



Consultation on a new National Public Health Body: 'Public Health Scotland'

July 2019

About Hospice UK

Hospice UK is the national charity for hospice care, supporting over 200 hospices in the UK. We believe that everyone matters throughout their life right up until they die, and that no one should die in avoidable pain or suffering.

Hospice UK supports the breadth, dynamism and flexibility of modern hospice care by influencing national and local policy, improving quality of care through the sharing of good practice, and providing resources, education and training, and grant programmes.

Across the UK, hospice care supports more than 200,000 people every year, through inpatient, outpatient, day hospice and hospice at home services.

In Scotland, 58,503 people died in 2018¹. There is no robust data on need and unmet need for palliative and end of life care in Scotland. However estimates, based on methodology developed to assess need in England², have suggested that three-quarters of people who die could benefit from palliative and end of life care in Scotland and potentially one in four, about 11,000 people per year in Scotland, are not receiving the right care at the end of life³. Children's Hospices Across Scotland (CHAS) estimate there are over 15,000 babies, young people and children in Scotland with life-shortening conditions, with two-thirds not being known to their services⁴.

Consultation response

Question 8: What are your views on the functions to be delivered by Public Health Scotland?

Key point: Public Health Scotland's remit should include a focus on improving outcomes and tackling inequalities at the end of life.

¹ General Registrar Office for Scotland, June 2019 <https://www.nrscotland.gov.uk/files//statistics/vital-events-ref-tables/2018/vital-events-ref-tables-18-publication.pdf>

² Murtagh F et al. (2014) How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, Vol 28(1) 49–58

³ Health and Sport Committee (2015) A report for the Scottish Parliament by Professor David Clark: International comparisons in palliative care provision: what can the indicators tell us?, 9th Report, 2015 (Session 4)

⁴ McLaughlin, T and Robb, S (2018) *Children in Scotland Requiring Palliative Care (CHiSP) 2* Children's Hospices Across Scotland (CHAS)

The role and functions of Public Health Scotland should make it clear that its remit applies to improving public health and wellbeing, and tackling inequalities, at *all stages of life*, including at the end of life. We welcome that the consultation document refers to improving wellbeing, not just improving public health. This is important to ensure that there is scope to focus on improving quality of life when deteriorating health becomes inevitable. However, we would like to see this go further to explicitly state that Public Health Scotland's roles and functions will support a public health approach around death, dying and bereavement.

There is increasing evidence of the benefit of having a public health approach to palliative and end of life care^{5,6}. A public health approach can build a greater understanding of the need for palliative and end of life care at a population level, as well as where there are inequalities in access and the experience of care. A public health approach is also crucial to promote public openness, empower communities and tackle the stigma around death, dying and bereavement.

In the Strategic Framework for Action on Palliative and End of Life Care, the Scottish Government made clear that "*palliative and end of life care are matters of public health*". It recognises that a public health approach is necessary to ensure that we meet the aim that everyone who needs palliative and end of life care can access it. As such, it is a missed opportunity that palliative and end of life care is not reflected in the new Public Health Priorities for Scotland.

The consultation document states that it wants Public Health Scotland to support organisations that are responsible for tackling inequalities and improving health and wellbeing outcomes. Organisations delivering palliative and end of life care, such as hospice care providers, are doing exactly that. They work to tackle inequalities around access to palliative and end of life care and to improve health and wellbeing outcomes around death, dying and bereavement in their communities. There is a wealth of work happening in Scotland promoting public discourse around death, dying and bereavement, such as the Good Life Good Death Good Grief Alliance and compassionate communities initiatives. But we need a systematic, national approach alongside these organisations and campaigns.

Public Health Scotland has a key role to play in working with these organisations and initiatives, and providing strategic leadership for a public health approach to palliative and end of life. The legislative framework that will create the new body should make clear that its role and functions include a focus on tackling inequalities and improving public health and wellbeing outcomes at the end of life.

**Question 7: (a) What suggestions do you have in relation to performance monitoring of the new model for public health in Scotland?
(b) What additional outcomes and performance indicators might be needed?**

⁵ Gillies, M (2016) *Palliative and end of life care in Scotland: The rationale for a public health approach*. Scottish Public Health Network

⁶ Good Life Good Death Good Grief and Scottish Partnership for Palliative Care (2018) *A Road Less Lonely. Moving forward with public health approaches to death, dying and bereavement in Scotland*

Key point: Outcomes and indicators that focus on the end of life should be included in the performance monitoring of Public Health Scotland.

The proposals for monitoring progress of the new model for public health focus on the National Performance Framework and the Public Health Priorities. Relying solely on these would risk an inability to monitor progress around health and wellbeing outcomes at the end of life.

The current Public Health Priorities do not include a focus on end of life. In addition, the National Outcome for health within the National Performance Framework is “*we are healthy and active*”. The accompanying indicators only refer to end of life in terms of premature mortality and healthy life expectancy. While these are obviously important, they do not capture progress in how we are improving people’s wellbeing and providing a ‘good death’ when people are at the end of life.

The consultation document emphasises the importance of improving public health *and wellbeing* outcomes. We therefore suggest there need to be outcomes and indicators that monitor progress of delivering outcomes around wellbeing at the end of life. These should tie in to other outcomes, such as the National Health and Wellbeing Outcomes and monitor progress against other Scottish Government commitments where public health has a key role, such as those in the Strategic Framework for Action on Palliative and End of Life Care.

Question 15: What are your views on the arrangements for data science and innovation?

Key point: Public Health Scotland should ensure there is a robust population-level data and evidence base around palliative and end of life care.

We welcome the focus on data and evidence to improve health and wellbeing outcomes, in particular the role of innovation in public health intelligence and the importance of lived experience.

The creation of a new Public Health body is an important opportunity to ensure that there is a robust data and evidence base around palliative and end of life care. This is vital to support work to tackle inequalities and improve outcomes around access to and experiences of care at the end of life, for people at the end of life and their family and carers.

The recent Children in Scotland Requiring Palliative Care (CHiSP) 2 study⁴ found evidence of significant unmet need of specialist palliative and end of life care to babies, children and young people, as well as a strong correlation between poverty and a child having a life-shortening condition. This is powerful evidence, but also highlights by comparison the lack of data available for the adult population.

Currently there is no reliable population level data around palliative and end of life care need and unmet need for adults in Scotland. There is a lack of data to support service design and delivery of specialist palliative care services to meet the needs of

particular populations. There is no national data set on preferred place of death. In addition there is no Scottish-wide data set on the experience of palliative and end of life care. In England, Public Health England has established the National End of Life Care Intelligence Network⁷ to collate data and intelligence on end of life care for adults in England.

The lack of data in Scotland means there is currently no way of knowing what progress we are making towards meeting Scottish Government's aim to ensure access to palliative and end of life care for everyone who needs it by 2021, or of assessing variation in access.

Question 17: Equalities Impact Assessment

Key point: Public Health Scotland should include a focus on death, dying and bereavement to ensure that people at the end of life are not negatively impacted.

The formation of a new public health body is an important milestone for Scotland to come together to tackle inequalities around public health and wellbeing. The new body needs to ensure that all life stages are recognised including the end of life, or risk unintentionally widening inequalities.

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⁷ <http://www.endoflifecare-intelligence.org.uk/home>