Consultation questions

Note: All answers to the questions in this section may be published (unless your response is “not for publication”).

Aim and approach

1. **Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?**

- [x] Strongly agree
- [ ] Partially agree
- [ ] Neutral (neither support nor oppose)
- [ ] Partially disagree
- [ ] Fully disagree
- [ ] Unsure

Please explain the reasons for your response, including what you think a right to palliative care should deliver.

The Royal College of Physicians of Edinburgh strongly agrees with the proposed right to palliative care, based on the views of Fellows working within relevant specialties.

While a legal right to palliative care might not be a panacea, it is however a necessary and essential step towards improving quality and equitable access for all Scots living with life limiting conditions. A legal right to this most fundamental and universal need within of health and social care would bring clarity for commissioners in every Health Board about their duties and responsibilities.

The College would like to highlight that there are fewer doctors working in specialist palliative care in Scotland than there are MSPs at present. This is at a time when the medical and nursing workforce of Scotland is under extreme pressure and estimated palliative care need is to rise to an extra 10,000 per year by 2040. Marie Curie research projects over 60,000 people will die with palliative care needs by 2040, with over 85s accounting for 45% of all deaths

The right to palliative care should deliver;

- Responsive and values based palliative care in every care setting and every geographical area with consistency of quality across the in hours and out of hours periods.
- Access to responsive specialist advice and assessment by a confident and competent health and social care workforce.

- Equitable access to rapid relief of distressing symptoms both physical, and psycho-spiritual

- Support for Future Care Planning and sustained commitment to resourcing digital interoperable solutions (such as the National Digital Platform) which ensure access to person-centred information when it can actually work for that individual in a crisis.

- Support for a national palliative care infrastructure to support evaluation and research with a focus on responsiveness and ability to share findings and promote research into practice initiatives.

2. **What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?**

Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

We consider that the WHO definition of palliative care is helpful in defining the scope and broad aims of palliative care and carries the necessary authority to be helpful for the purposes of legislation. This definition would require to be supplemented with additional guidance as to who is entitled to palliative care (the BASRIS guidance could be helpful here) and also a set of nationally agreed standards for palliative care which would be essential both for commissioners but also for public and professional understanding.

3. **Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).**

   What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?

- ☐ Strongly agree
- ☒ Partially agree
- ☐ Neutral (neither support nor oppose)
- ☐ Partially disagree
- ☐ Fully disagree
- ☐ Unsure

Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

Fellows stated that any new legislation would need to address existing reasons for inequity of access to palliative care in Scotland. The Inverse Care Law applies to palliative care as much, if not more, than it does for any other aspect of health and social care. In a palliative care context, the Inverse Care Law most severely affects people experiencing socio-economic deprivation and financial hardship, older people, women, minoritised ethnicities, LGBTQ+ people, people with learning disabilities and rural and island communities. The rising cost of living has worsened the impact of poverty on those living with terminal illness and these issues must be addressed within the scope of any new legislation.
Any new law presents an opportunity to address the existing inequities of access to palliative care by marginalised groups and the new law must highlight

the responsibility of commissioning bodies to prioritise specific actions to improve outcomes for those currently most disadvantaged.

4. **What is your view on how a right to palliative care should be implemented? For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented.**

   Please explain the reasons for your response.

   We consider that national standards for palliative care would need to be developed alongside a range of outcome measures and quality indicators which are sensitive and responsive to equity of access and to the wide variation in needs and preferences across different groups, cultures, geographical locations and care settings. Fellows considered that the Scottish Partnership for Palliative Care is already well placed to co-ordinate the collaborative effort which would be required to deliver and maintain such standards and funding for the SPPC should be secured at National level within any legislation to enable its work to continue and to expand. Standards should be independently and collaboratively developed and maintained and the SPPC is the organization with the focus and authoritative experience to most effectively share practice and oversee this essential work.

   Commissioning bodies and those able to provide the required standard and responsiveness of service must be clear about their responsibilities. Clear lines of reporting and accountability must be kept separate from funding streams. Placing local implementation responsibility with the Integrated Joint Care Boards allows local need and preferences to be identified and addressed. Board level budget and quality accountability must be transparent for palliative care so that community initiatives resulting in acute hospital care cost savings (such as rapid response or hospice at home) or vice versa can be clearly shown to be financially sustainable and therefore commissionable at a Board level.

   Data for evaluation, quality improvement and governance must be delivered and shared on a Nationally agreed basis, ideally on the National Digital Platform, with intuitive and easy integration from existing electronic care records commonly used within all third sector and NHS organisations providing palliative care.

   Some Fellows suggested education for palliative care should be mandatory across all health and social care disciplines and responsibility for this could potentially sit with NES in collaboration with regulatory bodies for health and social care (HIS and the Care Inspectorate). A national approach to competencies could mitigate much of the existing variation in access to quality education across different Boards and particularly for those within social care and care homes. For this to be effective it is crucial that the larger national organisations have the financial ability to take a longer-term view of palliative care initiatives rather than relying on one or two year funding for discrete projects which is the current scenario and is hugely inefficient and wasteful of public resource.

Research into aspects of palliative care currently receives minimal funding (0.23% of all Health related research in 2022) and is not prioritised other than by charities such as Marie Curie whose focus is improving palliative and end of life care. A responsibility to initiate and fund research to improve palliative care experience and service delivery must be an explicit part of any new legislation.

A five year and ten year strategy specific for palliative care improvements and addressing agreed quality indicators should be mandatory for all National Health and Social care organisations and all Integrated Joint Boards as part of new legislation. Third sector organisations currently delivering generalist and specialist palliative care must be included as equal partners in strategic planning at Board level. A values-based approach to service delivery should be prioritised in local and national strategy and cross-sector evaluation of quality experience, cost and cost savings must be made possible and supported at a National level such as via the National Digital Platform.

A National Digital Plan for palliative care should also be a requirement of legislation. This plan should include public access to health and planning and should specifically address digital literacy and health literacy issues which currently impact access to future care planning and negatively impact the experience of accessing person centred care in care crises and at the end of life. Public engagement must be part of any digital plan for palliative care.

5. Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability?

Please explain the reasons for your response.

Some Fellows stated that the science of economics of palliative care has had little National level support or resource, and this is an area that must be prioritised in any new legislation to ensure Boards are clear about financial and experiential value for commissioning. A National Approach to data collection as well as data sharing is already possible via the National Digital Platform and the potential for this to link with economic evaluation and real time values based experience feedback should be fully explored. The possibilities for using the National Digital Platform to mitigate the impact of poor health literacy and inequity should be part of any National Digital Plan around palliative care. Initial investment in this National Approach should be part of legislation for a right to Palliative Care.

A focus on values based care would result in better use of resources and better care experience for the most vulnerable in our society. For those trying to live well with a terminal illness and for those dying imminently a legal right to values based palliative care would provide benefit for patients, families and for health and social care providers. A long-term view is essential as short term ‘quick fixes’ are

unsustainable and more costly in time.

Other Fellows indicated their strong support for access for individuals to have good conversations with family, friends and those they trust around future care planning. This would be best approached by a public health model built on self-empowerment, information and choice. In addition to this Bill, primary and secondary care services need to work in partnership to identify individuals with life shortening conditions and optimise management.