

Response ID ANON-DUR2-4Y8S-N

Submitted to Palliative Care Matters for All: strategy consultation
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Section A: Overall strategy

Question 1a Do you agree with the aims for this strategy?

Agree

Please add any comments you have about the strategy aims here.:

We agree with the overarching aims of the strategy, which are broad and aspirational. We commend the clear recognition of the value of palliative care, as well as the need to improve access and take a whole systems approach towards the provision of palliative care. We also commend the strategy's approach to joint working across services and teams, as well as the inclusion of user experience. However, we believe that there are significant omissions, feasibility issues, and unconsidered implications for vulnerable groups which need to be addressed.

While the broad aims are optimistic and to be commended, we are concerned that achieving these goals is dependent on resource availability. Any choice regarding palliative care will only be meaningful if the required services and support are in place. The proposals as outlined in the strategy must be sufficiently resourced and funded across all health boards in order to achieve the desired equitable outcomes.

The strategy document does not define 'specialist palliative care' nor 'general palliative care' – yet refers to these separate services and structures throughout. It is essential that these items are clearly defined. If the definitions follow NICE guidance, this should be made clear. In its current form, it is not entirely clear what the differences between the two are. For example, which settings should these be available in? Which clinicians would be expected to be involved in general versus specialist care? What are the criteria for receiving specialist versus general care?

This strategy has major implications for the mental health sector, and although mental health is mentioned in several places (and psychology is briefly mentioned), there is no reference to psychiatry. We have concerns that there may be some conflation between mental wellbeing/mental health and mental illness. Capacity is also not considered.

We are also concerned that the strategy does not sufficiently consider individuals who cannot advocate for themselves, and where the complexity of health needs is often high: such as those with severe mental illness, intellectual disabilities, non-verbal patients, or individuals in secure psychiatric care. These groups require proactive support to ensure they are not excluded from accessing palliative care. The strategy must also address capacity and supported decision making. The strategy should acknowledge that vulnerable groups may need additional consideration. An impact assessment of such vulnerable groups should be carried out to ensure that the introduction of such a strategy does not inadvertently widen health inequalities.

The strategy does outline the aspiration to address inequalities, but does not specify exactly which inequalities it seeks to address, and therefore there is limited detail of how, for example – individuals with severe mental illness or intellectual disability (who currently face major barriers in accessing healthcare) will be better served by the provisions of this strategy. More detail is required.

We are also concerned that the strategy does not account for the fact that it is not always entirely clear in all cases when someone is near the end of life or whose condition may otherwise be such that they could benefit from palliative care – especially for those vulnerable groups as highlighted above. The strategy must account for the differences in prognosis certainties and therefore make recommendations around variations in pathways to palliative care which account for this.

The strategy should also include specific recognition of the barriers faced by people living in remote and rural areas, where access to services is often limited by geography and infrastructure – and choices around palliative care may be limited by factors outside of NHS or Governmental control.

Question 2a Do you agree with the strategy cornerstones, which form the basis for the strategy and delivery plans?

Agree

Question 2b: Please add any comments you have about the four strategy cornerstones here.:

We support the strategy cornerstones, but believe there are areas that require further attention.

We stress the importance of ensuring that care is centred on the needs of the individual receiving palliative care – even when the wishes of the person receiving palliative care and treatment may not always align with the preference of families or carers. This should be specifically addressed in the strategy.

Again, we are concerned that the strategy fails to recognise marginalised groups such as individuals in secure psychiatric care, people with intellectual disabilities, and others in complex health settings. Equity measures must explicitly include these populations and the barriers they face in receiving palliative care and support.

We have concerns that the strategy underestimates the scale of developing the proposed infrastructure to connect services. The number and diversity of teams involved in delivering palliative care means this will be a monumental challenge. The strategy perhaps miscalculates the extensive undertaking of developing infrastructure to connect diverse services, given the complexity and number of individuals/teams involved.

Section B: Strategy outcomes

Question 3a Do you agree with strategy outcome 1 and the proposed actions being developed to deliver this outcome?

Agree

Question 3b: Please add any comments you have about outcome 1 and its actions here.:

We note that there is no mention of people with mental illness or intellectual disabilities, individuals in secure psychiatric care, inpatient psychiatric units, or residents in care homes in the proposed actions of the outcome. There is also no mention of other vulnerable groups such as those experiencing homelessness. These groups are often overlooked and face unique challenges in accessing care and advocating for themselves. It is essential for this strategy to be developed in ways which will reduce barriers to receiving treatment and care for these groups – who often have issues in acquiring (and sometimes comprehending) information and supporting themselves with the skills to advocate for equitable treatment and care. The strategy outlines how information will be improved – but does not give an explanation of how the barriers to accessing this information and acting with it will be addressed. Simply increasing and/or improving the information provided could actually risk a widening of health inequalities for people with mental illness and/or intellectual disability.

While we recognise the need for improved infrastructure, we believe that the strategy underestimates the challenge of connecting the wide range of services involved. We seek clarification on whether there has been any mapping of current palliative care provision and whether the scale of existing gaps is understood and available. For example, primary care has not been referenced to a great extent – and yet would be absolutely core to the proposals as outlined. There are also services outside of Integration Joint Boards and health and social care partnerships which must be considered and included – for example services carried out by special health boards or through policy custody healthcare. Integration Joint Boards, Health Boards, and Special Health Boards play distinct but interconnected roles within the healthcare and social care system and the implications of this strategy for each of these elements should be clear.

We believe the strategy places too much focus on information provision as a route to access services. Many individuals who need palliative care (particularly vulnerable individuals and those who cannot advocate for themselves) will not seek services and access information independently. Proactive measures are required to ensure that they receive support and access information.

Question 4a Do you agree with strategy outcome 2 and the proposed actions being developed to deliver this outcome?

Agree

Question 4b: Please add any comments you have about outcome 2 and its actions here.:

While we support collaboration, we question whether the proposed Managed Care Networks are appropriate for palliative care. Whilst we are aware that there is currently a network in place for palliative care at a less extensive level, the wide-ranging proposals as outlined in the strategy may require more broad oversight. MCNs typically focus on smaller, more defined areas. Palliative care, by contrast, is far broader and more complex.

We are concerned that primary care, a critical element in the delivery of palliative care, has not been adequately considered in this outcome.

We believe that the strategy does not sufficiently include teams already involved in palliative care delivery, such as forensic services, psychiatric units, and wider community-based teams. These services are vital but are often overlooked. As Leaders, stakeholders and delivery partners are identified – these teams must be involved and considered.

Question 5a Do you agree with strategy outcome 3 and the proposed actions being developed to deliver this outcome?

Agree

Question 5b: Please add any comments you have about outcome 3 and its actions here.:

We welcome the focus on patient feedback and user experience but believe that further clarity is required.

We stress the need to clearly define the difference between general and specialist palliative care, as well as the distinction between palliative care as a function and as a delivered service.

While auditing services already being delivered is important, we believe the strategy must also focus on identifying areas where palliative care is not currently available. Mapping these gaps is critical to achieving equity.

Question 6a Do you agree with strategy outcome 4 and the proposed actions being developed to deliver this outcome?

Agree

Question 6b: Please add any comments you have about outcome 4 and its actions here.:

We support the outcome of earlier identification but believe there are several critical issues – particularly surrounding equity of access to treatment and care earlier in the patient journey.

We highlight again here the fact that those with severe mental illness and/or intellectual disability are less likely to receive early identification of the need to transition to palliative care. The strategy must explicitly address barriers to transition to palliative care for vulnerable groups.

Responsiveness of care should also be addressed. Palliative care decisions must be flexible and responsive to changes in a patient's condition. We believe the strategy should reflect the need for ongoing review and reassessment, particularly in cases of diagnostic uncertainty (to ensure there is timeous

review of the needs of people in vulnerable groups when for example their condition changes either deteriorating or improving).

Again, this area does not sufficiently address the role of primary care, care homes, or mental health services in identifying palliative care needs and providing early support. The strategy must address (and make provision for) the fact that there are people who face significant barriers to accessing care - who need flexible approaches tailored to their (mental) health conditions.

Question 7a Do you agree with strategy outcome 5 and the proposed actions being developed to deliver this outcome?

Agree

Question 7b: Please add any comments you have about outcome 5 and its actions here.:

We welcome the aim of person-centred care planning, which should underpin all NHS planning.

We welcome the overarching goal of accessible digital records systems for health and social care across Scotland.

Whilst we support the aspiration for national care plans, we are concerned that the existing digital infrastructure is not currently capable of supporting this ambition. We would fully endorse and welcome systems that connect health and social care staff, primary care staff and out of hours services to share pertinent information. Such systems should be integrated across patients' health care rather than piecemeal for one specialist provision only. Consideration also needs to be given to ensuring that there is not an additional administrative burden.

There needs to be greater clarity and support around transitions from paediatric to adult services.

We also seek clarification on the differential wording in relation to children and adults in this outcome.

Question 8a Do you agree with strategy outcome 6 and the proposed actions being developed to deliver this outcome?

Agree

Question 8b: Please add any comments you have about outcome 6 and its actions here.:

We agree with the focus on improving experience and care around dying but feel the proposals need to go further. We reiterate the need to ensure that these proposals are accessible and equitable for individuals who cannot advocate for themselves in a range of settings, including those in secure psychiatric care, care homes, and mental health settings.

Simple actions such as rewriting a public information leaflet is insufficient. Broader, systemic actions are needed to address inequities and improve quality of care.

Question 9a Do you agree with strategy outcome 7 and the proposed actions being developed to deliver this outcome?

Agree

Question 9b: Please add any comments you have about outcome 7 and its actions here.:

We welcome the focus on paediatric palliative care. Again, we reiterate the need for a clear explanation of the difference between general and specialist paediatric palliative care.

We support the GIRFEC approach, as it recognises the importance of addressing the needs of families as well as children. Improved neonatal care has increased the number of children with life-limiting conditions, making this approach essential.

We believe that transition gaps and the loss of a keyworker role during transitions to adult services must be addressed to ensure continuity of care.

We also seek clarification on the differential wording in relation to care for babies, children and young people with 'serious health conditions' here - and whether the implication is that this group will have less strict criteria for accessing person-centred care planning (in comparison to adults - where wording varies).

Question 10a Do you agree with strategy outcome 8 and the proposed actions being developed to deliver this outcome?

Agree

Question 10b: Please add any comments you have about outcome 8 and its actions here.:

We agree with the focus on staff training but believe the following are essential:

Sustainability and Resources: Training must be practical, sustainable, cost-effective and adequately resourced to ensure effective delivery.

Complex scenarios: Staff need guidance and support for dealing with complex cases, such as diagnostic uncertainty changes in a patient's needs, or changes in a patient's condition who previously had been considered palliative. Training cannot substitute for direct access to specialist advice and where indicated input from a palliative care clinician.

Question 11 Please add any further comments you have about the draft strategy outcomes and actions here

Please add any further comments you have about the draft Strategy outcomes and actions here:

The strategy is aspirational but lacks:

1. Realistic details on resources and infrastructure to achieve its goals.
2. Specific actions and consideration for marginalised groups, including those with severe mental illness, those within secure psychiatric care, those with intellectual disability, residents of care homes, and remote and rural communities.

Section C: Strategy content

Question 12a Community action and support - Do you think this strategy explains why it is important to encourage people, families and communities to come together, support each other, take action and talk more openly?

Unsure / Don't know

Question 12b: Please add any comments you have about how to do this better in Scotland.:

While encouraging, the strategy fails to address that some individuals cannot actively participate in community-led support and will require proactive interventions.

We suggest referring to the guidance as part of the ongoing work around the Adults with Incapacity Act around measures to help those with varying levels of capacity to communicate their views.

Question 13a Earlier access to palliative care - Do you think this strategy explains why getting palliative care long before someone is dying can help adults, children, their families and carers?

Yes

Question 13b: Please add any comments you have about earlier access to palliative care here.:

The benefits of earlier access are clear, but concerns remain regarding instances where patients or carers may distrust services, particularly in marginalised groups.

Question 14a Improving access to palliative care and support - Do you think that the actions in this strategy can improve the experiences of people with different personal characteristics and circumstances?

Yes

Question 14b: Please add any comments you have about impacts of the strategy on these or other groups of people here.:

The strategy mentions equity but lacks specificity. Barriers faced by groups like those with intellectual disability, mental illness, impaired decision making ability about accessing care, or geographic isolation must be explicitly addressed.

Question 15a Language and terms used in the strategy - Do you think the strategy explains what is meant by the terms palliative care for adults; palliative care for children; care around dying; and future care planning?

Yes

Question 15b: Please add any further comments you have about any of the terms that are used in the draft strategy.:

While the definitions are generally clear, the distinction between general and specialist palliative care needs further clarification.

Section D: Further Comments

Question 16 Please add any other comments or suggestions you have about the draft Palliative Care Strategy here

Please add any other comments or suggestions about the draft Palliative Care Strategy here:

Our members highlighted the strategy's aspirational nature but stressed the need for:

1. Realistic resourcing.
2. Specific inclusion of marginalised and underserved populations.
3. Practical mechanisms for delivery, flexibility, and review of palliative care.

We would also seek clarity on how this strategy interlinks with any assisted dying proposals, should legislation around this be implemented.

About you

What is your name?

Name:

Jane Gordon

Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Royal College of Psychiatrists in Scotland

Further information about your organisation's response

Please add any additional context:

N/A

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

Do you consent to Scottish Government contacting you again in relation to this consultation exercise?

Yes

What is your email address?

Email:

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I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Please enter comments here.:

Asking for additional information