

Measuring What Matters Consultation

This is a joint submission by legal scholar, Dr Kate Falconer (**University of Queensland**) and cultural anthropologist, Dr Hannah Gould (**The University of Melbourne**). We are experts in the academic study of death and dying within Australia, having presented and published our research in numerous international and national forums. Additionally, we are co-founders and members of the executive committee of the [Australian Death Studies Society](#).

It is our contention that any revised measure of Australia's progress and wellbeing must include a holistic assessment of **Quality of the Death and Dying (QoDD)**. Such a measure would recognise the significant impact of death and bereavement on the wellbeing of all Australians and facilitate work to improve our healthcare and deathcare systems.

What is Quality Death and Dying?

A measure of quality of death and dying is both personal and communal, and it reflects the diversity of the Australian population. Within healthcare, a 'good death' is conventionally defined as "one that is free from avoidable distress and suffering, for patients, family, and caregivers; in general accord with the patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards".¹ A more holistic measure extends beyond this end-of-life phase to encompass the provision of a meaningful funeral service, access to burial or cremation choices, bereavement support, and appropriate estate planning.

What is Quality of Death and Dying (QoDD) important?

Death is a phenomenon like no other. It touches all dimensions of human experience, as an event of profound cultural, spiritual, economic, legal, and social significance. Experiences of dying and bereavement have an extraordinary impact on people's health and economic performance, with multidimensional costs and ripple effects.² [The Lancet Commission on the Value of Death](#) (2022) states that treatment in the last months of life is often costly, and can cause families to fall into poverty. In high-income countries like Australia, they estimate that "between 8% and 11.2% of annual health expenditure for the entire population is spent on the less than 1% who die in that year". It is thus vital that this expenditure delivers care of the highest quality and equitable access.

¹ Institute of Medicine. (1997) *Approaching death: improving care at the end of life*. National Academy Press.

² Corden, P. A. & Hirst, M. A. (2013) Economic components of grief. *Death Studies*: 725-749.

In Australia, our deathcare system has been critiqued for consumer dissatisfaction,³ crippling financial burdens,⁴ and troubling inequalities.⁵ These impacts are unequally felt across populations, disproportionately affecting women, Indigenous Australians, and migrant communities.

Deathcare provisions cut across multiple domains of Australian life and wellbeing. [The Royal Commission into Aged Care Safety and Quality](#) (2021) made recommendations to secure the rights of all Australians to “fair, equitable and non-discriminatory access to palliative and end-of-life care”. For its part, the [Royal Commission into Misconduct in the Banking, Superannuation and Financial Services Industry](#) (2018) identified the need for greater regulation and reform for funeral insurance products. Several State and Territory based inquiries have also issued reports and recommendations in relation to deathcare in Australia.

More expansively, the quality of our deathcare systems reflects the character of our society, and it cuts to the quick of what it means to be human, to live, grieve, and remember. As William E. Gladstone famously remarked:

‘Show me the manner in which a nation cares for its dead and I will measure with mathematical exactness the tender mercies of its people’

How might it be measured?

Australia should deploy a comprehensive, single metric that rates the Quality of Death and Dying, inclusive of services within the end-of-life, death, and bereavement phases. There are currently several tools available that partially meet this need:

[Quality of Death and Dying Index \(QODI\)](#). First released in 2010, and revised in 2015, this Index was published by the Economist Intelligence Unit and commissioned by the Singapore-based Lien Foundation. The 2015 Index used 20 quantitative and qualitative indicators across five categories to measure the quality and availability of palliative care across 80 countries. Example indicators include the certification for palliative care workers, and the availability of public funding for palliative care. In 2015, **Australia ranked 2nd in the world** (behind the UK) for Quality of Death and Dying.

[Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021.](#)

Released in 2021, this Index was established by the Lien Centre for Palliative Care at the Duke-NUS Medical School. Its fundamental goal was to systematically rank and grade 81 nations on

³ van der Laan, S. & Moerman, L. C. (2017). *An Investigation of Death Care and the Funeral Industry in Australia*. University of Sydney.

⁴ Carter, H. E., Winch, S., Barnett, A. G., et al. (2017). Incidence, duration and cost of futile treatment in end-of-life hospital admissions to three Australian public-sector tertiary hospitals: A retrospective multicenter cohort study. *BMJ Open*, 7(10): e017661.

⁵ Smith, R. (2018). Lancet Commission on the Value of Death. *The Lancet*. 3929(1055): 1291-1293.

available end-of-life care. This ranking was based on 13 key indicators specifically related to patient experience in the last 6 weeks of life, including the management of pain and discomfort, the cost of end-of-life care, and the meeting of spiritual needs and other non-medical concerns. In 2021, **Australia ranked 4th in the world** (equal with the Republic of Korea and Costa Rica) in the Quality of Death and Dying.

Measuring What Matters. In 2014, the American Academy of Hospice and Palliative Medicine and the Hospice and Palliative Nurses Association jointly issued ‘Top 10 Measures that Matter’. Related to the provision of end-of-life care, these recommendations operate as performance and improvement measures for use by hospice programs. Included in the 10 Measures are the documentation of discussions covering the patient’s emotional needs and compliance with patients’ wishes regarding the use of withdrawal of life-sustaining treatment.

Despite of these measures providing an assessment of Australia’s relative global position, each focuses almost exclusively on the provision of palliative care, thus inherently limiting its analytical force. As we have described, funerals, burial/cremation, bereavement and other services have significant impact on wellbeing beyond the narrow, ‘dying’ phase.

To address this gap, we propose the development of a comprehensive, single metric to rate the full trajectory of experiences involved in Quality of Death and Dying (‘QoDD’). This metric will collate multiple sources of data and indicators of QoDD, including:

Funeral Costs. The cost of arranging a funeral and body disposition (burial or cremation) in Australia is increasing. A recent report issued by funeral insurance provider [Sunlife](#) states that the average Australian funeral costs 7.9% of the average annual income in Australia. This percentage can be far higher for those on lower incomes, for whom [Social Ventures Australia](#) notes funeral costs can be as high as 40-45% of annual earnings. Indigenous Australians are more likely to be adversely affected by funeral poverty. Alongside a measure of funeral costs as a percentage of average annual income, the comprehensive QoDD measure could include a quantification of the number of applications made to the various funeral assistance schemes available throughout Australia (e.g. the Funeral Assistance Scheme administered by the Coroners Court of Queensland, or the charity Bereavement Assistance in Victoria).

Availability of cemetery space. It is increasingly recognised that Australia is running out of cemetery space, particularly in urban areas. Indeed, in 2020, the [11th Hour Report](#), commissioned by the NSW government, declared Sydney’s cemetery supply a “crisis”. The lack of available cemetery space will result in more people being denied their choice of final resting place. There are further flow-on effects for bereavement care, as family and friends may have to travel long distances to visit the deceased. The availability of cemetery space is of particular importance to Indigenous Australians, [as recent reporting from Palm Island indicates](#). One means

of assessing this data point is to calculate the amount of usable cemetery space in existing cemeteries, as well as approved future cemeteries, and comparing this figure with population forecasts on a regional basis.

Environmental impact of deathcare. Recently, [a report by the Australia Institute](#) revealed that 3 in 4 Australians are concerned about climate change. Environmental impact is now an important value for many Australians when planning services for themselves and their loved ones. Environmental concerns in the deathcare sector are not misplaced. The chemicals involved in embalming, the concrete associated with mausolea, and the irrigation required for lawn cemeteries (to list but a few examples) all carry an environmental cost. With this in mind, the comprehensive QoDD measure could include an environmental lifecycle assessment of memorial options.

What data is currently collected? What needs to happen?

Multiple sources of data that might feed into a comprehensive QoDD assessment are routinely collected across Australia. Most notably, the [Palliative Care Outcomes Collaboration \(PCOC\)](#) maintains a national, longitudinal database of palliative care outcomes. This is a core national palliative care program funded by the Department of Health and delivered through a partnership of four universities (UOW, QUT, UWA, UTS). Participation in PCOC by healthcare services is voluntary and could readily be expanded. Other organisations representing private and public service providers within our deathcare system undertake substantial and routine reporting activities, including the [Australasian Cemeteries & Crematoria Association](#) and the [Australian Funeral Directors Association](#).

Currently, data collection and reporting are not coordinated across the different sectors and actors that make up our deathcare system. A concerted effort is required to formulate a holistic measure of QoDD that can be used to benchmark wellbeing and progress in Australia. We are eager to share our knowledge and expertise in this endeavor, and to contribute to the inclusion of death and dying within a broader consideration of wellbeing in Australia.

Kind Regards,

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