attempting to get around this, several units have multiple meetings throughout the week, each with a slightly different configuration. The meeting at which the team come together to make treatment plans should be the hub of team working.

Recommendations

- As well as the staff shortages identified in the diagnostic specialties of radiology and pathology there are also shortages of breast surgeons and oncologists. These shortages do not just apply to breast cancer and will have to be tackled on a national basis with comprehensive manpower planning to meet the staffing needs of cancer services in Scotland.
- It is crucial that time is set aside so that all patients may be discussed and their treatment planned after the diagnosis of breast cancer. It is only by meticulous attention to detail that it is possible to ensure that each patient gets the best treatment for them as an individual and that they meet with the most appropriate team member to discuss results and future treatment. The CPC should be seen as a clinical commitment as important as clinics or operating sessions and needs to be included in individual job plans.
- Rural units should be linked to their nearest main breast unit when they have a case being discussed within the breast unit CPC in order to have multidisciplinary discussion of patients. This is most easily achieved by video linking.

Example of a local initiative

Ayrshire & Arran
In Crosshouse Hospital a CPC Co-ordinator facilitates the meetings by collecting the names of patients to be discussed, organising X-rays etc and keeping formal minutes of the meeting, which can be referred to at a later date if necessary. This helps to ensure that the CPC is comprehensive.

2.4 Standard 4: Support

Erratum: The criterion relating to BCN access was printed in the standards document at the end of standard 3. In this report it will be discussed under standard 4 as originally intended.

Standard Statement 4(a)
All women with a suspected or known diagnosis of breast cancer have access to a breast care nurse (BCN) throughout their treatment.

Essential Criteria

1. Access to BCN (or alternative in rural units).

This criterion was met in all 27 hospitals.

2. Patients are given a contact phone number for the BCN.

This criterion was met in 26 hospitals.

Standard Statement 4(b)
Patients with significant psychological problems are assessed by a liaison psychiatrist or clinical psychologist.

Essential Criterion

1. Access to psychology services.

This criterion was met in 12 hospitals.

Desirable Criterion

2. Clinical psychologist with special interest in cancer patients.

This criterion was met in 8 hospitals.

Strengths

- There is widespread recognition of the role of breast care nurses (BCN) and their invaluable input to supporting women throughout their treatment for breast cancer.
- In the UK as a whole there are some psychologists with a major commitment to cancer patients, both in service provision and research, and much of our insight into patients' needs comes from their work.

Challenges

- Most BCNs have too large a workload to have sufficient time with each patient. The remit of the job also varies greatly. While contact numbers are given to patients, some highlight the problem of only reaching an answerphone.
- There is a challenge to extend similar cancer nursing support to patients with other types of cancer.
- There is a dearth of psychology services with waiting times of up to six months or more for an initial appointment. This is a problem for any patient suffering from anxiety or depression but causes suffering in patients who are carrying the additional burden of cancer. The lack of psychology backup places further pressure on the BCNs to support a patient whom they feel needs more specialist help.

Recommendations

- Research and audit within the nursing field is required to establish an appropriate caseload of new patients for BCNs. This should take into account the number of those who may suffer future recurrence of disease and require further treatment with even greater support from the BCN. Improved linkage between BCNs and primary care staff such as health visitors and district nurses could allow additional support of patients who are cared for out in the community by their local primary care team.
- Recruitment to and expansion of psychology services is required. Consideration could then be given to increasing support through psychologists with special interest in cancer support.

Examples of local initiatives

Lothian
Patients attending the Western General Hospital, Edinburgh, have additional access both to support services and psychology services through the 'Maggie's Centre'. Urgent cases are seen the same day while routine appointments, to see a psychologist, are available within six weeks.

Borders
There is good access locally to psychology services in Borders and Northumberland. Patients who attend the Western General Hospital, Edinburgh, also have access to the 'Maggie's Centre'.

Fife
Patients are given a contact telephone number for the BCN prior to their first clinic appointment so that they can discuss anxieties they have regarding investigations at the clinic.

Direct referral can be made from the BCN to a psychologist and patients can be seen within two weeks. There is also access to a psychologist with a special interest in cancer.

Greater Glasgow
At the Beatson Oncology Centre psychology services can be accessed within two to four weeks.

Grampian
At the Aberdeen Royal Infirmary two psychologists have a special interest in cancer patients.

2.5 Standard 5: 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 25 hospitals.

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

This criterion was met in 9 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 19 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 21 hospitals.

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

This criterion was met in 24 hospitals.

Strengths

- In general most Trusts have policies to support professional development of their staff.
- Many Trusts run inhouse courses on communication and aspects of palliative care.

Challenges

- Although most Trusts have a policy of encouraging staff to take study leave, many find it difficult to take the time off as a result of problems with cross cover and staff shortages. In some Trusts, however, difficulties with funding were also experienced, especially for nursing staff, physiotherapists, pharmacists and radiographers.

Challenges

- While communication courses are widely available for junior medical and nursing staff, senior medical staff tend not to access them. It is equally important to have courses geared specifically for senior staff, as it is they who usually have to break bad news to patients or explain their treatment options.
- With the pressure on tertiary oncology centres causing major problems for service delivery, there is less time for teaching and therefore some training courses for oncology and chemotherapy nurses are no longer accessible.

Recommendations

- It is important that members of the team attend appropriate conferences or training courses to keep their knowledge and skills up to date.
- Funding and travelling out of Scotland is a problem for many staff and more national Scottish meetings should be arranged. The only formal extended learning course for breast physicians is based in London, which is not practicable for most staff.
- It is important to provide high-quality cancer education within primary care both from the point of view of breast disease as well as palliative care. Local and regional units are crucial in contributing to this.
- Communication courses should be available to all staff with courses specifically for senior staff, both nursing and medical. All staff with patient contact such as secretaries should be included in communication skills courses.

Examples of local initiatives

Shetland
The visiting team found that the majority of staff had personal educational development plans. While this is crucial in a small unit where one individual may have to supply several skills, it also applies in larger units.

Grampian, Greater Glasgow, Lanarkshire, Lothian
At Monklands District General Hospital, Airdrie; Dr. Gray's Hospital, Elgin; the Western Infirmary, Glasgow; the Victoria Infirmary, Glasgow; and the Western General Hospital, Edinburgh, senior consultants have attended communication courses.

Greater Glasgow
The Beatson Oncology Centre has a dedicated pharmacy trainer who runs courses in chemotherapy preparation.

2.6 Standard 6: Communication and Information Sharing

Standard Statement
Patients are fully informed of the different options for treatment and involved in decision making to the extent they wish. Clear lines of communication are maintained between the staff in the breast unit and the primary care team.

Essential Criteria

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

This criterion was met in 27 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 26 hospitals.

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

This criterion was met in 27 hospitals.

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

This criterion was met in 25 hospitals.

5. **GPs are informed quickly of patients who are diagnosed with breast cancer.**

This criterion was met in 26 hospitals.

Desirable Criteria

6. **Walk-in information centre.**

This criterion was met in 8 hospitals.

7. **Flexible multi-media information and interview audio recordings if requested.**

This criterion was met in 8 hospitals.

8. **There should be a system for giving patients follow-up investigation results quickly (eg annual check mammogram or symptomatic investigation results).**

This criterion was met in 25 hospitals.

Strengths

- Visiting teams found that generally care has been taken to allow sensitive discussion with patients. This is usually carried out by the consultant with the breast care nurse present, in private within a consulting room, with variation in the availability of quiet comfort rooms. In some clinics it is possible for the patient to leave without walking back through the waiting room.
- A good range of leaflets is now available, some inhouse, some prepared by charities. These all tend to have different strengths and weaknesses.
- Several Trusts have good recognition of the need for translation services with leaflets available in several languages, particularly those of the ethnic communities in their area. Translation services were also available for those with sensory disabilities.
- In the majority of Trusts the need for swift communication and information sharing with GPs and the other members of the primary care team is recognised. Many units have established systems of informing patients directly of routine results. This was usually by letter or telephone call if the results were 'clear' and at a clinic visit if further investigations were required.

Challenges

- One issue, which is difficult to tackle, is that patients are often given a slightly different view by each clinician. Communication sheets might be helpful and could be included in patient held records.
- Information leaflets vary in their clinical accuracy and approach. It should be possible to have fully researched leaflets in a wide range of languages and for patients with disabilities. Better information is required for patients with learning difficulties, which is perhaps one of the greatest challenges.
- Quiet rooms, when available, are often slightly detached from the main clinic area which decreases their usefulness for breaking bad news as they tend to gain a stigma as it can be considered a bad sign to be taken off in a different direction to the "bad news" room.
- Communication of results back to GPs, both regarding the diagnosis of breast cancer and the results of routine tests, was variable. There was also a great variation in the time taken to let patients know the results of follow-up tests.

Recommendations

- Consideration should be given to central production of high-quality generic leaflets, which could be available for Trusts to download and add in local information such as clinic details and contact phone numbers. These could be on a website for easy access. They could be produced in a wider range of languages than any local group can achieve and special leaflets for those with learning difficulties or disabilities could also be made available.
- When considering purpose-built spaces for breast clinics, quiet rooms should be available within the clinic.
- Communication of results to patients and their GPs should be enhanced. Some Trusts are involved in projects looking at electronic communication with GPs by secure e-mail, which could greatly enhance the exchange of information between secondary and primary care.
- Where possible patients should be informed directly of investigation results rather than having to keep contacting their practice to see if the result is available. A 'no news is good news' policy may lead to results being overlooked.

Examples of local initiatives

South East Scotland
The cancer information project, which has been established in South-East Scotland, is designed to address many of the issues regarding information materials and lead to a national roll-out at the end of the project.

Forth Valley
The Trust makes use of the National Interpreting Service which is accessible on a 24 hour basis. Communication in 140 languages is available within one minute. The local council also produces a guide on barrier free communication with regard to language and disability.

Grampian, Lothian
Patients in and around Edinburgh have access to 'Maggie's Centre' at the Western General Hospital. This provides a walk-in information centre as well as support services. More such centres are planned across Scotland. Aberdeen Royal Infirmary also has a walk-in information centre within the surgical breast unit.

Examples of local initiatives

Ayrshire & Arran, Grampian, Greater Glasgow, Highland, Lothian, West Lothian
Various systems were in place at Stobhill Hospital, Glasgow; Crosshouse Hospital, Kilmarnock; St. John's Hospital, Livingston; Dr. Gray's Hospital, Elgin; Western General Hospital, Edinburgh, and across Highland, Forth Valley and Lanarkshire hospitals to give patients the results of follow-up investigations as quickly as possible. These included a letter or telephone call if their result was 'clear' with recall to a clinic to explain any positive results or the need for further investigation.

Argyll & Clyde, Aryshire & Arran
The Royal Alexandra Hospital, Paisley, and Crosshouse Hospital, Kilmarnock, are planning to take part in the Electronic Clinical Communications Implementation (ECCI) pilot project which will help to improve the communication between primary and secondary care.

2.7 Standard 7: Audit

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

Essential Criteria

1. **Continuous collection of SIGN Breast Cancer core data set to facilitate audit.**

This criterion was met in 20 hospitals.

2. **Participation in the Scottish Cancer Therapy Network (SCTN) national data quality assurance programme.**

This criterion was met in 24 hospitals.

Desirable Criteria

3. **Expansion of core data set to include diagnostic accuracy (radiology, cytology, pathology) treatment, morbidity and communication issues.**

This criterion was met in 2 hospitals.

4. **Units should be encouraged to perform internal audit of aspects of care relevant to local service development.**

This criterion was met in 16 hospitals.

5. **Trusts and Health Boards provide the personnel and funding required to collect the minimum core data sets locally and regionally.**

This criterion was met in 19 hospitals.

Strengths

- The majority of Trusts are collecting the SIGN core data set with plans to update this to collect data for the CSBS assessment. Breast cancer has been at the forefront of cancer data collection because of the breast screening quality assurance standards. The principle of prospective audit is widely accepted and has been carried out by some enthusiasts for several years.
- There was also evidence of a growing acceptance by Trusts that audit requires appropriately trained staff to collect and analyse the data for it to be clinically useful. Twenty units were able to provide audit data on important clinical aspects of breast cancer treatment.

Challenges

- A few units have made little attempt to collect even the minimum data set on their patients. Others, who had been collecting data on local databases, found they were unable to access or analyse their clinical data to provide evidence for the CSBS assessment process. This is particularly disappointing if clinical staff have made efforts to support the clinical aspects of data collection. In many units data collection and entry into a database are still done with insufficient support staff and are therefore retrospective and incomplete.
- While clinical audit data were available in the majority of units, audit of the process of care, such as waiting times, was poorer.

Recommendations

- Data collection should become an integral part of all patient care preferably by the use of automated data collection during the processes of caring for a patient. Such systems should be developed on a national basis.
- It is imperative that sufficient audit staff are available to support clinical audit within cancer care. The audit should be expanded to include morbidity from treatment and diagnostic accuracy.
- As an interim measure direct data capture, particularly from pathology and radiology systems, should be used to avoid duplication of report writing.
- Common definitions are crucial to allow comparisons between units. Auditing patients across regional services such as cancer care requires a consistent, unique patient identification number such as the CHI number. Consideration should be given to this issue on a national basis.
- It is important that prospective audit for quality assurance is maintained as at present it is under threat if the current interpretation of the Data Protection Act is implemented. It would then not be possible to assess the quality of breast cancer care nationally and thereby improve these services.

Example of a local initiative

Greater Glasgow

One of the early Scottish breast cancer databases was developed at the Western Infirmary, Glasgow, and was then used to set up an audit network within Greater Glasgow Health Board in 1996. Regular audit feedback was given to the units taking part. This database provided the basis for the original SIGN core data set.

2.8 Standard 8: 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 17 hospitals.

2. A minimum of 5% entry into peer reviewed clinical trials.

Where data were available to assess this criterion it was met in 14 hospitals.

3. Informed consent.

This criterion was met in 17 hospitals.

4. Functioning ethics committee.

This criterion was met in 25 hospitals.

Desirable Criterion

5. A minimum of 10% entry into peer reviewed clinical trials.

Where data were available to assess this criterion it was met in 11 hospitals.

Strengths

- Scotland has a good record of entering patients into trials. The Scottish Breast Trials Group has encouraged trial entry across Scotland. It elects which trials should be focused on and promoted in Scotland so as to achieve significant input of patients.

Challenges

- The range of trials available through local chemotherapy units should be expanded, as some patients are discouraged from entering trials if this involves extra travel to the regional centre.

Recommendations

- Clinicians need time to explain trials to patients to allow them to make an informed decision and increase uptake. Nurses attached to cancer units could be invaluable, both in supporting and providing information to patients and in the collection of trial data. Consideration should therefore be given to the appointment of trials sisters locally or arranging outreach support from the cancer centres.

2.9 Standard 9: 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 all 27 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 all 27 hospitals.

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

This criterion was met in 26 hospitals.

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

This criterion was met in 25 hospitals.

5. There is evidence of regular review of problems and actions.

This criterion was met in all 27 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 6 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 24 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 20 hospitals.

Desirable Criteria

9. Integrated records.

This criterion was met in 7 hospitals.

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

This criterion was met in 7 hospitals.

Strengths

- Most hospitals are using care plans in routine care. Clinicians and BCNs are involved in assessing the needs of most cancer patients and some units have begun to develop multidisciplinary care plans that can be accessed by all the staff involved in the patient's care such as physiotherapists and pharmacists.
- Many Trusts have developed different approaches to increasing continuity between secondary and primary care, some of which appear to be very effective.

Challenges

- Documentation of patients' needs was variable with a greater emphasis on physical rather than emotional problems and little routine use of communication sheets.
- While there is recognition of the need for care planning and continuity across secondary care as well as with primary care, there is scope for improvement in the tools available.

Recommendations

- More systematic assessment of patients' needs is required and should address problems related to the diagnosis of cancer, the disease itself and its treatment. Specific breast care plans and palliative care plans should be developed. Individual care plans for breast cancer with an attachable palliative care component could be used for documentation throughout the whole journey of the breast cancer patient. The palliative care component could be generic for all cancer patients.
- Links with primary care should be developed and maintained throughout the journey of the cancer patient to allow the provision of seamless palliative care.
- There is scope to develop better assessment tools and care plans with an emphasis on multidisciplinary notes to enhance communication within the team caring for each patient. One component of this would be a patient held record which increases continuity between primary, and the different providers of secondary care. This could be produced nationally on a dedicated website and additional local information could be added as required.

Examples of local initiatives

Argyll & Clyde, Ayrshire & Arran, Greater Glasgow, Highland, Lanarkshire, Orkney
Vale of Leven District General Hospital, Alexandria; Raigmore Hospital, Inverness; Stobhill Hospital, Glasgow; Ayr Hospital, Wishaw General Hospital; and Balfour Hospital, Orkney, have developed individual care plans, where patient issues can be documented and a record of communication kept.

Greater Glasgow
A discharge sister is employed at the Victoria Infirmary, Glasgow, to plan and manage the discharge of patients by liaising with other services. There is access to a small budget to help in this process.

Argyll & Clyde, Ayrshire & Arran, West Lothian
Close liaison between the BCN and the local hospice palliative care team was identified in Royal Alexandra Hospital, Paisley; Ayr Hospital and St John's Hospital, Livingston.

Ayrshire & Arran, Greater Glasgow
The Southern General Hospital, Glasgow, and Victoria Infirmary, Glasgow, have an integrated care pathway for pain management with patient held records. Ayr Hospital and Crosshouse Hospital, Kilmarnock, have worked to develop patient held records to improve continuity between secondary and primary care.

Argyll & Clyde, Western Isles
In Western Isles Hospital, Stornoway, an individual care plan is used for every breast cancer patient. There are monthly meetings between the Macmillan nurses, district nurses and a specialist social worker to improve communication. In Lorn & Islands Hospital, Oban, the surgical team liaise with the Macmillan nurse to improve continuity of care in the community.

2.10 Standard 10: Waiting Time for Treatment

Standard Statement
Waiting times for treatment are within acceptable limits.

For the standards pertaining to waiting times the individual criteria are discussed to show more detail.

Waiting time for Surgery

Essential Criteria

1. **Surgery (diagnostic): A minimum of 70% within 2 weeks for first clinic visit.**

Where data were available to assess this criterion it was met in 11 hospitals.

2. **Surgery (therapeutic): A minimum of 70% within 3 weeks for first clinic visit.**

Where data were available to assess this criterion it was met in 10 hospitals.

Desirable Criteria

3. **Surgery (diagnostic): A minimum of 95% within 2 weeks of first clinic visit.**

Where data were available to assess this criterion it was met in 2 hospitals.

4. **Surgery (therapeutic): A minimum of 95% within 3 weeks of first clinic visit.**

Where data were available to assess this criterion it was met in 1 hospital.

Strengths

- The commitment to having patients seen, diagnosed and treated as quickly as possible was evident in all Trusts. Patients were not placed on waiting lists and were admitted for surgery at the earliest date possible particularly when a diagnosis of cancer had been made.

Challenges

- In some areas there is an increased wait for surgery. Quick access for breast surgery may result in a longer general surgical waiting list for the surgeon with delays for non-cancer patients.

Challenges

- The shortage of breast surgeons reduces access to surgery particularly when cross cover for leave is limited such as in single-handed units.
- There are pressures on in-patient beds and theatre time from the increasing surgical complexity of breast operations with the development of reconstruction.
- Five units were unable to provide audit data for this criterion.

Recommendations

- In addition to staff shortages identified in the diagnostic specialties of radiology and pathology, there are also shortages of breast surgeons and oncologists. These shortages will have to be tackled on a national basis with comprehensive manpower planning to meet the staffing needs of cancer services in Scotland.
- At a local level some roles could be taken on by other staff with role extension to allow development of a more flexible workforce.
- Within the larger units, a more flexible approach to theatre utilisation between surgeons might make it easier to respond to fluctuations in patient numbers.

Waiting time for Radiotherapy

Essential Criterion

1. Adjuvant radiotherapy: A minimum of 70% within 4 weeks of final operation/chemotherapy dose.

Where data were available to assess this criterion it was met in 0 hospitals.

Desirable Criterion

2. Adjuvant radiotherapy: A minimum of 95% within 4 weeks of final operation/chemotherapy dose.

Where data were available to assess this criterion it was met in 0 hospitals.

Strengths

- The need to improve radiotherapy delivery has already been recognised. Both additional and replacement linear accelerators (radiotherapy machines) are being purchased nationally.

Challenges

- The long waiting times for radiotherapy are a national problem. In addition to the shortage of hardware there is a shortage of oncologists, therapeutic radiographers and radiation physicists. Resources are wasted when treatment is cancelled at the last minute due to machine failure. This is particularly distressing for patients who have travelled a long distance to the regional centre.
- Unfortunately it takes a long time to install and commission (activate) a new linear accelerator and therefore this problem cannot be quickly rectified.

Recommendations

- The long waiting times for radiotherapy, which were identified in all of the Trusts, are a national issue. It therefore requires a national solution in terms of procurement of equipment for the future, along with expansion of the number of oncologists, therapeutic radiographers and physics staff needed to provide the service. This issue has been identified and is being addressed by a national group.

Waiting time for Chemotherapy

Essential Criterion

1. Adjuvant chemotherapy: A minimum of 80% within 4 weeks of final operation.
Where data were available to assess this criterion it was met in 5 hospitals.

Desirable Criterion

2. Adjuvant chemotherapy: A minimum of 95% within 4 weeks of final operation.
Where data were available to assess this criterion it was met in 0 hospitals.

Strengths

- Audit data when it was available suggested that many units were missing the target by only one week or less.
- Most are able to start treatment fairly quickly, after the decision to give chemotherapy is confirmed by the oncologist.

Challenges

- The waiting times vary greatly over the units reviewed; however, most units reported being only slightly outside the target waiting time.
- When the waiting time is reviewed it consists of three components: the wait to get the pathology results following surgery, waiting for an oncology clinic appointment, and waiting for the treatment to start. The major delay was reported to be the waiting time to attend the oncology clinic. However, as the use of chemotherapy in all types of cancer patients increases, pressure on chemotherapy units is growing which will also result in increasing the waiting time for the treatment to start.
- Fourteen units were unable to produce audit data for this criterion.

Recommendations

- The variation in waiting times for chemotherapy could be altered in many cases by service reorganisation after identification of the cause of delay locally. The variation in waiting times for chemotherapy is, to some extent, decreed by the waiting time to see an oncologist and could be shortened by organisational changes such as joint results clinics or forward planning of appointments although the shortage of oncologists may hamper this.
- Expansion of chemotherapy units will also be required to keep pace with growing demand.

2.11 Standard 11: Surgical Management

For the standards pertaining to clinical treatment the individual criteria are discussed to show more detail.

To allow comparison over time, results from the Scottish Cancer Therapy Network (SCTN) audits of 1987 and 1993(4) are quoted where applicable in the standards on the clinical treatment of breast cancer (Standards 11-13). This highlights the improvements made over the last decade in the treatment given to patients with breast cancer.

Standard Statement 11(a)
Patients with cancers that are operable are considered for surgery with or without preoperative chemotherapy or endocrine treatment.

Essential Criterion

1. A minimum of 80% of all breast cancers are surgically treated.

Where data were available to assess this criterion it was met in 20 hospitals.

Desirable Criterion

2. A minimum of 90% of all breast cancers are surgically treated.

Where data were available to assess this criterion it was met in 11 hospitals.

Strengths

- In 1987, 76% of all breast cancer patients in Scotland underwent surgery as part of their treatment. This rose to 81% in the 1993 audit. On this occasion the standard was set at 80% of all breast cancer patients undergoing surgery. Twenty units met this standard with 11 of them using surgery in more than 90% of their breast cancer patients.
- More of the older patients are treated actively with surgery and not just treated with Tamoxifen alone.

Challenges

- There are still a few units where Tamoxifen is given as the only treatment, even to elderly patients who are otherwise fit for surgery. The evidence is available to show that prolonged use of Tamoxifen without removal of the tumour often results in later regrowth.

Challenges

- If elderly patients are fit, or treatment of their other problems can be optimised, then they should be considered for surgery. Neo-adjuvant endocrine therapy may be used to provide time to deal with other medical problems or to shrink a large tumour prior to surgery.
- Five units were unable to provide audit data for this criterion.

Recommendations

- Time should be made available for a full Clinical Pathological Conference (CPC) to allow careful planning of each aspect of care for every patient.
- Research evidence exists to show that, within the limitations of their other health problems, elderly patients should be considered for surgery as a major component of their treatment.
- With the prolonged life expectancy of the older population, it is important that breast cancer is optimally treated to avoid later recurrence, with its associated anxiety and morbidity, particularly as patients may then be less fit for further treatment.

Standard 11: Surgical Management

Standard Statement 11(b)
Breast conservation is appropriate for small focal breast tumours.

Essential Criterion

1. A minimum of 70% conservation rate of surgically treated small invasive cancers (more than 15mm pathological diameter) excluding Ductal Carcinoma in Situ (DCIS) and multifocal disease.

Where data were available to assess this criterion it was met in 12 hospitals.

Desirable Criterion

2. A minimum of 80% conservation rate of surgically treated small invasive cancers (<15mm pathological diameter) excluding DCIS and multifocal disease.

Where data were available to assess this criterion it was met in 6 hospitals.

Standard 11: Surgical Management

Standard Statement 11(c)
Breast reconstruction is discussed with patients prior to mastectomy.

Essential Criterion

1. Mastectomy patients have access to breast reconstruction.

Where data were available to assess this criterion it was met in all 27 hospitals.

Desirable Criterion

2. Patients have straightforward access to immediate breast reconstruction.

Where data were available to assess this criterion it was met in 24 hospitals.

Standard Statement 11(d)
Tumours are adequately excised in breast conservation.

Essential Criterion

1. Not more than 10% rate with breast conservation of excision margins <1mm.

Where data were available to assess this criterion it was met in 15 hospitals.

Desirable Criterion

2. Not more than 5% rate with breast conservation of excision margins <1mm.

Where data were available to assess this criterion it was met in 12 hospitals.

Strengths

- Twelve out of 27 units reached the standard of 70% of patients with small focal tumours being treated by breast conservation with six units reaching the desirable target of 80%. There is a greater drive to offer breast conservation surgery for breast cancer when this is technically possible for smaller tumours. Some patients may still choose to undergo mastectomy rather than conservation and their wishes should be respected.

Strengths

- Patients undergoing mastectomy have increasing access to breast reconstruction and in particular greater access to immediate breast reconstruction where the reconstructive surgery is carried out at the same operation as the mastectomy. Some of this increase in accessibility is due to the number of breast units providing an inhouse reconstructive service provided by the breast surgeons. Other units provide this service by close collaboration with their local plastic surgery unit.
- In general there is now good recognition of the importance of clear margins if breast conservation is to be performed. In the 1987 SCTN audit an average of 21% of patients had positive margins dropping to 10% in the 1993 audit. The essential standard was therefore set at 10% and this criterion was achieved reached by 15 units with 12 of these also achieving the target of less than 5% of patients having close margins.

Challenges

- Six units did not meet the standard of 70% of small cancers being treated by breast conservation with eight units being unable to provide audit data. This shows that even in patients with clinical indications for breast conservation, mastectomy is often being performed.
- While some patients will prefer to have a mastectomy, the issue should be explored if the majority of patients are undergoing mastectomy routinely. It is important to assess whether this is due to surgeon preference or patient choice and whether it is driven by obstacles to treatment, such as difficulty in accessing radiotherapy treatment after breast surgery.
- Patients opting for immediate breast reconstruction may face delays before surgery and patients in rural units are likely to be put off by having to travel to plastic surgery clinics as well as for the surgery itself.
- Three units had higher rates of patients with positive excision margins which may reflect the treatment philosophy which was present several years ago suggesting that clear margins were unimportant and would be dealt with by later radiotherapy. Nine units were unable to provide data for this criterion.

Recommendations

- If a unit has a high mastectomy rate the staff should explore whether this is due to surgeon preference or to service issues such as radiotherapy access that are limiting patients' choice. Conservation of the breast should be offered where the size of the tumour and the size of the breast allow this to be carried out safely.
- Consideration should be given of video linking rural units to their regional plastic surgery unit to allow discussion with the plastic surgeon. Copies of clinical photographs and videos could be held locally to help the patient in the decision making process.
- There should be promotion, through the SIGN guidelines, of clear excision margins in surgery to the breast for cancer.

Examples of local initiatives

Lothian
The Western General Hospital, Edinburgh, provided the first 'inhouse' access to breast reconstruction and promotion of immediate reconstruction.

Argyll & Clyde, Ayrshire & Arran, Grampian, Greater Glasgow
Crosshouse Hospital, Kilmarnock; the Victoria Infirmary, Glasgow; the Royal Alexandra Hospital, Paisley; and Aberdeen Royal Infirmary are among breast units with 'inhouse' reconstruction by the local breast surgeons.

Fife, Greater Glasgow, Tayside
Hospitals within these NHS Boards have developed close ties with the regional plastic surgery units resulting in better promotion of and access to reconstruction. A joint trainee post is shared between Glasgow Royal Infirmary and the plastic surgery unit at Canniesburn Hospital, Glasgow, to allow breast reconstruction experience.

Standard 11: Surgical Management

Standard Statement 11(e)
Axillary surgery is performed in all patients with operable invasive breast cancer.

Essential Criterion

1. **A minimum of 85% of patients with invasive carcinoma undergoing axillary surgery.**

Where data were available to assess this criterion it was met in 21 hospitals.

Desirable Criterion

2. **A minimum of 95% of patients with invasive carcinoma undergoing axillary surgery.**

Where data were available to assess this criterion it was met in 14 hospitals.

Standard Statement 11(f)
A minimum of four nodes must be removed to predict the pathological node status (excluding patients in sentinel node trials).

Essential Criterion

1. **Not more than 10% of patients with inadequate axillary surgery (less than four lymph nodes).**

Where data were available to assess this criterion it was met in 21 hospitals.

Desirable Criterion

2. **Not more than 5% of patients with adequate axillary surgery (less than four lymph nodes).**

Where data were available to assess this criterion it was met in 16 hospitals.

Strengths

- In the 1987 audit an average of 79% of patients underwent axillary node surgery, rising to an average of 90% in 1993 with 9% of patients in whom less than four nodes were recovered. The standard for this assessment was set at 85% of patients which was met by all units who were able to provide data met this criterion. All of these units also achieved the standard of less than 10% of patients having inadequate axillary surgery, with less than four nodes removed. Fifteen of these units achieved the desirable levels of 95% of patients with invasive breast cancer having adequate axillary surgery.
- This standard was seen to be well met in all units that were able to provide data on axillary surgery. The importance of lymph node status as a prognostic indicator and indeed a guide to the need for further treatment appears to be well recognised across Scotland.

Challenges

- It is important to ensure that a minimum of four nodes are removed during axillary surgery to give dependable staging. Six units were unable to provide this data. As lymph node status is such an important prognostic indicator units should ensure that they know they are achieving this.

Recommendations

- It is vital that all units collect prospective audit data of breast cancer treatment which they review regularly themselves so as to improve their practice.
- As suggested previously discussion of each patient's treatment plan at the clinical pathological conference is likely to reduce the number of patients who do not undergo axillary surgery.
- Axillary specimens should be examined by the surgeon during surgery to ensure that at least four lymph nodes have been removed prior to completing the axillary surgery.

Standard 11: Surgical Management

Standard Statement 11(g)
Pathology reports of surgically treated breast cancers include the minimum details recommended by SIGN.

Essential Criteria

1. A minimum of 80% tumour grade known.

Where data were available to assess this criterion it was met in 21 hospitals.

2. A minimum of 80% oestrogen receptor (ER) status known.

Where data were available to assess this criterion it was met in 21 hospitals.

3. A minimum of 80% closest margin reported in millimetres (mm) separately for invasive tumour and in situ disease.

Where data were available to assess this criterion it was met in 20 hospitals.

Desirable Criteria

4. A minimum of 90% tumour grade known.

Where data were available to assess this criterion it was met in 20 hospitals.

5. A minimum of 95% oestrogen receptor (ER) status known.

Where data were available to assess this criterion it was met in 18 hospitals.

6. A minimum of 95% closest margin reported in mm separately for invasive tumour and in situ disease.

Where data were available to assess this criterion it was met in 14 hospitals.

Strengths

- In the 1987 audit 47% of tumours were graded rising to 75% in 1993. A total of 21 units could provide data and all of these met the standard of 80% of tumours being graded with 20 of these units grading more than 95% of all tumours.
- The same 21 units met the standard for testing for the oestrogen receptor (ER) with 18 meeting the desirable target. In 1987 this was achieved in 61% and in 1993 54%.
- Twenty units could provide information on excision margins and all of these met the standard of 80% with 14 units achieving the desirable standard of 95%. This again shows the improvement from the audits of 1987 and 1993 when 55% and 75% of cases respectively had the excision margins measured.
- Pathology services across Scotland are of a high quality with these standards met in all of the Trusts who could provide data. The importance of accurate pathology to allow good treatment planning is well recognised.

Challenges

- The shortage of pathologists means this is the area in which the least sub-specialisation is possible and some units are unable to have a pathologist present at the clinical pathological conference to discuss or review issues relating to patients' pathology results.
- As the adjuvant treatment choices are largely based on the pathology, it is crucial to have the contribution of a pathologist at the CPC to discuss cases where there is a pathological issue.
- Six units were unable to provide any audit data regarding pathology reporting.

Recommendations

- Accurate pathology is essential not only in the diagnosis of breast cancer but also in ensuring prognostic and treatment indicators are clearly reported so that the appropriate treatment can be selected. As the dependence on tumour cell markers and developing prognostic indicators grows, the need for specialised pathology input and additional pathologists becomes more pressing.

2.12 Standard 12: Radiotherapy

Standard Statement 12(a)
Radiotherapy is normally given to the breast after wide local excision.

Essential Criterion

1. **A minimum of 85% of patients receiving radiotherapy to the breast after conservation for invasive cancer (excluding trial patients).**

Where data were available to assess this criterion it was met in 15 hospitals.

Desirable Criterion

2. **A minimum of 95% of patients receiving radiotherapy to the breast after conservation for invasive cancer (excluding trial patients).**

Where data were available to assess this criterion it was met in 10 hospitals.

Standard Statement 12(b)
After axillary sampling, the axilla is only irradiated if node positive or inadequate sampling.

Essential Criterion

1. **A minimum of 85% of patients receiving radiotherapy to the axilla after node positive sample.**

Where data were available to assess this criterion it was met in 7 hospitals.

Desirable Criterion

2. **A minimum of 95% of patients receiving radiotherapy to the axilla after a node positive sample.**

Where data were available to assess this criterion it was met in 6 hospitals.

Strengths

- In the 1987 audit 55% of patients treated with breast conservation received breast radiotherapy. This improved to 75% in the 1993 audit. Of the 20 units who could give this information 15 met the standard with 10 of these meeting the desirable target. There is good recognition of the need for local control of the disease within the breast. Achieving clear excision margins at surgery (Standard 11d) and then giving radiotherapy to the breast significantly reduces the risk of local recurrence.

Strengths

- Ten units routinely carry out surgical removal of all the axillary lymph nodes (axillary clearance) and patients do not usually require axillary radiotherapy even if the nodes contain cancer cells. In seven of the ten units, where sampling of four nodes is routine, those with lymph node metastases did receive radiotherapy routinely. Indeed six of these met the desirable standard.

Challenges

- There are five units where more than 15% of patients have not received radiotherapy after breast conservation. Along with excision margins breast radiotherapy is important in reducing the risk of local recurrence within the conserved breast and it is therefore disappointing that these units are not using radiotherapy as widely as recommended in the SIGN guidelines. The units involved should check their audit data to see if this finding is correct or appears due to incomplete data collection. If it is verified they must consider how it has occurred so that they can put safeguards in place for the future.
- Axillary node sample, with removal of at least four nodes, is a staging procedure but has no therapeutic contribution. If the lymph nodes sampled are found to contain breast cancer, then the axilla must be treated with radiotherapy or cleared at a second operation. Three units, who performed axillary sampling, did not meet the standard for using radiotherapy when the sample showed disease in the nodes. Seven units did not provide data for this criterion.

Recommendations

- As with the other standards relating to clinical treatment this comes down to the quality of decision making for each individual patient. It is important that team members are not expected to make treatment decisions on the spot at the clinic, even about so called straightforward cases. Time should be made available at the clinical pathological conference so that the multidisciplinary team can discuss all patients with breast cancer.
- A copy of the treatment plan, held by the patients themselves, could help provide continuity during the patient's journey between primary care and different secondary care providers.

2.13 Standard 13: Adjuvant Systemic Therapy

Standard Statement 13(a)
All women with invasive breast cancer are considered for adjuvant systemic therapy.

Essential Criterion

1. A minimum of 85% of patients, ER positive, node positive, receiving adjuvant treatment, which includes hormonal therapy or ovarian ablation (excluding patients in clinical trials).

Where data were available to assess this criterion it was met in 21 hospitals.

Desirable Criterion

2. A minimum of 95% of patients, ER positive, node positive, receiving adjuvant treatment which includes hormonal therapy or ovarian ablation (excluding patients in clinical trials).

Where data were available to assess this criterion it was met in 17 hospitals.

Standard Statement 13(b)
Pre or perimenopausal women with intermediate or high-risk disease are offered adjuvant chemotherapy.

Essential Criterion

1. A minimum of 85% premenopausal, ER negative, node positive patients receiving adjuvant chemotherapy.

Where data were available to assess this criterion it was met in 17 hospitals.

Desirable Criterion

2. A minimum of 95% premenopausal, ER negative, node positive patients receiving adjuvant chemotherapy.

Where data were available to assess this criterion it was met in 16 hospitals.

Strengths

- There is widespread recognition of the importance of adjuvant systemic therapy. Scotland led the way in establishing routine oestrogen receptor (ER) testing and this is widely available, being a routine part of pathology reports. This allows endocrine treatment to be used appropriately in patients who are ER positive while it should not normally be used in those who are ER negative if also negative for the progesterone receptor (PR).

Strengths

- This standard was met in all of the 21 Trusts who could produce clinical audit data with 17 meeting the desirable standard of more than 95%.
- This standard was already fairly well achieved in the 1993 audit when 92% of the patients were on hormone treatment compared with 65% in the 1987 audit. As ER testing was not universal at that time these figures are likely to have included patients without the receptor in whom endocrine treatment would be ineffective.
- The premenopausal patients referred to in this standard defines a group of patients where there should be little controversy regarding their systemic treatment. Only 39% of these patients received chemotherapy in the 1987 audit, while in 1993 this had risen to 80% as the benefits of chemotherapy in this group became clearer. While in several Trusts there were no patients in this cohort during the audit period, all those who provided data did meet the standard and 16 out of 17 units, who could provide data on such patients, used chemotherapy in more than 95% of such patients.

Challenges

- While the use of Tamoxifen is well established it is important that PR testing becomes available for those with ER negative tumours. Then those who are ER/PR negative may be considered for other forms of therapy, which may be more effective in their case.
- Although small numbers of patients fall into the premenopausal category and any omission has a big impact on the audit figures, these are young patients and there should be very few who have chemotherapy omitted from their adjuvant treatment if they are ER negative and node positive.

Recommendations

- As with the other treatment standards the issue is making time available in the weekly clinical pathological conference to ensure appropriate treatment decisions are made for each patient.
- As adjuvant systemic treatment is often the subject of clinical trials and therefore treatment evolves rapidly, it is important that clinicians keep up to date by attending the appropriate meetings and conferences to hear trial results and debates on disease management.

2.14 Standard 14: Chemotherapy

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

Essential Criteria

1. **Chemotherapy to conform to Joint Council for Clinical Oncology (JCCO) (1994) guidelines.**

This criterion was met in 22 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 19 hospitals.

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

This criterion was met in 21 hospitals.

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

This criterion was met in 21 hospitals.

5. **Protocols to 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 multidisciplinary team.**

This criterion was met in 22 hospitals.

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

This criterion was met in 21 hospitals.

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

This criterion was met in 23 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 23 hospitals.

Strengths

- Many district units have developed or are in the process of developing local chemotherapy units, both in-patient and day units. This is to be commended as it allows chemotherapy to be delivered closer to the patient's home and reduces patient travelling at a vulnerable time. It is important that these units work strictly to protocols agreed with the supporting regional oncology centre to ensure high standards of practice.
- Most pharmacy departments meet the requirements for chemotherapy dispensing and in the majority of units the chemotherapy is administered to patients by oncology nurses with extended training.

Challenges

- Some devolved local chemotherapy units did not have the full range of protocols from the regional centre. In particular, protocols on the management of chemotherapy complications such as neutropenic sepsis were not held in all chemotherapy units.
- Within large cities, chemotherapy is often delivered in the regional centre and in these cases it is assumed that patients with complications are referred back to the regional oncology centre. However, no provision has been made for patients who cannot get a bed in the regional unit. Several units had not recognised their need to have protocols on the treatment of chemotherapy toxic effects, and also a local policy to ensure that these patients are admitted under the care of a team who can deal with their complications. The need for protocols for the common complications needs to be recognised even in those Trusts which do not have a chemotherapy unit.
- Pharmacy units are under considerable pressure due to the expanding role of chemotherapy in the adjuvant treatment of all cancers and this will have to be addressed so that standards do not fall. According to JCCO guidelines(5) chemotherapy should be given within working hours so that it is not left to junior medical staff who may lack training. As a result of pressure of numbers some units are working an extended day.

Recommendations

- The increasing use of chemotherapy in cancer treatment generally must be recognised and provision made for the expansion of facilities and staff in pharmacies as well as within the local chemotherapy units. As mentioned previously, manpower planning and recruitment will be required to address the acute shortage of oncologists to support this expansion.
- It is important that all local chemotherapy units develop nurse practitioner based administration of chemotherapy to ensure that trained staff are available as required and to avoid long waits for chemotherapy patients.
- Owing to the pressure on some regional oncology units there is less time available to run training courses for oncology and chemotherapy nurses. This is a problem for training staff and maintaining their skills and knowledge base. As raised under Standard 5, there is a need to address provision of breast cancer and oncology training nationally – perhaps with one of the major units taking on an additional educational role.

Example of a local initiative

Greater Glasgow
The Beatson Oncology Centre has a dedicated pharmacy trainer who runs courses in chemotherapy preparation.

2.15 Standard 15: 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 17 hospitals.

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

This criterion was met in 15 hospitals.

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

This criterion was met in 6 hospitals.

Strengths

- There is awareness of the importance of the symptom management of patients with cancer with increased referral of these patients to palliative care services.
- The SIGN guideline on pain management is being introduced in the practical management of patients with advanced cancer. There is an increase in joint consultant appointments between local hospices and hospitals.
- Lymphoedema (swelling of the arm) is a complication of breast cancer treatment to the axilla. Lymphoedema services were provided by 26 Trusts showing a widespread recognition of this symptom and its effect on quality of life.

Challenges

- There are many hospitals without formal specialist palliative care input although there is widespread ad hoc input from local hospice consultants. In some hospitals the specialist palliative care input is so little that only those who are terminally ill are seen rather than those at an earlier, albeit incurable, stage having access to palliation to improve their quality of life.

Challenges

- Even in units which had the input of palliative care consultants there was often a lack of liaison palliative care nurses.
- While lymphoedema services are widespread they are of variable quality with the more complex treatments often only available through hospice services.

Recommendations

- Joint consultant appointments between hospital and hospice should be increased with liaison sisters based in each hospital to provide a contact point for referral and advice.
- The links with primary care should be improved to allow more patients to be at home if they wish.
- Lymphoedema service access could be improved by redesigning services and advancing lymphoedema training, ideally at a Scottish training centre. Audit data on the occurrence of this and other morbidity after treatment need to be collected so that the extent of the problem is realised and can be planned for.

Examples of local initiatives

Greater Glasgow

The Victoria Infirmary, Glasgow, and Southern General Hospital, Glasgow, have developed a care pathway with the Prince and Princess of Wales Hospice, Glasgow, for co-ordination of local healthcare. This introduces a clinical tool for assessing and managing pain in palliative cancer treatment.

The Victoria Infirmary, Glasgow, has developed an individual care plan for pain management which is accompanied by a high-quality patient held record to improve continuity of care.

Dumfries & Galloway, Fife

In both areas the palliative care unit is based within the local district general hospital and therefore the palliative care team is able to offer close links to the breast care team. In Dumfries & Galloway Royal Infirmary a Chaplain and a Social Worker are included in the palliative care team thereby allowing greater flexibility in dealing with each patient's problems whether physical, emotional, spiritual or social.

Orkney

A patient care co-ordinator liaises between primary and secondary care to increase continuity.

2.16 Standard 16: Drugs

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

Essential Criteria

Drugs in Health Board Areas

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

This criterion was met in 24 hospitals.

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

This criterion was met in 26 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 20 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 20 hospitals.

Strengths

- There is an increasing availability of guidelines for the use of drugs in palliative care. Community pharmacies are able to provide palliative care drugs and out of hours GP co-operatives have good access to drugs.
- Many units are involved in schemes to enhance palliative drug availability in the community including the 'Model Scheme for Palliative Care'.

Challenges

- The arrangements for access out of hours could be enhanced further. All members of the patient care team need to be aware of the protocols and how to access drug advice and provision.
- More pharmacists with an interest in palliative care are required to drive the service forward and form the links between hospital and community pharmacy services. They are pivotal in providing advice and helping with the production of local formularies.

Recommendations

- All policies and protocols should be agreed between primary and secondary care. As far as possible only one type of syringe driver should be used to allow ease of maintenance and setting up at the time of discharge.

Examples of local initiatives

Greater Glasgow
Specialist pharmacists with a special interest in palliative care have pulled the service together across community pharmacies in the whole NHS Board area.

Argyll & Clyde
In the Royal Alexandra Hospital, Paisley, and Inverclyde Royal Hospital, Greenock, specialist palliative care pharmacists advise local pharmacies through the 'Model Scheme for Palliative Care'.

West Lothian
In St. John's Hospital, Livingston, link nurses update syringe driver training in their areas and run workshops for new staff.

2.17 Standard 17: 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 all 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 24 hospitals.

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

This criterion was met in 20 hospitals.

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

This criterion was met in 11 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 all 27 hospitals.

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

This criterion was met in 26 hospitals.

Equipment in Health Board Areas

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

This criterion was met in 7 hospitals.

Desirable Criterion

9. Health 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 22 hospitals.

Strengths

- It is widely recognised that there is a need for quick and unbureaucratic access to equipment for patients with palliative needs. Some areas have equipment stores run by store managers who are able to track and provide equipment very quickly.

Challenges

- There must be seamless access between secondary and primary care to equipment for palliative care patients. The equipment used by patients must be standardised for ease of training both for staff and patients. It is disappointing that so few NHS Board areas have achieved the provision of a single type of syringe driver.
- Improving access for patients to a greater range of equipment can allow their easier discharge from hospital and to stay at home longer if that is their wish.

Recommendations

- Joint equipment stores with an equipment store manager and a single syringe driver type should be set up in each NHS Board area. The range of equipment available to patients should be expanded. For less commonly required equipment this could even be co-ordinated between different equipment stores across the country supported by a common or central database.

Examples of local initiatives

Greater Glasgow, Lanarkshire, West Lothian
There is an NHS Board wide equipment store, which is run by store managers.

Fife
There is only one syringe driver type in this area.

Dumfries & Galloway
There is a joint equipment store with a manager and equipment database allowing 24-hour equipment delivery. They have one type of syringe driver.

2.18 Standard 18: Outcomes

Standard Statement
The aim of improving the breast service is to improve the outcome from breast cancer.

NB: Trusts tried hard to meet the requests for information about services, although what was provided was often incomplete or immature. 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)'.

Essential Criteria

1. Not more than 15% 5-year local recurrence rate.

Where data were available to assess this criterion it was met in 3 hospitals.

2. A minimum of 60% 5-year disease free survival.

Where data were available to assess this criterion it was met in 3 hospitals.

3. A minimum of 75% 5-year overall survival.

Where data were available to assess this criterion it was met in 4 hospitals.

Desirable Criteria

4. Not more than 5% 5-year local recurrence rate.

Where data were available to assess this criterion it was met in 3 hospitals.

5. A minimum of 70% 5-year disease-free survival.

Where data were available to assess this criterion it was met in 3 hospitals.

6. A minimum of 85% 5 year overall survival.

Where data were available to assess this criterion it was met in 3 hospitals.

Strengths

- The CRAG outcome data[1] show that 5-year survival after breast cancer treatment has steadily improved from 1987 (66%) to 1993 (75%). This improvement is evident across all NHS Board areas in Scotland. As this is associated with an improvement in all the treatment standards as audited by Scottish Cancer Therapy Network between 1987 and 1993 it can be seen that improving the standard of treatment for patients does result in survival of more patients after breast cancer.
- As this review process shows a further improvement in the standard of breast cancer treatment from 1993 until the present day it is to be expected that this will again result in improved outcomes in the future. However, the long-term results for current patients cannot be assessed for at least five years.

Challenges

- As many Trusts have only been collecting audit data for three years, very few units were able to offer data on outcomes five years after treatment for breast cancer.
- In some units who gave outcome data it was clear that some patients were missing from the audit thereby rendering the results misleading.
- The audit departments in many Trusts do not have a system for collecting follow up data on previously treated patients or a system to check their data with local cancer registries.

Recommendations

- Trusts need to produce five year outcome data from their prospective audit as a final assessment of service quality. These figures should be compared with figures from the Information and Statistics Division (ISD) which ascertains outcome data on a national basis for each NHS Board. The figures produced by ISD are verified by checking with the national cancer registries.
- It is often difficult to obtain detailed outcomes five years after treatment if a review through case sheets is required. Trusts need to verify their prospective audit data and add follow up data sheets (returned at the patients' review clinic visit) to update the data base and allow full generation of outcome data. It is particularly important to collect data on local recurrence as this is difficult to assess retrospectively and is related to the treatment (surgery and radiotherapy) of the breast and axilla.

Recommendations

- This would be more easily achieved by using an automated data collection system which would register every time there was contact with the patient with the processes of patient care generating accurate follow-up data.
- It is crucial that the ability to check the outcome of breast cancer treatment is maintained and indeed enhanced by better local data collection. It is also important that this can be compared with ISD data which is checked on a national basis.

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 breast cancer standards published by the Board in 2000.

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 has 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 not happening. 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 also be presented to the Scottish Cancer Group in support of the work underway 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 is taken. Considerable momentum has built up and it is important to use this enthusiasm to take forward the work on 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 who 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

Breast Cancer Project Group

Chair

Ms Philippa Whitford
Consultant Surgeon, Ayrshire & Arran Acute Hospitals NHS Trust

Project Group Members

Mr Udi Chetty
Consultant Surgeon, Lothian University Hospitals NHS Trust

Ms Kathy Clarke
National Cancer Audit Co-ordinator, Information & Statistics Division, Common Services Agency

Dr John Dewar
Consultant in Radiotherapy and Oncology, Tayside University Hospitals NHS Trust

Professor Fiona Gilbert
Roland Sutton Chair of Radiology and Head of Department, University of Aberdeen

Dr Bob Grant
Macmillan GP Facilitator, Fife Primary Care NHS Trust

Mrs Alice Lambert
Member, Argyll & Clyde Health Council

Dr Elizabeth Mallon
Consultant Histopathologist, North Glasgow University Hospitals NHS Trust

Ms Lynda McLennan
Breast Cancer Nurse, Grampian University Hospitals NHS Trust

Dr Chris Twelves
Senior Lecturer in Medical Oncology, North Glasgow University Hospitals NHS Trust

Mrs Heather Wallace
Member, Lothian Health Council

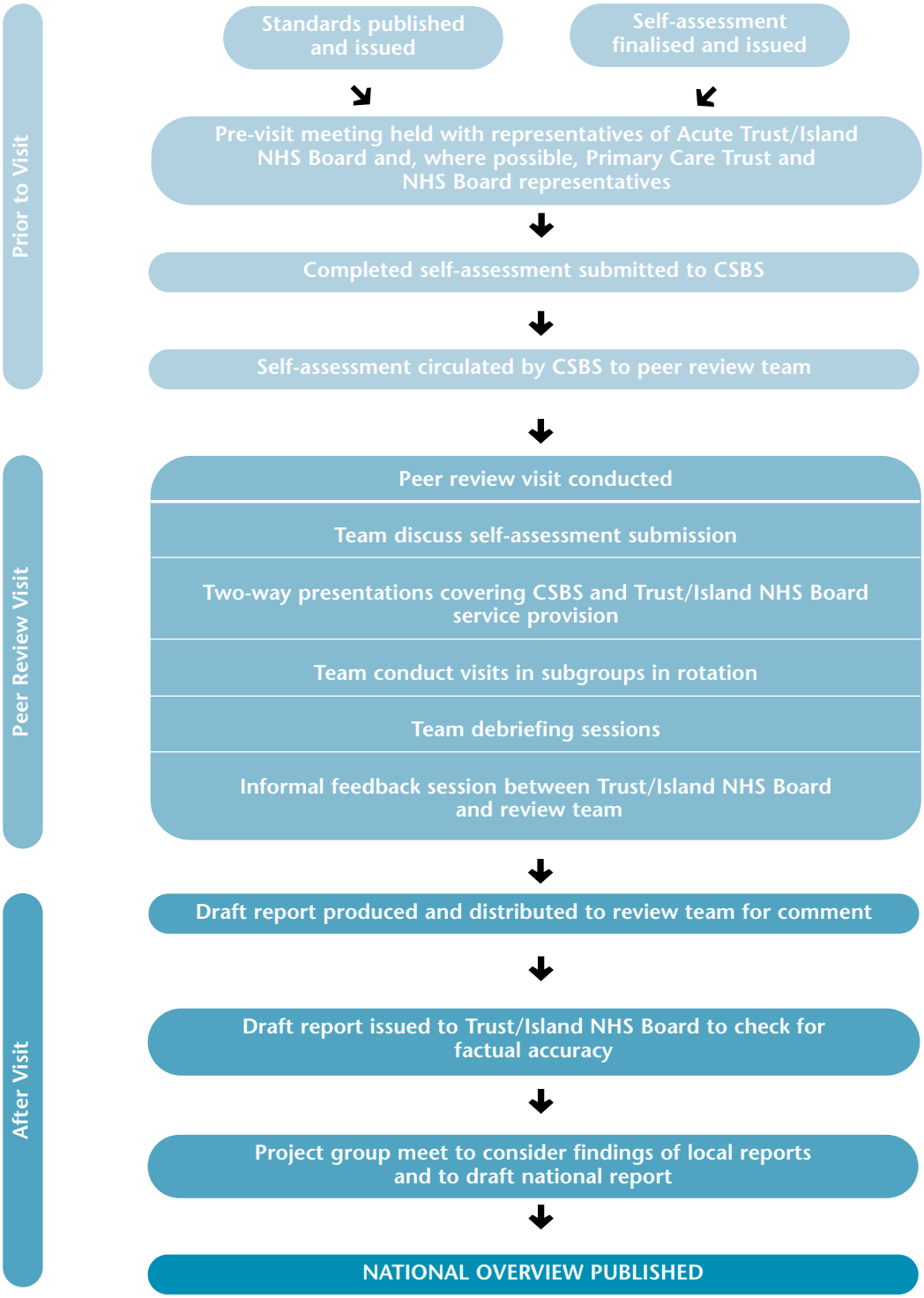
The Board member specifically working with the Breast Cancer Project Group was **Mr John McCormick, OBE**.

Ms Frances Smith (Director of Nursing and Quality), **Ms Sharon Keane** (Project Officer) and **Ms Susan Shields** (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 breast 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

Breast Cancer Review Team Members

Dr Ruth Adamson
Pathologist, Ayrshire & Arran Acute Hospitals NHS Trust

Dr Carole Alexander
Consultant Radiologist, Greater Glasgow Primary Care NHS Trust

Ms Debbie Archibald
Breast Screening Co-ordinator, Tayside University Hospitals NHS Trust

Ms Patricia Baird
Principal Pharmacist, West Lothian Healthcare NHS Trust

Mrs Doreen Bell
Member, Fife Health Council

Mrs Margo Biggs
Chairman, Forth Valley Health Council

Mr William Bowes
Member, Lothian Health Council

Dr Peter Canney
Consultant Oncologist, North Glasgow University Hospitals NHS Trust

Mrs Patricia Carlin
Member, Forth Valley Health Council

Mr Udi Chetty
Consultant Surgeon, Lothian University Hospitals NHS Trust

Ms Shona Cheyne
Principal Oncology/Haematology Pharmacist
Fife Acute Hospitals NHS Trust

Ms Suzanne Clark
Member, Greater Glasgow Health Council

Professor Tim Cooke
Professor of Surgical Oncology
North Glasgow University Hospitals NHS Trust

Dr Carolyn Cordiner
Deputy Clinical Director/Consultant Radiologist
Greater Glasgow Primary Care NHS Trust

Miss Sharley Crawford
Superintendent Radiographer (Breast Screening)
Grampian University Hospitals NHS Trust

Mrs Ann Crowe
Acting Imaging Services Manager, Forth Valley Acute Hospitals NHS Trust

Mrs Sue Cruickshank
Macmillan Breast Care/Oncology Nurse
Borders General Hospital NHS Trust

Ms Margaret Dakers Thomson
Chairman, Highland Health Council

Sister Cathy Davies
Breast Clinical Nurse Specialist
Dumfries & Galloway Acute & Maternity Hospitals NHS Trust

Dr John Dewar
Consultant in Radiotherapy and Oncology
Tayside University Hospitals NHS Trust

Ms Sandra Dickie
Breast Cancer Liaison Sister
Renfrewshire & Inverclyde Primary Care NHS Trust

Dr Hilary Dobson
Clinical Director – Breast Screening
Greater Glasgow Primary Care NHS Trust

Mr Philip Dolan
Member, Greater Glasgow Health Council

Dr Rosalie Dunn
General Practitioner, Lanarkshire Primary Care NHS Trust

Mrs Hazel Dykes
Head of Therapy Services
Dumfries & Galloway Acute & Maternity Hospitals NHS Trust

Ms Barbara Elliot
Lay Representative, Greater Glasgow

Mrs Elaine Ferguson
Breast Care Sister, Lanarkshire Acute Hospitals NHS Trust

Ms Frances Ferguson
Clinical Pharmacist Haematology/Oncology
South Glasgow University Hospitals NHS Trust

Mr John Ferguson
Consultant Surgeon, South Glasgow University Hospitals NHS Trust

Mr Paul Fisher
Consultant Surgeon, Highland Acute Hospitals NHS Trust

Dr Alan Foulis
Consultant Pathologist, North Glasgow University Hospitals NHS Trust

Professor Fiona Gilbert
Roland Sutton Chair of Radiology and Head of Department of Academic Radiology, University of Aberdeen

Mrs Maureen Graham
Breast Care Nurse, Greater Glasgow Primary Care Trust

Mr Spencer Green
Clinical Pharmacist, Argyll & Clyde Acute Hospitals NHS Trust

Ms Avril Gunning
Specialist Nurse Breast Care, Tayside University Hospitals NHS Trust

Mr John Heaney
Lay Representative, Greater Glasgow

Sister Shirley Herdman
Ward Manager, South Glasgow University Hospitals NHS Trust

Dr Andrew Hutcheon
Consultant Medical Oncologist, Grampian University Hospitals NHS Trust

Dr Jocelyn Imrie, OBE
Consultant Cytopathologist, Lanarkshire Acute Hospitals NHS Trust

Mrs Mareth Irvine
Vice-Chairman, Dumfries & Galloway Health Council

Dr Brian Junor (observer)
Consultant Nephrologist, North Glasgow University Hospitals NHS Trust

Miss Jean Laburn
Lay Representative, Tayside

Mrs Alice Lambert
Member, Argyll & Clyde Health Council

Dr Penny Law
Consultant Radiologist
Dumfries & Galloway Acute & Maternity Hospitals NHS Trust

Mrs Kathryn McCall
Macmillan Nurse, Highland Primary Care NHS Trust

Dr Linda MacCallum
General Practitioner, Lothian Primary Care NHS Trust

Dr Jean McCullough
Consultant Pathologist, Tayside University Hospitals NHS Trust

Ms Joyce McDermid
Senior Pharmacist, Ayrshire & Arran Acute Hospitals NHS Trust

Mr Angus MacDonald
Consultant Surgeon, Lanarkshire Acute Hospitals NHS Trust

Miss Roseanne McDonald
Lead Nurse – Cancer Services
Ayrshire & Arran Acute Hospitals NHS Trust

Mrs Alison McGilvray
Member, Forth Valley Health Council

Ms Pauline McIlroy
Macmillan Breast Care/Oncology Support Nurse
Argyll & Clyde Acute Hospitals NHS Trust

Miss Chris Mackie
Lay Representative, Borders

Mr Michael McKirdy
Consultant Surgeon, Argyll & Clyde Acute Hospitals NHS Trust

Sister Elspeth McLatchie
Sister, North Glasgow University Hospitals NHS Trust

Ms Lynda McLennan
Breast Care Nurse, Grampian Primary Care NHS Trust

Mrs Ellen McPake
Breast Care Nurse, South Glasgow University Hospitals NHS Trust

Dr Elizabeth Mallon
Consultant Histopathologist
North Glasgow University Hospitals NHS Trust

Mr William May
Member, Greater Glasgow Health Council

Dr David Millar
Macmillan GP Advisor, Grampian Primary Care NHS Trust

Mr Robert Murdoch
Consultant Surgeon, Tayside University Hospitals NHS Trust

Mr Glyn Neades
Consultant Surgeon, Fife Acute Hospitals NHS Trust

Mr Anthony D Newland
Consultant Surgeon, Ayrshire & Arran Acute Hospitals NHS Trust

Ms Eileen Nicol
Pharmacist, Borders General Hospital NHS Trust

Ms Gillian O'Mara
Oncology Nurse Specialist, Lothian University Hospitals NHS Trust

Mr John S O'Neill
Consultant Surgeon, Borders General Hospital NHS Trust

Mr Mark Parsons
Principal Oncology Pharmacist, Tayside University Hospitals NHS Trust

Dr Russell Pickard
Consultant Radiologist, Greater Glasgow Primary Care NHS Trust

Dr Colin Purdie
Consultant Pathologist, Tayside University Hospitals NHS Trust

Dr Alastair J Robertson
Clinical Group Director of Clinical Support Services
Tayside University Hospitals NHS Trust

Dr Gerry Robertson
Consultant Clinical Oncologist
North Glasgow University Hospitals NHS Trust

Miss Lesley-Jean Rugg
Superintendent Radiographer, Lothian University Hospitals NHS Trust

Mrs Doreen Scott
Member, Grampian Health Council

Ms Margaret Sherwood
Cancer Services Audit Officer, Argyll & Clyde Acute Hospitals NHS Trust

Mrs Anne Simpson
Lay Representative, Tayside

Mr David C Smith
Consultant Surgeon, South Glasgow University Hospitals NHS Trust

Ms Anne Stewart
Breast Care Nurse, West Lothian Healthcare NHS Trust

Mr Alastair Thompson
Consultant Surgeon, Tayside University Hospitals NHS Trust

Ms Angela Trueman
Member, Borders Health Council

Dr Chris Twelves
Senior Lecturer in Medical Oncology
North Glasgow University Hospitals NHS Trust

Dr Ramsay Vallance
Consultant Radiologist, North Glasgow University Hospitals NHS Trust

Ms Susan Vaughan
Clinical Effectiveness Manager, NHS Highland

Dr Christine Walker
Consultant Radiologist, Tayside University Hospitals NHS Trust

Mrs Heather Wallace
Member, Lothian Health Council

Mr Iain Watt
Consultant Surgeon, Argyll & Clyde Acute Hospitals NHS Trust

Mrs Patricia Weir
Member, Argyll & Clyde Health Council

Professor John Welsh
Professor of Palliative Medicine
North Glasgow University Hospitals NHS Trust

Ms Philippa Whitford
Consultant Surgeon, Ayrshire & Arran Acute Hospitals NHS Trust

Ms Andrea Wilson
Clinical Governance Co-ordinator, Fife Acute Hospitals NHS Trust

Mrs Suzanne Wotherspoon
Lay Representative, Lothian

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 micro-organisms. 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.
axilla	The armpit.
axillary clearance	Operation to remove all the lymph glands from under the arm.

BASO	British Association of Surgical Oncologists.
BCN	Breast Care Nurse.
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.
breast conservation	The removal of a breast lump together with some surrounding tissue. This may be for diagnosis or treatment.
breast reconstruction	Breast reconstruction is an operation to replace breast tissue lost during mastectomy or lumpectomy, restoring the breast shape.
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.
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.
chemotherapy	Systemic therapy with medications that reach every cell in the body.

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. Abbreviated as CT.
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 biopsy	Removal (using a needle) of a piece of a breast tissue for diagnosis.
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.
DCIS	Ductal carcinoma in situ – when the breast cancer cells are completely contained within the ducts (the channels in the breast that carry milk to the nipple) and have not spread into the surrounding breast tissue.
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.
EBCTCG	Early Breast Cancer Trialist's Collaborative Group.
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.
endocrine	Glandular tissues that secrete (make and release) hormones directly into the blood stream.
ER	Oestrogen receptor. A specific site on the surface of a cell that binds to the hormone oestrogen. Anti-oestrogens used for treating breast cancer act by preventing the binding of oestrogen to these receptors.
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 contemporaneous 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.
fine needle aspiration	The withdrawal of fluid, containing cells, from the body by means of suction using a fine needle. The samples obtained are used to provide information on the cells of tumours or cysts. Abbreviated as FNA.
FNA	See Fine Needle Aspiration.
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.
hormone therapy	Treating a disease with hormones, or by blocking the action of hormones.
hormones	Natural chemicals made in one part of the body which travel in the bloodstream and make things happen in another part of the body. Some cancers are stimulated to grow by hormones, particularly the sex hormones (testosterone in men and oestrogen in women).
ICP	See integrated care pathway.
imaging	The production of images of organs or tissues using radiological procedures, particularly using scanning techniques.
immediate reconstruction	Breast reconstruction carried out at the same time as the operation to remove the breast.
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.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.
ISD	See Information and Statistics Division.
Island NHS Board	Island NHS Boards do the work of both 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.
Local Health Care Co-operative	A grouping of general medical practices.
local information pack	Information relevant to a specific service.
lumpectomy	See breast conservation.
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.
mammography	X-ray examination of the breast. Using low-energy X-rays, fine details of breast tissue can be visualised, particularly the presence of calcification or soft tissue masses enabling the early diagnosis of breast cancer.
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.
mastectomy	Surgical removal of a breast.
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.
menopause	'Change of life'. Period of time between the early forties and late fifties when women stop producing sex hormones.
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.
National Breast Screening Programme	National programme inviting all women in the UK between 50 and 64 years old for a health check for breast cancer. The test used is a mammogram which is offered every 3 years.
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.
NHSBSP	National Health Service Breast Screening Programme. See National Breast Screening Programme.
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.
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.
oestrogen	See hormones.
oestrogen blocker	See hormone therapy.
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 rehabilitation. 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.
ovarian ablation	Removal of the ovaries.
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.
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.
postmenopausal	Women who have been through the 'change of life' or menopause.
pre	Prefix meaning before or preceding.
premenopausal	Women who have not yet been through the 'change of life' or menopause.
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.
psychology	The scientific study of human behaviour and the corresponding mental processes. A psychologist is a non-medical professional who has completed special advanced training and is therefore qualified to undertake psychological research, treatments and therapy.
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.
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.
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).
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.
tamoxifen	An anti-oestrogen drug that may be given to women with oestrogen receptive tumours to block oestrogen from entering the breast tissues.
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.
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.
wide local excision	This is the removal of the breast lump together with some surrounding tissue.
Wide local excision	The removal of a breast lump together with some surrounding tissue. This may be for diagnosis or treatment.
WTE	Whole Time Equivalent.
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.

Clinical Standards Board for Scotland
Elliott House 8-10 Hillside Crescent Edinburgh EH7 5EA
T: 0131 623 4300 F: 0131 623 4299

comments@clinicalstandards.org