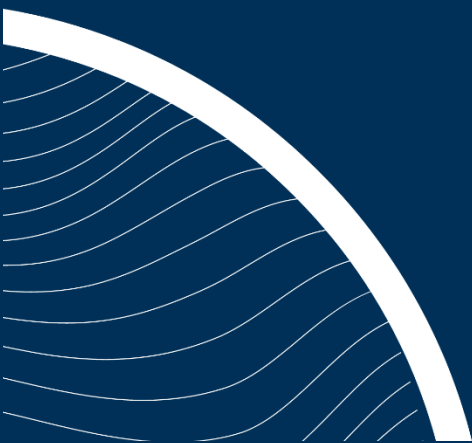




AIHW EXPLORING FUTURE DATA AND INFORMATION NEEDS FOR AGED CARE ISSUES PAPER

Submission from Palliative Care Australia (PCA)

MARCH 2022



PalliativeCare
AUSTRALIA

Palliative Care Australia Response to the AIHW *Exploring Future Data and Information Needs for Aged Care Issues Paper*

Introduction

Palliative Care Australia (PCA) is the national peak body for palliative care and represents those who work towards high quality palliative care for all Australians who need it. Working closely with consumers, our Member Organisations and the palliative care workforce, we aim to improve access to, and promote palliative care.

Response to the AIHW *Exploring Future Data and Information Needs for Aged Care Issues Paper*

PCA welcomes the opportunity to provide feedback on the Australian Institute of Health and Welfare's (AIHW) *Exploring Future Data and Information Needs for Aged Care Issues Paper* (Issues Paper). Our response to the Issues Paper is outlined below.

PCA's role in the Aged Care System

As the national peak body for palliative care, PCA advocates for palliative care to be core business in aged care and ensure that all Australians receiving aged care have access to high quality palliative care where and when they need it. PCA is actively engaged in aged care through membership of the National Aged Care Alliance (NACA) and as a member of the End of Life Directions for Aged Care (ELDAC) national consortium.

PCA was actively engaged throughout the life of the Royal Commission into Aged Care Quality and Safety (Royal Commission) including providing eight submissions, a witness statement and PCA's then Board Chair providing direct evidence at the June 2019 Perth Hearing. PCA continues to engage in the implementation of the recommendations of the Royal Commission including providing submissions on the Care and Support Sector Code of Conduct and the *Aged Care and Other Legislation Amendment Bill 2021* (including giving evidence to the Senate Standing Committee on Community Affairs).

Palliative Care in Aged Care

Currently, over a third of all deaths in Australia occur in residential aged care.ⁱ As Australia's population ages the number of people using aged care services will further increase as will the demand for palliative care in community and residential aged care. The Royal Commission final report acknowledges that evidence heard during the life of the Royal Commission shows that too few people receive evidence-based end-of-life and palliative care, and instead experience unnecessary pain or indignity in their final days, weeks and months. The Royal Commission recognised the significant role palliative care has in aged care and the need for it to be core business:

*'Palliative and end-of-life care, like dementia care, should be considered core business for aged care providers. People at the end of their lives should be treated with care and respect. Their pain must be minimised, their dignity maintained, and their wishes respected. Their families should be supported and informed'*ⁱⁱ

Palliative Care Data

PCA believes it is critical to have access to good data to support people living with life-limiting illness who are also receiving care through Australia's aged care system. PCA uses whatever data is available to support our advocacy for people with palliative care needs in aged care. Currently the only official data available is obtained from Aged Care funding instrument (ACFI) appraisals in residential aged care. This data is limited by the narrow definition of palliative care used within the ACFI. The ACFI only recognises and funds palliative care at the 'end-of-life' where the definition of end-of-life is referenced as the 'last week or days' of life. In 2019–20, only 3,178 (1.3%) or 1 in 77 of aged care residents had an ACFI appraisal indicating the need for palliative care.ⁱⁱⁱ Given the narrow definition of palliative care in the ACFI, it is difficult to determine if the current data reflects the actual level of palliative care delivered in residential aged care. Additionally, there is no incentive for aged care providers to claim for palliative care for a resident who is already receiving the maximum ACFI subsidy as it does not change the subsidy they would receive. PCA acknowledges that the ACFI will be replaced by the AN-ACC on 1 October 2022, and this is likely to mean improved funding for the delivery of palliative care.

As noted in the AIHW report *Interfaces between aged care and health systems in Australia—where do older Australians die?* the data captured by ACFI:

'Seriously under-estimates the level of palliative and end of life care currently delivered to aged care residents and does not provide any information on unmet need.'

As outlined in the report, analysis of linked data indicates that 1 in 6 (18%) of those who died in residential aged care received some form of palliative care services.^{iv}

Currently, there is no data available on the delivery of palliative care in home care and flexible care. PCA also notes that the Issues Paper acknowledges the lack of person-centred data, including palliative care data, currently collected in the aged care system.

In 2021, PCA published the commissioned KPMG report *Information gaps in Australia's palliative care*^v, to explore the existing evidence on palliative care funding and provision across Australia. KPMG found that reporting of palliative care activities and expenditure in Australia ranges from excellent to non-existent. This makes it difficult to determine the current levels of palliative care services and funding, identify gaps or areas of overlap and evaluate and track progress over time. Palliative care data is not consolidated or accessible, and the consistency of reporting is poor. KPMG found that there are significant limitations in using the available data on palliative care activity and expenditure in aged care. These limitations are summarised in the table at *Attachment A*.

If palliative care is to become core business in aged care, then robust data is essential. Without targeted data collection and better linkages, Australia is not able to adequately analyse how many people are accessing palliative care services and in what settings, the demographics of those accessing care, and their preferences for place of care and place of death. This data is crucial for governments to adequately plan for, and invest in, palliative care needs into the future. Highly quality aged care and palliative care data will also help to guide future planning for funding, policy, programs, legislation and standards.

Highly quality palliative care data collection also aligns with Goal 6 of the *National Palliative Care Strategy 2018*. This goal recognises the current lack of consistent collection and reporting of data on palliative care and prioritises nationally consistent data collection that can be used to ‘*monitor, evaluate and report on access to and outcomes of palliative care*’.^{vi}

PCA welcomes the newly established Palliative Aged Care Outcomes Program (PACOP) and acknowledges this will provide improved outcomes and benchmarking data in aged care and contribute to improved care and outcomes in participating services.

Data Improvement

PCA would like to see the following improvements in the collection of palliative care data in aged care:

- A palliative care definition that aligns with the World Health Organization (WHO) definition:
‘Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’^{vii}.
- A person-centred approach to data collection, rather than the current administrative focus. Comprehensive and consistent person-centred data can provide a better picture of the nature and level of care that people are receiving and identify gaps and issues in the aged care system. We note that this person-centred data collection is already a focus of PACOP
- Data collected on palliative care in residential aged care to include both the delivery of palliative care by staff working in the aged care facility and any services provided by external staff including palliative care specialists, geriatricians, GPs, nurse practitioners, allied health and local health services.
- Expanding palliative care data collection to include palliative care delivered in the Home Care Packages (HCP) Program, Commonwealth Home Support Programme (CHSP) and the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (NATSI FACP)
- Comprehensive demographic data including diversity to provide a better picture of the care being provided to vulnerable population and those with diverse needs.
- The Aged Care National Minimum Data Set (NMDS) to include linkages with other health data to provide a comprehensive picture of the health and wellbeing of older Australians.
- More robust and comprehensive data collection on workforce including: the workforce profile on numbers and roles of staff trained in palliative care, skills and training provided, care needs, care pathways and outcomes.

- More robust and comprehensive data collection on workforce including: the workforce profile on numbers and roles of staff trained in palliative care, skills and training provided, care needs, care pathways and outcomes.
- Palliative Care data collection in aged care aligns with the vision outlined in the [National Palliative Care and End-of-Life Care Information Priorities^{viii}](#), including:
 - A greater focus on the design and collection of meaningful data, including data on outcomes and experiences, and data on vulnerable populations.
 - More patient-reported data including patient experience, outcomes and preferences and advance care planning.
 - Carer information including identifying needs and understanding the carer experience and identifying people who do not have access to an informal carer.
 - Data on the complexity and capacity of the workforce to deliver person-centred palliative care.
 - Data on unmet need and demand for palliative care.
 - Data that easy to understand and accessible.

Data Collection

PCA acknowledges that aged care providers are currently overwhelmed with the level of reporting required in aged care. So, it is essential that the new aged care NMDS is fit for purpose and provides robust and highly quality data that benefits providers, consumers, governments and other interested groups. Providers must be supported with appropriate training and information on the how to collect data, what it will be used for and the long-term benefits for both providers and consumers. Financial support should be available to providers who may struggle to meet the increased IT infrastructure and staffing costs of collecting this data. In particular, this is critical for providers in rural and remote locations and who deliver services to diverse needs groups and vulnerable populations.

The development of an aged care NMDS provides a unique opportunity to reset data in aged care and ensure that it has a person-centred focus and can provide long term benefits for older Australians, now and into the future.

PCA welcomes and strongly supports the ongoing work that AIHW is undertaking to improve aged care data and embed the *National Palliative Care and End-of-Life Care Information Priorities*. Palliative care and end-of-life care is crucial for people receiving aged care services, so it is very important that palliative care data is part of any future data and information changes across the aged care system.

ⁱ KPMG (2020), *Investing to Save – The economics of increased investment in palliative care in Australia*, commissioned by PCA: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>

ⁱⁱ Royal Commission into Aged Care Quality and Safety (2021), *Final Report: Care, Dignity and Respect, Volume 1 Summary and Recommendations*, pg. 94

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- iii Australian Institute of Health and Welfare (7 January 2022). *Palliative care services in Australia*, retrieved from: <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/about>
- iv Australian Institute of Health and Welfare (9 June 2021). *Interfaces between aged care and health systems in Australia—where do older Australians die?* Retrieved from: <https://www.aihw.gov.au/reports/aged-care/where-do-older-australians-die/summary>
- v KPMG (2021), *Information Gaps in Australia's Palliative Care*. Retrieved from: <https://palliativecare.org.au/information-gaps-in-australias-palliative-care/>
- vi Australian Department of Health (2018). *The National Palliative Care Strategy 2018*. Retrieved from: <https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018>
- vii World Health Assembly, *Strengthening of Palliative Care as a Component of Comprehensive Care Throughout the Life Course*, WHA Res 67.19, 67th session, 9th plen mtg, Agenda Item 15.5, A67/VR/9 (24 May 2014) 2.
- viii National Palliative Care and End-of-Life Care Information Priorities. Retrieved from: chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/viewer.html?pdfurl=https%3A%2F%2Fwww.aihw.gov.au%2Fgetmedia%2F17b82c56-83ff-45dc-be93-392bc5669fab%2Fnational-palliative-care-and-end-of-life-care-information-priorities.pdf.aspx&clen=913323&chunk=true



Source(s)	What is captured?	What is not?
ACFI/ NACDC	✓ Admissions and residents with an ACFI-appraised palliative care status.	✗ Does not capture the full scope of palliative care need (persons) or receipt (provision).
MBS/AIHW	✓ Number of patients, services and total benefits paid for palliative care items in the home or community: 3018, 3028, 3032, 3040, 3044, 3051, 3055, 3062, 3069, 3074, 3078, 3083, 3088, 3093.	✗ Cannot identify residential aged care from the services provided. ✗ Cannot identify consumers' out-of-pocket expenditures. ✗ Cannot attribute the wider range of services accessed with palliative intent to 'palliative care', including services provided by GPs and more.
PBS/AIHW	✓ Number of patients, prescriptions and government expenditure by prescriber for palliative care-related medicine types (subsidised and under co-payment): analgesics, anti-epileptics, anti-inflammatory/anti-rheumatic, drugs for functional gastrointestinal disorders, constipation, psycholeptics and stomatological preparations.	✗ Cannot identify residential aged care from the medications prescribed. ✗ Excludes medicines such as private prescriptions, over-the-counter medicines, and those supplied to inpatients in public hospitals. ⁶⁰ ✗ Includes prescribing of palliative care-related medicines for non-palliative purposes. ✗ Cannot attribute the wider range of medicines accessed with palliative intent to 'palliative care', included new palliative care medicines.
Commonwealth programs and initiatives	✓ Total funding over investment period and some detail on distribution of money to states if applicable.	✗ Funding and attribution versus actual expenditure (e.g. education, provision, in RACFs). ✗ Systematic public reporting post announcement is limited.
State programs and initiatives	✓ As above.	✗ As above. ✗ Mention of palliative care in state budgets is often not guaranteed.

Source: KPMG (2021), *Information Gaps in Australia's Palliative Care*, Pg. 15, Table 3, retrieved from: <https://palliativecare.org.au/information-gaps-in-australias-palliative-care/>