

Clinical Standards Board for Scotland



Clinical Standards
**Specialist
Palliative Care**

June 2002



CSBS

Promoting
Public Confidence
in NHSScotland

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Contents

1	Introduction	3
2	Background on the Clinical Standards Board for Scotland (CSBS)	5
3	Background on Clinical Standards – Basic Principles	7
4	Development of the Clinical Standards for Specialist Palliative Care	11
5	Membership of the Specialist Palliative Care Project Group	13
6	Overarching Principles	15
7	An Introduction to Specialist Palliative Care	17
8	Evidence Base for the Clinical Standards for Specialist Palliative Care	19
9	Clinical Standards for Specialist Palliative Care	23
10	Glossary of Terms	57

1 Introduction

This document introduces the Clinical Standards Board for Scotland (CSBS) *Clinical Standards for Specialist Palliative Care*. These standards were developed in partnership with the Scottish Partnership for Palliative Care (formerly known as the Scottish Partnership Agency) and apply to specific elements of the service. They cover the following areas:

- Access to Specialist Palliative Care Services
- Key Elements of Specialist Palliative Care
- Managing People and Resources
- Professional Education
- Inter-professional Communication
- Communication with Patients/Carers
- Therapeutic Interventions
- Patient Activity

The standards will be used by the CSBS (the Board) to assess performance in these areas in hospital, community and hospice settings throughout Scotland where specialist palliative care services are provided.

The initial sections of this document provide background information on the Board and on the process used to develop the standards (Sections 2 and 3, respectively).

The development of the *Clinical Standards for Specialist Palliative Care* is outlined in Section 4 and the membership of the project group undertaking this work is given in Section 5. The overarching principles underpinning the standards are provided in Section 6.

Section 7 provides basic information about the topic and the evidence underpinning the standards is presented in Section 8.

Section 9 contains the *Clinical Standards for Specialist Palliative Care*.

Finally, Section 10 provides a glossary of terms used in the standards.

2 Background on the Clinical Standards Board for Scotland (CSBS)

The CSBS was established as a special Health Board in April 1999.

The Board's remit is to develop and run a national system of quality assurance of clinical services, with the aim of promoting public confidence in NHSScotland. The Board, in partnership with healthcare professionals and members of the public, sets standards for clinical services, assesses performance throughout NHSScotland against these standards, and publishes the findings. The standards are based on the patient's journey as they move through different parts of the health service.

The Board develops standards to improve the quality of clinical care across Scotland. A wide range of diseases and services are at present being addressed including infection control, post-mortem and organ retention and adult renal services.

Project Groups

For each service in the work programme, the Board appoints a project group comprising appropriate healthcare professionals and members of the public to oversee the development and consultation on the standards, to manage external peer review, and to report on its findings to the Board.

As part of their rolling programme, individual project groups ensure the standards are regularly evaluated and revised so that they remain relevant and up-to-date (reflecting new procedures and treatments), and that targets of achievement are raised as performance improves.

Development of Standards

The way in which standards are developed is a key element of the process. Groups working on behalf of the Board are expected to:

- adopt an open and inclusive process involving a wide range of both members of the public and professional people through a variety of mechanisms;
- work within the Board's policies and procedures as set out in the *Quality Assurance and Accreditation Manual* (August 2000); and
- test standards through undertaking pilot reviews to ensure that they meet the principles of the Board.

In addition to standards for specific services or conditions, the Board has set generic standards, which apply to all clinical services; more detail on the generic standards is provided in Section 3.

Review

The framework for the Board's review process is as follows:

- once the standards have been finalised, each relevant Trust/hospice is asked to undertake a self-assessment of its service against the standards;
- a review team visits the Trust/hospice on behalf of the Board and follows up this self-assessment exercise with an external peer review of performance in relation to the standards; and
- the Board reports the findings for the Trust/hospice, based on the self-assessment exercise and on the external peer review.

Peer review teams are multidisciplinary, including both healthcare professionals and members of the public. All teams are led by an experienced clinician and are supported by staff from the Board.

All the processes that the Board is developing are subject to review and evaluation, and this will help the Board improve its quality assurance system.

Further Information

Further details on the process by which the Board will achieve its objectives can be found in its *Quality Assurance and Accreditation Manual* (August 2000). Copies of this manual are available from:

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For further information about the Board, and to obtain additional copies of the standards, please visit the Board's website (www.clinicalstandards.org).

3 Background on Clinical Standards – Basic Principles

The standards set by the Board are:

- focused on clinical issues and include non-clinical factors that impact on the quality of care;
- written in simple language;
- based on evidence (recognising that levels and types of evidence will vary);
- written to take account of other recognised standards and clinical guidelines;
- clear and measurable;
- achievable but stretching;
- developed by healthcare professionals and members of the public;
- consulted on widely;
- published on paper and electronically (on the Internet); and
- regularly reviewed and revised to make sure they remain relevant and up-to-date.

Some standards are common to all clinical services, others specific to particular conditions.

Generic Standards

In addition to condition-specific standards such as those set out in this document, the Board has developed generic standards, which apply to clinical services generally.

These generic standards are grouped under two broad headings:

1. Patient Focus

These are designed to ensure that *“all services respond to patients’ needs and preferences, and that patients are involved in decisions about their own care through effective two-way communication and information-sharing”*, and cover:

– *assessment*

The initial assessment helps staff determine what care each patient needs and prefers, and requires the collection of information and the development of a plan of care in response.

– *patient involvement*

Patient care outcomes are improved when patients and, as appropriate, their carers, are involved in clinical care decisions.

-
- *patient information*
Information helps patients make informed choices, which can reduce anxiety and encourage participation in recommended treatment.
 - *patient/staff communication*
Good communication between patients and healthcare professionals is essential for effective individual treatment and patient well-being. Poor communication can lead to less effective diagnosis or reduced compliance with treatment, and can create anxiety, distress and dissatisfaction.
 - *patient feedback*
Encouraging patients/carers to make comments, suggestions and complaints about the organisation's services allows the organisation to gain a patient's perspective to inform the review and development of services.
 - *access to services*
Patients should have access to the services of the healthcare organisation based upon identified healthcare needs and individual preferences.
 - *discharge arrangements*
Effective discharge planning begins on, or shortly after, admission and is a continual process. Communication and transfer of information among healthcare professions is essential to a seamless process.

2. Safe and Effective Clinical Care

These are designed to ensure that “*all patients receive safe and effective care and treatment based on available evidence*”, and cover:

- *clinical guidelines*
Care delivered in accordance with clinical guidelines produces better outcomes for patients.
- *clinical audit*
The review of clinical practice through audit is a well-established means of promoting the quality of clinical care by identifying shortfalls in performance against standards and best practice.
- *risk management*
The management of risk results in a safer system of work, safe practices and an enhanced awareness of possible risk areas.
- *risk environment*
Healthcare organisations work to reduce and control hazards and risk, prevent injury, and generally, to maintain a safe, functional environment for all patients and staff.

3 Background on Clinical Standards – Basic Principles

– *staff*

A healthcare organisation requires appropriately qualified staff to meet the needs of the patients it serves. Review of individual competencies and continuing professional development are essential.

The Board developed the generic standards for two key reasons:

1. To cover aspects of healthcare that are common (or generic) to all conditions and services. As a result, it is not necessary to duplicate these generic standards in every set of condition-specific standards; and
2. To support NHSScotland organisations in the development of a framework for clinical governance, by highlighting key issues that should be addressed to ensure the quality of clinical services and to respond to patients' needs and preferences.

To avoid duplication, the issues covered by the generic standards are mentioned in the condition-specific documents only when the relevant project group concludes that there is an additional dimension warranting inclusion. Trusts and hospices will be alerted in advance to any other generic issues that the review team wishes to raise during the visit.

Format of Standards and Definition of Terminology

All standards set by the Board follow the same format:

- Each standard has a **title**, which summarises the area on which that standard focuses.
- This is followed by the **standard statement**, which explains the level of performance to be achieved.
- The **rationale** section provides the reasons why the standard is considered to be important.
- The standard statement is fleshed out in the section headed **criteria**, where it states exactly what must be achieved for the standard to be reached.

As already mentioned, the Board aims to set standards that are **achievable but stretching**. This is reflected in the criteria. Most criteria are **essential** in that it is expected that they will be met wherever a service is provided. Other criteria are **desirable**, in that 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. Each project group is responsible for determining which criteria are essential and which are desirable.

The criteria are numbered, for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority. The distinction between essential and desirable is the only way in which criteria have been prioritised.

4 Development of the Clinical Standards for Specialist Palliative Care

Introduction

The Board was established to promote public confidence in NHSScotland. Working with healthcare professionals, managers, patients and the general public, the Board sets standards for services and monitors performance against these standards. During Phase 1 of its work programme, the Board developed standards for a range of topics including lung, breast, colorectal and ovarian cancer, which follow the patient's journey from referral to discharge and incorporate standards for palliative care for cancer patients. A programme of peer review visits to monitor service performance against these standards was recently completed, and the national overviews (and individual reports on each local service) have now been published. Part of Phase 2 of the Board's work programme has involved the development of standards for specialist palliative care in collaboration with the Scottish Partnership for Palliative Care (SPPC).

The SPPC is the national umbrella and representative body for palliative care in Scotland. It is an independent body with charitable status that was set up in 1991 to promote the extension and improvement of palliative care services in Scotland, whether provided by voluntary organisations or by the NHS.

A joint CSBS/SPPC project group was established in September 2000 to develop the standards, and two open meetings were held in Perth and Glasgow in April/May 2001 to consult on these draft standards. Following this open consultation period, the Specialist Palliative Care Project Group carried out a comprehensive revision of the standards, in light of the valuable feedback received. This process has taken a number of months to complete, however the project group felt it was important to consider all comments before amending the standards where appropriate.

Scope of the Standards

The majority of specialist palliative care services in Scotland are provided by voluntary hospices working in close collaboration with local NHS Boards and Trusts. The voluntary hospices were eager to be included in the development of a national system of standards and peer review, and a number of pilot visits were conducted during August and September 2001 to ensure that the standards were measurable and could be applied across a variety of settings.

These standards are applicable to all patients, including those with non-malignant disease, who are identified, through assessment by the specialist team,

as requiring access to specialist palliative care services. The standards aim to be flexible in that they may be applied across the range of specialist palliative care services currently provided in Scotland. Criteria which relate only to specific settings (such as specialist palliative care units or hospital palliative care support teams) are clearly indicated.

The Specialist Palliative Care Project Group recognises the limited specialist paediatric input available during the development of these standards. However, following consideration, the project group agreed that the *Clinical Standards for Specialist Palliative Care* should be applied across paediatric and adult specialist services.

5 Membership of the Specialist Palliative Care Project Group

The membership of the Specialist Palliative Care Project Group, chaired by Professor John Welsh, Olav Kerr Professor of Palliative Medicine, University of Glasgow is presented below:

Name	Title	NHS Board Area/ Organisation
Ms Joan Adam	Macmillan Clinical Nurse Specialist	Lothian
Ms Alison Barclay	Senior Occupational Therapist	Lothian
Ms Margaret Colquhoun	Nurse Lecturer in Palliative Care, St Columba's Hospice	Lothian
Dr Cath Dyer	Macmillan Lead GP, Forth Valley	Forth Valley
Ms Kate Macleod	Social Worker – Family Support, Rachel House	Tayside
Dr Lindsay Martin	Consultant in Palliative Medicine, Alexandra Unit	Dumfries & Galloway
Rev David Mitchell	Chaplain, Hunters Hill Hospice	Greater Glasgow
Dr Alison Morrison	Medical Director, Ardgowan Hospice	Argyll & Clyde
Ms Susan Munroe	Centre Director, Hunters Hill Hospice	Greater Glasgow
Mrs Margaret Smith	Lay Representative	West Lothian
Ms Margaret Stevenson	Director	Scottish Partnership for Palliative Care (SPPC)
Ms Cara Taylor	Nurse Manager, Macmillan Service	Tayside
Ms Jane Urie	Senior Pharmacist	Greater Glasgow

The CSBS Board member specifically working with the Specialist Palliative Care Project Group was Mr Norman Sharp.

Mr Jack Blaik, Lay Representative, also provided input to the project group during the initial drafting of the standards.

Ms Frances Smith (Director of Nursing & Quality), Ms Hilary Davison (Review Team Manager), Ms Susan Shields (Project Officer), Ms Claire Higgins (Project Officer) and Mrs Elaine MacKay (Project Administrator) provided support from the Board.

The Specialist Palliative Care Project Group would like to acknowledge the work of the CSBS Palliative Care Cancer Project Group whose standards provided a valuable resource during the development of the *Clinical Standards for Specialist Palliative Care*.

6 Overarching Principles

Specialist Palliative Care Philosophy Statement

In developing the standards, the CSBS/SPPC Specialist Palliative Care Project Group noted that there are a number of important principles which define what specialist palliative care aims to accomplish.

These principles were developed into a specialist palliative care philosophy statement:

Specialist palliative care is the active total care of patients with progressive, far-advanced disease and limited prognosis, and their families, by a multi-professional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support, and will involve practitioners with a broad mix of skills.

(Tebbit 1999)

Specialist Palliative Care Seeks to:

- meet complex needs through a **multidisciplinary team** that meets **regularly**, and where individual team members understand and respect each other's roles and specialist expertise;
- enable team members to be **proactive** in their contact, assessment and treatment of patients and their families/carers and to meet their complex needs;
- **discern, respect and meet** the cultural and religious needs, traditions, and practices of patients and their families/carers;
- recognise the importance of **including the needs of families** in the patient's care, since good family care improves patients' quality of life and **contributes positively** to the bereavement process;
- **share** knowledge and expertise as widely as possible; and
- **promote** and **participate** in research in order to advance the specialty's knowledge base for the benefit of patients and carers.

In the context of these standards, complex needs are defined as needs that cannot be addressed through simple or routine interventions/care.

7 An Introduction to Specialist Palliative Care

Specialist Palliative Care

The World Health Organisation (WHO) definition of palliative care is: *“the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families”*.

Palliative care was first recognised as an important element of health services in Britain in the late 1960s, although initially palliative care was provided by non-specialists in hospitals, general practice, and community nursing. Further progress in the 1970s and 1980s focused on the development of specialist palliative care services, initially in hospices and then in home care teams and hospitals. It is now recognised that many aspects of the palliative care approach can be applied for patients who are in the initial stages of their illness as well as for those with chronic and terminal disease.

Specialist palliative care requires effective multi-disciplinary working within specialist teams and co-ordination across a wide range of professions to ensure that all appropriate patients, including those with non-malignant disease, can access this service and achieve the best quality of life possible.

Care is provided by multidisciplinary teams, who have undergone recognised specialist palliative care training. These teams work in partnership with those providing generalist palliative care to ensure that patients' and families' complex needs are met.

There are a number of essential components that make up a specialist palliative care service. These include:

- effective communication;
- symptom control;
- rehabilitation;
- education and training;
- research and audit;
- continuity of care;
- terminal care; and
- bereavement support.

The Provision of Specialist Palliative Care in Scotland

The need for specialist palliative care is highlighted in the Scottish Executive's cancer strategy, *Cancer in Scotland: Action for Change*. Significant progress has been made in the provision of specialist palliative care services; however, it is important to continue the development of this work in partnership with all relevant professionals throughout Scotland.

Depending upon definition, there are now 23 adult hospice or specialist units providing specialist palliative care in Scotland. There is also a children's hospice which provides specialist services across Scotland for children and their families and carers. Together these services provide 338 beds.

Specialist Palliative Care Units

Specialist palliative care is provided in specialist units, which can be found in:

- Independent voluntary hospices
- Marie Curie hospices
- NHS palliative care units

Patients can be admitted to these units for specialist care for a few days or for a number of weeks. These units also provide day hospice facilities, home care, support for appropriate patients cared for in care homes and bereavement support, together with advice services and education.

Hospital Palliative Care Support Teams

Hospital palliative care teams provide specialist palliative care within hospitals, which involves attending to patients on a variety of different wards and providing advice to other clinicians.

Community

Specialist palliative care in the community is provided through the integration of the specialist palliative care service and the primary healthcare team. This enables patients to remain at home during their terminal illness, if possible and if this is their wish, with the full support and care they need during this time. These teams may also provide services for appropriate patients who are cared for in care homes.

It is important to highlight that specialist palliative care services communicate, co-operate and integrate across all healthcare settings.

8 Evidence Base for the Clinical Standards for Specialist Palliative Care

The *Clinical Standards for Specialist Palliative Care* build on the standards for palliative care, which form part of the CSBS standards for the four common cancers (lung, breast, colorectal and ovarian). The palliative care standards include locally agreed policies for pain management based on the Scottish Intercollegiate Guidelines Network (SIGN) guideline for the *Control of Pain in Patients with Cancer*. SIGN guidelines are developed according to a methodology in which one of the key elements is the use of systematic reviews to identify and collate evidence. There are as yet, however, no SIGN guidelines covering aspects of specialist palliative care other than the control of pain. There is also a recognised scarcity of firm scientific evidence in palliative care due to the ethical and practical difficulties of conducting research with this group of patients.

In drafting the *Clinical Standards for Specialist Palliative Care*, the Specialist Palliative Care Project Group drew on published evidence as referenced in the standards, including expert committee reports from the SPPC and the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS).

At the beginning of its work, the Specialist Palliative Care Project Group consulted with the service about the aspects of specialist palliative care which they believed to be key factors in determining quality of care. Members of the group visited voluntary and NHS hospices and hospital specialist palliative care teams throughout Scotland, and met multidisciplinary teams and patient/carer representatives. The views from these meetings shaped the group's work and have ensured that the standards reflect current experience in Scotland.

The evidence base for the *Clinical Standards for Specialist Palliative Care* was principally drawn from the following source documents:

1. Addington-Hall J, McCarthy M. Dying from Cancer: Results of a National Population-Based Investigation. *Palliative Medicine* (1995); 9 (4): 295-305.
2. Association for Palliative Medicine. The Which Tool Guide: Preliminary Review of Tools to Measure Clinical Effectiveness in Palliative Care. Southampton: (September 2001).
3. Bosanquet N, Salisbury C, ed. Providing a Palliative Care Service: Towards an Evidence Base. Oxford: Oxford Medical Publications, Oxford University Press (1999).
4. Cantwell P, Turco S, et al. Predictors of Home Death in Palliative Care Cancer Patients. *Journal of Palliative Care* (2000); 16 (1): 23-28.

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5. Ellershaw JE, Peat SJ, et al. Assessing the Effectiveness of a Hospital Palliative Care Team. *Palliative Medicine* (1995); 9 (2): 145-152.
 6. Hearn J, Higginson IJ. Do Specialist Palliative Care Teams Improve Outcomes for Cancer Patients? A Systematic Literature Review. *Palliative Medicine* (1998); 12 (5): 317-332.
 7. Hearn J, Higginson I. Development and Validation of a Core Outcome Measure for Palliative Care: The Palliative Care Outcome Scale. *Quality in Health Care* (1999); 8 (4): 219-227.
 8. Karlsen S, Addington-Hall J. How Do Cancer Patients Who Die at Home Differ from Those Who Die Elsewhere? *Palliative Medicine* (1998); 12 (4): 279-286.
 9. Middlewood S, Gardner G, et al. Dying in Hospital: Medical Failure or Natural Outcome? *Journal of Pain and Symptom Management* (2001); 22 (6): 1035-1041.
 10. National Council for Hospice and Specialist Palliative Care Services (NCHSPCS). Education in Palliative Care. London: NCHSPCS (1996).
 11. National Council for Hospice and Specialist Palliative Care Services (NCHSPCS). Fulfilling Lives: Rehabilitation in Palliative Care. London: NCHSPCS (2000).
 12. National Council for Hospice and Specialist Palliative Care Services (NCHSPCS). Minimum Data Sets - Five Years On. (Nov 2000); (Briefing Bulletin 7): London: NCHSPCS.
 13. NHS Centre for Reviews and Dissemination. Effective Health Care. (December 2000); 6 (6): University of York - NHS Centre for Reviews and Dissemination.
 14. Rees WD. How Do Patients Who Die at Home Differ from Those Who Die Elsewhere? [Letter; Comment]. *Palliative Medicine* (1999); 13 (2): 169-170.
 15. Scottish Cancer Co-ordinating and Advisory Committee. Commissioning Cancer Services in Scotland: Primary and Palliative Care Services. Report to the Chief Medical Officer. Edinburgh: Scottish Office Department of Health (1997).
 16. Scottish Executive Health Department (SEHD). Cancer in Scotland: Action for Change. NHS HDL(2001)54. Edinburgh: Scottish Executive. <http://www.scotland.gov.uk/library3/health/csac-01.asp> url cited 14/05/02.
 17. Scottish Intercollegiate Guidelines Network (SIGN). SIGN Guideline 44: Control of Pain in Patients with Cancer. Edinburgh: SIGN (2000). www.sign.ac.uk/guidelines/published/index.html url cited 16/05/02.

8 Evidence Base for the Clinical Standards for Specialist Palliative Care

18. Scottish Partnership Agency (SPA). Palliative Cancer Care: The Integration of Palliative Care with Cancer Services - a Review by the Scottish Partnership Agency. (1996).
19. Scottish Partnership Agency with the Clinical Resource and Audit Group (SPA & CRAG). Palliative Cancer Care Guidelines. Edinburgh: Scottish Office Home and Health Department (1994).
20. Tebbit P. Palliative Care 2000: Commissioning through Partnership. London: National Council for Hospice and Specialist Palliative Care Services (NCHSPCS) (1999).
21. The National Palliative Care Information Group of ISD and the Scottish Partnership for Palliative Care. Scottish Minimum Data Set for Specialist Palliative Care. Edinburgh: (2002 - not published at 14/05/02 - date to be confirmed).
22. Townsend J. Terminal Cancer Care and Patients' Preference for Place of Death. *British Medical Journal* (1990); 301: 415-417.
23. World Health Organisation (WHO). Cancer Pain Relief and Palliative Care: Report of a Who Expert Committee. Technical Report Series, No. 804. Geneva: WHO (1990). The definition can be viewed in full at: <http://www.who.int/dsa/justpub/cpl.htm>. url cited 14/05/02.

9 Clinical Standards for Specialist Palliative Care

**STANDARD 1a – Access to Specialist Palliative Care Services:
Specialist Palliative Care Unit**

**STANDARD 1b – Access to Specialist Palliative Care Services:
Hospital Palliative Care Support Team**

**STANDARD 2a – Key Elements of Specialist Palliative Care:
Specialist Palliative Care Unit**

**STANDARD 2b – Key Elements of Specialist Palliative Care:
Hospital Palliative Care Support Team**

**STANDARD 3a – Managing People and Resources:
Specialist Palliative Care Unit**

**STANDARD 3b – Managing People and Resources:
Hospital Palliative Care Support Team**

STANDARD 4 – Professional Education

STANDARD 5 – Inter-professional Communication

STANDARD 6 – Communication with Patients/Carers

STANDARD 7 – Therapeutic Interventions

STANDARD 8 – Patient Activity

Standards 1-3 have been divided into separate sections to clearly identify those criteria which apply specifically to the specialist palliative care unit (section a) and those which apply to a hospital palliative care support team (section b). All remaining standards (4-8) are appropriate to both settings.

**STANDARD 1(a) – Access to Specialist Palliative Care Services:
Specialist Palliative Care Unit**

Standard Statement	Rationale
<p>Specialist palliative care services can be accessed according to need.</p>	<p>Patients with life-threatening disease, and those important to them, may have complex needs, which require the input of the specialist palliative care team.</p> <p>References: 2,5,7</p>

Criteria

Essential

- 1.a.1 There is a clear access policy specific to each service delivered detailing:
- the criteria for access;
 - the person with responsibility for access decisions;
 - the preferred route of referral;
 - who can refer.
- 1.a.2 Specialists and generalists work together to agree on criteria and routes for referral/access.
- 1.a.3 The criteria for access demonstrate that priority is given to patients with the most complex needs.
- 1.a.4 There is evidence that the access policy is being adhered to.
- 1.a.5 There is evidence that service providers and referrers discuss individual patients' needs.
- 1.a.6 There is 24-hour access to the in-patient service which includes specialist medical and adequate specialist nursing cover (as defined in the Managing People and Resources Standard).
- 1.a.7 There is 24-hour access to the advice service which includes specialist medical and adequate specialist nursing cover (as defined in the Managing People and Resources Standard).
- 1.a.8 There is access to day services during working hours.
- 1.a.9 There is access to community specialist palliative care services during working hours.
- 1.a.10 In specialist palliative care units, the time from receipt of referral to initial contact with the patient/carer/professional (either by telephone or face to face) is a maximum of two working days.
- 1.a.11 The reasons for not making initial contact with the patient/carer/professional within two working days are clearly documented.
- 1.a.12 The referrer is advised of the outcome of the referral within two working days of initial contact.

Desirable

- 1.a.13 A validated assessment tool is used to assess need and prioritise admission to the service – eg Palliative Care Outcome Scale (POS).
- 1.a.14 There is 24-hour access to community specialist palliative care services.

**STANDARD 1(b) – Access to Specialist Palliative Care Services:
Hospital Palliative Care Support Team**

Standard Statement	Rationale
<p>Specialist palliative care services can be accessed according to need.</p>	<p>Patients with life-threatening disease, and those important to them, may have complex needs, which require the input of the specialist palliative care team.</p> <p>References: 2,5</p>

Criteria

Essential

- 1.b.1 There is a clear access policy specific to each service delivered detailing:
- the criteria for access;
 - the person with responsibility for access decisions;
 - the preferred route of referral;
 - who can refer.
- 1.b.2 Specialists and generalists work together to agree on criteria and routes for referral/access.
- 1.b.3 The criteria for access demonstrate that priority is given to patients with the most complex needs.
- 1.b.4 There is evidence that the access policy is being adhered to.
- 1.b.5 There is evidence that service providers and referrers discuss individual patients' needs.
- 1.b.6 There is access to the hospital support services during working hours which includes specialist medical and adequate specialist nursing cover (as defined in the Managing People and Resources Standard).
- 1.b.7 There is 24-hour access to an advice service which includes specialist medical and adequate specialist nursing cover (as defined in the Managing People and Resources Standard).
- 1.b.8 In specialist palliative care teams, the time from receipt of referral to initial contact with the referrer (either by telephone or face to face) is a maximum of one working day.
- 1.b.9 The reasons for not making initial contact with the referrer within one working day are clearly documented.
- 1.b.10 The referrer is advised of the outcome of the assessment within one working day of the assessment visit.

Desirable

- 1.b.11 A validated assessment tool is used to assess need and prioritise admission to the service.
- 1.b.12 There is 24-hour access to hospital specialist palliative care services.

**STANDARD 2(a) – Key Elements of Specialist Palliative Care:
Specialist Palliative Care Unit**

Standard Statement	Rationale
<p>Specialist palliative care is made available to patients and their carers through a range of integrated service components and facilities, designed to respond to varied individual needs.</p>	<p>A variety of models of care may have a contribution for different purposes, or for patients at different stages of the disease process.</p> <p>References: 3,15,18</p>

Criteria

Essential

2.a.1 Dedicated environment with:

- quiet/private areas provided;
- chapel/prayer room;
- facilities for relatives to stay overnight.

2.a.2 In-patient care facilities:

- for the purposes of symptom management, rehabilitation or terminal care.

2.a.3 24-hour telephone advice:

- available for any healthcare professionals.

2.a.4 24-hour telephone support service:

- available for known out-patients and their carers.

2.a.5 Day services are provided (for example, by an out-patient model or a day hospice model).

2.a.6 Hospital services:

- formalised arrangements for specialist input to local and community hospitals.

2.a.7 Education programme:

- see Education Standard.

2.a.8 Research and audit are undertaken within a framework of clinical governance.

**STANDARD 2(a) – Key Elements of Specialist Palliative Care:
Specialist Palliative Care Unit (continued)**

Standard Statement	Rationale
<p>Specialist palliative care is made available to patients and their carers through a range of integrated service components and facilities, designed to respond to varied individual needs.</p>	<p>A variety of models of care may have a contribution for different purposes, or for patients at different stages of the disease process.</p> <p>References: 3,15,18</p>

Criteria

2.a.9 Written referral guidelines to:

- bereavement services;
- community specialist palliative care services;
- complementary therapies;
- counselling services;
- day services;
- hospital specialist palliative care services;
- lymphoedema services;
- patient transport services;
- psychological services;
- social services;
- spiritual support services.

Desirable

2.a.10 Formalised arrangements for specialist input to care homes.

**STANDARD 2(b) – Key Elements of Specialist Palliative Care:
Hospital Palliative Care Support Team**

Standard Statement	Rationale
<p>Specialist palliative care is made available to patients and their carers through a range of integrated service components and facilities, designed to respond to varied individual needs.</p>	<p>A variety of models of care may have a contribution for different purposes, or for patients at different stages of the disease process.</p> <p>References: 3,15,18</p>

Criteria

Essential

2.b.1 Access to a dedicated environment with:

- quiet/private areas provided;
- chapel/prayer room;
- facilities for relatives to stay overnight.

2.b.2 Each specialist palliative care team has:

- a nominated office within the hospital;
- access to an interview room on each ward.

2.b.3 Access to in-patient care facilities:

- for the purposes of symptom management, rehabilitation or terminal care.

2.b.4 24-hour telephone advice:

- available for any healthcare professionals.

2.b.5 24-hour telephone support service:

- available for known out-patients and their carers.

2.b.6 Education programme:

- see Education Standard.

2.b.7 Research and audit are undertaken within a framework of clinical governance.

**STANDARD 2(b) – Key Elements of Specialist Palliative Care:
Hospital Palliative Care Support Team (continued)**

Standard Statement	Rationale
<p>Specialist palliative care is made available to patients and their carers through a range of integrated service components and facilities, designed to respond to varied individual needs.</p>	<p>A variety of models of care may have a contribution for different purposes, or for patients at different stages of the disease process.</p> <p>References: 3,15,18</p>

Criteria

2.b.8 Written referral guidelines to:

- bereavement services;
- community specialist palliative care services;
- complementary therapies;
- counselling services;
- day services;
- lymphoedema service;
- patient transport services;
- psychological services;
- social services;
- specialist palliative care in-patient unit;
- spiritual support services.

**STANDARD 3(a) – Managing People and Resources:
Specialist Palliative Care Unit**

Standard Statement	Rationale
<p>Specialist palliative care is provided by a highly qualified multidisciplinary team.</p>	<p>There is evidence that specialist teams in palliative care improve patient satisfaction and deal more effectively with patient and family needs.</p> <p>Moreover, multidisciplinary approaches to palliative care reduce the amount of time patients spend in specialist units.</p> <p>Reference: 6</p>

Criteria

Essential

3.a.1 The core team comprises dedicated sessional input from:

- chaplain;
- doctors;
- nurses;
- occupational therapist;
- pharmacist;
- physiotherapist;
- social worker.

3.a.2 There is ready access to other professionals including:

- anaesthetist (who is a specialist in pain management);
- bereavement specialists;
- complementary therapists;
- dentist;
- dietician;
- lymphoedema specialists;
- oncologist;
- psychiatrist;
- psychologist and/or counsellor;
- speech and language therapist.

3.a.3 All clinical staff are supported by administrative staff.

3.a.4 Formal arrangements are jointly agreed between stand-alone nurse specialists in palliative care and their local specialist palliative care service to ensure multidisciplinary working.

3.a.5 There is a policy/procedure for the provision of a staff support system.

**STANDARD 3(a) – Managing People and Resources:
Specialist Palliative Care Unit (continued)**

Standard Statement	Rationale
<p>Specialist palliative care is provided by a highly qualified multidisciplinary team.</p>	<p>There is evidence that specialist teams in palliative care improve patient satisfaction and deal more effectively with patient and family needs.</p> <p>Moreover, multidisciplinary approaches to palliative care reduce the amount of time patients spend in specialist units.</p> <p>Reference: 6</p>

Criteria

3.a.6 The following qualifications are required:

- a consultant who is on the specialist medical register for palliative medicine;
- a lead nurse of a service who has either a Masters degree in palliative care or is recorded as a specialist practitioner in palliative care.

3.a.7 The unit can demonstrate how they are working towards all community specialist nurses and one nurse per shift in an in-patient unit having a degree or postgraduate qualification in palliative care.**

3.a.8 In a setting where children are being cared for there is at least one nurse on each shift with an RSCN qualification.

3.a.9 All professions allied to medicine (who are members of the multidisciplinary team) are active members of their specific specialist interest group.

3.a.10 All practitioners are registered with their relevant accrediting body.

3.a.11 There is evidence that all professionals have personal development plans which demonstrate that training needs are identified and addressed.

Desirable

3.a.12 All professions allied to medicine (who are members of the multidisciplinary team) have a multidisciplinary diploma in palliative care.

3.a.13 There is ready access to complementary therapists who provide a range of therapies.

3.a.14 The professionals listed in 3.a.2 can demonstrate a specific interest in palliative care.

**The Specialist Palliative Care Project Group acknowledges that palliative care qualifications at degree and postgraduate level have only recently been available and accessible in Scotland. Degree and postgraduate level qualifications in cancer nursing will be recognised as equivalent if commenced before 2002.

**STANDARD 3(b) – Managing People and Resources:
Hospital Palliative Care Support Team**

Standard Statement	Rationale
<p>Specialist palliative care is provided by a highly qualified multidisciplinary team.</p>	<p>There is evidence that specialist teams in palliative care improve patient satisfaction and deal more effectively with patient and family needs.</p> <p>Moreover, multidisciplinary approaches to palliative care reduce the amount of time patients spend in acute hospital settings.</p> <p>Reference: 6</p>

Criteria

Essential

3.b.1 The core team comprises dedicated sessional input from:

- doctors;
- nurses.

3.b.2 The core team has ready access to other co-opted staff (who have agreed service level input) including:

- anaesthetist (who is a specialist in pain management);
- bereavement specialist;
- chaplain;
- dentist;
- dietician;
- lymphoedema specialist;
- occupational therapist;
- oncologist;
- pharmacist;
- physiotherapist;
- psychiatrist;
- psychologist and/or counsellor;
- social worker;
- speech and language therapist.

3.b.3 All clinical staff are supported by administrative staff.

3.b.4 Formal arrangements are jointly agreed between stand-alone nurse specialists in palliative care and their local specialist palliative care service to ensure multidisciplinary working.

3.b.5 There is a policy/procedure for the provision of a staff support system.

**STANDARD 3(b) – Managing People and Resources:
Hospital Palliative Care Support Team (continued)**

Standard Statement	Rationale
<p>Specialist palliative care is provided by a highly qualified multidisciplinary team.</p>	<p>There is evidence that specialist teams in palliative care improve patient satisfaction and deal more effectively with patient and family needs.</p> <p>Moreover, multidisciplinary approaches to palliative care reduce the amount of time patients spend in acute hospital settings.</p> <p>Reference: 6</p>

Criteria

3.b.6 The following qualifications are required:

- a consultant who is on the specialist medical register for palliative medicine;
- a lead nurse of a service who has either a Masters degree in palliative care or is recorded as a specialist practitioner in palliative care.

3.b.7 The team can demonstrate how they are working towards all hospital team nurses having a degree or postgraduate qualification in palliative care.**

3.b.8 All professions allied to medicine (who are members of the multidisciplinary team) are active members of their specific specialist interest group.

3.b.9 All practitioners are registered with their relevant accrediting body.

3.b.10 There is evidence that all professionals have personal development plans which demonstrate that training needs are identified and addressed.

Desirable

3.b.11 All professions allied to medicine (who are members of the multidisciplinary team) have a multidisciplinary diploma in palliative care.

3.b.12 There is ready access to complementary therapists who provide a range of therapies.

3.b.13 The professionals listed in 3.b.2 can demonstrate a specific interest in palliative care.

**The Specialist Palliative Care Project Group acknowledges that palliative care qualifications at degree and postgraduate level have only recently been available and accessible in Scotland. Degree and postgraduate level qualifications in cancer nursing will be recognised as equivalent if commenced before 2002.

STANDARD 4 – Professional Education

Standard Statement	Rationale
<p>The specialist palliative care unit/team provides palliative care education at all levels, ie for staff providing generalist palliative care and for staff providing a specialist palliative care service.</p>	<p>Palliative care education should be planned in partnership with the community, hospital and specialist palliative care unit, if it is to be successful. It should mirror the patient's journey by involving all professionals who have input along the way.</p> <p>Education of healthcare staff leads to improved symptom control for patients with malignant and non-malignant disease.</p> <p>References: 10,17</p>

Criteria

Essential

- 4.1 There is a member of the unit/team with designated sessions, or a remit in their job description, for planning and implementing in-house and out-reach education programmes.
- 4.2 The unit/team has access to an educator in order to facilitate curriculum development.
- 4.3 Members of the unit/team who are involved in teaching have attended a course on teaching and learning.
- 4.4 The unit/team has on-site teaching facilities and a range of audio-visual aids.
- 4.5 The unit/team has local access to specialist palliative care library and internet facilities, and databases relevant to specialist palliative care.
- 4.6 The unit/team has access to international, national and local syllabi, which can be referred to in the process of devising an innovative and dynamic curriculum.
- 4.7 Communication skills training programmes are in place to enable all team members to respond sensitively and effectively to patients' needs.
- 4.8 The unit/team provides an evidence-based programme of education for professionals addressing:
 - physical, psychological, social and spiritual aspects of palliative care;
 - ethical issues for patients approaching the end of life;
 - communication issues.
- 4.9 Within this education programme there is evidence of multidisciplinary teaching and learning.
- 4.10 There is evidence of teaching at different levels of palliative care.
- 4.11 The unit/team produces an annual report on its education activities, including needs assessment and evaluation.
- 4.12 The unit/team has established links with an institution of higher education and contributes to pre-registration, undergraduate and postgraduate education in palliative care.

STANDARD 5 – Inter-professional Communication

Standard Statement	Rationale
<p>There are effective channels of communication within the specialist palliative care team and with all others involved in the patients' care.</p>	<p>Effective communication improves patient care. Reference: 13</p>

Criteria

Essential

- 5.1 There is clear documentation in patients' notes (specialist palliative care notes) of all key professionals from primary, secondary and tertiary care who are involved in their care.
- 5.2 There is evidence of a system to disseminate information to these key professionals.
- 5.3 Regular multidisciplinary meetings are held to discuss the care of new and existing patients. All members of the core team attend these meetings and further professionals can be co-opted when necessary.
- 5.4 Advice given by telephone is clearly documented.
- 5.5 There is notification of anticipated patient problems from the specialist palliative care team to those providing the local specialist 24-hour telephone advice service.
- 5.6 There is notification of anticipated patient problems from the specialist palliative care team to the relevant member(s) of the primary care team.
- 5.7 Key members of the care team are informed of a patient's death (within a specialist service) by the next working day and members of the extended care team are informed within five working days.
- 5.8 Practitioners in a specialist palliative care service are members of their local managed clinical network in palliative care.

Desirable

- 5.9 Integrated records.
- 5.10 Representation on site-specific managed clinical network multidisciplinary meetings.

STANDARD 6 – Communication with Patients/Carers

Standard Statement	Rationale
<p>Patients and those important to them are helped to communicate their feelings and priorities.</p>	<p>Effective communication enhances quality of life.</p> <p>Reference: 19</p>

Criteria

Essential

- 6.1 There is a needs assessment and care plan for each patient to pro-actively focus on communication and information needs.
- 6.2 There is supported access to information and education resources for patients and their families/carers.
- 6.3 There is information specifically for children/adolescents and for those adults and children with sensory impairment or special needs.
- 6.4 There is evidence that the team regularly carries out patient/family satisfaction surveys in order to evaluate staff communication skills.
- 6.5 Evidence exists that guidance and advice are offered to patients and their families/carers to facilitate rehabilitation of the patient in the community.
- 6.6 The patient's preferred place of care is identified, agreed and regularly reviewed with the patient/carer.
- 6.7 There is provision of bereavement information booklets which give information on emotional and practical issues.

STANDARD 7 – Therapeutic Interventions

Standard Statement	Rationale
<p>All patients with progressive incurable disease have access to specialist palliative care services which address pro-actively all the symptoms of their condition and the effect these symptoms have on them and their family/carers.</p>	<p>Patients with complex palliative care needs require a wide range of therapeutic interventions for symptom control.</p> <p>The relevant specialist palliative care services must have access to the necessary level of trained staff to safely manage these interventions.</p> <p>References: 1,19</p>

Criteria

Physical

Essential

- 7.1 There is evidence that:
- patients are actively involved as partners in symptom assessment and control;
 - the changing pattern of pain and other symptoms is anticipated;
 - a variety of methods are used to assess pain and other symptoms;
 - a plan of symptom management is devised to include pharmacological and non-pharmacological approaches;
 - review of pain and other symptoms is regularly undertaken.
- 7.2 A wide range of modalities of treatment are available for symptom management.
- 7.3 Guidelines are in place to ensure safe and effective use of these modalities of treatment.
- 7.4 There is evidence of safe and effective management of specialist interventions (eg tracheostomy, percutaneous gastrostomy and epidurals) to allow patients to be cared for in their place of choice.
- 7.5 Systems are in place to ensure 24-hour access to necessary specialist drugs for all patients.

Desirable

- 7.6 Self-contained units holding a stock of medicines employ a pharmacy technician to manage the supply system.

Psychological

Essential

- 7.7 Evidence exists of ongoing support to assist patients and those important to them to address emotional issues, including those arising from the process of loss and change.
- 7.8 There is evidence of referral to specialist psychological and/or counselling support services according to identified need.
- 7.9 Specialist services demonstrate that the needs of children as patients, and as relatives, have been recognised and met with services suitable to age and stage of development.

STANDARD 7 – Therapeutic Interventions (continued)

Standard Statement	Rationale
<p>All patients with progressive incurable disease have access to specialist palliative care services which address pro-actively all the symptoms of their condition and the effect these symptoms have on them and their family/carers.</p>	<p>Patients with complex palliative care needs require a wide range of therapeutic interventions for symptom control.</p> <p>The relevant specialist palliative care services must have access to the necessary level of trained staff to safely manage these interventions.</p> <p>References: 1,19</p>

Criteria

Spiritual

Essential

- 7.10 Evidence exists that patients and those important to them have had the opportunity for their spiritual needs to be assessed and addressed.
- 7.11 Evidence exists that religious needs have been assessed and addressed.
- 7.12 There is evidence of referral to specialist spiritual support services according to identified need.

Social

Essential

- 7.13 Evidence exists that patients and those important to them have their social needs assessed and addressed.
- 7.14 Systems are in place to ensure patients and their family/carers have access to priority assessment of their service requirements.
- 7.15 Evidence exists that staff are assisting patients and families/carers to address anticipated change in the family structure and that children affected by illness/disability are given support to cope with changes in their, or their family's, circumstances.

Bereavement

Essential

- 7.16 Evidence exists that families'/carers' bereavement needs have been assessed and addressed.
- 7.17 There are local guidelines for referral to a bereavement service.

STANDARD 8 – Patient Activity

Standard Statement	Rationale
<p>There is efficient and effective use of specialist resources in order to enable patients with complex needs to have access to the services according to identified need.</p>	<p>A short length of stay and a high proportion of discharges are two measures that demonstrate a focus on active management and rehabilitation.</p> <p>The service must be able to support patients with non-malignant, progressive, degenerative diseases as well as those patients with cancer.</p> <p>There is evidence that, generally, dying patients would prefer to be at home, if practical. Currently, the majority of cancer patients die in hospital.</p> <p>References: 4,8,9,11,21</p>

Criteria

Essential

8.1 A system is in place to collect the data specified in the Scottish Minimum Data Set for Specialist Palliative Care under the following headings:

- general;
- in-patient units;
- day services/out-patients;
- home care;
- hospital support;
- place of death.

10 Glossary of Terms

Term	Definition
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.
anaesthetist	A medically qualified doctor who administers an anaesthetic to make a patient unconscious before a surgical operation and who may also be a specialist in pain management.
assessment	The process of measuring patients needs and/or the quality of an activity, service or organisation.
audit	A process which allows for the systematic and critical analysis of the quality of care.
bereavement services	Bereavement services aim to acknowledge and contain the emotional impact of a death on the family and carers affected by it, through a variety of activities or means, such as one-to-one counselling, support groups, telephone support, memorial services, the provision of information and literature on grief processes.
cancer	The name given to a group of diseases that can occur in any organ of the body, and in blood, and which involves abnormal or uncontrolled growth of cells.
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.
chaplain	A person appointed to provide spiritual and religious care to all patients, visitors, staff and volunteers in the healthcare setting, regardless of faith or no faith. A chaplain can be ordained or lay with an acknowledged status within a mainstream faith community.
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 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.
complementary therapies	Alternative therapies such as aromatherapy.
complex needs	Needs that cannot be addressed through simple or routine interventions/care.
core team	A multidisciplinary group made up of an identified number of healthcare professionals who are considered essential for the management of patients. All members of this team meet on a regular basis to discuss the care of new and existing patients.
counselling services	Counselling services offer a 'being with' kind of support, to allow an open-ended exploring of feelings to help someone express and work through their feelings and grief.
CRAG	See Clinical Resource and Audit Group.
criterion/criteria	Criterion (singular)/criteria (plural) provide the more detailed and practical information on how to achieve the standard and relate to structure, process or outcome factors.
CSBS	See Clinical Standards Board for Scotland.
degenerative disease	A condition which results in progressive deterioration and loss of function.
dentist	A member of the dental profession who in the UK must be registered with the General Dental Council unless he/she holds a medical qualification.
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.
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.
dietician	An expert in nutrition who helps people with special health needs plan the kinds and amount of foods to eat.

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 Professions Allied to Medicine (see PAM) discharge.
educator	An educator is a healthcare individual who has undertaken a recognised qualification in teaching and learning in higher education.
endoscope	Any instrument used to obtain a view of the interior of the body.
epidural	Administration of anaesthetic by injection into the space surrounding the spinal cord to suppress sensation, usually in the lower part of the body.
essential (criterion/criteria)	A criterion that should be met wherever a service is provided.
evaluation	The study of the performance of a service (or element of treatment and care) with the aim of identifying successful and problem areas of activity.
evidence-based	The process of systematically finding, appraising, and using current research findings as the basis for clinical decisions.
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 healthcare for specific clinical conditions.
healthcare professional	A person qualified in a health discipline.
hospice	A place where specially trained doctors, nurses and others are committed to the care of patients with active, progressive, far-advanced illness, and to the support of their relatives.
intervention	Action intended to benefit the patient.
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 the patient.
lead nurse	A nurse at senior level with input into strategic planning.
lymphoedema	The swelling of an arm, leg or another part of the body which sometimes happens when lymph nodes and vessels in the armpit or groin have been removed or damaged by surgery or radiotherapy, or have been blocked by a tumour.

malignant	Cancerous. Malignant tumours can invade and destroy surrounding tissue and have the capacity to spread.
Managed Clinical Network	A formally organised network of clinicians. The main function is to audit performance on the basis of standards and guidelines, with the aim of improving healthcare across a wide geographic area, or for specific conditions.
median	The middle value or average of the two middle numbers in an ordered sequence of numbers.
minimum data set	A list of required and specific information.
multidisciplinary	A multidisciplinary team is a group of people from different disciplines (both healthcare and non-healthcare) who work together to provide and/or improve 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.
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 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.
NHSScotland	The National Health Service in Scotland.
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.
occupational therapist	A health professional, also known as an OT, who finds ways to help people live at home and be independent, despite their illness.
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.
palliative care	Palliative care is the active total care of patients and their families by a multidisciplinary team when the patient's disease is no longer responsive to curative treatment.
PAM	See professions allied to medicine.

patient	A person who is receiving care or medical treatment. 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.
peer review	Review of a service by those with expertise and experience in that service, either as a provider, user or carer, but who are not involved in its provision in the area under review. In the CSBS approach all members of a review team are equal.
percutaneous gastrostomy	A gastrostomy is where an opening is made into the stomach from the outside and is usually performed to allow food and fluid to be poured directly into the stomach when swallowing is impossible because of disease or obstruction of the oesophagus. This procedure was formerly always performed surgically but it can now be done using an endoscope (percutaneous endoscopic gastrostomy).
pharmacist	A qualified professional who understands the nature and effect of medicines and how they are 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.
pharmacy technician	An individual working in a healthcare setting who, under the supervision of a licensed pharmacist, assists in activities not requiring the professional judgement of a pharmacist.
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.
procedure	The steps taken to fulfil a policy/the agreed way in which a task is done.
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.
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.

quality assurance	Improving performance and preventing problems through planned and systematic activities including documentation, training and review. Abbreviated as QA.
quality of life	The overall appraisal of an individual's situation and subjective sense of well-being.
rationale	Scientific/objective reason for taking specific action.
referral	The process whereby the care of a patient is transferred from one professional to another, usually for specialist advice and/or treatment.
RSCN	Registered Sick Children's Nurse
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/
Scottish Partnership for Palliative Care	The Scottish Partnership for Palliative Care (formerly known as the Scottish for Partnership Agency) is the national umbrella and representative body for palliative care in Scotland. It is an independent body with charitable status that was set up in 1991 to promote the extension and improvement of palliative care services in Scotland, whether provided by voluntary organisations or by the NHS. Website address: www.palliativecarescotland.org.uk
self-assessment	Assessment of performance against standards by individual/clinical team/Trust providing the service to which the standards are related.
sensory impairment	Reduction of the input from the senses.
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	A person who, after education, training and experience, has become an expert in their field.

specialist palliative care	Specialist Palliative Care is the active total care of patients with progressive, far-advanced disease and limited prognosis, and their families, by a multi-professional team who have undergone recognised specialist palliative care training. It provides physical, psychological, social and spiritual support, and will involve practitioners with a broad mix of skills.
SPPC	See Scottish Partnership for Palliative Care.
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 psychological abnormality.
systematic	Methodical, according to plan and not casually or at random.
telephone advice	This is a service which is available to professional callers wishing guidance in clinical management. This may involve recommendations on drug use and dosage.
telephone support	This service is available to patients and lay carers who make contact with the specialist palliative care unit/hospital palliative care support team. As well as empathetic listening it will include advice about contacting the appropriate GP and district nursing services. It is not anticipated that specific instruction will be given regarding drugs and dosages.
terminal care	Specialised care during the final stage of an illness, with the emphasis on relief of symptoms in order to allow the patient to feel as comfortable as possible.
therapeutic intervention	A medical or non-medical initiative which increases the comfort or wider well-being of a patient.
therapy	A word often used to mean treatment.
tracheostomy	An operation in which an opening is made in the windpipe (trachea), through the neck, to relieve obstruction to breathing.
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.
WHO	World Health Organisation. A United Nations agency dealing with issues concerning health and disease around the globe.

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.



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