

Submission to the Review of National Outcomes

A case for change

Everyone dies. Everyone loses people they care about. Everyone is deeply affected by these experiences. Everyone has a story about the care and support that made the worst of times more bearable. Or a story about a failure of communication, or a lack of compassion and dignity when it was needed most.

Death, dying and bereavement are *the most universal human experiences*. Over 60,000 people die in Scotland each year, and this is projected to rise significantly. Almost one-third of the people being cared for in a Scottish acute hospital ward today will have died within 12 monthsⁱ. 72% of UK adults report having been bereaved in the last five yearsⁱⁱ. Over 50% of all children in Scotland are bereaved of a parent, sibling, grandparent or other close family member by age 8 and this rises to 62% by age 10.ⁱⁱⁱ

How Scotland responds to these experiences are a true litmus test of our values and a test of how effectively as a nation we put those values into action. Yet this part of our national life is invisible in the current National Outcomes and associated indicators. Below we make positive and constructive suggestions about how this deficit could be addressed, using the questions suggested on the Review website.

What Should be Done

1. Are there any changes to the current set of 11 National Outcomes that you would propose? If so, in summary, what would these be?
2. Are there new National Outcomes that should be included in the National Performance Framework, if so why should they be included?

The language used around the national health outcome tends to exclude people who are approaching the end of life. Inevitably towards the end of life many people cannot easily be described as “healthy” or “active”, regardless of upstream preventative measures and medical interventions. Yet in these circumstances the care which people receive can make a huge difference to their quality of life and wellbeing, and that of their friends, family and colleagues. The current outcomes and underlying indicators do not currently acknowledge this huge domain or the opportunity for improvement. We would like to see the adoption of more inclusive language and propose this change to the health outcome.

“We are healthy and active, and our wellbeing, dignity and values are affirmed as we reach the end of life.”

3. Are there any changes you would propose to the wider National Performance Framework on set of National Indicators?

We would like to see an indicator which relates to people's experiences of care at the end of life. The current indicator on Quality of Care Experience is based on data about people's experiences of their GP extracted from the bigger Health and Care Experience Survey. Unfortunately the methodology of the Health and Care Experience Survey deliberately omits any measurement of experiences of palliative and end of life care. Informal family carers of people who have died are often keen to give back on their experiences and observations, but these people are screened out from receiving the survey.

Many other jurisdictions have developed and implemented national surveys of bereaved family carers as a way of measuring and understanding progress in this phase of life. **We would like to see the introduction of such a survey in Scotland.**

The VOICES survey which has been used in England, the NACEL Quality Survey (England, Wales, Northern Ireland) and the Lothian project to pilot a form of VOICES are other examples of surveys of informal carers who have been bereaved. This year the Republic of Ireland has introduced such a survey. The advantages of such an approach are:

- Such a survey can generate findings on the quality of patient and carer experiences and outcomes, rather than measuring processes which are not adequate proxies for quality.
- Such a survey can cover a wide range of issues which patients, carers and the public say are important to them, and response rates can be good.
- Findings from such a survey can support a specific focus at national level on palliative and end of life care, providing public assurance and encouraging professional and public engagement on these issues.
- If centrally administered the survey allows a consistent nationwide approach with zero measurement burden for frontline staff.
- Such a survey is capable of repetition at different time points.
- With appropriate sample sizes such a survey can also be used at local level to provide data specific to local services. It would be possible to explore local variants to provide more rapid feedback.

The VOICES surveys, which was developed in collaboration with bereaved relatives and patients, have been in operation for years, so there is a body of methodological experience to build on¹.

A further model which might be drawn on is the end of life experience survey conducted as part of the Irish Longitudinal Study of Aging^{iv}.

The Scottish Care Experience Programme^v has relevant experience and expertise in identifying family members of people who have died since it is part of the methodology of the Health and Care Experience Survey mentioned above^{vi}. There is potential to combine this expertise and approaches mentioned to develop a bespoke approach for Scotland.

4. What impact does the current National Outcomes have on your work?

The blind spot in the current National Outcomes and associated indicators reinforces a general institutional lack of attention paid to this phase of life. This makes improvement more difficult to achieve.

¹ There are information governance issues which prevent straight forward replication of the VOICES approach in Scotland.

About Scottish Partnership for Palliative Care

The Scottish Partnership for Palliative Care (SPPC) brings together health and social care professionals from hospitals, social care services, primary care, hospices and other charities, to find ways of improving people's experiences of declining health, death, dying and bereavement. We also work to enable communities and individuals to support each other through the hard times which can come with death, dying and bereavement. SPPC recently won a Public Service Award for its portfolio of work.

SPPC was founded 30 years ago and has grown to be a collaboration of over 100 organisations involved in providing care towards the end of life. SPPC's membership includes all the territorial NHS Boards, all IJBs, all Local authorities, the hospices, a range of professional associations, many national charities and social care providers.

ⁱ *Likelihood of death within one year among a national cohort of hospital inpatients in Scotland.* D. Clark et al (2016) *Journal of Pain and Symptom Management*, 52(2), e2-e4. (doi:10.1016/j.jpainsymman.2016.05.007) (PMID:27262261) [http://www.jpsmjournal.com/article/S0885-3924\(16\)30140-3/fulltext](http://www.jpsmjournal.com/article/S0885-3924(16)30140-3/fulltext)

ⁱⁱ *A better grief.* Sue Ryder. March 2019 <https://www.sueryder.org/sites/default/files/2019-03/a-better-grief-report-sue-ryder.pdf>

ⁱⁱⁱ *The prevalence of childhood bereavement in Scotland and its relationship with disadvantage: the significance of a public health approach to death, dying and bereavement.* Sally Paul & Nina Vaswani. Sage Journals. Dec 2020 <https://journals.sagepub.com/doi/full/10.1177/2632352420975043>

^{iv} *End of life experience for older adults in Ireland: results from the Irish longitudinal study on ageing (TILDA).* Peter May et al. BMC Health Services Research. Feb 2020 <https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-020-4978-0>

^v *Health and Care Experience Surveys.* Scottish Government. <https://www.webarchive.org.uk/wayback/archive/20150528232957/http://www.gov.scot/Topics/Statistics/Browse/Health/careexperience>

^{vi} *Health and care experience survey 2017 to 2018: technical report.* Scottish Government. April 2018 <https://www.gov.scot/publications/health-care-experience-survey-2017-18-technical-report/>