Palliative Care Matters for All
Respondent Information Form

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☐ Individual

☒ Organisation

Full name or organisation's name

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We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

☒ Yes

☐ No

Section A: Overall Strategy

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

The aims of the strategy are that, by 2030:

- adults and children in Scotland have more equitable access to well-coordinated, timely and high-quality palliative care, care around dying and bereavement support based on what matters to them, including support for families and carers.

- Scotland is a place where people, families and communities can support each other, take action and talk more openly about planning ahead, serious illnesses or health conditions, dying and bereavement

- adults and children have opportunities to plan for future changes in their life, health and care with their families and carers.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don't know

Question 1b: Please add any comments you have about the strategy aims here:

The BGS is highly supportive of the three aims of this strategy. It is crucial that everyone has equitable access to well-coordinated, timely and high-quality palliative care. Currently, this is not a reality, and many older people do not receive the end-of-life care that they need. The current model does not serve an ageing population, particularly older people with frailty, dementia, and multimorbidity. The palliative and end of life care needs for this demographic group is different to those with illnesses such as cancer and they often need significant social support over a considerably longer period. Older people also face a great degree of diagnostic and prognostic uncertainty, unpredictability and escalating care needs which do not fit into traditional models of palliative care. Scotland's population is ageing, and research indicates that by 2040, the biggest increase in palliative care demand will be in those over the age of 85 (1). There are also more people dying with multi-morbidities, and this will increase by 80% by 2040 (1). Therefore, it is important that the aims of this strategy have a particular focus on the provision of personalised end of life care for older people whose terminal decline is due to multimorbidity, dementia, and/or frailty, requiring complex care needs which may be different to other groups.

Geographical equity is also important to recognise within the aims of the strategy considering the geographical disparities in high quality provision and accessibility. Rural, remote and island communities are ageing at a faster rate than urban areas and these areas typically have fewer specialist healthcare provisions, including palliative care (2). Therefore, a particular focus is needed to ensure equity of provision in these areas.

Service equity should also consider the use of digital technologies within palliative care provision. While digital services can increase access to health and social care for some people, it can increase inequalities and create barriers for other groups. For example, older people are more likely to be digitally excluded than other demographic groups, and, therefore, digital should never be the only way to access care (3).

Advance care planning is vital in ensuring that older people receive the care that they want at the end of their life. This requires an open culture, characterised by people talking about dying, death, and grief. Therefore, it is vital that the aims have a focus on creating a country that can support one another talk about death, and plan appropriately for it.

(1) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0490-x.
(2) https://spcare.bmj.com/content/3/1/129
(3) https://www.hospiceuk.org/publications-and-resources/digital-health-and-inclusion-palliative-and-end-life-care

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

We used four 'cornerstones' as the foundations for change and improvements in palliative care policy, service delivery and public involvement. These are:

- Working together to provide the care that's right for each adult or child, their family and carers.
- Taking a whole-system population health approach using data and people's experiences
- Ensuring equity and equality of access to palliative care for anyone who needs it
- Leadership across health and social care systems and with wider delivery partners, including third sector organisations (charities)

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don’t know

The BGS is fully supportive of the four strategy cornerstones. The first cornerstone vitally recognises the importance of person-centred care and shared decision making in palliative care. This is important as research shows that patients who have the opportunity to make decisions about their care are more satisfied with their care, more likely to choose treatments based on their values, more likely to have better health outcomes, and tend to choose less invasive and costly treatments (1). The BGS also recommends specifically referring to "older people" in the first cornerstone, similar to how children are referenced. Older people with multimorbidity, dementia, and/or frailty have specific, complex care needs that are distinct to other adult groups, and it is important this is recognised within the strategy. As mentioned in our response to question 1b, older people with frailty will require social support over a considerably longer period than those with illnesses such as cancer.

The BGS is also fully supportive of a whole-system approach to palliative care, as highlighted in the second cornerstone. This is significant as care is rarely received in one system touchpoint. As highlighted in BGS's *Joining the dots: A blueprint for preventing and managing frailty in older people* (2), many older people will simultaneously require care or support from several system touchpoints. It is important that palliative care is considered in the whole health and care system, so that older people have a 'wrap around' system of care that supports co-ordinated and compassionate end of life care. We are pleased to see that Scotland's ageing population is recognised within this cornerstone, and a recognition of an increased number of people living with multimorbidity. However, we would also like to see frailty included within this section. Frailty affects up to half of the population over the age of 85 (3). Considering the biggest increase in palliative care demand will be in those over the age of 85 in Scotland (4), it is vital that the strategy addresses caring for older people with frailty. We would also like to see the inclusion of a "life course approach" to complement the "whole system approach". The World Health Organization defines a life course approach as a method of ensuring people's well-being at all ages by addressing people's needs, ensuring access to health services, and safeguarding the human right to health throughout their lifetime (5).

We are pleased to see that equity and equality are included within the cornerstones of the strategy. For the reasons outlined in our response to question 1b, it is important that geographical equity is considered within this cornerstone due to the inequity in access particularly in rural, remote, and island communities in Scotland, which are ageing faster than urban areas.

Finally, we recommend the inclusion of proactive care within these cornerstones. Frailty is not an inevitable part of ageing, and proactive care aims to reduce or delay negative health outcomes through targeting those at risk of frailty and tailoring health interventions to support them live well for longer. It aims to delay the onset of health deterioration, maintain independent living, and reduce avoidable periods of ill health, thereby reducing unplanned care. The BGS has recently published two documents outlining both the evidence behind proactive care and guidance on how to implement it in community and primary care settings in the UK (6). Following the process of identifying individuals at risk of frailty and undertaking holistic assessments, proactive care allows for personalised care and support planning, including advanced care planning for those identified to have palliative and end of life care needs. Overall, proactive care will enable the early recognition of frailty and incurable diseases, triggering earlier conversations around palliative care planning. This facilitates personalised care goals to be achieved, a shared understanding of future wishes, and evolving conversations around the benefit and burden of active treatment.

(1) https://www.health.org.uk/resources-and-toolkits/quick-guides/person-centred-care-made-simple
(2) https://www.bgs.org.uk/Blueprint
(3) https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)62167-9/abstract
(4) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0490-x
(5) https://www.who.int/our-work/life-course
(6) https://www.bgs.org.uk/resources/be-proactive-delivering-proactive-care-overview

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

Section B: Strategy outcomes

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

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.

Proposed actions:

- Take forward work across relevant policy areas to improve the wider experiences of people receiving palliative care and care around dying; remove barriers to access; and maximise support, including areas related to children and young people, equalities, justice, fair work, housing and tackling poverty.

- Explore ways to promote access to financial benefits for adults or children with serious illnesses or health conditions and increasing health and care needs under the Benefits Assessment for Special Rules in Scotland (BASRiS) application process through improved public information and professional education and guidance.

- Work with agencies, statutory and third sector organisations responsible for housing and services for people who are homeless or vulnerably housed to develop and promote ways to enable adults and children living with serious illnesses or health conditions to access the social, practical and financial assessments and support they need.

- Collaborate with NHS 24 and wider partners to make sure the NHS inform website provides relevant, up to date and accessible public information about future care planning, palliative care and care around dying for adults and children, families and carers, including links to support organisations and resources for people from diverse groups and communities.

- Support the Scottish Partnership for Palliative Care (SPPC) to provide a sustainable, national infrastructure that enables statutory and third sector organisations, palliative care providers, staff, community groups and individuals to work together to promote understanding and awareness of living and dying with serious or life-threatening illnesses and serious health conditions; and to contribute towards empowering people to be more informed and equipped to plan ahead and support each other through serious illness, dying, death and bereavement.

- In partnership with the third sector, widen access to community-led public education opportunities which provide knowledge, skills, resources and training to help more people be comfortable and confident in supporting family, friends and people in their local community when someone is dying, caring or bereaved.

- Work with Integrated Joint Boards (IJBs) and Health and Social Care Partnerships (HSCPs) to explore options for their strategic plans for palliative care to recognise and work collaboratively with local community groups, networks and projects that offer support for adults with serious illnesses; children and young people with serious health conditions; and their families and carers.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don't know

The BGS recommends that proposed action 1.1 includes reference to removing barriers of access and increasing support to older individuals, particularly those with frailty, multimorbidity, and dementia, similar to how children and young people are referenced. As mentioned in previous responses, Scotland's population is ageing and the biggest increase in palliative care needs will be individuals over the age of 85. It is important that there is a policy focus on this growing population age group, and associated health challenges. For older people living with frailty and multiple health problems, the range of trajectories of decline will be wider than those with a single disease. Pathways of decline may include sudden death, slow progressive deterioration (such as in advanced dementia), catastrophic events (such as stroke or hip fracture), and periods of prolonged uncertainty associated with fluctuating episodes of acute illness associated with delirium or functional decompensation. As recovery from acute illness in the context of severe frailty is uncertain, parallel planning for recovery or deterioration is essential. Recognition of advanced frailty and incurable illness should trigger early sensitive and evolving conversations related to the benefit versus burden of active treatment, the identification of realistic personalised goals of care related to current circumstances as well as a shared understanding of future goals and wishes.

Within action 1.3, we recommend that other methods of disseminating relevant, up to date and accessible public information about future care planning, palliative care and care around dying are also prioritised. The number of older individuals who are digitally excluded has decreased significantly in recent years, however, there is still a substantial group of older individuals not using the internet. The Scottish HouseHold Survey identified that 23% of adults aged 60-74 and 62% of adults aged 75+ were not internet users (1). This has the potential to create inequalities in access between users and non-users of digital health care services. Physical copies of information that is available on the NHS Inform website should be available in a range of settings such as GP surgeries, pharmacies, and noticeboards in community centres and shops. Utilisation of other traditional media forms should also be considered, such as TV adverts, newspapers, and magazines. This will inform individuals who may not be using the internet, ensuring they have relevant up to date information about end-of-life care. It is vital that a similar approach is used when promoting BASRiS, as outlined in action 1.2.

(1) https://www.gov.scot/publications/scotlands-people-annual-report-results-2018-scottish-household-survey/pages/7/

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

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

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.

Proposed actions:

- Develop guidance with IJBs and Health Boards to support the identification of a clinical and a managerial / executive lead, and to establish a Managed Care Network (MCN), updating previous guidance for Health Boards on MCNs.

- Work with Health Boards to establish new requirements for inclusion of integrated specialist palliative care services within annual delivery plans and performance monitoring.

- Work with HSCPs and adult independent hospice organisations to develop a national guidance framework to support and improve consistency of local planning and commissioning of independent hospice services.

- Work with the Scottish Partnership for Palliative Care to establish a national Palliative Care Innovation Network, where people and teams involved in palliative care delivery; community-led initiatives; improvement and research; or education can come together to share learning and ideas for improvement and innovation.

- Continue to engage with palliative care delivery partners on how the proposed National Care Service Board and the reformed Integration Authorities will improve national and local governance, roles, responsibility, commissioning, monitoring and reporting of specialist palliative care services and general palliative care

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don’t know

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

The BGS is fully supportive of outcome 2 and its actions. It is vital that palliative care is a whole system approach, incorporating primary care, hospitals, care homes, hospices, palliative care services, and the third sector. In *Joining the dots: A blueprint for preventing and managing frailty in older people* (1), the BGS outlines that principles of palliative care are fully consistent with geriatric medicine, including Comprehensive Geriatric Assessment (CGA) and the principles of person-centred care. This includes meticulous assessment of problems, open communication with patients, families, and other stakeholders, setting realistic goals and expectations, good understanding of potential therapies and their likelihood of success, minimisation of treatment burden, anticipating and planning for the future, and attention to social, emotional, psychological, and spiritual aspects of care. We recommend that a model integrating the principles of palliative, geriatric, and rehabilitative medicine is created. An integrated approach will allow older people to access to specialist palliative care to enable the best possible end of life care.

Considering plans for a National Care Service in Scotland has been delayed by the Scottish government, considerations should be made around alternatives to actions outlined in 2.5.

(1) https://www.bgs.org.uk/Blueprint

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

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.

Proposed actions:

- Work with Public Health Scotland, Health Boards, HSCPs, and other key partners, including paediatric palliative care planners and service providers, across all sectors to improve the quality and range of palliative care data collected, analysed and reported. Such data can be used to inform improvement, experiences, and delivery of palliative care for adults and children, families and carers, and includes:
    - updating and improving the existing adult palliative care population data reporting systems; and providing access for service planners and health and care staff.
    - developing a national approach to data collection on paediatric palliative care services for babies, children and young people (0 -18 years) and developing a new dashboard that can be accessed by paediatric palliative care service planners, and health and care staff.
    - working with HSCPs and Health Boards to develop a data template that supports them to collect, analyse and report high quality data on general palliative care and specialist palliative care services delivered to adults, children and young people for service planning and improvement, which includes user experiences in all places of care.

- development of a Scottish minimum data set for all adult specialist palliative care services.

- development of a Scottish minimum data set for all paediatric and neonatal specialist palliative care services and transitions.

- Explore evidence based and emerging co-design approaches to hearing and measuring people's experiences of palliative care, care around dying and bereavement support in palliative care for all places of care, and establish a consistent national approach to help improve these experiences.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don't know

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

The BGS is supportive of this outcome to collect and use data to inform the planning and delivery of palliative care services; and to monitor and evaluate the outcomes and experiences of people receiving palliative care. BGS members working in palliative care tell us that it is often difficult to gather feedback from older patients, especially through means such as text messages. Therefore, it is crucial that new approaches are co-designed to develop national approaches to help improve experiences of palliative care and that the needs of older people with frailty and multimorbidity are considered. It is also important that data is collected across the life course in all care settings in an integrated long-term approach to end of life care. Most tools to measure outcomes for end-of-life care have been designed to meet the needs of individuals with single life limiting diseases, such as cancer. Hospice UK recommend person-centre approaches, such as the Adults Social Care Outcome Toolkit (ASCOT), Goal Attainment Scaling (GAS), Measure Yourself Concerns and Wellbeing (MYCAW), strength and asset based outcomes, Most Significant Change (MSC), and Support Needs Approach for Patients (SNAP) to capture outcomes and experiences of those living with frailty, to measure palliative care outcomes for this group (1). The BGS recommends the consideration of these measures within the strategy.

(1) https://www.hospiceuk.org/innovation-hub/clinical-care-support/extending-frailty-care-programme/measuring-what-matters

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

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.
Proposed actions:

- Work with Healthcare Improvement Scotland (HIS) to improve guidance and promote improvements in use of evidence-based tools to support proactive identification and review of adults with unmet palliative care needs, their

families and carers, by staff and teams working across health and social care in all HSCPs and Health Boards.

- Work with NHS National Services Scotland (NSS) and HIS and digital science experts to explore further development and implementation of national health records screening tools to improve identification of adults with serious or life-threatening illnesses for earlier palliative care and future care planning.

- Explore viable options with NHS 24 and other delivery partners to provide a 24/7 national palliative care advice line (via the 111 system) for patients, families and carers that reduces delays in access to urgent primary care and social care and connects with locally delivered palliative care telephone helplines and services.

- Support collaborative working to promote inclusion of palliative care and care around dying in service planning and delivery for people with one or more long term health conditions.

- Support innovative models of care and consider options for service developments and partnership working to increase equity of access to adult specialist palliative care both in-hours and out-of-hours in all Health Boards and HSCPs, including a specific focus on people who have more barriers to accessing the specialist palliative care they need.

- Explore options with Health Boards and HSCPs to make sure there is consistent access at all times (24/7) to specialist clinical care from a consultant in palliative medicine and from senior nurse specialists whenever a person is receiving inpatient hospital or community hospital specialist palliative care, including contractual arrangements to support rural and island Health Boards.

- Work with Health Boards, HSCPs and third sector organisations to improve access to urgent palliative care services in the community that can reduce avoidable hospital admissions and shorten inpatient stays, and provide more effective, timely admission processes for those needing hospital care. This includes improving access to specialist palliative care advice in hospital and at home within wider national and local work on unscheduled care and early hospital discharge.

- Work with Health Boards, HSCPs and third sector organisations to support improved provision of professional-to-professional specialist palliative care clinical advice lines, ensuring these are available 24/7 in all parts of Scotland, so that other health and care staff providing palliative care, including the Scottish Ambulance Service, can access specialist palliative care advice at all times.

- Work with Health Boards, HSCPs, third sector organisations, other delivery partners, and community groups to improve palliative care, care around dying and bereavement support for people from minority communities and other groups who face barriers to accessing palliative care or who need flexible

approaches tailored to their health conditions, situation, personal circumstances, values and preferences.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don't know

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

The BGS strongly supports the inclusion of this outcome which outlines a proactive approach to palliative care. Particularly, we are pleased to see the recognition of the Electronic Frailty Index to identify frailty in older adults within the commentary of this outcome, but we would also like to see this included in the proposed actions. The BGS has recently published two documents outlining the evidence base around proactive care and recommendations on how to deliver it in community and primary care settings across the UK (1). These documents outline approaches for identifying a cohort of older people who may have frailty, carrying out holistic assessments, developing personalised care plans, working in a co-ordinated and multi-professional manner, and providing continuity of care. Importantly, this approach will identify life threatening illnesses and refer patients to the most appropriate support potentially at an earlier stage. We advise that the authors of the new palliative care strategy consider the recommendations outlined in *Be proactive: Delivering proactive care for older people with frailty* (1).

In Scotland, 33,352 residents live in care homes and 92% of these are living in care homes for older people (3). Considering that older people are the biggest users of palliative care services, it is important that care homes are recognised as a setting for proactive care within the actions for outcome 4. This will ensure a whole system approach to proactive palliative care focussed on personalised care, promoting independence, and recognising the life course of people living in care homes.

We also recommend that an additional action is included which is needs-focussed and not prognosis-focused. This will ensure that people's preferences, needs and values guide clinical decisions and provides care that is respectful and responsive to the individual.

(1) https://www.bgs.org.uk/ProactiveCare
(2) https://www.bgs.org.uk/ProactiveCare
(3) https://www.publichealthscotland.scot/publications/care-home-census-for-adults-in-scotland/care-home-census-for-adults-in-scotland-statistics-for-2012-2022

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

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.

Proposed actions:

- Support a national partnership programme for future care planning, overseen by the National Future Care Planning Working Group, that is person-centred,

inclusive and takes a ‘Once for Scotland’ and ‘digital’ approach to development and delivery for children, young people and adults whose life, health or care may change, and which is suitable for all places of care.

- Continue to work with NHS Education for Scotland (NES) Digital, other national organisations and partners to develop and implement a national electronic urgent and emergency care plan for health and social care accessible to staff working in the community, NHS unscheduled care services and hospitals in all Health Boards, starting with health care staff and extending to social care staff, care homes and independent hospices.

- Continue to work with NES Digital, other national organisations and partners to develop and implement a national electronic hospital urgent care plan to improve treatment and care during a single hospital admission that connects digitally with community urgent and emergency care plans.

- Continue to work with NHS Education for Scotland, other national organisations and partners to develop and deliver national education and implementation resources on future care planning for use across Scotland.

- Promote future care planning across all sectors and involve a wide range of stakeholders in development and delivery including members of the public, adults, young people, families, parents and carers, minority groups, patient support groups and third sector organisations, and to develop accessible and inclusive resources and information about future care planning with them.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don’t know

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

The BGS supports the proposed actions outlined in outcome five. However, whilst it is important that adults with life-threatening illnesses are offered person-centred future care planning, we recommend that this group is extended to include those with frailty. The range of trajectories of decline is greater for older people living with frailty than other groups, and there is a significant risk of decline which is less predictable. As recovery from acute illness in the context of severe frailty is uncertain, parallel planning for recovery or deterioration is essential. Therefore, the BGS recommends an inclusion of parallel planning, involving the older individual, within the actions of outcome 5.

We welcome the development of digital platforms for staff across the health and social care to access patient care plans. This ensures that healthcare professionals and carers have the most up-to-date information on the wishes and needs of the patient as quickly as possible in an emergency, enabling personalised care based on what is important to the patient.

Future care planning is vital in ensuring that patients feel valued and that they have autonomy over their health and care choices. It also helps to reduce health inequalities, improves quality of care, and enables people to die in the right place for them. Whilst we agree with action 5.5 that future care planning should be promoted, we recommend that this should be mandatory and that there should be staff resource available within all areas of the health and social care sector in Scotland to enable this.

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

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.

Proposed actions:

- Oversee an update to the national guidance on *Care around Death* and work with Health Boards and HSCPs to make sure it is implemented as best practice in all places of care in Scotland.

- Work with Health Boards, HSCPs, primary care teams and pharmacy services to promote timely provision and use of ‘just in case medicines’ for adults dying at home and residents in care homes and improve staff education and public information.

- Work with HSCPs and Health Boards to promote and develop effective models of urgent palliative care able to provide rapid access to coordinated health and social care support for adults dying at home, their families and carers.

- Work with Scottish Ambulance Service and NHS Education for Scotland to ensure palliative care continues to be part of core training and professional development for ambulance clinicians.

- Oversee an update the public information leaflet “*When someone has died – information for you*” with NHS Education for Scotland and other partners, and

promote its use along with additional local information through Health Board Bereavement Leads, HSCPs, and other organisations, including NHS Inform.

- Continue to champion, co-ordinate and work in partnership with key stakeholders to ensure compassionate advice, resources and support are available for people experiencing bereavement, following the death of an adult with a serious or life-threatening illnesses, or with a child who has a serious health condition, and explore improvements to bereavement care.

- Work with NHS Education for Scotland and other partners to develop a new education and training resource on bereavement care for staff across health and social care that includes staff support and spiritual care as part of the Support Around Death resources.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don't know

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

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

The BGS is fully supportive of the actions outlined in outcome 6. However, we would like there to be more detail regarding the practicalities of how these actions will be achieved. For example, it would be beneficial to outline the infrastructure that will be in place to ensure that key stakeholders work together.

In Scotland, there were an estimated 33,352 individuals living in care homes in 2022 (1). If current trends continue, by 2040, the most common place of death will be in a care home (2). Therefore, it is vital that care homes are prioritised in this strategy to ensure that they provide high quality palliative and end of life care. Whilst care homes are mentioned within the actions of this outcome, there needs to be more detail around how care homes will be supported, particularly with educational resources and support for staff. One method of achieving this is through partnerships between hospices, palliative care staff and care homes. For example, palliative care staff can work with local residential care homes to run sessions to talk about death and dying and to support the completion of advance care planning forms. Increasing support and capacity for care homes will also reduce the numbers of deaths in hospital.

We also recommend the inclusion of an action that recognises the importance of out of hours palliative care support. People at the end of their lives will experience painful symptoms and out of hours support can relieve unnecessary suffering for people in their own homes or in care homes. Without the availability of 24 hours palliative care support, many may have no choice but to present at A&E, which can be a distressing experience. There is currently less resourcing for out of hours care, despite covering two thirds of the week (3).

(1) https://www.publichealthscotland.scot/publications/care-home-census-for-adults-in-scotland/care-home-census-for-adults-in-scotland-statistics-for-2012-2022
(2) https://journals.sagepub.com/doi/10.1177/0269216317734435
(3) https://journals.sagepub.com/doi/full/10.1177/0269216318817692

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.

Proposed actions:

- Work with key partners to develop a national approach to service planning for all paediatric palliative care, through a multi-agency steering group, to ensure children and families across Scotland have access to the services they need, wherever and whenever these are required, and to ensure that these services are equitable.

- Work with CHAS and Health Boards to review current models and develop a national specialist paediatric palliative care service available at all times (24/7) to meet the needs of children, families and staff across Scotland in all places of care.

- Support and develop improved transitions for young people with serious health conditions based on Getting It Right For Everyone (GIRFE) practice model, and the co-designed GIRFE ‘team around the person’ toolkit for young people in transition from GIRFEC (Getting it Right for Every Child) to GIRFE.

- Draw on best practice models to develop and agree paediatric palliative care standards to children and families across Scotland have equitable access to

high quality general and specialist paediatric palliative care services wherever and whenever these are required.

- Explore options for a national approach to providing ethical clinical review of decision making in paediatric palliative care.

[Please only mark **one** box below]

☐ Agree
☐ Disagree
☒ Unsure / Don't know

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

The BGS is a specialist society for healthcare professionals working with older people, and therefore, we do not have the expertise to comment on issues relating to babies, children and young people.

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

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

Proposed actions:

- Work with Healthcare Improvement Scotland (HIS) to ensure there is sustainable management, updating and extension of the Scottish Palliative Care Guidelines as recommended best practice for symptom management across Scotland on the Right Decision Service; and explore options to develop and include Scottish paediatric palliative care guidelines.

- Work with NHS Education Scotland (NES) to develop a designated online learning space readily available to all health and social care staff who deliver palliative care to adults, children and young people that provides a single point of access to relevant training and education resources on palliative care, care around dying and bereavement support.
- Work with NHS Education for Scotland (NES), statutory and third sector organisations, and education providers to support and enable local and national education and training for health and care staff to equip them to have sensitive and effective person-centred conversations with adults or children, families and carers, that are central to future care planning, palliative care, and care around dying, including NES Having Realistic Conversations resources.

- Work with NHS Education for Scotland (NES) and third sector palliative care education providers to promote and develop online learning opportunities and

networks for health and social care staff across Scotland such as Project ECHO.

- Work with universities and further education colleges that provide pre-registration courses and undergraduate education programmes to enable all health and social care staff (including doctors, nurses, pharmacists, allied health care professionals and social workers) and to receive a level of adult or paediatric palliative care education appropriate to their roles.

- Encourage HSCPs and Health Boards to employ palliative care practice educators to support the sustainable delivery of palliative care education and training in line with the NES/SSSC Palliative Care Education Framework and work collaboratively with adult and paediatric palliative care specialists offering education and training.

[Please only mark **one** box below]

☒ Agree
☐ Disagree
☐ Unsure / Don't know

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

The BGS is fully supportive of this outcome to improve palliative care training for those providing care to patients at the end of their life. However, we recommend that the wording in action 8.6 is changed from "encourage" to "ensure". Palliative care educators are vital in ensuring palliative care training adheres to the NES/SSSC Palliative Care Education Framework. We also recommend the inclusion of mentorship schemes within this action, as this provides professionals working in the palliative care sector with vital one to one guidance on issues impacting their working life. There are a growing number of health care professionals working in palliative care in Scotland who are from other countries, where cultural attitudes around dying and death may differ. For example, in some countries end of life care is provided by the family. Therefore, we recommend the inclusion of an action that specifically focussed on the educational training and support needs of this group.

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

The BGS strongly recommends the inclusion of an outcome specifically focussed on providing palliative care for older people. We suggest the wording of this outcome as follows: “Older people will experience improved timely recognition of terminal decline due to underlying disease processes including multimorbidity, advanced dementia and severe frailty. Their distinctive needs will be addressed by specialist palliative care which should align with the principles of Comprehensive Geriatric Assessment and person-centred care.” We suggest the following actions to be included:

- Ensure that community and primary care settings are proactively identifying older individual who may be at risk of moderate and severe frailty, and therefore ensuring palliative care support and care plans are in place at an earlier stage.
- Ensure that all older people presenting in acute settings are offered a Comprehensive Geriatric Assessment which may identify palliative care needs.
- Ensure that there are processes in place so that all older individual living with dementia, multimorbidity, and frailty have the opportunity to co-produce a personalised care plan which considers multiple care scenarios recognising the range of potential trajectories of decline often experienced by older people with frailty. This should consider the benefits versus burdens of active treatment.
- Ensure geographical equity in palliative care service provision, with a particular focus on improving services in rural, remote, and island communities, which are ageing at a faster rate than urban areas.
- Ensure that resources, information, and support that is available through digital means is also available in physical resources so that it is accessible to older individuals who may not be using the internet.
- Ensure all healthcare professionals working in palliative care receive education and training in how to care for older individuals with frailty. The British Geriatrics Society Frailty elearning course is free and should be rolled out across all palliative care settings: https://www.bgs.org.uk/elearning/frailty-elearning-course

The strategy also lacks consideration for individuals who lack capacity to consent to care plans and the role of healthcare professionals acting on behalf of individuals who can’t consent. We strongly recommend that this is addressed in revisions of the draft.

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?

Living well with serious illnesses and health conditions, dying and loss are universal experiences affecting everyone.

☒ Yes
☐ No
☐ Unsure / Don't know

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

There needs to be a lifecourse approach to education around death and the dying process. Professionals, those receiving palliative care, carers, and the general public should be educated on issues related to the end of life. This will enable death and the dying process to be less of a shock and more normalised. There also needs to be a societal shift to de-medicalise death and support to wider societal care provision to alleviate distress in terminal disease. Effective communication channels between health and care professionals and family members will enable a greater understanding of the dying process, and therefore, mean they are less likely to opt for unnecessary interventions, and focus on comfort. All healthcare professionals need to be supported to discuss end of life issues on a regular basis in consultations.

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?

Many people don't understand that palliative care helps adults with serious illnesses or children with serious health conditions to live as well as possible. Some people think they can only get palliative care in the last weeks or days of life. In fact, some adults and children can benefit from palliative care over many years.

☒ Yes
☐ No
☐ Unsure / Don't know

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

Whilst the strategy does recognise the need for proactive interventions to identify those with palliative care needs, we recommend a stronger focus on identifying older individuals with frailty. Implementing proactive care services will identify those who may have frailty living in the community and ensure earlier planning for multiple trajectories of decline.

The strategy has a strong focus on how to it implement a proactive approach to palliative care but does not outline why this is important. We recommend some of the actions in this strategy addresses how to ensure the public has a greater understanding of what palliative care is and why it is important to intervene at an earlier stage.

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?

How adults and children, their families and carers experience living and dying with different illnesses; access health and care services; and use their own community support networks is affected by their health conditions, situation, location, culture and personal circumstances. These include:

- age
- disability
- race or ethnic group
- religion or belief
- gender
- sex

- sexual orientation
- rural or island areas
- socio-economic deprivation (poverty)
- illnesses or health conditions

☐ Yes
☒ No
☐ Unsure / Don't know

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

The strategy lacks consideration for the palliative care needs for older people whose terminal decline is due to multimorbidity, dementia, and/or frailty. The palliative and end of life care needs for this demographic group is different to those with illnesses such as cancer and they often need significant social support over a considerably longer period. They also face a great degree of diagnostic and prognostic uncertainty, unpredictability and escalating care needs which do not fit into traditional models of palliative care. The range of trajectories of decline are often wider that those living with single diseases, requiring parallel planning for recovery and deterioration. Recognition of advanced frailty and incurable illness should trigger early sensitive and evolving conversations related to the benefit versus burden of active treatment, the identification of realistic personalised goals of care related to current circumstances as well as a shared understanding of future goals and wishes.
This is a vital challenge to address as Scotland population continues to age. By 2040, the biggest increase in palliative care demand will be in those over the age of 85 (1). There are also more people dying with multi-morbidities, and this will increase by 80% by 2040 (2). Urgent action is needed to address evidence that older adults with frailty have disproportionately less access to palliative care services (3). It is vital that the needs of this population group are addressed, and the BGS strongly recommends that there is a specific outcome focussed on addressing the needs of older people with dementia, multimorbidity, and/ or frailty, as outlined in our response to question 11.

Geographical equity is also important to recognise within the strategy aims because there are geographical disparities in high quality provision and accessibility across Scotland. Rural, remote and island communities are ageing at a faster rate than urban areas and these areas typically have fewer specialist healthcare provisions, including palliative care (4). Therefore, a particular focus is needed to ensure equity of provision in these areas.

Older individuals from some ethnicity groups have poorer health than their white counterparts. Research suggests that the health of different ethnic groups begins to diverge at 30 years of age, with the gap between ethnic minority groups and white majority groups increasing with age (5). Pakistani and Bangladeshi older people experience the highest rates of poor self-rated health, with their health equivalent to those of white people who are at least 20 years older. Therefore, they may require palliative care due to frailty at a much earlier age. Distinct policy is needed to address how ethnic health inequalities can be mitigated to prevent inequality widening with age.

The LGBTQ+ population aged 50 and over is set to grow over the next ten years. There is evidence to suggest that there are health inequalities between older LGBTQ+ population and the rest of the older population (6). Despite progress, past and present discrimination directly impacts health and causes people to engage in unhealthy habits to cope. Evidence also indicates that LGBTQ+ older individuals find it harder to access healthcare than other population groups, including palliative care. This causes delays in seeking treatment which leads to worse health outcomes. There is also shocking evidence of homophobic abuse in care settings, with a report from Compassion in Care called Stripped of Pride highlighting 423 reported incidents to their helpline (7). Policy is needed to address health inequalities amongst the LGBTQ+ older population and protect them in care settings. This may include specialised LGBTQ+ awareness training for healthcare professionals, guidance to account for homophobia and transphobia, and more robust safeguarding procedures.

With better treatments and advances in care for people with certain conditions, diseases, and disabilities, there is a new generation of older people with uncharted health and palliative care needs. For example, we are seeing the first wave of individuals ageing with HIV who have been on antiretroviral therapy (ART) for a substantial period; and more people than ever before being diagnosed with HIV aged 50 and over (8). The Terrence Higgins Trust has put together a set of recommendations on how to support an ageing generation of people with HIV in a report called Uncharted Territory which should be considered for the new palliative care strategy. Another example is the increased life expectancy of individuals with Down's syndrome, who are more likely to have clinical vulnerabilities and to develop dementia in older age. Distinct policies are needed to support a generation of older individuals living and dying with unique health challenges.

(1) https://journals.sagepub.com/doi/full/10.1177/0269216318817692
(2) https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-019-0490-x
(3) https://edwebcontent.ed.ac.uk/sites/default/files/atoms/files/lloyd_a_et_al_why_do_older_people_get_less_palliative_care.watermark_copy.pdf
(4) https://spcare.bmj.com/content/3/1/129
(5) https://ageing-better.org.uk/resources/ethnic-health-inequalities-in-later-life
(6) https://www.ageuk.org.uk/discover/2021/february/the-health-and-care-needs-of-older-lgbt-people/
(7) https://compassionincare.com/wp-content/uploads/2023/01/stripped-of-all-pride.pdf
(8) https://www.tht.org.uk/sites/default/files/2018-03/uncharted_territory_final_low-res.pdf

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?

It is important to use consistent terms and language that everyone can understand.

- Care around dying - care around dying means whole person care for an adult or child who is dying and in the last hours, days or weeks of their life, care after their death, and support with loss and grief for families and carers throughout this time and when they are bereaved.

- Future care planning - future care planning means supporting adults and children, their families and carers, to think and plan ahead for changes in their life, care or health.

- Palliative care for adults - palliative care is holistic care that prevents and relieves suffering through the early identification, assessment and management of pain and other problems – whether physical, mental health, social or spiritual.

- Palliative care for children and young people - palliative care for children and young people is an active and total approach to care, from the point of diagnosis or recognition throughout the child's life. It includes physical, emotional, social, and spiritual elements, and focuses on enhanced quality of life for the child or young person and support for their family.

☒ Yes
☐ No
☐ Unsure / Don't know

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

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