

# **Living and Dying Well: Building on Progress**

The Scottish Government, January 2011

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# Foreword



The launch of *Living and Dying Well: A national action plan for palliative and end of life care in Scotland* in October 2008 marked a new era in the Scottish Government's commitment to the implementation of a cohesive, person-centred and sustainable approach to the equitable provision of high quality palliative and end of life care across Scotland.

Since then, considerable progress has been made in implementing the actions identified and in undertaking the further development and collaborative work required to achieve the full range of *Living and Dying Well's* aims. That process has been marked by the enthusiastic and effective engagement of key stakeholders across all relevant sectors. Moreover, the palliative care approach, with its emphasis on advance care planning based on empathic relationships and clear communication between patients and carers and all the professionals who work with them, is now firmly embedded in the wider healthcare policies of the Scottish Government.

The Healthcare Quality Strategy for NHSScotland, launched in May 2010, is about putting people at the heart of everything we do. It is based on the priorities people in Scotland have told us they want to see in their health services:

- caring and compassionate staff and services
- clear communication and explanation about conditions and treatment
- effective collaboration between clinicians, patients and others
- a clean and safe care environment
- continuity of care and
- clinical excellence.

*Living and Dying Well* is one of the key building blocks already in place which will help us to achieve our Quality Ambition of ensuring mutually beneficial partnerships between patients and families and those delivering healthcare services which:

- respect individual needs and values and
- demonstrate compassion, continuity, clear communication and shared decision-making.

I am delighted to endorse the achievements celebrated in this document, and welcome the future actions identified in taking us further towards our aim of ensuring that the right palliative and end of life care, at the right time, in the right place and of the highest standard is consistently and equitably available across Scotland for everyone who needs it.

A handwritten signature in black ink that reads "Nicola Sturgeon".

Nicola Sturgeon MSP  
Deputy First Minister and Cabinet Secretary for Health and Wellbeing



# **1 Introduction**

1 The launch of *Living and Dying Well: A national action plan for palliative and end of life care in Scotland*<sup>1</sup> in October 2008 followed the Scottish Government's acceptance, in its December 2007 action plan for health and wellbeing *Better Health Better Care*<sup>2</sup>, of the recommendations made in the Scottish Partnership for Palliative Care (SPPC)'s May 2007 report *Palliative and end of life care in Scotland: the case for a cohesive approach*<sup>3</sup>. Two years on, there is widespread evidence that the cohesive national approach outlined in *Living and Dying Well*<sup>1</sup> is well on the way to ensuring the provision of consistent and equitable palliative and end of life care for all people and their families across Scotland who need it.

2 Key to the success of *Living and Dying Well*<sup>1</sup> is its dual emphasis on a person-centred approach to care and care planning and on the importance of communication, collaboration and continuity of care across all sectors and at all stages of the patient journey. Those values also form the basis of the *Scottish Government's Healthcare Quality Strategy for NHSScotland*<sup>4</sup>, launched in May 2010. The *Quality Strategy*<sup>4</sup> recognises the importance of anticipatory approaches and advance care planning, based on mutually empathic dialogue between patients, families and all of the individual professionals involved, as a key component of person-centred care. *Living and Dying Well*<sup>1</sup> outlines this process as follows:

- early identification of palliative care needs
- holistic assessment, with the patient and carer, of their physical, social, emotional, cultural, religious and spiritual care needs and other relevant life circumstances
- planning, co-ordination and delivery of appropriate care based on the needs identified
- appropriate sharing and communication across all care settings of the needs and plans identified and actions taken
- regular review and repetition of the assessment and planning cycle.

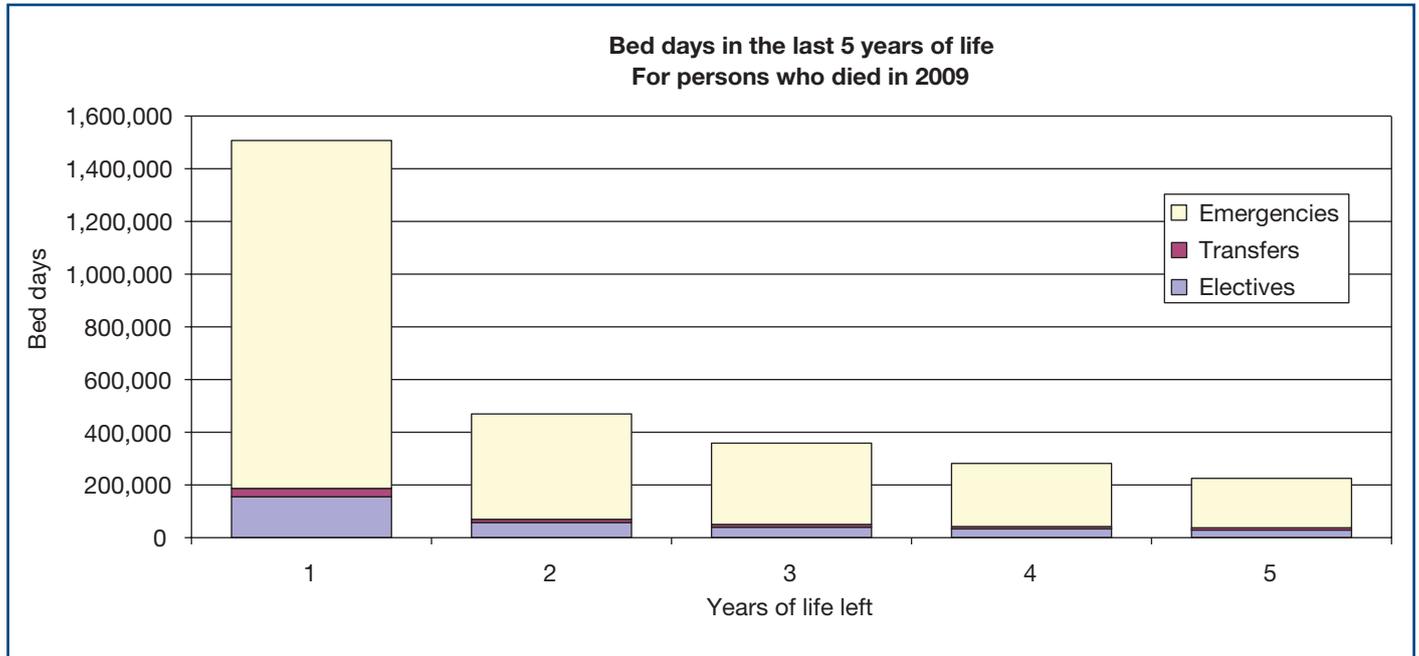
3 This approach is now firmly embedded in Scottish Government healthcare policy, and underpins workstreams such as the *Long Term Conditions Collaborative*<sup>5</sup>, *Scotland's National Dementia Strategy*<sup>6</sup>, *Reshaping Care for Older People*<sup>7</sup>, and *Getting it Right for Every Child*<sup>8</sup>. Its particular significance in palliative and end of life care is highlighted by the 2009 data from Information Services Division (ISD) (figures 1-2) for hospital admissions and bed days during the last five years of life. These figures demonstrate the reality of a population living longer with multiple long term and life threatening conditions and show that, in the five years before death, people are admitted to hospital more and more frequently, often on an emergency basis, and remain there for increasing lengths of time. These admissions also represent an increasing proportion of all hospital admissions. Figures produced by ISD for the Scottish Government show that those in the final year of life accounted for around 30% of all bed days.

4 *Living and Dying Well*<sup>1</sup> advocated a comprehensive and cohesive approach to the planning and improving of palliative and end of life care. It describes palliative and end of life care as integral aspects of the care delivered by any health or social care professional, focusing on the person, not the disease, and applying a holistic approach to meet the physical, practical, functional, social, emotional and spiritual needs of patients and carers facing progressive illness and bereavement. It is essential that NHS Boards, with key stakeholders, including, for example, the voluntary sector and social care partners, work together in order for the aims of *Living and Dying Well*<sup>1</sup> to be fully realised.

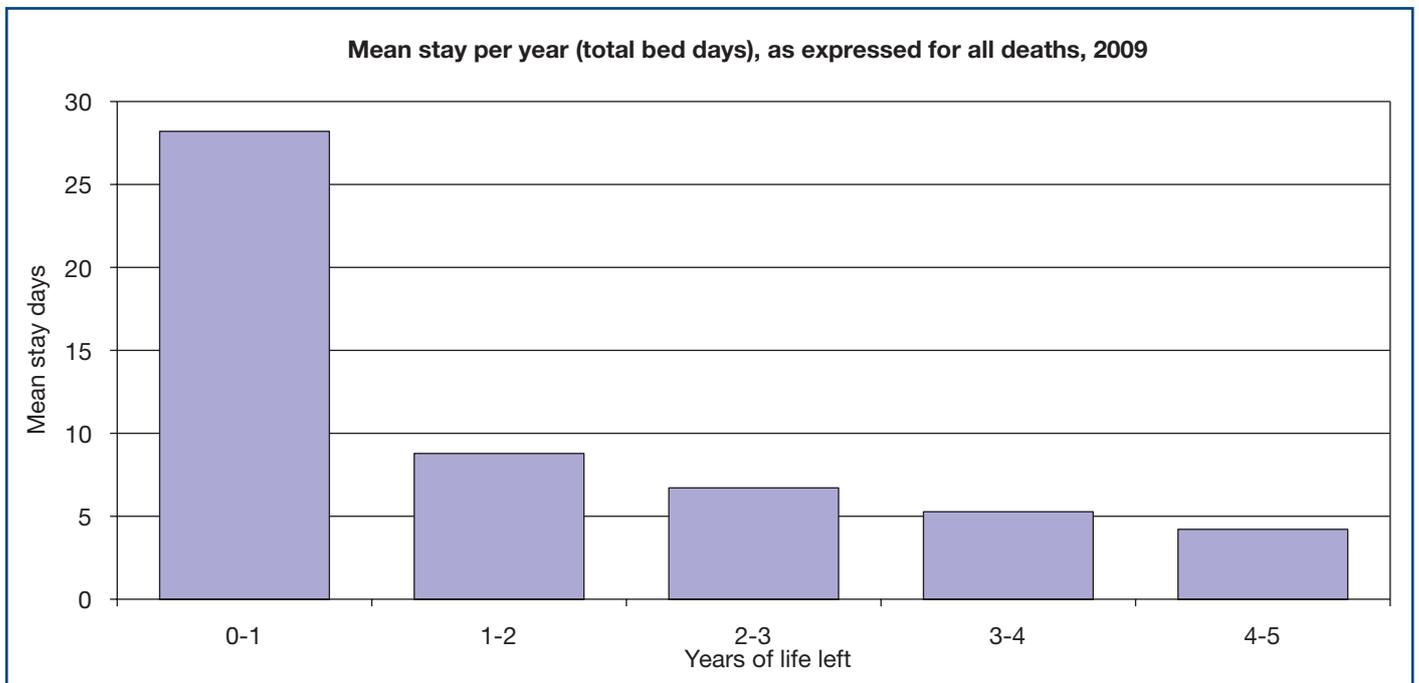
5 The collaboration and continuity of care is significant for patients and carers with palliative and end of life care needs. It is important to note the patients and their carers within other sectors particularly care homes and people at home. For example, there are

approximately 38,000 beds in care homes for older people and 55,000 people over 65 years receiving home care. Whilst these figures do not specifically relate to palliative care need, they do reflect a population of older people who may require palliative care and who may wish for support to be provided within that setting.

**Figure 1**



**Figure 2**



6 These figures do not signify any failing in the approach which supports *Shifting the Balance of Care*<sup>9</sup> and related strategies. The hospital admissions reported in Figure 1 will frequently, but not always, represent the right care in the right place and at the right time for a particular patient and his/her family. However, we know from the findings of the National Patient Experience Programme<sup>10</sup>, that additional support for patients and carers is required around the times of entering and leaving hospital. Planning ahead with patients and families while the patient is in the community, for example, at home or in a care home

setting, according to the philosophy of advance/anticipatory care planning, is crucial in ensuring that care provided is appropriate and in accordance with the patient's wishes, and key to improving patients' and carers' experience of care.

7 The cycle of hospital admission and discharge evident in the last five years of life means that the entire health and social care system, including the interfaces for example, between primary care, acute care, care at home, care homes and out of hours care, is necessarily involved on a 24/7 basis in delivering and ensuring the quality of palliative and end of life care. Much of the *Living and Dying Well*<sup>1</sup> development work described below has been devoted to this area, and there is now widespread recognition of the complexity involved. The *Scottish Patient Safety Programme*<sup>11</sup> emphasises the particular importance of timely and effective communication at the time of transfers of care while the recently published General Medical Council guidance *Treatment and care towards the end of life: good practice in decision making*<sup>12</sup> advises:

*“As treatment and care towards the end of life are delivered by multi-disciplinary teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs.”*

(paragraph 50)

8 Getting this right will go a long way towards bringing about the improvements required to achieve the Quality Ambitions<sup>4</sup> of NHSScotland, as well as the aims of *Living and Dying Well*<sup>1</sup>.

9 Those aims were ambitious and wide-reaching, but *Living and Dying Well*<sup>1</sup> did not claim to have all the answers. Since October 2008 it has been the catalyst for a huge amount of collaborative and development work across a range of areas. These include the short life working groups established following its launch to explore specific issues and make recommendations to the *Living and Dying Well*<sup>1</sup> National Advisory Group, as well as a number of parallel initiatives and developments relevant to its aims. The resulting outputs and recommendations, outlined below, are testament to the enormous level of engagement and commitment which have characterised the contributions of individuals and organisations across all sectors of health and social care. This document records the very substantial progress which has been made by all concerned towards achieving the aims of *Living and Dying Well*<sup>1</sup>, and sets out the next phase of actions required in order to continue building upon that progress.

Progress to date includes:

- robust ongoing governance and leadership to support improvement
- ongoing national roll out of the electronic palliative care summary (ePCS)
- the publication of the *NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy*<sup>13</sup>
- the publication of the *NHSScotland Resuscitation Policy for Children and Young People*<sup>14</sup>
- the commitment and support of organisations including NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Partnership for Palliative Care
- strong links across national strategies and policies including the *Healthcare Quality Strategy*<sup>4</sup>
- the development of palliative care guidelines
- recommendations on palliative care assessment tools
- the development of NHSScotland referral criteria to specialist palliative care and
- publication of guidance on advance care planning.



# **2 Governance and leadership**

10 The establishment of robust systems of governance and leadership has from the outset played an important part in the successful implementation of *Living and Dying Well*<sup>1</sup>. A National Advisory Group, with a membership including NHS Board Palliative and End of Life Care Executive Leads and the Chairs of *Living and Dying Well*<sup>1</sup> short life working groups as well as representatives from NHS Quality Improvement Scotland (NHS QIS), NHS Education for Scotland (NES), the Care Commission and the Scottish Partnership for Palliative Care (SPPC) was set up in October 2008 with the following remit:

- to ensure that the aims of *Living and Dying Well*<sup>1</sup> are met in a manner that is sustainable and compatible with quality improvement and patient experience programmes, and based on recognised good practice
- to ensure that governance arrangements are in place to support the implementation of *Living and Dying Well*<sup>1</sup> and to ensure that its integration with other national initiatives is managed appropriately
- to communicate and link effectively with NHS Board Executive Leads for Palliative and End of Life care to ensure that Board delivery plans for Palliative and End of Life care are implemented and integrated with other programmes
- to agree the objectives and monitor progress of the Short Life Working Groups and to ensure robust communication as these groups develop, to maximise the opportunities and avoid duplication of work
- to advise on guidance and communications to be issued to NHS Boards, Scottish Government Health and Community Care national improvement programmes, the Scottish Primary Care Cancer Group, the Care Commission, the Scottish Partnership for Palliative Care (SPPC), academic bodies, palliative care networks and key representatives of the voluntary sector, including voluntary hospices, national charities and umbrella bodies.

11 Since then, the National Advisory Group has kept under review the delivery plans of NHS Boards, monitored the progress of all *Living and Dying Well*<sup>1</sup> working groups and approved a number of outputs and recommendations, and maintained an overview of the activities of the National Clinical Leads and of collaborative work with organisations such as NHS QIS and NES.

12 An Executive Leads Group was established in October 2008 under the direction of the National Clinical Lead for Palliative and End of Life Care to bring together the Palliative and End of Life Care Executive Leads of NHS Boards. This group has met on a quarterly basis and has ensured that all Boards have direct and timely access and the opportunity to contribute to national information and thinking, has provided a forum for the open discussion of complex operational issues, and has helped to promote the sharing of information, policy and good practice among Boards.

13 Dr Elizabeth Ireland's post of National Clinical Lead for Palliative and End of Life Care from March 2008 - July 2010 was crucial to the development and launch of *Living and Dying Well*<sup>1</sup>, and she has played a key role in its successful implementation to date. The National Clinical Lead for Palliative and End of Life Care has visited all NHS Boards to discuss their developments, possible risks and barriers to implementation and progress in the drawing up and implementation of sustainable delivery plans for the future. She has also initiated and maintained contact with a wide range of individuals and organisations throughout Scotland, the UK and beyond, ensuring the comprehensive implementation of *Living and Dying Well*<sup>1</sup> and its appropriate and ongoing integration with other relevant national initiatives at home and the sharing of policy initiatives, ideas and expertise beyond.

14 The appointment of Dr Peter Kiehlmann as National Clinical Lead Palliative Care eHealth has also made a significant contribution to the implementation of *Living and Dying Well*<sup>1</sup> and the development of key national policies. Both National Clinical Leads have welcomed opportunities to engage with the Academic Council of Deans regarding palliative care in undergraduate medical education, with NHS Education for Scotland and the General Medical Council regarding palliative care in postgraduate medical education and with the Scottish Government Health Directorates regarding specialist palliative care workforce planning.

15 The Scottish Government will continue to support the implementation, governance and leadership of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress*. The National Advisory Group will continue, under the current chairmanship. As necessary, the membership, remit and function will be reviewed to ensure continued governance of palliative and end of life care in Scotland.





# **3 National developments**

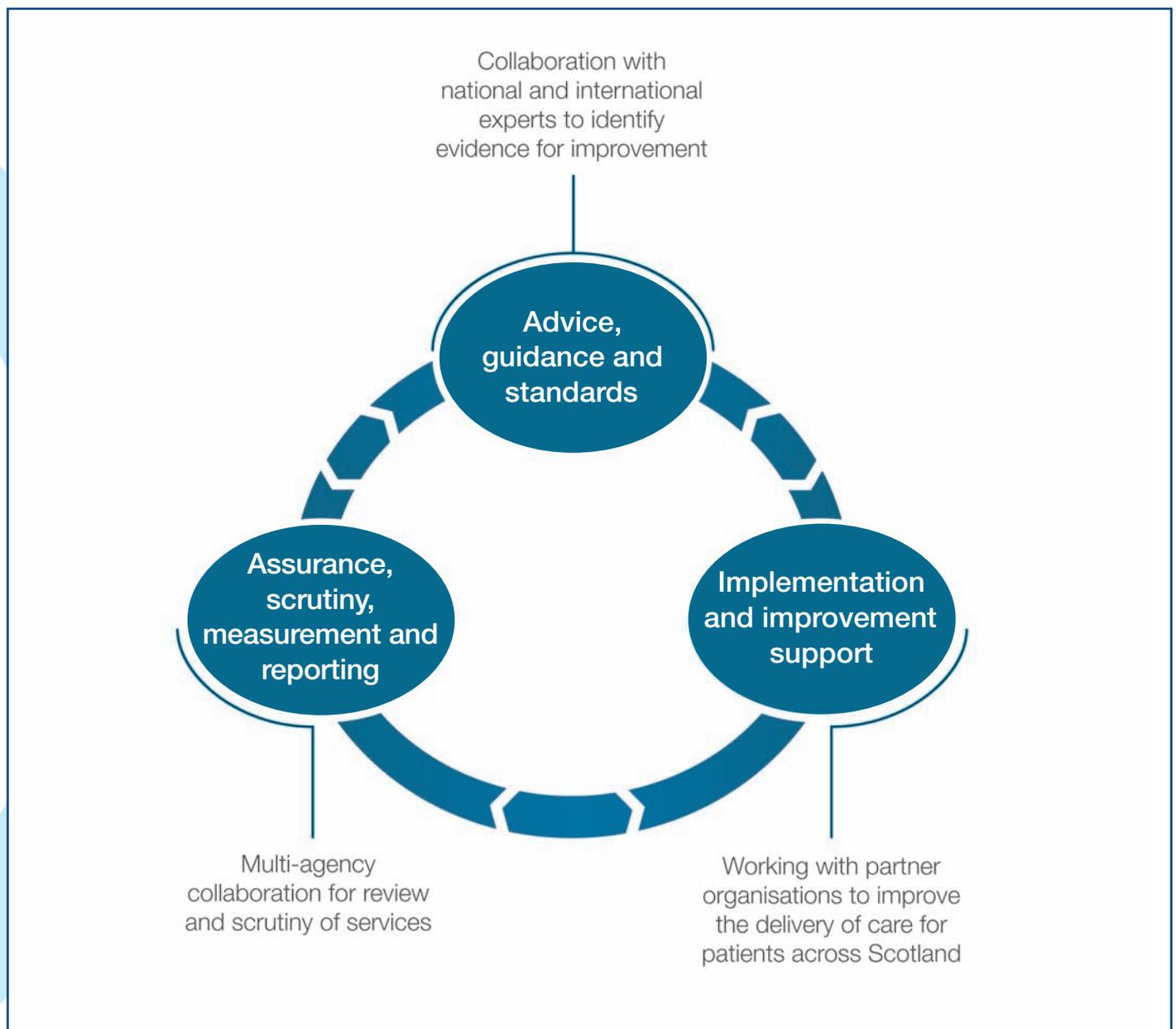
16 The Scottish Government is committed to an integrated approach to its key policies and strategies. The recently launched *Healthcare Quality Strategy for NHSScotland*<sup>4</sup> provides the opportunity to bring together all aspects of patient care in a new quality improvement model (figure 3) which will ensure a unified approach to ensuring the best quality care for every patient every time at every stage of their lives.

17 NHS Quality Improvement Scotland has agreed that palliative and end of life care, and the continuing implementation of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress* should be included as one of the integrated work programmes through which it will support implementation of the *Healthcare Quality Strategy*<sup>4</sup>.

18 The NHS QIS approach is based on an integrated cycle of improvement incorporating:

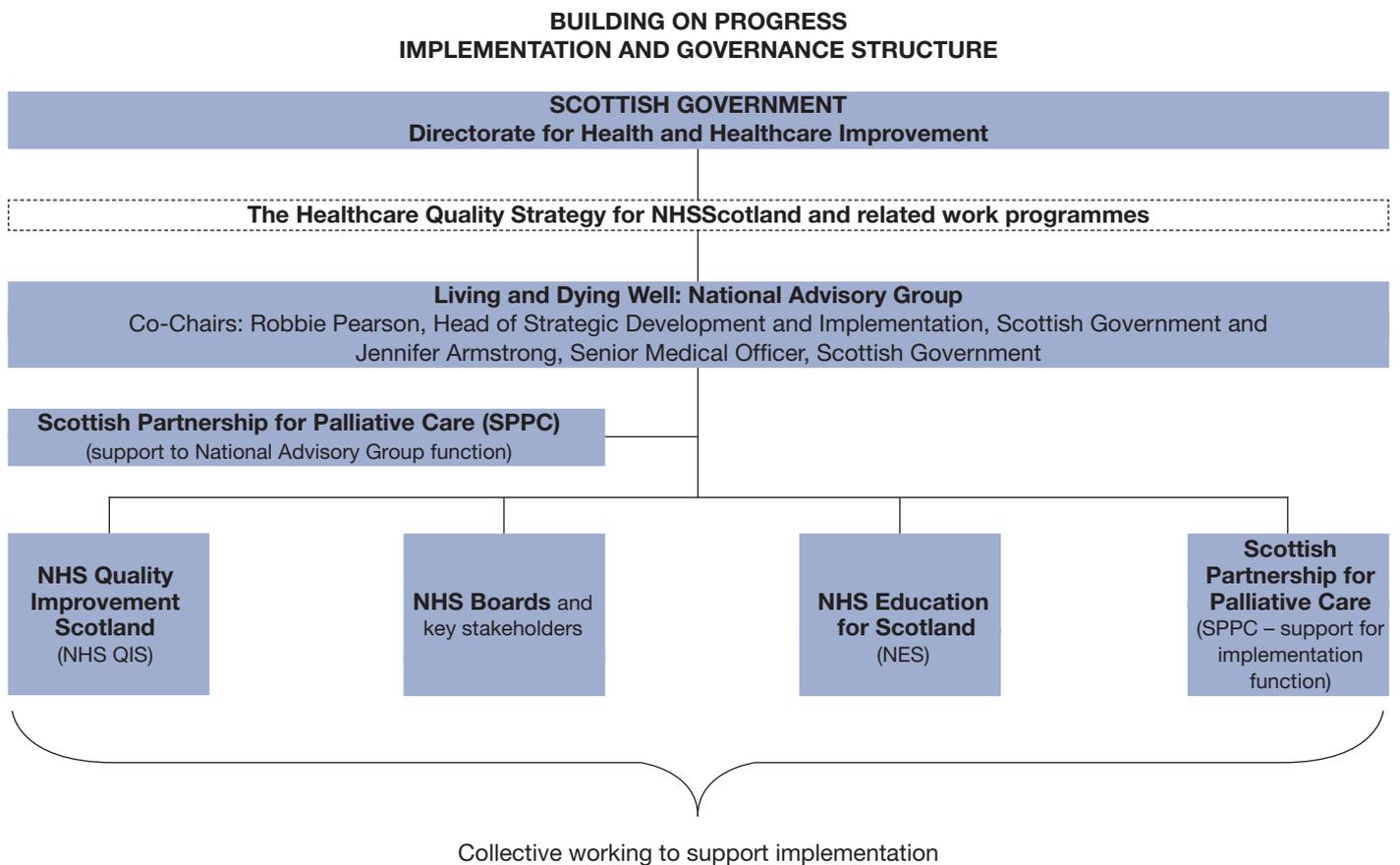
- advice and guidance
- implementation and improvement support
- assessment, monitoring and reporting.

**Figure 3**



19 In its role of supporting continuous quality improvement within palliative and end of life care, NHS QIS will work closely with the Scottish Government, with NHS Boards, Special Health Boards such as NHS Education for Scotland, the Scottish Partnership for Palliative Care and other partner organisations to promote integration and alignment of national initiatives and programmes of work. It will liaise closely with NHS Boards regarding further priority areas of activity and will ensure that any future developments are taken forward in partnership with SPPC and NES through the *Living and Dying Well*<sup>1</sup> National Advisory Group (see figure 4). The strengths of NHS QIS (quality improvement), NES (education and workforce development) and SPPC (innovation, setting the agenda (leadership) and sharing beyond traditional palliative settings) will collectively maintain the development of palliative and end of life care which will bring together best practice and support improvement in a continuous cycle.

**Figure 4**



20 In addition, the Analytical Services Division of the Scottish Government has identified a senior statistician to work with the *Living and Dying Well*<sup>1</sup> National Advisory Group and appropriate policy leads to develop local and national indicators and appropriate targets aligned with the potential quality outcome measures identified in the *Healthcare Quality Strategy*<sup>4</sup>.

21 Significant quality improvements in palliative and end of life care have already been achieved through a number of national developments arising out of the implementation of *Living and Dying Well*<sup>1</sup>, in particular the Palliative Care Directed Enhanced Service in Scotland, the electronic Palliative Care Summary (ePCS) and the *NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy*<sup>13</sup>.

22 The Scottish Government introduced its Palliative Care Directed Enhanced Service (DES) in Scotland in November 2008 as part of its cohesive and integrated approach to meeting the palliative and end of life care needs of patients and families on the basis of clinical need rather than diagnosis or prognosis, and to addressing the need for effective communication at times of transfer and transition of care. Continued funding has been agreed for the year(s) 2010-2012, and reporting systems were reviewed between April and June 2010 by representatives of the GP community across Scotland to take account of feedback received. Alignment with the ePCS has also been assured. Revised guidance will be issued shortly to reflect developments arising from the implementation of *Living and Dying Well*<sup>1</sup> and to support practices in:

- ensuring that they identify appropriate patients for the palliative care register
- sharing assessed needs through anticipatory care plans with patients, those close to them and with health and social care professionals who provide care both on hours and out of hours – especially when needs change
- determining a patient's preferred place of end of life care and seeking to meet this wish where possible.

23 In order to sustain the continued progress in palliative and end of life care a collaborative approach to support improvement is required. The experience and expertise of organisations such as, NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Partnership for Palliative Care will collectively support quality assurance and quality improvement in palliative and end of life care.

24 The support to NHS Boards and key stakeholders will be further defined through the specific actions within this document and through further exploration with NHS Boards. In general terms, and summarised as Action 1, NHS Quality Improvement Scotland, will provide support in line with the integrated cycle of improvement illustrated in Figure 3, NHS Education for Scotland will provide the education focus to the listed priorities and the Scottish Partnership for Palliative Care will manage and review the progress against the actions of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress* through which potential areas for future support and/or development will be identified.

## Action 1

The Scottish Partnership for Palliative Care (SPPC), NHS Education for Scotland (NES) and NHS Quality Improvement Scotland (NHS QIS) should work together to support NHS Boards and key stakeholders to implement the priorities and actions of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress*, in line with the integrated improvement cycle illustrated in Figures 3 and 4, specifically:

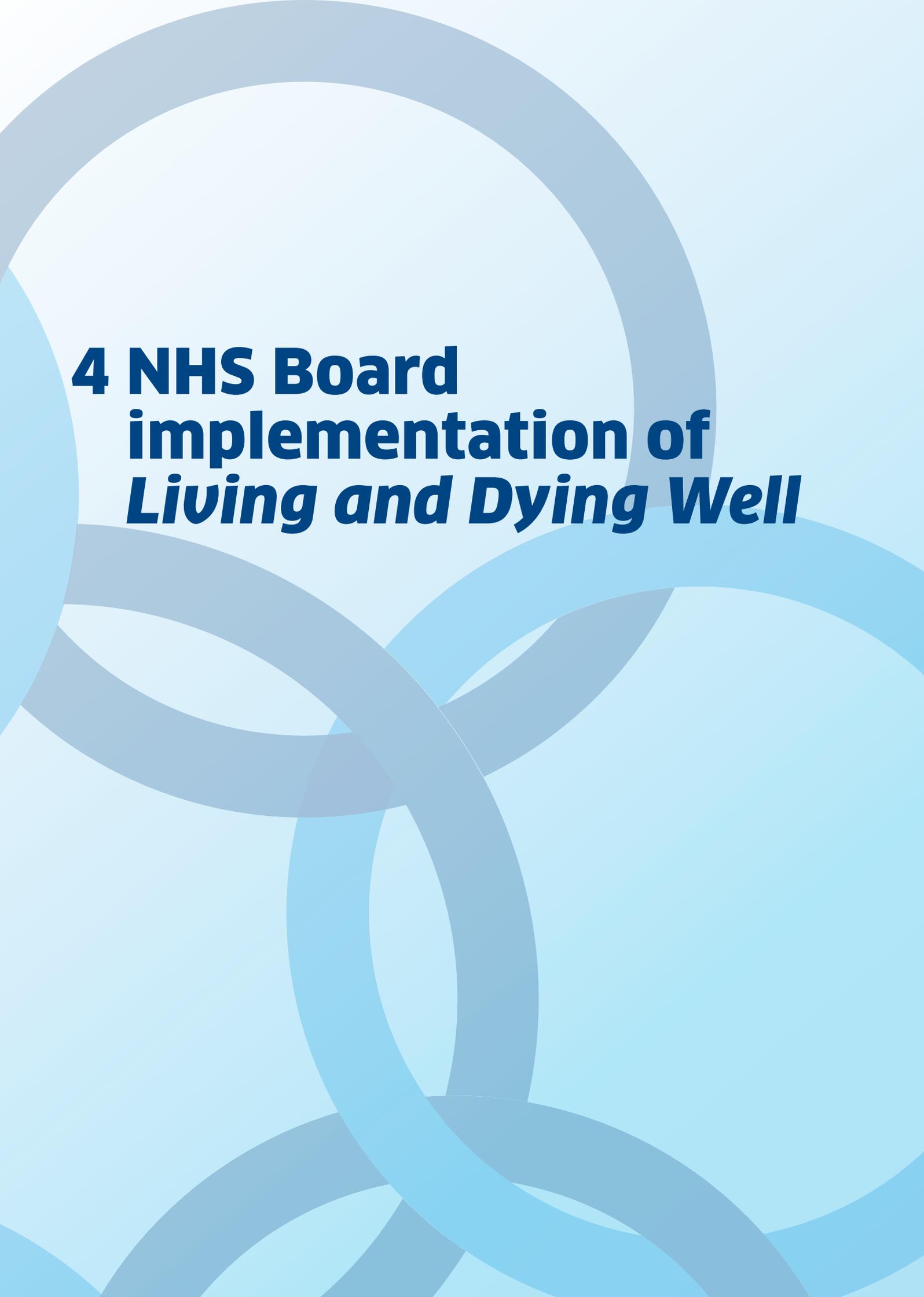
NHS QIS will work with partner organisations and in collaboration with NHS Boards and key stakeholders to integrate quality improvement in the development of palliative and end of life care services.

- NES will continue to develop education solutions in line with the priorities and aims of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress*
- SPPC will support NHS Boards and key stakeholders to implement the priorities and actions of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress* through the specific identified actions.

In addition, SPPC will support the National Advisory Group (NAG), fulfilling the roles outlined below:

- produce regular reports on implementation to NAG (based on intelligence gathering through SPPC networks and NHS board returns). It is suggested that a baseline report be developed. Thereafter exception reporting and taking periodic focus on specific actions could be employed
- identify common issues (e.g. which are not necessarily Board-specific) and escalate, as appropriate, to Members of the NAG
- in discussion with the NAG provide initiation of interventions to address common issues (where work at a national level offers appropriate solutions)
- ensure regular communication with stakeholders across sectors regarding activity, progress and good practice
- ensuring linkage between *Living and Dying Well*<sup>1</sup> work and work ongoing in relation to other national work streams (e.g. Long Term Conditions, Dementia, Older People)
- provide the secretariat to the NAG.





**4 NHS Board  
implementation of  
*Living and Dying Well***

25 NHS Board implementation of *Living and Dying Well*<sup>1</sup> has been characterised by the ongoing and enthusiastic involvement of those concerned at every level of operation, and the high level of progress achieved has been due in no small measure to this widespread sense of engagement and commitment. NHS Board Palliative and End of Life Care Executive Leads have established appropriate infrastructures and communication mechanisms with their clinical communities, and many have adopted an integrated approach to the implementation of *Living and Dying Well*<sup>1</sup> and related national policy areas, such as Long Term Conditions<sup>5</sup>, *Better Together*<sup>10</sup> and the *Scottish Patient Safety Programme*<sup>11</sup>. NHS Board Executive Leads, IT Leads and Resuscitation Leads have also contributed through their engagement with and support of National Clinical Leads in the development of the ePCS and the *National DNACPR Integrated Adult Policy* as well as to the overall implementation of *Living and Dying Well*<sup>1</sup>.

26 Each NHS Board has also identified a palliative and end of life care education champion to liaise with NHS Education for Scotland and to facilitate the spreading and sharing of good practice. Facilitators to support and cascade the implementation of advance/anticipatory planning have also been identified. NES provides support and resources for these education champions and facilitators, potentially enhancing the local delivery of education and training related to *Living and Dying Well*<sup>1</sup> within NHS Boards.

27 All NHS Boards were asked to submit *Living and Dying Well*<sup>1</sup> delivery plans against the actions required in March 2009 and to review progress in October 2009. These reviews demonstrate that substantial progress has been achieved across Scotland against all of the relevant actions in *Living and Dying Well*<sup>1</sup>. Many of the developments and recommendations outlined in *Living and Dying Well: Building on Progress* will contribute to the continuing efforts of NHS Boards in this regard.



# **5 Working Group progress and recommendations**

28 One of the key actions arising from *Living and Dying Well*<sup>1</sup> was the establishment of a series of short life working groups (SLWGs) to undertake collaborative and development work and make recommendations to the National Advisory Group on a number of areas identified as requiring further detailed consideration. The majority of this work is now complete.

29 Six SLWGs (numbers 2-7 below) were formed, drawing their membership from across relevant areas of health and social care and beyond. Their progress may be summarised as follows:

### **Standards for Palliative and End of Life Care in Scotland**

30 The establishment of this group, SLWG 1, was deferred pending the outcomes of some of the other working groups, and will now be subsumed within the plans for continuous quality improvement previously outlined.

### **Palliative and End of Life Care Guidelines**

31 National palliative and end of life care guidelines were considered by SLWG 2, which recognised that the relative absence of good quality evidence in this area made it difficult to create national guidelines using a process such as the Scottish Intercollegiate Guidelines Network (SIGN). Instead, the group mapped the availability of existing palliative and end of life care guidelines within NHS Boards and found that while several Board areas had developed and maintained their own set of guidelines, the availability of such guidance across Scotland was variable. The group decided that rather than set up and maintain a process for agreeing national guidance, there should be an agreed list of topics for which NHS Boards should provide guidelines. In consultation with NHS Boards, SLWG 2 has therefore developed a list of 30 core topics for which guidelines should be available in all NHS Board areas ([see Appendix 1](#)).

#### **Action 2**

NHS Boards with key stakeholders should review the recommendations within the final report of SLWG 2 ([see Appendix 1](#)) and update as necessary their *Living and Dying Well*<sup>1</sup> Delivery Plans to ensure that guidance on all the core topic areas identified in the report is available throughout the Board area.

#### **Action 3**

To support the implementation of Building on Progress NHS Quality Improvement Scotland will work with NHS Boards and the Scottish Partnership for Palliative Care to agree a national guideline in each topic area and a mechanism for reviewing and updating its content in the light of developing evidence and expertise. NHS Boards who do not currently have their own guidelines should use those of NHS Lothian in the meantime. [www.palliativecareguidelines.scot.nhs.uk](http://www.palliativecareguidelines.scot.nhs.uk)

## Referral Criteria to Specialist Palliative Care

32 SLWG 2 also addressed the issue of consistent and appropriate referral to specialist palliative care. The group agreed that referrals should be made on the basis of need rather than diagnosis, in situations where generalist practitioners require specialist advice on the patient's complex needs. Referrals should also be made in a manner which reflects the diversity of people's life circumstances, whether they relate to age, disability, gender, race, religion/belief or sexual orientation. SLWG 2 undertook a literature search, surveyed NHS Boards, voluntary hospices and key stakeholders, and collated referral criteria currently in use to produce a set of criteria recommended for use in all NHS Boards in the future ([see Appendix 1](#)).

### Action 4

NHS Boards should review the recommendations within final report of SLWG 2 ([see Appendix 1](#)) and update as necessary their *Living and Dying Well*<sup>1</sup> Delivery Plans to ensure their current criteria for referral to specialist palliative care reflect the recommendations.

## Recommendations for Assessment Tools

33 *Living and Dying Well*<sup>1</sup> recognised that the key to providing appropriate palliative and end of life care is first of all to identify those likely to benefit from it, and then to initiate a cyclical process of assessment and review to determine the ongoing palliative care needs of patients and their families. This may be at any time from the point of diagnosis, at the point of actual or anticipated deterioration, or on presentation of difficult or complex symptoms. In each of these cases, the consistent use of appropriate assessment tools is essential. To ensure a coherent national approach to this issue, SLWG 3 was established to develop recommendations regarding:

- assessment tools for early identification of patients who may need palliative care
- assessment tools to identify patients with increasing palliative care needs
- assessment tools for symptoms.

34 In their exploration of each of these areas, the group undertook extensive literature reviews and consultation with NHS Boards. Their final report presents detailed recommendations on particular tools and their use. These are summarised in the Actions below and included in the Appendices.

## Action 5

NHS Boards should review the recommendations within final report of SLWG 3 (Assessment Tools – (see Appendix 3) and update as necessary their *Living and Dying Well*<sup>1</sup> Delivery Plans, the recommendations include:

- all relevant staff and contractors are aware of the Gold Standards Framework – Prognostic Indicator Guidance (GSF-PIG) as a tool for identifying patients with increasing palliative care needs and limited prognosis. In addition, the Supportive and Palliative Care Indicator Tool (SPICT) – (see Appendix 2) developed by the University of Edinburgh and NHS Lothian, can be used to help identify patients for holistic assessment.
- NHS Boards should ensure that tools to identify patients with increasing palliative care needs, such as, the Palliative Performance Scale version 2 (PPS v2) (see Appendix 4) are adopted to identify changing dependency and increasing support and palliative care needs in all settings including acute hospitals, community hospitals, hospices and care homes.
- NHS Boards should ensure the use of appropriate tools for symptom assessment, such as:
  - The Edmonton Symptom Assessment Scale (ESAS) – (see Appendix 5)
  - M.D. Anderson Symptom Inventory (MDASI) – (see Appendix 6)
  - Condensed Memorial Symptom Assessment Scale (CMSAS) – (see Appendix 7)
  - The Cambridge Palliative Assessment Schedule (CAMPAS-R) – (see Appendix 8)

35 Appropriate assessment of palliative and end of life care needs in turn allows for a more person-centred approach and the appropriate planning of care. *Living and Dying Well*<sup>1</sup> recognised that pro-active care planning can enhance quality of life and help to prevent crises and unscheduled hospital admissions. It also gives healthcare professionals the opportunity to listen to patients and families and to develop a shared understanding of their needs and goals in a relationship based on empathy and mutual respect. Without this, the implementation of a high quality/appropriate palliative care approach is not possible.

## Advance Care Planning

36 SLWG 3 was tasked with the additional remit of producing recommendations on advance care planning. A sub-group was formed to advise on a consistent approach and to provide clarity in the face of the existing variety of documentation in use. This group examined the concept of advance care planning, reviewed evidence and best practice, and consulted widely. It also worked with the Long Term Conditions Collaborative<sup>5</sup> on guidance and recommendations on the development and sharing of anticipatory care plans.

37 The group's final report (see Appendix 9) distinguishes between the philosophy of advance care planning and the process/practicality of completion of an anticipatory care plan. The group proposes the following working definition of advance care planning:

*“Advance care planning, as a philosophy, promotes discussion in which individuals, their care providers and often those close to them, make decisions with respect to their future health or personal and practical aspects of care.”*

38 Advance care planning (often referred to as ACP) means adopting a “thinking ahead” philosophy of care that allows practitioners and their teams to work with patients and those close to them to set and achieve common goals that will ensure the right thing being done at the right time, by the right person, with the right outcome, to the right quality standard. It is important to note that, as with any decision-making and consent process, the capacity of the patient is taken into consideration and the Adults with Incapacity (Scotland) Act applied accordingly. Advance care planning can facilitate a patient’s previously expressed wishes about what is to happen to them at the end of life, by informing decision making when he/she is no longer able to communicate.

39 The GMC (2010)<sup>12</sup> advises advance care planning for patients in whom loss of capacity is expected. An anticipatory care plan is the document which captures the outputs from these discussions, and which should, with the patient’s consent, be shared in cross-care settings with others involved in his/her care. The electronic palliative care summary and the SBAR tool (Situation/Background/Assessment/Recommendations) are examples of documentation which may form an anticipatory care plan and include the core elements ([hyperlink](#)). The group has provided within its final report an example toolkit on how to document the outcome of applying the concept of Advance Care Planning and a set of guidance for local teams under the heading *Anticipatory Care Planning: Frequently asked questions* ([see Appendix 9](#)).

40 The group concludes in its final report that the philosophy of advance care planning needs to be accepted as an overall concept, covering an umbrella of terms and processes, and including anticipatory care planning for patients with long term conditions. This aim is echoed in the *Healthcare Quality Strategy*<sup>4</sup> and in the key Quality Ambition of mutually beneficial partnerships between patients and families and those delivering services which respect individual needs and values and demonstrate compassion, continuity, clear communication and shared decision-making. The group’s recommendations towards bringing this about are reflected in the Actions below.

#### **Action 6**

NHS Boards with key stakeholders should review the recommendations within the final report of SLWG 3 (Advance/Anticipatory Care Planning – [see Appendix 9](#)) and update as necessary their *Living and Dying Well*<sup>1</sup> Delivery Plans, the recommendations include:

- anticipatory care plans include the core components, such as the electronic palliative care summary and SBAR are in place for patients with both malignant and non-malignant disease
- with the appropriate patient consent they are shared with and accessed by all health and social care professionals working with the patient and family.

#### **Action 7**

NHS Education for Scotland and NHS Boards should work together to plan and implement a co-ordinated, staged approach to the acquisition by relevant staff of the necessary skills and confidence to initiate sensitive communication by:

- identifying a lead in each Board area to co-ordinate the education/implementation process over a two- to three-year period
- providing sessions to multi-disciplinary groups on advance/anticipatory planning that includes communication skills to enable health professionals to focus on shared decision-making

- providing sessions to particular teams with identified operational leads taking forward the implementation process.

### Action 8

NHS Quality Improvement Scotland and NHS Boards should work together to carry out formal audit and evaluation of the consistent use and the outcomes of anticipatory care planning documentation for example, ePCS and SBAR.

## Information for Patients and Carers

41 If patients and carers are to become full partners in decision-making and the planning of care, it is essential that appropriate, timely and easily accessible information is available to them. SLWG 4 was therefore set up as a National Palliative Care Patient and Carer Information Project. Following a successful bid by NHS Forth Valley for Scottish Government *Living and Dying Well*<sup>1</sup> funding, a project manager was appointed to take the work forward. Core and reference groups were established with key representation from Scottish Government, NHS and national voluntary organisations, and project phases and objectives were agreed as follows:

- obtaining patient, carer and healthcare professional's perspectives in terms of types of information required
- scoping of existing information resources and similar projects
- design and pilot of patient and carer information
- final production, launch and public awareness-raising
- exit strategy.

42 Considerable progress has now been made, and following feedback on pilot materials the project will go live in the near future. An integrated approach to patient and carer information has been assured through the links established with a number of key organisations and initiatives and the list of topics to be included in the final resource has been agreed. It is established that the final outcome will be a web-based resource, hosted by NHS Inform (see Additional Resources). The content will be reviewed and updated as appropriate by the Scottish Partnership for Palliative Care, in consultation with key stakeholders.

## Palliative and End of Life Care in Acute Setting

43 The Scottish Government aims to provide consistently high quality palliative and end of life care to everyone in Scotland who needs it in every care setting. The particular significance of hospital care during the last five years of life, and thus in the implementation of *Living and Dying Well*<sup>1</sup>, has been previously noted. Part of that implementation was the setting up of SLWG 5 to develop recommendations on the delivery of palliative and end of life care in acute care settings. For the purpose of the SLWG report, an acute hospital is defined as one to which patients with serious illness can be admitted as an emergency for assessment diagnosis and treatment.

44 Palliative care in the UK has traditionally been community focussed, originating in independent or NHS funded hospices which were often physically separate from acute hospitals. The provision of good quality palliative care is a core function of hospitals. Every hospital admission to an acute hospital of a patient with an advanced illness is an essential opportunity to assess the patients' palliative care needs. These needs may include symptom

control, information about their illness in addition to current and future care plans – well in advance of the patient reaching the last few days of life. Clear documentation and transfer of this information to other care settings will support the continued planning and delivery of palliative and end of life care.

45 For the aims of *Living and Dying Well*<sup>1</sup> to be achieved in hospitals, the SLWG report highlights the importance of embedding palliative care in the culture and practice of acute hospitals across Scotland. The report goes on to recommend how this can be achieved through a clear structure that includes the development of a Acute Hospital Palliative Care Service.

46 The Acute Hospital Palliative Care Service is defined as a structured planned service or programme by which palliative care is provided by acute hospital staff, involving specialist palliative care when necessary. In many hospitals this will involve mixed models of hospice/hospital service provision depending on the local situation.

47 Following extensive consultation, this group has made a series of recommendations.

### Action 9

NHS Boards should review the recommendations within the final report of SLWG 5 ([see Appendix 10](#)) and update, as necessary, their *Living and Dying Well*<sup>1</sup> Delivery Plans, the recommendations include:

- All acute hospitals should have a clear organisational structure by which to implement *Living and Dying Well*<sup>1</sup>. This should be planned and supported by an Acute Hospital Palliative Care Service that (a) supports all hospital staff to deliver palliative care and (b) provides a specialist service for those with complex needs. The Hospital Palliative Care Service should facilitate and lead the implementation of actions 2-9 within the report.
- The Scottish Partnership for Palliative Care will set up a National Group for Palliative Care in Hospitals to provide support for the implementation of SLWG 5 recommendations. This may include providing advice, guidance, disseminating learning and sharing good practice.

### Service Configurations to Meet the Needs of Adolescents and Young Adults with Palliative and End of Life Care Needs

48 *Living and Dying Well*<sup>1</sup> aims to ensure a cohesive and consistent approach to palliative and end of life care based on clinical need regardless of diagnosis or of age. The specific needs of adolescents and young adults have been addressed by SLWG 6 which was set up to examine the following areas:

- examining and making recommendations on the service configurations necessary to meet the palliative care needs of adolescents and young adults
- ensuring continuity as young people move into adult services, including adult palliative care services
- providing guidance to improve the quality of care at the end of life to this same group of individuals.

49 This group included input from young people who have palliative care needs and a parent whose child died in young adulthood, as well as from social work and health professionals. A survey of NHS Boards was undertaken to obtain a picture of current services addressing the needs of young adolescents and young adults with palliative and end of life needs and good practice identified informed the group's final recommendations (see [Appendix 11](#)). The group has noted in its final report that effective provision of care for this age group demands adaptation and preparation from professionals working in both children's and adult services, and that integration with other Scottish Government national policies such as *Delivering a Healthy Future*<sup>15</sup> and *Getting it Right for Every Child*<sup>8</sup> will facilitate and enhance such collaboration.

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#### **Action 10**

NHS Boards should review the final report of SLWG 6 (see [Appendix 11](#)) - and update as necessary their *Living and Dying Well*<sup>1</sup> Delivery Plans to ensure the recommendations within the report are addressed.

#### **Action 11**

NHS Education for Scotland, NHS Quality Improvement Scotland and the Scottish Partnership for Palliative Care should work in partnership to support the implementation of SLWG 6 recommendations, specifically; NHS Education for Scotland should:

- continue to develop educational resources about the care of adolescents and young people
- further develop the Managed Knowledge Network (MKN) for all staff working in Scotland with an interest in young people's health.

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### **Exploration of Ideas and Issues Addressing Palliative and End of Life Care from a Public Health and Health Promotion Perspective**

50 *Living and Dying Well*<sup>1</sup> recognised that the provision of palliative and end of life care is influenced by the social and cultural context in which it takes place. It also noted that cultural resistance in modern western societies to acknowledging the reality of death and dying as inevitable and integral parts of life, and reluctance to discuss these, can contribute to poor communication and planning of end of life care. SLWG 7 was therefore established to explore public attitudes to care, loss, dying, death and bereavement and to consider what approaches might be taken in this area to underpin improvements in palliative and end of life care.

51 Many people are denied the opportunity they may wish for to discuss and plan for their death and dying. There is limited general understanding of the long term effects of bereavement and loss, together with a lack of opportunity to share common experiences. The group reported that there are potential benefits to be derived from a more open approach to these issues – for society, its public services and communities, and for individuals. SLWG 7 developed a vision of a Scottish society in which:

- people are able to talk about death and deal with related issues in a constructive way
- children grow up treating dying as an inevitable part of ordinary life
- people are comfortable using words such as ‘death’, ‘dead’, and ‘dying’ and are able to make choices relating to their own dying and death
- health and social care professionals and volunteers in all care settings feel able to have discussions relating to death, dying and bereavement with patients and families, and with colleagues
- communities of all kinds are empowered to provide effective support to those dealing with death, dying, bereavement and loss.

52 SLWG 7 explored the potential of public health and health promoting approaches to these issues and consulted widely on its vision and on suggested approaches to bringing it about. The group’s final report notes the *Healthcare Quality Strategy*<sup>4</sup> ambition to improve person-centredness by delivering care based on mutually empathic relationships between staff, patients, carers and families and points out that for such developments to occur in the context of palliative and end of life care, and for appropriate advance/anticipatory care planning and effective person-centred care and support to be in place for everyone, there needs to be a culture of 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. The report makes ten recommendations (see [Appendix 12](#)) towards achieving these aims, including the recommendation that a broad-based coalition be established to lead and co-ordinate further work in this area, and tasked in particular with raising public awareness and promoting community involvement in the issues of death, dying and bereavement across central and local government and appropriate agencies and organisations in all sectors of Scotland’s multi-cultural and multi-faith society.

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### **Action 12**

The Scottish Partnership for Palliative Care should facilitate and lead the establishment of a broad-based coalition to take forward the work recommended by SLWG 7 (see [Appendix 12](#)).

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# **6 Additional areas of development**

53 In addition to the work carried out by the short-life working groups above, key developments have occurred in additional areas of key relevance to the implementation of *Living and Dying Well*<sup>1</sup>. These include the electronic Palliative Care Summary, resuscitation, standards of palliative care in care homes, the provision of palliative care for children and young people, bereavement care, and the relationship between NHS Boards and independent adult hospices in the provision of specialist palliative care services.

### **Electronic Palliative Care Summary (ePCS)**

54 The electronic Palliative Care Summary (ePCS), rolled out Board-wide in NHS Lothian in September 2009 following a series of successful pilots using different GP systems in NHS Lothian, NHS Grampian and NHS Ayrshire and Arran, is now subject to national rollout on a Board by Board basis. The ePCS improves communication between patients, carers and professionals at all stages of the patient journey by allowing data to be sent automatically and on a daily basis from GP systems to Out of Hours (OOH) services. In particular it allows practices to:

- replace the fax form used to send patient information to Out of Hours services
- clearly see essential information on patients with palliative care needs
- view or print lists of patients on the practice Palliative Care Register
- set review dates to ensure regular review of patients.

55 It helps provide the opportunity to develop Anticipatory Care Plans which may include:

- medical diagnoses as agreed between GP and patient
- patient and carer understanding of diagnosis and prognosis
- patient wishes on preferred place of care and DNACPR
- information on medication and equipment left in the patient's home 'just in case'.

56 Development of the ePCS and its practical implementation has been supported by the Scottish Government's National Clinical Lead Palliative Care eHealth and the Palliative Care eHealth Advisory Group, as well as by NHS Board IT Leads. This support will continue through the sometimes complex, practical technical implications of local roll out through which we expect a considerable increase in uptake and usage over the coming months. The governance for implementation will be monitored through the Scottish Government eHealth Group and progress will be reported through the *Living and Dying Well*<sup>1</sup> National Advisory Group.

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#### **Action 13**

NHS Boards, supported by the National Clinical Lead Palliative Care eHealth, will complete the roll out of the electronic palliative care Summary within locally agreed timescales.

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### **Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Adult Policy**

57 The *NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy* (see [Appendix 13](#)) was launched in May 2010, with a joint Chief Medical and Chief Nursing Officer letter (see [Appendix 14](#)). This has become a crucial part of addressing the increasing movement of patients and staff between different care settings across Scotland. The policy has been developed as part of the implementation of *Living and Dying*

*Well<sup>1</sup>* following both the recommendations regarding consistent DNAR policy in the 2008 Audit Scotland *Review of Palliative Care Services*<sup>16</sup> and in the *End of Life Care Plan*<sup>17</sup> published jointly by the Scottish Ambulance Service and the Scottish Partnership for Palliative Care in the same year, and the subsequent emphasis by the Scottish Parliament Public Audit Committee on the need for a single consistent Scotland-wide policy.

58 The development of this national policy has been led by the Scottish Government's National eHealth Clinical Lead, with additional clinical expertise from NHS Lothian, and brought to fruition through the extensive involvement of NHS Board Resuscitation Leads and a DNACPR Steering Group established for the purpose. The policy, based on the integrated DNAR policy of NHS Lothian, reflects the current evidence base and UK best practice guidance on decisions relating to Cardiopulmonary Resuscitation such as the 2007 revised *Joint Statement*<sup>18</sup> produced by the British Medical Association, Royal College of Nursing and Resuscitation Council (UK) and the General Medical Council's 2010 guidance *Treatment and care towards the end of life: good practice in decision making*<sup>12</sup>. It aims to support patients in achieving personal goals for their end of life care in any care setting, but its use does not preclude other active interventions or care. It does not apply to children, for whom a separate and appropriate policy is currently being developed. Implementation of the DNACPR Integrated Adult Policy has been supported by NES through the production of a training resource DVD for healthcare professionals and the provision of training the trainer sessions across Scotland by the Scottish Government.

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#### **Action 14**

NHS Quality Improvement Scotland with support from NHS Education Scotland and the Scottish Partnership for Palliative Care will work with NHS Boards and key stakeholders to support the implementation of the *NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy* (see [Appendix 13](#)). The progress of implementation will be reported through the *Living and Dying Well<sup>1</sup>* National Advisory Group.

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#### **Children and Young Person Resuscitation Policy**

59 In conjunction with the adult policy, the SCYPPEX group has developed a resuscitation policy for Children and Young People, titled Children and Young People Acute Deterioration Management (see [Appendix 15](#)). This policy and related materials, has recently been published and has been developed with the wide support of paediatric services within Scotland. It will mainly be used within Children's Services Departments to support the management of acute deterioration in children and young people.

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#### **Action 15**

NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Partnership for Palliative Care will work with NHS Boards to support the implementation of the *Resuscitation Planning Policy for Children and Young People*.

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**Care Homes**

60 With a population living longer and suffering from a growing range of long-term and life-limiting conditions, care homes in Scotland are playing an increasingly important role in the provision of palliative and end of life care. Considerable progress has been made in recent years to raise standards of care, in particular through *Making good care better: National practice statements for general palliative care in adult care homes in Scotland*<sup>19</sup>, published by the Scottish Partnership for Palliative Care and the then Scottish Executive in May 2006 and used as an inspection focus by the Care Commission between March 2007 and March 2008. The Care Commission’s subsequent report, *Better Care Every Step of the Way*<sup>20</sup>, highlights both the good practice achieved and what has still to be done to achieve a uniformly high standard of palliative and end of life care in care homes throughout Scotland. The report makes a series of recommendations for bringing this about.

61 *Living and Dying Well*<sup>1</sup> also highlighted the increasing importance of care homes in meeting the palliative and end of life care needs of older people and tasked the National Clinical Lead for Palliative and End of Life Care with initiating discussions leading to liaison between the Scottish Government and the Care Commission regarding appropriate quality mechanisms in this area. A meeting of interested stakeholders, led by Scottish Care, the umbrella body of the independent care sector in Scotland, took place in October 2009 leading to the establishment of a new national Palliative Care in Care Homes Steering Group. This group includes representation from the Scottish Government, NHS, care home providers in the private, voluntary and public sectors, NHS Education for Scotland, COSLA, Association of Directors of Social Work, the Care Commission and the Scottish Partnership for Palliative Care. It aims:

*“to develop the capacity of care homes to deliver good quality palliative and end of life care, consistent with Scottish Government policies, regulatory requirements and good practice guidance, thereby ensuring that people can make a positive choice to remain in their care home unless there is a need to access specialist care in another environment.”*  
(see Appendix 16)

62 In a significant linking of cross-sector policy initiatives, this Steering Group will support the implementation of the recommendations in *Better Care Every Step of the Way*<sup>20</sup>, work which will inform the potential review of the National Care Standards proposed in *Living and Dying Well*<sup>1</sup>. A national stakeholder conference for care home providers on sharing good practice took place in the autumn of 2010. To further support a cohesive approach to the provision of palliative and end of life care in care homes, the Palliative Care in Care Homes Steering Group will in future be represented on the *Living and Dying Well*<sup>1</sup> National Advisory Group. To address the need for consistent and accessible opportunities for education and training in care homes, NHS Education for Scotland has made its training materials available to all care home staff.

**Action 16**

The Palliative Care in Care Homes Steering Group should continue, through the agreed objectives to implement the work plan to develop the capacity of care homes to deliver good quality palliative and end of life care, consistent with Scottish Government policies, regulatory requirements and good practice guidance.

**Action 17**

The Palliative Care in Care Homes Steering Group should work with NHS Boards with the support of NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Partnership for Palliative Care to ensure a national approach to quality assurance and quality improvement in palliative and end of life care in care homes, specifically:

- NHS Education for Scotland should continue to make its education and training resources available to care home staff whenever possible.
- At an appropriate time the Scottish Government will liaise with the Scottish Commission for the Regulation of Care (Care Commission) regarding possible revision of the National Care Standards as they relate to the provision of palliative and end of life care in care homes.

**Children and Young People**

63 *Living and Dying Well*<sup>1</sup> Short Life Working Group 6, in making recommendations for meeting the palliative and end of life care needs of adolescents and young people, noted that many of its recommendations were also applicable to children. A Scottish Children's and Young People's Palliative Care Executive (SCYPPEX) has now been formed to address the specific palliative care needs of children and young people. This group brings together formal and informal networks concerned with the palliative care of children and young people across Scotland in a single unified voice to provide:

- clinical leadership to influence and develop the delivery of palliative care services to children and young people with all types of long term and life limiting illness and their families across Scotland and
- strategic leadership to influence the wider health, social care and education policy agendas to achieve the best outcomes for children and young people with palliative care needs and their families in Scotland.

64 SCYPPEX has suggested extending the recommendations of SLWG 6 to embrace the needs of children and young people (see [Appendix 17](#)), and has a number of suggestions regarding the implementation of *Living and Dying Well*<sup>1</sup> as it applies to the specific palliative and end of life care needs of children and young people and their families. SCYPPEX is represented on the *Living and Dying Well*<sup>1</sup> National Advisory Group, and has been central to the development of a national resuscitation planning policy for children and young adults.

**Action 18**

The Scottish Children's and Young People's Palliative Care Executive (SCYPPEX) should work with NHS Boards, NHS Quality Improvement Scotland, NHS Education for Scotland and the Scottish Partnership for Palliative Care to support a national approach to quality assurance and quality improvement in palliative and end of life care for children and young people.

**Bereavement**

65 The Audit Scotland *Review of Palliative Care Services*<sup>16</sup> in August 2008 noted the inconsistency of bereavement support across Scotland. *Living and Dying Well*<sup>1</sup> Short Life Working Group 7 also recognised the importance of bereavement care when it included within its remit and examination of attitudes to death and dying the issues of bereavement and loss.

66 In a speech in September 2008, the Minister for Public Health and Sport referred to the long overdue introduction of bereavement guidance in Scotland. That guidance is now in draft form and available for consultation in the discussion document *Shaping Bereavement Care A Framework for Action for Bereavement Care in NHSScotland* (see Appendix 18). This document builds on work commissioned in 2005 by the then Scottish Executive, NHS QIS and NES and carried out by Robert Gordon University, and is the culmination of an extensive process of debate and collaboration across professions and sectors. *Shaping Bereavement Care* is addressed to NHS Boards in Scotland to guide them in the development of good quality bereavement care. Its key messages include the following:

- there is a need to recognise that good care of the dying, the person who has died and of relatives and carers at the time of death leads to better outcomes in grief for those who are bereaved
- quality bereavement care starts, where possible, before death and certainly at the time of death
- quality bereavement care, at least in the period around death, is the responsibility of the health services
- all healthcare staff require education and training in grief and loss at a level appropriate to their degree of involvement with the bereaved
- health boards have a responsibility for the care and support of staff working with the dying and bereaved
- the delivery of quality bereavement care within health boards requires to be coordinated
- healthcare services should work in partnership with other stakeholders in the planning and delivery of care for the bereaved.

67 *Shaping Bereavement Care* contains recommendations for NHS Boards, as well as for NHS QIS and NES and advocates a coordinated approach both within NHS Boards and nationally. In support of this, it is hoped to establish a national networking hub for those working in the field of grief and bereavement. *Shaping Bereavement Care* also seeks to interface with *Living and Dying Well*<sup>1</sup> and supports the need highlighted by SLWG 7 for greater public acceptance of death and dying as part of the ordinary cycle of life and of bereavement as a normal human experience.

**Action 19**

The *Living and Dying Well*<sup>1</sup> National Advisory Group should be mindful of the recommendations in the final version of *Shaping Bereavement Care A Framework for Action for Bereavement Care in NHSScotland* (see Appendix 18) and should work in collaboration with any *Shaping Bereavement Care* implementation group to maximise the achievement of a cohesive national approach to all aspects of palliative and end of life care.

**Action 20**

NHS Boards should ensure that implementation of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress* and of *Shaping Bereavement Care A Framework for Action for Bereavement Care in NHSScotland* are closely aligned within Board areas.

**Action 21**

The coalition to be established by the Scottish Partnership for Palliative Care to take forward the work recommended by SLWG 7 should include representation relating to the implementation of *Shaping Bereavement Care A Framework for Action for Bereavement Care in NHSScotland*.

## **Funding Arrangements Between NHS Boards and Voluntary Hospices**

68 Historically, specialist palliative care services have in some areas been provided through independent adult hospices partly funded by their NHS Boards. Scottish Executive HDL (2003) 18 set out a commitment to build a partnership between NHS Boards and adult voluntary hospices that would ensure 50% funding of agreed annual running costs. However, the Audit Scotland 2008 *Review of Palliative Care Services*<sup>16</sup> noted a lack of consistency in these arrangements, and recommended that Boards put in place commissioning and monitoring arrangements which would ensure that value for money was achieved. In examining the Audit Scotland report, The Public Audit Committee of the Scottish Parliament recommended robust commissioning arrangements in the delivery of palliative care services to ensure value for money, and also recommended that the Scottish Government should supplement existing guidance on what should be included in NHS Board funding allocations to voluntary sector bodies.

69 The Scottish Government accepted these recommendations and a short life working group was established with representation from the Scottish Hospices Forum and the six NHS Boards with voluntary hospices in their areas. This group, chaired by one of the co-chairs of the *Living and Dying Well*<sup>1</sup> National Advisory Group, adopted a collaborative approach and has explored approaches, within the context of today's challenging financial environment and increasing expertise in quality assurance issues, to building a viable and enduring partnership and commissioning framework between NHS Boards and voluntary hospices in Scotland.

70 The group has now submitted its final report and recommendations, *A Partnership for Better Palliative and End of Life Care: Creating a New Relationship between Independent Adult Hospices and NHS Boards in Scotland* (see [Appendix 19](#)) to the Scottish Government. The report will be considered and revised guidance issued in due course.

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### **Action 22**

The Scottish Partnership for Palliative Care, with key stakeholders, including representatives from NHS Boards and voluntary hospices, should facilitate and lead the establishment of a performance forum to build a collection of measures linked to the six dimensions of quality (Recommendation 5.5 of the report).

### **Action 23**

The Scottish Government will consider the working group's final report and recommendations and will issue revised guidance to NHS Boards in due course.

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# **7 Education and workforce development**

71 Both *Living and Dying Well*<sup>1</sup> and the SPPC report *Palliative and end of life care in Scotland: the case for a cohesive approach*<sup>3</sup> which preceded it, emphasised the crucial role of education, training and workforce development in achieving their aims and objectives. *Living and Dying Well*<sup>1</sup> summarised its educational aims as follows:

*“To ensure that all health and social care professionals are equipped with the knowledge, skills, competence and confidence to care for the diversity of patients and families living with and dying from any advanced, progressive or incurable condition.”*

72 To help bring this about, the Scottish Government undertook to support the delivery of improved palliative and end of life care by working in partnership with NHS Education for Scotland (NES) to develop an educational infrastructure and a national plan for facilitating and delivering education and training for generalists through support for education and training that could be delivered locally. NES appointed a projects manager to take the work forward and established a Palliative Care Project Reference Group. Initial priorities for education and training were identified as advance/anticipatory care planning, communication and general principles of palliative care in a project plan which recognised the need for local flexibility within its intention of developing an infrastructure to support local delivery of nationally agreed education and training.

73 NES has supported the implementation of Advance/Anticipatory Care Planning (ACP) through a series of awareness raising events and facilitators training, delivered as a result of a successful tender exercise in the summer of 2009. Evaluation of these initiatives has indicated the need for further education and training in ACP and further support for facilitators, and NES will work with NHS Boards identifying specific needs in this area. NES will also work with the Scottish Social Services Council to help meet the need for ACP education and training across sectors. As part of ACP, NES has also supported the implementation of the National DNACPR Policy with the development of a DVD media resource to support facilitators and trainers in relations to ‘conversations on DNACPR’.

74 Communication skills have long been recognised as of crucial importance to effective palliative and end of life care, and in collaboration with the NES Long Term Conditions workstream, support has been provided for a range of communication and related projects arising from locally identified needs. NHS Boards were offered the opportunity in July 2009 to bid for funds to pilot or implement existing communication skills education training opportunities using rapid improvement methodology. The information derived from evaluation of these projects will inform further educational initiatives. NES will continue to develop education solutions which support the health and social care workforce to acquire, develop and integrate communication and relationship based skills, values, approaches and attitudes which are consistent with person centred care.

75 A key action of *Living and Dying Well*<sup>1</sup> was the identification by each NHS Board of an education champion to liaise with NES and to facilitate the sharing and spreading of good practice. To these were added facilitators to support and cascade the implementation of ACP. NES will continue to support the infrastructure which underpins local delivery of education and training by further building on and developing support for education champions and facilitators. To date NES has established a quarterly newsletter and conducted events for education champions and facilitators, and a palliative care education website and Managed Knowledge Network (see Additional resources) has been developed to facilitate sharing of resources and good practice and encourage discussion with others.

76 *Living and Dying Well*<sup>1</sup> also identified a role for NES in supporting NHS Boards' implementation across all are settings of the Liverpool Care Pathway for the Dying Patient (LCP)<sup>21</sup> or equivalent integrated care pathway. Many NHS Boards have appointed facilitators to take this forward, and NES will continue to work with any NHS Board identifying specific needs in this area. NES will also work with the key stakeholders, including Palliative Care in Care Homes Steering Group to identify needs and support implementation across sectors.

77 In addition to these developments, NES is also engaging with the Higher Education providers or institutions regarding support for palliative care education within nursing and Allied Health Professionals disciplines.

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#### **Action 24**

NHS Education for Scotland will support continuing implementation of *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress* by:

- working with NHS Boards and key stakeholders, including the Palliative Care in Care Homes Steering Group to support implementation of national initiatives such as Communication skills, ACP, DNACPR, and the LCP or equivalent care pathways across sectors
- supporting local delivery of education and training by continuing to build on and develop support for education champions and facilitators
- developing education solutions which support the health workforce to acquire, develop and integrate communication and relationship-based skills, values, approaches and attitudes which are consistent with person-centred care.

#### **Action 25**

NHS Education for Scotland will work with the Higher Education providers or institutions to support palliative care education in nursing and Allied Health Professions disciplines.

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# **8 Conclusion**

78 The achievements outlined in this document demonstrate the very substantial progress which has been made towards the equitable provision of high quality palliative and end of life care across Scotland for everyone, whenever and wherever they need it. Moreover, that progress has been made in a manner which is sustainable for the future. Although there is still some way to go before the full aims of *Living and Dying Well*<sup>1</sup> reach fruition, the Scottish Government, NHS Boards, key stakeholders and individual practitioners across all sectors remain committed to the process which has begun. In the short term, governance and operational arrangements to ensure implementation of all of the actions in *Living and Dying Well*<sup>1</sup> and *Living and Dying Well: Building on Progress* will continue through the Scottish Government, the National Advisory Group and the Executive Leads. In the longer term, clinical leadership and quality assurance will continue to develop within the NHS QIS integrated cycle of improvement in partnership with, NES and the Scottish Partnership for Palliative Care.

79 Sustainability is also ensured by the fact that *Living and Dying Well*<sup>1</sup> continues to interface with a wide range of national policies and strategies across health and social care. At the same time, the work of the working groups and the additional development areas outlined above demonstrate repeatedly that palliative care is an integral part of healthcare in all settings and that, in the words of one consultation respondee, palliative care is 'everyone's business'. Most importantly, we have seen the palliative care approach of mutual respect, sensitive communication and holistic care embedded firmly throughout NHSScotland in the *Healthcare Quality Strategy*<sup>4</sup> and its Quality Ambition of mutually beneficial partnerships between patients, their families and those delivering healthcare services, based on respect for individual needs and values, and demonstrating compassion, continuity, clear communication and shared decision-making. With these solid achievements in the implementation of *Living and Dying Well*<sup>1</sup> behind us, and as we continue to build on the progress to which so many have contributed, Scotland can be justly proud of an integrated, person-centred, equitable and needs based provision of high quality palliative and end of life care which leads the world.



# **Annexes**

## Annex A

### Overview of Actions

#### Action 1

Implementation and governance arrangements

#### Actions 2 and 3

Implement, review and update guidelines

#### Action 4

Implement referral criteria to specialist palliative care

#### Action 5

Implement assessment tools

#### Actions 6, 7 and 8

Implement advance/anticipatory care planning

#### Action 9

Implement palliative care in acute hospitals

#### Actions 10 and 11

Implement service configuration young people service recommendations

#### Action 12

Health promotion/public health

#### Action 13

Electronic Palliative Care Summary (ePCS)

#### Action 14

Adult Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Policy

#### Action 15

Children's resuscitation policy

#### Actions 16 and 17

Development of care home agenda

#### Actions 18

Scottish Children's and Young People Palliative Care Executive (SCYPPEX)

#### Actions 19, 20 and 21

Bereavement

#### Actions 22 and 23

Partnership between NHS Boards and independent hospices

#### Actions 24 and 25

Education and workforce development

\*Monitoring of progress will be undertaken by the Scottish Government Health Directorates through the Living and Dying Well National Advisory Group.

## Annex B

### Appendices (All appendices available through hyperlink)

No.	Title
1	SLWG 2 – Guidelines and referral criteria <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix1GandRC">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix1GandRC</a>
2	Supportive and Palliative Care Indicator Tool <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/SPCITool">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/SPCITool</a>
3	SLWG 3 – Assessment Tools <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix2AS">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix2AS</a>
4	Palliative Performance Scale V2 <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix3PPS">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix3PPS</a>
5	The Edmonton Symptom Assessment System (ESAS) <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix4ESAS">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix4ESAS</a>
6	M.D. Anderson Symptom Inventory (MDASI) <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix5MDASI">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix5MDASI</a>
7	Condensed Memorial Symptom Assessment Scale (CMSAS) <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix6CMSAS">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix6CMSAS</a>
8	The Cambridge Palliative Assessment Schedule (CAMPAS-R) <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix7CPAS">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix7CPAS</a>
9	SLWG 3 – Advance/Anticipatory Care Planning (ACP) <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix8">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix8</a>
10	SLWG 5 – Hospital Palliative Care <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix9HPC">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix9HPC</a>
11	SLWG 6 – Service configurations for adolescents <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix10SCFA">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix10SCFA</a>
12	SLWG 7 – Public Health/Health Promotion <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix11PHHP">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix11PHHP</a>
13	NHSScotland Adult DNACPR Policy <a href="http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix12DNACPR">http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix12DNACPR</a>

- 14 CMO/CNO Letter (DNACPR)  
<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix13CMOCNOletter>
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<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/CYPADM>
- 16 Care Home Group Remit  
<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix15CHGremit>
- 17 SCYPPEX remit  
<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix16SCYPPEXToR>
- 18 Shaping Bereavement Care  
<http://www.scotland.gov.uk/Topics/Health/NHS-Scotland/LivingandDyingWell/Appendix17SBC>
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## Annex C

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## **Annex D**

### **Additional Resources**

#### **NHS Inform**

[www.nhsinform.co.uk](http://www.nhsinform.co.uk)

#### **NHS Lothian Palliative Care Guidelines project**

[www.palliativecareguidelines.scot.nhs.uk](http://www.palliativecareguidelines.scot.nhs.uk)

#### **Scottish Partnership for Palliative Care**

[www.palliativecarescotland.org.uk](http://www.palliativecarescotland.org.uk)

#### **National End of Life Care Programme in England (Department of Health)**

[www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

#### **The Knowledge Network (NHS Education for Scotland)**

[www.knowledge.scot.nhs.uk](http://www.knowledge.scot.nhs.uk)



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