Scottish
Partnership
for Palliative Care

SPPC Response to the public consultation on the SG Strategy for Palliative Care

Process

This response draws on engagement with SPPC members and other stakeholders. SPPC routinely engages with practitioners across the health and social care system, and with lay people and communities through the Good Life, Good Death, Good Grief alliance. This engagement provides insights into issues, concerns and priorities. This draft response was additionally informed by a series of bespoke stakeholder workshops. The response was then further refined through input from members of SPPC's Council, who bring a range of perspectives and leadership roles from different fields. In some of the discussions there were sometimes quite divergent views on some aspects of the strategy, particularly around specific detail. The paper aims to emphasise areas of broad consensus or majority view.

Congratulations on the good work done!

SPPC recognises the huge amount of work which has gone into the development of the draft strategy and the associated papers which provide detailed evidential support. SPPC also recognises that a government strategy is developed and written within specific constraints. All the comments and suggestions offered in this paper are offered in a constructive spirit, in support of shared aims.

SPPC's Approach to this consultation

This response does not aim to provide comprehensive detailed comment on what is a long document. Rather, at this late stage in a long process, this paper aims to focus on making practical suggestions which could have most effect in increasing the impact of the strategy document. The SG Policy Team have rightly said a strategy *document* is only one aspect of a wider process.

Strategy documents take many different forms and perform different functions in different contexts. SPPC's view is that this strategy document should:

- **Make a compelling case for change**
- **Describe the aspiration for change (vision/outcomes)**
- **Provide a sense of how the envisaged change will be delivered**

- **Engage key audiences.** SPPC views the key audiences for this strategy document to be: senior leadership at NHS Boards and IJB/HSCPs; local management; those delivering services; and Ministers and senior officials within SG. (see also comment on Public Understanding below).

Comments

Brevity

The strategy is too long. Because palliative care is not well understood the strategy includes a lot of explanation and description. However this gets in the way of clear messaging. **Suggestion** *Add a clear and succinct executive summary.* **Alternative suggestion** *Undertake a more major redraft which focusses on content which is essential to the purposes of a strategy document.*

Stronger links to system priorities

Suggestion *make explicit, and highlight clearly, the links between improving experiences of living with serious illness, dying and bereavement and the key pressures which senior leaders in the health and social care system are prioritising and struggling with: unsustainable financial pressures; unscheduled care; acute capacity; delayed discharge; aligning resource use to value; quality of care experience.*

Honestly and powerfully articulate bad experiences

Part of any case for change are the things which must be improved. **Suggestion** *Include some examples of the poor experiences towards the end of life which the strategy intends to address.*

"How will that happen?"

Although the aims and outcomes in the strategy are generally supported (see below) most stakeholders are unconvinced that they will all be delivered. A mix of reasons is associated with this scepticism:

1. Readers are aware of financial challenges across the system
2. Readers are aware of workforce challenges across the system
3. Lack of clarity on organisational responsibilities and accountability for delivery – how is what the strategy proposes impactfully different from the current organisational arrangements which are widely viewed as inadequate?
4. A feeling that the actions in the strategy aren't sufficient to achieve the outcomes (especially in the context of 1] and 2] above)……..

5. ....sometimes linked to a lack of awareness that the strategy will have an associated delivery plan and/or a feeling that there isn't an opportunity to comment on crucial detail
6. Minimal mention of investment (and a realism about what can be done in the absence of funds)
7. No mention of mechanisms which would enable repurposing of existing resources, for example where this could reduce avoidable admissions and promote timely discharge

1,2 & 6 **Suggestion** *Acknowledge briefly but explicitly the financial challenges facing providers of palliative care (NHS, third and independent/private sector).* **Suggestion** *Be more explicit about how it is envisaged change can happen in the current climate, for example: positioning work in the palliative care strategy within other SG workstreams which have priority/resource (synergies); better planning/commissioning processes which may lead to better use of resource across the system; focussing on actions with small/minimal financial bottom line but some impact.* **Suggestion** *Cross reference more of the wider NHS and social care reform agenda, and SG workforce strategy which may have an impact on general settings.*

3 **Suggestion** *Include clear statements and graphics on the roles, responsibilities, connections and reporting mechanisms of NHS Boards, IJBs and central government.* ***Suggestions*** *Include explanatory links to the infrastructures referred to on p7: "National Clinical Framework"; "Strategic Networks"; "portfolios of care"; "Operating models"; and "service standards".*

4, 5 The draft strategy already says that the final version will itself be clearer, and will be accompanied by a more specific delivery plan which will set out how things will be achieved. **Suggestion** *Ensure that there is a single consistent hierarchy of Aims, Outcomes, Actions, Outputs etc across the two documents.* **Suggestion** *Give delivery partners adequate opportunity to inform relevant sections of the delivery plan.*

7 **Suggestion** *Clearly and strongly encourage palliative care initiatives which simultaneously align treatment decisions with people's priorities and whilst reducing high-cost overmedicalisation. ~~Direct~~ Clearly and strongly encourage the reinvestment of a % of any savings into palliative care.* **Suggestion** *Is there a specific action by SG which can be added to the strategy which would make re-alignment of resources more possible? e.g. A commitment to work with SG finance and IJB/NHS planning and commissioning colleagues to address the current system rigidities?*

Aims

There is general support for the intended aims of the strategy.

Outcomes

There is general agreement that the outcomes in the strategy express very relevant intentions for change / improvement.

There is curiosity and concern about how and whether the outcomes can be achieved given the very challenging context (and because much of the detail of intent is, by design, not in the strategy itself). Stakeholders are keen to understand what, how, who, by when. Stakeholders are also keen to understand whether some aspects of the strategy have particular priority.

Some additional comments are given under each outcome at the end of this document.

Terminology and Clarity

Public understanding of the strategy

Suggestion *Run the text through some plain English or readability software to identify potential improvements on clarity.*

Suggestion *Produce a summary version of the strategy for the public (which would also be useful for marginally interested professionals).*

"palliative care", "palliative care service(s)" and "access to palliative care"

To avoid confusion and promote understanding the strategy should be more rigorous in its use of these terms. The term "palliative care service(s)" only really makes plain English sense when referring to a specialist service (like a hospice or a hospital palliative care team). People receive palliative care from GPs, DNs and in care homes but these aren't readily understood as palliative care services. The phrase "accessing palliative care" is similarly problematic for care which is embedded within general services. People can generally "access" their GP, but they may or may not then receive palliative care. People will be admitted to ("access") hospital but not receive the palliative care they need. **Suggestion** *Run a word search of the strategy and only use the phrase "palliative care service(s)" where referring to specialist services (and consider using "specialist palliative care service" if that is the intended meaning).* **Suggestion** *Replace "access to palliative care" with references to "receiving palliative care" (or "not receiving").* **Suggestion** *Consider whether "the needs of palliative care service users" clearly defines whose needs are being described (and also whether this phrase excludes people living with serious illness who may not be using palliative care services [and who have unmet needs]).*

Definition of palliative care

The definition of palliative care used at the beginning of the second section on p5 (and in the glossary) doesn't seem to relate fully to the WHO reference cited. It makes no mention of life-threatening illness as context. As ever there is a diversity of view amongst stakeholders about the best way to define and the best way to explain palliative care.

"Care around dying"

Stakeholders are confused about this completely new term until they reach the definition provided later in the document. **Suggestion** *Add a definition in a footnote the first time it is used*. Stakeholders are unclear why this term has been adopted. **Suggestion** *Include a more comprehensive rationale for the decision to adopt this new terminology, including the element about achieving distinction between palliative care and dying. Explain the relationship between palliative care and care around dying: is care around dying part of palliative care?*

Service-centric language

The language used in the draft tends to consider people in relation to services/processes, rather than foregrounding people's experiences of living with serious illness, dying and bereavement. For example, 2 of the 3 aims relate to whether people do or do not access services/processes. Most of the outcomes are similarly service or system-centric in the way that they are presented.

Use of Headings

The text in the Outcome chapters is sometimes an undifferentiated mix of: explanation of palliative care policy and practice; rationale; description of how things work in theory; aspiration; problem analysis. **Suggestion** *Consider use of consistent subheadings within chapters to structure the lengthy text and help orientate the reader.* **Suggestion** *Have a clearly formatted heading "Actions" in each of these chapters.*

Graphics

Suggestion - *Graphics could be helpful in helping to explain some of the concepts and practicalities in the strategy for example: relationship between specialist/general and complexity; tiers of support for bereavement; curative/palliative care/bereavement; who provides palliative care; and major demographic drivers.*

Mental Health

The strategy tends to use the term 'mental health' to encompasses a wide range of different issues and circumstance: normal emotional reactions to serious illness; spiritual/existential concerns and distress; clinically diagnosable mental ill health. **Suggestion** *Consider using "mental wellbeing" if needing a broad term, and use more specific language where particular issues or circumstances are being expressed.*

Other Miscellaneous Comments

SPPC as a delivery partner

SPPC welcomes the clear recognition of its valuable role in supporting implementation/delivery, with a number of specific roles explicitly mentioned in the strategy: providing an infrastructure for sector-wide communication, collaboration and innovation; providing an infrastructure and leadership in public health palliative care; provision of public information and community-led education.

Advanced Old Age

Given the scale of demographic change the distinct experiences and circumstances of frail, older people, approaching the end of life should be more prominent in the strategy. Palliative care is needed at all ages, but it is mostly (and increasingly) needed in advanced old age, and there is a strange imbalance in the draft strategy.

Social Care

Linked to the previous comment the strategy could emphasise more the important role of social care.

Hearts, minds, stakeholder management and progress

Underlying many examples of progress in Scotland are senior decision-makers who have acquired an understanding of and commitment to improving palliative care. **Suggestion** *The strategy (and/or delivery plan) should include clear actions designed to educate and influence senior decision makers.*

Emotional and Psycho-social Impacts

The enormous emotional impacts of being diagnosed with, living with or caring for someone with a serious life-threatening illness are rather understated in the strategy, with the limited references to emotion being made only in the context of grief/bereavement and children's palliative care.

Inequities

Suggestion - *Consider whether there is a need for more actions which are specifically directed towards addressing inequities, given that "ensuring equity…." is a described as a cornerstone of the strategy.*

Clarifying Requirements and Expectations

There is a lack of current standards relating to palliative care (either minimum standards, or "stretch standards" such as the recent HIS Frailty standards). The Scottish Clinical Standards for Specialist Palliative Care were published over 22 years ago and have not been reviewed/revised. It is difficult to plan for equitable and optimal use of resources without defining what services are expected to be delivered. Discussions around commissioning and manpower are unmoored without an agreed articulation of basic outputs. Such standards would also help the public understand and know what to expect of services. **Suggestion** *Some of the high-level outcomes in the strategy could be underpinned by some more detailed standards of care.* **Suggestion** *Focus initially on the more manageable objective of standards for specialist palliative care (including standards for access).* (See also comment below on data and standards of care)

Comments on Specific Outcomes (and associated text)

Outcome 1: People have the understanding, information, skills and confidence to support themselves and others to live well with serious illnesses or health conditions; to plan for the future; and to support each other through dying and bereavement.

It is welcome that the strategy acknowledges the importance of determinants of experiences and outcomes which lie beyond services.

Suggestion *Avoid language which might suggest that building informal individual and community capacity is a substitute for adequate service provision – emphasise complementary roles.*

Outcome 2: Leaders, stakeholders and delivery partners will work together in partnership, with clear roles and responsibilities, to make sure there is reliable and effective planning, delivery, accountability and improvement of palliative care services and wider support.

There is a strong desire on the part of stakeholders to see more detail on the arrangements envisaged for leadership, organisational roles and responsibilities, reporting and accountability. There are specific issues which the strategy should aim to address (for example the arrangements for planning and commissioning palliative care in hospitals). **Suggestion** – *Undertake a problem analysis of current arrangements to inform the delivery plan.*

Outcome 3: National and local leaders will have access to relevant data to inform planning and delivery of services, and will put in place improved ways to monitor and evaluate the outcomes and experiences of children and adults receiving palliative care, as well as their families and carers.

The strategy should have clear arrangements for monitoring and evaluation, including consideration of baselines. Consideration should be given to specifying standards against which services can be specified/commissioned, and progress measured. Standards also have a role in supporting public understanding of palliative care and what people and their supportive networks can expect from services.

Outcome 4: Adults with serious or life-threatening illnesses will be identified earlier and be able to access general palliative care and specialist palliative care services whenever and wherever needed.

Outcome 5: Adults living with serious or life-threatening illnesses and children with serious health conditions will be offered person-centred future care planning involving their families and carers, and care plans will be recorded and shared using national digital systems

Outcome 6: Quality and experiences of care around dying and bereavement support are improved for adults, their families and carers, in all places of care.

Outcome 7: Babies, children and young people living with serious health conditions, and their families and carers, will experience improved support as their distinctive needs are recognised and addressed by paediatric palliative care, including care around dying, or as they transition into adult services.

Outcome 8: Employers, professional bodies and education providers will make sure that staff who deliver palliative care are trained, skilled and supported.

The strategy doesn't address workforce issues beyond education, yet recruitment, retention, staffing levels, staff welfare and skill-mix are critical to delivering the strategy.

Suggestion – *Acknowledge the wider workforce agenda, and current / anticipated challenges. Link to the Health and social care: national workforce strategy. Consider specific actions in relation to specialist palliative care manpower planning.*