

Palliative Care Matters for All Consultation

RCGP Scotland Response

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.

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland welcomes the opportunity to respond to this consultation. As the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care. GPs play a major role in the care of patients undergoing palliative care, particularly in cases where a patient has decided to be cared for in a community setting.

We believe that given the established practice of inviting people to express choices and wishes, that any new palliative care strategy should act towards informing these choices and supporting people to be able to have a good death. The new strategy should be matched with adequate funding to ensure that this choice is not constrained by lack of resource. Fundamentally, decisions relating to palliative care should be person centred, informed, and involve close family members where possible.

We recognise the invaluable work of Children's Hospices Across Scotland (CHAS) but note that access to these hospices for paediatric palliative patients can be limited due to geography. More children are being born with life limiting illnesses and surviving longer due to advances in modern medicine meaning the number of children requiring palliative care will increase with time. As such, the strategy must address availability of and access to paediatric palliative 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)

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland agrees with the proposed four cornerstones of the strategy. However, we recommend the cornerstones include a reference to the sustainability of services provided by charity partners, including inpatient hospice services, Macmillan specialist nurses and overnight services such as Marie Curie nurses, all of which play an important role in palliative care in the community.

In Scotland, the whole time equivalent (WTE) number of GPs continues to fall while the number of patients registered with GPs has risen. GPs and their teams provide important input for the care of palliative patients in the community and the GP workforce shortage is hampering the ability of practices to provide high quality patient care. For GPs to be able to deliver high quality palliative care input the workforce and workload crisis must be addressed.

We welcome cornerstone number four's focus on leadership. However, leadership does not come about by itself and requires development, training opportunities, and support. The strategy should address how it will nurture leadership roles for GPs and other clinicians who have an interest in palliative care.

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.

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland broadly welcomes outcome 1 and the proposed actions to deliver it. We note however that the outcome does not mention health inequity. Many patients who require access to palliative care will face access barriers due to health inequalities and this must be addressed to ensure patients from deprived backgrounds requiring palliative care can access it. Marie Curie notes that every year, 11,000 people in Scotland who need palliative care are not accessing it. People living in deprivation can have smaller social networks and may live in isolation, making palliative care at home more challenging. Those in the most deprived areas are 33% less likely to die at home than those in the least

deprived areas. There are also significant differences in referral rates for people living in different areas. Even where people had the same diagnosis, there were fewer referrals in areas with multiple and income deprivation. Even after referral to specialist palliative care services, variation in place of death by deprivation persists. This should be a key part of the Strategy.

We believe that education around death and dying is paramount to enabling people to access palliative care in a timely manner. People generally have a poor understanding of the process of dying, and GPs along with other healthcare professionals can offer guidance and support. GPs have a relationship with people and their families across the stages of life. GPs give holistic care and may opportunistically be able to discuss future planning, even before illness occurs or a terminal diagnosis is made. Palliative and end of life care forms an integral part of the work of GPs and primary health care teams. End of life care is covered in RCGP's curriculum: <https://www.rcgp.org.uk/mrcgp-exams/gp-curriculum/life-stage-topic-guides#end> . RCGP has also developed a framework to describe capabilities for GPs that have an extended role in palliative and end of life care: <https://www.rcgp.org.uk/your-career/gp-extended-roles/palliative-care-in-general-practice> . Consideration should be given to how best to reach and support patients requiring palliative care who may be geographically or digitally isolated.

It is currently the case due to the workload on clinicians and social workers that a patient often relies on family members to advocate for their best interests. This is particularly the case in relation to a palliative patient's financial situation. We note the exceptional work of Macmillian in helping to support patients and their families with such issues.

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

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland broadly welcomes outcome 2 and the proposed actions to deliver it. We would like to see clear responsibilities declared for each new leadership position being created with a continual audit of performance.

There is also a need to improve working between Health and Social Care Partnerships (HSCPs), Scottish Partnership for Palliative Care, and third sector hospices. Health Improvement Scotland is currently in the process of updating the new Scottish Palliative Care Guidelines. The new guidelines must be disseminated widely to spread awareness among clinicians. Health care professionals must be given an adequate amount of protected learning time to familiarise themselves with the new guidelines.

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.

Agree

Disagree

Unsure / Don't know

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

We reiterate our previous point regarding the forthcoming update to the Scottish Palliative Care Guidelines which are not mentioned in outcome 3. The updated guidelines should be disseminated widely to all healthcare staff who may encounter patients undergoing palliative care. Following the publication of the updated Scottish Palliative Care Guidelines resources should be provided to GP practices to allow for training at a local or cluster level.

RCGP Scotland supports the use of patient-reported experience measures (PREMs) and patient reported outcomes (PROMS), but our understanding is that there may be much development work still needed to make such tools suitable for these to be used in a consistent manner across a wide range of conditions.

RCGP Scotland welcomes the aspiration to increase the data available and we note that this will be particularly important for future service provision as the Scottish population continues to age. However, any improvement of data must also be met with increased investment into digital infrastructure. While improved data is important for service planning it is worth considering that a good death cannot be quantified. Ultimately, the best way to improve palliative care is to give clinicians the time and resource they need.

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.

Agree

Disagree

Unsure / Don't know

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

It is currently the case that for adult palliative care in the community, nursing care is usually provided by visiting community nursing teams (often with escalating need as a disease progresses) and GPs providing medical advice, prescribing support and often carrying responsibilities around treatment decisions including reviewing and stopping those which will no longer be effective. While the introduction of a national palliative care advice line is welcome, efforts should also be made to ensure palliative patients presenting to 111 are fast tracked to GPs or district nurses.

The aim of creating a screening tool to improve identification of adults with serious or life-threatening illnesses for earlier palliative care is an interesting proposal. Ultimately district nurses and GPs will know their patients due to continuity of care and will be able to identify people with palliative care needs.

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.

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland agrees with strategy outcome 5 and the actions proposed. The digital system that is currently used to relay a palliative patient's care plan is required to be updated manually using general practice systems. Proposed development and implementation of improvements to the current arrangements are wholeheartedly welcome. With multiple IT systems and records in use across the health and care system, there is the inherent risk whereby patients and their families will be asked to give the same details to multiple teams, or for information to be lost, both of which can impact on a patient's care.

Future care planning is not a new concept and is applicable to many specialities across the medical profession. We note the successful use of the three-question form currently being used in Lothian for advanced care planning consultations in the care home setting. The questions cover a range of scenarios important in advanced care planning such as what are the patient's wishes if they stop eating or drinking, fail to respond to antibiotics, have a sudden medical event like a heart attack, and if they want to be hospitalised.

Advanced care planning should be holistic in nature. One RCGP Scotland member noted that in their practice, as part of a holistic approach, they also ask whether there is a pet at home and what should happen to it following the death of a palliative care patient.

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.

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland broadly agrees with outcome 6 and the actions described. However, we note that there is no specific mention of hospices which provide care to palliative patients, but also offer holistic support for family members and friends. We observe that there can be a pressure on hospice beds which means that some people who have expressed a wish to die in a hospice will not be able to - a model with greater capacity will be needed if these preferences are to be met. Access to hospice care should not be a lottery depending on bed spaces, especially in cases where control of symptoms might be better achieved there.

NHS Tayside has already developed clinical policy with patient and carer administration documents for 'just in case' medication as well as variable dosing for nursing staff. Use of these arrangements mean that a patient should not endure a wait for symptomatic relief if someone can administer the medication. This is a particular advantage in remote and rural areas. We believe that NHS Tayside's approach to patient and carer administration documents offers a good example that could be rolled out nationally to increase understanding and use of 'just in case' medications.

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

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.

Agree

Disagree

Unsure / Don't know

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

RCGP Scotland agrees with outcome 7 and the associated actions. We note that resources and services designed for young people should be age-appropriate and sensitive to their developmental needs, particularly in terms of communication and care planning.

We repeat our previous point about the limited access to CHAS due to geography. RCGP Scotland also recognises the exceptional work occurring at Robin House and Rachel House, located in Balloch and Kinross respectively, to support paediatric palliative care patients. GPs tend not to have as much involvement with paediatric palliative care patients with many of this group having terminal care and dying at CHAS rather than at home.

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

Agree

Disagree

Unsure / Don't know

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

We welcome outcome 8 and the actions proposed to achieve it. All training resources relating to palliative care should be free, easily accessible, and well publicised. GPs and district nurses should be well supported, in recognition of the fact that most palliative care patients choose to die at home.

End of life care is covered in RCGP's curriculum: <https://www.rcgp.org.uk/mrcgp-exams/gp-curriculum/life-stage-topic-guides#end> . RCGP has also developed a framework to describe capabilities for GPs that have an extended role in palliative and end of life care: <https://www.rcgp.org.uk/your-career/gp-extended-roles/palliative-care-in-general-practice>

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

Following the introduction of the strategy there should be reviews to ensure it is delivering on the intended aims and outcomes. RCGP Scotland believes that this new Palliative Care Matters for All Strategy must be backed up with investment to enable its delivery.

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.

RCGP Scotland is supportive of efforts to encourage people to come together to talk more openly about dying and death. However, we note that 'living well' with serious illness is a lofty ambition given there are many patients who could not be classified as palliative patients who are currently failing to live well for factors out with their control. It is also the case that many unwell patients, with terminal illness, can live full and active lives.

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.

RCGP Scotland agrees that the strategy as currently drafted explains why getting palliative care long before someone is dying can help an individual and their families. We are strongly supportive of efforts to talk about death and dying sooner to remove any stigma surrounding palliative care.

GPs have a relationship with people and their families across the stages of life. GPs give holistic care and may opportunistically be able to discuss future planning, even before illness occurs or a terminal diagnosis is made. Palliative and end of life care forms an integral part of the work of GPs and primary health care teams. Having an established relationship with a GP and primary care team can be helpful when a person faces a life-limiting diagnosis.

RCGP Scotland has reflected on repercussions on the public view of palliative care and the experience of bereavement from the COVID-19 pandemic, which will have ongoing impact on how the public sees palliative care, and what their desires are for it today.

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.

We agree that the bullet points broadly address the issue of access to palliative care. Culture or language barriers could also be added to the list and these factors are already considered to be barriers in different areas of medicine. It may be beneficial to consider the above list as non-exhaustive.

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.

RCGP broadly agrees with the terms used above. We note however that the specific mention of pain as a symptom may be unhelpful as this could lead to people thinking that pain is the only symptom that palliative care can help with. The strategy rightly sets out to address the stigma and misunderstandings surrounding palliative care and perhaps the specific reference to pain could be removed from these definitions.

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.

RCGP welcomes this new Palliative Care Strategy and believes that it is well intentioned. However, for this strategy to have a positive impact on access to and the delivery of palliative care, it must be backed up with investment and reviewed regularly.

We note with disappointment that the strategy does not focus on GP practices despite them delivering the vast majority of at home palliative and anticipatory care planning. Palliative care in the community has always been most effective when coordinated by primary care teams, headed up by GPs, who know their patients well.

While improving data collection and creating new dashboards and data sets for monitoring palliative care needs is welcome, it may lead to increased bureaucratic burden at a time when GPs are already dealing with substantial workload and workforce pressures. A concerted effort must be made to minimise any bureaucratic burden associated with these changes.