



Strategic Framework for Action

1. Purpose of this position paper

This paper updates and sets out the current position with development of the Framework for Action and confirms the consensus around key themes based on inputs received by December 2014. This paper will be made available widely to facilitate wide participation in the development of the Framework.

2. Background

Death is normal. We can all help each other with death, dying and bereavement.

Good Life, Good Death, Good Grief is an Alliance of organisations and individuals that want to work together to:

- Raise public awareness of ways of dealing with death, dying and bereavement
- Promote community involvement in death, dying and bereavement

Good Life, Good Death, Good Grief is working to make Scotland a place where there is more openness about death, dying and bereavement so that:

- *People are aware of ways to live with death, dying and bereavement*
- *People feel better equipped to support each other through the difficult times that can come with death, dying and bereavement¹*

¹ Scottish Partnership for Palliative Care - Good Life Good Death Good Grief (2014) - more information available at <http://www.goodlifedeathgrief.org.uk/>



Key to achieving this is considered to be through the creation of a greater openness about these issues at a national, local and at individual level.

Context

More and more adults are now living longer sometimes with long term conditions. More children with life shortening conditions are now living into adulthood. The care provided, including palliative and end of life care, therefore matters to everyone across all health and care settings and across our wider community.

Over 54,000 people die in Scotland each year with the number of deaths expected to rise by 5% from 2013 to 2030². Of the people who died last year, 70% had palliative care needs³.

Death and dying has become more medicalised, in 1949 an estimated 81% of deaths occurred at home compared to around 45% who died at home or in a Care Home in 2013.⁴

*“...almost 1 in 10 patients in teaching or general hospitals at any given time will die during that admission. Almost 1 in 3 patients will have died a year later, rising to nearly 1 in 2 for the oldest groups.....”*⁵ This extract is from a study of inpatients in 25 Scottish teaching and general hospitals on 31 March 2010.

² Scotland's Population 2013 - The Registrar General's Annual Review of Demographic Trends

³ Palliative Care Funding Review - Funding the Right Care and Support for Everyone. 2011

⁴ National Records of Scotland

⁵ Clark, D; Armstrong, M; Ananda, A; Graham, F; Carnon, A; and Isles, C; Imminence of death among hospital inpatients: Prevalent cohort study – Palliative Medicine (2014), Vol. 28(6) 474 – 479.



National Position

Living and Dying Well (2008), Scotland's first national action plan for palliative and end of life care, was successful in raising awareness of the need for high quality palliative and end of life care across a range of groups, bringing together a range of disciplines and networks to develop a consensus position on the requirements for change.

Building on the good work of *Living and Dying Well*, the Scottish Government is committed to the development of a *Strategic Framework for Action*, in order to provide a focus and to further support the delivery of high quality palliative and end of life care for all across all health and care settings e.g. in hospital, at home, in Care and Nursing Homes, in Hospice or any other setting. The strategic framework will be published spring 2015.

Its development will be linked with the Scottish Government's 2020 Vision for Health and Social Care. The 2020 Vision is that by 2020 everyone is able to live longer healthier lives at home, or in a homely setting and, that we will have a healthcare system which, among other things, will have integrated health and social care.

The Strategic Framework will set out how key stakeholders can apply the 'Three Step Improvement Framework for Scotland Public Services' (the Scottish Government's ambitious programme of change in response to the Christie Review of Public Services) to the changes required to support improvement.

It is anticipated that the Strategic Framework will include for adults and children high level aims and ambitions within which all health and care providers will have the scope to work together to develop local plans in order to deliver improvements and to meet the palliative and end of life care needs of local populations.

Position Statement - Strategic Framework for Action – High-level milestones

- **February 2014** – Scottish Government commitment to develop a Framework for Action
- **April 2014** – Mapping and scoping exercise underway and ongoing through discussions with key stakeholders/visits to Boards and independent adult Hospices and CHAS/attendance at a variety of meetings and events.



- **April 2014** – Institute for Healthcare Improvement (IHI) Conversation Ready Pilots commenced and ongoing (due to report March 2015) the outputs of which will inform the development of the Framework for Action.
- **September 2014** - first meeting of NHS Board designated Palliative and End of Life Care Executive Leads
- **November 2014** – newly establish Palliative and End of Life Care National Advisory Group (NAG) met for the first time.
- **November 2014** – Review of the Do Not Attempt Cardiopulmonary Resuscitation Policy (DNACPR)– sub-group established and met for the first time. Review to conclude by end March 2015.
- **November 2014** – Publication of NHSScotland Palliative Care Guidelines on Healthcare Improvement Scotland website.
- **December 2014** – Care for people in the last days and hours of life - Guidance published.
- **January 2015** – First Framework for Action Progress Report
- **January 2015** – Healthcare Improvement Scotland Scottish Patient Safety/Deteriorating Patient and DNACPR Meeting
- **January 2015** – First NHS Education Scotland (NES) Scottish Grief and Bereavement Steering group meeting
- **February 2015** – NAG meeting
- **February 2015** – Hospice Quality Improvement Forum (HQIF) meeting – a NAG sub-group.
- **February 2015** – DNACPR Review Group second meeting

3. Development of the Framework – Guiding Principles and ways of working

The First Minister announced on 26 November 2014, The Programme for Government, founded on three key priorities – **participation, prosperity and fairness.**

Working in **participation** both at a national and local level through more public discussions, an open and accessible government – handing decision-making powers back to communities. This Strategic Framework will be developed following this guiding principle to help ensure its development is led and informed by the public, health and care professionals, academics and others all with an interest in palliative and end of life care.

The successful development and implementation of a Framework for action will be achieved through -



- **co-production** – enabling people to shape and co-design the services they use; and
- **an asset based approach** – valuing the strengths of people and communities to build social capital and capacity;

The development of bold and widely understood palliative and end of life care aims will link closely to and build on associated work and policy direction being developed through other work, for example, the ALLIANCE People Powered Health and Well-being work⁶, Stronger Voice⁷ and Person Centred Healthcare⁸. The collective communication and marketing expertise across a coalition of organisations will also be explored all with the aim of creating the conditions to raise awareness to allow both private discussions and a wider national conversation around *Good Life Good Death Good Grief*.

The Scottish Government Palliative and End of Life Care website portal is being refreshed and to further help facilitate public discussions, a dedicated e-mail address has been established to allow continuous feedback throughout the drafting process: PEOLC@scotland.gsi.gov.uk . Utilising social media channels for feedback opportunities is currently being explored.

4. Early Feedback

The undernoted 5 suggested key themes were considered and confirmed appropriate around which the Strategic Framework for Action will be structured.

1. What matters to me?
2. Change and Improvement
3. Leadership (national and local)
4. Education
5. Evidence Base

⁶ People Powered Health and Well-being – ALLIANCE - more information available at <http://www.alliance-scotland.org.uk/what-we-do/projects/people-powered-health-and-wellbeing/>

⁷ Stronger Voice – Scottish Health Council – more information available at http://www.scottishhealthcouncil.org/patient_public_participation/stronger_voice/stronger_voice.aspx

⁸ Person-Centred Healthcare Collaborative – more information available at http://www.healthcareimprovementscotland.org/our_work/person-centred_care/person-centred_collaborative.aspx



Annex A sets out some general feedback with comments/input that was structured around the agreed 5 key themes summarised at **Annex B** .

5. Next Steps

- 5.1 The Palliative and End of Life Care National Advisory Group and its sub-groups will lead the further development of the Framework.
- 5.2 The Person Centred Stakeholder Group is carrying out focussed work in January and the establishing Palliative and End of Life Care Stakeholder Group will input to and inform the on-going development of the Framework.
- 5.3 The dedicated Scottish Government website will be further refreshed and developed to update on progress throughout the early part of 2015. Consideration of social media as a vehicle for participation to be pursued.
- 5.4 A small working group to be established to consider an appropriate measurement infrastructure.
- 5.5 Progress Reports updating on the development of the Framework will be published regularly.
- 5.6 A small design group will be established to start an iterative process of drafting the Framework based on the continuous flow of comments and inputs received. This group will establish and publish a drafting and engagement timeline to fit with spring 2015 timescale.

**Health Quality and Strategy Directorate
January 2015**

General Feedback

1. Clear definitions required for 'palliative' and 'end of life' care. Generalist palliative care (or perhaps 'primary palliative care' – i.e. palliative care at point of need with a recognition by the professional in that setting (either in the community, hospital, hospice etc) on what can be provided, what are the limits and when does a referral to palliative care services need to be made?
2. Specialist palliative care/palliative care service - High level definition of what is expected from palliative care services in acute, nursing homes, community and hospice settings.
3. Palliative care service delivery perhaps considered in two strands -
 - symptom control throughout life/illness
 - end of life care
4. Change/ Improvement and Leadership perhaps merged into one key theme?
5. Education/evidence base/research perhaps merged into one key theme?
6. Co-production and building community capacity and assets to create communities less reliant of health and social care systems (with links to Good Life Good Death Good Grief) e.g. Highland utilising income generated from wind farms to build end of life care/care for older people facilities.
7. Specific actions for Boards and other agencies should be included in the Framework including what actions are required to deliver on the key high level priorities identified.



8. Clinical strategic top priorities made explicit within the Framework to penetrate various specialties/sub-specialties including medicine, surgery, Primary Care, community, Allied Health Professionals and Nursing.
9. The Framework should be seen as a system wide governance and accountability framework referencing leadership and local delivery mechanisms.
10. Health promoting/public health approaches to palliative care perhaps as a separate key theme?



Summarised comments and input received structured around the agreed 5 key themes

(1) What Matters to me?

Who is me? – needs to cover all including person; family members; carers; health and care professionals; volunteers providing care?

What is expected of me? As a health and care professional - where are the boundaries e.g. pain control/pain/palliative care services.

Identification of carers of patients with advance illnesses. Recognition of and emphasis on the role of the carer.

A carers assessment - The Community Care and Health (Scotland) Act 2002

A National Conversation - *Good Life; Good Death; Good Grief* aims and outcomes underpin this theme.

Anticipatory Care Planning (ACP) (and patient passports) - Anticipatory medicines, care planning and joint discussions about treatment intentions.

Person centred planning e.g. eight indicators of wellbeing SHANARRI (Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible, Included).

Self-directed support (SDS) - the support a person purchases or arranges to meet agreed health and social care outcomes.

Children and Young Adults

- Transition from children's to adult palliative and end of life care services.



- GIRFEC – Getting it right for every child – A Plan and model for all?
- United Nations Convention on the Rights of the Child – UN CRC (articles 3,5,12)
<http://www.scotland.gov.uk/Resource/0041/00417256.pdf>

Language used (see comments to specialist/generalist/palliative/supportive care at Annex A).

(2) Change and Improvement

Measurement and Data crucial e.g. to support assurance at a local, regional and national level and also locally by NHS Boards capacity plan and develop improvement plans.

Clear strategic direction setting and aims required in the Framework.

Systems to support communication of priorities and care plans across different care settings. IT/e-health support is a vital component.

Identify levels of care required – specialist/generalist/ care and compassion.

Evidence of Plan Do Study Act (PDSA) cycles to evidence change at and across a local level with local/regional and national sharing.

(3) Leadership

A common vision requires to be articulated in the Framework for Action.

Key role in quality and safety – “See it, Solve it, Own it”.



High profile national leadership as well as local leadership e.g. should every NHS Board have an identified lead/key doctor and nurse for adult and paediatric palliative care services (GIRFEC model?).

End of life not just a health topic - Leadership to facilitate integrated service delivery across primary/secondary care interface as well as health and social care.

Leadership to articulate the importance of palliative and end of life care in new integrated health and social care structures.

Accountability – system required to allow for accountability to be transparent at all levels.

Leadership around the measurement and reporting of end of life care complaints to facilitate change and improvement.

(4) Education

GIRFEC – child's plan – Children & Young People's Scotland ACT 2014 – Importance of knowledge of:

- Adults with Incapacity Act 2000
- Guardianship especially for those young people with non-verbal communication/CEN
- Children & Young People Scotland Act 2000

Communication – *Conversation Ready* and spread of learning from this Institute for Healthcare Improvement (IHI) project and the three pilot sites.

Clinical education role for palliative care at a national level?

The role of carers and volunteers in delivering support for people at end of life – how can they be better supported?

Build capacity and capability in generalist services.



Attitudes and compassion e.g. GG & C rapport work as an example.

Public attitudes and learning opportunities.

NHS Education Scotland Bereavement Hub – Supporting Scottish Grief and Bereavement Care.

Supporting all community settings to deliver good end-of life care.

Undergraduate and post-graduate education.

(5) Evidence base (to include research)

Are patients with palliative care needs identified? Is this a barrier to delivery to timely delivery of palliative care.

Local integrated care pathways for palliative care.

NHSScotland Clinical Guidance published on Healthcare Improvement Scotland website.

Care for people in the last few days and hours of life and links to the NES Clinical Knowledge Publisher site.