The Scottish Partnership for Palliative Care (SPPC) is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 15 of Scotland’s voluntary hospices, 18 national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at www.palliativecarescotland.org.uk. Through a collaborative approach, the Partnership supports and contributes at national level to the development and strategic direction of palliative care in Scotland and the promotion of service improvement at local level. The Partnership’s aims are to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis.

About Palliative Care

Palliative care is the term used to describe the care that is given when cure is not possible. The word comes from the Latin ‘palliatus’ (covered or hidden with a cloak) and is used to mean ‘relieving without curing’.

Palliative and end of life care are integral aspects of the care delivered by any health or social care professional to those living with and dying from any advanced, progressive or incurable condition. Palliative care is not just about care in the last months, days and hours of a person’s life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. A palliative care approach should be used as appropriate alongside active disease management from an early stage in the disease process. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement. The World Health Organisation (WHO) defines palliative care thus:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- will enhance quality of life, and may also positively influence the course of illness;

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.”

Specialist palliative care focuses on people with complex palliative care needs (e.g. complex pain management or psychological support) and is provided by a team of professionals who specialise in palliative care (e.g. consultants in palliative medicine and clinical nurse specialists in palliative care). General palliative care forms part of the routine care of patients and support for carers. It may be part of the work of a range of health and social care practitioners including GPs, community nurses, care assistants and hospital staff.

General Principles of the Bill

The SPPC has worked relentlessly to promote equitable access throughout Scotland to high quality palliative care for all patients and families on the basis of need not diagnosis. We agree with the author of the Bill about the importance of ensuring access to palliative care but we have reservations about the Bill as a means to achieve this end.

The SPPC’s report Palliative and End of Life Care in Scotland: the Case for a Cohesive Approach formed the basis of the Scottish Government’s action plan on palliative and end of life care, Living and Dying Well (2008) and the SPPC is active in supporting the implementation of that plan. The plan describes how palliative care will increasingly be available to patients and families regardless of their diagnosis, prognosis or place of care. Work is progressing across Scotland to improve the identification and assessment of people with palliative care needs, and to better meet those needs which have been identified.

Progress includes:

- The publication by each territorial health board of their plans to deliver relevant elements of Living and Dying Well.
- Increasing numbers of patients being added by GPs to palliative care registers.
- The continuing roll out across Scotland of the electronic palliative care summary which allows, with the consent of the patient, the efficient and timely sharing of information across different care settings.
- The development and launch in May of a national policy to support decision making by patients and clinicians around cardiopulmonary resuscitation, which will be implemented from 1st October 2010.
- Increasing use of end of life care pathways.
• The development and delivery of palliative care training by NES, boards and the voluntary sector and the presence of a Palliative Care Education Champion in each territorial NHS Board.

• Increasing use of anticipatory prescribing and Just in Case boxes.

• The organisation by SPPC, Scottish Care, NES and the Care Commission of a national palliative care conference for care home providers (to take place on 30/09/10).

• The development of palliative care information for patients and carers which will be launched on the NHS Inform website this autumn.

However, the SPPC acknowledges that there is much more work left to do before the goal of equitable access is achieved.

The SPPC therefore welcomes the anticipated review of progress by NHS Boards against their delivery plans. The SPPC also welcomes the commitment of the Scottish Government to a further phase of implementation of Living and Dying Well.

The SPPC welcomes the commitment by NHS QIS and NES to support this further implementation of Living and Dying Well. The SPPC will be working closely with NHS QIS and NES to support further improvement in the provision of palliative care.

The SPPC will also be establishing a broad-based coalition to raise public awareness and promote community involvement in the issues of death, dying and bereavement. The implementation of Living and Dying Well will be assisted by a culture of more open discussion about death, dying and bereavement. Staff must be comfortable addressing ‘difficult’ issues and patients must feel comfortable in expressing choices and feelings in the context of such discussions.

Creation of a Specific Duty on Provision of Palliative Care

Taking into account the progress noted in the preceding section and the commitment to further action by the Scottish Government, Health Boards and voluntary sector providers, the SPPC is not clear that the creation of the legal duties specified in the Bill is necessary nor that it will lead to more rapid improvements in palliative care than would otherwise be the case.

Provisions Concerning Reporting and Indicators

The measurement of access to palliative care is a complex matter, as is the measurement of the quality of care received. The complexity derives from, amongst other things:-

• The range of different conditions to which palliative care may be appropriate.

• The range of different points along a disease trajectory at which palliative care may be appropriate.
• The range of settings and sectors in which palliative care may be provided.
• The range of professionals who may be involved at different times in the provision of palliative care.
• Reluctance on the part of some professionals and patients to refer to care as “palliative” because of its association with dying.
• The fact that palliative care is very often an integral component of good general care and not identified as a distinct element by patients or practitioners.
• Practical and ethical difficulties and sensitivities in getting patient and family feedback on the quality of services experienced.

Apparently simple tasks such as identifying precisely when a patient has had palliative care needs identified and started to receive palliative care can be complex. Has an eighteen year old person recently diagnosed with MS who attends physiotherapy for a gait problem had palliative care needs identified and started to receive palliative care? Further refinement of the definitions contained in the Bill would be necessary if consistent and meaningful data is to be generated on all the indicators suggested across a range of potential scenarios.

Data is most reliably gathered when it is culled automatically from the routine use of operational clinical and care management systems. Current data systems are unlikely to be able to measure all the proposed indicators, not least because they are neither present in, nor integrated across, all settings. Data gathering tasks performed in addition to the routine delivery of care carry a cost in terms of staff time and tend to suffer from inaccuracy and incompleteness.

Indicators should be few in number, avoid bureaucratic burdens and focus on those things which most closely relate to the quality of care received by families and patients.

**Costs Identified in the Financial Memorandum Accompanying the Bill**

As acknowledged by Audit Scotland reliable estimates for the total costs of providing palliative care to the Scottish population are not available. Some data is available for the provision of specialist palliative care. The costs of general palliative care are “hidden” within primary care and other services.

As indicated in the Financial Memorandum the costs associated with implementing the Bill are likely to be of a similar order to the costs of implementing *Living and Dying Well* since both share similar aims. The costs of gathering data on the performance indicators proposed by the Bill may be greater than the costs of monitoring/performance management envisaged under *Living and Dying Well*.

The Financial Memorandum correctly recognises the considerable margin of uncertainty about the total costs of delivering *Living and Dying Well* and/or the
provisions of the Bill. The costs, which fall primarily to territorial health boards include:-

- The DES provided by GPs.
- 24/7 access to community nursing.
- Delivering training and education to support the provision of palliative care by generalist staff.
- Releasing staff to attend palliative care training and education.
- Ensuring sufficient access to specialist palliative care.
- Provision of an appropriate physical environment and sufficient staffing levels to support the delivery of palliative care (for example potentially lengthy and sensitive consultations/conversations).

There is considerable policy overlap between the aims of Living and Dying Well and some other national strategies and initiatives (e.g. the Dementia Strategy, the Long Term Conditions Collaborative) and so expenditure on each may contribute to the delivery of aims within more than one strategy. Living and Dying Well contributes very directly to the aims of the NHS Scotland Quality Strategy.

The provision of palliative care does have the potential to deliver efficiency savings (for example by reducing inappropriate admissions) as well as improving the safety and quality of the patient and carer experience.

**Oral Evidence**

As the umbrella organisation representing the major organisations involved in palliative care in Scotland the SPPC would welcome an opportunity to participate in future oral evidence sessions of the Committee.

**Background to Internal Consultation on this Evidence**

The membership of the SPPC was consulted on the content of this submission. 28% of nominated member representatives responded to the consultation. Of these responses 96% supported the submission.

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Scottish Partnership for Palliative Care  
26 August 2010