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Quality Division



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Franck David
Assistant to the Committee
Public Petitions Committee
T3.04
The Scottish Parliament
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Your ref: PE1105

21 October 2010

Dear Mr David

PE1105

Thank you for your letter of 7 October 2010 regarding Petition PE1105 submitted on behalf of the St Margaret of Scotland Hospice. The Committee requested an update on the availability of the report and recommendations made by the working group set up to review adult hospice funding set out in HDL(2003)18.

The report of the working group together with proposed revised guidance has been issued to a range of stakeholders including NHS Boards and hospices for comment. A copy of the information circulated is enclosed for the Committee's information. As noted in previous correspondence, NHS Boards and hospices were represented on the working group which developed the report.

This work forms part of a strategic approach to ensure the sustainable delivery of the intentions set out in Living and Dying Well and as subsequently recommended by a series of short life working groups.

On receipt of further comments, it is anticipated that the revised guidance will be issued to NHS Boards and be available on both the Scotland's Health on the Web and the Scottish Government's websites. It is hoped that this will be achieved by the end of November 2010.

I hope this information is helpful.

Yours sincerely

COLIN BROWN
DEPUTY DIRECTOR

Dear Colleague

PALLIATIVE AND END OF LIFE CARE IN SCOTLAND

Since the publication of *Living and Dying Well (LDW) a national action plan for palliative and end of life care in Scotland*¹ in October 2008 considerable progress has been made in implementing the actions and in undertaking the further development and collaborative work required to achieve the full range of Living and Dying Well aims. Less than two years on, there is widespread evidence that the cohesive national approach 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.

*LDW: Building on Progress*² records the progress which has been made by all concerned towards achieving the aims of LDW, and sets out the next phase of actions required in order to continue building on that progress. The outputs and recommendations, are testament to the enormous level of engagement and commitment which has characterised the contributions of individuals and organisations across all sectors of health and social care.

Key to the progress of LDW is its 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. In order to realise the necessary improvements in palliative and end of life care NHS Boards should review their progress against the LDW actions and the actions set out in *LDW: Building on Progress* – with particular priority on the implementing the following areas:

- Advance/Anticipatory Care Planning (Action 6-8)
- Palliative and End of Life Care in Acute Hospitals (Action 9)
- Electronic Palliative Care Summary (LDW Building on Progress – Action 13)
- Do Not Attempt Cardiopulmonary Resuscitation (Action 14)

The *Scottish Government's Healthcare Quality Strategy for NHSScotland*³, launched in May 2010 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. NHS Boards should take this opportunity, when you review and update your palliative and end of life care delivery plan, to reflect the associated nature of these actions with other workstreams and where possible integrate your delivery plans to reflect this. For example your Long Term Condition Action Plan.

The Scottish Government will continue to support the implementation, governance and leadership of *Living and Dying Well* and *Living and Dying Well:*

Building on Progress through the National Advisory Group. Additional support to NHS Boards will primarily be provided by NHS Quality Improvement Scotland, NHS Education Scotland and the Scottish Partnership for Palliative Care (SPPC).

The SPPC will continue to have a central role in supporting improvements in palliative and end of life care in Scotland through their involvement in specific actions as well as providing a direct function to the Living and Dying Well National Advisory Group.

Action:

NHS Boards should:

- review and update local palliative care delivery plans to ensure the relevant actions identified in *Living and Dying Well* and *Living and Dying Well: Building on Progress* are implemented in a planned and timely manner. This should include the identification of local priorities.*
- ensure that the initial focus of implementation is on the areas outlined above i.e. ACP, Hospitals, ePCS and DNACPR

Yours sincerely

1 Living and Dying Well a national action plan for palliative and end of life care in Scotland. The Scottish Government. Edinburgh, October 2008
<http://www.scotland.gov.uk/Publications/2008/10/01091608/0>

2 Living and Dying Well: Building on Progress. The Scottish Government. Edinburgh 2010
(Link to be added)

3 Scottish Government's Healthcare Quality Strategy for NHSScotland. The Scottish Government, Edinburgh 2010 (Link to be added)

*N.B. The LDW National Advisory group, through the Scottish Partnership for Palliative Care will be requesting details of NHS Boards priority areas for implementation (over and above those listed above). Further information to follow. We will not be asking NHS Boards to submit their updated Delivery Plans at this time.



Living and Dying Well: Building on Progress



Living and Dying Well: Building on Progress

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Foreword

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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 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.

Insert signature

DRAFT CEL – FUNDING BETWEEN NHS BOARD & VOLUNTARY HOSPICES

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*¹ in October 2008 followed the Scottish Government's acceptance, in its December 2007 action plan for health and wellbeing *Better Health Better Care*², 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*³. Two years on, there is widespread evidence that the cohesive national approach outlined in *Living and Dying Well* 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* 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*⁴, launched in May 2010. The *Quality Strategy* 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* outlines this process as follows:

- 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.

(*Living and Dying Well*, paragraph 14)

3 This approach is now firmly embedded in Scottish Government healthcare policy, and underpins workstreams such as the *Long Term Conditions Strategy*⁵, *Scotland's National Dementia Strategy*⁶, *Reshaping Care for Older People*⁷, and *Getting it Right for Every Child*⁸. 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 in February 2009 show that in 2007 those in the final year of life accounted for around 30% of all bed days.

Figure 1

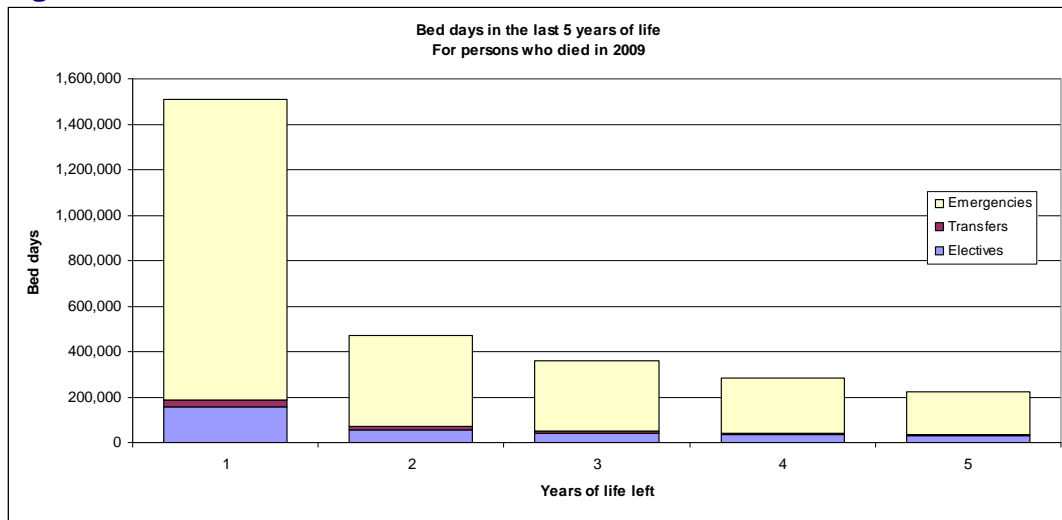
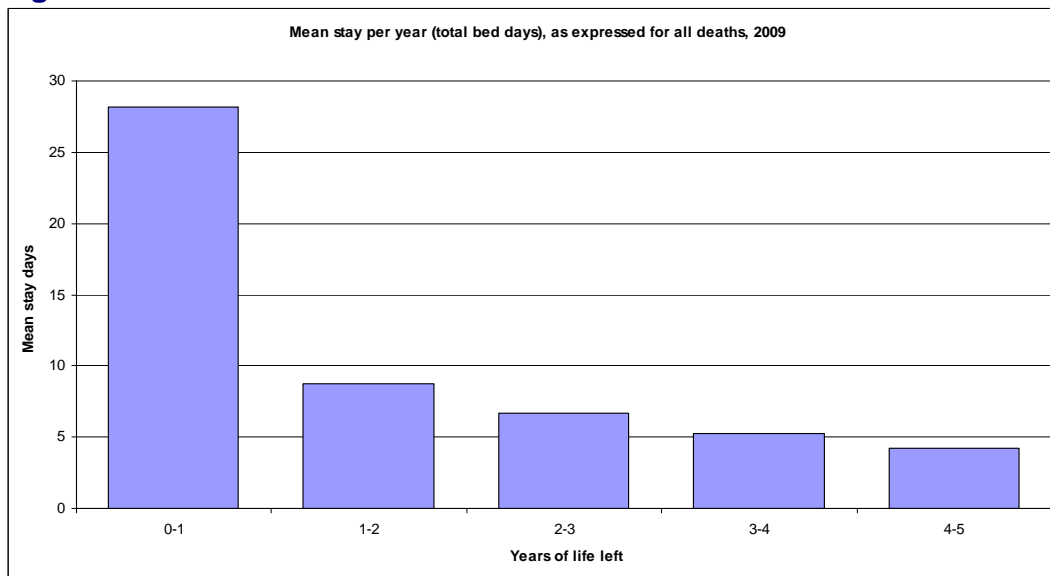


Figure 2



4 These figures do not signify any failing in the approach which supports *Shifting the Balance of Care* 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

Programme⁹, 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 still at home, 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.

5 The cycle of hospital admission and discharge evident in the last five years of life means that the entire healthcare system, including the interfaces between primary care, acute care 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* 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*¹⁰ 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*¹¹ 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)

6 Getting this right will go a long way towards bringing about the improvements required to achieve the quality ambitions of NHSScotland, as well as the aims of *Living and Dying Well*.

7 Those aims were ambitious and wide-reaching, but *Living and Dying Well* 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* 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*, and sets out the next phase of actions required in order to continue building upon that progress.

2 Governance and leadership

8 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*. 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* short life working groups as well as representatives from NHS Quality Improvement Scotland (NHS QIS), NHS Education for Scotland (NES) 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 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 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.

9 Since then, the National Advisory Group has kept under review the delivery plans of NHS Boards, monitored the progress of all L&DW 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.

10 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.

11 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*, 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, risk narratives 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* and its appropriate and ongoing integration with other relevant national initiatives at home and the sharing of policy initiatives, ideas and expertise beyond.

12 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* 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.

13 The Scottish Government will continue to support the implementation, governance and leadership of *Living and Dying Well* 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

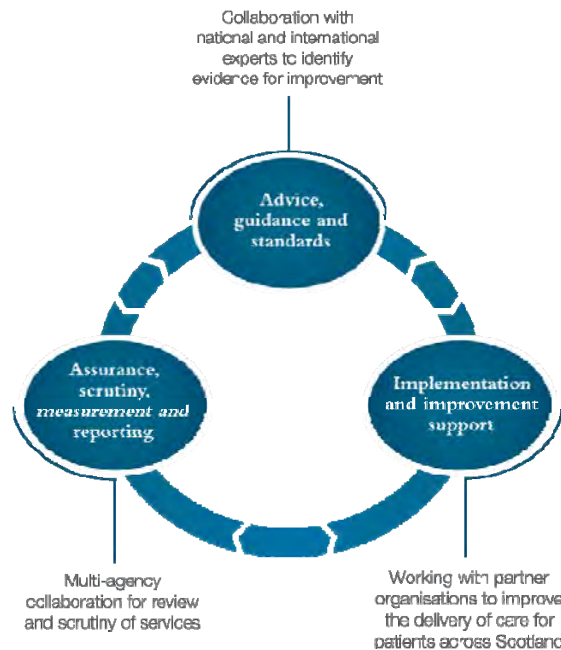
14 The Scottish Government is committed to an integrated approach to its key policies and strategies. The recently launched *Healthcare Quality Strategy for NHSScotland* provides the opportunity to bring together all aspects of patient care in a new quality improvement model (figure 3) which will ensure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

15 NHS Quality Improvement Scotland has agreed that palliative and end of life care, and the continuing implementation of *Living and Dying Well* 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*.

16 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

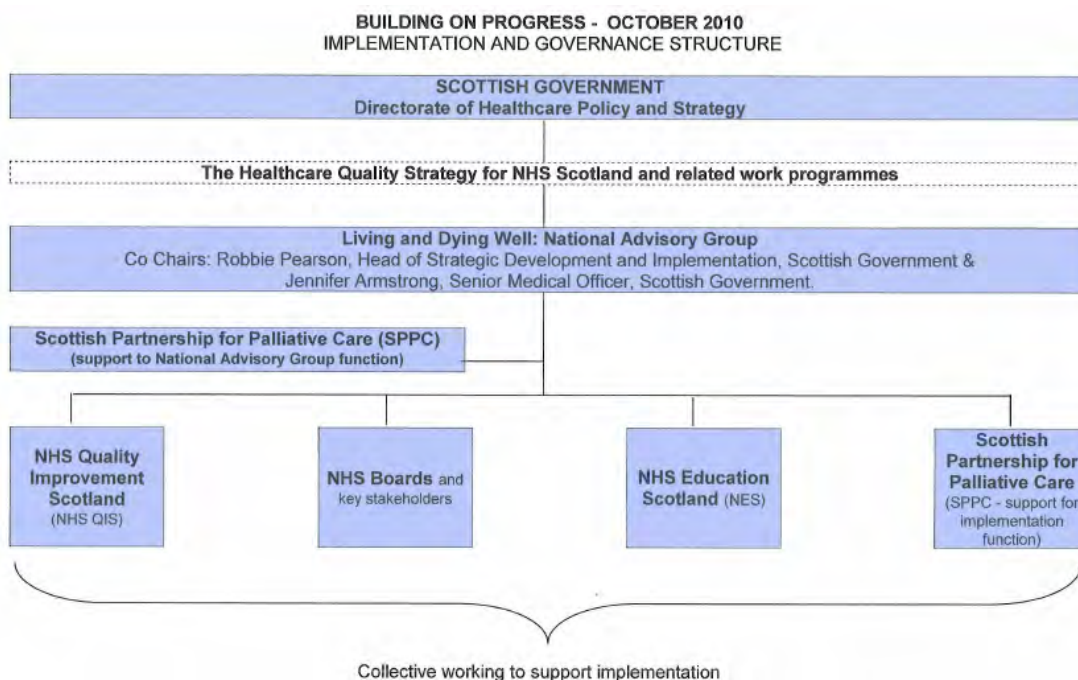


www.nhshealthquality.org

17 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 territorial 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* 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

DRAFT CEL – FUNDING BETWEEN NHS BOARD & VOLUNTARY HOSPICES



18 In addition, the Analytical Services Division of the Scottish Government has appointed a senior statistician to work with the *Living and Dying Well* 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*.

19 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*, 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.

20 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* 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 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.

21 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.

22 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 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* 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 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* and *Living and Dying Well: Building on Progress*, in line with the integrated improvement cycle illustrated in Figure 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* 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* 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 Chairs of NAG
 - in discussion with 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 work and work ongoing in relation to other national work streams (e.g. LTC, Dementia, Older People)
 - provide the secretariat to the NAG.
-

4 NHS Board Implementation of *Living and Dying Well*

23 NHS Board implementation of *Living and Dying Well* 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* and related national policy areas, such as Long Term Conditions, *Better Together* and the *Patient Safety Programme*. 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*.

24 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, thus enhancing the local delivery of education and training related to *Living and Dying Well* within NHS Boards.

25 All NHS Boards were asked to submit *Living and Dying Well* 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*. 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

26 One of the key actions arising from *Living and Dying Well* 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.

27 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

28 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 Guidelines

29 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 should review the recommendations within the final report of SLWG 2 ([see Appendix 1](#)) and update as necessary their Living and Dying Well 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 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 should use NHS Lothian Palliative Care Guidelines in the meantime.

Referral Criteria to Specialist Palliative Care

30 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 Delivery Plans to ensure their current criteria for referral to specialist palliative care reflect the recommendations.

Recommendations for Assessment Tools

31 *Living and Dying Well* 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.

32 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 ([see Appendix 2](#)) and update as necessary their Living and Dying Well 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.
- 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 3](#)) is 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) –([Appendix 4](#))
M.D. Anderson Symptom Inventory (MDASI) –([Appendix 5](#))
Condensed Memorial Symptom Assessment Scale (CMSAS) – ([Appendix 6](#))
The Cambridge Palliative Assessment Schedule (CAMPAS-R) – ([Appendix 7](#))

33 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* 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

34 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 on guidance and recommendations on the development and sharing of anticipatory care plans.

35 The group's final report (Appendix 8) 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.”

36 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.

37 The GMC (2010)¹⁴ 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 of [Practical Guidance](#) 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*. ([hyperlink](#))

38 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* 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. Reference should be made to the group's final report on the *Living and Dying Well* in implementing these.

Action 6

NHS Boards should review the recommendations within final report of SLWG 3 (see [Appendix 8](#)) and update as necessary their Living and Dying Well 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 to Patients and Carers

39 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* funding, a project manager was appointed from July 2009 to September 2010 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.

40 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

41 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 5 years of life, and thus in the implementation of *Living and Dying Well*, 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.

42 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.

43 For the aims of Living and Dying Well 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.

44 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.

45 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 9](#)) and update, as necessary, their Living and Dying Well Delivery Plans, the recommendations include:

- All acute hospitals should have a clear organisational structure by which to implement Living and Dying Well. 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

46 *Living and Dying Well* 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.

47 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 10](#)). 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*¹⁵ and *Getting it Right for Every Child*⁸ will facilitate and enhance such collaboration.

Action 10

NHS Boards should review the final report of SLWG 6 ([see Appendix 10](#)) - and update as necessary their Living and Dying Well Delivery Plans to ensure the recommendations within the report are addressed.

Action 11

NHS Education 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 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 a interest in young people's health

Exploration of ideas and Issue Addressing Palliative and End of Life Care from a Public Health and Health Promotion Perspective

48 *Living and Dying Well* 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.

49 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.

50 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* 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 11](#)) 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.

Action 12

The Scottish Partnership for Palliative Care should facilitate and lead the establishment of a broad-based collation to take forward the work recommended by SLWG 7 ([see Appendix 11](#)).

6 Additional areas of development

51 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*. 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)

52 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.

53 It helps to address the concerns referred to in paragraphs 2-5 above by providing 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'.

54 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 National Advisory Group.

Action 13

NHS Boards, supported by the National Clinical Lead Palliative Care eHealth, will complete the roll out of the electronic palliative care Summary by 31 March 2011.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Adult Policy

55 The NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy ([see Appendix 12](#)) was launched in May 2010, with a joint Chief Medical and Chief Nursing Officer letter ([see Appendix 13](#)), and should be implemented in all NHS Board areas by 1 October 2010. 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* following both the recommendations regarding consistent DNAR policy in the 2008 Audit Scotland *Review of Palliative Care Services* and in the *End of Life Care Plan*¹² 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.

56 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 CPR such as the 2007 revised *Joint Statement* produced by the British Medical Association, Royal College of Nursing and Resuscitation Council (UK)¹³ and the General Medical Council's 2010 guidance *Treatment and care towards the end of life: good practice in decision making*¹⁴. 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.

Action 14

NHS Quality Improvement Scotland with support from NHS Education Scotland and the Scottish Partnership for Palliative Care will work with NHS Boards to support the implementation of the *NHSScotland Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Integrated Adult Policy*. The progress of implementation will be reported through the Living and Dying Well National Advisory Group.

Children & Young Person Resuscitation Policy

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 (Appendix 14 *to be added*). 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.

Action 15

NHS Quality Improvement Scotland, NHS Education 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.

Care Homes

57 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*, published by the Scottish Partnership for Palliative Care and the then Scottish Executive in May 2006¹⁸ 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*¹⁹, 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.

58 *Living and Dying Well* 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 NHS, care home providers in the private and public sectors, NHS Education for Scotland, COSLA, 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.”
([Appendix 15](#))

59 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*, work which will inform the potential review of the National Care Standards proposed in *Living and Dying Well*. A national stakeholder conference for care home providers on sharing good practice will take 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* 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 develop and implement a 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

60 *Living and Dying Well* 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.

61 SCYPPEX has suggested extending the recommendations of SLWG 6 to embrace the needs of children and young people ([see Appendix 16](#)), and has a number of suggestions regarding the implementation of *Living and Dying Well* 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* National Advisory Group, and is involved in 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

62 The Audit Scotland *Review of Palliative Care Services* in August 2008¹² noted the inconsistency of bereavement support across Scotland. *Living and Dying Well* 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.

63 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*²⁰. 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

64 *Shaping Bereavement Care* contains recommendations for NHS Boards, as well as for NHS QIS and NES ([see Appendix 17](#)) and advocates a co-ordinated 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* 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* 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* 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* 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*.

Funding arrangements between NHS Boards and voluntary hospices

65 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* 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.

66 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* 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.

67 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* to the Scottish Government. The report has been issued (*still in draft*) with CEL xxx.

Action 22

NHS Boards (that host voluntary hospices) should implement the recommendations of - *A Partnership for Better Palliative and End of Life Care: Creating a New Relationship between Independent Adult Hospices and NHS Boards in Scotland* through CEL xxx ([see Appendix 18](#)). DRAFT

Action 23

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).

7 Education and workforce development

68 Both *Living and Dying Well* and the SPPC report *Palliative and end of life care in Scotland: the case for a cohesive approach* which preceded it, emphasised the crucial role of education, training and workforce development in achieving their aims and objectives. *Living and Dying Well* 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.”

69 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 to develop an educational infrastructure and a national plan for facilitating and delivering education for generalist staff in all care settings, including hospitals and care homes. 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.

70 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’.

71 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 workforce to acquire,

develop and integrate communication and relationship based skills, values, approaches and attitudes which are consistent with person centred care.

72 A key action of *Living and Dying Well* 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. In a significant cross-border agreement, this will shortly be augmented by the addition of training modules developed for the Department of Health End National End of Life Care Programme in England. [hyperlink](#)

73 *Living and Dying Well* 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) 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 Scottish Social Services Council to identify needs and support implementation across sectors.

74 In addition to these developments, NES is also engaging with the Higher Education providers or institutions regarding possible support for palliative care teaching within nursing and AHP disciplines.

Action 24

NHS Education for Scotland will support continuing implementation of *Living and Dying Well* and implementation of actions in *Living and Dying Well: Building on Progress* by

- working with NHS Boards and bodies such as the Scottish Social Services Council to support implementation of national initiatives such as 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

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

8 Conclusion

75 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* 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* 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.

76 Sustainability is also ensured by the fact that *Living and Dying Well* 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 short-life 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 respondent, 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* 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* 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.

Annex A

Overview of Actions

	Scottish Gov. HD*	NHS Boards	NHS QIS	NES	SPPC	Other
Action 1 Implementation & governance arrangements	●	●	●	●	●	● ^{1,2}
Action 2 & 3 Implement, review and update guidelines	●	●	●		●	
Action 4 Implement referral criteria to specialist palliative care	●	●				
Action 5 Implement assessment tools	●	●				
Action 6,7 & 8 Implement advance/anticipatory care planning	●	●	●	●		
Action 9 Implement palliative care in Acute Hospitals	●	●	●	●	●	
Action 10 & 11 Implement service configuration young people service recommendations	●	●		●	●	
Action 12 Health promotion / public health					●	
Action 13 ePCS	●	●				
Action 14 Adult DNACPR policy	●	●	●	●	●	
Action 15 Children’s resuscitation policy	●	●	●	●	●	● ²

DRAFT CEL – FUNDING BETWEEN NHS BOARD & VOLUNTARY HOSPICES

Action 16 & 17	●			●	●	● ¹
Development of care home agenda						
Action 18	●	●	●	●	●	● ²
SCYPPEX						
Action 19,20 & 21	●	●			●	● ¹
Bereavement						
Action 22 & 23	●	●			●	● ³
Partnership between NHS Boards and independent hospices						
Action 24 & 25	●	●		●		
Education and workforce development						

N.B.

1 – Palliative Care in Care Homes Steering Group

2 – Scottish Children’s and Young People’s Palliative Care Executive

3 – Independent hospices

*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
2	SLWG 3 – Assessment Tools
3	Palliative Performance Scale V2
4	Edmonton Symptom Assessment System (ESAS)
5	MD Anderson Symptom Inventory
6	Condensed Memorial Symptom Assessment Scale
7	The Cambridge Palliative Assessment Schedule
8	SLWG 3 - ACP
9	SLWG 5 – Hospital Palliative Care
10	SLWG 6 – Service configurations for adolescents
11	SLWG 7 – Public Health / Health Promotion
12	NHSScotland Adult DNACPR Policy
13	CMO/CNO Letter (DNACPR)
14	NHSScotland Children’s Resuscitation Policy (to be added)
15	Care Home Group Remit

16	SCYPPEx remit
17	Shaping Bereavement Care
18	Commissioning (NHS Board and voluntary hospice)

Annex C

References

LINKS / full reference TO BE ADDED

- 1 Living and Dying Well a national action plan for palliative and end of life care in Scotland
- 2 Better Health Better Care
- 3 Palliative and end of life care in Scotland: the case for a cohesive approach
- 4 Scottish Government's Healthcare Quality Strategy for NHSScotland
- 5 Long Term Conditions Strategy
- 6 Scotland's National Dementia Strategy
- 7 Reshaping Care for Older People
- 8 Getting it Right for Every Child
- 9 National Patient Experience Programme
- 10 NHSScotland's Patient Safety Programme
- 11 Treatment and care towards the end of life: good practice in decision making
- 12 Audit Scotland Review of Palliative Care Services and in the End of Life Care

Plan

- 13 Joint Statement produced by the British Medical Association, Royal College of Nursing and Resuscitation Council (UK)
- 14 General Medical Council's 2010 guidance Treatment and care towards the end of life: good practice in decision making

Annex D

Additional resources

www.nhsinform.co.uk

Dear Colleague

A Partnership for Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and NHS Boards in Scotland

The publication 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 and undertaking further development and collaborative work required to achieve the full range of *Living and Dying Well* aims. This is reflected in *Living and Dying Well: Building on Progress*.

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* 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. A short life working group was established and produced a report (Annex A) with representation from the Scottish Hospices Forum and the six NHS Boards with voluntary hospices in their areas to address the recommendations. This CEL replaces the guidance set out in NHS HDL (2003) 18.

It is crucial that there is a positive and constructive working relationship between NHS Boards and the voluntary hospices. Hospices play an important part in the mix of palliative care provision across Scotland. This CEL is intended to provide a focus for a structured and on-going working relationship between NHS Boards and the voluntary hospices by which value for money and agreed outcomes for patients and taxpayers is achieved. Annex A highlights an approach to commissioning that should be :

- transparent and open
- focus on outcomes

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- clinically effective
- cost effective and
- value for money

Action:

NHS Boards should ensure that the approach to commissioning is in line with Annex A; *A Partnership for Better Palliative and End of Life Care: Creating a New Relationship Between Independent Adult Hospices and NHS Boards in Scotland* (Annex A). Specifically NHS Boards in partnership with voluntary hospices should:

- define and agree a commissioning cycle (Recommendation 5.1)
- maximise the value from commissioning by ensuring the process is owned and led by the NHS Board Executive Lead for Palliative and End of Life care, working in partnership with Executive staff and trustees of local Independent Hospices (Recommendation 5.2)
- introduce a balanced scorecard approach that allows a consistent flow of information between NHS Boards and Hospices (Recommendation 5.3)
- move to affordable and sustainable 3 year service-level agreements that reflect a commitment to the 50% funding of mutually agreed specialist palliative care services. These should be linked to agreed outcomes, standards and shared strategic objectives. (Recommendation 5.4)
- introduce consistent service level agreement documentation building on examples of good practice (Recommendation 5.6).

In addition, the Scottish Partnership for Palliative Care has agreed to establish, with key stakeholders, a Performance Forum to build a collection of measures linked to the six dimensions of quality (recommendation 5.5).

Annex A recognises the further opportunities, for example the development of tools/measures to improve the partnership between NHS Boards and voluntary hospices. These developments will be undertaken with contribution from and in consultation with, key stakeholders. The Scottish Government, through the governance arrangements of Living and Dying Well will monitor the adoption of the more structured approach to commissioning and the progress of the Performance Forum. The implementation of this guidance will be monitored following the completion of the next full financial years cycle i.e. after April 2012.

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Yours sincerely

Annex A

A Partnership for Better Palliative and End of Life Care:

Creating a New Relationship Between Independent Adult Hospices and NHS Boards in Scotland

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Membership of the Review Group

1 Introduction

- 1.1 Over the next decade there will be a marked rise in the number of people with chronic illness and with cancer. This will lead to a substantial increase in demand for palliative and end of life care. In the United Kingdom about 20% of hospital bed days are covered by end of life care.¹
- 1.2 *Living and Dying Well*² affirmed palliative and end of life care as a national priority. A holistic and integrated approach to caring for the needs of patients is central to the national action plan, as is the commitment to work with a range of stakeholders. The recently published Healthcare Quality Strategy for NHSScotland also gave a commitment to deliver a service that is safe, effective and patient-centred. The ambitions in that strategy are central to the delivery of a more responsive service.³
- 1.3 The voluntary sector, as a whole, plays a crucial part in the life of Scotland, with a total annual income of over £4.1 billion. The voluntary sector has a vital role in the delivery of palliative and end of life care in Scotland, in the community and in hospices. This was acknowledged in *Living and Dying Well* and in the Audit Scotland Report on Palliative Care. Independent hospices deliver a specialist service in a number of areas of Scotland, with close working relationships between NHS Boards and independent providers essential in delivering the objectives in *Living and Dying Well*. The hospices are also part of a wider system of care (including MCNs) and operate with a range of partners in meeting the needs of the communities they serve. Central to the success of the hospices is the close and extensive involvement of users, fundraisers and volunteers.
- 1.4 The specialist services provided by the independent hospices includes in-patient care, day services, community services, counselling, education and training, and complementary therapies. In-patient beds are an important, but only part of a much wider integrated service. Appendix 6 sets out the spectrum of specialist palliative care.

¹ NAO: The Potential Cost of Savings of Greater Use of Home and Hospice Based End of Life Care in England page 3 (2008)

² <http://www.scotland.gov.uk/Publications/2008/10/01091608/4>

³ <http://www.scotland.gov.uk/Publications/2010/05/10102307/0>

- 1.5 Palliative and end of life care is a complex and not a linear journey. The Public Accounts Committee of the UK Parliament commented in its report on End of Life Care that the “Office for National Statistics has data on the number of deaths and where people die, commissioning end of life care services is complex due to variability in patient needs and the resources required.”⁴
- 1.6 HDL (2003) 18 sets out a commitment to build a partnership between NHS Boards and Voluntary Hospices that would ensure 50% funding of annual agreed running costs and which “did not compromise the essential independence of individual hospices.” The circular built upon an original commitment made in 1990 that Boards should meet 50% of the running costs of hospices providing specialist palliative care for adults.
- 1.7 The Audit Scotland Report on Palliative Care⁵ highlighted the diversity of provision across Scotland. The strategic importance of hospices in a number of Board areas was recognised as was the need to build strong relationships between the NHS Boards and the hospices. The report stated that “NHS boards are required to fund 50 per cent of the agreed annual running costs of independent voluntary hospices providing specialist palliative care within their area. In 2006/07, NHS boards funded between 41 and 53 per cent of the costs of voluntary sector hospices in their areas Commissioning arrangements between the NHS and the voluntary sector are improving but there remain difficulties in agreeing what should be included in the voluntary hospice funding allocation provided by boards. NHS boards hold annual meetings with their voluntary sector partners to discuss the 50 per cent funding arrangements. These meetings are also used to review and agree the services they expect voluntary hospices to deliver. **However, NHS boards do not currently evaluate value for money in the services they commission or provide.**” The Audit Scotland report went on to recommend that: Boards put in place commissioning and monitoring arrangements to ensure value for money is achieved.
- 1.8 As stated in the Kings Fund Report (2010): Delivering Better Care at End of Life (p13): “taxpayers...expect end-of-life care services to represent value for money, with appropriate, high-quality care provided efficiently and in the right settings

⁴ <http://www.publications.parliament.uk/pa/cm200809/cmselect/cmpublic/99/9902.htm>

⁵ http://www.audit-scotland.gov.uk/docs/health/2008/nr_080821_palliative_care.pdf

and a robust measurement and demonstration of the quality and effectiveness of care”.⁶

- 1.9 The Public Audit Committee of the Scottish Parliament recommended in its report⁷:
 - 1.9.1 The Committee believes that boards need robust commissioning arrangements with their partners for the delivery of palliative care services to ensure they deliver value for money.
 - 1.9.2 The Committee recommends that the Scottish Government issues guidance to boards on what should be included in their funding allocation to voluntary sector bodies, to supplement existing guidance.
- 1.10 The Scottish Government has accepted these recommendations and has established a short-life group to review the future commissioning arrangements (including the approach to funding) for adult voluntary hospices in Scotland).

2 Defining The Challenges

- 2.1 The voluntary hospices value their independence. As commented by the Public Accounts Committee of the UK Parliament: “The hospice movement developed as a result of a gap in the services provided by the NHS and has traditionally raised significant funds each year to provide services to people nearing the end of their life. Hospices place a high value on their independence...”⁸ Local communities therefore play a vital part in the fund raising of the annual £46m of running costs of the voluntary hospices in Scotland. Funding received from NHS Boards amounted to around £19m in 2008/09.

⁶ Delivering Better Care at End of Life: The Kings Fund Report 2010

⁷ <http://politicsforpeople.org/s3/committees/publicAudit/reports-09/paur09-01.htm#8>

⁸ <http://www.publications.parliament.uk/pa/cm200809/cmselect/cmpublic/99/9907.htm>

- 2.2 The objective has been to explore approaches to building a viable and enduring partnership and commissioning framework in Scotland between the NHS Boards and Voluntary Hospices.
- 2.3 Set against this, are the following challenges:
- 2.3.1 a significantly tighter financial climate for NHS Boards
 - 2.3.2 a demanding financial environment for hospices
 - 2.3.3 variability in the interpretation and progress in achieving the objective set out in HDL (2003) 18
 - 2.3.4 the commitment to make a step-change in caring for those with palliative and end-of-life care needs, in response to *Living and Dying Well*
 - 2.3.5 the need to shift the focus from inputs and outputs to making perceptible improvements in outcomes and the experience for patients and their families
- 2.4 HDL (2003) 18⁹ emphasises “***the importance of regular discussion between Boards and hospices, in the context of the palliative care strategy, local needs assessment and local health plan. The first round of discussions held after the issuing of this HDL should aim to clarify the position in respect of services which were introduced in the past without the full agreement of the Board. The running costs associated with those services should only be included in the 50% target if both parties now agree to the need for them. In relation to future developments, only by this sort of discussion will there be clarity about which services and functions are recognised by both parties as qualifying for the 50% target. In order to***

⁹ http://www.sehd.scot.nhs.uk/mels/HDL2003_18.pdf

promote the fullest possible mutual understanding of future plans, Boards must be included at the earliest stage in the consideration of any developments which could generate running costs that would be eligible for the 50% target.” The recurring theme through the HDL is the need for regular and on-going dialogue between Boards and the voluntary sector.

- 2.5 Despite HDL (2003) 18, there appears to be considerable debate about the definition of “agreed annual running costs”. Historical factors (such as perceptions of “creeping developments” in the absence of a more robust process), other competing demands on resources and, moreover the lack of a clearly defined baseline from which to measure progress towards the 50% target has prevented the target being achieved consistently. Consequently, funding decisions do not appear to be influenced by the distance from the 50% target, but a range of other factors such as affordability. Instead, a retrospective analysis takes place of the extent to which annual uplifts and investment decisions demonstrate progress towards the 50% target.
- 2.6 The December 2009 Survey by the Scottish Partnership for Palliative Care (see Appendix 1) demonstrated a variation between NHS Boards across Scotland and hospices in reaching a settled position re agreed running costs. Only 5 out of the 13 hospices had reached agreement with their Boards in 2009 (38%). However, further progress has been made since that survey was produced.
- 2.7 The position between the independent hospices and NHS Boards is mirrored in the study undertaken by the National Audit Office in England (2008): End of Life Care. The study found that: “on average, independent hospices received 26 per cent of their funding from PCTs in 2006-07, and this proportion varied up to 62 per cent. The proportion of expenditure on direct patient care which, for example, excludes fundraising costs is, however, 31 percent”.¹⁰ The study also pointed to the fact that “half of independent hospices responding to our survey were dissatisfied with their contractual arrangements with Primary Care Trusts (PCTs) and 70 per cent of contracts between independent hospices and PCTs are for one year only. By May 2008, only 56 per cent of hospices had agreed funding with the PCT for 2008-09, and respondents rated contracts lowly for transparency; stability; formality; and how representative they are of level of service.”¹¹ The study also cited the joint report by the Commission for the

¹⁰ http://www.nao.org.uk/publications/0708/end_of_life_care.aspx

¹¹ Ibid

Compact and *Help the Hospices* “that current contractual relationships would benefit from clearer output targets and establishment of agreed outcomes”.¹²

- 2.8 Many of the messages from the NAO study are applicable in Scotland. **In Scotland, the HDL should though only be one, albeit important, part of a larger commissioning framework between NHS Boards and the voluntary hospices.** Taken in isolation, there is a risk that the level of engagement between the NHS Boards and the voluntary hospices is measured with the pace of progress in implementing the HDL (2003) 18. The success of the relationship between the NHS Boards and the voluntary hospices should not be defined simply by the rate of progress in achieving the 50% target, but a wider set of factors, such as demonstration of value-for-money and delivery against mutually agreed objectives and criteria. As one individual commented: “the issue isn’t the agreement or not on 50% of annual agreed running costs, but the 100% of costs and how these are sustainable”.
- 2.9 At present, there is an inconsistent approach to the development of commissioning across Scotland between the Boards and the Voluntary Hospices. For instance, in some parts there are out-of-date Service Level Agreements, or unsigned documentation, whilst in other areas there are more mature and developed relationships.
- 2.10 Reflecting NHS Board allocations, funding is generally determined on an annual cycle creating uncertainty and undermining the ability to build longer strategic relationships. NHS Boards have to deal with a range of competing demands and pressures with regard to service investment and inevitably hospices have to negotiate funding within this context.
- 2.11 Hospices are also aware of the need to think quite differently about the future. For instance, St Christopher’s Hospice Chief Executive is cited in the Kings Fund Report (2010) and refers to the need for hospices to challenge their current service models in the changing operating environment but likewise points to their inherent strengths: “one of the benefits of hospices voluntary status is a lack of bureaucracy and short lines of communication, which means that ideas can be brought from concept to practice very rapidly...Hospices have rightly been challenged to deliver to a constituency

¹² Ibid

beyond their own, inevitably small, patient numbers. To do so they must create more formal partnerships and consider mergers. Size is essential to reduce back office costs and to offer sensible standard contracts for commissioners for direct care services, clinical support of others and education...Specialist staff should be shared between voluntary and NHS providers, improving skill development and avoiding professional isolation". (page 11)¹³ Some members of the Scottish Hospices Forum have already embarked on early exploratory work in the area of shared services.

- 2.12 The climate has clearly changed since the HDL was drafted in 2003. The financial environment now and for the foreseeable future will be significantly tighter for NHS Boards and hospices. In such an environment, moving NHS Boards and hospices to a more consistent, robust and systematic approach to commissioning and demonstrating value-for-money is essential. Such an approach won't remove the need for hard choices and difficult decisions but will make head way in ensuring a more open, better understood and transparent system.
- 2.13 This report seeks to outline where progress could be made in moving to a new commissioning framework.

3 Establishing Principles

- 3.1 Building a positive and constructive working relationship between the NHS Boards and the Voluntary Hospices is crucial. The hospices play an important part in the mix of palliative care provision across many areas of Scotland. A new partnership and commissioning framework is intended to provide a focus for a more structured and on-going working relationship between NHS Boards and the Voluntary Hospices. The partnership approach that has underpinned the work on this document needs to be carried through to its implementation. This will be reflected in trust, mutual respect and shared responsibility.
- 3.2 Commissioning is the means by which we secure value for money and agreed outcomes for patients and taxpayers.

¹³ Delivering Better Care at End of Life: The Kings Fund Report 2010

- 3.3 In respect of the commissioning framework between NHS Boards and Voluntary Hospices in Scotland the commitment is to ensure that there is an open and consistent approach to the relationship between NHS Boards and the Voluntary Hospices, based on mutual respect.¹⁴
- 3.4 *Help the Hospices* point to the need for commissioners should start to view hospices more as *partners* in commissioning than simply as *providers* of commissioned services.¹⁵ Similarly, hospices need to have a fuller understanding of the tight financial environment in which NHS Boards are operating and the need to make difficult choices between and within priority areas.
- 3.5 The following principles should underpin the approach to commissioning:
- 3.5.1 transparency and openness
 - 3.5.2 a focus on outcomes
 - 3.5.3 clinical effectiveness
 - 3.5.4 cost effectiveness
 - 3.5.5 value for money
- 3.6 The commissioning should also be shaped by the six dimensions of quality in the Healthcare Quality Strategy for Scotland. The principles also need to take into account disinvestment in services and how NHS Boards and Voluntary Hospices work together to ensure care remains targeted on mutually agreed priorities.

¹⁴ http://www.forthsectordevelopment.org.uk/publications/Commissioning_Public_Services.pdf

¹⁵ <http://www.healthcareforlondon.nhs.uk/assets/Publications/Consulting-the-Capital/Patient-and-public/HelptheHospices.pdf>

- 3.7 The Care Commission also has a systematic approach to the inspection and regulation of independent hospices in Scotland. It seeks to ensure a high quality of care is delivered and clinical indicators are included in that process. The report *Making The Grade?* showed that the majority of care services in Scotland are providing good quality of care for people who use care services, while only a small minority are performing below acceptable standards¹⁶. The establishment of Healthcare Improvement Scotland will allow a more integrated approach to the development of standards between the NHS and the independent hospices that can only be beneficial.

4 Building A Partnership And Commissioning Framework

- 4.1 A well-defined, agreed and understood commissioning framework is required to ensure value for money and priorities are delivered.
- 4.2 *The Scottish Compact*¹⁷ between the Government, its agencies and the voluntary sector set out the principles to govern the wider relationship between the voluntary sector and statutory sector. The principles of working together are attached to this document and apply to building a commissioning framework. See Appendix 5.
- 4.3 The Social Work Inspection Agency produced *A Guide to Strategic Commissioning* (September 2009)¹⁸ that provides a helpful framework in guiding this work. The guide defines strategic commissioning as:

***'strategic commissioning'** is the term used for all the activities involved in assessing and forecasting needs, agreeing desired outcomes, considering options, planning the nature, range and quality of future services and working in partnership to put these in place.*

¹⁶ http://www.carecommission.com/index.php?option=com_content&task=view&id=7500&Itemid=152

¹⁷ <http://www.scotland.gov.uk/Publications/2004/02/18723/31451>

¹⁸ <http://www.scotland.gov.uk/Resource/Doc/284958/0086536.pdf>

4.4 *The Joint Statement on the Relationship at Local Level Between Government and Third Sector* states: “There is now a widespread understanding that strategic commissioning offers a positive way forward for the assessment of need, design, procurement and monitoring of the effectiveness of services. The approach is inclusive and one that should create an environment where services users, their advocates, service providers and those with a statutory responsibility for service delivery can work together in constructive collaboration. This will be focussed on improving outcomes for service users but will be informed by the need for efficiency and will appreciate the constraints each other faces.....It is vital to recognise that commissioning is not just contracting or purchasing but involves analysing needs on an area basis, and also includes an element of forecasting and ‘horizon scanning’ in order to prepare for anticipated needs. It is only on this basis that individual services should be commissioned. In any area the current mix of services is likely to change over time as a result of the development of a commissioning strategy, and the concept of commissioning will also imply ‘de-commissioning’.”¹⁹

4.5 In building a new partnership relationship between NHS Boards and Voluntary Hospices there is scope to build a more structured approach to commissioning that is informed by:

4.5.1 value for money and efficiency

4.5.2 benchmarking

¹⁹ <http://www.scotland.gov.uk/Resource/Doc/1036/0087048.pdf>

- 4.5.3 quality indicators (such as the Department of Health, End of Life Care Quality Markers)²⁰
- 4.6 In following a structured commissioning cycle [**Recommendation 5.1**] between the NHS Boards and the Voluntary Hospices, it is essential that the approach is proportionate and does not create an additional layer of bureaucracy but is centred on improving care and demonstrating value for money. The commissioning cycle is not about determining *what* NHS Boards should commission in partnership but about setting up a framework to guide *how* NHS Boards should commission services in a systematic and consistent way. Ultimately, agreement should be reached in partnership.
- 4.7 It is obviously essential that such a commissioning cycle addresses in a very explicit way the expectations in HDL (2003) 18 and that there is absolute clarity about how funding is matched by delivery against agreed performance metrics.
- 4.8 The commissioning cycle should draw upon:
- 4.8.1 a common and consistent commissioning template between NHS Boards and the Voluntary Hospices
 - 4.8.2 an explicit statement of commissioning intentions by NHS Boards of what level of service that will be purchased and which fully reflect *Living and Dying Well* Delivery Plans
 - 4.8.3 an “open book” approach between NHS Boards and Voluntary Hospices to expenditure in the Voluntary Hospices
 - 4.8.4 a clear, consistent and detailed definition of agreed running costs

²⁰http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681

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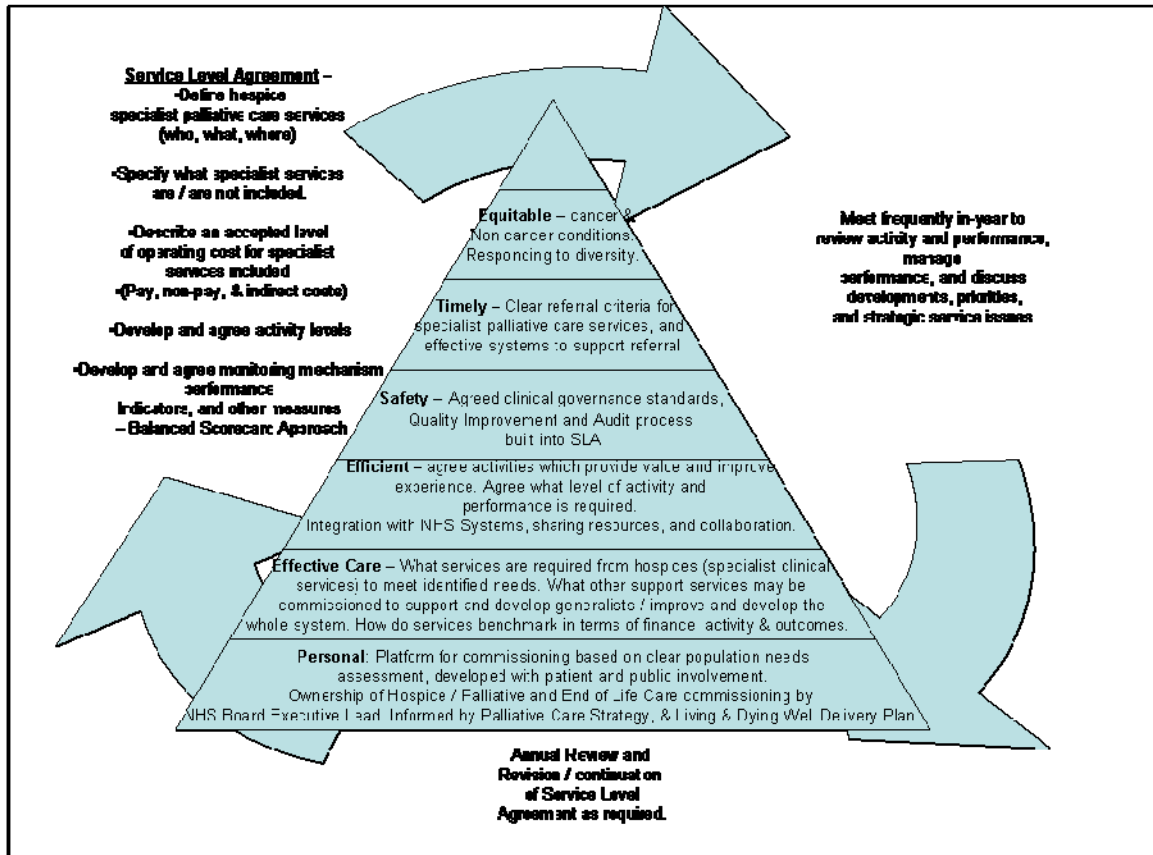
- 4.8.5 a balanced scorecard of performance metrics (quantitative and qualitative) with agreed performance trajectories - measures should be consistent with the NHS Scotland Quality Strategy and forthcoming NQIS standards

 - 4.8.6 a commitment to agree and sign-off Service Level Agreements in a timely fashion, as part of the overall commissioning cycle

 - 4.8.7 a commitment to regular, open dialogue and flow of information between NHS Boards and Voluntary Hospices
- 4.9 The new commissioning cycle, outlined in **Figure 1**, represents a mutual framework for use together by NHS Boards and Independent hospices in Scotland. The framework recognises that effective hospice commissioning requires a number of core dimensions to be developed and put in place in partnership (between hospices and NHS Boards) in each local health and social care system. These dimensions provide the platform for commissioning hospice care, and are outlined in the pyramid in the centre of the diagram. Hospice Service Level Agreements should be developed around these dimensions, clearly responding to identified need and in line with local plans, and should be regularly monitored and reviewed on an annual cycle. This reflects the Institute of Medicine Quality Framework.

Figure 1: A new mutual commissioning framework for hospice care – for use by NHS Boards and Independent Hospices in Scotland

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4.10 Pathways in Palliative and End of Life care are complex, and hospice teams offer the ability not only to provide a direct specialist clinical service but to support the whole system in improving and developing palliative and end of life care wherever it is provided. To maximise the value from commissioning therefore, the process needs to be owned and led by the Board Executive Lead for Palliative and End of Life Care, working in partnership with Executive staff and Trustees of local Independent Hospices. This would assist in building a more consistent on-going relationship between Boards and voluntary hospices that fosters a climate of mutual trust and openness. **[Recommendation 5.2]**

4.11 The Board's Palliative Care Strategy provides the overarching plan for all partners. This, in combination with NHS Board Delivery Plans for Palliative and End of Life Care, outlines the principal aims and objectives that will be supported by hospice commissioned services. Excellent commissioning arrangements will include clear links to wider strategies and programmes such as Long Term

Conditions, Dementia Strategy, Older People's strategies, Mental Health strategies, and Shifting the Balance of Care.

- 4.12 The Scottish Government would have an important role to play in monitoring how each NHS Board adopts a more structured approach.
- 4.13 It is important to emphasise that the commissioning cycle won't on its own deliver improvements – it is a necessary but not a sufficient step forward. Building close working relationships between NHS Board staff and the hospices is essential in creating a climate of mutual respect and understanding. *Help The Hospices* in its evidence to the Public Accounts Committee commented that in England: “the success of relationships between hospices and Primary Care Trusts relies upon effective personal relationships between key players rather than any external guidance.”²¹

Figure 2: Good Practice Example from Ayrshire and Arran

Representatives from NHS Ayrshire & Arran are in attendance at The Ayrshire Hospice Management Council main Board meeting and at the Finance & Staffing, Education and Clinical Governance standing committees of the Hospice. This partnership approach ensures transparent and open activity, quality, governance and financial reporting and monitoring, information sharing and discussion on potential developments. This approach has contributed toward The Ayrshire Hospice and NHS Ayrshire & Arran agreeing a funding framework, achieving 50% of agreed running costs and in the development of an up to date 3 year service level agreement. It has also contributed toward a fully clinically integrated provision of Specialist Palliative Care services across all care settings in Ayrshire & Arran. Representatives from The Ayrshire Hospice have also participated in NHS Ayrshire & Arran's Palliative and End of Life Care Co-ordinating Group, monitoring progress toward achieving the actions of Living and Dying Well.

In response to Living & Dying Well and the challenges of the current economic climate The Ayrshire Hospice has undertaken a strategic organisational review and has benefited from representation from NHS Ayrshire & Arran on their Financial, Education and Clinical

²¹ <http://www.publications.parliament.uk/pa/cm200809/cmselect/cmpubacc/99/8121710.htm>

Excellence Improvement Groups and on the Structure and Relationships Group. This participative process has strengthened the potential for the strategic development of Specialist Palliative Care services to be delivered in partnership across Ayrshire & Arran and the potential for mutual understanding on the demands for funding streams to support the developments.

- 4.14 A balanced scorecard approach that allowed an easier and more consistent flow of information between NHS Boards and hospices would ensure greater transparency as regards value for money and delivery. Such a balanced scorecard would be used to inform performance monitoring [**Recommendation 5.3**].
- 4.15 The survey of balanced score card approaches has been undertaken and the comments on the illustrative balanced scorecard (see Appendix 3) are shown in Appendix 4.
- 4.16 There is a need to consider moving to longer-term relationships between NHS Boards and hospices, with greater certainty re funding streams but also **commensurate explicit and challenging levels of service performance to be achieved**. Some NHS Boards have already introduced 3 year service agreements for agreed services with regular dialogue (such as quarterly meetings) to discuss strategic issues and delivery. NHS Boards and hospices should move to such longer-term service-level agreements and which are clearly linked to agreed outcomes, standards and shared strategic objectives.
- 4.17 Funding of **mutually agreed** specialist palliative care services (eg drawn from the list of core specialist palliative care services in Appendix 6) should be reached by NHS Boards and hospices on a 50% funding basis and over a 3 year basis (see example in **Figure 2**). [**Recommendation 5.4**].
- 4.18 Building a performance scorecard system that is shared and valued will take time. There is merit in considering establishing a national performance forum (which includes NHS Boards and hospices) building on the work that is already being progressed by ISD and to build a suite of measures that are linked to the six dimensions of quality [**Recommendation 5.5**]. Such an approach should not be limited to data for Scotland but approaches taken across the British Isles in measuring efficiency and benchmarking (eg the Findlay Review in Wales).

- 4.19 The inconsistent approach to service level agreement documentation should be addressed with a shift to more consistent documentation across Scotland with supporting balanced scorecard templates **[Recommendation 5.6]**. With regard to this, the work progressed in NHS Ayrshire and Arran NHS Greater Glasgow and Clyde and NHS Lothian (see example in **Figure 3**) should be considered.

Figure 3: Good Practice Example from Lothian

Marie Curie Hospice Edinburgh and Lothian NHS Board

A partnership approach has been developed not only in relation to the planning and development of an Service Level Agreement (SLA) document which specifies the services which are to be funded by the NHS but also in relation to an agreement on a shared vision for specialist services within Lothian.

Using this as a platform hospice service developments have been planned in partnership with NHS Lothian to make sure they fit with the strategic goals of the Board's strategy for palliative care in Lothian. For example:

- The move to increase access to specialist services for patients with a non-malignant disease by developing a model of specialist service provision for patients in Care Homes
- The development of a home based volunteer support service for carers which has reduced carer stress
- Linking CHP NHS specialist community and day services into the management and clinical systems of hospice care to ensure more patients have access to specialist services.

4.20 In delivering greater efficiency, hospices should consider the scope for even greater collaboration in the delivery of shared services and how such collaboration could allow greater pooling of expertise and skills [Recommendation 5.7].

5 Recommendations

5.1 A commissioning cycle should be defined and agreed between NHS Board and independent hospices. Such a cycle should be seen in the context of longer term service level agreements

- 5.2 To maximise the value from commissioning therefore, the process needs to be owned and led by the Board Executive Lead for Palliative and End of Life Care, working in partnership with Executive staff and Trustees of local Independent Hospices. This would assist in building a more consistent on-going relationship between Boards and voluntary hospices that fosters a climate of mutual trust and openness.**
- 5.3 A balanced scorecard approach that allowed an easier and more consistent flow of information between NHS Boards and hospices should be introduced**
- 5.4 NHS Boards and hospices should move to affordable and sustainable 3 year service-level agreements that reflect a commitment to the 50% funding of mutually agreed specialist palliative care services. These should be linked to agreed outcomes, standards and shared strategic objectives.**
- 5.5 A performance forum should be established to build a collection of measures linked to the six dimensions of quality**
- 5.6 Consistent service-level agreement documentation should be introduced building on good practice from elsewhere**
- 5.7 Hospices should advance work to develop more shared services to achieve greater efficiency and pooling of resources**

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APPENDIX 1

Implementation of HDL(2003)18										
NHS Board Funding of Specialist Palliative Care services provided by Scottish adult voluntary hospices for years ending 31 March 2008 and 31 March 2009 (Data Compiled December 2009)										
Data Compiled December 2009	TOTAL running costs for hospice as shown in the Annual Accounts / Statement of Financial Activities for:		Total AGREED costs for hospice with service level agreement with NHS Board(s) at 31 March 2008 and/or 31 March 2009:		Total income received from local NHS Board(s) in:		Percentage of TOTAL running costs NHS Board funding represented in:		Percentage of total AGREED running costs NHS Board funding represented in:	
	2008	2009	2008	2009	2007-2008	2008-2009	2008	2009	2008	2009
Accord (G G & C)	£ 2,075,938	£ 2,427,025	N/A	N/A	£ 958,190	£ 1,044,836	46.16%	43.05%	N/A	N/A
Ardgowan (G G & C)	£ 2,204,717	£ 2,352,588	N/A	N/A	£ 967,030	£ 1,054,622	43.90%	44.80%	N/A	N/A
Bethesda (W I) (1)	£ 464,161	£ 469,765	N/A	N/A	£ 231,840	£ 231,840	50%	49%	N/A	N/A
Highland (H)	£ 3,348,899	£ 3,671,165	£ 2,469,610	£ 2,642,850	£ 1,145,944	£ 1,276,077	34.22%	34.76%	46.40%	48.28
Marie Curie Fairmile (Lo)	£ 3,759,172	£ 3,869,945	N/A	N/A	£ 1,440,930	£ 1,440,999	38.33%	37.24%	N/A	N/A
Marie Curie Hunters Hill (G G & C)	£ 4,286,919	£ 4,364,645	N/A	N/A	£ 1,815,997	£ 1,887,820	42.36%	43.25%	N/A	N/A
Prince & Princess of Wales (G G & C) (2)	£ 3,396,050	£ 3,664,314	N/A	N/A	£ 1,399,800	£ 1,470,964	41.20%	40.10%	N/A	N/A
St Andrews (Lan) (3)	£ 4,378,288	£ 4,923,279	£ 3,773,785	£ 3,905,867	£ 1,713,361	£ 1,773,501	39.10%	36%	45.40%	45.40
St Columbas (Lo)	£ 5,834,384	£ 5,850,648	N/A	N/A	£ 2,445,440	£ 2,434,991	41.90%	41.60%	N/A	N/A
St Margarets (G G & C)	£ 1,943,624	£ 2,598,530	N/A	N/A	£ 938,040	£ 986,158	48.26%	37.95%	N/A	N/A
St Vincents (G G & C) (4)	£ 1,584,141	£ 1,698,345	N/A	£ 1,691,700	£ 826,121	£ 858,572	52%	50.70%	N/A	49.80
Strathcarron (FV & Lan)	£ 4,291,369	£ 4,865,455	£ 4,175,427	£ 4,282,489	£ 1,761,808	£ 1,934,511	41.00%	39.70%	42.20%	45
The Ayrshire (A & A)	£ 5,111,113	£ 5,589,878	£ 4,159,634	£ 4,482,088	£ 2,052,924	£ 2,217,591	40.20%	39.70%	49.40%	49.50
Average Percentage							42.97%	41.37%	45.85%	47.60

*** Footnote**

(1) **Bethesda Hospice**
 • Still being covered by locum doctors and this is reflected in the increased costs. Have not had an increase in the general running costs for three years. Although the health board have continued to fund 50% of costs, they do not have an SLA in place.

(2) **Prince & Princess of Wales Hospice**
 • These costs include the direct costs of their lottery (£321,422 – 2009, £299,179 – 2008) (45.2% -2008, 44% - 2009) which they would not expect NHS to fund. They also include other costs which they know that NHS are unlikely to fund.

(3) **St Andrew's Hospice**
 • NHS L pay their three consultants directly. If this was regarded as income and expenditure for them, the percentage of total costs would be 44.8% for 2008 and 41.4% for 2009, the percentage of agreed costs would be 51.2% for 2008 and 49.2% for 2009.
 • There are £600,000 fundraising costs included in total running costs for 2008 and £750K for 2009 for which they do not expect any contribution from NHS L. These are adventure trips, lottery, annual ball etc.

(4) **St Vincent's Hospice**
 • Although SLA not in place yet, work is progressing on that, the letter regarding funding was named 2008/09 Service Agreement.
 • Increased % due to extra projected funding for new posts

2.

3.

4. St Christopher's Hospice

Balanced Scorecard

Barbara Monroe, Chief Executive and Andrew Meadows, Finance Director

St Christopher's introduced a Balanced Scorecard about five years ago in response to a request from Trustees for a report that captured some of the most important performance indicators that the hospice uses to measure and monitor its own performance. The Balanced Scorecard is a business management system developed in the 1990s in the commercial sector to provide businesses with a way of clarifying strategy and translating it into action. It suggests that the organisation should be viewed from the perspectives of learning and growth, business processes, customers and finances, understanding that each of these perspectives is inter-linked and that a successful organisation needs to be effective in all the areas. Each perspective has an associated set of objectives with related systems for tracking and feeding back progress against key process outputs and outcomes.

The St Christopher's scorecard has four main themes:

1. Activity of the hospice
2. Quality of service
3. Finance and
4. Personnel

The scorecard is prepared every six months and the data is reported on a rolling two-year basis to give an indication of the relative performance compared with the previous year. The illustration shows a blank pro-forma.

4.1 Activity of the Hospice covers percentage occupancy of the Inpatient unit beds, caseload of the Homecare (i.e. average daily number of patients) and

Inpatient unit (i.e. total number of admissions in the six month period) teams, and new referrals for both the Homecare and Inpatient unit.

4.1.1 Quality of service measures the hospices' effectiveness in delivering service and attempts to give a customer perspective of the service provision. It also measures the error rate in drug administration, which is a key Department of Health (DoH) statistic.

Customer satisfaction is measured by recording the number of complaints received, both oral and written, and by the use of patient feedback from questionnaires for both the Inpatient unit and Homecare departments.

The key financial measures are surplus/deficit for the period; the level of cash over and above the Charity Commission minimum recommendation of six months' operating costs, and the value of legacies notified, which is a key barometer of financial performance in St Christopher's.

Personnel measures include headcount (actual v budget), staff sickness and turnover (annualised) and the total number of St Christopher's staff training/development days in the six months period.

It should be emphasised that the hospice has many other performance measures and prepares separate reports for the Health Care Commission and for PCTs broken down into individual components for monitoring against individual Service Level Agreements. The scorecard is intended to provide a regular snapshot of selected and relatively easy to measure indicators. It is deliberately designed as a single sheet document. The measures used are intended to be specific, yet general enough not to require too much background interrogation. One of the scorecard's strengths has been that it has been made available, not only to Trustees, but also to all staff and volunteers through our regular team briefing system. Everyone has a chance to ask questions and everyone has a regular and transparent perspective on finances, activity and some quality measures.

Recently Help the Hospices held two teleconferences on the use of scorecards and their future potential as a wider benchmarking tool. A small number of hospices are already using their own version, or one adapted from that used at St. Christopher's. Suggestions for additional measures include fundraising return on investment and some measure around volunteering, perhaps number of vacancies.

ACTIVITY				QUALITY		
IPU	Goal	Actual			Goal	Actual
Occupancy	80%			Medicine incidents		
Avg Length of stay (days)	15			Patient falls		
	Y-T-D	Y-T-D	Current Month	No. Of Complaints Oral		
	Previous	Current		No. Of Complaints Written		
New admissions				Patient Accidents/Incidents		
Re-admissions				Staff Accidents/Incidents		
Total admissions				Audits undertaken		
Referrals - malignant				Research		
Referrals - Non malignant				Policy development		
ACNS				Patient Feedback/surveys		
New patients				Professional feedback		
Total Caseload	N/A	N/A		Care Commission inspection		
Telephone Calls				Clinical audit against standards (eg contact time from referral)		
Visits						
LYMPHOEDEMA						
New patients						
Total patients						
Total contacts						
BEREAVEMENT						
New clients						
Total clients						
Total contacts						
FAMILY SUPPORT SERVICE						
AHP						
INFORMATION AND SUPPORT - No of patients seen						
Drop-In						
Comp. Therapy						
Classes						
Psychological Support						
DAY HOSPICE	Capacity	Attendance Planned	Actual	%		
Total no of patient days						
Outpatient Service						
Medical						
Professional						
Hospital Service						
No of referrals						
No of patient contacts						
Domicillary						
Medical						
Other Professional						
No of patient contacts						
Telephone Advice		No of calls				
Patient						
Carer						
Professional						
FINANCIAL				H. R.		
Current Month	Over	Under	Forecast		Budget	Actual
Cost to Budget				Headcount		
Income to Budget				Posts 50% funded		
	Surplus				Goal	Actual
	Defecit			Sickness	4%	
				Attrition	5%	
				External training hours		
	Goal	Actual		Employee Training Days	20	
Free reserves (minimum)				Appraisals Outstanding	0	
				Volunteer Vacancies	0	
				Volunteer hours		
	Budget	Actual		Vacancies over 3 months		
Value of Legacies Notified				Policy Reviews Outstanding	0	
				Disciplinary investigations		
Current Bank Balance				Grievances		
				Maternity leave over 3 months		
				Sickness over 3 months		

HDL 2003 (18) Working group:

Development of Adult Voluntary Hospices Commissioning Framework in Scotland

Contributions towards a comprehensive Balanced Scorecard reporting tool received from six Scottish Hospices

ACTIVITY

Activity information is also required for

1. Bereavement service-number of new clients/total number of clients/total number of contacts
2. Lymphoedema
3. Family support service (St Vincent's Hospice)
4. Chaplaincy
5. AHPs
6. Referrals to a particular service distinguished by malignant referrals/non malignant referrals
7. In Patient admissions-malignant and non-malignant/new and re-admissions
8. Day hospice admissions-malignant and non-malignant/total number of patient days
9. Out patients-medical and other professional/malignant and non malignant
10. Hospital service-number of referrals/number of patient contacts
11. Domiciliary-medical and other professional/number of patient contacts
12. Telephone advice-number of calls/list by patient, carer or professional (Highland Hospice)

General comments regarding **activity reporting**

Agreement required regarding

- identification of services eg are the bereavement and lymphoedema services stand alone services or should they be reported as out patient services (Marie Curie Edinburgh)
- the unit of activity eg number of referrals/number of patients/OBD

- efficiency measures eg occupancy/length of stay/length of time on caseload/re-admission rates
- demographic details eg diagnosis/age/ethnicity
- nationally agreed goal for In Patient activity
- definitions and terminology need to be agreed to ensure like for like comparison and linked to number of beds or WTE of staff members delivering the serv. This needs to be in line with Service Level Agreements, when agreed and in place (ACCORD Hospice)

QUALITY

Quality information is also required for

1. Audits undertaken
2. Patient falls
3. Research (Marie Curie Edinburgh)
4. Policy development (Marie Curie Edinburgh)
5. Latest Care commission inspection date-announced or unannounced/grades achieved
6. Clinical audit performance against standards eg contact time from referral (NHS QIS standards)
7. MRSA monitoring and clinical risk management (Ayrshire Hospice)
8. Record of audits/evaluations/surveys with feedback from patients, relatives, staff or referrers (ACCORD Hospice)

General comments regarding quality reporting

- Accident/incident information could be made more meaningful if presented as a % of occupancy (for patients) or % WTE(for staff/volunteers). Core principles for capturing this data would also need to be agreed i.e does the info include near misses/omissions etc. (Ayrshire Hospice)
- Measures should be objective eg evidence of meeting QIS standards eg 100% met /80% met (Marie Curie Edinburgh)
- We would see this being around audit of emerging trends, if any, in relation to incidents and accidents as opposed to numbers, to have a goal of zero is not realistic in some of these categories. All of this is currently reported on via Annual Clinical Governance report to the Health Board and Annual return to the Care commission, so some discussion around rationalisation of reporting is also required. (ACCORD Hospice)

FINANCE

Finance information is also required for

1. Forecast added to income and expenditure
2. Amount of free reserves and minimum solvency level
3. Agreed costs (Highland Health Board)
4. Actual costs

Agreement required regarding

- unit costs eg cost per bed day etc
- all budget included or just HDL relevant costs/income
- inclusion of all major and restricted donations
- inclusion of cost efficiencies/cost pressures
- separation of staff costs and running costs (all comments Marie Curie Edinburgh)
 - monthly and year to date P&L surplus and deficit

General comments regarding **finance reporting**

The GG+C financial framework delivers more information and we would not be keen to duplicate or have to produce information in yet another form. We have already submitted our first quarter to 30th June 2009 to the Health Board and will continue to do so quarterly. (ACCORD Hospice)

HR

HR information is also required for

1. Number of volunteer hours
2. External training hours delivered-higher education/study days and short courses/student numbers (medical, nursing and other)
3. Disciplinary investigations/grievances
4. Workforce planning (Ayrshire Hospice)
5. Vacancies over 3 months
6. Sick leave/Mat leave over 3 months (this would save variations of short term absence and give a clearer picture of problem areas where service provision might be affected)
7. Posts-50% funded by HB/100% funded by HB/100% funded by hospice (ACCORD Hospice)

General comments regarding HR reporting

- Not sure about including appraisals, training days or policy reviews. I realise they are important for us and why they might be included in internal documents but not for the NHS. (Highland Hospice)
- Medicine incident rate (number per month) could be problematic if comparing across hospices as there may be different reporting mechanisms, policies and definitions. (Highland Hospice)
- ? relevance of reporting on outstanding appraisals and policy review at HB level. (ACCORD Hospice)

General comments

If the purpose is to inform the Health boards what they are receiving for their funding and to ensure the charity is an ongoing viable organisation then the existing reporting and financial framework requested by GG+C HB would appear to cover all these points. The service level agreement details the services agreed to be delivered and the financial framework highlights the staffing and associated costs. (ACCORD Hospice)

Dorothy McElroy

Chief Executive Ardgowan Hospice

October 2009

The Scottish Compact

THE COMPACT BETWEEN THE SCOTTISH EXECUTIVE, ITS AGENCIES, NDPBS AND THE VOLUNTARY SECTOR IN SCOTLAND

UNDERLYING PRINCIPLES FOR WORKING TOGETHER

Aim of the Compact

The Compact is an agreement between the Scottish Executive, its Agencies and Non-Departmental Public Bodies (NDPBs) (referred to collectively as the 'Executive' throughout this document) and the voluntary sector on the principles of working in partnership. It is based on a mutual understanding of the distinctive values and roles of the Executive and the voluntary sector. Its aim is to develop robust relationships for the wider public good.

The Compact acknowledges that the voluntary sector and the Executive have their own spheres of action with different roles, responsibilities and resources. It is accepted that not all voluntary organisations will have an interest in seeking partnership with the Executive. Some will prefer to pursue their own objectives without reference to the state. Others may find themselves more often in opposition to the Executive than in partnership. But for the growing number of cases where partnership is sought by both the Executive and the voluntary sector, the Compact describes agreed principles for working together effectively.

Implementation of the Compact is a key role for intermediary voluntary organisations, whose purpose is to represent and support other voluntary organisations in a particular area or field of activity. Intermediaries include some bodies with a national remit, local councils for voluntary service, specialist 'umbrella' organisations, and many forums and alliances.

Remit of the Compact

The Scottish Compact is one of four Compacts providing a framework for national Government/voluntary sector relationships across the UK. Although the Scottish Compact applies specifically to Scotland, it is expected that relationships between UK voluntary organisations and the Scottish Executive, and between Scottish voluntary organisations and the wider UK government, will also embrace Compact principles.

The Scottish Compact sets out the high level principles that we are seeking to achieve in our relationship between the Executive and the voluntary sector. This latest version of the Compact has been updated to reflect renewed commitment to achieving an open and participative working relationship between the Executive and the voluntary sector in Scotland. The Compact commitments have also been

strengthened for all parties to demonstrate the current climate since devolution. The Scottish Compact Good Practice Guides, set out the detail on how we can work together to develop our relationships. These, and other relevant publications, can be accessed at both the SCVO and the Scottish Executive Voluntary Issues Unit, and can be accessed through their relevant websites ([≡](#) and www.scotland.gov.uk/viu).

The formal Compact documentation is supported by the work of the Scottish Executive/Voluntary Sector Forum and the Scottish Compact Implementation Strategy (2003). The Scottish Compact Implementation Strategy reflects the following key themes: strategic aims and vision; leadership; mainstreaming; raising awareness and promoting best practice; communication; and resources. Monitoring and evaluation issues are also covered.

The Scottish Parliament

The Scottish Executive cannot make commitments on behalf of the Scottish Parliament but it is hoped that they will endorse this updated Compact or draw on the work done to develop their own agreement.

Benefits of the Compact

The Compact will deliver benefits by:

- strengthening the relationship between the Executive and the voluntary sector;
- extending opportunities for the voluntary sector's members, supporters and users to contribute their experience and ideas to the development and implementation of public policy;
- making the policies and practice developed by the Scottish Executive, its Agencies and NDPBs, including NHS Boards, more responsive to the potential and needs of the voluntary sector;
- enabling voluntary organisations to communicate more effectively to the Executive, the needs of their users and wider constituencies;
- extending the opportunities to mobilise the voluntary sector behind Executive programmes when these coincide with the objectives of voluntary organisations;
- increasing understanding of how the Executive and the voluntary sector work;
- generating evidence and information on the value and impact of the work of the Executive and of the voluntary sector; and
- informing longer-term planning and strategic thinking.

Shared Values

The Executive and the voluntary sector in Scotland share a commitment to basic values including:

- A **democratic society** that acknowledges the value of voluntary sector activity and upholds the right of individuals to associate freely with one another in pursuit of a common purpose within the law.
- **Active citizenship** involving the widest possible participation by people in the lives of their national and local communities.
- **Pluralism**, which welcomes the diversity of identities and interests within Scotland, including minority groups such as ethnic minorities and disabled people, and upholds the right of each interest to speak on its own behalf.

- **Human rights** to promote us in a sense of strong community and to encourage respect for each other as both individuals and as members of a community with common values.
- **Equality of opportunity**, which maximises the opportunities for all people to contribute from their distinctive traditions, religions, cultures, values and abilities to the shared life of the wider community, as well as their own particular communities of need and interest. This includes opposing all forms of discrimination and promoting participation and inclusion. Equality of opportunity also encompasses the principle of fair access to the shared life of the wider community and to the public services provided.
- **Quality services**, which provide the highest achievable standards.
- **Cross-sectoral working** to promote effective cross-sectoral and cross-agency collaboration to respond to the complex needs of society, which often cannot be compartmentalised.
- **Sustainable development** that meets the needs of the present without compromising the ability of future generations to meet their own needs.

Scottish Executive Commitments Recognition

In working with voluntary organisations, volunteers and community development groups, the Executive will:

- acknowledge the value of the contribution which the voluntary sector makes to the social, economic, environmental and cultural life of Scotland;
- recognise and support the sector's independence, including its right to comment on and challenge Executive policy;
- recognise volunteering as an important part of citizenship and support volunteering initiatives as a means of extending people's participation in their community;
- recognise the importance of community action as a form of active citizenship and as contributing towards economic development;
- take positive steps to involve in the partnership, groups which face difficulties in making their voices heard; and
- promote an understanding of the value of voluntary sector activity to all public sector bodies and stakeholders.

Voluntary Sector Commitments Recognition

In working with the Executive, the sector undertakes to:

- acknowledge that the Executive works within a statutory framework laid down by the Scottish Parliament, to which it is accountable for its policy towards the voluntary sector;
- acknowledge the Executive's public accountability for the resources it provides to

voluntary organisations;

- recognise that the Executive, like all other agencies, acts within constraints;
- meet with the Executive to discuss issues of mutual interest;
- take positive steps to involve in the partnership, groups which face difficulties in making their voices heard; and
- promote an understanding of the value of voluntary sector activity to all public sector bodies and stakeholders.

Scottish Executive Commitments Representation

The Executive acknowledges its obligation to facilitate access for the voluntary sector to its processes. The Executive will:

- clearly state Executive objectives and priorities;
- ensure clear and accessible channels of communication;
- provide access and support, including the provision of information, to enable voluntary organisations to contribute to the policy development process;
- ensure all national infrastructure voluntary organisations are routinely informed of NDPB appointment vacancies that fall within the remit of the Commissioner for Public Appointments, including NHS bodies;
- ensure nominations are sought through open and transparent mechanisms from voluntary sector interests as appropriate for public boards, agencies, collaborative working groups and service user groups;
- consult as appropriate in a flexible and open way, communicate clearly using appropriate media and ensure feedback is provided to all respoondees and consultees; and
- consult fully and to a stated timetable, jointly agreed where possible.

Voluntary Sector Commitments Representation

No single body or group of bodies can represent the complete range of interests that the voluntary sector pursues with the Executive. However, where there are recognised representative lead bodies, these bodies commit themselves to:

- ensure clear and accessible channels of communication to the sector;
- represent accurately and honestly the views of their sectoral constituencies;
- publicise NDPB appointment vacancies as appropriate to relevant voluntary organisations;
- promote collaborative working between voluntary sector partners;
- promote the development of the voluntary sector infrastructure to allow particular interests and groups to develop and communicate their views to the Executive and other interests;
- demonstrate how they consult their members and supporters and are accountable to

them;

- contribute as appropriate to consultation and policy development exercises; and
- consult fully and to timetables agreed with the Executive.

Scottish Executive Commitments Partnership

In encouraging good practice and co-operative methods of decision-making, the Executive undertakes to:

- work collaboratively with the sector to develop policy and practice;
- promote effective dialogue, using an appropriate format and the efficient use of time;
- work with the sector on issues of concern to either party in the spirit of openness and partnership;
- recognise the role which intermediary bodies have in representing the views of their constituents without prejudice to the right of individual organisations to represent their own views;
- ensure that, in the process of policy-making, the impact of changes in policy and procedure on the sector and on volunteering and community groups are considered and taken fully into account (a process known as 'proofing');
- assume that information is not confidential unless otherwise stated; and
- be aware of the resource constraints on voluntary sector participation in partnerships.

Voluntary Sector Commitments Partnership

In working with the Executive, its Agencies, NDPBs and with other sectors, the voluntary sector undertakes to:

- promote the value of collaborative working with the public sector in the best interest of its members, users and the wider public;
- ensure that the full range of voluntary organisations and interests is, as far as possible, informed of, and represented in, collaborative working to develop policy and practice and to promote effective dialogue;
- work with the Executive on issues of concern to either party in the spirit of openness and partnership;
- ensure that representatives at partnership meetings are properly briefed and supported; and
- respect any agreed commitments to the confidentiality of Executive information.

**Scottish Executive
Commitments
Resources**

The Executive will pursue its interest in promoting a healthy voluntary sector through public funding based on clear measures of performance. It will:

- apply best practice in funding and in the administration of grants consistently, including prompt payment of agreed funds;
- recognise the need for full cost recovery in bids for service contracts;
- follow best practice in monitoring publicly funded work, and apply and promote Best Value processes in ways which secure equality of treatment for voluntary organisations;
- support, as appropriate, intermediary bodies and the infrastructure across the sector;
- target resources, including non-financial resources, effectively and in a way which takes account of changing needs;
- proof documents in order that potential impact on the voluntary sector is considered routinely as part of policy development; and
- respect the confidentiality of commercially sensitive information.

**Voluntary Sector
Commitments
Resources**

In using public resources, the sector undertakes to:

- champion the importance of good management of financial and non-financial resources and promote good management practice, including fulfilling conditions of funding;
- strive to secure Best Value for its declared objectives from the resources it uses, and apply and promote Best Value processes in ways which secure equality of treatment for voluntary organisations;
- maintain agreed monitoring, performance evaluation and report-back systems to secure effectiveness in the use of resources; and
- recognise that public resources are limited and that public funding is provided on the basis of value for money and its contribution to policy priorities.

**Scottish Executive
Commitments
Implementation**

In endorsing this Compact, the Scottish Executive, with the backing of Ministers and through the leadership of the Voluntary Issues Unit and the Departments having lead roles with the voluntary sector, undertake to:

- put in place effective and flexible arrangements to implement the Compact;
- establish a framework to monitor and evaluate its operations jointly with the sector;

- put in place mechanisms to facilitate cross-departmental working and the mainstreaming of Compact principles;
- ensure that there continues to be a dedicated Unit within the Scottish Executive to promote voluntary sector interests;
- promote the spirit and principles of the Compact throughout the Scottish Executive, its Agencies and NDPBs and to other public bodies, including local authorities and CoSLA;
- ensure all Scottish Executive Departments, NDPBs and Agencies have responsibility for their relations with the voluntary sector and to implement, review, monitor and evaluate implementation of the Compact; and
- report regularly on progress in implementing the Compact to the Scottish Executive/ Voluntary Sector Forum and the Scottish Parliament.

Voluntary Sector Commitments Implementation

By endorsing this Compact, the lead representative bodies of voluntary organisations, volunteering activities and community development groups undertake to:

- publicise to the sector the principles and understandings embodied in the Compact;
- promote and champion practices which are consistent with the Compact to voluntary organisations, volunteering activities and to community development groups;
- promote the spirit and principles of the Compact to all public bodies, including local authorities and CoSLA;
- ensure implementation of the Compact is a core function of national infrastructure and intermediary voluntary organisations;
- establish a framework to monitor and evaluate its operations jointly with the Executive;
- put in place systems to monitor the implementation and operation of the Compact throughout the voluntary sector; and
- report regularly on progress in implementing the Compact to the Scottish Executive/ Voluntary Sector Forum and the Scottish Parliament.

Specialist Palliative Care

Specialist Palliative Care is the active total care of patients with progressive, advanced disease and their families. Care is provided by a multi-professional team who have undergone recognised specialist palliative care training. The aim of the care is to provide physical, psychological, social and spiritual support, and it will involve practitioners with a broad mix of skills. (Tebbit, 1999)

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

These teams work in partnership with those who provide generalist palliative care, to ensure that patients' and families' complex needs are met.

Complex needs are identified as needs that cannot be addressed through simple or routine interventions/care.

Specialist Palliative Care seeks to:

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

A number of essential components make up a specialist palliative care service. These include:

- effective communication
- symptom control

- rehabilitation
- education and training
- research and audit
- continuity of care
- terminal care
- bereavement support

The core clinical specialist palliative care services comprise:

- **In-Patient care** facilities for the purposes of symptom management, rehabilitation and terminal care
- **24 hour access** to the In- Patient service which includes specialist medical and adequate specialist nursing cover
- **24 hour telephone advice service** for healthcare professionals
- **24 hour telephone support service** for known out-patients and their carers
- **Day services** provided by an out-patient model or day hospice model where patients attend for a determined part of the day (eg. from 11-3)
- **Education programme**
- **Research and audit** undertaken within a framework of clinical governance
- Formalised arrangements for specialist **input to local and community hospitals**

Key Elements of Specialist Palliative Care within a Specialist Palliative Care Unit

The core team comprises dedicated sessional input from

- Chaplain
- Doctors
- Nurses
- Occupational therapist
- Pharmacist
- Physiotherapist
- Social worker

The range of integrated service components which can meet patients' needs at different stages of the disease process will include written referral guidelines to;

- Bereavement services
- Community specialist palliative care services
- Complementary therapies
- Counselling services
- Day services
- Hospital specialist palliative care services

- Lymphoedema services
- Patient transport services
- Psychological support services
- Social services
- Spiritual support services

Clinical Standards Board for Scotland (2002) Clinical Standards Specialist Palliative Care
NHS Scotland

In addition to referring onto these services externally, many Scottish Hospices provide them as part of the holistic range of integrated care and services.

Increasingly this includes services which assist with people's information and education needs (patients and carers) and also working with community groups to develop a shared understanding of care, loss death and dying.

MEMBERSHIP OF REVIEW GROUP

Robbie Pearson, Co-Chair of the *Living & Dying Well* National Advisory Group (Chair)

Aileen Anderson, Ayrshire Hospice

Michael Cook, NHS Western Isles

Anne Harkness, NHS Greater Glasgow & Clyde

Mark Hazelwood, Scottish Partnership for Palliative Care (from 1 January 2010)

Dorothy McElroy, Ardgowan Hospice, Greenock

Maria McGill, Highland Hospice

Edward McGuigan, St Margaret of Scotland Hospice, Glasgow

Irene McKie, Strathcarron Hospice

Peter McLoughlin, NHS Lothian

Heidi May, NHS Highland

George Robertson, NHS Ayrshire and Arran

Geoff Sage, NHS Lanarkshire (to 31 January 2010)

Carole Sommerville, Bethesda Hospice

Pat Wallace, Scottish Partnership for Palliative Care (to 31 December 2009)

Anne Willis, Marie Curie Hospice, Edinburgh

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Mark Aggleton, Scottish Government Health Directorates