Grasping the nettle

What action can we take to improve palliative and end of life care in Scotland?

November 2015

Scottish
Partnership
for Palliative Care

Contents

Executive summary

Purpose

This position paper has been developed by the Scottish Partnership for Palliative Care (SPPC) to:

- articulate the views and expertise of SPPC member organisations and other SPPC stakeholders;
- support, enrich and inform the development of the forthcoming Scottish Government Strategic Framework for Action on Palliative and End of Life Care (SFA).

This work has been led by a multi-disciplinary subgroup of the SPPC Council and developed in consultation with SPPC members and other relevant stakeholders (see Appendix 1).

This document does not provide exhaustive references in support of its assertions. SPPC has used its extensive expert networks to inform reasonable judgements and estimates about the current state of palliative and end of life care in Scotland and about priorities for future action. SPPC is happy to provide references in relation to specific content, on request.

Structure

This paper:

- explores what people need when faced with the reality of deteriorating health and death, bearing in mind that these experiences are influenced by many factors outside formal service provision;
- explores and clarifies terminology;
- sets out a vision for a Scotland where people's wellbeing is supported even as their health declines;
- outlines the current landscape relating to palliative and end of life care, including policy, barriers, and key issues;
- describes how a Strategic Framework for Action can add value, sets out 4 outcomes it should work towards, and 15 key challenges that need to be addressed in order to achieve these outcomes;
- proposes a number of practical actions that should be undertaken in the next five years to improve people's experiences of death, dying and bereavement in Scotland.

Summary

Our vision is that Scotland will be a place where:

- people's wellbeing is supported even as their health declines;
- people die well;
- people are supported throughout bereavement.

Though in recent years there have been many improvements in palliative and end of life care in Scotland, there is not a reliable response to everyone's individual needs. There are a number of barriers (see section 4.2) and

challenges (see section 5) to improving palliative and end of life care in Scotland.

A key issue is inequalities - the type of condition someone has significantly influences where they are cared for, their referral pathways, who funds their support and accommodation, and therefore overall, the support they can access.

There is also a need for more awareness that most palliative care is provided out with specialist palliative care services, and that wider health and social care services can continue to make a significant difference to a person's wellbeing even when a 'cure' is impossible or unlikely, when health is deteriorating, and during the last months, weeks, days and hours of a person's life.

Improving palliative and end of life care is not just about improving formal services – we all need to take responsibility. There is the need for a culture shift across society, so that Scotland becomes a place where people can support each other, and be open and honest about death and dying and the uncertainties involved. Though there are clear advantages to focussing on the concept of 'healthy ageing' and promoting independence, this current policy narrative needs to be balanced with one which acknowledges the many individuals and families struggling each day with deteriorating physical and mental capacities.

The Strategic Framework for Action should therefore work towards achieving the following four outcomes:

- People receive health and social care which supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death. Each individual's care may look very different.
- People have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurs, and be supported to retain autonomy for as long as is possible.
- People know how to help and support each other at times of increased health need and in bereavement, and recognise the importance of families and communities working alongside formal services.
- Cultures, resources, systems and processes within health and social care empower staff to exercise their skills in providing good care for people and families, and to care about the people and families they work with.

Section 6 of this paper sets out specific actions relating to these key outcomes, under the themes of Leadership; Public Health approaches to palliative care; Education/ Training; Measurement; Change and Improvement. Taken together we believe the actions create the necessary conditions for change, describe specific changes required and specify a broad framework of accountability.

Small scale, locally led improvement work has an important role to play in improving systems and services. However, this paper also highlights that many challenges require a combination of local actions and system-wide change, with practical leadership and co-ordination across Scotland.

Though not addressed in detail within this report, it is also important to note that wider systemic issues impact on the quality of palliative care which people experience – most palliative care is provided within generalist settings of the

health and social care system, which are currently under significant pressure. We would support the growing recognition that substantial changes are required to create a health and social care system that is sustainable.

The Scottish Government recently announced that £3.5 million is being invested over the next 3.5 years to support improvements to palliative and end of life care. In this time, it is estimated that approximately 135,000 people will have died with palliative care needs of some kind[1]. As the actions identified in this paper make clear the scale of change required is large, and the necessary careful decision making about new investment should fully involve those who will be implementing that change.

Diagram 1: Illustrating how this paper links actions to the vision via outcomes

A VISION p.10

VISION

4 KEY OUTCOMES p.15

A SET OF ACTIONS p.23 - 34

Leadership | Public Health Approaches to Palliative Care | Education/ Training | Measurement | Change and Improvement

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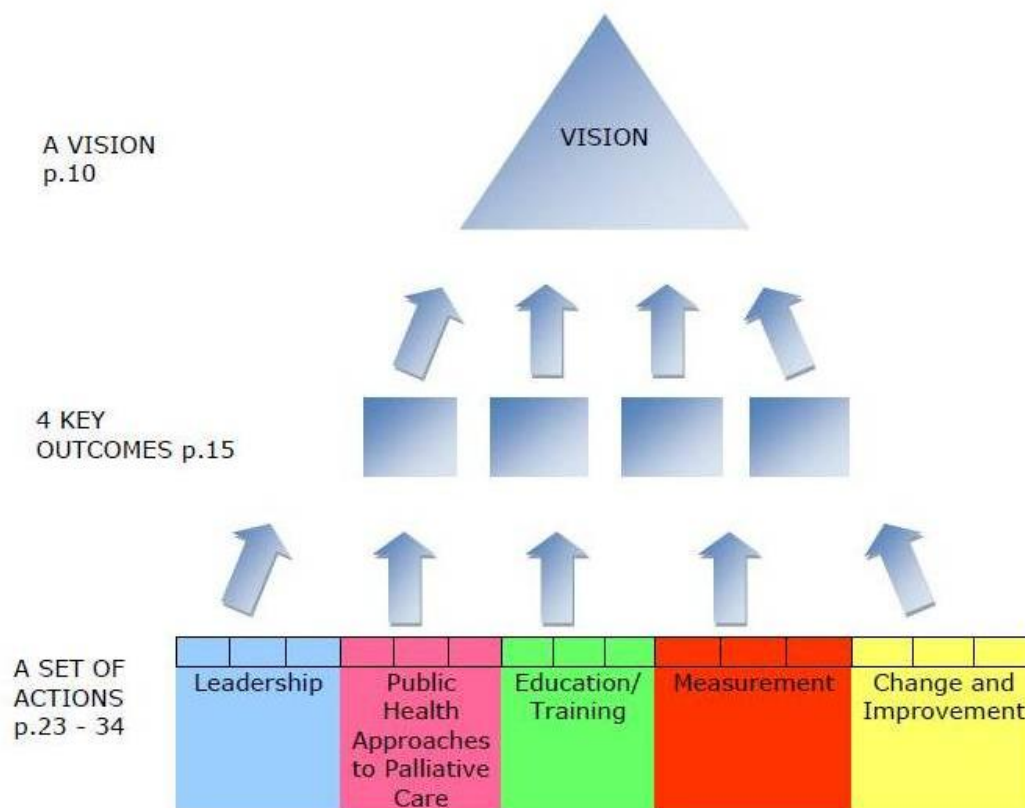
[1] This estimate is based on 55,000 people dying each year for the next 3.5 years, 70% of whom will have palliative care needs. The 70% estimate is drawn from the *Palliative Care Funding Review* which contains a detailed exploration of the factors for consideration when estimating how many people needed palliative care, and estimates that 70-80% of deaths are likely to need palliative care input: (see chapter 6)
Hughes-Hallet T, Craft A, Davies C, Mackay I, Nielsson T. *Palliative Care Funding Review: Funding the Right Care and Support for Everyone.* 2011

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215107/dh_133105.pdf

1. Purpose of the Strategic Framework for Action

1.1 Who is the Strategic Framework for Action for?

Undertaking the tasks required to improve palliative and end of life care in Scotland will require the participation of a great diversity of organisations and individuals. Responsibility for improving how people in Scotland live with advanced illness and how they experience death, dying and bereavement extends far beyond any single specialty or profession. People receive support from a wide range of health and social care services, and much care is provided informally, by family, friends and communities. Social and cultural factors also have a huge influence on people's experiences.

The Strategic Framework for Action should therefore be aimed towards, be read and implemented by, NHS Boards, Local Authorities, Health and Social Care Partnerships (including localities), hospices, other third sector organisations (eg Marie Curie, Macmillan Cancer Support, MND Scotland, British Heart Foundation, Parkinson's UK, etc), Healthcare Improvement Scotland (HIS), Care Inspectorate (CI), General Medical Council, Nursing and Midwifery Council, NHS Health Scotland, independent sector organisations, Scottish Care, Scottish Social Services Council (SSSC), other professional bodies and colleges, NHS Education Scotland and other education providers, and all relevant Scottish Government directorates including Health and Social Care, Communities, and Learning and Justice.

1.2 What is the Strategic Framework for Action for?

The Strategic Framework for Action should:

- facilitate improved palliative care and end of life care for all who need it, including adults, children and babies, with any advanced illness;
- highlight key issues which need to be addressed and set out how this will be done;
- provide a framework to prioritise activity and the use of scarce resources;
- provide terminological clarity around palliative care and end of life care;
- engage the public, professionals and organisations listed in section 1.1 in the important tasks of improving palliative and end of life care;
- guide the alignment and articulate the relevance of the work of these multiple and disparate organisations;
- prompt, guide and focus organisational change and development relating to palliative and end of life care;
- prompt and guide local improvement activity relating to palliative and end of life care, to retain focus on care, services and actions that are related to need;
- provide a broad framework of accountability to the Scottish public through appropriate reporting;
- demonstrate how improving palliative and end of life care is important and relevant to wider change programmes within health and social care and associated Scottish Government national outcomes, for example by making links to the outcomes for Integrated Joint Boards.

The Strategic Framework for Action is an opportunity to address the *3-Step Improvement Framework for Scotland's Public Services'* seven points 'to change the world' in one document, providing both a clear framework for improvement and a strategy to engage and empower the workforce.

2. Palliative Care

2.1 Palliative care: What matters to me?

When faced with the reality of deteriorating health and death, people need many things from the NHS and social care services, other formal services, and from their friends, families and communities.

What a person needs depends on their personal circumstances and what is important to them. For many of us, our needs will include:

- relief from distressing symptoms;
- reliable and consistent access to support and advice from healthcare and social care professionals who are compassionate, knowledgeable and competent;
- information about what is happening, what is likely to happen next, the uncertainties that might be involved, and ideas of some ways of responding;
- empathy and support in adjusting to coping with uncertainty and deteriorating health;
- support to get the most out of limited time left with the people we care about;
- access to short breaks/ respite;
- support with financial, legal and other practical issues, including the 'little things' like mowing the lawn, or taking the dog for a walk;
- understanding and support from family, friends, colleagues and communities when dealing with loss and bereavement, and access to more specialised support if bereavement becomes harder to cope with.

Compassion, practical support, human connections and thoughtful intervention can go a long way to giving people quality and meaning in their lives. Three inter-dependent factors are key:

- **Autonomy**

  People generally value a sense of being in control, yet ill-health often throws people into situations no-one would choose. The options available to an individual may be limited for various reasons, but it is important that people are supported to retain for as long as possible the autonomy to choose from the options that are available.

- **Opportunities to explore personal preferences**

  Planning ahead for deteriorating health increases the likelihood that a person will receive the kind of care they would want. Therefore, recent efforts to encourage this kind of planning and to promote more cultural openness about death are welcome. Not everyone will *want* to plan ahead or talk about death, but everyone should have *opportunities* to do so, accompanied by the recognition that people's needs and wishes can change over time. It is important that every individual has the opportunity to tell their own story, and that others listen to find out what matters to them and what support they might need.

- **Honesty and openness**

  Without honest information, individuals and families are ill-equipped to make decisions. Healthcare and social care professionals need to be honest about their expectations for a person's health, what uncertainties are involved, what support will be reliably available, and any limits there might be to the support provided.

2.2   What are palliative care and end of life care?

Though more specific definitions can be helpful (see Glossary), one way of thinking about 'palliative care' is to talk in terms of providing 'good care' to people whose health is in irreversible decline or whose lives are coming to an inevitable close. Perhaps what differentiates 'palliative care' from 'just good care' is the awareness that a person's mortality has started to influence clinical and/or personal decision-making. However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Therefore, in Scotland, much of the care that people receive when their health is deteriorating could be termed **generalist palliative care**, being provided by health and social care professionals to people living in the community, in care homes and in hospitals. It is palliative care regardless of whether someone has cancer, organ failure (including neurological conditions) or 'old age', or whether they are living at home, in a hospice, in a care home or in a medical ward, ICU or neonatal ward. Palliative care can and should be delivered alongside active treatment where that is appropriate.

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time.

Palliative care includes, but is *not exclusively about,* end of life care.   **End of life care** is that part of palliative care which should follow from the diagnosis of a patient entering the process of dying, whether or not he or she is already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories. There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

3.   A vision …

'… capable of stirring the heart of the community and able to serve as a constant reference and anchor point as the change moves forward'

The 3-Step Improvement Framework for Scotland's Public Services

Our vision is that Scotland will be a place where:

- people's wellbeing is supported even as their health declines;
- people die well;
- people are supported throughout bereavement.

4.   A story …

'… to enable people to recognise where they have been and where they are going'

The 3-Step Improvement Framework for Scotland's Public Services

4.1   Where have we been?

The policy journey in brief

Historically, 'palliative care' has been associated with hospices and with cancer care. *Our National Health: A Plan for Action, a Plan for Change* (SEHD 2000) stated that palliative care was important in cancer but should also be available to all those who need it regardless of diagnosis. *Better Health Better Care (SG 2007)* made a commitment to developing a national action plan for palliative care.

In 2008 the Scottish Government published *Living and Dying Well: a national action plan for palliative and end of life care in Scotland*, which set out a framework to support a person-centred approach to delivering consistently good palliative and end of life care on the basis of need not diagnosis. This was followed by the Scottish Framework for Children's palliative care in an attempt to meet the specific needs of children and young people. *Shaping Bereavement Care – a framework for action* was published by the Scottish Government in 2011, and set out guidance on the development and delivery of quality bereavement care services within NHS Scotland.

In 2011 the Scottish Government published a 2020 Vision and Route Map outlining a plan for achieving quality healthcare delivered in a person-centred fashion. There is no mention of death and dying in these two policy documents, and many significant pieces of policy and guidance (by Scottish Government and others) have been produced with little or no acknowledgment that deteriorating

health and dying are a reality[2]. This creates a risk that these issues are overlooked, particularly in a society where we find death and dying difficult to talk about. Caring well for people at that time in their lives is a significant issue that health and social care systems must be equipped to deal with. Though there are clear advantages to focussing on the concept of 'healthy ageing' and promoting independence, this current policy narrative needs to be balanced with one which acknowledges the many individuals and families struggling each day with deteriorating physical and mental capacities.

In March 2013 the Living and Dying Well National Advisory Group (NAG) established a short life working group to consider the care of dying patients and their families, in the context of adverse media coverage of the Liverpool Care Pathway (LCP) and the anticipated publication of an Independent Review of the LCP in England. In September 2013, the NAG issued a report and 26 recommendations to the Scottish Government. In December 2013 the Scottish Government announced that the LCP would be phased out, and issued guidance on caring for people in the last days and hours of life, which was later updated in December 2014. The Scottish Patient Safety Programme Deteriorating Patient work stream, in collaboration with SPPC, has done work to trigger more reliably discussions about goals of care with patients and families in acute hospitals.

Evolution of services

Data is not readily available to evidence the development of services or the improvement of outcomes. *Living and Dying Well: Building on Progress* (SG 2011) noted some of the achievements associated with the implementation of *Living and Dying Well*. Awareness of palliative care as an approach relevant to many people in Scotland regardless of diagnosis has probably increased. There is growing recognition that babies, children and young people have different needs from the needs of adults, and the Scottish Children and Young People's Palliative Care Network (SCYPPN) and Scottish Children and Young People's Palliative Care Executive (SCYPPEx) have formed to promote this further.

The numbers of people on palliative care registers has increased. Anticipatory prescribing has been rolled out in many NHS Boards. The profile of end of life care in hospitals was raised through on the LCP or equivalent pathways although early, integrated palliative care remains underdeveloped. The development of the electronic Palliative Care Summary (ePCS) and Key Information Summary (KIS) has provided a nascent ICT infrastructure to support sharing of information across settings.

Set against the above achievements are the capacity issues emerging with the financial pressures of more recent years. There is variable use of palliative care registers between different GP practices, and many people's palliative care needs are still not being identified soon enough.

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[2] Examples include Scottish Public Health Network Health and Social Care Needs Assessment of Older People in Scotland (2012); Scotland's National Inpatient Experience Survey; Route Map to the 2020 Vision; HIS Draft Standards of Care for Older People.

4.2 Where are we now?

Policy

Living and Dying Well has achieved a great deal but there are still challenges remaining. Ministers have announced that the 2020 vision will be reviewed in order to accommodate some wider issues and a longer term view. The 2020 Vision and Route Map are of necessity high level and need to be complemented by a more detailed strategy for palliative and end of life care. We therefore welcome the Scottish Government's commitment to publish a Strategic Framework for Action on Palliative and End of Life Care.

Human rights-based approaches have recently been increasingly influential, for example there is a *Charter of Rights for People with Dementia and their Carers in Scotland,* the *Children and Young People (Scotland) Act 2014* is influencing the design and delivery of relevant policies and services, and the revised National Care Standards are likely to take a rights-based approach.

Rights-based approaches can be helpful in raising public awareness and understanding of what people can expect to receive. In an environment of finite resources there are always practicalities to be considered with regard to ensuring that rights can be achieved. Framing policy in terms of people's needs and the outcomes we want to see is an alternative way of providing clarity about what people should be able to expect, while remaining mindful of the challenges involved in achieving the desired outcomes. Aside from human rights-based approaches, other practical measures can contribute to the empowerment of people and families – effective joint decision-making; clear accessible information (including information about what to expect from services); clear verbal communication; public health approaches (see 6.2).

Inequalities

The type of condition someone has significantly influences where they are cared for, their referral pathways, who funds their support and accommodation, and therefore overall, the support they can access. There are also other inequalities rooted in socio-economic and educational disadvantage, and associated with particular individual characteristics such as age, ethnic group and sexual orientation. Particular groups in society may also be disadvantaged, such as prisoners or gypsies/ travellers and people with learning disabilities.

Adults with cancer are more likely to get the palliative care support they need than people with organ failure (including neurological conditions), frailty and/or dementia, and this applies both to specialist and generalist palliative care support. Paradoxically this position is reversed for children; those with cancer are less likely to access early palliative care.

There are practical reasons why people with cancer diagnoses are more likely to access specialist palliative care services; for example, the *uncertainty* of prognosis in chronic obstructive pulmonary disease (COPD) and dementia makes it harder for people with these conditions to access specialist palliative care services. However, people's access to specialist and generalist palliative care support is influenced by many other factors:

- There is reluctance among professionals and the public to have open discussions about deteriorating health, death and the uncertainties involved.
- Public and professional perceptions are largely of palliative care as a specialist service for people dying with cancer.
- There can be a focus on death prevention measures instead of quality of life, even when a person's health is clearly deteriorating such that their life expectancy is limited.
- There is a lack of awareness that palliative care can and should be delivered alongside active treatment where that is appropriate.
- There is a lack of awareness that health and social care services can continue to make a significant difference to a person's wellbeing even when a 'cure' is not possible or unlikely.

All of this influences how generalists see their role, and how people are referred to specialist services. Research shows that people's experiences and expectations are different depending on whether they have cancer, organ failure (including neurological conditions), frailty and/or dementia[3]. It is important that these inequalities are recognised and addressed, while maintaining and improving palliative care for people with cancer, and with an awareness that the number of people living with cancer is growing.

Barriers

We are fortunate in Scotland to have well-trained and dedicated staff, access to advanced medical technologies, an excellent network of hospitals, care homes and community services, Third Sector organisations that provide good generalist and specialist support, dedicated informal carers, and a strong hospice movement. However, it is important to recognise that many areas of our health and social care system are under significant pressure, and there is growing recognition that substantial changes are required to create a health service that is sustainable[4].

Reliably responding to everyone's individual needs is difficult:

- The number of people with palliative care and end of life care needs is increasing, and their needs are becoming more complex. By 2037 it is estimated that the number of people dying each year will have risen by 12% to 61,600.
- Many different individuals and organisations are involved in a person's care, bringing challenges in co-ordinating and delivering care across organisational boundaries and out of hours.
- People with organ failure (including neurological conditions), frailty and/or dementia follow different trajectories and are cared for in different settings from people with cancer, who most commonly access specialist palliative care.

[3] Kendall M, Carduff E, Lloyd A, Kimbell B, Cavers D, Buckingham S, Boyd K, Grant L, Worth A, Pinnock H, Sheikh A, Murray SA, Different Experiences and Goals in Different Advanced Diseases: Comparing Serial Interviews with Patients with Cancer, Organ Failure or Frailty and Their Family and Professional Carers, *Journal of Pain and Symptom Management (2015),* doi: 10.1016/j.painsymman.2015,02.017.

Marie Curie, *Changing the conversation Care and support for people with a terminal illness now and in the future* April 2015

[4] *Building a more sustainable NHS in Scotland: Health professions lead the call for action* Royal College of Surgeons of Edinburgh; Academy of Medical Royal Colleges and Faculties in Scotland; Royal College of Nursing Scotland. 2015.

- The palliative care needs and the circumstances of babies, children and young people are very different from those of adults.
- Informal carers provide the bulk of support, yet are often unsupported and undervalued themselves, and many people don't have an informal carer to help them.
- The current workforce is often overstretched, and reportedly in many places there is insufficient staff to meet the needs of the people in their care adequately. Where staff are already overstretched it is hard for them to have time to conceptualise and implement improvements.
- Young adults with a life limiting condition face difficulties in transitioning from children's hospice services to adult palliative care services.
- Recent years have seen a significant amount of negative media coverage relating to the Liverpool Care Pathway, completion of DNACPR forms and GP Palliative Care Registers. The impact of this should not be underestimated - lack of trust among the public, and professionals' fears about media interpretation and reporting can make it harder to improve care.
- There is a cultural reluctance to discuss death, dying and bereavement.
- Too often, our culture sees death as a 'medical failure' and this leads to various barriers providing care to support people's individual wellbeing.
- There is little robust data currently available to inform improvements, and where useful evidence or learning has been gained it is hard to ensure that this is transferred into practice across Scotland.
- Care homes are undervalued and under-resourced, yet 22% of people die in care homes and care homes generally support residents with high levels of dependency.
- Over 50% of people die in hospitals, and it is currently very difficult to deliver person-centred palliative care and end of life care within busy hospital environments.
- An overstretched GP and community nursing workforce is leading to longer waits for patients to get an appointment with the GP of their choice, and less frequent support and monitoring at home, sometimes with shorter visits at the practice or at home.
- Significant numbers of GPs and community nurses are likely to retire within 5 years. This will mean reduced staffing including a loss of an experienced workforce at a time when need is increasing. There is also likely to be a reduction in medical acute care training posts. Currently there is no education for community children's nurses in Scotland.

4.3 Where are we going?

Sometimes ill-health and death are inevitable, but responding to these with honesty and empathy is a good basis for supporting people through these difficult times. There is a need for more awareness that palliative care is not simply a specialist service, and that health and social care services can continue to make a significant difference to a person's wellbeing even when a 'cure' is not possible or unlikely, and during the last months, weeks, days and hours of a person's life.

The majority of palliative care is, and should continue to be, provided by generalists. However, specialist palliative care services have a wealth of expertise that can benefit people with a range of conditions. While it is not appropriate to assume that a specialist palliative care model developed for

cancer will fit neatly for people with other conditions, it is important to find ways of ensuring people who can benefit from this expertise can access these services, for example through partnership with other specialties.

As a health and social care system, and as a society, we need to be aware that death is usually not a medical failure. When a person has one or more illnesses that cannot be fully resolved, we need to focus on what matters most to them and addressing the problems caused by their worsening health. As a society and as individuals we also need to recognise that there are benefits to exploring and planning in advance what we would want if and when our health declines.

There is also a need for a culture shift across society, so that Scotland becomes a place where people that want to plan ahead can be open and honest about death and dying and the uncertainties involved, and this is perceived as normal within families, communities and health and social care settings.

Outcomes

The Strategic Framework for Action should therefore work towards achieving the following four outcomes:

- People receive health and social care which supports their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death. Each individual's care may look very different.
- People have opportunities to discuss and plan for future possible decline in their health, preferably before a crisis occurs, and be supported to retain autonomy for as long as is possible.
- People know how to help and support each other at times of increased need and in bereavement, and recognise the importance of families and communities working alongside formal services.
- Cultures, resources, systems and processes within health and social care empower staff to exercise their skills in providing good care for people and families, and to care about the people and families they work with.

5. Key challenges

To achieve the preceding 4 outcomes, the Strategic Framework for Action needs to set out a plan of action which addresses the following key challenges:

5.1   Co-ordinating services across organisational boundaries and out of hours

Ensuring that people have timely access to high quality, person-centred, safe and effective palliative care when they need it, regardless of the time of day or the day of the week, requires a whole system approach. This means focusing on community and hospital services, and looking at models of care (including social care) that maximise the potential of different professions to meet the needs of patients and improve patient outcomes outwith core Monday to Friday services[5]. There is also scope to further explore the recruitment, education and role of volunteers.

Telephone advice from a palliative care specialist nurse supported by a medical consultant should be available 24/7 throughout Scotland. This could involve new models of working across NHS Boards supported by access to patient electronic records to make it sustainable for the professionals involved, cost-effective and safe. Patients and families also need and value continuity of care and support from generalist services at all times.

For a professional (eg GP) trying to set up and co-ordinate an urgent package of care, additional help to support people at home must be as easy to access as an unscheduled admission to hospital. There is therefore a need for a single point of access to a range of community services, for example community nurses, AHPs, community psychiatric nurses, Scottish Ambulance Service, social work and care providers. The single point of access should be someone who has the experience, ability and authority to access the services required.

People identified as having palliative care needs should have access to a priority response, out-of-hours phone number, linking them to local services. This could be via NHS 24, if there were streamlined algorithms/ protocols to speed up the process.

5.2   Health and Social Care Partnership local needs assessments and planning

Health and Social Care Partnerships should undertake local needs assessments involving relevant stakeholders, to establish current and future needs for palliative and end of life care. Planning for delivery should include: review of current workforce across agencies and skill base; leadership arrangements. Planning needs to be supported by good quality, accurate local data collection and analysis which can be shared.

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[5] For example pharmacy is the third biggest professional group in the health service and ensuring community pharmacists are incorporated into the multidisciplinary primary care team is essential for safe and effective medicines use.

5.3 Increasing the capacity of specialist palliative care to support generalist services more effectively

There is a need to increase the capacity of specialist palliative care to support generalist services better. This might include: 24/7 advice; better access to specialist assessment; education and training in all settings; and development of models of joint working with other specialties.

5.4 Anticipatory care planning[6]

Anticipatory care planning is an essential part of most aspects of healthcare and is not restricted to people whose deteriorating health and risk of dying is now impacting on decision making. Thus anticipatory care planning may well start before a person has palliative care needs and will evolve over time as a person's prognosis, understanding and priorities evolve. Anticipatory care plans should reflect what matters to the person, which is likely to be wider than just clinical issues.

Anticipatory care planning which encompasses palliative and end of life issues can improve the outcomes experienced by an individual and their family[7]. Sensitive, open and honest conversations about what matters to the person are the heart of anticipatory care planning. Documenting, reviewing, updating and sharing decisions and preferences identified during these discussions makes it more likely that care provided will reflect what the person wants. *My Thinking Ahead and Making Plans[8]* is a useful tool that can facilitate future care planning.

Initiating discussions and reviewing and updating plans may take place in any setting. For example it is important that care home staff are engaged in the process and empowered to respect the preferences recorded in a plan, for example by not initiating an unwanted hospital admission. Transitions between settings can provide a useful trigger for initiating or updating planning, for example on discharge from hospital.

Anticipatory care planning may include the development of personal emergency care plans which record what treatments will be of benefit and in line with the person's preferences in the event of a sudden deterioration. Such plans should also include actions for informal carers. To maximise the possibility of improving the quality of patient care such emergency care plans should be widely accessible and recognisable and a consistent approach across Scotland would be essential to ensure appropriate engagement with eHealth systems (particularly the Key Information Summary), and out of hours and emergency healthcare services.

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[6] This document avoids exploring the terms and concepts around 'advance care planning' and 'anticipatory care planning'. Useful background on these issues can be found here: http://www.palliativecareinpractice.nes.scot.nhs.uk/advance-anticipatory-care-planning-toolkit/what-is-advance-anticipatory-care-planning.aspx

[7] *The impact of advance care planning on end of life care in elderly patients: randomised controlled trial*
Karen M Detering, Andrew D Hancock, Michael C Reade, William Silvester. BMJ 2010;340:c1345
Anticipatory care planning and integration: a primary care pilot study aimed at reducing unplanned hospitalisation Adrian Baker, Paul Leak, Lewis D Ritchie, Amanda J Lee and Shona Fielding Br JGenPract 2012;

[8] Accessible at: http://www.nhsggc.org.uk/your-health/health-services/palliative-care/thinking-ahead/my-thinking-ahead-and-making-plans/

5.5   Involving and supporting carers

People generally spend only a small proportion of their time seeing professionals and receiving formal services. Informal carers such as family and friends generally provide the bulk of support that is needed when someone's health is deteriorating. Carers can have a wealth of understanding, knowledge and experience relating to the preferences and needs of someone they've been caring for, and are usually keen to share this knowledge with anyone who can use it to improve the person's care. There is therefore a need for formal services to recognise the value and knowledge of informal carers, and work together with them in the best interests of the individual involved.   Informal carers also require support and information to deal with the practical and emotional difficulties they face.

5.6   Shared decision-making

Currently people can choose to have a family member or friend or advocate with them for most appointments, consultations and meetings with healthcare professionals. However many people are not aware of this and so speak with health professionals when they are alone. The benefits of having someone else present should be highlighted and facilitated in all healthcare settings. Having someone there who knows the individual may help health professionals to make a better assessment of the wider needs of the individual. It also supports and empowers family members and informal carers to be actively involved in supporting people at home or in other care settings.

5.7   Best practice in making decisions with people with reduced capacity

There is good legislation to support best practice in making decisions with people whose capacity is affected by advancing illness but more needs to be done to ensure this framework is used as well as possible in clinical practice. Capacity fluctuates and an approach that involves those who are close to the patient as much as possible is important. If a person lacks capacity professionals will always need to talk with the people who are close or related to them to find out about what they think that person would want to happen[9]. Staff must also be aware of the issues related to the age of legal capacity in Scotland and the implications for involving children and young people in decisions.

5.8   Talking about patient goals, deteriorating health, dying and 'what matters'

Effective communication is central to good care for people with deteriorating health who are at risk of further deterioration and death. This includes conversations with individuals and families about what matters to them, planning for deteriorating health and making decisions together about possible treatment and care options as a person becomes less well and is dying. Such conversations need to take place at a time and in a manner which enables the person and those closest to them to best understand the situation. Work has

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[9] *Keys to Life*, the national strategy for people with learning disabilities, commits to implementing a palliative care pathway developed as part of the Building Bridges Project http://keystolife.info/learning-disability-and-palliative-care-the-building-bridges-project/

been done looking at sensitive and effective ways of opening and continuing such conversations[10]. This work needs to be accessed more widely, and staff also require time and training to enable them to engage in these potentially difficult but important conversations.

5.9   Identifying people with palliative care needs

Timely and more systematic identification of people likely to benefit from beginning open and honest conversations about what their priorities and preferences might be in the context of deteriorating health is important. It may be helpful to consider using the Supportive and Palliative Care Indicators Tool (SPICT), which is a guide to help health and social care professionals identify people with one or more advanced conditions, deteriorating health and a risk of dying, for assessment and care planning[11].

5.10   Public engagement

The culture we live in and the support we receive from our family, friends, workplaces, education system, government bodies and wider society have a huge impact on how we live, and die.

Discussion is a prerequisite for shared decision making, planning and preparation but is often absent in a culture reluctant to acknowledge death and dying. Low levels of public knowledge and awareness of practical, legal, medical, and emotional aspects of death, dying and bereavement limit capacity for self management and provision of informal support.

Lack of consistency in use of terminology can cause misunderstandings, and there is a need to work towards consistent communications, terminology and messages across the system. There are a number of complexities involved in coming to agreement on appropriate use of terminology, but progress is possible, and efforts to reach a consensus should be made with appropriate input from various stakeholders.

5.11   Improving and fully exploiting the IT infrastructure

Using the Key Information Summary (KIS) to share anticipatory care planning information created by in-hours GPs across care settings and out of hours has great potential to improve care, but much remains to be done to complete and consolidate implementation.

There is a need to address technical issues so that the KIS can be readily accessed in all settings. This should include information sharing with social care. There is also a need to address human factors: people need to be aware that the KIS exists; general practice needs to know that the data they enter will be accessed and used; professionals in other settings need to find that on accessing the KIS it provides data which is of use in informing care; admission and discharge processes and need to handover information effectively to primary care to update the KIS; the public should be aware of the existence of the KIS and the potential benefits of discussing preferences with their GP. In the longer

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[10] For example, see Effective Communication for Healthcare: http://www.ec4h.org.uk/
[11] SPICT is a tool developed by staff at the University of Edinburgh and NHS Lothian: http://www.spict.org.uk/

term a single shared record which can be updated from within different settings should be developed. Eventually patients should have opportunity to update relevant parts of the record.

There is also a need to make better use of data which is already gathered by ISD (but not analysed) and which can inform policy and service planning.

5.12 Care Homes

Many of the key challenges highlighted in this chapter intersect in care homes. People living in care homes have high levels of palliative care need, frequently have reduced capacity for decision-making, but have patchy access to appropriate care. Levels of staff knowledge, skills and confidence are very variable. Strong links to general practice make a big difference but are also very variable. Access to specialist palliative care input is also inadequate. Nearly all people living in care homes need an anticipatory care plan and KIS, but around 40% do not have one yet. Timely hospital/ hospice discharge information is often not available to care homes. Health and Social Care Partnerships should support partnerships between care homes, general practice/ primary care and hospices to address these challenges. There is some very good palliative and end of life care in Scotland's care homes, but there is a need to achieve this success more widely.

5.13 Research

The recent Palliative and End of Life Care Priority Setting Partnership (PeolcPSP) facilitated by the James Lind Alliance highlighted that palliative and end of life care is an under-researched area, and identified a number of unanswered research questions, and evidence uncertainties, in palliative and end of life care[12]. There is a need to generate robust research evidence to inform policy, practice and service design, and to speed up the translation of research findings into practice. The creation of a palliative care research network for Scotland would be helpful.

5.14 Education and Training

A workforce with the right skills, knowledge, attitudes and behaviours is critical to the improvement of palliative and end of life care. Examples of areas where training and education are required include:

- what palliative care and end of life care are;
- professional awareness of indications that an individual's deteriorating health (or new diagnoses) should inform personal priorities and clinical decision-making;
- communicating and engaging sensitively, openly and honestly with individuals and families about deteriorating health and death;
- supporting people to make plans that recognise and make provision for significant uncertainties in individual situations;
- shared decision-making;

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[12] *Palliative and end of life care Priority Setting Partnership (PeolcPSP) Putting patients, carers and clinicians at the heart of palliative and end of life care research* http://www.palliativecarepsp.org.uk/wp-content/uploads/2015/01/PeolcPSP_Final_Report.pdf

- supporting staff wellbeing eg reflection on own feelings and experiences related to death, dying and bereavement and their self-care needs;
- specific technical skills and knowledge (for example relating to the implementation of the Scottish Palliative Care Guidelines).

In broad terms there is a particular need to support generalists at different levels and in all settings to acquire relevant palliative care skills and knowledge. Adequate uptake of high quality education and training is part of the necessary workforce development. The challenges relating to education and training include:

- the lack of a systematic and comprehensive approach to workforce development relating to palliative and end of life care;
- the number and diversity of staff which require education and training of different sorts in different settings;
- barriers to accessing training (inadequate time for workplace-based and online training, staff not released for offsite training due to no backfilling), leading to inadequate and unequal opportunities for learning;
- inconsistency of education and training;
- translation of education and training into adequate practice;
- palliative care is not always adequately covered on pre-registration courses and as a result some newly qualified staff are inadequately prepared;
- inadequate support for continuous improvement in practice through education and training in the workplace;
- integration has created uncertainty about future roles and training budgets.

5.15 Bereavement

Shaping Bereavement Care[13] sets out principles of good bereavement care, and highlights that:

'There is a range of evidence (Stephen et al 2006) that the way those who have been bereaved experience the events around the time of death will influence the trajectory of their grief journey. Where health services get it right, showing empathy and providing good quality care, bereaved people are supported to accept the death, and to move into the grieving process as a natural progression. Conversely if the health services get it wrong, then bereaved people may experience additional distress, and that distress will interfere with their successful transition through the grieving process, with implications for them, those around them and for the social economy of the nation. Each individual's response to the death will be different and other factors aside from the quality of end of life care will also be important.'

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[13] http://www.sehd.scot.nhs.uk/mels/CEL2011_09.pdf

6.   A set of actions

'… to take us to the next steps towards realising the vision'

Section 4 sets out key outcomes the Strategic Framework for Action should work towards. Section 6 sets out specific actions relating to each of these key outcomes, under the following themes:

• Leadership;
• Public Health approaches to palliative care;
• Education/ Training;
• Measurement;
• Change and Improvement.

Taken together the actions create the necessary conditions for change, describe specific changes required and specify a broad framework of accountability.

For each action we suggest in parentheses the key organisation(s) involved in taking action (though many require wider collaboration), with the first named best placed to act as the lead.

Critical systemic challenges

It is important to highlight that there are several key challenges that fall outwith the scope of this report to address, as they are not issues that relate solely or mainly to the provision of palliative and end of life care.   Most palliative care is provided within generalist settings of the health and social care system and so wider systemic issues impact on the quality of palliative care which people experience. Key requirements include:

1. Terms and conditions of employment which support better recruitment, retention and skills/knowledge development in the social care sector. Care homes for older people, for example, support residents with typically high levels of need and 22% of people die in a care home.

2. Adequate capacity in general practice/ primary/ community care to support sensitive conversations, continuity and co-ordination of care.

3. Adequate capacity (and environment) to provide palliative and end of life care in very busy acute hospital wards. Often dying at home will not be possible (or ultimately desired) by the person/family, so there is a need to consistently enable ways of dying in hospital which reflect elements of a 'homelike' experience (for example privacy, peace, contact with loved ones, connections to meaningful memories).

6.1 Leadership

Leadership is about creating the conditions necessary to empower and engage people and organisations in exercising their influence to achieve a vision they can relate to. This means that leadership encompasses much more than deciding what needs to be done, setting out targets, and delegating tasks. To be effective, leaders need to listen to find out what support they can provide to empower others to make meaningful contributions towards achieving a shared vision. The Strategic Framework for Action is an opportunity to set out clear leadership roles.

Scottish Government

The Scottish Government has a key role to play in co-ordinating work in this area, ensuring accountability, and exemplifying openness and honesty about deteriorating health, end of life and death. The Scottish Government is also in a good position to inform and influence various national work undertaken, for example by special health boards, such as NHS Education Scotland and Healthcare Improvement Scotland.

ACTION:

1. The Scottish Government should exemplify a culture of openness and honesty relating to declining health and death. Publications, policy documents and speeches produced by the Scottish Government should openly acknowledge deteriorating health, death, dying, uncertainty and bereavement as part of the human experience, and the eventual end point of all lives, whether short or long.

2. The Scottish Government should describe a clear framework of accountability for the aims, objectives and outcomes of the Strategic Framework for Action.   The strategic and operational plans of Health and Social Care Partnerships and Special Health Boards should be required to link to the aims, objectives and outcomes in the Strategic Framework for Action. Key milestones should be identified.

3. The Scottish Government should ensure the alignment of relevant Scottish Government work streams to promote embedding of palliative and end of life care, and that they explicitly acknowledge that palliative care, death, dying and bereavement are key issues for the health and social care system to address. Relevant work streams include Dementia; Carers; GIRFEC; Clinical Strategy; Out of Hours and Primary Care; Residential Care Taskforce; Chief Nursing Officer Review of Education: Setting the Direction and the Transforming Nursing Roles; Person Centred Care; Patient Safety and Unscheduled Care. By 'alignment' we mean that these work streams should set out explicitly activities, outputs and objectives which contribute to the outcomes of the Strategic Framework for Action.

4. The Scottish Government should ensure that key stakeholders are fully involved in decision making about how the recently announced £3.5 million new investment to support improvements to palliative and end of life care is spent.

A guiding coalition

The 3-Step Improvement Framework for Scotland's Public Services suggests that '*a guiding coalition*' is necessary to ensure the success of any change

programme: '*a team of key people to drive the change when the going gets tough, and to sustain support*'. Establishment of this type of coalition would be a helpful step towards maintaining ongoing focus on this area.

ACTION:

5. The Strategic Framework for Action should set out plans for fulfilling the function of a '*guiding coalition*', linked to a clear framework for accountability. The coalition should include a mix of subject experts and high level strategic influencers including those leading the major service delivery organisations. (**SG**)

Scottish Partnership for Palliative Care (SPPC)

The Scottish Partnership for Palliative Care is a collaboration of all the major organisations involved in delivering palliative care and end of life care in Scotland. The SPPC brings together the views and expertise of provider organisations and of practitioners from across sectors and professions. The SPPC exemplifies many of the features of the 'network' element of John P Kotter's dual system structure, and when appropriately resourced, is ideally placed to lead information sharing and collaboration across Scotland[14].

ACTION:

6. The SPPC should maintain intelligence about what is going on in the many different settings and work streams which are relevant to improving palliative care so that policy and practice is well informed and opportunities for collaboration are identified.

7. The SPPC should advocate the importance, value and specific contributions of palliative and end of life care in delivering national outcomes for health and social care so that they are more likely to be achieved.

8. The SPPC should provide a network for the champions who are at the forefront of change and innovation so that innovation is encouraged and learning is shared.

9. The SPPC should broker strategic collaboration to deliver specific projects where this avoids wasteful local duplication of effort and/ or where a national approach is necessary.

Health and Social Care Partnerships

The establishment of Health and Social Care Partnerships and the inclusion of palliative care in their responsibilities provides opportunities for improved co-ordination of services across organisational and institutional boundaries. This will require strong clinical and managerial leadership. The new structures also present challenges of organisational change and alignment of diverse cultures which are faced in the context of significant resource constraint.

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[14] In his book, XLR8 (Accelerate), John P Kotter outlines a dual system structure with a hierarchy on one side and a network on the other: 'The hierarchy part of the dual operating system differs from almost every other hierarchy today in one very important way. Much of the work ordinarily assigned to it that demands innovation, agility, difficult change, and big strategic initiatives executed quickly... has been shifted over to the network part. That leaves the hierarchy less encumbered and better able to perform what it is designed for: doing today's job well, making incremental changes to further improve efficiency, and handling those strategic initiatives that help a company deal with predictable adjustments such as routine IT upgrades.'

ACTION:

10. In the short term there is a need to achieve clarity about how health and social care integration will affect the organisation and delivery of palliative and end of life care, especially services which operate across several Health and Social Care Partnerships. An identified individual at senior level within each NHS Board should ensure clear arrangements are established and published for:
    o commissioning of hospice services;
    o palliative care within acute hospitals;
    o children and young people's palliative care.

11. Health and Social Care Partnerships should have an identified lead for palliative and end of life care, who should be invited to join the local palliative care MCN.

12. Health and Social Care Partnerships should include palliative care within their strategic and operational plans, and these should be linked to delivery of national outcomes.

13. The Health and Social Care Partnership(s) within each NHS Board geographical area should establish a truly integrated and fully functioning strategic body, such as an MCN, focused on improving palliative and end of life care.

14. Health and Social Care Partnerships should ensure that their strategic planning and decision making is informed by adequate representation from local service users and providers of palliative and end of life care.

15. In commissioning care at home, care homes and other relevant social care services, Health and Social Care Partnerships should include explicitly the provision of care for people with palliative and end of life care needs, stipulating clear quality standards. Contracts need to resource adequately the development and retention of leadership and a workforce equipped to provide the care required by people with high levels of need. The Key Challenges relating to care homes identified in Section 5 need to be addressed.

Healthcare Improvement Scotland and the Care Inspectorate

ACTION:

16. HIS and CI scrutiny and improvement activities should include a focus on palliative and end of life care (including bereavement), reinforcing the priority attached to this area.

Hospices and other providers of specialist palliative care

ACTION:

17. Hospices and other providers of specialist palliative should continue to lead in:
    o advocating the importance and contribution of palliative and end of life care;
    o innovation of practice and models of care including early palliative and supportive care and integration with other specialties and services;
    o brokering collaboration and partnerships with other specialities and other providers;

o   the development and delivery of education.

Leadership by individuals

ACTION:

18.   Influential individuals within all the organisations listed in section 1.1 (page 7) should play a key role in raising the profile of palliative and end of life care and exemplifying a culture of openness and honesty relating to declining health, death and bereavement through their words and actions.

19.   Individuals working in all organisations and at all levels should contribute to the creation of a caring and honest culture in their own workplace - treating staff, patients and those who matter to them with empathy and creating a supportive environment of staff reflection and support while acknowledging resource constraints.

20.   Individuals should all use appropriate language which is honest about deteriorating health, death and the uncertainties involved.

6.2   Public Health approaches to palliative care

People's experiences of declining health, death and bereavement are only partially determined in their interaction with traditional formal health and social care services. The social and cultural environment is a key influence on people's experiences as well as being a limiting factor in service improvement. This was acknowledged in *Living and Dying Well,* and growing recognition of this is illustrated by the Scottish Public Health Network's recent commission of a report looking at palliative and end of life care from a public health perspective.

In Scotland we have a cultural reluctance to think and talk about declining health, death, dying and bereavement. This reluctance operates at individual, organisational and policy levels:

*   Health and social care policies and strategies often fail to mention death, dying and bereavement.
*   Organisations providing services for older people or for those with life limiting long term conditions often fail to acknowledge explicitly that they support people for whom uncertainty and the possibility of death are strong influences in their lives.
*   Individuals and/or their families are often reluctant to discuss or formulate preferences and to plan for end of life care. This may be for various reasons: because the potential benefit is not understood; because of a lack of information about choices and options; because it is not perceived as something people 'normally' do; because suitable opportunity is not provided. For some people disavowal of dying may be part of their coping strategy which must be respected.

Promoting more openness about death, dying and bereavement can lead to:

*   policies which more adequately address this phase of life;
*   services which are better aligned to meet people's preferences for care towards the end of life;
*   individuals and communities becoming more able to identify, build and harness skills, knowledge, networks, passions and resources to plan for and support each other with decline, uncertainty, death, dying and bereavement;

- organisational cultures that are more supportive of staff and volunteers, recognising the emotional impact that working in this field can have on an individual;
- employers offering support to staff whose health is deteriorating, to carers of a person who is dying, and to the bereaved.

Policy Origins

As part of *Living and Dying Well,* the Scottish Government established a short life working group to explore ideas, issues and recommendations for addressing palliative and end of life care from a public health perspective. The group's report and recommendations was approved by Nicola Sturgeon, then Cabinet Secretary for Health and Wellbeing, in June 2010. As a result, the Scottish Government asked the Scottish Partnership for Palliative Care to establish a broad based alliance to address the recommendations set out within the final report.

Good Life, Good Death, Good Grief (GLGDGG)

GLGDGG was established by the Scottish Partnership for Palliative Care in 2011, with reference to the theory of Professor Allan Kellehear and drawing on UK and international approaches. The *GLGDGG* approach was also built on a number of key principles as outlined within SLWG7 report, for example:

- *"There is a risk that imposing public health initiatives on a community may be counter-productive, since without community involvement in the development of initiatives, they are likely to lack local support, be misguided and therefore be unsustainable."*

- *"Any approach taken to addressing the discussion of death, dying and bereavement in Scotland should encourage community resilience, while maintaining a keen awareness that different communities will have different strengths, weaknesses, problems and priorities relating to death, dying and bereavement; what might work for one community may be completely inappropriate in another."*

- *"any approach taken to addressing the discussion of death, dying and bereavement in Scotland will require a communications strategy and informed and sensitive engagement with media in its various forms."*

In line with these principles, *GLGDGG* has sought to 'work with' people rather than imposing 'interventions', and its key messages are about supporting open cultures, rather than attempting to raise awareness and change attitudes in a top-down fashion.

GLGDGG exemplifies an approach which involves finding ways of supporting and engaging with communities to empower and educate in ways that are respectful to cultural and individual needs and preferences.

GLGDGG has a well developed action plan and monitoring in place. Twice awards-nominated[15], *GLGDGG* has achieved significant recognition within the international community and in the national media for its innovative work. Its

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[15] Finalist in Scottish Charity Awards – Cracking Campaign 2014 for *To Absent Friends*
Good Funeral Awards – finalist in *Best Internet Bereavement Resource*

membership includes all NHS Boards, many local and national voluntary organisations, universities, schools, faith-based organisations, local authorities, arts organisations, and interested individuals.

The absence of recurrent and predictable funding for *GLGDGG* has posed challenges in terms of making mid- and long- term work plans, and to evaluating the impact of work undertaken. *GLGDGG* has good networks and a reputation for innovation – with an appropriate level of recurrent funding *GLGDGG* would be well placed to scale up work and add to the evidence base.

ACTION:

21. Scale up a programme of activity to promote a culture of openness about death, dying and bereavement in Scotland **(SPPC supported by SG and NHS Health Scotland)**, including the following key actions:
     o undertake proactive and sensitive public and media engagement in the development of a *Charter for a Good End of Life*, empowering the general public and health and social care professionals by listening to views, establishing clear terminology, and developing honest and accessible information about the support people can expect to receive as they approach the end of life;
     o draw on work already carried out by Public Health England and the National Council for Palliative Care and develop a practical toolkit to assist Scottish communities in identifying and addressing local problems relating to death, dying and bereavement;
     o develop and promote an engaging resource which supports people from socio-economically disadvantaged communities to discuss and plan for the financial, medical, legal, practical and emotional issues which arise towards the end of life;
     o promote, within the framework of Curriculum for Excellence, wider use of existing resources which encourage conversation, education and support around death, dying and bereavement experiences for children and school staff in primary and secondary education;
     o identify and proactively address the barriers people face in making wills, powers of attorney and advanced directives including provision of free legal advice where appropriate;
     o develop better mechanisms to enable direct patient and carer involvement in policy, service and practice development.
22. In the context of welfare reform and the forthcoming Bill relating to burial and cremation and other related matters in Scotland develop measures to reduce funeral poverty. (**SG**)
23. Develop leaflets appropriate for all ages and cultures, on '*What to expect when someone you care about is becoming more unwell and dying'* for distribution to health centres and other public places around Scotland. (**NHS Health Scotland**)

(See also section *6.4 Measurement* for actions relating to the need for public health data and intelligence to inform planning and service design at population level.)

6.3 Education/ Training

Continuing professional development is required to equip staff with the skills and confidence to integrate palliative care with the other care they provide. Education is required from undergraduate level onwards, for all healthcare and social care professionals, volunteers and for unpaid carers. There are many excellent training and education resources available, but no framework, structure or priority to translate this into an adequately equipped workforce.

ACTION:

24. Drawing on the EAPC White Paper on palliative care education, and learning from implementation of *Promoting Excellence in Dementia,* develop, publish and promote a Targeted Educational Framework for palliative and end of life care. The framework should be built on the premise that all health and social care workers need a level of knowledge and skills to care for people facing the difficulties and uncertainties of deteriorating health. The framework should be underpinned by values and principles that reflect what people in such circumstances (and their families and carers) say are important to them. The educational framework should have a number of levels which relate not simply to the seniority of an individual in an organisation or profession but also to their level of involvement with people with deteriorating health and their families. (**NHS Education Scotland/ Scottish Social Services Council**)

25. Develop a directory of existing educational resources which can support provider organisations to implement the Targeted Educational Framework. Further development and regular updating of the Knowledge Network online resources could be considered. (**NHS Education Scotland/ Scottish Social Services Council**)

26. Include relevant palliative and end of life content in undergraduate, postgraduate and pre-qualification curricula. For example a palliative care curriculum for undergraduate medical students in Scotland has been developed but not fully implemented. (**Professional bodies/ Regulators; Colleges/ Universities/ other education providers**)

27. Using the Targeted Educational Framework outlined above, and informed by the proposed directory (action 25), develop and deliver a systematic and structured approach to workforce development in palliative and end of life care in which attainment of the requisite level of skills and knowledge is *mandatory*. Key areas for focus are likely to include the expected contribution of different staff groups to: palliative care; earlier identification; supporting wellbeing; initiating and facilitating individualised and sensitive conversations relating to planning for the future; managing uncertainty; death and bereavement; compassionate care and connecting with empathy; knowledge of local resources/ services and pathways. Modes of training/ education are likely to include workplace-based, shadowing and reflective practice. (**Health and Social Care Partnerships/ SG/ NES**)

28. Where the relevant model of validation permits, link competencies in palliative and end of life care to professional revalidation processes. (**General Medical Council/ Nursing and Midwifery Council etc**)

6.4 Measurement

Palliative care in Scotland suffers from a lack of good data for many purposes: for local improvement; for performance management; for quality assurance; to assess current and future needs; to characterise patterns of service use (including inequalities); and patterns of resource use. At national level, data currently relates to processes and activities and not to outcomes which are meaningful to patients and families.

It is important that we can evaluate whether the actions undertaken as a result of the Strategic Framework for Action are having a positive influence on people's experiences of deteriorating health, death and bereavement.

The Strategic Framework for Action should review and address data needs for all of these purposes.

ACTION:

29. A national approach to gathering feedback about palliative and end of life care from bereaved family members should be put in place. Initially this should be done by using the *VOICES* methodology which has been validated and used extensively in other parts of the UK and some Scottish Boards. (**SG**)

30. Establish a short life working group to develop as a priority a robust measurement framework for the Strategic Framework for Action, scope existing data and to identify the other key data (and non-quantitative information) required to support future improvement of palliative care in Scotland. (**SG**)

    Input should be sought from information/ data specialists currently working in this area, those with relevant academic expertise, and others with relevant knowledge and experience. The Group's work should include consideration of:

    o patient-reported outcome measures;
    o outcome measures that are meaningful to individuals and families;
    o audit of key information summary (KIS) data;
    o case note reviews (including KIS data)/ after death analysis;
    o use of Patient Opinion and Care Opinion websites, collection of carer stories, and rapid feedback mechanisms (eg postcards);
    o coding of complaints to allow end of life and bereavement issues to be recorded and analysed;
    o thematic case review by the Office of the Scottish Public Ombudsman Service;
    o outputs of any forthcoming Scottish Child Death Review System;
    o Professor David Clark's report to the Scottish Parliament: *International comparisons in palliative care provision: what can the indicators tell us?*
    o the *OACC Palliative Care Outcome Measures Resource Pack* produced by the Cicely Saunders Institute and Hospice UK;
    o alignment of scrutiny by HIS and the Care Inspectorate;

- o data extractable through linkage and analysis of existing sources[16] to inform:
  - assessment of current and future needs population needs;
  - characterisation of patterns of service use (including inequalities);
  - characterisation of patterns of resource use.

6.5 Change and Improvement

The purpose of the Strategic Framework for Action is to deliver changes which achieve improvements in the experiences of individuals and families. All improvements must have some element of local implementation if they are to make a difference to people in local communities. However, many of the key challenges outlined in Section 5 cannot be addressed purely through local work, but require a combination of local actions and system-wide changes.

6.5.1 System-level solutions and improvements

Some system-wide change is about creating the conditions for improvement. For example the actions relating to strategic leadership and accountability detailed in earlier sections are about creating conditions for change.

System-wide action is also necessary where issues transcend the geographic boundaries of NHS Boards, Local Councils or Health and Social Care Partnerships. For example, improvements to ICT infrastructure, and a consistent approach to terminology are issues that cannot be addressed at a purely local level.

Collaborative work at a national level can avoid local duplication of effort and provide consensus about good practice. The Scottish Palliative Care Guidelines are a good example of national collaboration which shared expertise and avoided local-level duplication of effort and wasted resource. More recently, many NHS Boards have been developing their own end of life care documentation and resources in response to the national end of life care guidance published in December 2014. There is also a range of work underway to support:

- timely identification that someone is at risk of deteriorating and dying, including dealing with uncertainties involved;
- the assessment of supportive and palliative needs, including finding out about an individual's personal priorities and wishes;
- engaging people and those close to them in shared decision-making about treatment and care both for the current episode and in planning ahead;
- improving documentation and sharing of these personal care plans between professionals and services.

It is important to share learning across Scotland of how to address common issues. This is helpfully articulated in the 3-step Improvement Framework as '*an understanding of how the change will work locally (everywhere) – recognising communities are different and creativity should be nurtured and released at a local level'*.

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[16] For example ISD has generated lots of relevant data at Health and Social Care Partnership level

ACTION:

Where national/ system-wide actions have been identified under other themes (Leadership, Education, Public Health, Measurement) we have not restated them here.

31. The **Scottish Government** should ensure the right resources are available to support local improvement activities by:
    - o ensuring the alignment of existing improvement infrastructure (Healthcare Improvement Scotland/ Joint Improvement Team/ Quality Improvement Support Team) to support activity focussed on palliative and end of life care;
    - o establishing a 'Change Fund' for palliative and end of life care to resource innovation and free up champions to combine improvement work with existing clinical commitments.

32. The **Scottish Government** should take advantage of opportunities for cost-effective national collaboration, for sharing and spreading learning, and harnessing of expertise by supporting and resourcing national activities co-ordinated by the Scottish Partnership for Palliative Care.

33. Establish properly functioning and accessible ICT infrastructure to support embedding of KIS (**SG/ NHS National Service Scotland/ NHS Boards**)

34. Mandate the development of a consistent national approach to policy, communication and documentation of CPR decisions and emergency treatment plans. (**SG/ HIS**)

35. The revised National Care Standards, and the new general standards for palliative care expected from HIS, should be developed in a way which reflects outcomes important to individuals and families, and provides a helpful focus for local service delivery and improvement. (**Care Inspectorate/ HIS**)

36. Palliative care is holistic care. Whilst healthcare is free at the point of delivery people with palliative care needs may be charged for other equally important support (eg home care, respite care). In the context of integration, SG and Health and Social Care Partnerships should provide clear information for the public about charging policies, and also work towards the reduction of inconsistencies in charging policies. (**SG/ Health and Social Care Partnerships**)

37. **HIS and the Care Inspectorate** should include palliative and end of life care in their scrutiny processes and provide periodic thematic reviews of key issues.

6.5.2 Local-level improvement

Small scale, locally led improvement work has an important role to play in improving systems and services, and it is essential to support local models and improvements underway now and in the future across Scotland. The IHI model is one tried and tested process for achieving improvement.

ACTION:

38. Where the right conditions have been created by national level actions, then the following key challenges (as detailed in Section 5) will require local improvement activity to develop, test and implement effective, local arrangements:
    - co-ordinating services across organisational boundaries and out of hours;
    - increasing the capacity of specialist palliative care to support generalist services better in hospitals, the community and care homes;
    - best practice in making decisions when people have reduced capacity;
    - anticipatory care planning;
    - shared decision-making;
    - involving and supporting carers;
    - Health and Social Care Partnership local needs assessments and planning;
    - talking about patient goals, deteriorating health and dying;
    - identification;
    - public engagement;
    - improving and fully utilising IT infrastructure;
    - care homes;
    - research;
    - education/training;
    - bereavement.

(Much of this work will require collaboration between different organisations, settings, professionals and sectors, and would benefit from engagement with the public.)

Glossary

World Health Organization Definition of Palliative Care

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

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organization Definition of Palliative Care for Children[17]

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other paediatric chronic disorders (WHO; 1998a):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

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[17] An alternative and commonly used definition is provided by Together for Short Lives 'Palliative care for children and young people with life-limiting conditions is an active and total approach to care, from the point of diagnosis or recognition, embracing physical, emotional, social and spiritual elements through to death and beyond. It focuses on enhancement of quality of life for the child/young person and support for the family and includes the management of distressing symptoms, provision of short breaks and care through death and bereavement.' www.togetherforshortlives.org.uk

Appendix 1 – Process

SPPC Council subgroup membership

A multidisciplinary sub-group of the SPPC Council with a range of expertise and perspectives has led the production of this paper:

Deans Buchanan	Consultant in Palliative Medicine NHS Tayside
Scott Davidson	Consultant in Respiratory Medicine NHS Greater Glasgow and Clyde
Shirley Fife	Nurse Consultant Cancer and Palliative Care NHS Lothian
Tanith Muller	Parliamentary and Campaigns Officer, Scotland Parkinson's UK
Euan Paterson	General Practitioner NHS Greater Glasgow and Clyde
Kenny Steele	Chief Executive Highland Hospice
Elaine Stevens	Nurse representative and Chairman International Association of Nurses in Palliative Care
Mandy Yule	Chief Executive Ayrshire Hospice

Development

This work has been developed in three stages:

- Stage 1: Environmental scan (Appendix 2), situation analysis and vision.
- Stage 2: Articulation of key issues which the strategic framework should address.
- Stage 3: Consideration of specific practical action that can be undertaken to improve palliative and end of life care in Scotland.

Each stage has culminated in a draft paper which has been circulated to SPPC members for consultation, and shared with Scottish Government colleagues and Professor David Clark for information. Drafting has been by SPPC staff, and each stage has been informed and shaped by comments received in the previous consultation.

SPPC membership

This paper has been developed in full consultation with SPPC membership organisations. The SPPC is the umbrella body representing the major organisations involved in palliative care in Scotland. Our membership includes all 14 territorial health boards, all 14 of Scotland's voluntary hospices, 17 major national health charities, 7 professional associations and 1 local support organisation. The membership of the Partnership is detailed at
www.palliativecarescotland.org.uk

Drawing on other resources

As well as three membership consultations, we have drawn on a range of additional relevant information to inform this final draft, including:

- the *3-Step Improvement Framework for Scotland's Public Services;*
- the final report of the Commission into the Future of Hospice Care, (October 2013): *Future ambitions for hospice care: our mission and our opportunity;*
- discussions relating to the Strategic Framework for Action at the Cross Party Group in the Scottish Parliament on Palliative Care, on 10 December 2014 and 9 September 2015;
- discussions at SPPC constituency group meetings;
- discussions held at the Palliative and End of Life Care Stakeholder Group on 23 March, 28 April and 11 August 2015;
- discussions at a round table event co-hosted with the Health and Social Care Alliance on 10 August;
- Marie Curie's report *Triggers for palliative care: Improving access to care for people with diseases other than cancer. Implications for Scotland* (June 2015);
- summary reports from the Scottish Government's summer public engagement events in Edinburgh (05 June), Glasgow (12 June) and Aberdeen (16 July);
- written evidence provided by a range of stakeholders in response to the Scottish Parliament Health and Sport Committee inquiry into palliative care over the summer;
- Professor David Clark's report for the Scottish Parliament Health and Sport Committee: *International comparisons in palliative care provision: what can the indicators tell us?*
- discussions relating to the Out of Hours Review at the meeting of the Cross Party Group in the Scottish Parliament on Palliative Care on 11 March 2015, and input from the palliative care representative on the OOH Review reference group;
- *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020* published by the National Palliative and End of Life Care Partnership in September 2015;
- discussions with Alzheimer Scotland about their development of an Advanced Dementia Model.

Accessing additional expertise

In addition to the above process, we have also sought views from:

John Birrell	Chair of the Scottish Working Group on Funeral Poverty, former Convenor of the Scottish Grief and Bereavement Hub.
Theresa Fyffe	Director, RCN Scotland
Maggie Grundy	Programme Director, NHS Education for Scotland
Beth Hall	Policy Manager, Health and Social Care Team Convention of Scottish Local Authorities
Ranald Mair	Chief Executive, Scottish Care
Scott Murray	St Columba's Hospice Chair of Primary Palliative Care University of Edinburgh
Tommy Whitelaw	Lay Carer and Project Engagement Lead Dementia Carer Voices, The ALLIANCE

Appendix 2: Environmental scan

Living, dying and bereavement are all constants, but political, economic and cultural landscapes change over time. The position paper is informed by an awareness of the various current and anticipated factors likely to impact on the future of palliative and end of life care in Scotland. The SPPC's environmental analysis is presented below:

Political environment

- political and policy divergence within UK;
- referendum on Scottish independence;
- possible EU exit;
- politicians face difficulties in acknowledging resource pressures and the hard choices these necessitate;
- the tacit endorsement by many politicians of NHS 'death is failure' culture.
- centralisation of NHS Boards?
- integration of health and social care;
- the possibility of ministerial changes;
- Scottish Parliament election in 2016;
- wider policy environment (eg Dementia Strategy, 2020 Vision refresh, Out of Hours review, Person Centred Care, Primary Care , GIRFEC etc);
- cross party consensus on no significant tax increases to fund health and social care;
- Scottish Parliament Health and Sport Committee inquiry into palliative and end of life care;
- possible future changes to the Scottish GP contract.

Economic

- very tight public finances;
- health and social care system struggling to cope with population needs;
- manpower shortages (eg GPs, palliative care specialists, home care workers, district/ community nurses), compounded by increasing elderly/ retired population and shrinking workforce;
- sustainability of health and care system;
- tough fundraising environment for third sector;
- poverty, economic and health inequalities;
- the balance between personal responsibility and state responsibility for care costs, particularly in old age;
- the perceptions and reality of the health economics of palliative care;
- the cost of care homes, care at home and respite care – How can care be provided in a way that is sustainable for providers yet affordable for those in need?

Social/cultural

- baby-boomer expectations of choice and control;
- paternalism (still present, though weakening);
- the stigma of aging;
- the pre-eminence of celebrity;
- continuing growth of secularism and declining role of faith;

- demographics (aging population, baby and child survival, patterns of disease, immigration);
- patterns of social connection and community;
- composition and locations of families and households;
- denial of aging and death;
- fear of dying and lack of openness about death, dying and bereavement;
- dominance of cancer discourse on death and dying;
- scepticism about palliative care as an 'unequivocally good' since LCP media furore;
- healthcare system equates death with failure;
- growth and changing models of volunteering;
- media influence on public opinion and political decision-making;
- perceptions that hospital is always the best place to be when you are unwell;
- informal carers providing large amounts of care, but often unsupported, unrecognised and undervalued.

Technological

- telehealth;
- telecare;
- further advances in postponing death/extending dying (from neonates to centenarians);
- better drugs for symptom management;
- technologies to support independent older living;
- social media;
- technologically mediated community (support groups, care circles, Skyping relatives);
- sharing of clinical information across settings;
- electronic measurement of activity and outcomes;
- marginalisation of the technologically disenfranchised (eg frail old people, sensory impaired people, very sick people, poor people) and risk of reduced face to face contact for those who value it.

Legal

- Duty of Candour Bill;
- Deliberate Neglect/ Ill treatment legislation;
- litigiousness and consequent risk aversion vs. promotion of autonomy, control, candour;
- increasing 'rights-based' approaches to health;
- Children and Young People Act (Scotland) 2014;
- data protection vs. information sharing across all settings;
- continuing care framework;
- review of Adults with Incapacity;
- barriers to: power of attorney, advance directives, wills;
- changes in HIS and Care Inspectorate regulatory approaches and national care standards;
- interplay of legal and regulatory issues with professional and personal ethics;
- further possible assisted suicide bills;
- Social Care (Self-directed Support) (Scotland) Act 2013;
- Community Empowerment and Carers Bill.

Appendix 3: Summary of actions

Taken together these actions create the necessary conditions for change, describe specific changes required and specify a broad framework of accountability. For each action we suggest in parentheses the organisation(s) involved in taking action, with the first named best placed to act as the lead.

Actions are grouped under the following themes:

- Leadership;
- Public Health approaches to palliative care;
- Education/ Training;
- Measurement;
- Change and Improvement.

Critical systemic challenges

It is important to highlight that there are several key challenges that fall outwith the scope of this report to address, as they are not issues that relate solely or mainly to the provision of palliative and end of life care.   Most palliative care is provided within generalist settings of the health and social care system and so wider systemic issues impact on the quality of palliative care which people experience. Key requirements include:

1. Terms and conditions of employment which support better recruitment, retention and skills/knowledge development in the social care sector. Care homes for older people, for example, support residents with typically high levels of need and 22% of people die in a care home.

2. Adequate capacity in general practice/ primary/ community care to support sensitive conversations, continuity and co-ordination of care.

3. Adequate capacity (and environment) to provide palliative and end of life care in very busy acute hospital wards. Often dying at home will not be possible (or ultimately desired) by the person/family, so there is a need to consistently enable ways of dying in hospital which reflect elements of a 'homelike' experience (for example privacy, peace, contact with loved ones, connections to meaningful memories).

6.1   Leadership
Scottish Government

1. The Scottish Government should exemplify a culture of openness and honesty relating to declining health and death. Publications, policy documents and speeches produced by the Scottish Government should openly acknowledge deteriorating health, death, dying, uncertainty and bereavement as part of the human experience, and the eventual end point of all lives, whether short or long.

2. The Scottish Government should describe a clear framework of accountability for the aims, objectives and outcomes of the Strategic Framework for Action.   The strategic and operational plans of Health and

Social Care Partnerships and Special Health Boards should be required to link to the aims, objectives and outcomes in the Strategic Framework for Action. Key milestones should be identified.

3. The Scottish Government should ensure the alignment of relevant Scottish Government work streams to promote embedding of palliative and end of life care, and that they explicitly acknowledge that palliative care, death, dying and bereavement are key issues for the health and social care system to address. Relevant work streams include Dementia; Carers; GIRFEC; Clinical Strategy; Out of Hours and Primary Care; Residential Care Taskforce; Chief Nursing Officer Review of Education: Setting the Direction and the Transforming Nursing Roles; Person Centred Care; Patient Safety and Unscheduled Care. By 'alignment' we mean that these work streams should set out explicitly activities, outputs and objectives which contribute to the outcomes of the Strategic Framework for Action.

4. The Scottish Government should ensure that key stakeholders are fully involved in decision making about how the recently announced £3.5 million new investment to support improvements to palliative and end of life care is spent.

5. The Strategic Framework for Action should set out plans for fulfilling the function of a 'guiding coalition', linked to a clear framework for accountability. The coalition should include a mix of subject experts and high level strategic influencers including those leading the major service delivery organisations.

Scottish Partnership for Palliative Care

6. The SPPC should maintain intelligence about what is going on in the many different settings and work streams which are relevant to improving palliative care so that policy and practice is well informed and opportunities for collaboration are identified.

7. The SPPC should advocate the importance, value and specific contributions of palliative and end of life care in delivering national outcomes for health and social care so that they are more likely to be achieved.

8. The SPPC should provide a network for the champions who are at the forefront of change and innovation so that innovation is encouraged and learning is shared.

9. The SPPC should broker strategic collaboration to deliver specific projects where this avoids wasteful local duplication of effort and/or where a national approach is necessary.

Health and Social Care Partnerships

10. In the short term there is a need to achieve clarity about how health and social care integration will affect the organisation and delivery of palliative and end of life care, especially services which operate across several Health and Social Care Partnerships. An identified individual at senior level within each NHS Board should ensure clear arrangements are established and published for:

   o commissioning of hospice services;
   o palliative care within acute hospitals;
   o children and young people's palliative care.

11. Health and Social Care Partnerships should have an identified lead for palliative and end of life care, who should be invited to join the local palliative care MCN.

12. Health and Social Care Partnerships should include palliative care within their strategic and operational plans, and these should be linked to delivery of national outcomes.

13. The Health and Social Care Partnership(s) within each NHS Board geographical area should establish a truly integrated and fully functioning strategic body, such as an MCN, focused on improving palliative and end of life care.

14. Health and Social Care Partnerships should ensure that their strategic planning and decision making is informed by adequate representation from local service users and providers of palliative and end of life care.

15. In commissioning care at home, care homes and other relevant social care services, Health and Social Care Partnerships should include explicitly the provision of care for people with palliative and end of life care needs, stipulating clear quality standards. Contracts need to resource adequately the development and retention of leadership and a workforce equipped to provide the care required by people with high levels of need. The Key Challenges relating to care homes identified in Section 5 need to be addressed.

Healthcare Improvement Scotland and the Care Inspectorate

16. HIS and CI scrutiny and improvement activities should include a focus on palliative and end of life care (including bereavement), reinforcing the priority attached to this area.

Hospices and other providers of specialist palliative care

17. Hospices and other providers of specialist palliative should continue to lead in:
    o advocating the importance and contribution of palliative and end of life care;
    o innovation of practice and models of care including early palliative and supportive care and integration with other specialties and services;
    o brokering collaboration and partnerships with other specialities and other providers;
    o the development and delivery of education.

Leadership by individuals

18. Influential individuals within all the organisations listed in section 1.1 (page 7) should play a key role in raising the profile of palliative and end of life care and exemplifying a culture of openness and honesty relating to declining health, death and bereavement through their words and actions.

19. Individuals working in all organisations and at all levels should contribute to the creation of a caring and honest culture in their own workplace - treating staff, patients and those who matter to them with empathy and creating a supportive environment of staff reflection and support while acknowledging resource constraints.

20. Individuals should all use appropriate language which is honest about deteriorating health, death and the uncertainties involved.

6.2 Public Health approaches to palliative care

21. Scale up a programme of activity to promote a culture of openness about death, dying and bereavement in Scotland **(SPPC supported by SG and NHS Health Scotland)**, including the following key actions:
    o undertake proactive and sensitive public and media engagement in the development of a *Charter for a Good End of Life*, empowering the general public and health and social care professionals by listening to views, establishing clear terminology, and developing honest and accessible information about the support people can expect to receive as they approach the end of life;
    o draw on work already carried out by Public Health England and the National Council for Palliative Care and develop a practical toolkit to assist Scottish communities in identifying and addressing local problems relating to death, dying and bereavement;
    o develop and promote an engaging resource which supports people from socio-economically disadvantaged communities to discuss and plan for the financial, medical, legal, practical and emotional issues which arise towards the end of life;
    o promote, within the framework of *Curriculum for Excellence*, wider use of existing resources which encourage conversation, education and support around death, dying and bereavement experiences for children and school staff in primary and secondary education;
    o identify and proactively address the barriers people face in making wills, powers of attorney and advanced directives including provision of free legal advice where appropriate;
    o develop better mechanisms to enable direct patient and carer involvement in policy, service and practice development.

22. In the context of welfare reform and the forthcoming Bill relating to burial and cremation and other related matters in Scotland develop measures to reduce funeral poverty. (**SG**)

23. Develop leaflets appropriate for all ages and cultures, on '*What to expect when someone you care about is becoming more unwell and dying*' for distribution to health centres and other public places around Scotland. (**NHS Health Scotland**)

(See also section *6.4 Measurement* for actions relating to the need for public health data and intelligence to inform planning and service design at population level.)

6.3 Education/Training

24. Drawing on the EAPC White Paper on palliative care education, and learning from implementation of *Promoting Excellence in Dementia,* develop, publish and promote a Targeted Educational Framework for palliative and end of life care. The framework should be built on the premise that all health and social care workers need a level of knowledge and skills to care for people facing the difficulties and uncertainties of

deteriorating health. The framework should be underpinned by values and principles that reflect what people in such circumstances (and their families and carers) say are important to them. The educational framework should have a number of levels which relate not simply to the seniority of an individual in an organisation or profession but also to their level of involvement with people with deteriorating health and their families. (**NHS Education Scotland/ Scottish Social Services Council**)

25. Develop a directory of existing educational resources which can support provider organisations to implement the Targeted Educational Framework. Further development and regular updating of the Knowledge Network online resources could be considered. (**NHS Education Scotland/ Scottish Social Services Council**)

26. Include relevant palliative and end of life content in undergraduate, postgraduate and pre-qualification curricula. For example a palliative care curriculum for undergraduate medical students in Scotland has been developed but not fully implemented. (**Professional bodies/ Regulators; Colleges/ Universities/ other education providers**)

27. Using the Targeted Educational Framework outlined above, and informed by the proposed directory (action 25), develop and deliver a systematic and structured approach to workforce development in palliative and end of life care in which attainment of the requisite level of skills and knowledge is ***mandatory***. Key areas for focus are likely to include the expected contribution of different staff groups to: palliative care; earlier identification; supporting wellbeing; initiating and facilitating individualised and sensitive conversations relating to planning for the future; managing uncertainty; death and bereavement; compassionate care and connecting with empathy; knowledge of local resources/services and pathways. Modes of training/education are likely to include workplace-based, shadowing and reflective practice. (**Health and Social Care Partnerships/ SG/ NES**)

28. Where the relevant model of validation permits, link competencies in palliative and end of life care to professional revalidation processes. (**General Medical Council/ Nursing and Midwifery Council etc**)

6.4 Measurement

29. A national approach to gathering feedback about palliative and end of life care from bereaved family members should be put in place. Initially this should be done by using the VOICES methodology which has been validated and used extensively in other parts of the UK and some Scottish Boards. (**SG**)

30. Establish a short life working group to develop as a priority a robust measurement framework for the Strategic Framework for Action, scope existing data and to identify the other key data (and non-quantitative information) required to support future improvement of palliative care in Scotland. (**SG**)

Input should be sought from information/data specialists currently working in this area, those with relevant academic expertise, and others with relevant knowledge and experience. The Group's work should include consideration of:

- o patient-reported outcome measures;
- o outcome measures that are meaningful to individuals and families;
- o audit of key information summary (KIS) data;
- o case note reviews (including KIS data)/ after death analysis;
- o use of Patient Opinion and Care Opinion websites, collection of carer stories, and rapid feedback mechanisms (eg postcards);
- o coding of complaints to allow end of life and bereavement issues to be recorded and analysed;
- o thematic case review by the Office of the Scottish Public Ombudsman Service;
- o outputs of any forthcoming Scottish Child Death Review System;
- o Professor David Clark's report to the Scottish Parliament: *International comparisons in palliative care provision: what can the indicators tell us?*
- o the OACC Palliative Care Outcome Measures Resource Pack produced by the Cicely Saunders Institute and Hospice UK;
- o alignment of scrutiny by HIS and the Care Inspectorate;
- o data extractable through linkage and analysis of existing sources[18] to inform:
  - ▪ assessment of current and future needs population needs;
  - ▪ characterisation of patterns of service use (including inequalities);
  - ▪ characterisation of patterns of resource use.

6.5 Change and Improvement

System-level solutions and improvements: Where national/system-wide actions have been identified under other themes (Leadership, Education, Public Health, Measurement) we have not restated them here.

31. The **Scottish Government** should ensure the right resources are available to support local improvement activities by:
    - o ensuring the alignment of existing improvement infrastructure (Healthcare Improvement Scotland/ Joint Improvement Team/ Quality Improvement Support Team) to support activity focussed on palliative and end of life care;
    - o establishing a 'Change Fund' for palliative and end of life care to resource innovation and free up champions to combine improvement work with existing clinical commitments.
32. **Scottish Government** should take advantage of opportunities for cost-effective national collaboration, for sharing and spreading learning, and harnessing of expertise by supporting and resourcing national activities co-ordinated by the Scottish Partnership for Palliative Care.
33. Establish properly functioning and accessible ICT infrastructure to support embedding of KIS (**SG/ NHS National Service Scotland/ NHS Boards**)
34. Mandate the development of a consistent national approach to policy, communication and documentation of CPR decisions and emergency treatment plans. (**SG/ HIS**)
35. The revised National Care Standards, and the new general standards for

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[18] For example ISD has generated lots of relevant data at Health and Social Care Partnership level

palliative care expected from HIS, should be developed in a way which reflects outcomes important to individuals and families, and provides a helpful focus for local service delivery and improvement. (**Care Inspectorate/ HIS**)

36. Palliative care is holistic care. Whilst healthcare is free at the point of delivery people with palliative care needs may be charged for other equally important support (eg home care, respite care). In the context of integration, SG and Health and Social Care Partnerships should provide clear information for the public about charging policies, and also work towards the reduction of inconsistencies in charging policies. (**SG/ Health and Social Care Partnerships**)

37. **HIS and the Care Inspectorate** should include palliative and end of life care in their scrutiny processes and provide periodic thematic reviews of key issues.

Local-level improvement: Small scale, locally led improvement work has an important role to play in improving systems and services, and it is essential to support local models and improvements underway now and in the future across Scotland. The IHI model is one tried and tested process for achieving improvement.

38. Where the right conditions have been created by national level actions, then the following key challenges (as detailed in Section 5) will require local improvement activity to develop, test and implement effective, local arrangements:
    o co-ordinating services across organisational boundaries and out of hours;
    o increasing the capacity of specialist palliative care to support generalist services better in hospitals, the community and care homes;
    o best practice in making decisions when people have reduced capacity;
    o anticipatory care planning;
    o shared decision-making;
    o involving and supporting carers;
    o Health and Social Care Partnership local needs assessments and planning;
    o talking about patient goals, deteriorating health and dying;
    o identification;
    o public engagement;
    o improving and fully utilising IT infrastructure;
    o care homes;
    o research;
    o education/training;
    o bereavement.

(Much of this work will require collaboration between different organisations, settings, professionals and sectors, and would benefit from engagement with the public.)

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